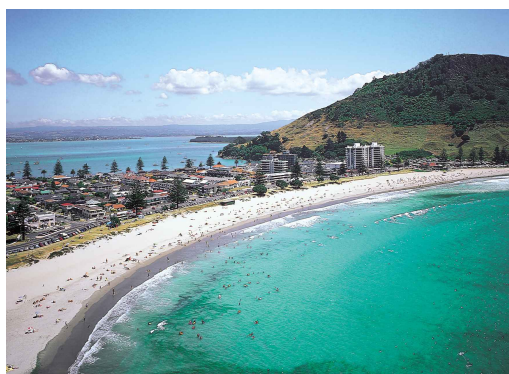




Midland Early Stage Breast Cancer Patient Mapping

Report and Action Plan

2007 – 2010



This report has been produced by the Midland Cancer Network for Bay of Plenty, Lakes and Waikato DHBs.

Prepared by: Jan Hewitt, Manager Midland Cancer Network
Loryn Scanlan, Patient Mapping Manager, Midland Cancer Network

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CONTACT

The Midland Cancer Network is responsible for the publication and distribution of this document and related information. In the first instance, queries about the document should be forwarded to:

Jan Hewitt
Manager, Midland Cancer Network
Waikato DHB
PO Box 3200
Hamilton 3240
New Zealand
Hewittj@waikatodhb.govt.nz

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Midland Cancer Network Executive Group

Jan Adams, Chairperson, Chief Operating Officer, Waikato DHB

Mike Agnew, Portfolio Manager, Planning and Funding, Bay of Plenty DHB

Diana Bowen, Support Services Manager, Waikato/Bay of Plenty Cancer Society of New Zealand Inc.

Barbara Garbutt, Manager, Population Health Service, Waikato DHB

Kevin Harris, Medical Service Manager, Lakes DHB

Jan Hewitt, Manager, Midland Regional Cancer Network

Dr Jeremy Long, Clinical Director Midland Cancer Network

Riana Manuel, General Manager, Te Puna Oranga (Māori Health Service), Waikato DHB

Rachel Poaneki, Portfolio Manager, Planning and Funding, Waikato DHB

Suzanne Ryder, Regional Oncology Nurse Education, Waikato DHB

Rosemary Viskovic, Portfolio Manager, Planning and Funding, Lakes DHB

Peng Voon, Medical Services Manager, Bay of Plenty DHB

PARTICIPATING MIDLAND DHBs

The Midland DHBs comprises five DHBs Bay of Plenty, Lakes, Tairāwhiti, Taranaki and Waikato. Bay of Plenty, Lakes and Waikato DHBs come under the Midland Cancer Network. Tairāwhiti and Taranaki DHBs come under the Central Cancer Network. For the purpose of this report the Midland region refers to the three Midland DHBs which have participated in the patient mapping work programme, namely Bay of Plenty, Lakes and Waikato DHBs.

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EXECUTIVE SUMMARY

In 2005 the Bay of Plenty, Lakes and Waikato DHBs sponsored a project to map the patient journey for early stage breast cancer. The project linked to recommendations made in the Non-Surgical Cancer Treatment Service Plan for the Midland region (2004) and the New Zealand Cancer Control Strategy Action Plan (2005). This report consolidates the significant amount of work that has been undertaken over a two-year period to understand the patient's breast cancer journey and how services are delivered across the three Midland DHBs which are affiliated to the Midland Cancer Network, namely Bay of Plenty, Lakes and Waikato DHBs.

The work programme used to inform this report and facilitate a better understanding of the patient's journey and the associated clinical and support services included:

- mapping the patient journey and parallel processes for early stage breast cancer
- mapping 15 individual patient journeys
- identifying variations in clinical practices and breast cancer service delivery
- collating staff perspectives on issues and constraints
- obtaining consumer perspectives and experiences
- auditing of waiting times across key stages of the breast cancer journey
- ethnic inequalities sub-analysis
- comparison of journey times with national and international standards and benchmarks
- analysis of breast cancer statistics and breast screening coverage trends
- discussion of findings in workshops with relevant staff at each of the participating DHBs
- development of an action plan.

The breast cancer care pathways were mapped for both asymptomatic (screening-detected) and symptomatic patients. The steps of the patient journey that were captured cover the cancer continuum including screening, assessment and diagnosis, treatment and follow-up care.

Ten key attention areas have been identified, these include:

- establishment of the breast cancer work group
- reducing inequalities and improving outcomes for Māori and Pacific women with breast cancer
- improving access to clinical services and reducing variations in service provision
- improving multidisciplinary care
- improving care co-ordination
- improving communications across the breast cancer care community
- improving access to supportive care
- workforce monitoring
- service planning and technology assessment
- improving breast screening coverage and reducing inequalities in breast screening programmes across the Midland region.

The report and action plan focuses on how the systems of service delivery and the patient's experience of the breast cancer journey can be improved across the whole pathway of care. Extracts from the interviews and focus groups held with the 48 women treated for breast cancer have been included in the report. Common complaints from the patients interviewed were long waiting times from referral to treatment and poor co-ordination of care. A number of women provided positive feedback about the standard of care and support they received from staff, the experience of staying at the Lions Cancer Lodge in Hamilton and the benefits of interacting with other patients undergoing treatment.

The service through patients' eyes

'The surgeon (named) and oncologist (named) were marvellous – I would trust them with my life. Everyone was professional and caring.'

'Can't speak highly enough of the staff and the fantastic care I have received from them.'

'I was treated very well and with respect by staff. Congratulations to all the wonderful people who care for cancer sufferers.'

'Receptionist provided a smiling welcome and an excellent and helpful service'

'I felt able to talk to the nurses if I had questions. I found the health professionals supportive.'

'The Cancer Lodge is tops, the food is good and the experience of talking to other cancer patients is very therapeutic.'

'It's wonderful at the Cancer Lodge with lots to do and friendships formed.'

Source: Patient interviews and focus groups

The action plan that is derived from the key attention areas is the starting point for service improvement initiatives. It provides a framework for guiding regional and local activities and unifying efforts to reduce the impact of breast cancer in the Midland region. The action plan describes activities to:

- reduce barriers and improve access to care, in particular for Māori and Pacific women
- ensure all patients receive consistent care which is based on best practice
- ensure a streamlined, co-ordinated and timely delivery of services
- strengthen relationships and sharing of information between service providers, including community and primary health service providers
- increase the provision of psychosocial and supportive care.

The breast cancer work group, which represents the breast cancer care community, will contribute to and lead the implementation of the action plan over the next three years. The Midland Cancer Network will provide advice, support and report on progress to the participating Midland and other organisations. Key stakeholders from the Bay of Plenty, Lakes and Waikato districts together with the Regional Cancer Centre and BreastScreen Midland will be integral to successful implementation of the action plan.

SECTION ONE - INTRODUCTION

This section:

- provides the strategic background to implementing the patient mapping work programme and related work
- discusses how the programme links with national and regional cancer control strategies
- discusses how the programme has been funded
- outlines the stages in the journey of early stage breast cancer
- explains process mapping methodology and how the programme's different work streams have been supported and conducted.

Strategic Context

The Midland Region Non-Surgical Cancer Treatment Service Implementation Plan (Midland DHBs, 2005) recommended that mapping of the patient's cancer journey be undertaken for the major tumour groups. Mapping of the patient's cancer journey had been identified by the Ministry of Health as one of the actions necessary for achieving the goals and objectives set out in the New Zealand Cancer Control Strategy Action Plan 2005 – 2010 (Ministry of Health, 2005). Mapping of the patient journey is an action linked to Objective 3 ensuring patient-centred and integrated care for those with cancer, their family and whānau. The outcome desired from mapping is a seamless cancer journey for the patient.

The Midland DHB patient mapping work commenced in July 2005 and involved Bay of Plenty, Lakes and Waikato DHBs (referred to as the participating DHBs). This area of work has been jointly funded by the participating DHBs with some additional support from the Ministry of Health Cancer Control Implementation Fund. The one-off support from the Cancer Control Implementation Fund covered the patient mapping work for the 6-month period January – June 2006. More recently (since January 2007) the project has been funded through the newly established Midland Cancer Network (Regional Cancer Network, Omnibus Crown Funding Agreement).

Up until September 2006 the patient mapping work was guided by a steering group comprising clinical and managerial representatives from the participating DHBs (now known as the Midland Region Non-Surgical Cancer Treatment Service Operations Network). The Midland Cancer Network was established in October 2006 and, as a consequence, the patient mapping work now has become part of the sustainable work programme of the network. The patient mapping work links with the Non-Surgical Cancer Treatment Service Plan for the Midland Region (Barber, 2004) and DHB-level strategic and Cancer Control Action Plans.

Cancer care is delivered in a variety of settings and involves a range of services including diagnosis, treatment, follow-up care, palliative and end-of-life care. Cancer treatment includes surgery, supporting clinical services (e.g. diagnostics) and non-surgical treatment services, namely medical and radiation oncology. The patient mapping work has focussed on referral, assessment/diagnosis, treatment and follow-up stages of the journey, and only for services provided by public hospital and health services.

The patient mapping work programme commenced with mapping the journey for a patient with early stage breast cancer.

Breast cancer is the leading cause of cancer registrations and deaths for non-Māori women in New Zealand and the leading cause of cancer registrations and the second leading cause of death (after lung cancer) for Māori women.

Breast services provided through hospital and health services cover most of the cancer continuum and include early intervention, diagnosis and treatment, follow-up, rehabilitation and support and palliative care. The breast cancer journey includes an additional stage which is screening for asymptomatic women in the target range 45 - 69 years and other women who are at high risk for developing breast cancer due to having a strong family history or having previously been diagnosed with breast cancer or ductal carcinoma in situ.

All breast cancer service elements are generally well co-ordinated as a consequence of New Zealand's National Breast Screening Programme and its policy and quality standards. Breast screen programme service providers (DHBs and private sub-contractors) are required to deliver services to screening-detected women according to the national policy and quality standards. There is a multidisciplinary approach to assessment, diagnosis and treatment planning for screening-detected patients and some symptomatic patients.

Patient Mapping Programme

The following areas of work have informed this report and the Midland breast cancer action plan:

- mapping the patient's cancer journey for early stage breast cancer
- mapping 15 individual patient journeys
- identifying variations in breast cancer service delivery across the participating DHBs
- collating staff perspectives on issues and constraints
- analysis of compliments, complaints and patient satisfaction survey data
- obtaining consumer perspectives and experience
- audit of waiting times across key stages of the breast cancer journey
- inequalities analysis
- analysis of incidence and mortality data
- DHB-level breast cancer workshops.

Mapping the Breast Cancer Journey

The patient mapping approach used was based on process mapping methodology utilised by the then Cancer Services Collaborative Improvement Partnership, a National Health Service (NHS) programme to make improvements in the way cancer services were delivered to patients. Process mapping involves looking in detail at all the separate steps in a patient's journey from referral through assessment, treatment and discharge. Information about the journey is collected through focussing on what happens to the patient (patient processes) and the accompanying flow of information (known as parallel processes). Parallel processes include communication, administrative and diagnostic related processes.

The process involved consultation with all relevant staff groups involved with providing care to patients with breast cancer, either in individual or small group meetings. The staff contributed what happens to the patient. The information collected was presented as flowcharts using VISIO. The flowcharts were circulated to staff to review and adapt until they accurately represented what happens in the current care processes.

