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Standards of Service Provision for Breast Cancer Patients in New Zealand – *Provisional*

National Breast Cancer Tumour Standards Working Group

New Zealand Government

2013

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Background

Breast cancer epidemiology

Breast cancer is a significant health issue for New Zealand and is the leading cause of cancer death in non-smoking New Zealand women.

In 2009 breast cancer was the most commonly registered cancer for women (2759 cases, accounting for 28.4 percent of all female cancer registrations). Annually, there are 125 new cases per 100,000, with an age-standardised rate (using the World Health Organization (WHO) standard world population) of 93 per 100,000.

Breast cancer was the second most common cause of death from cancer (after lung cancer) for women in 2009 (658 deaths, accounting for 16.3% of female cancer deaths), with a mortality rate of 30 per 100,000 females (age-standardised 19.9 per 100,000) (Ministry of Health 2012a).

The cumulative survival rate after adjusting for expected other causes of death is approximately 82 percent after five years. Internationally, New Zealand has high breast cancer incidence and mortality. Within the Organisation for Economic Co-operation and Development (OECD), New Zealand had the ninth-highest cancer incidence and the seventh highest mortality for female breast cancer (World Health Organization 2010).

While registration (recorded incidence) rates for breast cancer in females remained relatively stable between 1999 and 2009, female breast cancer mortality has reduced by 21.5 percent over the last decade. New Zealand breast cancer trends over time mirror international trends. The reduction in mortality is generally believed to be a result of earlier detection through breast cancer screening and the greater use and effectiveness of adjuvant treatment (Ministry of Health 2012a).

In 2009, 22 men were diagnosed with breast cancer in New Zealand, and seven men died from breast cancer. The age-standardised incidence rate for men was 0.7 per 100,000 (WHO world standard population) and the age-standardised mortality rate was 0.2 deaths per 100,000.

Ethnic differences

Ethnic disparities among New Zealand women with breast cancer are well known. Inequities in breast cancer deaths contribute to 18 percent of the overall inequities in cancer deaths between Māori and non-Māori women (Robson et al 2010). Māori women have the highest incidence of breast cancer of any indigenous population in the world (Jemal et al 2010; Condon et al 2003) and have a 28 percent higher age-standardised incidence of breast cancer compared to non-Māori in New Zealand (117.2 compared to 90.6 per 100 000 population for 2006–2009). Over the last decade, the age-standardised incidence for breast cancer has declined for non-Māori women and increased by around 10 percent for Māori women. Both Māori and non-Māori women have experienced a decrease in breast cancer mortality rates over the same period. However, the mortality rate is decreasing more rapidly among non-Māori women, resulting in a widening gap in mortality disparity between Māori and non-Māori (Robson et al 2010). Furthermore, the gap between Māori and non-Māori women is bigger for breast cancer mortality than it is for incidence, suggesting there may be disparities in cancer survival (Cunningham et al 2010).

Pacific women have a lower breast cancer incidence compared to Māori and European women in New Zealand (Meredith et al 2012). This somewhat lower rate is largely in keeping with known risk factors for breast cancer (Cunningham et al 2010). That is, Pacific women are more likely to bear children at an earlier age than European women, and more likely to be multiparous. In New Zealand, Pacific women are more likely to be younger than European at diagnosis, to present with more advanced disease and to have prognostic phenotypes, which are associated with worse disease-free and overall survival (Weston et al 2008; McKenzie et al 2008).

Registrations are lower but continue to represent a significant health issue among Asian ethnic groups in New Zealand also.

Walker et al (2008) examined the experience of Māori cancer patients, survivors and their family/whānau. This research provides some valuable points as to how health care services can improve Māori cancer experience; for example through:

- staff alerting Māori to their entitlements (eg, transport, benefits, home help and equipment)
- coordinated service delivery, to avoid patients ‘getting the run-around’ from service to service
- more frequent specialist clinics for rural participants
- flexibility in accommodation arrangements (eg, ‘an extension of the rapuora concept, namely where people can stay for a number of days’ to get the care they need)
- addressing the needs of rural patients (given that they often travel for treatment)
- staff accommodating tikanga (cultural practices), wairua (spirituality), hinengaro (emotional and mental aspects), tinana (physical aspects) and whānau

- a navigator to help patients across the cancer control continuum
- a care plan at diagnosis
- Māori support groups for cancer patients, survivors and their family/whānau
- counselling and support for family/whānau
- systems to provide good information to everyone, preferably kanohi ki te kanohi (face-to-face), and written material to provide support
- an increased Māori workforce, including Māori oncology nurses and liaison people
- preventative education
- allowing female patients the choice to receive care from female health professionals
- an explanation of the impact of treatment on patients (eg, on their sexuality (Walker et al 2008)).

An evidence-based approach is a process through which scientific and other evidence is accessed and assessed for its quality, strength and relevance to local Māori. An understanding of the evidence is then used in combination with good judgment, drawing on a Māori knowledge and experience to inform decision-making that maximises the effectiveness and efficiency of Māori health policy, purchasing, service delivery and best practice (Hill et al 2013).

Breast cancer screening

Breast cancer and cervical cancer are the two cancers for which New Zealand operates a national population-based screening programme. The Ministry of Health encourages all eligible women from 45 to 69 to undergo screening mammography through the free national programme run by BreastScreen Aotearoa (eligibility criteria are listed in NSU 2008, pp 8–9).

One of the essential requirements of an effective screening programme is that women who have breast cancers detected subsequently receive optimal treatment. The national screening programme has developed its own National Policy & Quality Standards (NSU 2008).

This document provides standards for all women with a symptomatic or screened detected cancer from general practitioner (GP) referral on.

Objective

Tumour standards for all cancers are being developed as a part of the 'Faster Cancer Treatment' (FCT) programme's approach to ensuring timely and high-quality care for patients with cancer. When used as a quality improvement tool the standards will promote nationally coordinated and consistent standards of service provision across New Zealand. They aim to ensure efficient and sustainable best-practice management of tumours, with a focus on equity.

The standards will be the same for all ethnic groups. However, we expect that in implementing the standards district health boards (DHBs) may need to tailor their efforts to meet the specific needs of populations with comparatively poorer health outcomes, such as Māori and Pacific people.

How the breast cancer service standards were developed

The breast cancer service standards were developed by the National Breast Tumour Standards Working Group, representing key specialties and interests across the breast cancer pathway of care, chaired by a lead clinician, Associate Professor Ian Campbell. The group included screening, Māori, Pacific and consumer representation, and had access to expert advisors in genetic services and supportive care services.

Tumour-specific national standards were first developed for lung cancer in the *Standards of Service Provision for Lung Cancer Patients in New Zealand* (National Lung Cancer Working Group 2011); these standards have already been used by DHBs to make improvements to service delivery and clinical practice.

Subsequently provisional standards have been developed for an additional ten tumour types: bowel, breast, gynaecological, lymphoma, melanoma, myeloma, head and neck, sarcoma, thyroid and upper gastrointestinal.

The Ministry of Health required all tumour stream work groups to:

> Maintain a focus on achieving equity and whānau ora when developing service standards, patient pathways and service frameworks by ensuring an alignment with the Reducing Inequalities in Health Framework and its principles (Ministry of Health 2002b).

These standards broadly follow the format of the *Standards of Service Provision for Lung Cancer Patients in New Zealand*.

The scope of this document includes the management of:

- early breast cancer (ductal carcinoma in situ (DCIS) and invasive)
- locally advanced breast cancer
- advanced breast cancer.

It covers the diagnosis and management of screening-detected and symptomatic breast cancers in both men and women. It also covers screening, surveillance and management of women at increased breast cancer risk.

Note that, throughout this document, because most breast cancers occur in women, the word ‘women’ has been used. Most of the standards and good practice points apply equally to men. Individual clinicians should use judgment to determine where a recommendation does not apply.

These standards recognise the need for evidence-based practice. Numerous evidence-based guidelines and standards already exist, so the standards in this document have largely been developed by referring to established national and international guidelines in the breast cancer literature (see Appendix 8).

Equity and Whānau Ora

Health inequities or health disparities are avoidable, unnecessary and unjust differences in the health of groups of people. In New Zealand, ethnic identity is an important dimension of health disparities. Cancer is a significant health concern for Māori, and has a major and disproportionate impact on Māori communities.

Inequities exist between Māori and non-Māori in exposure to risk and protective factors for cancer, in incidence and outcomes, and in access to cancer services. There are disparities between Māori and non-Māori women in both the incidence of breast cancer and deaths from breast cancer (Robson et al 2010). Barriers to health care are recognised as multidimensional, and include health system and health care factors (eg, institutional values, workforce composition, service configuration and location), as well as patient factors (eg, socioeconomic position, transportation and patient values). Addressing these factors requires a population health approach that takes account of all the influences on health and how they can be tackled to improve health outcomes.

A Whānau Ora approach to health care recognises the interdependence of people; health and wellbeing are influenced and affected by the ‘collective’ as well as the individual. It is important to work with people in their social contexts, and not just with their physical symptoms.

The outcome of the Whānau Ora approach in health will be improved health outcomes for family/whānau through quality services that are integrated (across social sectors and within health), responsive and patient/family/whānau-centred.

These standards will address equity for Māori patients with breast cancer in the following ways.

- They focus on improving access to diagnosis and treatment for all patients, including Māori and Pacific.
- They prioritise screening for Māori and Pacific women.
- They address inequities between Māori and non-Māori regarding timely access to cancer services.
- They require ethnicity data to be collected on all access measures and the FCT indicators, to identify and address disparities.
- They require linking of Māori and Pacific women to Māori and Pacific nurse coordinators or providers where possible.
- They specify that information developed or provided to patients and their family/whānau must meet Ministry of Health guidelines (Ministry of Health 2012e).
- They prioritise opportunities for Māori patients with breast cancer to participate in research trials.

Summary of the clinical standards for the management of breast cancer services

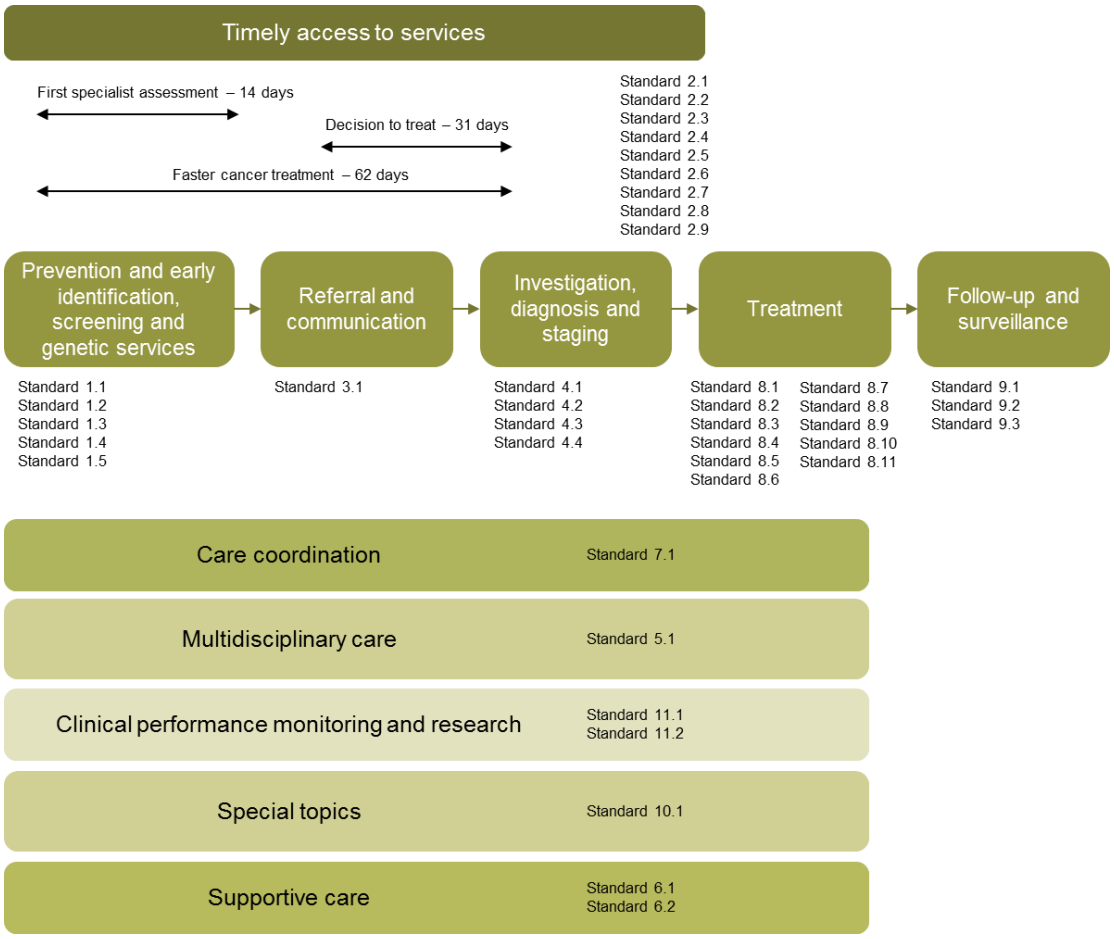
Format of the standards

Each cluster of standards has a title that summarises the step of the patient journey or the area on which the standards are focused. This is followed by the standard itself, which explains the level of performance to be achieved. The rationale section explains why the standard is considered to be important.

Attached to the clusters of standards are good practice points. Good practice points are either supported by the international literature, the opinion of the National Breast Cancer Tumour Standards Working Group or the consensus of feedback from consultation with New Zealand clinicians involved in providing care to patients with breast cancer. Also attached to each cluster are the requirements for the monitoring of the individual standards.

Standards of service provision pathway

The breast cancer tumour standards are reflected in the following pathway.



Summary of standards

The standards for the management of breast cancer have been divided into 11 clusters:

- prevention and early identification, screening and genetic services
- timely access to services
- referral and communication
- investigation, diagnosis and staging
- multidisciplinary care
- supportive care
- care coordination
- treatment
- follow-up and surveillance
- special topics – breast cancer and pregnancy and breast cancer in younger women
- clinical performance monitoring and research.

The standards are as follows.

Prevention and early identification, screening and genetic services

Standard 1.1: All eligible women in the age range 45–69 years should be strongly encouraged to undergo screening mammography through the free national programme BreastScreen Aotearoa.

Standard 1.2: Women who are known to carry a breast cancer susceptibility gene mutation (BRCA) have annual breast magnetic resonance imaging (MRI) and consider annual mammography from 10 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 are considered for annual breast MRI in addition to mammography (over the age of 30 years) and clinical examination.

Standard 1.4: Referral to Genetic Health Service New Zealand is discussed and offered for women whose family history meets the risk level for referral in the *eviQ Cancer Genetics – Breast and Ovarian Referral Guidelines*.

Standard 1.5: Women should not undergo prophylactic mastectomy or oophorectomy without being offered genetic services referral.

Timely access to services

Standard 2.1: Women referred urgently with a high suspicion of breast cancer have their first specialist assessment (FSA) within 14 days.

Standard 2.2: Women referred with a moderate suspicion of breast cancer have their FSA within 30 days.

Standard 2.3: Women referred with a low suspicion of breast cancer have their FSA within 90 days.

Standard 2.4: Women referred urgently with a high suspicion of breast cancer receive their first cancer treatment within 62 days.

Standard 2.5: Women with a confirmed diagnosis of breast cancer receive their first cancer treatment within 31 days of the decision to treat.

Standard 2.6: Women recommended adjuvant systemic therapy by a multidisciplinary team (MDT) and fit to receive it commence treatment within six weeks of surgery for breast cancer.

Standard 2.7: Women with inflammatory breast cancer have their FSA with a medical oncologist within two weeks of receipt of referral.

Standard 2.8: Women with breast cancer referred for radiation oncology assessment have their FSA with a radiation oncologist within two weeks of receipt of referral (where chemotherapy is not part of the management).

Standard 2.9: Women consenting to radiation therapy after surgery commence treatment once the surgical site has healed and within six weeks of surgery (where chemotherapy is not part of the management).

Referral and communication

Standard 3.1: Women and their GPs are kept informed throughout their breast cancer journey, and women are provided with verbal and written information about their breast cancer, diagnostic procedures, treatment options (including effectiveness and risks), final treatment plan and support services.

Investigation, diagnosis and staging

Standard 4.1: All women with suspected breast cancer are worked up in a dedicated breast care unit using triple assessment to enable a preoperative definitive diagnosis.

Standard 4.2: Every primary breast cancer is submitted for testing of oestrogen and progesterone receptor and human epidermal growth factor receptor 2 (HER2) status.

Standard 4.3: Reporting laboratories participate in an approved external quality assurance programme for receptor testing (eg, the Royal College of Pathologists of Australasia (RCPA) Quality Assurance Program) and achieve at least satisfactory performance.

Standard 4.4: All breast cancer pathology reports use structured pathology reporting, including on all items in the current RCPA *Invasive Breast Cancer Structured Reporting Protocol*.

Multidisciplinary care

Standard 5.1: All women with a confirmed breast cancer have their treatment plan discussed at a multidisciplinary meeting (MDM), and the outcomes of this are clearly documented in the woman's medical records and communicated to the woman and her GP.

Supportive care

Standard 6.1: Women with breast cancer are screened with a validated tool to identify psychological and social needs at key points of their breast cancer experience.

Standard 6.2: Women or their family/whānau found to be experiencing significant psychological distress or facing particularly difficult treatment decisions are offered prompt referral to a specialist psychological service, as part of an integrated cancer service.

Care coordination

Standard 7.1: All breast care units have a dedicated breast cancer or cancer nurse coordinator to facilitate patients' treatment pathway and provide guidance and support from diagnosis through to follow-up.

Treatment

Standard 8.1: All women requiring breast cancer surgery are treated by surgeons who are full members of Breast Surgeons of Australia and New Zealand Inc (BreastSurgANZ) or provisional full members. Membership is a credentialling requirement for practice of breast cancer surgery.

Standard 8.2: All women with early-stage invasive breast cancer who are candidates for breast-conserving surgery are offered the choice of breast-conserving surgery or mastectomy.

Standard 8.3: Women undergoing breast conserving surgery for invasive cancer or ductal carcinoma in situ (DCIS) require complete excision of tumour with clear margins. Circumferential or radial margins of ≥2mm should be achieved where possible.

Standard 8.4: Surgical assessment of axillary lymph node status is undertaken for most early invasive breast cancer.

Standard 8.5: Axillary lymph node dissection is not performed in women with DCIS only.

Standard 8.6: Clinicians discuss delayed or immediate breast reconstruction with all women who are due to undergo mastectomy, and offer it except where significant comorbidity precludes it. All appropriate reconstruction options are offered and discussed with women, irrespective of whether they are all available locally.

Standard 8.7: Women with inflammatory breast cancer receive primary chemotherapy, and not surgery, as their first cancer treatment.

Standard 8.8: Women with invasive breast cancer ≥5mm or node-positive, demonstrating HER2 over expression or amplification, and fit for chemotherapy are offered adjuvant treatment with HER2 targeted therapy and chemotherapy.

Standard 8.9: Women with endocrine-responsive invasive breast cancers are considered for endocrine therapy.

Standard 8.10: Women with invasive breast cancer having breast-conserving surgery are offered radiation therapy unless low risk of recurrence, age, medical condition or prior radiation therapy mitigates against treatment.

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 and when breast cancer treatment cannot be offered or if such treatment is declined.

Follow-up and surveillance

Standard 9.1: Annual mammography is undertaken for at least 10 years after diagnosis for all women treated for breast cancer who are in good health.

Standard 9.2: Postmenopausal women receiving adjuvant therapy with an aromatase inhibitor and women experiencing premature menopause (ie, younger than 45 years of age) due to chemotherapy, ovarian function suppression or oophorectomy have a baseline dual energy X-ray absorptiometry (DEXA) scan and two-yearly repeat DEXA scans.

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

Special topics

Standard 10.1: Women with a breast cancer diagnosed during pregnancy are managed by a specialist multidisciplinary care team that includes an obstetrician and a gynaecologist (if appropriate).

Clinical performance monitoring and research

Standard 11.1: All breast care units submit standardised core data to a cancer register on all women diagnosed with breast cancer, at the level of detail currently present in the Auckland Breast Cancer Register.

Standard 11.2: Women with breast cancer are offered the opportunity to participate in research projects and clinical trials.