Detailed views of the patient and parallel processes related to the breast cancer journey were produced for Lakes and Waikato DHBs. For Bay of Plenty DHB, detailed views of patient and parallel processes were produced for both Tauranga and Whakatane hospitals to reflect local circumstances. In addition, views showing just the patient processes for symptomatic and screening-detected (asymptomatic) patients were developed.

The maps describe the current patient journey and have allowed a greater understanding of the whole pathway between staff from various services involved in providing care. The maps do not necessarily identify gaps and issues and, as a consequence, other areas of work have been undertaken to facilitate a better understanding of the patient's journey and processes within the system.

Detailed analysis of 15 individual patient journeys

A detailed retrospective review of the breast cancer journey was undertaken for 15 randomly selected patients across the participating DHBs. This area of work identified every step in an individual patient's journey to allow confirmation of the detailed journey views put together with input from staff.

Variations in Breast Cancer Service Delivery

The maps of the patient's journey for early stage breast cancer for each of the participating DHBs and hospitals were reviewed for variations in the delivery of services for breast cancer.

Staff Participation

As well as contributing information about the patient journey and parallel processes, staff were asked for their perspectives on issues and constraints pertaining to the cancer journey, based on their knowledge and direct experience.

Consumer Participation

Two main approaches were used to involve patients in the patient mapping work. These included analysis of DHB compliments and complaints data related to cancer services, and focus groups and interviews with breast cancer patients from across the region.

Compliments and Complaints

Compliments, complaints and patient satisfaction survey data related to the Breast Care Centre (Waikato Hospital), Oncology and Haematology services and the Cancer Lodge received between April 2004 and September 2005 were analysed. It should be noted that the compliments and complaints were from all cancer patients and are not specific to breast cancer patients or breast cancer services.

Patient Focus Groups and Interviews

Focus groups and individual patient interviews were held involving women who had been diagnosed and treated for breast cancer between 2004 and 2006. In total 48 women participated, 27 via focus groups held at Rotorua, Tauranga and Whakatane, and 21 via individual interviews with women from Waikato DHB and Māori women from Lakes DHB. A total of ten Māori women participated. Ethnicity was self-identified. The information has been analysed from a regional perspective as a comparison between Māori and non-Māori was not able to be undertaken due to identification issues.

Audit of Waiting Times across Key Stages of the Breast Cancer Journey

Routinely collected data relating to inpatient and outpatient activity were requested from the participating DHBs. The data was supplemented with information from patient notes, oncology new patient histories and data provided by BreastScreen Midland relating to assessment, surgery and treatment details for screening-detected patients. Data was analysed from a number of different perspectives including regional, individual DHB, hospital level, screening-detected (asymptomatic) women, symptomatic women and ethnicity (non-Māori / Māori).

For Waikato DHB the period of investigation was twelve months ending December 2005. For Bay of Plenty and Lakes DHBs data was used from the two-year period January – December 2004 and 2005, where available, in order to increase sample size. Most of the data collation was carried out by a medical student during a twelve week summer studentship.

A framework was developed for assessing waiting times across the care continuum which involved recording dates pertaining to key events and then calculating waiting times/transit times (number of days) between events.

Key events recorded included:

- date of mammography (journey start point for screening-detected patients)
- date of referral to hospital treatment provider (journey start point for symptomatic patients)
- date of First Specialist Assessment (FSA)
- date of First Treatment (generally surgery)
- date referral was received by Regional Cancer Centre
- date of Oncology First Specialist Assessment
- date of first chemotherapy or radiotherapy treatment.

Note: Symptomatic and screening-detected patients have different journey start points.

The key steps measured in relation to symptomatic patients were:

- from referral to hospital treatment provider to FSA
- from FSA to date of first treatment.

The key steps measured in relation to screening-detected patients were:

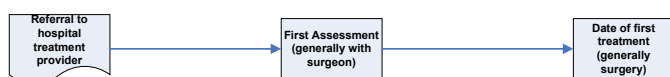
- from imaging to FSA
- from FSA to date of first treatment.

The key steps measured for all breast cancer patients (includes symptomatic and asymptomatic) referred to the Regional Cancer Centre following surgery were:

- from surgery to referral for oncology received by Regional Cancer Centre
- from referral to oncology to FSA Oncology (medical or radiation oncology, whichever occurred first)
- from FSA Oncology to start date for non-surgical cancer treatment (either chemotherapy or radiotherapy).

FLOW CHART OF KEY STEPS IN THE BREAST CANCER TREATMENT PATHWAY THAT WERE USED FOR THE AUDIT OF WAITING TIMES

First part of journey for Symptomatic Patients from Waikato and Bay of Plenty DHBs



Note: different start point for symptomatic patients from Lakes DHB

First part of journey for Screening Detected Patients from all DHBs + Symptomatic patients from Lakes DHB



Second part of journey (i.e. surgery to non-surgical cancer treatment) – for all patients from three participating DHBs



* if > 1 surgery then date of the last surgery was used

Ethnicity Sub-Analysis

The same key events were recorded and key stages were measured for the ethnicity sub-analysis. The three ethnic groupings used for the audit of waiting times by ethnicity are NZ European, NZ Māori and Others. The Other group includes all the other ethnicities recorded grouped together.

Comparison of Journey Times with National Standards and International Benchmarks

A comparison of Midland and participating DHB-level waiting time information against national evaluation targets and international benchmarks was undertaken.

National standards and benchmarks used for this analysis included:

Source	Evaluation Target
BreastScreen Aotearoa	<ul style="list-style-type: none"> three weeks from imaging to assessment clinic four weeks from diagnosis to treatment eight weeks from surgery to start of either chemotherapy or radiotherapy
Ministry of Health Cancer Waiting Time Targets ¹	<ul style="list-style-type: none"> four weeks from initial oncology assessment to start of either chemotherapy or radiotherapy

¹ Ministry of Health Health Targets were not developed at the time of the waiting time analysis.

International benchmarks used for this sub-analysis included:

Source	Evaluation Target
UK National Health Service (NHS) Cancer Waiting Time Targets	<ul style="list-style-type: none">• 14 days from GP referral to first assessment by specialist• 31 days from decision to treat to first treatment• 62 days from GP referral to first treatment

Breast Cancer Statistics

An analysis of breast cancer statistics by mortality, incidence and ethnicity has been undertaken. The analysis also includes information on breast screening coverage and cancer waiting times. Information for the analysis was obtained from TAS Health Needs Assessment 2007 CD-Rom, BreastScreen Aotearoa, the Health Targets Quarter One Report November 2007 and from staff at the Regional Cancer Centre, Waikato Hospital.

For this particular analysis ethnicities have been categorised as Māori, Pacific or Other. In this case everyone who is not Māori or Pacific is referred to as "Other". The ethnicity categorisation used in this section is not the same as the ethnicity categorisation used for the audit of waiting times.

Refer to Appendix Four of this report.

Workshops

Workshops were held at each of the participating DHBs to bring together members of the local breast cancer care teams to discuss and peer review the results from the breast cancer patient mapping work. A document was developed and circulated to participants in advance of the workshop. The document outlined the methodology and approach, variations in breast cancer service delivery across the three DHBs, staff perspectives on issues and patients' experience of the breast cancer journey. Workshop participants discussed the work programme findings and corrected and closed gaps in the knowledge.

Lessons Learnt

The patient mapping work programme has proven to be both labour and time intensive. Reaching this stage has taken a great deal of work and has involved the participation of many staff over a two-year period. While the process mapping did produce an end product map of the patient's breast cancer journey for each of the participating DHBs, the maps are of the current journey and will need to be continually reviewed to be kept up to date as changes are implemented. The report and findings from this area of work are just the starting points to improvement projects.

One of the major issues was the lack of best practice guidelines to compare against the actual pathway and service delivery. In October 2007 the New Zealand Regional Cancer Networks, along with the Ministry of Health, agreed in principle to scope the feasibility of adapting the Victorian Patient Management Frameworks (<http://www.health.vic.gov.au/cancer/pmfsnew.htm>) for New Zealand. The patient management frameworks are a guide to the optimal care

management of patients in each tumour stream. They are intended to improve patient outcomes by facilitating consistent care based on evidence and best practice. They set out the key requirements for the provision of optimal care. The frameworks are designed to be used to facilitate local benchmarking, service mapping and service development. The patient management framework sets out a common pathway of care for all tumour streams with seven critical steps: recognition of potential signs of cancer; initial diagnosis and referral; determination of treatment; treatment; follow-up care; determination of plan and treatment for recurrence and end-of-life care. Principles underpinning the pathway are: patient-centred care; safe and high quality care; multidisciplinary care; support care and care co-ordination. An adaptation for New Zealand would need to incorporate a reducing inequalities focus. While this work programme has not used the framework, there is some alignment with key aspects/concepts addressed by the frameworks.

The process mapping of the patient's journey worked best with one-to-one or small group meetings rather than large workshops. It was difficult getting a representative of all staff groups involved in part of the patient's breast cancer journey together at the same time. Barriers to attending workshops were geographical distance and clinical commitments. It was also hard to capture the journey in sufficient detail across the whole care continuum with a large group. Half day workshops were not the most efficient use of staff time as they were only required to contribute their part of the journey but had to be in attendance for the entire length of the workshop.

At some of the DHBs there were difficulties engaging staff so, as a consequence, there is a risk that the map of the patient's journey may be based on the perspective of a single representative. It was difficult maintaining the momentum and keeping staff involved throughout the rounds of consultation.

A number of limitations need to be acknowledged with the audit of waiting times. The collating and processing of data was complicated by the requirement to mesh data from different sources, including three different DHBs. The meshing of data required significant manual manipulation. Some data was either missing or conflicting and, as a consequence, there was the potential for misinformation and misinterpretation. Descriptive statistics were used as sample size for the sub-analyses were too small to show statistical significance. This work has highlighted that we need a more comprehensive cancer care co-ordination information system to collect valid and relevant waiting time information to manage the monitoring of local and regional access to services and service performance. The system is unable to easily identify the number of women with breast cancer and where these women are on the pathway and the waiting times to transit between critical points of the journey.

Translation difficulties were encountered with the comparison of journey times with national and international benchmarks. Some of the standards and benchmarks were not directly comparable with the waiting time intervals we calculated. This meant alternative steps had to be substituted which had the effect of negatively biasing our waiting times from complying with standards.

The waiting time information that had been calculated is not up to date. There was around a twenty-four month time delay between mapping of the patient's journey for early stage breast cancer and presenting the findings at workshops. During the interval between capturing information and presenting findings, some patient and parallel processes had changed and the DHBs had implemented a number of initiatives which were likely to have had an impact on breast cancer journey transit times. The waiting time information that had been calculated was not up to date.

The work programme has been a learning opportunity for all staff involved in the care of women with breast cancer and has resulted in greater understanding of the roles and functions across the breast cancer continuum. In some areas staff and services are now working

together to implement improvements which have been identified or emphasised from this work (Refer Section Three for cancer control initiatives which are underway).

Supplementary Information

Working papers relating to each of the patient mapping work streams for early stage breast cancer are not included in this report but are available on request should further information be required. The working papers are too large to be included in the print version of the report. Where supplementary information is available it has been referenced in the text of the report.

Refer to Appendix One of this report for a list of additional information and documents related to the patient mapping work programme for early stage breast cancer.

SECTION TWO

KEY FINDINGS

This section summarises findings and themes emerging from each of the areas of work. The key findings and themes have been grouped into ten attention areas and are discussed in more detail in Section Four of this report.

Mapping the Patient's Breast Cancer Journey

The patient mapping work confirms there is an agreed high-level approach to the treatment of breast cancer for both symptomatic and screening-detected (asymptomatic) patients across the participating DHBs. This work has raised the awareness of the complexity of the journey and improved staff knowledge around the processes involved in the whole patient journey, and not just their part.

We calculated that a hypothetical journey for breast cancer could involve more than eighty steps or attendances for the patient. It is not uncommon for patients to be seen by many clinicians with different expertise and for care to extend across nine or more clinical departments/services and organisations.

For additional information on mapping the patient's breast cancer journey refer to the following supplementary information:

- Flowcharts detailing the care pathways for early stage breast cancer for Waikato DHB, Bay of Plenty DHB (Tauranga Hospital and Whakatane Hospital) and Lakes DHB
- Flowcharts detailing the view of just the patient processes for symptomatic and screening-detected (asymptomatic patient) – hypothetical journey.

Detailed analyses of individual patient journeys

More detailed work on fifteen individual patient journeys highlighted precise details of each patient's journey. It allowed more detailed identification of the key parts of the journey. It also clearly shows variations in the patient journeys and that not all patients follow every step of the pathway.

Variations in Service Delivery

Variations in breast cancer service delivery exist between symptomatic and screening-detected patients and exist across the region, DHBs, hospitals and clinicians.

Key variations include:

- differences in actual care delivery between screening-detected and symptomatic patients
- differences in models of care. As a general guide, a sequential model applies in relation to symptomatic patients and a multidisciplinary clinic model applies in relation to screening-detected patients
- differences in terms of which and at what points in the care pathway patients are discussed at clinical multidisciplinary review meetings

- access to some services is limited. We refer to the centralisation of sophisticated investigations and treatments at Waikato DHB or at Anglesea Women's Clinic in Hamilton. Services included stereotactic biopsies, nuclear medicine services, mastectomy with reconstruction, initial oncology assessments and radiotherapy.

For additional information refer to the following supplementary information:

- Profile of breast cancer services provided by each of the participating DHBs
- Report on Early Stage Breast Cancer for DHB Workshops (April 2007).

Staff Participation

Key themes from staff perspectives included:

- discrepancies in standards and actual care delivery between screening-detected and symptomatic patients and concerns about uneven quality of care provided across the region
- widening gap between demand for services and capacity to deliver services across the continuum of care
- long waiting times to access some services – surgery (some DHBs only), non-surgical cancer treatment services and some diagnostic services
- the ability of existing clinical resources and facilities to cope with current and future demand
- need for better integration and co-ordination of care as some patients still experience a fragmented service with major gaps or long waits at points in the care process
- lack of supportive and psycho-oncology services across the Midland region.

For additional information refer to the following supplementary information:

- Report on Early Stage Breast Cancer for DHB Workshops (April 2007).

Consumer Participation

Compliments and Complaints Data

Most comments were positive and acknowledged the high level of care provided, the compassion shown to patients by staff and the willingness of staff to assist patients. Negative comments included lack of car parking facilities at Waikato and Bay of Plenty DHBs. Parking problems at Waikato and Tauranga hospital campuses are compounded by campus redevelopment. A new car parking building (800 parking spaces) opened in February 2008 at Waikato Hospital. Car parking at Tauranga Hospital is unlikely to improve until the construction and refurbishment programme is completed which is anticipated for 2009.

Patient Interviews and Focus Groups

Analysis of interviews with patients revealed several consistent themes.

Key themes identified from interviews and focus groups with patients included:

- lack of care co-ordination/continuity of care
- lack of psychosocial support
- patients perceive there is some urgency to get underway with treatment, which is different from clinicians' view. Clinicians consider there is time for most patients to consider the diagnosis and treatment options
- excessive waiting times for surgery (Waikato and Lakes DHBs only) and initial oncology assessment

- unclear timelines
- reduced access to both public and private diagnostic and treatment services around public holidays
- dissatisfaction with the adequacy, appropriateness and the way in which information was provided
- financial burden of cancer and the lack of information about resources, support and entitlement arrangements.

For additional information refer to the following supplementary information:

- Report on Early Stage Breast Cancer for DHB Workshops (April 2007)
- Report on Breast Cancer Focus Groups and Interviews
- Understanding the Breast Cancer Journey Thematic Analysis of Interviews and Focus Groups.

Audit of Waiting Times across Key Steps of the Breast Cancer Journey

The audit of waiting times shows there are variations in waiting times for service delivery for breast cancer services between the participating DHBs and between symptomatic and screening-detected patients.

Key findings from the audit include:

- Patients from Bay of Plenty DHB have the shortest journey time from start point to surgery
(25 days for symptomatic patients vs. 45 days for screening-detected patients)
- Patients from Lakes and Waikato DHBs have the longest journey time from start point to surgery
(For Lakes DHB: 54 days for symptomatic patient vs. 57 days for screening-detected patients. For Waikato DHB: 53 days for symptomatic patients vs. 56 days for screening-detected patients)
- Patients from Bay of Plenty and Lakes DHBs have the longest journey time between surgery and referral being received by the Regional Cancer Centre
(16 days for Bay of Plenty DHB and 15 days for Lakes DHB vs. 10 days for Waikato DHB).

For additional information refer to the following supplementary information:

- Report on Early Stage Breast Cancer for DHB Workshops (April 2007)
- Report on Waikato DHB Early Stage Breast Cancer Patients Pathway. Waiting Times at Key Stages (Marcus Ghuman, February 2007)
- Regional high level report on the audit of waiting times across key stages of the breast cancer journey (Loryn Scanlan, April 2007).

Audit of Waiting Times by Ethnicity

From the audit of waiting times by ethnicity it appears that there are differences for Māori patients in terms of which pathway they enter the breast cancer treatment journey by. Once they enter assessment and treatment services they may also take longer to transit some of the stages in the journey.

Key findings from audit of waiting times by ethnicity include:

- Māori women account for a higher percentage of the symptomatic sample than the screening-detected
(28% symptomatic vs. 16% screening-detected)
- Māori women are more likely to present with symptoms
- Māori women may have longer waiting times from journey start points to first treatment
(For symptomatic patients: 46 days for Māori vs. 41 days for non-Māori. For screening-detected patients, 63 days for Māori vs. 55 days for non-Māori)
- Māori women may have longer waiting times for the interval between surgery and referral to oncology
(14 days for Māori vs. 10 days for non-Māori).

For additional information refer to the following supplementary information:

- Report on Early Stage Breast Cancer for DHB Workshops (April 2007)
- Access to Breast Cancer Services for Māori.

Comparison of Journey Times with National Standards and International Benchmarks

The comparison between waiting times against national and international standards showed that regional and local journey times do not comply with all national and international standards and benchmarks. Journey times for screening patients are more likely to align with benchmarks than journey times for symptomatic patients. Journey times for patients from Bay of Plenty DHB are more likely to align with benchmarks than journey times for patients from Lakes and Waikato DHBs.

National and international standards and benchmarks that were achieved:

BreastScreen Aotearoa	<ul style="list-style-type: none">• 3 weeks from imaging to initial assessment clinic (achieved for screening-detected patients only)• 4 weeks from diagnosis to surgery (achieved for BOP DHB patients only)• 8 weeks from surgery to start of chemotherapy
Ministry of Health Cancer Waiting Time Best Practice Guideline	<ul style="list-style-type: none">• 4 weeks from oncology assessment to start of non-surgical cancer treatment.
National Health Service Cancer Waiting Time Target	<ul style="list-style-type: none">• 62 days from referral to initial treatment.

National benchmarks that were not achieved:

- BreastScreen Aotearoa evaluation target for waiting time from diagnosis to surgery, which is four weeks. This evaluation target was not achieved for patients from Lakes and Waikato DHBs.
- BreastScreen Aotearoa evaluation target for waiting time from surgery to start of radiation, which is eight weeks.

Note: The health target for radiation waiting time of eight weeks between first specialist assessment and the start of radiation treatment had not been introduced at the time this comparison was undertaken.

For additional information refer to the following supplementary information:

- Report on Early Stage Breast Cancer for DHB Workshops (April 2007)
- Regional high level report on audit of waiting times across key stages of the breast cancer journey (Loryn Scanlan April 2007).

Workshops

There was overall agreement with the findings of the patient mapping work programme. There was acknowledgement of the key themes which were emerging at individual DHB level and also at regional level relating to breast cancer service delivery.

Key concerns expressed from DHB level workshops included:

- long waiting times for surgery at both Waikato and Lakes DHBs
- limited access to some of the specialised imaging services (stereotactic biopsies and Breast MRIs). Breast screening programmes do not subsidise MRIs for screening-detected patients
- variations in practices around which patients with breast cancer have their case discussed by clinical multidisciplinary team
- delays in accessing services due to surgeon, radiologist and imaging technologist workforce shortages
- lack of up to date information on waiting times. Data incompatibility between administrative and clinical systems and between individual DHBs across region. Lack of determinants or benchmarks to measure performance
- lack of psycho-oncology services available, especially at the Regional Cancer Centre.

The following opportunities for service improvements were identified:

- introduction of nurse-led clinics to provide patients with more information to reduce anxiety about oncology treatments and waiting times to see oncologists
- establishment of kaupapa Māori oncology clinics run by Māori nurses or Māori health workers
- more active follow-up of patients who do not attend clinic appointments and treatment.

For additional information refer to the following supplementary information:

- File notes of the three workshops held at each of the three participating DHBs.

SECTION THREE

CANCER CONTROL INITIATIVES UNDERWAY

The Ministry of Health, Midland Cancer Network and the participating DHBs have already funded a number of initiatives in line with the actions recommended in the New Zealand Cancer Control Strategy Action Plan and regional strategic documents, such as Midland Region Non-Surgical Treatment Service Plan and other related documents.

National

Key national level cancer control initiatives related to breast cancer and cancer control activities as at May 2008 include:

- development of guidelines by the New Zealand Guideline Group for access and referral to cancer services, management of malignant melanoma, management of early stage breast cancer and revised guidance on prostate cancer
- colorectal cancer programme includes feasibility study for colorectal screening and proposal to improve colonoscopy capacity
- development of adolescent / young adult oncology and haematology service specifications and care co-ordination
- supporting the development of national-level guidance on planning and delivering supportive care for adults with cancer and their families and whānau
- supporting the implementation of three pilot projects to improve community based support for newly diagnosed Māori/rural patients and their whānau
- supporting regional networks to develop an inequalities programme to address systematic changes to improve equity
- supporting the development of a set of national indicators to measure radiation oncology output and performance at all cancer centres to support meeting the national target for radiation oncology waiting times
- development of protocols for the public interface with potential private radiation oncology services and capacity sharing by cancer centres
- workforce development e.g. radiation therapist new graduate programme, co-ordination of medical physicist training, palliative care workforce initiatives
- developing a cancer information system
- developing new palliative care service specifications, funding for supporting the implementation of the new specialist palliative care service components and progressing the future leadership body for palliative care
- development of a specialist palliative care nursing competency framework and educational needs report
- ongoing development of regional cancer networks

Regional

Key regional level cancer control developments include:

- establishment of the Midland Cancer Network with Waikato DHB as the lead DHB
- appointment of Regional Clinical Director and Manager for the Midland Cancer Network
- establishment of the Midland region non-surgical cancer treatment operations network which is tasked with advancing recommendations made in the Midland Region Non-Surgical Cancer Treatment Service Plan
- commencement of comprehensive patient mapping of major tumour groups across Bay of Plenty, Lakes and Waikato DHBs

- all participating Midlands DHBs have developed local cancer control action plans that link and align initiatives across the region
- establishment of a Midland cancer care co-ordinators forum and palliative care work group
- development of a Midland Cancer Network care co-ordination and continuity of care framework
- development of a regional adolescent and young adult oncology haematology service

DHB Level

Bay of Plenty DHB

- employment of breast and generic cancer care co-ordinators in secondary services
- provision of psychosocial support services through the provider arm
- introduction of telemedicine into rural areas to improve access to diagnostic services (Te Kaha, Opotiki)
- redesign of palliative care services and the development of a palliative care network
- provision of home-based support services for palliative care patients
- patient pathway mapping for palliative care
- support for the Project Hope Cancer Centres in Tauranga and Whakatane
- development of a business case for the establishment of a resident medical oncology and haematology service at Tauranga Hospital
- development of modifiable chronic conditions programme of care.