1 Prevention and Early Identification, Screening and Genetic Services

Screening

Standard 1.1	All eligible women in the age range 45–69 years should be strongly encouraged to undergo screening mammography through the free national programme BreastScreen Aotearoa.

Screening – population screening

Rationale

The aim of population-based breast screening programmes is to reduce mortality from breast cancer. Through screening mammography that achieves 70 percent coverage, population breast cancer mortality reductions of 20 percent (Independent UK panel on breast cancer screening 2012) or 25–31 percent (EUROSCREEN Working Group 2012) are expected. Among women who have regular mammograms, the EUROSCREEN Working Group (2012) has estimated that mortality may be reduced by 38–48 percent (depending on the studies used).

Women with screen-detected breast cancers are less likely to require mastectomy or chemotherapy as part of their breast cancer treatment.

Māori women have a significantly higher incidence and mortality from breast cancer. BreastScreen Aotearoa coverage for Māori nationally remains lower than that of other New Zealand women, and is therefore a priority.

Good practice points

1.1 Encouraging Māori and Pacific women to be screened is given priority in accord with BreastScreen Aotearoa policy.

1.2 Women are fully informed of the benefits and risks of screening, including the risk of anxiety, false negative and false positive results and over-diagnosis.

Monitoring requirements

MR1A	Screening – surveillance of women who are known to carry a breast cancer susceptibility gene mutation (eg, BRCA).

Screening – and surveillance of women at increased breast cancer risk

Screening – risk assessment

Rationale

Women with a family history of breast cancer frequently overestimate their own risk.

Good practice points

1.3 Women are offered evidence-based information on risk factors, prevention and early detection.

1.4 Consistent risk assessment is essential so relatives of the same family who live in different areas of New Zealand are provided with the same risk estimate.

1.5 The following risk categories developed by the National Breast and Ovarian Cancer Centre (now Cancer Australia)[1] should be used.

Categories of risk (lifetime up to age 75)

- **At or slightly above average/population risk** – This includes women with no family history, and women with one first degree relative or one or two second degree relatives diagnosed at age 50 or older (see 1.1.6 below). Lifetime risk of breast cancer is between 1 in 8 and 1 in 11 (9–12%). Covers more than 95 percent of the female population.
- **Moderately increased risk** – This includes women who have a first degree relative diagnosed before age 50, or two or more first degree relatives on the same side of the family diagnosed at any age (see 1.1.6 below). Lifetime risk of cancer is between 1 in 4 and 1 in 8 (12–25%). Covers less than 4 percent of the female population.
- **High risk** – Potential high risk and known high risk includes women who are known to carry a breast cancer susceptibility gene mutation (eg, BRCA1 or BRCA2) and women who have a strong family history with at least two first degree relatives affected, plus other features (see 1.1.6 below). Lifetime risk of breast cancer is between 1 in 2 and 1 in 4 (>25%). Covers less than 1 percent of the female population.

1.6 For more details refer to the National Breast and Ovarian Cancer Centre guideline *Advice about Familial Aspects of Breast Cancer and Epithelial Ovarian Cancer* (NBOCC 2010), available from: www.canceraustralia.gov.au/sites/default/files/publications/nbocc-bog-2010-web-a4-printable_504af02a673fd.pdf.

[1] The National Breast and Ovarian Cancer Centre amalgamated with Cancer Australia in 2011.

1.7 The National Breast and Ovarian Cancer Centre guideline is primarily based on familial risk assessment. It does not include other risk factors, such as biopsy showing atypical ductal hyperplasia, age at menarche, age at menopause, age at first child birth, previous radiation therapy and breast density. Other tools may be better to assess risks associated with medical and reproductive history; for example, the National Cancer Institute Breast Cancer Risk Assessment Tool (www.cancer.gov/bcrisktool) and the IBIS (also called the Tyrer-Cuzick) Breast Cancer Risk Evaluation Tool (www.ems-trials.org/riskevaluator).

1.8 Health care professionals should discuss risk issues fully so that the woman understands what she can and cannot do to modify her risk of breast cancer, and the effect this will have on her risk of other disease and conditions.

1.9 Genetic testing may be appropriate for some families assessed as potentially high-risk by Genetic Health Service New Zealand. The *eviQ Cancer Genetics – Breast and Ovarian Referral Guidelines* should be used to determine appropriate referrals to Genetic Health Service New Zealand. See Genetic services section and Appendix 5.

1.10 Breast care units should have documented policies for managing women with increased risk (expert opinion).

1.11 Women who fall in risk category 1 (at or slightly above average/population risk) should be screened as per population screening (see Standard 1.1)

Screening – surveillance of women at moderately increased risk

Good practice points

1.12 Women who are at moderately increased risk or greater should be considered for yearly mammography from age 40–50, then two-yearly mammograms after age 50.

1.13 A specialist may recommend that mammography commences at a younger age under certain circumstances.

1.14 A specialist may recommend that mammography continues annually in some women after age 50 (eg, those with dense breast tissue).

1.15 Women should be encouraged to report any breast changes (such as lumps, nipple discharge, discolouration, development of abscesses, pain or swelling) promptly to their clinician.

1.16 Women should have an annual clinical breast examination with a clinician from 10 years prior to the age of onset for the youngest affected family relative, or starting at 25–30 years of age (Genetic Health Service New Zealand 2012).

Screening – surveillance of women who are known to carry a breast cancer susceptibility gene mutation (eg, BRCA)

Standard 1.2	Women who are known to carry a breast cancer susceptibility gene mutation (BRCA) have annual breast MRI and consider annual mammography from 10 years prior to the age of onset for the youngest affected family relative. Mammography is not recommended before 30 years of age.

Rationale

Breast MRI is the most sensitive and specific test for early breast cancer detection in breast cancer susceptibility gene mutation carriers. Mammography and ultrasound have been shown to be relatively insensitive in this group.

Good practice points

1.17 Women with p53, PTEN and CDH-1 (E-cadherin) gene mutations are managed similarly to breast cancer susceptibility gene mutation carriers.

1.18 Mammography is not recommended under 30 years of age, because of the low sensitivity of the test and the risk of radiation-induced cancer (NHS Cancer Screening Programmes 2013; Pijpe et al 2012; expert opinion).

1.19 Women with p53 mutations are especially at risk of radiation induced malignancy so should not have mammograms. Whole body MRI may be considered in view of the complex of malignancies associated with p53 mutations.

1.20 Women are encouraged to report any breast changes (such as lumps or swelling, nipple discharge, skin puckering or discolouration) promptly to their clinician.

1.21 Women have a clinical breast examination every six to 12 months with a clinician who specialises in breast care from 10 years prior to the age of onset for the youngest-affected family relative or starting at 25–30 years of age (Genetic Health Service New Zealand 2012).

1.22 The specialist responsible for a woman's ongoing management should follow general high-risk surveillance recommendations developed by Genetic Health Service New Zealand (Genetic Health Service New Zealand 2012).

See Standard 1.4 and Genetic services section (Surveillance of women of potentially high risk but mutation status not known).

Surveillance of women of potentially high risk but mutation status not known[2]

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

Good practice points

See good practice points for Standards 1.2 and 9.2.

[2] The National Breast Cancer Tumour Standards Working Group considers that an appropriate model of care for women at increased breast cancer risk is developed. This is outside the scope of these standards to make recommendations about the appropriate model of care.

Genetic services

Standard 1.4	Referral to Genetic Health Service New Zealand is discussed and offered for women whose family history meets the risk level for referral in the *eviQ Cancer Genetics – Breast and Ovarian Referral Guidelines*.

Rationale

The newly formed national organisation, Genetic Health Service New Zealand, provides expert genetic diagnosis and advice.

Assessment by this specialist service enables women and their family/whānau to be fully informed on the complex issues surrounding genetic testing.

For potentially high risk women, and for some women at moderately increased risk who are eligible and choose to undertake genetic testing, this will be arranged.

Good practice points

1.23 For more details regarding referral see *eviQ Cancer Genetics – Breast and Ovarian Referral Guidelines.* See Appendix 5, and available from www.eviq.org.au. Login required. Click on Cancer Genetics then Referral Guidelines and then Breast and Ovarian Referral Guidelines.

1.24 Referrals to Genetic Health Service New Zealand include a brief family history and any pathology information available.

1.25 Women are encouraged to obtain accurate details about relatives who have had cancer, including cancer type and age of onset.

1.26 Where appropriate, genetic testing is considered for women without a family history; in particular for:

- women diagnosed with a high-grade triple negative breast cancer under 40 years
- women with epithelial ovarian cancer; in particular, serous ovarian cancer and especially when cancer was diagnosed under 60 years
- women of Ashkenazi Jewish ancestry.

1.27 The current threshold for breast cancer susceptibility gene mutation (BRCA) testing using a BRCA scoring model (eg, BRCAPRO or BOADICEA) is 20 percent or more for detection of a mutation.

1.28 Initial mutation analysis is undertaken using a deoxyribonucleic acid (DNA) sample from an affected family member.

1.29 Asymptomatic relatives are offered genetic testing only if a mutation is identified in their family. For women with Ashkenazi Jewish ancestry and a

personal or family history of breast or ovarian cancer, genetic testing of three Ashkenazi founder mutations is offered.

1.30 The implications of the test result for the extended family should be discussed, and a plan made for informing at-risk family members.

1.31 Genetic Health Service New Zealand provides a general 'family letter' to all families when a BRCA gene mutation is identified.

1.32 Women who undergo genetic testing must be willing to share test results with family members and relatives (Genetic Health Service New Zealand 2012).

Genetic services – timeliness of services

Good practice points

1.33 Genetic Health Service consultations take place within the following timeframes:

- semi-urgent referrals – initial contact by phone within five working days
- priority referrals – consultation in next available clinic within three months of referral
- routine referrals – consultation within six months of referral date.

1.34 Genetic Health Service works to specific referral priority categories (Genetic Health Service New Zealand 2012).

Semi-urgent

- Affected woman with terminal cancer.
- Unaffected woman with a family history including an affected relative who is seriously unwell – DNA storage for sick relatives may be required urgently. Contact by phone then reassess priority.
- Newly diagnosed woman with high risk family history being referred for surgical decision-making purposes (eg, whether to undergo breast-conserving surgery or mastectomy; or whether to undergo bilateral mastectomy with or without reconstruction).

Priority

- Affected individual with high risk features.
- Predictive testing of unaffected individuals.
- Unaffected patient with a family history, being referred for surgical decision-making purposes.

Routine

- Unaffected with family history.
- Affected, but currently well with no high risk features (Genetic Health Service New Zealand 2012).

Genetic services – management of mutation carriers and women with high risk

Standard 1.5	Women should not undergo prophylactic mastectomy or oophorectomy without being offered genetic services referral.

Rationale

Genetic testing helps inform decision-making, and may avoid the risk of prophylactic surgery being carried out in women at no increased risk – a decision that can lead to significant anguish and regret.

Good practice points

Management of mutation carriers

1.35 Women who carry a breast cancer susceptibility gene (eg, BRCA) mutation may want to consider risk-reducing mastectomy.

1.36 It is currently suggested that women carrying a breast cancer susceptibility gene-1 (BRCA1) or breast cancer susceptibility gene-2 (BRCA2) mutation consider risk-reducing salpingo oophorectomy at about age 40.

1.37 The risk of delaying risk-reducing surgery (breast or ovarian) until after child bearing is low.

1.38 The effects of early menopause must be discussed with any woman considering risk-reducing bilateral oophorectomy.

1.39 Options for management of early menopause must be discussed with any woman considering risk-reducing bilateral oophorectomy, including the advantages, disadvantages and risk impact of hormone replacement therapy (NICE 2006; NZGG 2009).

Management of women at moderate to high risk

1.40 Tamoxifen, which has been demonstrated to reduce risk in women at moderate to high risk, should be considered as an option for those women.

2 Timely Access to Services

Timely access – referral

Standard 2.1	Women referred urgently with a high suspicion of breast cancer have their FSA within 14 days.
Standard 2.2	Women referred with a moderate suspicion of breast cancer have their FSA within 30 days.
Standard 2.3	Women referred with a low suspicion of breast cancer have their FSA within 90 days.

Rationale

Timely access to quality cancer management will result in better health outcomes for New Zealanders. Key components of successful cancer management include early recognition and reporting of symptoms, expertise in identifying patients requiring prompt referral and rapid access to investigations and treatment.

A suspicion of cancer or a cancer diagnosis is very stressful for patients and their family/whānau. It is important that patients and family/whānau receive a clear expectation giving certainty about how quickly patients can receive treatment. Long waiting times may affect local control and survival benefit for some cancer patients, and can result in delayed symptom management for palliative patients.

Timed patient pathways have been put in place to ensure:

- patients receive timely quality clinical care
- patients are managed through the pathway and experience well-coordinated service delivery
- delays are avoided as far as possible.

The FCT indicators (Standards 2.1, 2.4 and 2.5) adopt a timed patient pathway approach across surgical and non-surgical cancer treatment, and apply to inpatients, outpatients and day patients (Ministry of Health 2012b; 2012c).

Shorter waits for cancer treatments are a government health target. This health target includes all radiation treatment patients and chemotherapy patients.

Timely access to services is especially important to address inequities. It is well demonstrated that Māori tend to wait longer for cancer care. A major goal of these standards is to address this issue.

Good practice points

2.1 GP practices refer women to secondary care services within one working day of a consultation resulting in high clinical suspicion of breast cancer.

2.2 GPs include all appropriate information in referral correspondence, including that the referral is for a high suspicion of breast cancer (see Appendix 6 for definition of high suspicion of cancer, and ‘Referral and communication’ for information that should be included in a referral).

2.3 Breast cancer services should have mechanisms in place to ensure attendance at appointments.

See Referral and Communication section and Appendix 6.

Monitoring requirements

MR2A	Ensure that 90 percent or more of services meet the performance level specified in the standards.
MR2B	Track FCT indicators.
MR2C	Record ethnicity data on all access targets and indicators.

Timely access – treatment

Standard 2.4	Women referred urgently with a high suspicion of breast cancer receive their first cancer treatment within 62 days.
Standard 2.5	Women with a confirmed diagnosis of breast cancer receive their first cancer treatment within 31 days of the decision to treat.

Rationale

Timely access to treatment results in improved outcomes for women. See rationale at the start of this section.

Some women with breast cancer have more complex diagnostic work-up or treatment decisions to make. The FCT indicators should be achievable for most women with a simple pathway, but will not be for some women with more complex pathways. It is important not to set unrealistic expectations for this group (see Appendix 3 for examples of breast cancer diagnostic and treatment decision pathways).

Referral to a non-surgical treatment provider following breast cancer surgery

Most women with early breast cancer will require adjuvant therapy using radiation therapy, or systemic therapy, and many will require a combination of these.

It is important to start adjuvant systemic or radiation therapy as soon as clinically possible after the completion of surgery.

Good practice points

Surgery treatment

2.4 Date of surgery should be set in consultation with both the surgeon and the woman. Ideally, the woman should be notified of the date for surgery at the time the decision to treat is made. A lot of the anxiety around wait times is not due to the length of the wait but due to not knowing when the surgery date will be.

Referral to a non-surgical treatment provider following breast cancer surgery

2.5 Women requiring consideration of adjuvant therapy have a referral made to a non-surgical cancer treatment provider within 14 days of surgery for breast cancer.

2.6 The surgeon responsible ensures that each woman is informed of treatment recommendations agreed at the MDM and appropriately referred.

Monitoring requirements

MR2D	Ensure that 80 percent or more of women receive services that meet standards 2.4 and 2.5.
MR2E	Track FCT indicators.
MR2F	Collect and analyse ethnicity data on all access targets and indicators.

Timely access – systemic therapy treatment

Standard 2.6	Women recommended adjuvant systemic therapy by an MDT and fit to receive it commence treatment within six weeks of surgery for breast cancer.

Rationale

Waiting times for assessment and treatment should be kept within acceptable limits, to minimise anxiety for women and their family/whānau and maximise the potential benefit of treatment (NHS Quality Improvement Scotland 2008; expert opinion).

The evidence for the effect of delays in delivery of adjuvant chemotherapy after breast cancer surgery comes from case series that by design are potentially open to bias. The data therefore should be interpreted with caution. Trials are generally small, with no standardised cut-off. It is generally agreed that a wait of more than 12 weeks is bad, but there are conflicting results on shorter waits. This may be in part due to the small numbers of patients whose treatment is after the arbitrary cut-off. Lohrisch et al (2006) and Hershmann et al (2006) suggest that prognosis is worse if chemotherapy is more than 12 weeks after surgery. Gagliato et al (2013) indicate outcomes to be worse after 60 days for women with stage II or greater breast cancer, and Alkis et al (2010) show worse outcomes for more than six weeks' delay. Colleoni et al (2000) suggest even shorter waits (eg, 21 days) may be desirable. Cold et al (2005) found no difference with delay but a trend towards worse prognosis after five weeks (HR1.5), lacking statistical power. These standards recommend no more than a six-week delay because:

- there is no clinical reason to delay chemotherapy once the surgical wound is healed – normally within three to four weeks
- the only difference between micrometastatic disease (which is curable in a proportion of women) and metastatic disease (which is not) is time for the cancer to grow. It is therefore logical to provide the cancer with as little time as possible, and not truly justifiable to delay when some of the better studies suggest it is harmful after six weeks
- it was an eligibility criterion for many of the trials of adjuvant chemotherapy that treatment had to commence within six weeks of surgery, so treatment outside this timeframe is not based on clinical trial evidence.

Good practice points

2.7 Women with high-risk breast cancers (for example, where four or more lymph nodes are involved) who are accepted for and fit to receive treatment commence that treatment within two calendar weeks from the decision to treat (Ministry of Health 2010a).

Monitoring requirements

MR2G	Ensure that 90 percent or more of women receive services that meet the standard.

Standard 2.7	Women with inflammatory breast cancer have their FSA with a medical oncologist within two weeks of receipt of referral.

Rationale

Women with inflammatory breast cancer have rapidly growing aggressive cancer with high risk of systemic disease at diagnosis. They therefore need systemic therapy as soon as possible, to have the best chance of controlling the disease.

Monitoring requirements

MR2H	Ensure that 90 percent or more of women receive services that meet the standard.

Timely access – radiation treatment

Standard 2.8	Women with breast cancer referred for radiation oncology assessment have their FSA with a radiation oncologist within two weeks of receipt of referral (where chemotherapy is not part of the management).
Standard 2.9	Women consenting to radiation therapy after surgery commence treatment once the surgical site has healed and within six weeks of surgery (where chemotherapy is not part of management).

Rationale

The evidence for the effect of delays in delivery of adjuvant radiation therapy after breast cancer surgery comes from case series that by design are potentially open to bias. The data therefore should be interpreted with caution. A 2004 study in Canada indicated that delays in receiving radiation therapy of over 12 weeks from surgery resulted in reduced local control rates, predominantly in women who did not receive adjuvant chemotherapy (Hébert-Croteau et al 2004). Similarly, another Canadian study found that a delay in receiving radiation therapy of 14 weeks compared to 8 weeks increased local recurrence rates, even if women received adjuvant chemotherapy (Benk et al 2004). The study by Punglia et al (2010) of 18,050 women found a significant increased risk of recurrence if radiation therapy was commenced over six weeks from surgery. Additionally, there was no sudden jump in recurrence; risk accumulated daily with delay.

It is therefore felt to be best practice for women to receive adjuvant radiation therapy within six weeks of breast cancer surgery; particularly if adjuvant chemotherapy is not being administered.

Good practice points

2.8 All women accepted for treatment and fit to receive it commence that treatment within four weeks of being ready to treat or earlier, depending on urgency (Ministry of Health 2011).

2.9 Women referred to multiple specialities for ongoing care should attend FSAs in an ordered fashion. For example, women referred for both chemotherapy and radiation therapy may have their FSA with a radiation oncologist delayed until the latter stages of chemotherapy.

2.10 Radiation therapy should commence one month after the last of dose of chemotherapy (expert opinion).

2.11 Women referred for palliative radiation therapy are seen and commence treatment in as short a time as possible according to the nationally agreed timeframes in the Radiation Oncology Prioritisation Guidelines (Ministry of Health 2011).

3 Referral and Communication

Standard 3.1	Women and their GPs are kept informed throughout their breast cancer journey, and women are provided with verbal and written information about their breast cancer, diagnostic procedures, treatment options (including effectiveness and risks), final treatment plan and support services.

Rationale

Good communication skills are fundamental to the development of an effective relationship between a woman with breast cancer and her health practitioner, as is a multidisciplinary approach to care, which ensures that the woman remains the centre of care.

Good communication is likely to reduce anxiety, and increase a woman's trust and confidence in cancer care providers. This will increase the chance that she receives the treatment that is most appropriate for her. Good information may improve compliance with treatment, reduce complaints and enhance health outcomes.

Good practice points

3.1 Women are kept informed of the status of their referral and appointments and the results of investigations.

3.2 Appropriate information, in written form or via face-to-face communication, is required to support women and their family/whānau throughout the cancer journey (Ministry of Health 2010b).

3.3 Health professionals are sufficiently skilled and supported to effectively communicate with all those affected by breast cancer, including Māori, Pacific and those from other ethnic minorities.

3.4 Cultural advisors, trained patient advocates and interpreters are offered to Māori, Pacific and other cultural groups.

3.5 Clinicians and breast cancer or cancer nurse coordinators, in consultation with women, determine the level and amount of information that will be most effective in enabling them to understand their condition and treatment options, and the degree to which they want to be involved in decision-making.

3.6 Women must be given adequate time to discuss treatment options with both senior clinicians and their breast cancer or cancer nurse coordinator, and to reflect and discuss with family/whānau, before being expected to make any decisions about treatment.

3.7 Health practitioners acknowledge that the needs of the family/whānau are very important; for some women, family/whānau needs may take priority.

3.8 An information/support pack should be offered to women at the time of diagnosis.

Communications with other health care professionals

Rationale

The rationale for this standard is to ensure rapid and effective two-way information flow between service providers transferring and sharing information on referral, diagnosis, treatment, follow-up and supportive/palliative care.

Good practice points

3.9 Referral for any woman with a new problem includes:

- presenting symptoms
- duration of symptoms
- examination findings
- details and dates of any investigations or previous breast imaging and location/facility where the investigation was done
- a copy of any pathology results
- medical history and medication
- language of preference, for women with English as a second language.

3.10 At completion of hospital-based treatment, a treatment summary and follow-up plan should be supplied to the woman and her GP that includes:

- tumour details, treatment carried out to date and expected side-effects
- current medication and dates for review
- frequency of future visits, and the name of the health professional designated to provide follow-up care
- dates of surveillance mammography; how this will be organised; and for how long
- the need for any other ongoing investigations, such as bone density
- the name of a key contact if the woman has a clinical concern between appointments.

See Appendix 7 for an example of a treatment summary and follow-up guidance for women treated for early breast cancer.

4 Investigations, Diagnosis and Staging

Diagnosis

Standard 4.1	All women with suspected breast cancer are worked up in a dedicated breast care unit using triple assessment to enable a preoperative definitive diagnosis.

Rationale

A dedicated breast care unit is defined as a single integrated unit with the necessary facilities to allow rapid assessment and diagnosis of women with breast problems including cancer. At a minimum, this includes surgeons, radiologists, pathologists, breast care/breast cancer nurses and medical radiation therapists with access to onsite mammography and ultrasound, preferably with stereotactic facilities, and ready access to MRI, nuclear medicine and computed tomography (CT) scanning. A dedicated unit should have sufficient cases to allow effective working and continuing expertise by breast specialists in all the required disciplines, working in a multidisciplinary fashion. It provides all the necessary services, from prevention through to treatment of primary disease, advanced care and palliative care. A breast care unit provides patient support and undertakes data collection and audit. A unit does not have to be contained within a single geographic entity, although this is preferable (Blamey and Cataliotti 2006).

Triple assessment consists of clinical examination, mammography/ultrasound and core biopsy or fine needle aspiration (FNA). Generally, the triple assessment is deemed to give a positive result if any of its components are reported as ‘suspicious’ or ‘malignant’. The use of other diagnostic modalities in place of or in addition to these traditional components is increasing.

The true positive rate for the triple test and for each component is 99.6 percent for the triple test, 85 percent for clinical examination, 90 percent for mammography and 91 percent for FNA cytology (National Breast Cancer Centre 2006).

Use of all three components of triple assessment has the highest sensitivity for the detection of breast cancer, thereby minimising the risk of failing to diagnose a breast cancer.

A positive finding on any one of the components of the triple assessment will steadily increase the probability of cancer, and is an indication for further investigation or treatment. A negative triple assessment suggests that the probability of breast cancer is less than 1 percent, and usually further invasive investigations can be avoided.

Ideally, for women with a benign diagnosis, triple assessment should be performed at a single visit so they can be reassured as soon as possible (NHS Quality Improvement Scotland 2008). This group comprises over 90 percent of breast care unit referrals. Women presenting with findings suspicious of breast cancer may benefit from a staged approach.

Good practice points

Overriding principles of diagnosis and staging

4.1 All women with breast cancer should have clinical assessment and work-up undertaken by an experienced clinician.

4.2 Imaging is reviewed by a radiologist with a specialist interest in breast cancer radiology.

4.3 Pathology should be reviewed by a pathologist with a special interest in breast cancer pathology.

4.4 Investigations required for diagnosis and staging work-up are accessible and available in a timely manner (ie, within one or two weeks of the request).

Clinical examination

4.5 Clinical examination includes an assessment of breast symptoms, past breast problems, general health, breast cancer risk factors and physical examination.

Appropriate imaging

4.6 Mammography for women 35 and over and ultrasound for women under 35 are the initial investigations. Younger women with cancer or highly suspicious findings should also have mammography.

4.7 Ultrasound should be performed for most women with likely invasive cancer including the axilla.

4.8 Image-guided needle biopsy, rather than palpation-guided, should be used for smaller lesions.

4.9 If morphologically abnormal axillary lymph nodes are found on ultrasound and could change patient management, they should undergo image-guided needle biopsy.

4.10 All relevant prior imaging should be available for consultations, prior to any intervention and for MDMs or any decision-making meeting.

4.11 Referrers should receive imaging reports within two working days of the examination. (For mammograms this may be an interim report, if images have not had a second read.)

4.12 Electronic report distribution is desirable.

4.13 Further investigation (such as additional imaging or biopsy) is carried out if imaging results are not consistent with each other or with the history and clinical breast examination.

4.14 In a diagnostic mammogram report, breast density is reported using BI-RADS or a percentage score, given the increased risk of breast cancer and decreased sensitivity of mammography strongly associated with higher breast density (Sauber et al 2013; Boyd et al 2007; Mandelson et al 2000; McCormack et al 2006; ACR 2003; National Breast and Ovarian Cancer Centre 2009).

Role of MRI

4.15 MRI is considered preoperatively in specific clinical situations; where other imaging modalities are not reliable, or have been inconclusive; and where there are indications that it is useful (see NZGG 2009 for further information). These include:

Pre-operative

- invasive lobular carcinoma (recommended)
- suspicion of multicentricity
- lesions of the breast not detectable on other clinical or imaging modalities (eg, T0N+)
- genetic high risk
- breast implants
- age <40 years
- follow-up of neoadjuvant treatment
- dense breasts
- if there is discrepancy between clinical and imaging assessment of disease extent

Post operative

- diagnosis of recurrence.

4.16 MRI in pre- or peri-menstrual women is performed during days 7–14 of the next cycle, but within one week if clinically urgent.

Monitoring requirements

MR4A	Ensure that 90 percent or more of women receive services that meet the standard.

Pre-operative diagnosis

Rationale

Preoperative diagnosis reduces the number of unnecessary operations and allows for patient counselling to plan complete assessment and an appropriate treatment approach before the first operation.

Good practice points

4.17 A preoperative diagnosis should be obtained in over 95 percent of cases.

Pathology

Standard 4.2	Every primary breast cancer is submitted for testing of oestrogen and progesterone receptor and HER2 status.
Standard 4.3	Reporting laboratories participate in an approved external quality assurance programme for receptor testing (eg, the RCPA Quality Assurance Program) and achieve at least satisfactory performance.

Rationale

These factors not only have prognostic influence but also predict response to certain types of therapy. They are therefore part of the core data set on breast cancers.

Oestrogen receptor and progesterone receptor status must be measured by a standard immunohistochemical technique using validated methods. Units offering receptor testing must have rigorous quality assurance processes in place and participate in regular external quality assurance assessments. Such external quality assurance programmes need to mandate minimum performance standards, to ensure the laboratory's ongoing competency. The quality of receptor testing has been shown to vary widely by laboratory and therefore external and independent quality control is essential.

Good practice points

4.18 The following prognostic/predictive parameters are recorded for women with invasive breast cancer, whether or not they have surgery as a primary treatment (Rosselli del Turco et al 2010):

- histological type
- grading (Elston and Ellis modification of the Bloom and Richardson grading system)
- oestrogen receptor and progesterone receptor status
- HER2 receptor status.

4.19 Pathology reports formally state both the proportion of positive nuclei and intensity of staining for oestrogen receptor and progesterone receptor to which a simple semi-quantitative scoring system (eg, Allred/Quickscore) can be applied (NZGG 2009).

4.20 In situ hybridisation testing for HER2 is undertaken for all early breast cancers in line with the RCPA *Invasive Breast Cancer Structured Reporting Protocol*.

Standard 4.4	All breast cancer pathology reports use structured pathology reporting, including all items in the current RCPA *Invasive Breast Cancer Structured Reporting Protocol*.

Rationale

Reporting of all these items is necessary in order to best inform a woman regarding her likely prognosis and to inform further treatment planning.

Good practice points

4.21 Breast cancer pathology should be reported by a pathologist with an interest in breast cancer pathology.

4.22 Pathology report available for:

- FNA: ideally within 24 hours of receipt in laboratory, but 100 percent within 48 hours
- core biopsy: 80 percent within three working days (see NSU 2008)
- Excision specimens (hookwire and mastectomy): 80 percent within five working days and 100 percent within 10 working days.

4.23 Specimens are handled as specified by the current RCPA *Invasive Breast Cancer Structured Reporting Protocol*. All wide local excision and mastectomy specimens are incised and fixed in 10 percent buffered formalin as soon as possible (ideally within an hour) after removal from the woman.

4.24 When a woman is referred to a different provider/institution for definitive surgery, the diagnostic core biopsy or other pathology specimens are reviewed by the pathologist and presented at the MDM where the surgery is planned.

4.25 With breast-conserving surgery or mastectomy, tumour-free margins are measured in both radial and anteroposterior (superficial or deep) directions, for both invasive and in situ cancer.

Staging

Rationale

All women with breast cancer should be staged clinically according to the current tumour node metastases (TNM) staging system for carcinoma of the breast, to define the anatomic extent of the disease and facilitate the planning of subsequent management. Planning of appropriate treatment relies on effective assessment prior to primary treatment (American Joint Committee on Cancer 2009: www.cancerstaging.org/staging/posters/breast24x30.pdf).

While routine use of specialised staging investigations for women with early breast cancer is not indicated, it must be recognised that staging tools are continually evolving and will become increasingly sophisticated.

Currently clinical studies show that the percentage of women with stage I disease with asymptomatic metastases detected by staging tests is very low, and the risk of false positive results is much higher. Staging tests are therefore harmful in this setting (Rosselli del Turco et al 2010).

Women with stage III breast cancer or with clinical signs and symptoms or laboratory values indicating the presence of metastases should have baseline staging tests routinely done if this may affect treatment (NZGG 2009).

In relation to blood tests, some adjuvant therapies may be contraindicated in the presence of liver disease, and in the literature there is an incidence of hypercalcaemia or other conditions in asymptomatic women from a variety of causes (NZGG 2009).

Good practice points

4.26 Women with breast cancer all undergo a clinical staging ‘work-up’ at the time of diagnosis (ie, an assessment of clinical tumour size and loco-regional node involvement and a general physical examination), along with a history to check for possible symptoms of distant metastatic disease.

4.27 Women have a preoperative full blood count, renal function tests, liver functions tests and calcium levels for assessment of fitness for surgery and adjuvant drug therapies.

4.28 Routine preoperative serum biomarkers are not recommended unless there are clinical indications (eg, more advanced breast cancer, comorbidity or preoperative chemotherapy).

4.29 Women with stage I breast cancer should not undergo baseline staging tests (Rosselli del Turco et al 2010).

4.30 Women with stage III breast cancer or with clinical signs and symptoms or laboratory values indicating the presence of metastases undergo baseline staging tests (Rosselli del Turco et al 2010).

4.31 Bone scintigraphy and CT of the chest and liver should be considered for women if it will affect management.

4.32 Results of staging investigations including CT or bone scan are available within one or two weeks of request.

Role of positron emission tomography-computed tomography (PET-CT) in the staging of breast cancer

4.33 PET-CT sodium fluoride (NaF) bone scan including diagnostic contrast-enhanced CT is widely accepted as a superior investigation for assessment of potential osseous metastatic disease, and includes current visceral staging (RCP and RCR 2012).

4.34 PET-CT with 18F-fluorodeoxyglucose (FDG) should currently be reserved for selected women with breast cancer in a problem-solving role, such as equivocal hepatic/pulmonary findings on conventional imaging.

4.35 The role of combined/dual FDG/NaF PET-CT scan has not yet been established.

4.36 FDG and NaF PET-CT imaging studies currently require regional PET-CT variance committee approval.

Role of FDG PET-CT in breast cancer recurrence

4.37 FDG PET-CT should be considered in selected women for:

- differentiation of treatment-induced brachial plexopathy from tumour infiltration in symptomatic women with equivocal or normal MRI
- assessment of response to chemotherapy in women whose disease is not well demonstrated or is equivocal on other imaging
- assessment of recurrence in women with dense breasts (National Collaborating Centre for Cancer 2009; RCP and RCR 2012)
- a problem solving role (eg, equivocal hepatic/pulmonary findings on conventional imaging).

5 Multidisciplinary Care

Standard 5.1	All women with a confirmed breast cancer have their treatment plan discussed at an MDM, and the outcomes of this are clearly documented in the woman's medical records and communicated to the woman and her GP.

Rationale

International evidence shows that multidisciplinary care is a key aspect of best-practice treatment and care for patients with cancer. Multidisciplinary care involves a team approach to treatment planning and care provision along the complete patient cancer pathway.

Cancer MDMs are part of the philosophy of multidisciplinary care. Effective MDMs result in positive outcomes for patients receiving the care and for health professionals involved in providing the care and health services overall. Benefits include improved treatment planning, improved equality of outcomes for patients with cancer, more patients being offered the opportunity to enter into relevant clinical trials, improved continuity of care and less service duplication, improved coordination of services, improved communication between care providers and more efficient use of time and resources (National Breast Cancer Centre 2005; NZGG 2009).

Good practice points

5.1 Every specialist involved in breast cancer care regularly participates in a breast MDM. For further information on expected frequency of attendance, refer to the professional requirements section of the *BreastScreen Aotearoa National Policy & Quality Standards* (NSU 2008).

5.2 The breast cancer MDT should meet weekly or at least fortnightly (NSU 2008).

5.3 The breast MDM membership should include at least the following: a radiologist, a pathologist, oncologists – radiation and medical, breast surgeons, a breast cancer or cancer nurse coordinator, a breast radiographer and psychosocial service representation (as appropriate) (NHS Quality Improvement Scotland 2008). Core members are present for the discussion of all cases where their input is needed.

5.4 Locally agreed referral pathways clearly establish who can refer, how to refer and the timeframes within which referrals are expected (along with processes for late referrals) (Ministry of Health 2012d).

5.5 Treatment recommendations should be available as an electronic record and accessible to other members of a woman's health care team, including her GP (expert opinion).

5.6 The MDM identifies women at high risk for inequitable care so that a special effort can be made to avoid this outcome.

5.7 The MDM report may be used as a basis of referral to a treatment provider, to reduce referral to treatment waiting times.

5.8 Breast cancer core data are collected prior to and during MDMs. Data sets are consistently and routinely captured for use in clinical audit and pathway monitoring for ongoing quality improvement.

5.9 Women are informed about the MDM's recommendations and, in consultation with members of the treating team, make final decisions about their own treatment and care plan.

6 Supportive Care

Guidance for Improving Supportive Care for Adults with Cancer in New Zealand (Ministry of Health 2010b), defines supportive care as 'the essential services required to meet a person's physical, social, cultural, emotional, nutritional, information, spiritual and practical needs through their experience with cancer'. The following domains of supportive care were identified:

- information resources
- interpersonal communication
- psychological support
- social support (including financial)
- complementary and alternative medicines
- support for living long term with cancer
- spiritual and cultural support
- coordination of care and support.

Some of these domains of supportive care are covered in other sections and not repeated in this section.

This section concentrates on the following domains: psychological; social; self-help and support; financial; spiritual and cultural support.

Screening, assessment and referral

Standard 6.1	Women with breast cancer are screened with a validated tool to identify psychological and social needs at key points of their breast cancer experience.

('Validated tools' include the 'Distress Thermometer' or a cancer-related distress self-assessment tool (see Appendix 4). 'Key points' include at diagnosis; at the start, during and at the end of treatments; during follow-up; and in the event of relapse or terminal disease.)

Rationale

A diagnosis of cancer has a huge impact on an individual and their family/whānau. A patient-centred approach provides for the emotional, psychological, social, cultural, economic and spiritual requirements of the individual and their family/whānau, along with their physical needs.

Most women affected by breast cancer experience some form of distress. For most women, this resolves with time and general support, without the need for specialised interventions.

Many women and their families will need additional support to help them cope. Assessment of women and their family/whānau support needs should be undertaken at key points along the breast cancer care pathway.

For some, the distress can be significant and enduring, and may lead to depression, an anxiety disorder or other problems requiring specialist intervention. It is estimated that up to 30 percent of women diagnosed with breast cancer develop psychological morbidity within one year of diagnosis (NZGG 2009).

Support from everyone surrounding the woman with cancer – especially providers of cancer services – is crucial. Evidence suggests that when women with cancer receive good social, psychological and cultural support the quality of their life improves.

Health professionals as a group are proven to be poor at identifying cancer-related distress in women and their family/whānau without use of a formal tool.

Women with breast cancer are often reluctant to discuss their distress with health professionals for fear of judgement, or they may perceive staff to be too busy. Some minimise their issues, believing 'others are worse off than me'.

An accurate assessment is more likely if information is gathered from a variety of sources including the use of a validated tool and a consideration of the risk factors, or vulnerability for distress.

Between 15 and 55 percent of cancer patients may require specialised assessment and intervention (Howell et al 2009).

Good practice points

6.1 All health and social care professionals offer women and their family/whānau (including children) supportive care throughout their cancer journey.

6.2 Care professionals acknowledge each woman's individual supportive care needs, depending on her ethnicity, culture, religion, sexuality, region (rural/urban), education, family circumstances, employment status, economic status and tumour stage.

6.3 Care professionals maintain a high level of cultural competence and understanding of the Māori world view.

6.4 Care professionals make women with breast cancer and their family/whānau aware of all their support entitlements, provide current good quality information about them, and if they choose, guide women through the process of accessing them in a timely manner.

6.5 Up-to-date supportive care services directories are accessible by all staff and people affected by cancer.

6.6 Staff are trained on the use of screening tools and appropriate referral pathways.

6.7 When a woman's distress score meets the threshold for an assessment (eg, ≥4 on a distress thermometer), she is assessed by a health professional who has undertaken relevant training.

6.8 Services develop criteria and pathways for an intervention approach to ensure women are efficiently referred to relevant social or specialist psychological support services (modified Baken and Sutcliffe 2012).

See Appendix 4 for an example of a validated screening and self-assessment tool.

Monitoring requirements

MR6A	Ensure that all women receive services that meet the standard.

Access to specialist psychological services

Standard 6.2	Women or their family/whānau found to have significant psychological distress or facing particularly difficult treatment decisions are offered prompt referral to a specialist psychological service, as part of an integrated cancer service.

Rationale

Most women are able to cope with the emotional impact of cancer using the skills that they have; their response is a normal reaction to a stressful health event.

For others, significant acute or ongoing distress interferes with their medical treatment and quality of life. These women need prompt access to specialist psychological expertise (Howell et al 2009; Baken and Sutcliffe 2012).

Specialist psychological care to reduce the ongoing burden of cancer has been shown to not only benefit affected women but also their family/whānau, supporters and health services.

A variety of psychological interventions, including cognitive behavioural, supportive, group, family and couples therapy, as well as relaxation techniques, reduce psychological distress (NZGG 2009).