Lakes DHB

- employment of a generic cancer care co-ordinator in secondary services
- employment of a Māori cancer care co-ordinator in secondary services
- Ministry of Health sponsored pilot project with Hunga Manaaki (Māori health provider based at Rotorua Hospital) to establish a community-based cancer support service for Maori
- development of a business case for the establishment of a specialist palliative care outreach service.

Waikato DHB

- employment of breast cancer (1.5 FTE), gynae-oncology (0.5 FTE) and colorectal (1.0 FTE) care co-ordinators
- employment of an oncology liaison nurse to educate, train and support outreach nurses in relation to chemotherapy (0.5 FTE)
- developing a model of care for a high risk genetic assessment service
- developing a psycho-oncology model of care and business case
- developing a cancer care co-ordination database (pilot involves care co-ordination system for managing patients with breast cancer)
- initiatives to reduce surgery waiting times including short term contract with private surgical service and appointing additional surgical resource
- employment of a MDT co-ordinator based in the Regional Cancer Centre.

BreastScreen Midland

BreastScreen Midland has also developed an action plan for 2007 and 2008 which focuses on the early detection and cancer screening parts of the cancer control continuum. Key initiatives include:

- providing six monthly reports to stakeholders on progress with coverage
- increasing mobile service capacity
- focussing health promotion activity on reducing inequalities and linking to the breast screening mobile schedule to increase screening uptake in areas where mobile mammography is provided once every two years
- undertaking a project to determine the most effective way to reduce inequalities in BreastScreen Midland area, and implement recommendations
- continuing to work with the primary health sector to promote the breast screening programme to eligible women and supporting general practitioners to enrol eligible women and align activity with the PHO performance management programme
- facilitating electronic enrolment for all general practitioners in BreastScreen Midland
- employment of a BreastScreen Midland Clinical Nurse Specialist (0.5 FTE) to integrate with participating DHB secondary service cancer care co-ordinators.

SECTION FOUR

KEY ATTENTION AREAS

This section consolidates the significant amount of information gathered from the patient mapping work programme into ten key attention areas. Each attention area is discussed in turn below.

1. *Establishment of a Midland Breast Cancer Work Group*

It is recommended that a Midland breast cancer work group be established which will report through the Midland Cancer Network. This group will have a mandate to take a proactive clinical leadership approach to breast cancer, oversee the implementation of the regional action plan and advise on possible initiatives to reduce inequalities across the breast cancer care continuum and the impact breast cancer has on patients and their families/whānau.

The breast cancer work group membership will comprise representatives of the breast cancer care team from each of the participating organisations and services that provide care along the breast cancer care continuum, including screening, diagnosis and treatment. A clinician with expertise in managing patients with breast cancer will be appointed as clinical lead across the region and will take on the role of leading and supporting other members of the Midland breast cancer work group.

The membership of this group would include:

- Breast surgeons
- Plastic surgeons
- Breast physicians
- Breast/cancer care co-ordinators
- Representatives of BreastScreen Midland
- Medical and radiation oncologists
- Radiologists
- Pathologist
- Consumer representative
- Māori and Pacific representatives
- Primary sector representative
- NGO representative
- DHB Planning and Funding representatives
- Waikato Breast Trust

The group will need to consult with and involve representatives of allied health services, clinical diagnostics, palliative care and nuclear medicine services where appropriate.

The establishment of the working group will be co-ordinated by the Midland Cancer Network with overall DHB/organisation support to promote cross-regional participation and communication. The Midland Cancer Network will provide support in terms of infrastructure and set-up, secretariat functions and project support for regional activities where possible (restricted due to limited network budget). DHBs and other organisations will be expected to support and meet the costs of staff attending work group meetings. The major costs to organisations will be time for staff to attend meetings and transport. Staff clinical practice is expected to benefit from attending work group meetings as a consequence of improved awareness and focus on quality improvement. There is unlikely to be any reduction in capacity to deliver services because of staff participation at work group level.

One of the first tasks of the breast cancer work group will be to review and prioritise the recommended activities/initiatives as set out in the action plan (refer Section 5 of this report). The breast cancer work group will have an opportunity to review the breast cancer pathways and models of care that apply across the participating DHBs and hospitals in the Midland region. A major purpose of the review is to develop a view on the application of “best practice” in the context of current patterns of service delivery. If there are issues that emerge, then it will consider how best to provide aspects of breast cancer treatment services across the Midland DHBs provider network.

The draft terms of reference of the breast cancer work group is not included in the report but is listed as supplementary information (see Appendix One) and will be supplied on request.

2. *Improving Outcomes for Māori and Pacific Women with Breast Cancer*

There are ethnic differences in terms of participation in breast screening programmes, breast cancer registrations, and survival from breast cancer. Breast cancer is the most common cancer registered for both Māori and non-Māori females. Māori and Pacific women are less likely to receive breast cancer screening services. As at June 2007, BreastScreen Aotearoa data shows that participation in breast screening was significantly lower for Māori and Pacific (39%) women than for non-Māori/non-Pacific women (59%). Māori females have a breast cancer registration rate 1.3 times that of non-Māori females and a breast cancer mortality rate twice that of non-Māori females.

The audit of waiting times by ethnicity identified that there appears to be differences for Māori women in terms of the pathway by which they enter the service, with the majority of Māori women entering via the symptomatic pathway. From the audit it also appears that Māori women may take longer to transit some stages of the journey. This particular finding is supported by some more recent work undertaken at Waikato DHB which looked at the possible reasons for inequalities among Māori women diagnosed with breast cancer through BreastScreen Midland. The study concluded that within BreastScreen Midland Māori women present with later stage breast cancer and their breast cancers are higher grade suggesting more aggressive cancer but few are hormone receptor negative. Māori women received appropriate treatment through the screening programme and treatment was no different to non-Māori. The study also showed that there is a trend for Maori women to take longer to have treatment. Further work is required on determining the reasons for the possible treatment delays. (Campbell, 2008)

At the time the breast mapping work programme was undertaken there were no dedicated Māori cancer services across the participating DHBs. Lakes DHB has recently employed a Māori Clinical Nurse Specialist (Co-ordinator) for cancer and implemented a Māori cancer support service pilot project.

There is evidence late diagnosis occurs for Māori women and that they are diagnosed with larger tumours and are more likely to have metastases at presentation than non-Māori women. There is also growing national evidence that indicates disparities in cancer outcomes for Māori are linked with type and timeliness of care that people receive. Māori experience a greater delay in diagnosis of their cancer as a result of differential access to screening and/or primary health care. That Māori experience poorer outcomes from treatment is associated with differential access to treatment, patterns of referral, and/or quality of care within the care pathway.

The Midland region, with a high proportion of Māori in its population, needs a stronger commitment to tackle inequalities and make improvements to breast cancer services for Māori women. Better information is needed to understand disparities, develop effective interventions and, ultimately, eliminate them.

Further investigation is required on whether and how ethnic differences may be occurring on the entire breast cancer pathway. More services are required that are better targeted at Māori women with breast cancer so they achieve better access rates and the same level of health outcomes as non-Māori.

Specific activities identified in the action plan include:

- investigating Māori and Pacific women's access to and through the breast cancer treatment pathway. It is proposed that more in-depth mapping of the patient journey, including transit times, be undertaken for Māori and Pacific women across the participating DHBs
- developing a culturally effective method of care co-ordination that is tailored to Māori and Pacific patients. Review the Midland Cancer Network care co-ordination framework and other existing models of culturally effective care co-ordination
- investigate and support targeted cancer-related initiatives for Māori and Pacific women with breast cancer
- supporting BreastScreen Midland initiatives to improve screening coverage for Māori and Pacific patients.

There are a number of other activities related to improving outcomes for Māori and Pacific people that are not specific to breast cancer. These activities will be included in the strategic plan for the Midland Cancer Network and the Midland region collectively will be responsible for actioning them.

These activities include:

- improving the cancer workforce understanding of ethnic and other inequalities in cancer
- ensuring Māori and Pacific participation at all levels of network decision making and in the planning, developing and implementing of service initiatives
- investigating and supporting targeted cancer-related initiatives for Māori and Pacific people
- improving access to patient information that is culturally effective
- improving access to supportive care to address the needs of Māori and Pacific patients and their families.

Note: Cancer inequalities that exist for Pacific people are considered more comparable with Māori than with New Zealand European/Other. After discussion with Māori Health Service representatives and a Pacific advisor for DHBs it was agreed that the needs of Māori and Pacific people were similar in terms of reducing inequalities and the impact breast cancer has on patients and whānau/families.

3. Access to Services and Reducing Variations in Clinical Practice

This section focuses on clinical and system areas which have been identified as needing attention in the patient mapping work programme for early stage breast cancer. The clinical and system areas discussed include:

- waiting time for breast surgery
- waiting time for initial oncology assessment

- differences in standards and in actual service delivery between symptomatic and screening-detected patients
- establishing and monitoring service waiting times
- eliminating variations in service provision and problems of inequality of access.

Breast Surgery Waiting Times

The service through patients' eyes

'I felt forced to pay for private treatment because of delays in the public system. The waiting time for private treatment was half the waiting time for public treatment.'

'Everything closes down over public holidays which cause a backlog. I felt if the biopsy and treatment commenced in early January then I would have had a reasonable chance.'

'On the day I was given the diagnosis I felt pressured to make a decision about whether or not to have reconstructive surgery.'

'I felt there was pressure to make decisions about treatment at the appointment.'

'Why does the surgeon have to order the biopsy and not the general practitioner? To me it seemed an unnecessary delay and poor use of resources.'

Source: Patient interviews and focus groups

There are concerns about waiting times for breast surgery at both Waikato and Rotorua Hospitals. The waiting time for surgery at these facilities is longer than the waiting time for breast cancer surgery at both Bay of Plenty DHB hospitals and is longer than the waiting time recommended in the BreastScreen Aotearoa National Policy and Quality Standards.

Some of the factors contributing to the delays in accessing surgery at Waikato and Lakes DHBs include:

- increases in cases as a consequence of age extension for breast screening
- increases in case complexity and changes in clinical practice
- clinical resource constraints
- lack of theatre capacity
- treating out-of-area patients.

Increase in case complexity is driven in part by presenting conditions and change in clinical practice. Sentinel node based management of the axilla has now become established treatment for small breast cancers. This change in practice has decreased the need for axillary node dissection, but may mean that exploration of internal mammary nodes is required in addition to axillary. If women prove to have a sentinel node involved with cancer, then an axillary node dissection needs to be undertaken which requires a second operation.