Good practice points

6.9 All major cancer units employ a clinical psychologist specialising in psycho-oncology, available to women and their family/whānau.

6.10 Service delivery models provide a tiered approach to supportive care for women and their supporters: that is, provision for psycho-education for many; and one-to-one counselling, cognitive behaviour therapy, short-term group therapy or psychiatric care for a few, where required (modified Baken and Sutcliffe 2012).

6.11 Health care providers are particularly aware of factors associated with an increased risk of psychosocial problems among women diagnosed with breast cancer (NHMRC 2003; expert opinion).

Table 1: Factors associated with an increased risk of psychosocial problems among women diagnosed with cancer

Characteristics of the individual	Characteristics/stages of disease and treatment
• Younger • Single, separated, divorced or widowed • Living alone • Children younger than 21 years • Economic adversity • Lack of social support, perceived poor social support • Poor marital or family functioning • History of psychiatric problems • Cumulative stressful life events • History of alcohol or other substance abuse	• At the time of diagnosis and recurrence • During advanced stage of the disease • Poorer prognosis • More treatment side-effects • Greater functional impairment and disease burden • Experiencing lymphoedema • Experiencing chronic pain • Fatigue

Additional risk factors and issues relating to breast cancer requiring particular attention that have been identified by the National Breast Cancer Tumour Standards Working Group

- Difficult or multiple therapeutic decisions needing to be made (eg, breast reconstruction, or where the risk benefit profile of a treatment is not great)
- Women with significant family history or genetic risk
- Previous personal or family history of exposure to a bad cancer outcome or cancer experience
- Where prophylactic surgery is being considered
- Desire to retain fertility
- Pregnant at time of diagnosis
- Impact of treatment on sexuality
- Impact of treatment on body image
- Men with breast cancer
- Māori and Pacific people may be in particular need of support services
- Recent immigrants/refugees or women/families with English as a second language
- Disability or other significant co-morbidities or health concerns
- Difficulties getting to treatment centre
- Conflict within family regarding appropriate treatment

Monitoring requirements

MR6B	Demonstrate that all women have access to a clinical psychology service.

Cultural and spiritual support

Rationale

Women may have difficulty accessing cultural and/or spiritual support unless health professionals have appropriate knowledge and training to advise how to seek such support.

Good practice points

6.12 Health and social care professionals help women and their family/whānau (including children) access cultural and spiritual support.

6.13 All women with breast cancer who identify as Māori are asked if they would like to be referred to their local Māori support provider at key points in their journey.

6.14 All women who identify as an ethnicity other than European or Māori are asked if they would like to be referred to specific support services or providers.

6.15 All health care providers are aware of, acknowledge and where possible incorporate specific cultural norms into their practice.

6.16 All women are made aware of available spiritual supportive care services and asked if they would like a referral at key points in the journey.

See also ‘Referral and communication’.

7 Care Coordination

Standard 7.1	All breast care units have a dedicated breast cancer or cancer nurse coordinator to facilitate the treatment pathway and provide guidance and support from diagnosis through to follow-up.

Rationale

The cancer journey is complex, and it is not uncommon for a woman to be seen by many specialists within and across multiple DHBs and across the public and private sectors.

Care coordination is a comprehensive approach that aims to:

- provide continuity of care
- improve the experience for women with breast cancer or suspected breast cancer and for their family/whānau
- improve overall access and timeliness of access to services.

Breast cancer and cancer nurse coordinators have a specialist knowledge of the breast cancer care pathway and treatment options, and act as advocates for women: facilitating coordination of the diagnostic and treatment pathway, providing continuity and ensuring they know how to access information and advice.

Implementing breast cancer and cancer nurse coordinator roles is a strategy that contributes to the aims of care coordination. Key responsibilities of breast cancer and cancer nurse coordinators include:

- early identification and assessment of women at greatest need of support
- care coordination (see Table 1: ‘Factors associated with an increased risk of psychosocial problems among women diagnosed with breast cancer’ in the Supportive Care section).
- provision of information, support and nursing care
- provision of advice/education to other nurses and health professionals
- ensuring best-practice service provision
- collaboration with other health professionals to improve outcomes for women.

Given the specialised knowledge required and the range and level of responsibilities involved, care coordinators should be clinical nurse specialists.

Good practice points

7.1 Women with breast cancer and their family/whānau have equitable and timely access to appropriate medical, allied health and supportive care services (Ministry of Health 2010b).

7.2 All women are assigned a care coordinator, and their GPs are informed who this person is.

7.3 Sometimes (eg, during long-term follow-up), this role may be undertaken by other staff; for example, a primary care team member or other specialist, as appropriate (NICE 2004).

7.4 Large DHBs employ a dedicated breast cancer nurse coordinator. Small DHBs may employ one cancer care coordinator for several types of cancer.

7.5 If there is no Māori or Pacific care coordinator in the breast care unit, units consider linking women with Māori and Pacific providers, or working in partnership with such providers to provide better support for Māori and Pacific women.

7.6 Care coordination remains the responsibility of all health professionals and should be included in all health professionals' practice.

See also 'Supportive care'.

8 Treatment

Overriding principles of breast cancer treatment

Breast cancer treatments must be carried out and monitored by appropriately trained surgeons, medical oncologists and radiation oncologists, all of whom will be regularly attending breast MDMs. See Multidisciplinary Care section.

Women with breast cancer should have equitable access to all approved treatments, where clinically appropriate, in order to provide those women with the best possible chance of long-term survival and quality of life.

Refer to participation in clinical trials, section 11: 'Clinical performance monitoring and research'.

Surgery

Surgery – surgeon expertise

Standard 8.1	All women requiring breast cancer surgery are treated by surgeons who are full members of BreastSurgANZ or provisional full members. Membership will be a credentialling requirement for practice of breast cancer surgery.

Rationale

Breast cancer surgery should be carried out by surgeons with a special interest and expertise in the treatment of breast cancer.

Good practice points

8.1 Membership of BreastSurgANZ requires full participation in the society's audit and in the Royal Australasian College of Surgeons (RACS) Continuing Professional Development Program.

Monitoring requirements

MR8A	Ensure that all surgeons credentialled to perform breast cancer surgery are full members (or provisional full members) of BreastSurgANZ.

Surgery – choice of breast-conserving surgery versus mastectomy

Standard 8.2	All women with early-stage invasive breast cancer who are candidates for breast-conserving surgery are offered the choice of breast-conserving surgery or mastectomy.

Rationale

The aim of surgery for early invasive breast cancer is to eradicate the primary tumour and any local extension, with a view to achieving local disease control.

Breast-conserving surgery aims to achieve complete local excision of the cancer with an adequate margin, leaving a reasonably shaped and symmetrical breast.

Breast-conserving surgery is less major surgery than mastectomy (especially when reconstruction is also involved), and is associated with less morbidity and quicker recovery. It is less invasive and less disfiguring, and enables women to retain a sensate and much more normal breast than mastectomy with or without reconstruction.

Good practice points

8.2 The choice of surgery should be tailored to the individual, who should be fully informed of the options, and made aware that radiation therapy is required following breast-conserving surgery and that further surgery may be required if the margins are positive or close (NZGG 2009).

8.3 Breast-conserving surgery may be considered for a woman with a centrally located tumour, although it may require excision of the nipple and areola, which may compromise cosmesis (NZGG 2009).

8.4 A woman with early-stage invasive breast cancer is informed of the benefits and harms of radiation therapy prior to making a decision on surgery (NZGG 2009).

8.5 Following local excision of malignant lesions, the cavity may be marked with radio-opaque markers to facilitate radiation therapy planning. Surgeons and the regional radiation oncologists should develop a regional policy to determine appropriate marking of the excision cavity (National Health Committee and RACS 1997).

8.6 Mastectomy, rather than breast-conserving surgery, should be considered if:

- the ratio of the size of the tumour to the size of the breast and location of the tumour would not result in acceptable cosmesis
- there is multifocal/multicentric disease, or extensive malignant microcalcification on mammogram that breast-conserving surgery cannot adequately clear with an acceptable cosmetic result

- there is a contraindication to local radiation therapy (eg, previous radiation therapy at the site, connective tissue disease, severe heart or lung disease or pregnancy)
- mastectomy is the woman's preference (NZGG 2009).

Surgery – disposal of tissue

Rationale

The disposal of tissue may be of particular significance to some women, particularly for Māori and Pacific women, so health professionals should approach this issue with sensitivity and awareness. Respect for tissue and body parts shows respect for the woman from whom the tissue or body part was taken.

Pacific women may wish to be buried as a whole person if they are to die. This has implications for whether Pacific women will opt for mastectomy and if so whether the woman chooses to retain the tissue postoperatively (NZGG 2009).

Health professionals will support the return of tissue or body parts to those women for whom it has personal significance and to Māori and Pacific women and others where it has cultural significance.

Good practice points

8.7 Surgeons consult with all women undergoing surgery for breast cancer about final disposal of tissue or body parts surgically removed, and support the return of tissue or body parts to those women for whom it has personal or cultural significance (modified NZGG 2009).

8.8 Women, particularly Māori and Pacific women, are given the option of retaining the tissue postoperatively (NZGG 2009).

Surgery – surgical specimen

Rationale

Requests from the surgical team for pathology of a specimen of breast tissue must include all of the information necessary for pathologists to perform an examination properly. Care taken in recording data is crucial to ensure accuracy of the final pathology report, and this requires the commitment of the surgeons involved.

Good practice points

8.9 The surgical team provides clear information to the pathologist regarding the side and position the specimen has come from, and appropriate clinical and imaging findings (eg, calcification, stellate or cystic lesions) and previous biopsy results (NZGG 2009).

Surgery – margins of excision for breast-conserving surgery

Standard 8.3	Women undergoing breast conserving surgery for invasive cancer or DCIS require complete excision of tumour with clear margins. Circumferential or radial margins of ≥2 mm should be achieved where possible.

Rationale

If breast cancer is not adequately excised, the local recurrence rate will be unacceptably high.

Adequate excision of the cancer is important to minimise local recurrence and optimise survival.

On the other hand, returns to theatre for second and third operations provoke anxiety for women and incur additional morbidity, cost and use of resources. Additionally, re-excisions frequently result in worse cosmetic outcomes.

Good practice points

8.10 For women with invasive breast cancer with margin widths <2 mm, several factors should be considered in determining whether re-excision is required:

- age and comorbidity (as risk of local recurrence decreases with increasing age)
- tumour histology (lymphovascular invasion, grade, extensive in situ component (EIC) and tumour type (eg, lobular carcinoma)
- which margin is approximated by the tumour (smaller margins may be acceptable for deep and superficial margins)
- extent of cancer approaching the margin (NZGG 2009).

8.11 In the case of invasive cancer or DCIS extending up to a margin of excision, further surgery – either wider excision or mastectomy – is required to achieve clear margins in the absence of contraindications (NZGG 2009).

8.12 For women with DCIS with margin widths <2 mm, several factors should be considered in determining whether re-excision is required:

- age and comorbidity (as risk of local recurrence decreases with increasing age)
- size grade, and the presence or absence of comedo necrosis

- which margin is approximated by DCIS (smaller margins may be acceptable for deep and superficial margins, as by definition DCIS does not go into muscle or subcutaneous fat)
- extent of DCIS approaching the margin (NZGG 2009).

Single excisional procedure

8.13 Women undergoing breast-conserving surgery should preferably have complete surgical excision at their first operation (Jeevan et al 2012).

8.14 Specimen imaging is performed for all cases of impalpable mammographically detected lesions to ensure adequate removal, and where specimen X-ray may facilitate pathological examination (eg, for a palpable invasive carcinoma with associated impalpable calcification (DCIS)) (NZGG 2009).

Monitoring requirements

MR8B	Ensure that 90 percent or more of women receive services that meet standard.

Surgery – surgical management of the axilla

Standard 8.4	Surgical assessment of axillary lymph node status is undertaken for most early invasive breast cancer.

Rationale

Surgical assessment of axillary lymph node status is undertaken in order to stage the disease, to minimise the risk of loco-regional recurrence and to assist in the planning of adjuvant therapy. Axillary lymph node status remains the single most significant prognostic factor (although it may be surpassed by molecular markers in the near future).

Good practice points

8.15 Surgeons performing sentinel lymph node biopsy are appropriately trained and experienced in the technique, and demonstrate an acceptable sentinel node identification rate. The RACS 'Sentinel Node versus Axillary Clearance' trial requirement for accreditation was a sentinel lymph node identification rate of 90 percent or greater in 20 consecutive cases (Grantley Gill 2004).

8.16 Women with unifocal breast cancer clinically ≤30 mm in size and clinically negative axilla undergo sentinel-node-based management (NZGG 2009).

8.17 Women with involved lymph nodes identified preoperatively should be managed with axillary lymph node dissection.

Monitoring requirements

MR8C	Ensure that 90 percent or more of women receive services that meet the standard.

Standard 8.5	Axillary lymph node dissection is not performed in women with DCIS only.

Rationale

DCIS by definition has not spread to axillary lymph nodes. A finding of involved nodes when only DCIS is found in the breast is rare. Women with DCIS should therefore be spared the morbidity of axillary lymph node dissection.

Sentinel node biopsy may be appropriate after a core biopsy has shown DCIS and where the DCIS is extensive or of high grade. In this circumstance there is a greater risk of invasive breast cancer within the lesion that may not have been detected by core biopsy.

Monitoring requirements

MR8D	Ensure that all women receive services that meet the standard.

Surgery – breast reconstruction

Standard 8.6	Clinicians discuss delayed or immediate breast reconstruction with all women who are due to undergo mastectomy, and offer it except where significant comorbidity precludes it. All appropriate reconstruction options are offered and discussed with women, irrespective of whether they are all available locally.

Rationale

Breast reconstruction is an important means of enhancing body image and self-confidence after mastectomy, for women who are prepared to undergo more major surgery.

Breast reconstruction is not associated with a higher risk of recurrence. Women who have breast reconstruction report a number of benefits, including: a feeling of being whole again, better psychological and social adjustments to their cancer and mastectomy, more positive body image, better sexual adjustment, less depression and feeling more comfortable without a prosthesis (Scottish Intercollegiate Guidelines Network 2005).

Some potential morbidities and complications are associated with breast reconstruction, including: those associated with more major surgery, longer recovery time, higher risk of wound healing problems, loss of autologous tissue, loss of implant, a frequent need for subsequent surgery, reduced muscle strength at donor sites and pain and scarring at donor sites.

Immediate reconstruction has the advantage, to those women for whom loss of body image is a concern, of having one primary breast procedure and offering the possibility for limited skin removal. However, a large quantity of information about reconstruction has to be discussed with women for them to make informed decisions; this can be difficult when a woman is at the same time absorbing a diagnosis of breast cancer. Furthermore, potential complications of reconstruction may delay subsequent adjuvant therapy. Chest wall radiation therapy, if it is required, may significantly reduce the cosmetic outcomes of immediate reconstruction (NZGG 2009).

Methods of reconstruction include implant-based techniques, pedicled flaps and free tissue transfers There are pros and cons of each method that need to be considered with other patient characteristics when deciding which approach is best for each individual. Those informing women about the procedure must have a thorough knowledge of the techniques available. Furthermore, well-defined referral pathways must be in place where not all methods can be carried out locally (NZGG 2009).

One of the goals of breast cancer surgery is to restore a woman's breast to as normal a state as practical, as part of her treatment, and in keeping with her wishes. To achieve this many women require more than one operation to the same breast and/or contralateral breast surgery for symmetry to attain an appropriate result after reconstruction and sometimes after breast-conserving surgery.

Good practice points

8.18 Where breast reconstructive surgery is not carried out locally, or where more complex reconstruction procedures are required, any women identified as requiring specialist input from an oncoplastic breast surgeon or a tertiary plastic and reconstructive service should be referred on through well-defined referral pathways.

8.19 Discussion about immediate breast reconstruction should include the fact that a complication may occasionally delay adjuvant chemotherapy or radiation therapy. Neo-adjuvant chemotherapy may avert the possibility that a complication of immediate breast reconstruction delays postoperative chemotherapy.

8.20 If post-mastectomy radiation therapy is likely then delayed reconstruction may be preferred because radiation therapy may impact on the cosmetic outcome of immediate breast reconstruction. Women should be made aware of this risk (NZGG 2009).

8.21 Revisional surgery, implant exchange, capsulectomy, nipple areola reconstruction, contralateral reduction or mastopexy and delayed reconstruction are all available to women in the public health service, within a reasonable timeframe.

8.22 Women who have undergone breast-conserving surgery who are unhappy with the outcome (including symmetry) are referred for discussion of reconstruction, revisional or contralateral breast surgery.

Systemic therapy

Systemic therapy – primary (neoadjuvant) systemic therapy

Rationale

Primary systemic therapy is indicated for locally advanced breast cancer (stages IIIA–B) in order to control systemic and local disease and for larger operable tumours for reducing tumour size in order to possibly perform breast-conserving surgery (Aebi et al 2011).

It is indicated for some women requiring mastectomy, to give them more time to consider choices, issues and planning processes around breast reconstruction.

Increasingly, neoadjuvant therapy is also being used for women with earlier stage breast cancer. This enables observation of the response of the primary tumour to treatment.

Good practice points

8.23 Primary (neoadjuvant) systemic therapy should be followed by both surgery and radiation therapy according to the principles as outlined in the respective subsections of this cluster ('Surgery' and 'Radiation therapy') (Aebi et al 2011).

8.24 Before primary (neoadjuvant) systemic therapy, a biopsy (preferably core needle) is essential to confirm an invasive cancer and its characteristics, including hormone receptor and HER2 status.

8.25 If preoperative (neoadjuvant) systemic therapy is planned, additional investigations such as chest X-ray or CT scan of the chest and abdomen and bone scintigraphy should be considered, to exclude metastatic disease (modified Aebi et al 2011).

8.26 Neoadjuvant chemotherapy is chosen based on predictive factors similar to the way adjuvant treatment is chosen.

8.27 Neoadjuvant endocrine therapy may be useful, but this has not been investigated in randomised controlled clinical trials (Aebi et al 2011).

Standard 8.7	Women with inflammatory breast cancer receive primary chemotherapy, and not surgery, as their first cancer treatment.

Rationale

Women with inflammatory breast cancer have systemic disease at diagnosis and accordingly need systemic therapy as soon as possible. With this approach 50 percent five-year survivals have been obtained, compared to historical series where survival to five years was rare (Harris et al 1991).

Good practice points

8.28 Inflammatory breast cancer is a clinical diagnosis. See Glossary for a definition of inflammatory breast cancer.

Monitoring requirements

MR8E	90 percent or more of women receive services that meet the standard.

Systemic therapy – adjuvant chemotherapy

Rationale

Data from meta-analyses and from multiple individual clinical trials offer evidence of benefit from adjuvant chemotherapy in terms of relapse-free survival, overall survival and long-term quality of life in appropriately selected women.

Administration of radiation therapy first (in studies where chemotherapy has been delayed as a result) has resulted in some worse distant disease-free survival outcomes.

Good practice points

8.29 A multiplicity of chemotherapy regimens acceptable for adjuvant treatment exists.

8.30 Adjuvant chemotherapy should be administered prior to whole-breast radiation therapy.

8.31 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. Consultation with a fertility specialist is arranged for those women who wish to preserve fertility. Women must receive timely access to fertility assessment and treatment.

Systemic therapy – adjuvant targeted therapy

Standard 8.8	Women with invasive breast cancer ≥5 mm or node-positive, demonstrating HER2 over expression or amplification, and fit for chemotherapy are offered adjuvant treatment with HER2 targeted therapy and chemotherapy.

Rationale

Clinical trials have shown that adjuvant trastuzumab improves relapse-free survival and overall survival in women with node-positive or node-negative T >10 mm HER2 positive early breast cancer above chemotherapy alone (Rosselli del Turco et al 2010).

While randomised trials have excluded women with small primaries (<10 mm), over-expression of HER2 confers a poorer prognosis even in these small breast cancers, and the use of trastuzumab should be discussed with women with small (≥5 mm), node-negative breast cancers who are fit for chemotherapy (Aebi et al 2011).

Good practice points

8.32 The weight of evidence supports a year of treatment with trastuzumab as the current standard.

8.33 Women receiving trastuzumab have their cardiac function monitored regularly (eg, three-monthly) using multi-gated acquisition scans (MUGA) or echocardiography (NZGG 2009).

Monitoring requirements

MR8F	Ensure that 80 percent or more of women receive services that meet the standard. (This target accepts that the MDT will not recommend some women for chemotherapy, and that some breast cancers are of low enough risk not to be considered for these treatments.)

Systemic therapy – endocrine therapy

Standard 8.9	Women with endocrine-responsive[3] invasive breast cancers are considered for endocrine therapy (Aebi et al 2011).

Rationale

Data from meta-analyses and from multiple individual clinical trials offer evidence that appropriately selected women with breast cancer may benefit from endocrine treatment in terms of relapse-free survival, overall survival and long-term quality of life.

The clinical trials of adjuvant endocrine therapy generally limited enrolment to women with ≥10 percent oestrogen-positive breast cancers, but retrospective analysis of archival material indicates that oestrogen expression as low as 1 percent may confer sensitivity to endocrine therapy.

Good practice points

8.34 In premenopausal women, tamoxifen alone and/or ovarian function ablation/suppression are standard therapies (Aebi et al 2011).

8.35 In women considering oophorectomy a trial of at least three months of a gonadotrophin-releasing hormone (GnRH) analogue is recommended to allow an assessment of the tolerability of such treatment before committing to an irreversible procedure (NZGG 2009).

8.36 Tamoxifen should not be used simultaneously with chemotherapy. The best use of GnRH analogues or aromatase inhibitors (concurrent or sequential with chemotherapy) is unknown (Aebi et al 2011).

8.37 Currently there is no randomised controlled trial evidence to support the use of ovarian function suppression (GnRH analogue or oophorectomy) in conjunction with an aromatase inhibitor in premenopausal women. This is not recommended outside the remit of a clinical trial.

8.38 In postmenopausal women, an aromatase inhibitor for five years is standard therapy. For women being treated with tamoxifen, a switch to aromatase inhibitors after two to three years of tamoxifen is recommended. In postmenopausal women, five years of tamoxifen alone is still a good option for those at low risk of recurrence and when an aromatase inhibitor is contraindicated or not tolerated. For some women there may be an additional benefit for ten years of tamoxifen over five years (Aebi et al 2011; NZGG 2009).

[3] Endocrine responsive is defined as any detectable (≥1%) expression of oestrogen and/or progesterone receptors.

8.39 Measurement of oestrogen and gonadotrophin levels is recommended before initiating treatment with an aromatase inhibitor where there is a chance that a woman is still premenopausal. Particular care is required in treating younger women just after chemotherapy or on tamoxifen, as amenorrhoea can occur when normal premenopausal ovarian oestrogen production is present.

8.40 Tamoxifen leads to elevated gonatrophin levels, even in the presence of normal premenopausal ovarian endocrine function. Follicle-stimulating hormone (FSH) and luteinising hormone (LH) are therefore not useful indicators of menopause in these women. Postmenopausal low levels of oestradiol need to be found (modified NZGG 2009).

8.41 For women who have completed five years of tamoxifen, the addition of an aromatase inhibitor for a further period of two to five years may be recommended, especially for women at higher risk (eg, women with node-positive disease) (Aebi et al 2011).

8.42 The total duration of optimal adjuvant endocrine treatment is between five and 10 years (Aebi et al 2011).

8.43 In men with early breast cancer, tamoxifen is the preferred endocrine therapy. Efficacy of aromatase inhibitors in men is uncertain.

Drug treatment of bone issues

Refer to monitoring of bone density Standard 9.2.

Rationale

Premature menopause (ie, in women younger than 45 years) and aromatase inhibitors cause accelerated loss of bone density; especially in the first two years. Women to whom both risks apply have especially high rates of loss of bone density.

Bisphosphonates prevent bone loss in women with iatrogenic premature menopause and in postmenopausal women being treated with aromatase inhibitors (Reid et al 2008).

Good practice points

8.44 A DEXA scan is recommended for women commenced on aromatase inhibitors (see Standard 9.2).

8.45 Women who are osteoporotic or over 75 years of age, and who are either on adjuvant endocrine therapy that enhances loss of bone density or have undergone premature treatment-induced menopause, are recommended to commence treatment with a bisphosphonate (barring contraindications).

8.46 For these women, consideration should be given to changing to endocrine therapy that is less harmful to bone density.

8.47 Postmenopausal women taking aromatase inhibitors are recommended to commence treatment with a bisphosphonate if the T-score (bone mineral density measurement) is ≤-2.0, or ≤-1.0 in the presence of a vertebral fracture or premature menopause (Reid et al 2008).

8.48 Postmenopausal women taking aromatase inhibitors are recommended to commence treatment with a bisphosphonate if the annual rate of bone loss is >4 percent and/or the T-score is ≤-2.0, at the lumbar spine or hip, on the two-year DEXA scan (Reid et al 2008).

8.49 Secondary causes of osteoporosis are excluded and standard lifestyle advice on smoking and exercise and adequacy of vitamin D and calcium intake is provided (modified NZGG 2009).

Radiation therapy

All women who wish to receive and who could potentially benefit from an assessment by a radiation oncologist should have the right to see a radiation oncologist in the New Zealand public health system (Ministry of Health 2011).

Radiation therapy – after breast-conserving surgery for invasive breast cancer

Standard 8.10	Women with invasive breast cancer having breast-conserving surgery are offered radiation therapy unless low risk of recurrence, age, medical condition or prior radiation therapy mitigates against treatment.

Rationale

Post-operative radiation therapy decreases the local recurrence risk and increases long-term survival. Radiation therapy reduces the risk of local recurrence by approximately two-thirds, and for every four recurrences avoided at 10 years approximately one life is saved at 15 years of follow-up (EBCTCG 2011). Depending on patient and tumour-related prognostic factors, the absolute gain varies so that for selected women (those with a short life expectancy based on poor general health, age or low-risk breast cancer), follow-up alone might be selected (Rosselli del Turco et al 2010).

Good practice points

8.50 Radiation therapy may be omitted for older women with early-stage disease if they are receiving adjuvant hormonal therapy, with no survival disadvantage but a slight increase in risk of local recurrence (Hughes et al 2004, 2006; Fyles et al 2004; Tinterri et al 2009; Holli et al 2009).

Monitoring requirements

MR8G	Ensure that 90 percent or more of women receive services that meet the standard.

Radiation therapy – after breast-conserving surgery for DCIS

Rationale

Radiation therapy following breast-conserving surgery for DCIS reduces the risk of local recurrence compared to breast-conserving surgery alone (Wapnir et al 2011; EBCTCG 2010). To date there is no evidence that adjuvant radiation therapy improves overall survival. To date, no prospective randomised trial has been able to select a group of women undergoing breast-conserving surgery for DCIS who do not gain benefit from adjuvant radiation therapy; local recurrences higher in the groups not receiving adjuvant radiation therapy. There are case series that have identified low-risk groups for recurrence without radiation therapy (see, eg, the Van Nuys Group and their prognostic index (Silverstein 2003)).

Good practice points

8.51 Adjuvant radiation therapy reduces the risk of local recurrence in women undergoing breast-conserving surgery for DCIS, but the advantages for some will be small. Women must be advised of the benefits and risks of this treatment.

8.52 All women with DCIS for whom the MDT recommends radiation therapy following adequate breast-conserving surgery are offered a discussion with a radiation oncologist on the risks and benefits.

Radiation therapy – after mastectomy

Rationale

The Early Breast Cancer Trialists' Collaborative Group (EBCTCG)'s analysis of node-positive women in 2005 indicated that adjuvant radiation therapy significantly reduced local recurrence at five years compared to no adjuvant radiation therapy (6% vs 23%) and this translated into an absolute survival benefit with radiation therapy of 4.4 percent at 15 years (EBCTCG 2005). The EBCTCG data suggests that post-mastectomy radiation therapy is beneficial in women who have a 20 percent risk of local recurrence at 10 years. American Society of Clinical Oncology guidelines (2001) recommend radiation therapy for women at high risk of recurrence, including those with ≥4 positive axillary lymph nodes and women with T3 or T4 tumours or close margins.

Controversy exists regarding women at lesser risk. Data from the EBCTCG and Danish and British Columbia studies indicate an improvement in local recurrence and overall survival in women with one–three nodes positive. However, concerns have been raised regarding the quality of the surgery in these studies. Node-negative women are not generally considered to be at sufficient risk to warrant radiation therapy, but high risk node-negative women may be identified who could benefit. These questions are being addressed by the SUPREMO Trial.

Good practice points

8.53 After mastectomy, women at high risk of loco-regional recurrence are referred for an assessment with a radiation oncologist to be considered for adjuvant radiation therapy except where age, medical condition or previous radiation therapy preclude this option.

Radiation therapy – inflammatory breast cancer

Rationale

Women with inflammatory breast cancer have a high risk of local and distant recurrence of disease. There is a paucity of randomised controlled trials in inflammatory breast cancer to guide management. However, an international expert panel in 2012 recommended that all women with inflammatory breast cancer who undergo a modified radical mastectomy receive post-mastectomy radiation therapy (Dawood et al 2012).

Good practice points

8.54 Women with inflammatory breast cancer are offered radiation therapy as part of their treatment, which should also include primary chemotherapy and surgery.

Advanced breast cancer

Advanced breast cancer can be locally advanced, metastatic or both. Locally advanced breast cancer is defined as stage III disease. This covers a diverse range of breast cancer, from women with a large primary with or without invasion of local structures to those with ≥4 axillary lymph nodes involved, or regional nodes involved beyond the axilla, through to inflammatory breast cancer.

Metastatic disease is defined as stage IV (M1) distant detectable metastases as determined by classic clinical or radiological means and/or histologically proven (Edge et al 2010).

Also refer to Standards 2.7 and 5.1.

Advanced breast cancer – multidisciplinary care

(Cardoso et al 2012; National Collaborating Centre for Cancer 2009)

Rationale

The care of women with metastatic breast cancer must take into account multiple disease-related factors, both clinical and biological, as well as patient-related factors. Compared with early breast cancer there are few proven standards of care.

Women diagnosed with metastatic breast cancer face the double burden of an illness associated with significant symptoms and the knowledge that while the disease is usually treatable it is ultimately incurable.

The management of advanced breast cancer is complex and, therefore, involvement of all appropriate specialties in a multidisciplinary care team (including but not restricted to medical and radiation oncologists, surgeons, radiologists, pathologists, psycho-oncologists, social workers, breast cancer or cancer nurse coordinators and palliative care specialists) is crucial.

Good practice points

8.55 Multidisciplinary care is particularly important for women with advanced breast cancer.

8.56 From the time of diagnosis of advanced breast cancer, women should be offered appropriate psychosocial care, supportive care and symptom-related interventions as a routine part of their care.

8.57 Following a thorough assessment and confirmation of metastatic breast cancer, the potential treatment goals of care are discussed. Women should be told that metastatic breast cancer is incurable but treatable, and that they can live with metastatic breast cancer for extended periods of time (many years in some circumstances).

8.58 There are few standards of care for advanced breast cancer. Inclusion of women in well-designed, prospective, randomised trials is therefore a priority.

8.59 Balanced decisions should be made in all instances; a woman's wellbeing, length of life and preferences must always guide decisions.

8.60 Validated patient reported outcome measures provide useful information about symptom severity and the burden and the impact of these symptoms on overall quality of life. Systematic collection of such data should be integrated with other clinical assessments and form part of the decision-making about treatment and care.

Advanced breast cancer – management

Rationale

Women with advanced breast cancer frequently have pain or other distressing symptoms at presentation. A major goal of care is prompt relief of such symptoms to maximise quality of life.

Good practice points

8.61 Staging work-up for metastatic breast cancer will normally include a history and physical examination, haematology and biochemistry tests, and imaging of chest, abdomen and bone (See 'Investigation, diagnosis and staging' section for information on staging investigations indicated for stage III breast cancer).

8.62 Not all advanced breast cancer patients require staging, and there will be situations where not all staging modalities are required.

8.63 Age alone must not be a reason to withhold effective therapy; other factors need consideration.

8.64 Tumour markers may be of use (if elevated) as an aid to evaluate response to treatment, particularly in patients with non-measurable metastatic disease. A change in tumour markers alone should not be used to initiate a change in treatment.

8.65 A biopsy (preferably providing histology) of a metastatic lesion should be performed where feasible if it will alter management and if easily accessible, to confirm diagnosis particularly when metastasis is diagnosed for the first time. Where there is a long interval between the breast cancer and the diagnosis of metastatic cancer, the possibility that the metastases have arisen from a different origin must be considered.

8.66 Biological markers (especially oestrogen receptor, progesterone receptor and HER2 status) should be reassessed at least once in the metastatic setting, if clinically feasible.

8.67 The use of targeted therapy (endocrine and/or anti-HER2 therapy) is considered when receptors are positive in at least one biopsy, regardless of timing.

8.68 Loco-regional disease management (including surgery and/or radiation therapy) is an important symptom control measure to avoid distressing symptoms even in the presence of metastatic disease, in some cases.

8.69 Radiological assessments are required in women with persistent and localised pain due to bone metastases to determine whether there are impending or actual pathological fractures.

8.70 Neurological symptoms and signs that suggest the possibility of spinal cord compression must be investigated as a matter of urgency. This requires a full radiological assessment of the potentially affected area as well as adjacent areas of the spine. Magnetic resonance imaging is the method of choice. An emergency surgical (neurosurgery or orthopaedic surgery) opinion may be required for surgical decompression. If no decompression/stabilisation is feasible, emergency radiation therapy is the treatment of choice.

8.71 Brain imaging should only be performed in symptomatic patients.

8.72 Where a woman is fit, has a potentially resectable brain metastasis, and has a limited metastatic disease burden she is considered for treatment with surgery or radiosurgery. Whole brain radiation therapy is also an option.

8.73 For receptor positive breast cancer, which represents the majority of cases, endocrine therapy is the preferred first treatment option, unless there is concern or proof of endocrine resistance or rapidly progressive disease needing a fast response. In males, tamoxifen is the preferred option. For those men needing to receive an aromatase inhibitor, a concomitant gonadotrophin-releasing hormone (GnRH) analogue or orchiectomy is necessary.

8.74 Supportive care allowing safer and more tolerable delivery of appropriate treatments is always part of the treatment plan. See ‘Supportive care’ section.

8.75 Expert palliative care, including effective control of pain and other symptoms, is a priority. Access to effective pain treatment (including morphine) is necessary for all women in need of pain relief (Cardoso et al 2012).

8.76 Optimally, discussions about a woman’s preferences at the end of life should begin early in the course of metastatic disease. See ‘Palliative care’ section.

Palliative care

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.

Rationale

Optimising quality of life for women with breast cancer needing palliative care through optimal symptom control and care planning, along with culturally appropriate psychological, social and spiritual support, is important to minimise patient and family/whānau distress (Hospice New Zealand 2012).

Good practice points

8.77 All women with advanced breast cancer are screened for palliative care needs when advanced disease is confirmed, at appropriate intervals and as clinically indicated (NCCN 2012b).

8.78 Health service providers ensure that women and their family/whānau have easy access to a range of high-quality and culturally appropriate information resources about cancer, palliative care and advance care planning (NICE 2004) (see 'Referral and communication').

8.79 Women and their family/whānau have access to spiritual care, either from the clinical care team or from community spiritual care resources (NICE 2004).

8.80 When active treatment is no longer able to control widespread and life-threatening disease, and the toxicities of remaining options outweigh benefits, clinicians and other members of the health team initiate discussions with the woman and her family/whānau about advance care planning and end-of-life goals and treatment. An electronic or hard copy of the advance care plan should be available within the woman's clinical records (expert opinion).

8.81 When active treatment is no longer able to control the disease, women have equitable access to primary palliative care services, irrespective of location. Women with more complex needs have access to specialist palliative care services (expert opinion).

8.82 All health professionals recognise dying patients in a timely manner and implement an integrated care pathway for the dying (expert opinion).

8.83 Formal mechanisms should be in place to ensure that family/whānau and other carers have access to bereavement care and support services (NICE 2004; Palliative Care Australia 2005).

9 Follow-up and Surveillance

Standard 9.1	Annual mammography is undertaken for at least 10 years after diagnosis for all women treated for breast cancer who are in good health.

Rationale

Follow-up is necessary to:

- detect early in-breast and local recurrences or contralateral breast cancer
- evaluate and treat therapy-related complications (such as menopausal symptoms, osteoporosis and second cancers)
- provide psychological support and information in order to enhance the return to normal life after breast cancer.

In asymptomatic women, there is no data to indicate that other laboratory or imaging tests produce a survival benefit (Aebi et al 2011).

Good practice points

9.1 Continuity of care is encouraged and follow-up should be undertaken by a clinician (eg, breast specialist, breast physician, breast cancer or cancer nurse coordinator) experienced in the surveillance of breast cancer and in breast examination, including the examination of irradiated breasts.

9.2 Follow-up care may be shared with GPs in appropriate circumstances. An open access policy enables GPs to refer women back to the breast-care team without delay if they suspect recurrent cancer or problems related to treatment for breast cancer.

9.3 While women remain on endocrine therapy there is evidence to suggest that they should be managed by a specialist service with expertise in this treatment.

9.4 Consistent information is provided to women and their GPs about follow-up care, including name of the follow-up provider, frequency of recommended follow-up visits and tests required. See Appendix 7 for an example of a treatment summary and follow-up guidance form for women treated for early breast cancer.

9.5 Providers of follow-up care assess psychosocial distress and the impact of the disease and its treatment (including checking for signs of lymphoedema).

9.6 Mammograms ideally continue yearly beyond 10 years while a woman is in reasonable health.

9.7 Ongoing surveillance mammography in women presenting with metastatic disease is unhelpful and not recommended (Stevens et al 1999).

9.8 Breast MRI in addition to an annual mammography is considered if appropriate (eg, in a woman previously at high risk of cancer).

9.9 Women are instructed to contact their clinician or breast cancer or cancer nurse coordinator immediately in case of symptoms suggestive of recurrent or progressive disease or treatment complications.

Monitoring of bone density

Refer to treatment section – 'Drug treatment of bone issues'.

Standard 9.2	Postmenopausal women receiving adjuvant therapy with an aromatase inhibitor and women experiencing premature menopause (ie, younger than 45 years of age) due to chemotherapy, ovarian function suppression or oophorectomy have a baseline DEXA scan and two-yearly repeat DEXA scans.

Rationale

Menopause and aromatase inhibitors cause accelerated loss of bone density, especially in the first two years. Women to whom both these risks apply have especially high rates of loss of bone density (Reid et al 2008).

Good practice points

9.10 The baseline DEXA scan is ordered by the treating clinician, and repeat scans (usually two-yearly) are ordered by the GP in accordance with advice from a specialist service or breast care unit.

9.11 DEXA scans are available to all women within two–four weeks of referral.

9.12 Patient reminder and recall systems in primary care settings are used to ensure women have their bone density monitored appropriately (NZGG 2010).

9.13 Women with early breast cancer at risk of bone mineral loss are provided with appropriate advice for good bone health. This includes:

- a healthy diet with adequate dietary calcium (low fat dairy products, wholegrain bread, tinned fish with bones and broccoli) and if necessary vitamin D (oily fish)
- maintenance of a healthy body mass index
- regular weight-bearing exercise
- cessation or continuing abstinence from smoking

- adequate sun exposure (when ultraviolet index is low) for vitamin D levels (NZGG 2009).

Monitoring requirements

MR9A	Demonstrate all women have access to the DEXA scan service.

Secondary prevention strategies (Cancer Australia 2010)

Rationale

Healthy diet and body weight have been shown to improve outcomes from breast cancer and reduce complications (eg, lymphoedema).

Research indicates that physical activity after a diagnosis of breast cancer may be beneficial in improving survival, fitness, psychological wellbeing and quality of life, and reducing fatigue and weight gain.

Physical activity can reduce a woman's risk of other significant chronic diseases, such as heart disease and diabetes. Published data have shown that post-diagnosis physical activity reduces all-cause mortality, regardless of body mass index.

Increased alcohol intake is a risk factor for breast cancer development.

Good practice points

9.14 All clinicians actively promote secondary prevention strategies, including maintaining a healthy body weight, healthy diet, regular exercise and limiting alcohol intake (Cancer Australia 2010).

Management of lymphoedema

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

Rationale

Lymphoedema remains a significant problem for some women after breast cancer treatment; it may cause swelling, pain or heaviness. Lymphoedema can be both physically and psychologically distressing, and serves as a constant reminder of the woman's cancer diagnosis (National Collaborating Centre for Cancer 2009).