Waikato Hospital participated in a recent sentinel node biopsy trial which showed that overall operating time is reduced by this practice change. However, the breast surgeons now have the ability to offer breast reconstruction, remodelling and reduction procedures at the time of mastectomy for some women who would traditionally have been referred to a plastic surgeon for a separate operation. This change is having a further impact on the theatre time allocated to breast surgery, given the extended time these cases take.

Waikato DHB has implemented regular monitoring of waiting times for breast surgery and, as at September 2007, the waiting time was still around 6.5 weeks, which is still outside the national standard. Waikato DHB has recruited a fulltime replacement consultant general surgeon who started at Waikato Hospital in September 2007. A further consultant is due to start in August 2008. In the interim, a locum has been appointed. It is expected that the additional consultant resource should begin to result in a decrease in waiting lists and a drop in waiting times for breast surgery towards the targeted four weeks. The use of private hospital services to provide operating facilities is being continued.

The main factors contributing to the long waiting times for breast surgery at Lakes DHB are: one surgeon carries the bulk of the breast surgery workload; lack of theatre capacity (surgeon has a half day list each week); and treating out of town patients. Lakes DHB currently performs surgery for the majority of screening-detected patients from Eastern Bay of Plenty. This is a consequence of screening-detected patients from Whakatane and surrounding areas being referred to BreastScreen Midland assessment clinics and MDT meetings held in Rotorua. For Lakes DHB there has been no drop in waiting times for breast surgery since the audit. Lakes DHB might be able to impact its waiting time for breast surgery by shifting the surgical care of Eastern Bay of Plenty women back to Bay of Plenty DHB and sharing the breast surgery caseload across other competent surgeons.

Factors contributing to shorter waiting times from journey start point to surgery at Bay of Plenty DHB are the level of clinical resource and increased access to operating theatre facilities. Since the audit of waiting times for breast surgery, Bay of Plenty DHB has appointed an additional breast surgeon who is undertaking around 80% of the breast cases, and a breast care nurse in secondary services. The recruitment of additional clinical resources and, in particular, the additional surgeon, has resulted in a drop in waiting times for breast surgery from around 16 days to 7 days. At Tauranga Hospital there are up to five elective operating sessions each week for breast surgery. Surgery that is cancer-related carries a high priority and therefore is rarely cancelled. For many patients with breast cancer from the Bay of Plenty region initial diagnosis is made at community level through a one-stop assessment clinic, rather than through surgical outpatient services. A confirmed diagnosis is available at the time of the first assessment with the surgeon. In Bay of Plenty and Lakes DHB regions there also appears to be stronger links between general practitioners, surgeons and radiologists which means there is the ability to get patients seen quickly and to co-ordinate care to the patient's advantage.

Specific activities identified in the action plan which are aimed at improving access to breast surgery include:

- establishing appropriate service waiting times for critical points in the pathway
- implementing monthly monitoring of waiting times
- developing specific, sustainable strategies for Waikato and Lakes DHBs that will bring waiting times into line with the currently accepted service waiting time of four weeks.

Initial Oncology Assessment Waiting Time

The service through patients' eyes

'What I found very difficult is not knowing when my oncology appointment would be. I rang the hospital who told me no appointment had been made and that I was not in the system. I have been advised by other women who had been through the process that you had to be a squeaky wheel.'

'I had to undergo further imaging before my oncology assessment. There was a six week waiting time to access the scans in the public system. For me it was particularly difficult and stressful not knowing when my I would get called up for the scans or for my first oncology appointment. I ended up paying to have the scans done in private so my oncology appointment would not have to be deferred.'

'My referral was lost between the surgeon (private) and oncology. I had to arrange for the referral to be re-sent. There was no attempt made to compensate for the three week delay. I had to wait twelve weeks for my first oncology appointment.'

Source: Patient interviews and focus groups

The audit of waiting times identified that there is a long waiting time (around five weeks) to transit the step between surgery and initial oncology assessment. For patients, the wait during this step in their journey was considered too long and was a major source of anxiety. The interval is dominated by parallel (internal) processes such as pathology reporting, generating referral letters which is often slow, referral management, triaging of referrals and booking processes.

The participating DHBs' and the Regional Cancer Centre's internal processes warrant further investigation with a view to generating efficiencies and reducing the time a patient has to wait for an initial assessment by the oncologist. At the Waikato DHB workshop it was proposed that nurse-led clinics be introduced where patients would be offered an opportunity to meet with a breast cancer care co-ordinator in advance of the assessment by the oncologist. The clinic provides an opportunity for patients to gain general information about chemotherapy and radiotherapy treatments, learn and ask questions about their likely treatment pathway. A supportive care screen is completed and referral to support services initiated as required. This initiative was implemented at the Breast Care Centre at Waikato Hospital in early 2008.

Specific activities identified in the action plan which are aimed at reducing waiting times for initial oncology assessment include:

- in-depth mapping of the interval between surgery and initial oncology assessment for all participating DHBs and the Regional Cancer Centre
- developing strategies to reduce waiting time between surgery and initial oncology assessment.

While the activities in the action plan have been aimed at reducing waiting time for an initial oncology assessment, it is hoped that they will be a starting point for driving improvements for more timely access to non-surgical cancer treatments (chemotherapy and radiation treatment).

Differences in standards and actual service delivery between symptomatic and screening-detected patients

Symptomatic and screening-detected patients must have access to the same level of care. The breast cancer work group will ensure there is a consistent regional approach to clinical management of breast cancer, based on evidence-based practice, that unwanted variations in practice are reduced and all patients are assessed and managed appropriately through each stage in the journey, irrespective of the pathway by which women enter the service.

A consistent approach will be achieved through care pathways being agreed and understood and then treatment being planned and carried out in accordance with the pathway. There also needs to be guideline concordance for diagnosis and assessment (including imaging), surgery and non-surgical treatment, so all breast cancer patients undergoing care can be confident that the establishment in which they will be cared for offers a level of quality in keeping with requirements.

There is work underway at a national level to develop an evidence-based guideline to promote nationwide consistency in the management of early breast cancer. The guideline, which is being developed by the New Zealand Guideline Group, is due for completion in 2009.

The specific action identified in the action plan is the adoption of national guidelines once these have been developed. While waiting for the national guidelines to be developed, the breast cancer work group will identify and influence crucial elements of care that can be improved and reinforce best practice in relation to the treatment of breast cancer across the care continuum for all women with breast cancer. The actions are aimed at ensuring uniform practices and improving patient outcomes and the quality of care for each breast cancer patient through the Midland region.

Establishing and monitoring service waiting times

The patient mapping work has identified gaps and fragmentation of data and information with the need for more sophisticated, timely and complete data capture on all cancer encounter information (diagnosis/assessment, surgery, medical oncology and radiotherapy) across the continuum. The audit of waiting times has identified a lack of reliable, timely and standardised data about surgical and non-surgical cancer services provided at DHB level. There are also significant gaps in the information about breast cancer service delivery, including little information about private sector diagnostic, surgical and chemotherapy services provided to patients.

BreastScreen Midland, Regional Cancer Centre, Waikato Breast Cancer Register, Waikato Breast Cancer Care Co-ordination system (once it is developed) and DHB activity reporting all capture information related to breast cancer.

BreastScreen Midland was able to provide reliable data on services that are provided to screening-detected patients across the Midland region. Lead providers of mammography screening have developed complex information systems. The system covers both the operational needs of lead providers and provides information for BreastScreen Aotearoa statistical database. The system is building up a cumulative record of each woman's screening and treatment history and is closely integrated with the NHI system.

The Waikato breast cancer register is a comprehensive database which was set up in 2005. Data is collected relating to presenting conditions, risk factors, diagnostic procedures undertaken, surgical procedures, pathological findings, adjuvant treatments (chemotherapy, radiotherapy or hormone treatment) and on-going follow-up. It is intended, through the analysis of data, to create a clearer, more accurate picture of breast care incidence, care and outcomes in the Waikato area. It will assist in providing baseline breast cancer statistics, data for audit purposes, and national and international comparison, assist in planning of cancer services and provide data regarding different ethnic/racial groups.

Waikato DHB is currently investigating the development of a care co-ordination database for breast cancer. Functions of the system include:

- patient tracking from the time they are diagnosed with breast cancer to the end of their treatment journey
- information to improve the proactive management of care pathways
- calculation of waiting times between stages.

Health targets are being used both internationally and nationally to improve performance. Ten national health targets were introduced in 2007/2008 by the Minister of Health. One of the targets is aimed at improving radiation treatment capacity and ensuring all patients (except Category D patients) wait less than eight weeks between first specialist assessment and the start of radiation oncology treatment. The Health Targets Quarter One Report (Ministry of Health, November 2007) indicates DHBs are on track to meet the cancer waiting time target for radiation treatment. For the Midland region (which in this particular case includes Tairāwhiti and Taranaki DHBs as well as Bay of Plenty, Lakes and Waikato DHBs) the majority of patients are being treated within the “best practice” time of four weeks and over 90% of patients started treatment within eight weeks. It is understood that the Ministry of Health will be introducing regular reporting on medical oncology waiting times in 2008/2009.

A DHB/Ministry of Health project to establish nationally agreed quality and output indicators has commenced. It is possible that some indicators may be introduced that are specific to breast cancer. This is an area that will be developed and evolve over time.

Specific actions included in the action plan include establishing/adopting appropriate service waiting times and implementing monthly monitoring of waiting times. The data will be used to report cancer service delivery, benchmark performance against appropriate national/international standards, and ensure quality of care. The measuring of waiting times across key stages of the patient’s breast cancer journey will provide a profile of cancer waits regionally and locally and will be a good indicator of how well the system is working.

An area for improvement highlighted by the work programme is information management, including accessibility, timeliness, reliability of information, and reducing duplication across multiple data collections. Data should be captured for all patients with breast cancer from the Midland region including symptomatic patients and patients from Bay of Plenty and Lakes DHB areas. The action plan also identifies specific activities to support the development and co-ordination of consistent regional and local data measure and collection processes to enable better reporting across the breast cancer pathway. The processes must reflect the priority for better information related to ethnicity. The intention is that, where possible, robust information and resources should be co-ordinated and shared across areas.

Eliminating variations in service provision and problems of inequality of access

Breast cancer services which are centralised in the Midland region include:

- stereotactic biopsies
- breast MRI
- nuclear medicine services (for injecting radioisotopes)
- mastectomy with reconstructions
- initial oncology assessments and radiotherapy.

These services are provided in Hamilton by either the Breast Care Centre at Waikato Hospital or a private provider.

Clinicians who attended the workshops at Bay of Plenty DHB and Lakes DHB expressed frustration with the current service provision for stereotactic biopsies. For symptomatic patients the biopsies are undertaken at the Breast Cancer Centre (on-site at Waikato Hospital) and for screening-detected patients the biopsies are undertaken at Anglesea Women's Health Clinic in Hamilton (a private provider).

The clinicians' frustrations related to different arrangements for symptomatic and screening-detected patients, longer waiting times to access stereotactic biopsies through the Breast Care Centre, and the location of stereotactic biopsies in Hamilton only. The Breast Care Centre has had a high number of vacancies for medical radiation technologists. The vacancies have had an impact on throughput in the diagnostic procedure areas. Delays are sometimes due to the appropriate clinical information and imaging not being available at the time the referrals are triaged. For Bay of Plenty and Lakes DHBs patients, centralised services may mean longer waiting times for diagnosis, additional costs, and time to travel to Hamilton. For these DHBs there may also be higher service costs associated with having to outsource the service from another provider.