Good practice points

9.15 After axillary surgery, women are referred for upper body and arm physiotherapy to reduce arm or shoulder stiffness.

9.16 Lymphoedema assessment and therapy services are available to all women within a reasonable timeframe. Women are advised about lymphoedema prevention and support services available locally and nationally.

9.17 Clinicians advise women regarding risk factors associated with lymphoedema, such as high body mass index, having undergone axillary surgery and/or radiation therapy, infection in the surgical wound or subsequently infection or injury to the ipsilateral arm (modified NZGG 2009).

9.18 Women are advised that gentle exercise can help in both the prevention and management of lymphoedema.

9.19 Women with progressive or late-onset lymphoedema (more than five years from diagnosis) have recurrent disease ruled out as a cause.

Monitoring requirements

MR9B	DHBs demonstrate that all women have access to a lymphoedema assessment and therapy service.

10 Special Topics – Breast Cancer and Pregnancy and Breast Cancer in Younger Women

Standard 10.1	Women with a breast cancer diagnosed during pregnancy are managed by a specialist multidisciplinary care team that includes an obstetrician and a gynaecologist (if appropriate)..

Rationale

Breast cancer is one of the most commonly diagnosed cancers during pregnancy. Pregnancy-associated breast cancer is usually defined as any breast carcinoma diagnosed during pregnancy or during the first post-partum year.

Women who are pregnant when diagnosed or who become pregnant during treatment need to be aware of potential risks to themselves and the unborn child.

Treatment of a pregnant woman is particularly complex because of the limited evidence base to inform decision-making and frequent perceived conflict between treatment of the cancer and compromise of the foetus. Insufficient treatment of the cancer, presumed to protect the foetus, can potentially compromise the health of the mother, and consequently the child (Loibl et al 2006).

Additionally, women who have been treated for breast cancer often have concerns about subsequent pregnancy (in terms of advisability and possibility) and their ability to breastfeed.

Good practice points

10.1 Diagnostic and staging imaging for pregnant women is carefully considered, and benefit is balanced against risk of harm. Some imaging techniques may expose both mother and foetus to ionising radiation, which could be dangerous to the foetus. Ultrasound and mammography are not contraindicated (NZGG 2009; NHS Cancer Screening Programme 2012).

10.2 Decisions regarding management of the pregnancy and the breast cancer are based on the gestational age of the foetus and the woman's requirements for fertility and ovarian function. Some women who are diagnosed to have breast cancer in early pregnancy may be advised and/or wish to consider termination of the pregnancy. Women in a later stage may be offered early delivery.

10.3 A woman who wishes to continue her pregnancy is informed of the risks (to herself and the foetus) associated with treatment.

10.4 Women are advised that risks associated with surgery during pregnancy include premature delivery, though this is very uncommon, especially after the first trimester.

10.5 Women are advised that the evidence base for the safety of chemotherapy during pregnancy is limited, especially from a foetal outcome perspective. First-trimester chemotherapy is not advised. Risks of chemotherapy during the second and especially the third trimester may be acceptable. Risks include that delivery will occur at a time of neutropenia and/or thrombocytopenia, increasing the risk of birth complications.

10.6 Endocrine therapy does not commence until after delivery.

10.7 Exposure of the foetus to ionising radiation is not considered safe; therefore radiation therapy must be delayed until after delivery.

10.8 Women are advised not to breastfeed while receiving chemotherapy or endocrine treatments.

10.9 Women are advised that pregnancy is possible after breast cancer, although most of the available evidence on safety, risk of recurrence and future prognosis comes from low-quality studies. The limited evidence suggests that pregnancy will not adversely affect prognosis (NZGG 2009).

Breast cancer in younger women

Rationale

Younger women often have especially complex needs, and may frequently need additional support.

On average, younger women have more aggressive cancers and lower survival rates. As a result many need every possible treatment modality (surgery, chemotherapy, radiation therapy and endocrine therapy).

A higher proportion of younger women undergo mastectomy, and the impact of this tends to be greater (eg, in terms of body image, self-esteem, sexuality and relationships).

A higher proportion of younger women having mastectomy wish to have breast reconstruction. This further complicates surgical decision-making.

Younger women often have a young family, and need to communicate appropriately with their children about their diagnosis and treatment. They may need extra help looking after family.

Younger women may feel isolated, since breast cancer occurs at a much lower rate in younger women than in older women.

Younger women die more frequently from breast cancer than any other cancer.

Good practice points

10.10 Health care professionals place emphasis on arranging care coordination and supportive care for younger women with breast cancer.

10.11 Other issues of special importance to many younger women with breast cancer where additional advice and support may be required include:

- that mammographic screening is less effective
- family history and genetic concerns
- possibility of early menopause
- effects on fertility need to be discussed and consultation with a fertility specialist must be arranged for young women who wish to preserve fertility (National Child Cancer Network 2013)
- questions about pregnancy after diagnosis
- concerns about body image
- impact on sexuality and intimacy

- impact on relationships
- financial challenges (eg, getting health or life insurance can be more difficult when you have had breast cancer)
- impact on career.

10.12 For further information refer to *Clinical Practice Guidelines for the Management and Support of Younger Women with Breast Cancer* (Cancer Australia 2003) and *Breast Cancer in Young Women* (Young Survival Coalition (nd)).

11 Clinical Performance Monitoring and Research

Data collection

Standard 11.1	All breast care units submit standardised core data to a cancer register, on all women diagnosed with breast cancer, at the level of detail currently present in the Auckland Breast Cancer Register.

Rationale

The only current national cancer database is the New Zealand Cancer Registry, which is a population-based register of all primary malignant tumours diagnosed in New Zealand. The registry includes information on each cancer case (such as site and pathology), as well as demographic information (such as age, gender and ethnicity). This information is gathered from laboratory reports, discharge reports from public and private hospitals, death certificates and autopsy reports. While the database is virtually complete, it lacks information on service provision, and detail on tumour type and TNM stage.

Other breast cancer data collections include:

- four Breast Cancer Patient Registers (Auckland, Waikato, Christchurch and Wellington) representing approximately 63 percent of the expected number of new breast cancer cases diagnoses, and with the most detailed dataset
- BreastScreen Aotearoa's collection of detailed data for screen-detected cancers, representing 41 percent of all breast cancer diagnoses
- BreastSurgANZ's (previously Royal Australasian College of Surgeons) audit.

Collection of standardised breast cancer data on 100 percent of breast cancer diagnoses is important for service planning, for monitoring the standards in this document and for achieving sustained improvements in quality of care, patient survival and quality of life. A standardised national data set (data definitions and business rules), of ABCR level, that includes the BreastScreen Aotearoa and BreastSurgANZ datasets would reduce duplication of effort and cost, and ensure collection of demographic, diagnostic, treatment, outcome and other medical information in sufficient detail to allow monitoring, service planning, benchmarking and research to improve patient outcomes. This was the highest priority recommendation from the New Zealand Guideline Group in its *Management of Early Breast Cancer: Implementation Plan* (2010).

Good practice points

11.1 Patients are informed that information is being recorded in a breast cancer database to help the MDT propose a treatment plan and to monitor and evaluate compliance with standards, quality of care and breast cancer outcomes.

11.2 Where data are collected, it is compiled in accordance with the National Cancer Core Data Definition Standards and other relevant data definitions (IT Health Board 2011).

11.3 Ethnicity data are collected according to *Ethnicity Data Protocols for the Health and Disability Sector* (Ministry of Health 2004).

11.4 Data on service performance, clinical outcomes and patient satisfaction are reported by ethnicity (expert opinion).

11.5 Tissue banking is encouraged for future therapy and research.

Research and participation in clinical trials

Standard 11.2	Women with breast cancer are offered the opportunity to participate in research projects and clinical trials.

Rationale

Quality research, of all types, underpins obtaining better outcomes for women with breast cancer.

Clinical trials are an essential component of the process of finding better treatments for breast cancer, and there is indirect evidence that women who participate in clinical trials have better outcomes than women given similar treatments outside trials.

A high participation rate in clinical trials enables questions of scientific importance to be answered more rapidly.

Well-conducted clinical trials set high standards of practice for participating centres, involving very careful audit and review of many aspects of the treatment process. This helps ensure optimal breast cancer management in individual centres.

Clinical trials have been proven to be cost-effective.

Good practice points

11.6 High-quality research needs to be actively encouraged in the New Zealand health care setting. One way to achieve this is by reducing barriers to participation such as charging for standard costs of care or unduly rigorous reporting requirements, and by providing infrastructure funding to support clinical trials work as being done in Australia and United Kingdom.

11.7 Research with Māori cancer patients and their family/whānau and communities is prioritised to reflect the high-level goal of reducing inequalities.

11.8 The websites of the following groups provide information and/or links and some protocols of ongoing national and international collaborative trials:

- Australia & New Zealand Breast Cancer Trials Group (www.anzbctg.org)
- New Zealand Clinical Trials (www.clinicaltrials.health.nz)
- New Zealand Cancer Society (www.cancernz.org.nz)
- University of Auckland Cancer Trials New Zealand (www.fmhs.auckland.ac.nz/sms/oncology/ctnz)
- Australian New Zealand Clinical Trials Registry (www.anzctr.org.au)
- Australian Cancer Trials (www.australiancancertrials.gov.au)
- International Breast Cancer Study Group (www.ibcsg.org)
- National Ethics Advisory Committee (www.neac.health.govt.nz)
- Cancer Research UK (www.cancerresearchuk.org)
- Register4 (www.register4.org.au).

Appendix 1: National Breast Cancer Tumour Standards Working Group Membership

Chair

Assoc Prof Ian Campbell, Breast and General Surgeon, Waikato DHB

Members

Anne Allan-Moetaua, Pacific Representative, National Screening Unit
Mr Grant Broadhurst, Breast and General Surgeon, Hawke's Bay DHB
Libby Burgess, Consumer Representative, Breast Cancer Aotearoa Coalition
Raewyn Calvert, Consumer Representative, Midland Cancer Network
Dr Mary Christie, Pathologist, Counties Manukau DHB
Dr Birgit Dijkstra, Breast and General Surgeon, Canterbury DHB
Prof Mark Elwood, Epidemiologist, University of Auckland
Dr Alison Foster, Primary Care and Breast Physician
Dr Marli Gregory, Screening Representative and Breast Physician, BreastScreen Aotearoa
Dr Claire Hardie, Radiation Oncologist, MidCentral DHB
Dr Gavin Harris, Pathologist, Canterbury DHB
Dr Barbara Hochstein, Radiologist, Lakes DHB
Dr Marion Kuper, Medical Oncologist, Waikato DHB
Cheryl MacDonald, Clinical Nurse Specialist, MidCentral DHB
Glenys Mitchell, Clinical Nurse Specialist, Southern DHB
Kiri Peita, Māori Representative, Midland Cancer Network Hei Pā Harakeke member, Bay of Plenty DHB
Mr Garth Poole, Breast and General Surgeon, Counties Manukau DHB
Dr David Porter, Medical Oncologist, Auckland DHB
Dr Glenys Round, Radiation Oncologist and Palliative Care Physician, Waikato DHB
Dr Jeremy Sharr, Radiologist, Christchurch Radiology Group
Ms Meredith Simcock, Plastic Surgeon, Counties Manukau DHB
Loryn Scanlan, Project Manager, Midland Cancer Network
Mary-Ann Hamilton, Project Manager, Midland Cancer Network
Jan Smith, Manager, Midland Cancer Network

Advisors

Alison McEwan (screening and genetic services)
Julie Holt (supportive care)
Rawiri Blundell (equity)
Dr Nina Scott (equity)

Appendix 2: Glossary

Adjuvant therapy	Additional treatment to increase the effectiveness of the main treatment (often surgery), such as chemotherapy, systemic therapy or radiotherapy
ACR	American College of Radiology
Breast Imaging – Reporting and Data System (BI-RADS)	A quality assurance tool originally designed for use with mammography. The system is a collaborative effort of many health groups, but is published and trademarked by the ACR
BOADICEA	A BRCA gene mutation risk-scoring model
BRCA	A breast cancer susceptibility gene mutation, in either of the genes BRCA1 or BRCA2
BRCAPRO	A BRCA gene mutation risk-scoring model
BreastSurgANZ	Society of Breast Surgeons of Australia and New Zealand
CAM	Complementary and Alternative Medicine
Cancer Networks	Cancer Networks were formed in response to national policy to drive change and improve cancer services for the population in specific areas. There are four regional networks: Northern, Midland, Central and Southern
CDH-1	A gene mutation; also referred to as the E-cadherin gene
Chemotherapy	The use of drugs that kill cancer cells, or prevent or slow their growth (also see Systemic therapy)
DCIS	Ductal carcinoma in situ
Computed tomography (CT)	A medical imaging technique using X-rays to create cross-sectional slices through the body part being examined
Decision to treat (used in FCT indicators)	A decision to begin a woman's treatment plan or other management plan, following discussion between the woman and treating clinician
DHB	District Health Board
Extensive in situ component (EIC)	Extensive in situ component
Endocrine-responsive invasive cancer	Any detectable expression (≥1%) of oestrogen and/or progesterone receptors
Family/whānau	Can include extended family/whānau, partners, friends, advocates, guardians and other representatives
Faster Cancer Treatment (FCT)	A Ministry of Health programme that will improve services by standardising care pathways and timeliness of services for cancer patients throughout New Zealand

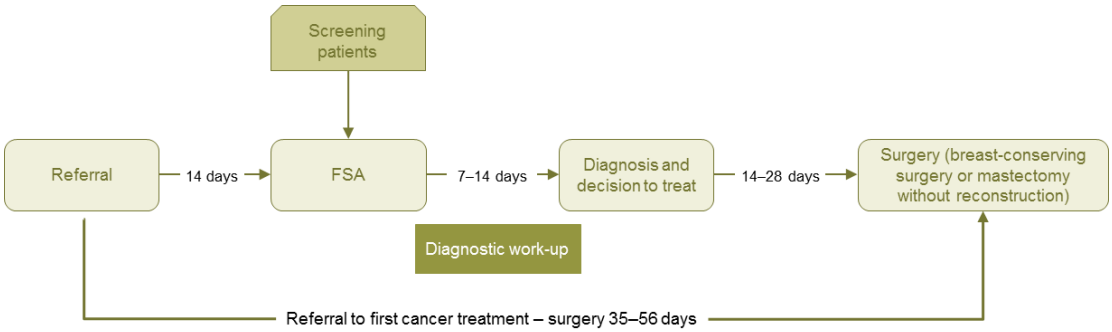
First specialist assessment (FSA)	Face-to-face contact (including telemedicine) between a woman and a registered medical practitioner or nurse practitioner for the purposes of first assessment for their condition for that specialty
FISH	Fluorescence in situ hybridisation
FNA	Fine needle aspiration
FSH	Follicle-stimulating hormone
GP	General practitioner
Inflammatory breast cancer	Characterised by diffuse, brawny induration of the skin due to oedema and peau d'orange (orange skin)-like appearance with erysipeloid edge, often with no discrete underlying palpable mass. Primary tumour classification for inflammatory breast cancer is T4d
Immunohistochemistry (IHC)	A technique that uses antibodies to show up specific proteins in tissues seen down a microscope
Lymphoedema	A condition in which excess fluid collects in tissue and causes swelling. It may occur in the arm after lymph vessels or lymph nodes in the underarm are removed or treated with radiation
Multidisciplinary meeting (MDM)	A deliberate, regular, face-to-face meeting (which may be through videoconference) to facilitate prospective multidisciplinary discussion of options for patients' treatment and care by a range of health professionals who are experts in different specialties. 'Prospective' treatment and care planning makes recommendations in real time, with an initial focus on the patient's primary treatment. Multidisciplinary meetings entail a holistic approach to the treatment and care of patients
Magnetic resonance imaging (MRI)	A non-invasive method of imaging, which allows the form and metabolism of tissues and organs to be visualised (also known as nuclear magnetic resonance)
Multidisciplinary team (MDT)	A group of specialists in a given disease area. The MDT meets regularly to plan aspects of patient treatment. Individual patient cases might be discussed at an MDM, to best plan approach to treatments
NaF	Sodium fluoride
OECD	Organisation for Economic Co-operation and Development
p53	A breast cancer susceptibility gene
Positron emission tomography and computed tomography (PET-CT)	An advanced imaging technique combining an injected material (18F fluorodeoxyglucose) which is taken up by cancer cells and a CT scan
PTEN	A breast cancer susceptibility gene
RACS	Royal Australasian College of Surgeons

Systemic therapy	Treatment using substances that travel through the bloodstream, reaching and affecting cells all over the body
Targeted therapy	A general term for a medication or drug that targets a specific pathway in the growth and development of a tumour
TNM (Tumour node metastases)	The internationally accepted cancer staging system
Trastuzumab	A manufactured antibody that binds to the HER2 receptor on some breast cancers
T-score	A bone mineral density measurement

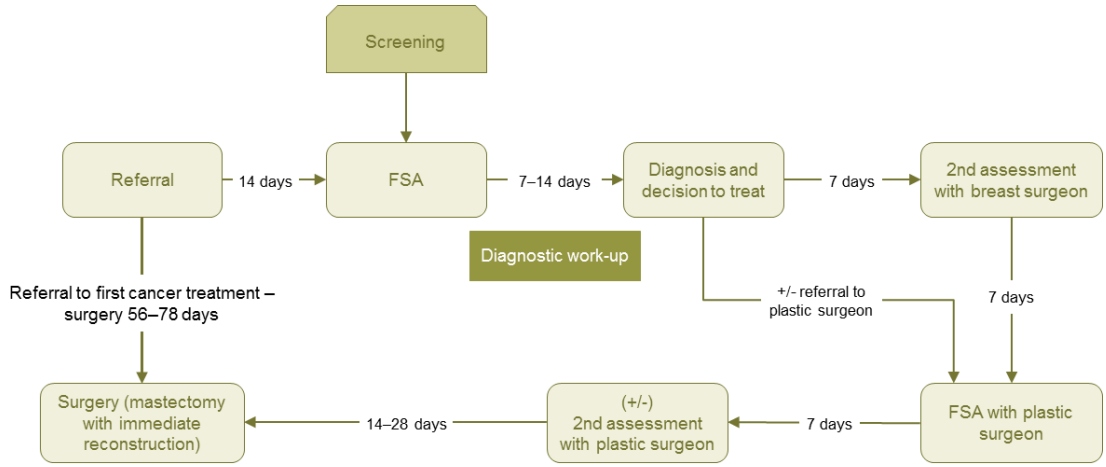
Appendix 3:
The Breast Cancer Patient Pathway

The following pathways, which incorporate realistic good practice timeframes, demonstrate that women on the simple pathway are likely to meet the FCT indicator timeframes, whereas, from a practical perspective, women on the more complicated pathways will frequently not.

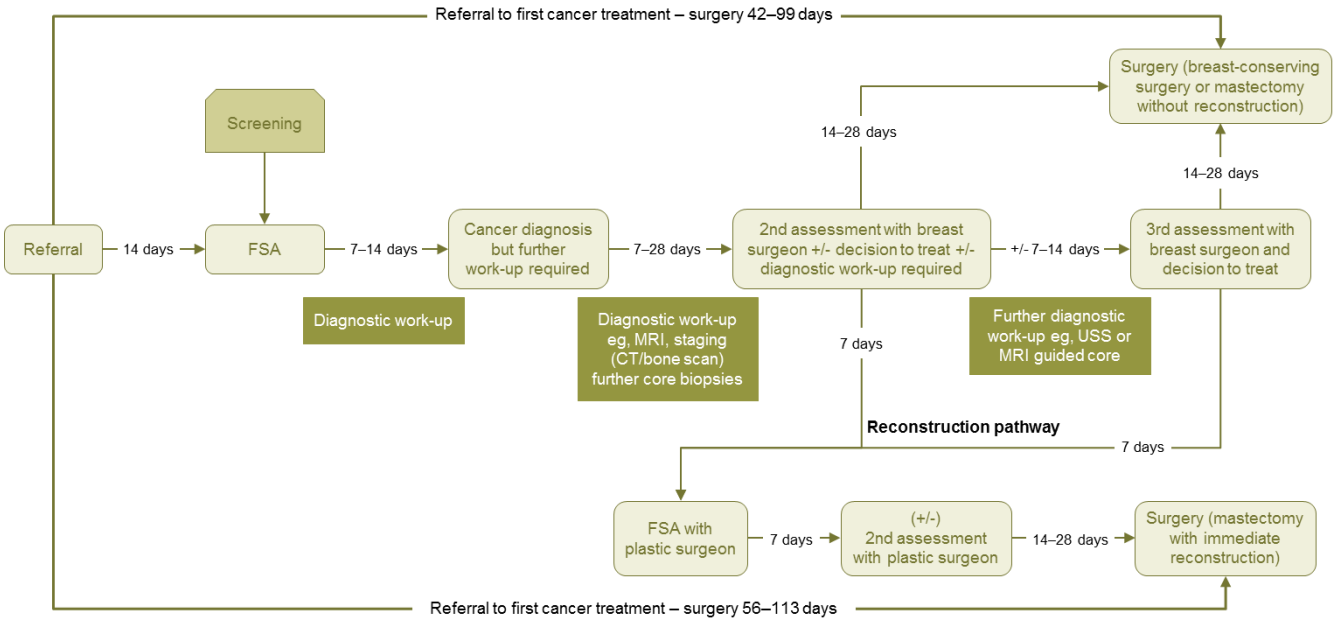
Simple pathway



Mastectomy with immediate reconstruction pathway



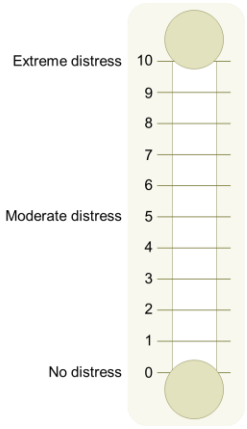
Complex work-up pathway



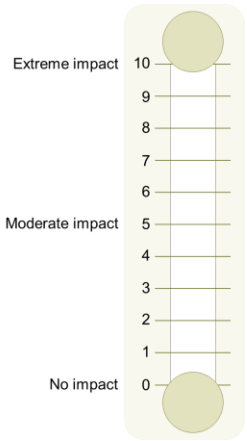
Appendix 4:
Cancer-related Distress Self-assessment Tool

Attach Bradma	**Cancer-related distress self-assessment**	Date:

Please circle the number (0–10) that best describes how much distress (mamae) you have been experiencing in **the past week** including today



Please circle the number (0–10) that best describes how much impact this distress (mamae) has had on your life



Please indicate if any of the following has been a problem for you in the past week including today. Be sure to check Yes or No for each.

Yes	No	**Spiritual (wairua) concerns**
		Practical problems
☐	☐	Childcare
☐	☐	Housing
☐	☐	Financial
☐	☐	Transportation
☐	☐	Work / school
☐	☐	Cultural obligations
☐	☐	Hospital processes
		Family (whānau) problems
☐	☐	Dealing with children
☐	☐	Dealing with partner
☐	☐	Other family members
☐	☐	Family/whānau dealing with the situation
		Emotional (hinengaro) problems
☐	☐	Depression
☐	☐	Fears
☐	☐	Anxiety
☐	☐	Sadness
☐	☐	Worry
☐	☐	Loss of interest in usual activities

Yes	No	**Physical (tinana) problems**
☐	☐	Appearance
☐	☐	Bathing / dressing
☐	☐	Breathing
☐	☐	Changes in urination
☐	☐	Constipation
☐	☐	Diarrhoea
☐	☐	Eating
☐	☐	Fatigue
☐	☐	Feeling swollen
☐	☐	Fevers
☐	☐	Getting around
☐	☐	Indigestion
☐	☐	Memory / concentration
☐	☐	Mouth sores
☐	☐	Nausea
☐	☐	Nose cry / congested
☐	☐	Pain
☐	☐	Sexual
☐	☐	Skin dry / itchy
☐	☐	Sleep
☐	☐	Tingling in hands / feet

Other problems

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Appendix 5:
Cancer Genetics – eviQ Breast and Ovarian Cancer Referral Guidelines

ID: 000650 (V.4)	Approved: 14 May 2010	Last reviewed: 25 March 2013	Review due: 25 March 2015

All of the people who fall into the categories below warrant a referral to a Family Cancer Clinic for genetic counselling and risk management advice.

The categories highlighted by ## have a high probability of being offered germline testing.

Those highlighted by # may be offered germline testing following review by a Family Cancer Clinic.

BREAST AND OVARIAN	
Individual characteristics	
Blood relative of known BRCA mutation carrier (whose personal mutation status is unclear)	##
Blood relative of known carrier of a mutation in a gene conferring a high risk of breast and/or ovarian cancer (eg, TP53, PTEN, STK11) (whose personal mutation status is unclear)	##
Individual with BOTH epithelial ovarian cancer* AND breast cancer (any ages)	##
Epithelial ovarian cancer ≤70 years*	##
Breast cancer diagnosed under the age of 30 years	#
Bilateral breast cancer with first diagnosis under age 50 years	#
Male breast cancer	#

Family history characteristics	
Personal or family history of breast or epithelial ovarian cancer* and Ashkenazi Jewish ethnicity	##
Woman with epithelial ovarian cancer and a family history of breast and/or epithelial ovarian cancer*	#
Woman with bilateral breast cancer and a family history of breast and/or epithelial ovarian cancer*	#
Woman with breast cancer and a personal or family history of oral pigmentation and/or gastrointestinal polyposis (which suggests the family may have Peutz Jegher Syndrome)	#
Woman with breast cancer and a personal or family history of features suggestive of Cowden Syndrome (eg, macrocephaly, specific mucocutaneous lesions, endometrial or thyroid cancer)	#
Woman with breast cancer ≤50 years and a personal and/or family history of the spectrum of cancers associated with Li-Fraumeni syndrome (eg, adrenocartiococarcinoma, sarcoma, brain tumours)	#
Two or more first or second degree relatives diagnosed with epithelial ovarian cancer*	##
Family history of both breast cancer and epithelial ovarian cancer*	#
Two first or second degree relatives diagnosed with breast cancer if: • one women was diagnosed under age 40 years OR • both women were diagnosed under age 50 years	#
Three or more first degree or second degree relatives with breast and/or ovarian cancer* at any age	#
Tumour pathology characteristics	
Triple negative breast cancer (TNBC) ≤40 years at diagnosis (TNBC: oestrogen, progesterone and HER2 receptor negative)	##
TNBC >40 years at diagnosis and any family history of breast or epithelial/ovarian cancer*	#
Lobular breast cancer and a family history of lobular breast cancer or diffuse type gastric cancer	#

* If the type of ovarian cancer is not known consider referral: The Family Cancer Clinic will attempt to verify the histological type of ovarian cancer and determine whether testing is appropriate or not.

The currency of this information is guaranteed only up until the date of printing; for any updates please check www.eviq.org.nz

21 June 2013

Appendix 6:
Definition of 'High Suspicion of Breast Cancer'

Two of the FCT indicators relate to women referred with a high suspicion of cancer (Ministry of Health 2012c).

High suspicion of breast cancer

A high suspicion of cancer refers to a person who presents with clinical features typical of cancer, or who has less typical signs and symptoms, but a clinician suspects that there is a high probability of cancer. In this case, the referrer is fairly certain that the individual has cancer. If this term applies to a particular woman, it can be said that the likelihood of a diagnosis of breast cancer being confirmed is at least one in two (or 50%). 'High suspicion of cancer' is likely to apply to women of any age with:

- a diagnosed cancer on fine needle aspiration or core biopsy
- a suspicious fine needle aspirate result
- any imaging suspicious of malignancy
- a discrete, hard lump with fixation, with or without skin tethering (Leis et al 1989; Vargas et al 2002).

Moderate or low suspicion of breast cancer

When a clinician thinks cancer may be one of a couple of possible diagnoses, a woman does not meet the criteria for high suspicion of cancer.

Moderate suspicion of breast cancer

If this term applies to a particular woman, it can be said that the likelihood of a diagnosis of breast cancer being confirmed is at least one in four (25%). This is likely to apply to women:

- aged 30 years and older with a discrete lump that persists after their next period, or presents after menopause
- aged younger than 30 years:
  - with a lump that enlarges
  - with a lump that is fixed and hard
  - with a lump and in whom there are other reasons for concern, such as family history
- of any age with previous breast cancer who present with a further lump or suspicious symptoms
- with unilateral eczematous skin or nipple change that does not respond to topical treatment

- with nipple distortion of recent onset
- with spontaneous unilateral bloody nipple discharge
- with suspected inflammatory breast cancer or symptoms of breast inflammation that have not responded to a course of antibiotic.

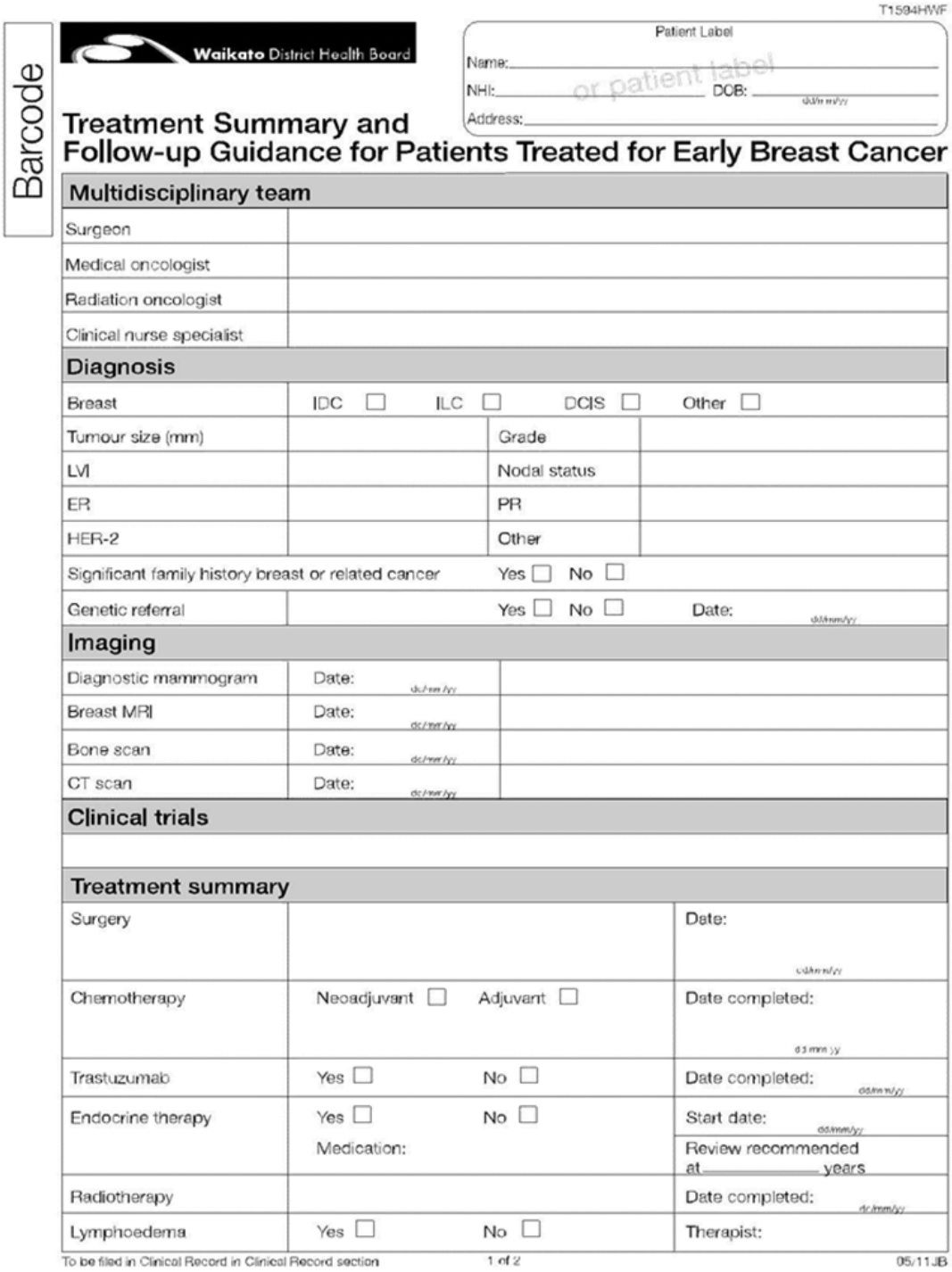
It may also apply to men aged 50 years and older with a unilateral, firm sub-areolar mass, with or without nipple distortion or associated skin changes.

Low suspicion of breast cancer

Clinicians should consider non-urgent referral in the case of women:

- aged younger than 30 years with a lump
- with breast pain and no palpable abnormality, when initial treatment fails and/or with unexplained persistent symptoms (NICE 2011b).

Appendix 7:
An Example of a Treatment Summary and Follow-up Guidance Form



T1594HWF

Barcode

Waikato District Health Board

Patient Label
Name:
NHI: or patient label DOB: dd/mm/yy
Address:

Treatment Summary and Follow-up Guidance for Patients Treated for Early Breast Cancer

Multidisciplinary team			
Surgeon			
Medical oncologist			
Radiation oncologist			
Clinical nurse specialist			
Diagnosis			
Breast	IDC ☐ ILC ☐ DCIS ☐ Other ☐		
Tumour size (mm)		Grade	
LVI		Nodal status	
ER		PR	
HER-2		Other	
Significant family history breast or related cancer		Yes ☐ No ☐	
Genetic referral		Yes ☐ No ☐	Date: dd/mm/yy
Imaging			
Diagnostic mammogram	Date: dd/mm/yy		
Breast MRI	Date: dd/mm/yy		
Bone scan	Date: dd/mm/yy		
CT scan	Date: dd/mm/yy		
Clinical trials			
Treatment summary			
Surgery			Date: dd/mm/yy
Chemotherapy	Neoadjuvant ☐ Adjuvant ☐		Date completed: dd/mm/yy
Trastuzumab	Yes ☐ No ☐		Date completed: dd/mm/yy
Endocrine therapy	Yes ☐ No ☐ Medication:		Start date: dd/mm/yy Review recommended at ____ years
Radiotherapy			Date completed: dd/mm/yy
Lymphoedema	Yes ☐ No ☐		Therapist:

To be filed in Clinical Record in Clinical Record section 1 of 2 05/11JB

Follow-up **Guidance** for Patients Treated for Early Breast Cancer - continued

Patient Label
Name:
NHI: or patient label DOB: dd/mm/yy
Address:

Plan		
Dexa scan	Yes ☐ No ☐	Recommended review 1-2 years depending on initial Dexa scan results
First after treatment mammogram	Due:	
MRI (if required)	Due:	
Other:		

The multidisciplinary team at Health Waikato will work jointly with the general practitioner and other relevant clinicians in the follow-up of the patient after treatment for breast cancer. The outcomes of the reviews will be communicated to the relevant clinicians involved in the care of this patient.

The proposed review schedule is attached.

Our specific recommendations for clinical review include:

To detect potentially curable local-regional recurrence and contralateral breast cancer
- Clinical breast examination at each review
- Annual imaging of the conserved breast, if applicable, and other breast

To monitor patient progress on hormonal therapy
- Assess treatment compliance
- Manage potential treatment side effects

To monitor specific potential treatment complications
- Lymphoedema of the affected arm
- Second malignancy

To manage survivorship and lifestyle issues
- Menopausal symptoms
- Loss of bone density
- Fertility
- Sexuality
- Weight management, diet and exercise
- Annual review of family history / genetic considerations

To provide psychosocial support

Should the patient develop disease recurrence, a revised management plan will be provided as necessary

Reference: New Zealand Guidelines for Management of Early Breast Cancer www.nzgg.org.nz

Signature: Date: dd/mm/yy
Name: Designation:
Copy to general practitioner and patient

2 of 2

Appendix 8: References

Development of the national breast cancer standards was informed by key national and international guidelines and policy documents. Those documents that most directly influenced the development of the standards are listed below.

Aebi S, Davidson T, Gruber G, et al. 2011. Primary breast cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Annals of Oncology* 22(6): vi12–vi24.

Association of Breast Surgery at BASO. 2009. Surgical guidelines for the management of breast cancer. *European Journal of Surgical Oncology* 35(Suppl 1): 1–22.

Baken D, Sutcliffe S. 2012. *National Standards for Supportive Care*. Unpublished.

Cancer Australia. 2010. *Recommendations for Follow-up of Women with Early Breast Cancer*. Sydney: Cancer Australia.

Cancer Care Ontario. 2013. *Breast Cancer Evidence-based Series and Practice Guidelines*. URL: www.cancercare.on.ca/toolbox/qualityguidelines/diseasesite/breast-ebs (accessed 15 April 2013).

Cancer Services Co-ordinating Group. 2005. *National Standards for Breast Cancer Services 2005.* Cardiff: NHS Wales.

Cardoso F, Costa A, Norton L, et al. 2012. 1st International consensus guidelines for advanced breast cancer (ABC 1). *The Breast* 21: 242–52.

Genetic Health Service New Zealand. 2012. *Draft Familial Breast and Ovarian Cancer Protocol.* Wellington: Genetic Health Service New Zealand.

Health Outcomes International Pty Ltd. 2011. *An Implementation Plan for the Guidance for Improving Supportive Care for Adults with Cancer in New Zealand*. Auckland: Health Outcomes International Pty Ltd.

Howell D, Currie S, Jones G, et al. 2009. *A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient*. Toronto: Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology.

IT Health Board. 2011. *National Cancer Core Data Definitions*. Wellington: IT Health Board.

Jeevan R, Cromwell D, Browne J, et al. 2012. *National Mastectomy and Breast Reconstruction Audit 2011*. London: National Health Service.

Khatcheressian J, Hurley P, Bantug E, et al. 2013. Breast cancer follow-up and management after primary treatment: American Society of Clinical Oncology Clinical Practice Guideline Update. *Journal of Clinical Oncology* 31(7): 961–5.

Ministry of Health. 2002b. *Reducing Inequalities in Health*. Wellington: Ministry of Health.

Ministry of Health. 2005. *Access to Cancer Services for Māori*. Wellington: Ministry of Health.

Ministry of Health. 2010b. *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand*. Wellington: Ministry of Health.

Ministry of Health. 2010b. *Medical Oncology Prioritisation Criteria*. www.nsfl.health.govt.nz/apps/nsfl.nsf/pagesmh/401 (accessed 6 August 2013).

Ministry of Health. 2011. *Radiation Oncology Prioritisation Guideline*. URL: www.midlandcancernetwork.org.nz/file/fileid/44264 (accessed 6 August 2013).

Ministry of Health. 2012c. *Faster Cancer Treatment Indicators: Data definitions and reporting for the indicators*. Wellington: Ministry of Health.

Ministry of Health. 2012d. *Guidance for Implementing High-Quality Multidisciplinary Meetings: Achieving best practice cancer care*. Wellington: Ministry of Health.

National Breast Cancer Centre. 2006. *Evidence Relevant to Guidelines for the Investigation of Breast Symptoms*. Sydney: National Breast Cancer Centre.

National Collaborating Centre for Cancer. 2009. *Advanced Breast Cancer: Diagnosis and treatment*. London: National Institute for Health and Clinical Excellence.

National Lung Cancer Working Group. 2011. *Standards of Service Provision for Lung Cancer Patients in New Zealand*. Wellington: Ministry of Health.

NBOCC. nd. *Standard of Care for Breast Diagnostic Services*. National Breast and Ovarian Cancer Centre.

NCCN. 2012a. *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) – Breast Cancer*. Fort Washington: National Comprehensive Cancer Network.

NHS Cancer Screening Programmes. 2012. *Screening for Breast Cancer in High Risk Women During Pregnancy and Lactation*. Sheffield: NHS Cancer Screening Programmes.

NHS Cancer Screening Programmes. 2013. *Protocols for the Surveillance of Women at Higher Risk of Developing Breast Cancer*. Sheffield: NHS Cancer Screening Programmes.

NHS Quality Improvement Scotland. 2008. *Management of Breast Cancer Services*. Edinburgh: NHS Quality Improvement Scotland.

NICE. 2002. *Improving Outcomes in Breast Cancer*. London: National Institute for Clinical Excellence.

NICE. 2006. *Familial Breast Cancer: The classification and care of women at risk of familial breast cancer in primary, secondary and tertiary care*. London: National Institute for Health and Clinical Excellence.

NICE. 2009. *Early and Locally Advanced Breast Cancer: Diagnosis and treatment*. London: National Institute for Health and Clinical Excellence.