The issue of access to stereotactic biopsies warrants further investigation. Bay of Plenty and Lakes DHBs have the specialist knowledge and expertise to perform stereotactic biopsies, but not the equipment, which is costly. Clarification of local economies of scale for developing this service concept is outside the parameters of this particular report.

Specific actions identified in the action plan include the need for the breast cancer work group to review regional, DHB and facility-specific strategies to ensure equitable access to the full range of breast cancer services (including the more specialised services), ensuring services are responsive to the needs of different patients, and encouraging the development of local solutions wherever possible. It is acknowledged that the delivery of breast cancer services across the Midland region will be a combination of regional and local service delivery initiatives.

Risk Assessment and Surveillance Service for Women with a Family History of Breast Cancer

There is demand across the Midland region for a breast cancer risk assessment and surveillance service for women with a family history of cancer. There are a number of potential candidates for risk assessment, but currently the Midland DHBs, and in particular Breast Care Centre at Waikato Hospital, do not have the resources to see these women/families. Some patients are referred to the Northern region genetic service which provides a visiting specialist service at the Breast Care Centre on the Waikato Hospital campus. This service is not sufficiently resourced to meet the increasing demands and for patients it means significant waiting times.

Women “at risk” need specialist advice on their actual level of risk and appropriate surveillance strategies. At-risk services have been set up in some institutions overseas, particularly in the UK. It is intended that the Midland breast cancer risk assessment service would focus on determining an accurate assessment of risk, providing ongoing surveillance, providing access to genetic counselling and genetic testing if required, and providing psychological support and reassurance. The service would link in with the Northern region genetic service. The Midland risk assessment service would be developed as a regional generic risk assessment service for use by all patients at increased risk of cancer (not breast cancer specific) across the Midland region. Such a service would benefit the women across the Midland region that are at increased risk of breast cancer.

Improving Access to Clinical Trials and Maintaining a Watching Brief on Breast Cancer Research

Supporting clinical trials in cancer care is extremely important as a means of exploring and deciding on the most effective and efficient means of treating cancer. Some clinical trials impact on or change clinical practice. For patients, there are benefits from participating in trials. There is an opportunity to receive new, potentially more effective treatment, detailed special monitoring and close medical and nursing supervision.

The action plan includes activities related to supporting improved access to clinical trials and maintaining a watching brief on research related to breast cancer. The aim is to improve the integration of research with clinical practice which will ultimately lead to improved outcomes for patients.

The new resident medical oncology and haematology service at Tauranga Hospital will mean that some cancer patients from the Bay of Plenty region are now able to participate in clinical trials.

4. *Multidisciplinary Care*

Multidisciplinary care is not a new concept, but increased focus and emphasis is being placed on the benefits of supporting multidisciplinary care. The rationale for multidisciplinary team working is to improve decision making and co-ordination of care, thereby reducing errors and improving quality of care. It is well documented and accepted that multidisciplinary care represents best practice in terms of treatment planning and care for cancer patients.

A number of DHB-level and facility-specific differences relating to models of care and multidisciplinary care of patients with breast cancer were identified. There are variations in the coverage and quality of the provision of multi-disciplinary care, the types of cases and at what points in the care pathway patients are discussed.

Assessment services for screening-detected patients must involve a multidisciplinary approach to care and, generally, this is provided via a multidisciplinary “one stop” clinic in which all clinical specialities (surgeon and radiologist +/- breast physician) are present within one setting. Symptomatic patients from across the region are managed through a combination of multidisciplinary clinics (Waikato and Whakatane Hospitals) and the more traditional sequential model of care (Rotorua and Tauranga Hospitals) where patients are referred from the general practitioner to a surgeon and then to other specialists as required.

There are differences in terms of which patients with breast cancer are discussed at the multidisciplinary clinical review meetings. All screening-detected patients diagnosed with breast cancer are required to be discussed at BreastScreen multidisciplinary review meetings. However, not all symptomatic patients diagnosed with breast cancer have their case discussed at a multidisciplinary review meeting.

There are two types of clinical multidisciplinary review meetings. The main multidisciplinary review meetings are the three BreastScreen clinical review meetings held across the region which comply with BreastScreen Aotearoa National Policy and Quality Standards. The membership comprises medical and nursing specialists providing clinical services in relation to breast cancer. The problem with the BreastScreen multidisciplinary review meetings is that they are targeted to screening-detected patients and not all of the surgeons involved in the provision of breast surgery at public hospitals attend these meetings. The BreastScreen multidisciplinary review meetings with their high number of cases cause significant workloads for pathologists and radiologists and often meetings overrun the time allotted.

The other type of clinical multidisciplinary review meeting is the hospital-organised meeting. Symptomatic patients only are discussed at these meetings. Hospital-organised meetings do not comply with BreastScreen Aotearoa National Policy and Quality Standards because the complete clinical care team for breast cancer, and in particular pathologists and oncologists, are not always able to attend meetings.

For symptomatic patients there are also differences in terms of whether the multidisciplinary case review takes place pre or post surgery. Ideally, multidisciplinary discussion should occur prior to surgery. Locally advanced cancers and metastatic disease must be discussed prior to treatment.

Regional clinicians had a variety of views regarding clinical multidisciplinary review meetings. Some clinicians voiced concerns that it was not possible to discuss all patients with breast cancer at meetings and review of clear cut cases may provide no additional benefit.

Specific actions identified in the action plan relating to multidisciplinary care include:

- developing a regional multidisciplinary framework specific to breast cancer
- supporting and improving multidisciplinary care in breast cancer

Protocols would be developed defining the degree of multidisciplinary input required for individual patients. The model of care and guidelines will apply to all women diagnosed with breast cancer, regardless of the pathway by which they enter the service, and be cognisant of regional and local variations in service delivery as well as any national standards that may apply. DHBs and other organisations will need to ensure that there are procedures and systems in place to support multidisciplinary care.

Waikato DHB has commenced the process to implement a multidisciplinary team meeting co-ordinator for cancer care. This role will assist improving clinical multidisciplinary review meetings and implementing systems and processes to meet national standards.

5. Care Co-ordination

The service through patients' eyes.....

'There is no one person who you see all the way through.'

'I felt penalised because some treatments were carried out in the private sector.'

'I came from private to public. I did not feel connected to hospital staff and felt the staff did not connect with me.'

'I seem to have slipped through the gap at each stage of my journey.'

'Getting into the system is difficult. Once in the system things seemed to be ok.'

'I felt like a food product that is baked daily and ushered out the door without delay so the next one can be processed.'

Source: Patient interviews and focus groups

As confirmed in the patient mapping work, patients with breast cancer move frequently between sectors, organisations, departments or services and care teams. The site where the assessment and diagnosis interventions take place is some times different for screening-detected and symptomatic patients and across DHBs and hospitals.

Symptomatic patients and screening-detected patients referred for treatment services at Waikato Hospital and Whakatane Hospital are seen in breast care clinics. Patients treated at Tauranga Hospital and Rotorua Hospital are managed in a similar way to general surgical patients via outpatient clinics.

For screening-detected patients there is a requirement for all elements of the service, including imaging, assessment and diagnosis, to be co-ordinated. The screening-detected patients we interviewed considered that their experience of care was generally well co-ordinated through multidisciplinary "one-stop" clinics. The patients considered that the BreastScreen breast nurse contributed to the experience of continuity of care. The breast care nurse guides the patient from the time of detection of an imaging abnormality up until the time of diagnosis. During this time patients are distressed and face a bewildering array of consultations and procedures. Contact with the BreastScreen breast nurse generally ends when the patient is transferred to a hospital service provider for treatment.

All patients (symptomatic and asymptomatic) considered that the diagnosis/assessment and surgical stages of the journey are generally well co-ordinated. Service co-ordination appears to deteriorate after surgery and if responsibility for care is transferred between hospitals or departments/services.

Interviews with patients uncovered a number of issues with co-ordination of care. Patients commented that they often had to wait at every point of care. They were seen by different doctors and received conflicting advice which led to concerns about different levels of care, depending on where they live. Patients moving between providers had to repeat their story and felt they underwent duplicate tests and work-up. Delays were experienced due to the appropriate information for clinical decision making not being available in a timely and useful format for doctors to review at clinic attendances.

Access to Patient Cancer Information

The service through patients' eyes.....

'My support and learning of the system came from other patients.'

'You are told a lot of information but not given time to take it in.'

'I found the number of treatment options difficult to understand and take in. I couldn't make up my mind and wanted the doctor to advise me but he wouldn't.'

'You do not know what information you need initially.'

'I had difficulty deciding whether to have a mastectomy or breast-conserving surgery. I would have liked more information about the different options for surgery.'

'The information was provided but my head was in such a spin I had trouble digesting and understanding it.'

Source: Patient interviews and focus groups

The interviews identified that there are opportunities to improve patients' experience of the cancer journey. For patients there were a number of issues around adequacy and appropriateness of the information and the way in which it was provided. Patients often find it difficult to take in information given during the consultations, especially after the delivery of bad news. Some specific information gaps identified by patients included information about complex treatments, alternative and complementary treatments, and what questions to ask to assist them with decision making regarding different treatments. Most of the information resources provided by DHBs and the Cancer Society are in written format and there are few resources which are tailored to different cultures or refer to cancer inequalities.

There should be more regional consistency and availability of information. The provision of information is important in reducing anxiety and stress for patients with cancer. It is crucial to enable patients and carers to make informed choices about care. Information should be offered to patients at key stages in the patient journey and be available in places where it can be easily accessed.

Many patients commented about the significant expense of cancer care. Some of the costs include travel to see the doctor and for treatments, loss of income and for pharmaceuticals. Patients have to meet the upfront cost as many of the financial assistance policies are based on reimbursement. Patients often learn about support that is available and the best way to access it from other patients in similar situations. There is little published information about resources, support and entitlement arrangements. There appears to be no published information specific to Māori and/or Pacific people.

Continuity of care in the context of cancer is the delivery of services by different providers in a coherent, logical and timely fashion, consistent with the patient's medical needs and personal context. Care co-ordination is an integral component of continuity of care. It is a process designed to promote continuity, although it does not necessarily ensure that patients experience a system that is connected and coherent.

To achieve continuity of care there will be a number of care co-ordination strategies at an individual, team, service and system level. Key care co-ordination interventions include the appointment of care co-ordinators, multidisciplinary care, standardised care pathways and methods for improving communications. All health professionals have some role in ensuring care co-ordination at different times of the patient journey.

Since conducting the interviews with patients, cancer care co-ordinators (breast or generic) have been appointed at all of the participating Midland DHBs. The appointment of cancer care co-ordinators was recommended in the Non-Surgical Cancer Treatment Service Plan for the Midland Region (Barber, 2004) and these positions have been funded from sustainable cancer control money. A key role of the cancer care co-ordinators is to support the patient through their journey, ensure continuity of care, and integrate care across the continuum of clinical services and between secondary hospitals and the Regional Cancer Centre.

Since the completion of the patient mapping work programme the Midland Cancer Network has developed and adopted a continuity of care framework to be used for all major tumour groups. This framework will be used to develop a model of care co-ordination that is specific for patients with breast cancer.

Specific actions in the action plan related to care co-ordination and improving information include:

- embedding the role of cancer care co-ordinators
- supporting the development of cancer care co-ordinator-led service initiatives
- enabling patients to access relevant information and supportive care during all steps of their care
- mapping of local DHB patient information delivery pathways for breast cancer
- stocktake and review of resources, support and entitlement arrangements available to patients
- developing a strategy to address gaps in patient/carer information.

The outcome expected is that every woman with breast cancer experiences a streamlined patient journey with minimal duplication, co-ordinated and timely delivery of services, efficient transfer of information about their disease, as well as their preferences and improved relationship continuity.

6. *Communication across the breast cancer care community*

Interviews with patients identified there is a significant amount of distrust by patients of the hospital referral and appointment system and, in particular, for oncology assessment. For patients there is a strong desire to know they are moving swiftly to the next stage of their journey. Surgeons are not able to provide patients with a clear timeline for the initial oncology assessment, so patients are often left wondering whether they have been overlooked or are still waiting to be booked. Patients did not recall receiving an acknowledgement of the referral and the experience of uncertainty caused them to frequently phone oncology booking staff to check on progress.

Both patients and clinicians commented on the unavailability of information causing delays in journeys. This seems to be an issue for patients moving between providers (e.g. from private to public or between secondary hospitals and the Regional Cancer Centre or the Breast Care Centre at Waikato Hospital).

The New Zealand Guideline Group has been contracted to develop referral guidelines to provide nationally consistent, evidence-based guidance on the timeliness of care and treatment

offered to people with cancer. It involves a New Zealand modification of the NICE referral guidance. The referral guidelines are intended to improve referral patterns and potentially increase the proportion of people presenting with earlier stage of disease at diagnosis. This guideline is due for completion in 2008.

The breast cancer work group may want to develop and implement systems that ensure rapid and effective communication between all healthcare professionals and, in particular, between different services and hospitals and between secondary and tertiary and public and private sectors of care. District nurses providing care to patients with breast cancer must be linked into the communication network and be aware of treatment plans, treatment given and routes to access the breast care team.

Communication between DHBs and general practitioners needs improvement, especially since general practitioners are providing ongoing and more follow-up care for patients with cancer. General practitioners tend to lose contact with their cancer patients once the patient has been referred to specialist services. The general practitioner is a stable, local contact available to the patient and their families. The general practitioner needs to understand their patient's whole medical situation.

Specific activities identified in the action plan to improve inter-professional communication include:

- developing better guidance for all referrers referring patients with breast cancer or symptoms suggestive of breast cancer for diagnostics, assessment or treatment
- reviewing local referral and acknowledgement processes and communication links between participating DHBs
- reviewing communications and communication points with general practitioners
- reviewing communications with district nurses.

The outcomes expected are strengthened relationships between service providers, improved sharing of information, reduced transfer delays which hopefully will lead to improved clinical management and care processes.

7. Supportive Care

The service through patients' eyes.....

'Cancer is a lonely place. Only you (the patient) experience it and undergo the treatment.'

'Once you have finished treatment it feels like you are marooned.'

'There is a financial impact on the person with cancer and their family. There is no financial support available to you if your partner is working.'

'I would have liked some assistance and support for my husband and children but there did not seem to be anything available.'

Source: Patient interviews and focus groups

A lack of psychosocial support was raised as a concern by both patients and staff in the patient mapping work. Issues from the patient's perspective include the loneliness of the cancer journey, the feeling of being cut adrift once treatment had finished, and the need for support for partners and family/whānau which did not appear to be recognised and was not able to be addressed when there was a need. While some emotional and practical support is provided to cancer patients and their families and whānau by hospital staff and community agencies, they are not able to meet all the needs of patients. Staff may refer to a psychological intervention service when it is apparent that problems are impacting on treatment, but this is often too little too late. A number of national, regional and local strategic documents related to cancer all identify the need for the benefits of increased psychosocial support for cancer patients and their families.

Difficulties and inequalities in accessing community-based support services have been identified for cancer patients living rurally, for Māori, and for those of other ethnicities. In some of the smaller areas (e.g. Whakatane), support agencies are limited. Lakes and Bay of Plenty DHBs have some cancer-focused health services specifically for Māori. Bay of Plenty DHB has a whānau cancer support nurse (Kaitiaki Service) which is based in the primary sector. Lakes DHB supports a community-based Māori cancer support group (Aroha Mai) in Rotorua and is involved with a Māori cancer support service pilot that is community based. There are no cancer-focused health services specifically designed for Māori in the Waikato DHB area.

Some of the patients interviewed identified that they needed more support after completing treatment. At a recent national Regional Cancer Networks forum it was identified that cancer survivors had specific needs. Cancer survivorship should be developed as a phase of cancer care and the requirements for appropriate survivorship care need to be defined. Work is underway at a national level on supportive care and rehabilitation services for people with cancer. The outcome of this work will be some national guidance on supportive care.

Financial costs of travel may prevent or make it difficult for patients to access Hamilton and/or Waikato Hospital-based services. Patients living more than 100 kilometres from the hospital may be eligible for assistance under the Ministry of Health National Travel Assistance (NTA) scheme. The NTA scheme is based on reimbursement, so for patients this means they need to pay upfront costs. Concerns were raised that there may be regional inconsistencies in terms of application of the NTA scheme and access to subsidised accommodation. Patient transport and accommodation co-ordinators have been appointed at each of the participating DHBs. It is hoped that the introduction of these roles will mean more consistent application of the National Travel Assistance Scheme at both DHB and regional level.

The Cancer Society provides a number of psychosocial support services. It attempts to complement the services provided by DHBs. Some of the support services and education programmes which are aimed to support the emotional needs of patients with cancer and their families include a national cancer helpline (0800 CANCER), the community liaison nurses, the Lions Cancer Lodge, transport to treatment, meal service, lymphoedema services, complementary services (e.g. therapeutic massage), breast cancer support groups, peer support, Look Good Feel Better and Living with Cancer education programmes. It also provides emergency grants to assist individuals with transport costs, household expenses, special equipment and therapeutic grants for clients needing psychological intervention. In many of the smaller centres there are trained volunteer area representatives. The range of services offered differs in each region.

The Waikato/Bay of Plenty Cancer Society can offer some assistance with, for example, petrol vouchers, transport co-ordination and volunteer driver services, but the volunteer driver service is not available in all areas. The Cancer Society transport co-ordinator now based at the Regional Cancer Centre tries to facilitate transport through rural volunteers, local trusts and shuttle services.

The perception is that Māori are less likely than non-Māori to utilise the support services provided by the Cancer Society. However, many Māori stay at the Lion's Cancer Lodge in Hamilton along with other ethnic groups.

The specific activities in the action plan related to supportive care for patients with breast cancer include:

- supporting the establishment of a psycho-oncology service within the Midland DHB region for patients with breast cancer
- supporting the development of a supportive care service directory for patients with cancer
- collaborating with NGOs to develop strategies to improve community-based breast cancer support services for Māori, Pacific, and rural patients with breast cancer.

Some of the activities related to improving supportive care are not specific to breast cancer. These activities will be included in the strategic plan for the Midland Cancer Network. The Midland Cancer Network will also take a lead role in progressing all components of supportive care including the establishment of a psycho-oncology service within the Midland DHB region.

There is work being undertaken at a national level in relation to support for people with cancer. An expert advisory group has been established to develop national level guidance on supportive care. The Ministry of Health is also funding a pilot community cancer support service to address issues faced by cancer patients and their families living in rural areas.

8. Workforce

Workforce shortages were raised as a concern by clinicians attending the workshops. At the time the workshops were held, surgeon, radiologist, nuclear medicine and imaging technologist (including medical radiation technologist and sonographer) workforce shortages were acknowledged. Screening programmes are facing workforce capacity issues as a consequence of the screening extension to 45 to 69 years back in 2004.

The workforce shortages were considered to be causing delays in imaging and surgery for patients at both Lakes and Waikato DHBs. Strategies to resolve workforce shortages have been implemented by the affected DHBs, breast screen programmes and other organisations.

The recently published cancer workforce stocktake has identified a significant number of recommendations (refer www.moh.govt.nz/cancercontrol/publications). Further work will be undertaken at a national level on matters related to the cancer workforce.

An important role of the breast cancer work group will be to ensure the professionals working in the area of breast cancer care have the necessary skills to carry out those aspects of cancer care they undertake and that each facility where care is undertaken has the capacity (equipment, staffing and skill mix) to support such care.

Clinicians, particularly at the outreach centres, need to have links with a range of specialities and/or the multidisciplinary care team required for breast cancer care for the purpose of clinical advice, referral and continuing education. The breast cancer work group will need to feel confident that all clinicians and other personnel follow evidence-based practice or treatment recommendations and decisions made by a multidisciplinary care team and that protocols and care pathways are in line with current best practice.

Specific activity in the action plan related to workforce includes:

- monitoring of the breast cancer workforce, including identifying shortages and issues, developing strategies for overcoming and promoting training, and continuing professional development.

9. *Service Planning and Technology Assessment*

The breast cancer work group will have a role in assessing and advising about the adoption of advances in technology and research related to breast cancer care. Wherever possible, advice around clinical management of patients will be based on best practice. However, it is acknowledged that in some instances advice will be a statement of consensus regarding currently accepted approaches to treatment.

In the patient mapping work it was identified that a number of different techniques are being used to identify the sentinel lymph node for the sentinel node biopsy across the participating hospitals. All hospitals have the capability to identify the sentinel node (first draining node) using blue dye. In addition to the blue dye method, Waikato Hospital and Tauranga Hospital have the capability to identify the sentinel lymph node by radioactive dye. The radioactive dye method requires special equipment (gamma probe to measure the radioactivity), access to special facilities for injecting radioactive dyes (nuclear medicine department), specifically trained clinicians (nuclear medicine specialists) for injecting dye, and surgeons who have been trained and are deemed competent to perform sentinel node biopsy. The breast cancer work group may want to consider issuing a position statement on the surgical management of axilla and, in particular, the place of sentinel node biopsy and the techniques used to identify the sentinel node. There are increasing demands for sentinel node biopsy. There are a number of system constraints associated with this particular procedure which may require investigation. Constraints identified include limited staff to undertake the procedure and equipment, limited capacity because of need to fit in with surgeons' theatre schedules and the location of the procedure. Some patients are required to be transferred within the campus or off-site for injection of dyes and hook wires.

Specific activities identified in the action plan related to service planning and technology assessment include:

- advice and involvement in the planning of diagnostic and treatment services for breast cancer on a regional basis including identification of issues, recommendations and options for managing future demand
- providing regional guidance on new or existing treatments and procedures to ensure standardised care across the region.

10. *Improving Breast Screening Coverage and Reducing Inequalities in Breast Screening Programmes*

Access to appropriate screening and treatment remains critical to reducing the impact of breast cancer. By 2008/2009 BreastScreen Aotearoa aims to screen 70% of the eligible population (women aged 45 – 69) every two years to achieve a 30% reduction in breast cancer mortality.

BreastScreen Aotearoa's two-year coverage as at 30 June 2007 is around 54% for Bay of Plenty DHB, 51% for Lakes DHB and 58% for Waikato DHB. The average coverage rate is around 54% for the Midland region. BreastScreen Aotearoa coverage has been reported on the full age range 45-69 years for the first time and, as a consequence, the overall coverage rate has decreased since earlier reports. Coverage rates for Māori and Pacific women are around 20% less than coverage rates for non-Māori/non-Pacific women.

During the patient mapping work concerns were raised by health professionals regarding BreastScreen Aotearoa's consent model and notification of results processes. The health professionals had concerns with the "opt-in" approach which requires women to consent to screening and also to register their willingness for mammography results to be sent to general practitioners. A more appropriate consent model may be the "opt-out" approach which would mean that women in consenting to screening give permission to imaging reports being sent to general practitioners. Under an "opt-out" model the woman would need to register an objection if she is not agreeable for her results to be shared with her general practitioner.