NICE. 2011a. *Breast Cancer Quality Standard*. London: National Institute for Health and Clinical Excellence.

NICE. 2012. *Familial Breast Cancer: Evidence Update May 2012*. London: National Institute for Health and Clinical Excellence.

NZGG. 2009. *Management of Early Breast Cancer: Evidence-based best practice guideline*. Wellington: New Zealand Guidelines Group.

Reid D, Doughty J, Eastell R, et al. 2008. Guidance for the management of breast cancer treatment-induced bone loss: A consensus position statement from a UK Expert Group. *Cancer Treatment Reviews* 34(Suppl 1): S3–S18.

Rosselli del Turco M, Ponti A, Bick U, et al. 2010. Quality indicators in breast cancer care. *European Journal of Cancer* 46: 2344–56.

SIGN. 2005. *Management of Breast Cancer in Women*. Edinburgh: Scottish Intercollegiate Guidelines Network.

Introduction

Condon J, Armstrong B, Barnes A, et al. 2003. Cancer in indigenous Australians: a review. *Cancer Causes & Control* 14(2):109–21.

Cunningham R, Shaw C, Blakely T, et al. 2010. Ethnic and socioeconomic trends in breast cancer incidence in New Zealand. *BMC Cancer* 10: 674.

Hill S, Sarfati D, Robson B, et al. 2013. Indigenous inequalities in cancer – what role for health care? *ANZ Journal of Surgery* 83: 36–41.

Jemal A, Siegel R, Xu J, et al. 2010. Cancer Statistics, 2010. *CA: A Cancer Journal for Clinicians* 60(5): 277–300.

McKenzie F, Jeffreys M, 't Mannetje A, et al. 2008. Prognostic factors in women with breast cancer: inequalities by ethnicity and socioeconomic position in New Zealand. *Cancer Causes & Control* 19(4): 403–11.

Meredith I, Sarfati D, Ikeda T, et al. 2012. Cancer in Pacific people in New Zealand. *Cancer Causes & Control* 23(7): 1173–84.

Ministry of Health. 2002a. *Cancer in New Zealand: Trends and projections*. Wellington: Ministry of Health.

Ministry of Health. 2012a. *Cancer: New Registrations and Deaths 2009*. Wellington: Ministry of Health.

Ministry of Health. 2012e. *Rauemi Atawhai: A guide to developing health education resources in New Zealand*. Wellington: Ministry of Health.

National Lung Cancer Working Group. 2011. *Standards of Service Provision for Lung Cancer Patients in New Zealand*. Wellington: Ministry of Health.

NSU. 2008. *BreastScreen Aotearoa National Policy and Quality Standards*. Wellington: National Screening Unit.

Robson B, Purdie G, Cormack D. 2010. *Unequal Impact II: Māori and non-Māori cancer statistics by deprivation and rural–urban status, 2002–2006*. Wellington: Ministry of Health.

Walker T, Signal L, Russell M, et al. 2008. The road we travel: Maori experience of cancer. *New Zealand Medical Journal* 121(1279): 27–35.

Weston M, Moss D, Stewart J, et al. 2008. Differences in breast cancer biological characteristics between ethnic groups in New Zealand. *Breast Cancer Research and Treatment* 111(3): 555–8.

World Health Organization. 2010. *Breast Cancer Incidence and Mortality Worldwide in 2008*. URL: http://globocan.iarc.fr/factsheets/cancers/breast.asp (accessed 15 April 2013).

Prevention and early identification, screening and genetic services

Cancer Australia. 2010. *Recommendations for Follow-up of Women with Early Breast Cancer*. Sydney: Cancer Australia.

EUROSCREEN Working Group 2012. Summary of the evidence of breast cancer service screening outcomes in Europe and first estimate of the benefit and harm balance sheet. *Journal of Medical Screening* 19(Suppl 1): 5–13.

Genetic Health Service New Zealand. 2012. *Draft Familial Breast and Ovarian Cancer Protocol.* Wellington: Genetic Health Service New Zealand.

Independent UK Panel on Breast Cancer Screening 2012. *The Benefits and Harms of Breast Cancer Screening: An independent review.* London: Independent UK Panel on Breast Cancer Screening.

NBOCC. 2010. *Advice about Familial Aspects of Breast Cancer and Epithelial Ovarian Cancer*. Sydney: National Breast and Ovarian Cancer Centre.

NHS Cancer Screening Programmes. 2013. *Protocols for the Surveillance of Women at Higher Risk of Developing Breast Cancer*. Sheffield: NHS Cancer Screening Programmes.

NSU. 2008. *BreastScreen Aotearoa National Policy and Quality Standards*. Wellington: National Screening Unit.

Pijpe A, Andrieu N, Easton D, et al. 2012. Exposure to diagnostic radiation and risk of breast cancer among carriers of BRCA1/2 mutations: retrospective cohort study (GENE-RAD-RISK). *British Medical Journal* 345: e5660.

NICE. 2006. *Familial Breast Cancer: The classification and care of women at risk of familial breast cancer in primary, secondary and tertiary care*. London: National Institute for Health and Clinical Excellence.

NZGG. 2009. *Management of Early Breast Cancer: Evidence-based Best Practice Guideline*. Wellington: New Zealand Guidelines Group.

Timely access to services

Alkis N, Durnali A, Arslan U, et al. 2010. Optimal timing of adjuvant treatment in patients with early breast cancer. *Medical Oncology* 28: 1255–59.

Benk V, Joseph L, Fortin P, et al. 2004. Effect of delay in initiating radiotherapy for patients with early stage breast cancer. *Clinical Oncology* 16(1): 6–11.

Cold S, Düring M, Ewertz M, et al. 2005. Does timing of adjuvant chemotherapy influence the prognosis after early breast cancer? Results of the Danish Breast Cancer Cooperative Group (DBCG). *British Journal of Cancer* 93: 627–32.

Colleoni M, Bonetti M, Coates A, et al. 2000. Early start of adjuvant chemotherapy may improve treatment outcome for premenopausal breast cancer patients with tumors not expressing estrogen receptors. *Journal of Clinical Oncology* 18(3): 584–90.

Gagliato D, Gonzalez-Angulo A, Lei X, et al. 2013. Impact of delaying initiation of adjuvant chemotherapy in breast cancer patients. *Journal of Clinical Oncology* 31 (suppl; abstr 1022).

Hébert-Croteau N, Freeman C, Latreille J, et al. 2004. A population-based study of the impact of delaying radiotherapy after conservative surgery for breast cancer. *Breast Cancer Research and Treatment* 88: 187–96.

Hershmann D, Wang X, McBride R, et al. 2006. Delay of adjuvant chemotherapy initiation following breast cancer surgery among elderly women. *Breast Cancer Research and Treatment* 99: 313–21.

Lohrisch C, Paltiel C, Gelmon K, et al. 2006. Impact on survival of time from definitive surgery to initiation of adjuvant chemotherapy for early-stage breast cancer. *Journal of Clinical Oncology* 24: 4888–94.

Ministry of Health. 2010a. *Medical Oncology Prioritisation Criteria*. URL: www.nsfl.health.govt.nz/apps/nsfl.nsf/pagesmh/401 (accessed 6 August 2013).

Ministry of Health. 2011. *Radiation Oncology Prioritisation Guideline*. URL: www.midlandcancernetwork.org.nz/file/fileid/44264 (accessed 6 August 2013).

Ministry of Health. 2012b. *Faster Cancer Treatment Database: Business rules*. Wellington: Ministry of Health.

Ministry of Health. 2012c. *Faster Cancer Treatment Indicators: Data definitions and reporting for the indicators*. Wellington: Ministry of Health.

Ministry of Health. 2012d. *Guidance for Implementing High-Quality Multidisciplinary Meetings: Achieving Best Practice Cancer Care*. Wellington: Ministry of Health.

NHS Quality Improvement Scotland. 2008. *Management of Breast Cancer Services*. Edinburgh: NHS Quality Improvement Scotland.

Punglia R, Saiti A, Neville B, et al. 2010. Impact of interval from breast conserving surgery to radiotherapy on local recurrent in older women with breast cancer: retrospective cohort analysis. *British Medical Journal* 340: c845.

Investigations, diagnosis and staging

ACR. 2003. *Breast Imaging Reporting and Data System Atlas*. Reston: American College of Radiology.

American Joint Committee on Cancer. 2009. *Breast Cancer Staging* (7th edition). Chicago: American Joint Committee on Cancer.

Blamey R, Cataliotti L. 2006. Eusoma accreditation of a breast unit. *European Journal of Cancer* 42(10): 1331–3.

Boyd N, Guo H, Martin L, et al. 2007. Mammographic density and the risk of detection of breast cancer. *New England Journal of Medicine* 356: 227–36.

Mandelson M, Oestreicher N, Porter P, et al. 2000. Breast density as a predictor of mammographic detection: comparison of interval- and screen-detected cancers. *Journal of the National Cancer Institute* 92: 1081–7.

McCormack V, dos Santos S. 2006. Breast density and parenchymal patterns as markers of breast cancer risk: a meta-analysis. *Cancer Epidemiology, Biomarkers and Prevention* 15: 1159–69.

National Breast Cancer Centre. 2006. *Evidence Relevant to Guidelines for the Investigation of Breast Symptoms*. Sydney: National Breast Cancer Centre.

National Collaborating Centre for Cancer. 2009. *Advanced breast cancer: diagnosis and treatment*. London: National Institute for Health and Clinical Excellence.

NBOCC. 2009. *Breast Cancer Risk Factors: A review of the evidence*. Sydney: National Breast and Ovarian Cancer Centre.

NHS Quality Improvement Scotland. 2008. *Management of Breast Cancer Services*. Edinburgh: NHS Quality Improvement Scotland.

NSU. 2008. *BreastScreen Aotearoa National Policy and Quality Standards*. Wellington: National Screening Unit.

NZGG. 2009. *Management of Early Breast Cancer: Evidence-based Best Practice Guideline*. Wellington: New Zealand Guidelines Group.

RCP and RCR. 2012. *Evidence-based indications for the use of PET-CT in the United Kingdom 2012*. London: Royal College of Physicians and Royal College of Radiologists.

Rosselli del Turco M, Ponti A, Bick U, et al. 2010. Quality indicators in breast cancer care. *European Journal of Cancer* 46: 2344–56.

Sauber N, Chan A, Highnam R. 2013. BI-RADS breast density classification – an international standard? Poster No: C-1762. Congress: ECR 2013. Wellington: Authors.

Multidisciplinary care

Ministry of Health. 2012d. *Guidance for Implementing High-Quality Multidisciplinary Meetings: Achieving Best Practice Cancer Care*. Wellington: Ministry of Health.

National Breast Cancer Centre. 2005. *Multidisciplinary Meetings for Cancer Care: A guide for health service providers*. Sydney: National Breast Cancer Centre.

NHS Quality Improvement Scotland. 2008. *Management of Breast Cancer Services*. Edinburgh: NHS Quality Improvement Scotland.

NSU. 2008. *BreastScreen Aotearoa National Policy and Quality Standards*. Wellington: National Screening Unit.

NZGG. 2009. *Management of Early Breast Cancer: Evidence-based Best Practice Guideline*. Wellington: New Zealand Guidelines Group.

Supportive care

Baken D, Sutcliffe S. 2012. *National Standards for Supportive Care*. Unpublished.

Howell D, Currie S, Jones G, et al. 2009. *A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient*. Toronto: Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology.

Ministry of Health. 2010b. *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand*. Wellington: Ministry of Health.

NHMRC. 2003. *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer*. Canberra: National Health and Medical Research Council.

NZGG. 2009. *Management of Early Breast Cancer: Evidence-based best practice guideline*. Wellington: New Zealand Guidelines Group.

Care coordination

Ministry of Health. 2010b. *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand*. Wellington: Ministry of Health.

NICE. 2004. *Improving Supportive and Palliative Care for Adults with Cancer*. London: National Institute for Clinical Excellence.

Treatment

Aebi S, Davidson T, Gruber G, et al. 2011. Primary breast cancer: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. *Annals of Oncology* 22(6): vi12–vi24.

American Society of Clinical Oncology. 2001. *Guidelines*. Alexandria, VA: American Society of Clinical Oncology.

Dawood S, Ueno N, Valero V, et al. 2012. Identifying factors that impact survival among women with inflammatory breast cancer. *Annals of Oncology* 23: 870–5.

EBCTCG. 2005. Effects of radiotherapy and of differences in the extent of surgery for early breast cancer on local recurrence and 15-year survival: an overview of the randomised trials. *The Lancet* 366: 2087–106.

EBCTCG. 2010. Overview of the randomized trials of radiotherapy in ductal carcinoma in situ of the breast. *Journal of the National Cancer Institute Monographs* 41: 162–77.

EBCTCG. 2011. Effect of radiotherapy after breast-conserving surgery on 10-year recurrence and 15-year breast cancer death: meta-analysis of individual patient data for 10,801 women in 17 randomised trials. *The Lancet* 378(9804): 1707–16.

Fyles AW, McCready DR, Manchul LA, et al. 2004. Tamoxifen with or without breast irradiation in women 50 years of age or older with early breast cancer. *New England Journal of Medicine* 351(10): 963–70.

Grantley Gill P. 2004. Sentinel lymph node biopsy versus axillary clearance in operable breast cancer: the RACS SNAC trial, a multicentre randomized trial of the Royal Australian College of Surgeons (RACS) Section of Breast Surgery, in collaboration with the National Health and Medical Research Council Clinical Trials Center. *Annals of Surgical Oncology* 11(3): 216S–221S.

Harris J, Hellman S, Henderson I, et al (eds). 1991. *Breast Diseases*. Philadelphia: Lippincott.

Holli K, Hietanen P, Saaristo R, et al. 2009. Radiotherapy after segmental resection of breast cancer with favorable prognostic features: 12-year follow up results of a randomized trial. *Journal of Clinical Oncology* 27(6): 927–32.

Hospice New Zealand. 2012. *Standards for Palliative Care: Quality review programme and guide*. Wellington: Hospice New Zealand.

Hughes K, Schnaper, LA, Berry, D. 2006. Lumpectomy plus tamoxifen with or without irradiation in women 70 years of age or older with early breast cancer: a report of further follow-up. *Breast Cancer Research and Treatment* 100 (Suppl 1): S8.

Hughes KS, Schnaper LA, Berry D, et al. 2004. Lumpectomy plus tamoxifen with or without irradiation in women 70 years of age or older with early breast cancer. *New England Journal of Medicine*. 351(10): 971–7.

Jeevan R, Cromwell D, Trivella M, et al. 2012. Reoperation rates after breast conserving surgery for breast cancer among women in England: retrospective study of hospital episode statistics. *British Medical Journal* 345: e4505.

Ministry of Health. 2011. *Radiation Oncology Prioritisation Guideline*. URL: www.midlandcancernetwork.org.nz/file/fileid/44264 (accessed 6 August 2013).

National Health Committee and RACS. 1997. *Guidelines for the Surgical Management of Breast Cancer*. Wellington: Ministry of Health.

NCCN. 2012a. *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) – Breast Cancer*. Fort Washington: National Comprehensive Cancer Network.

NCCN. 2012b. *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) – Palliative Care*. Fort Washington: National Comprehensive Cancer Network.

NICE. 2004. *Improving Supportive and Palliative Care for Adults with Cancer*. London: National Institute for Clinical Excellence.

NICE. 2009. *Early and Locally Advanced Breast Cancer: Diagnosis and treatment*. London: National Institute for Health and Clinical Excellence.

NZGG. 2009. *Management of Early Breast Cancer: Evidence-based best practice guideline*. Wellington: New Zealand Guidelines Group.

Palliative Care Australia. 2005. *Standards for Providing Quality Palliative Care for all Australians*. Canberra: Palliative Care Australia.

Reid D, Doughty J, Eastell R, et al. 2008. Guidance for the management of breast cancer treatment-induced bone loss: a consensus position statement from a UK Expert Group. *Cancer Treatment Reviews* 34: S3–S18.

Rosselli del Turco M, Ponti A, Bick U, et al. 2010. Quality indicators in breast cancer care. *European Journal of Cancer* 46: 2344–56.

SIGN. 2005. *Management of Breast Cancer in Women*. Edinburgh: Scottish Intercollegiate Guidelines Network.

Silverstein M, 2003. The University of Southern California/VanNuys prognostic index for ductal carcinoma in situ of the breast. *American Journal of Surgery* 108: 337–43.

Tinterri C, Gatzemeier W, Zanini V, et al. 2009. Conservative surgery with and without radiotherapy in elderly patients with early-stage breast cancer: a prospective randomised multicentre trial. *Breast* 18(6): 373–7.

Wapnir L, Dignam J, Fisher D, et al. 2011. Long-term outcomes of invasive ipsilateral breast tumor recurrences after lumpectomy in NSABP B-17 and B-24 randomized clinical trials for DCIS. *Journal of the National Cancer Institute* 103: 478–88.

Follow-up and surveillance

Aebi S, Davidson T, Gruber G, et al. 2011. Primary breast cancer: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. *Annals of Oncology* 22(6): vi12–vi24.

Brennan M, Houssami N. 2011. Overview of long term care of breast cancer survivors. *Maturitas* 69(2): 106–12.

Cancer Australia. 2010. *Recommendations for Follow-up of Women with Early Breast Cancer*. Sydney: Cancer Australia.

Khatcheressian J, Hurley P, Bantug E, et al. 2013. Breast cancer follow-up and management after primary treatment: American Society of Clinical Oncology Clinical Practice Guideline Update. *Journal of Clinical Oncology* 31(7): 961–5.

National Collaborating Centre for Cancer. 2009. *Advanced Breast Cancer: Diagnosis and treatment*. London: National Institute for Health and Clinical Excellence.

NZGG. 2009. *Management of Early Breast Cancer: Evidence-based best practice guideline*. Wellington: New Zealand Guidelines Group.

NZGG. 2010. *The Management of Early Breast Cancer: Implementation Plan*. Wellington: New Zealand Guidelines Group.

Stevens K, Smith S, Denley H et al. 1999. Is mammography of value in women with disseminated cancer of unknown origin? *Clinical Oncology* 11(2): 90–2.

Special topics – breast cancer and pregnancy and breast cancer in younger women

Cancer Australia. 2003. *Clinical Practice Guidelines for the Management and Support of Younger Women with Breast Cancer*. Sydney: Cancer Australia.

Loibl S, von Minckwitz G, Ellis P, et al. 2006. Breast carcinoma during pregnancy. *Cancer* 106(2): 237–46.

National Child Cancer Network. 2013. *Draft Fertility Preservation for People Affected by Cancer: New Zealand Guideline: Version 1*. Auckland: National Fertility Preservation Working Group.

National Collaborating Centre for Cancer. 2009. *Advanced Breast Cancer: Diagnosis and treatment*. London: National Institute for Health and Clinical Excellence.

NHS Cancer Screening Programmes. 2012. *Screening for Breast Cancer in High Risk Women During Pregnancy and Lactation*. Sheffield: NHS Cancer Screening Programmes.

NZGG. 2009. *Management of Early Breast Cancer: Evidence-based Best Practice Guideline*. Wellington: New Zealand Guidelines Group.

NZGG. 2010. *The Management of Early Breast Cancer: Implementation Plan*. Wellington: New Zealand Guidelines Group.

Young Survival Coalition. (nd). *Breast Cancer in Young Women*. URL: www.youngsurvival.org/breast-cancer-in-young-women/overview (accessed 31 August 2013).

Clinical performance monitoring and research

IT Health Board. 2011. *National Cancer Core Data Definitions*. Wellington: IT Health Board.

Ministry of Health. 2004. *Ethnicity Data Protocols for the Health and Disability Sector*. Wellington: Ministry of Health.

NZGG. 2010. *The Management of Early Breast Cancer: Implementation Plan*. Wellington: New Zealand Guidelines Group.

Appendices

Leis HP, Cammarata A, La Raja R, et al. 1985. Breast biopsy and guidance for occult lesions. *International Surgery* 149: 789.

Ministry of Health. 2012c. *Faster Cancer Treatment Indicators: Data definitions and reporting for the indicators*. Wellington: Ministry of Health.

NICE. 2011b. *Referral Guidelines for Suspected Cancer*. London: National Institute for Health and Clinical Excellence.

Vargas H, Romero L, Chlebowski R. 2002. Management of bloody nipple discharge. *Current Treatment Options in Oncology* 3: 157–61.