Women are not eligible for MRI under the BreastScreen Aotearoa programme. MRI is not used routinely for breast screening. However, it is sometimes used to assess abnormal areas that are seen on a mammogram, or after a cancer diagnosis it may be used to determine the extent of the tumour in the breast. Screening-detected women who require a MRI must pay for the imaging themselves or be referred for assessment by a surgeon at a DHB outpatient clinic. For the patient it may mean additional steps in the pathway (additional clinic attendances) and extend the time for patients to transit the interval between diagnosis and surgery. For the DHB it may mean duplication of effort as a consequence of an additional assessment by a surgeon employed by the DHB. This matter was raised as a concern by surgeons at Bay of Plenty DHB.

Specific activities in the action plan related to the breast screening programme include:

- supporting BreastScreen Midland initiatives to reduce inequalities and increase breast screening coverage to 70% by 2008/2009
- proposing a change to BreastScreen Aotearoa consent and notification of results processes
- proposing a review of diagnostic and treatment services subsidised by BreastScreen Aotearoa for screening-detected patients.

SECTION FIVE THE ACTION PLAN

The action plan is derived from the key attention areas and provides a framework for guiding regional and local activities and unifying efforts to reduce the impact of breast cancer in the Midland region. The action plan describes activities to reduce barriers and improve access to care, to ensure patients receive consistent care based on best practice and opportunities for collaboration with organisations such as BreastScreen Midland and the Cancer Society.

Key attention areas identified from the patient mapping work programme, together with specific actions, are outlined in brief below.

1. Establishment of the Breast Cancer Work Group

- 1.1 Determine membership of the Midland breast cancer work group.
- 1.2 Appoint a lead clinical person responsible for co-ordinating breast cancer work group.
- 1.3 Formalised structure in place to support operations of breast cancer work group.
- 1.4 Review of breast cancer pathways and models of care in terms of best practice and prioritisation of action plan recommendations.
- 1.5 Monitor and report on progress with implementing work programme.
- 1.6 Publicise and promote early stage breast cancer work.

2. Reducing inequalities and improving outcomes for Māori and Pacific women with Breast Cancer

- 2.1 Detailed analysis of individual Māori and Pacific women's breast cancer journeys.
- 2.2 Identify variations in access, transit times and pathways, together with reasons for variations.
- 2.3 Develop strategies to address and reduce inequalities in the breast cancer treatment pathway.
- 2.4 Investigate and support targeted cancer-related initiatives to address inequalities for Māori and Pacific women with breast cancer.
- 2.5 Develop a culturally responsive model of care co-ordination for early stage breast cancer.
- 2.6 Develop process for implementation and proceed with implementation of strategies.

3. Improving access to clinical services and reducing variations in service provision

- 3.1 Establish appropriate service waiting times for critical points in the pathway and implement monthly monitoring.
- 3.2 Review current waiting times for surgery at Lakes and Waikato DHBs and develop specific strategies that are sustainable to align waiting times with currently acceptable service standards.
- 3.3 In-depth mapping of the interval between surgery and initial oncology assessment for all participating DHBs and develop strategies to reduce waiting time between surgery and initial oncology assessment.
- 3.4 Develop/adopt guidelines to promote consistent management of early stage breast cancer.

- 3.5 Review volumes and existing arrangements for stereotactic biopsies across the participating Midland DHBs and agree framework for future provision.
- 3.6 Support investigating the establishment of a breast cancer risk assessment service with the Midland region.
- 3.7 Support improving access to clinical trials and maintain a watching brief on research related to breast cancer.

4. Improving Multidisciplinary Care

- 4.1 Develop and implement a Midland region multidisciplinary model for breast cancer service delivery.
- 4.2 Support developments to improve multidisciplinary care in breast cancer.

5. Improving Care Co-ordination

- 5.1 Develop a care co-ordination model for breast cancer.
- 5.2 Support the promotion of breast/cancer care co-ordination services.
- 5.3 Support the development of breast/cancer care co-ordinator led services initiatives.
- 5.4 Mapping of local DHB/organisation patient information delivery pathway for breast cancer.
- 5.5 Stocktake and review of resources, support and entitlement arrangements available to patients with breast cancer.
- 5.6 Develop a strategy to address gaps in patient/carer information.

6. Improving Communications between Breast Cancer Care Community

- 6.1 Review local referral and acknowledgement processes and communication links between participating Midland DHBs and other organisations.
- 6.2 Review communications and communication points with community, primary and private healthcare services.
- 6.3 Develop better guidance for all referrers referring patients with cancer or symptoms suggestive of cancer for diagnostic assessments or treatment.

7. Improving Access to Supportive Services

- 7.1 Support the establishment of a psycho-oncology service within the Midland region.
- 7.2 Support the development of a supportive care service directory within the Midland region.
- 7.3 Develop strategies to improve community-based breast cancer support services for Māori, Pacific and rural cancer patients.
- 7.4 Develop strategies to improve community-based services for breast cancer survivors.

8. Workforce Planning

- 8.1 Monitor breast cancer workforce including identifying shortages, issues and strategies for overcoming, promoting training and continuing professional development.

9. Service Planning and Technology Assessment

- 9.1 Advice and future planning of diagnostic and treatment services for breast cancer on a regional basis including identification of issues, recommendations and option for managing future demand.
- 9.2 Provide regional guidance on new/existing treatments and procedures to ensure standardised care across the region.

10. Improving breast screening coverage and reducing inequalities in breast screening programmes across the Midland Region

- 10.1 Support BreastScreen Midland initiatives to reduce inequalities and increase breast screening coverage to 70% by 2008/2009.
- 10.2 Propose a change to BreastScreen Aotearoa consent and notification of results processes from “opt on” to “opt off”.
- 10.3 Propose a review of diagnostic and treatment services subsidised by BreastScreen Aotearoa for screening-detected patients.

The action plan is attached in Appendix Two to this report. The action plan details specified tasks that may need to be undertaken, key stakeholders that may need to be involved in this area of work, milestones, indicative timeframe for completing, resources/funding and other relevant comments. Further work is needed in some areas to clarify some of the specific activities and to assess some of the gaps that have been identified through the patient mapping work programme. Implementation of the action plan will be subject to further work around confirmation of costs and an agreed programme of investment.

SECTION SIX

ACTIONING THE PLAN

Support for the Breast Cancer Work Group

The establishment of the work group will be co-ordinated by the Midland Cancer Network with overall DHB and organisation support to promote cross-regional participation and communication. The Midland Cancer Network will provide support in terms of infrastructure and set-up, secretariat functions and initial project support to support the work group. DHBs and other organisations will be expected to support and meet the costs of staff attending work group and project meetings. The major costs to organisations will be time for staff to attend meetings and transport. Staff clinical practice is expected to benefit from attending work group meetings as a consequence of improved awareness and focus on quality improvement. There is unlikely to be any reduction in capacity to deliver services through staff participation at work group level.

A Midland Cancer Network project officer position has been identified (0.5 FTE for one year) to take responsibility for actioning the plan under the direction of the breast cancer work group. International and other local networks have identified that it takes time to improve services to patients through a site specific group as training and integration of the membership is required. Therefore it is recommended that dedicated resource be allocated to support the work group and rollout of the plan and implement service improvements. The Midland Cancer Network will fund initial support for the first year and will evaluate the value of this investment.

Prioritisation of Activities

One of the first tasks of the breast cancer work group will be to review and prioritise the recommended activities/initiatives set out in the action plan and to agree the work programme for the remainder of 07/08 and for 08/09.

Prioritisation provides an opportunity to allocate funding and resources to initiatives that are more effective in improving health and independence, reduce inequalities, are acceptable, accessible, and value for money. The breast cancer work group will need to be guided by the principles and values of the Treaty of Waitangi and ensure its decisions align with the objectives of the New Zealand Cancer Control Strategy and action plan and other regional cancer and DHB strategic documents.

There are a number of tools that can be used to make informed prioritisation in a transparent and systematic way. Some of the tools likely to be utilised by the breast cancer work group in its decision-making include the Ministry of Health's Health Equity Assessment Tool (HEAT or Equity Lens) and the Ministry of Health cancer control planning and prioritisation framework.

The HEAT tool is used for tackling inequalities in health and considers people experiencing health status inequalities. It asks a series of questions including 'how does the initiative contribute to improving Māori health outcomes and reducing health disparities.' The Midland Cancer Network and the breast cancer work group will seek to ensure that inequalities do not increase by developing specific Māori and Pacific initiatives to reduce barriers that may be contributing to inequalities in or between different cultures for breast cancer services in the Midland region.

The planning and prioritisation framework has been endorsed by the Ministry of Health incorporates a decision matrix grid (previously used by the Midland Cancer Network) that assesses how amenable the intervention is to implementation and the impact of the intervention on improving functioning and wellbeing, reducing prevalence of the condition, compressing morbidity, and reducing premature deaths.

The three key stages of the prioritisation process are identification, analysis and decision. The activities/initiatives are identified in the action plan. There is increased emphasis on an evidence-based approach. For some of the activities, further analysis may be required to assess how the activity contributes to the prioritisation principles and impacts on resources and budget. For activities where evidence in terms of effectiveness is lacking, then the Plan, Do, Study, Act (PDSA) cycle may be utilised. The Plan, Do, Study, Act cycle is a process for testing changes by putting the initiative into effect on a temporary basis and small scale and learning from its potential impact before introducing the change. By building on the learnings from the test cycles in a structured and incremental way, a new idea can be implemented with greater chance of success.

The breast cancer work group will take a quality improvement approach and will adopt the Ministry of Health's Improving Quality framework and Service Planning and New Health Intervention Assessment (SPNIA) framework. Improving quality is a systems approach where quality is the degree to which the service for individuals or populations increase the likelihood of desired health outcomes, and/or increase the participation and independence of people with a disability and are consistent with professional knowledge. The SPNIA framework covers regional decision-making related to service reconfiguration.

The breast cancer work group will make recommendations based on evidence, consistent with the principles, goals and obligations and within available funding. In making final allocation decisions consideration will need to be given to how acceptable the decision will be to stakeholders, including Māori and Pacific people, and ease of implementation.

Stakeholders

There are a number of stakeholders and organisations that will need to be involved in and contribute to planning and implementing the activities identified in the Midland region action plan for early stage breast cancer. They include:

- Breast cancer work group
- Midland Cancer Network
- Participating DHBs – Bay of Plenty, Lakes and Waikato
- Regional Cancer Centre at Waikato Hospital
- Māori Health Services and Māori representatives
- Pacific representatives
- Non-government organisations e.g. Cancer Society
- Consumer representation
- BreastScreen Midland
- PHOs/general practitioners

The breast cancer work group represents the breast cancer care community. It will contribute to the design and lead the work programme. The Midland Cancer Network manages the cancer control work programme for the participating Midland DHBs and will provide advice and support, review and report about progress. The DHBs, Regional Cancer Centre and BreastScreen Midland will be key partners in the implementation of the action plan for early stage breast cancer.

Particular emphasis will be given to ensuring Māori Health Services, Māori and Pacific expertise, non-government organisations and consumers are involved or consulted as an important aspect of all actions. It is recognised that some of the stakeholders have limited resources, so a number of ways will need to be used to consult with them. If it is not possible for a project group to contain representatives of these stakeholders, then separate consultation will be held with them. There will be meaningful involvement from Primary Health Organisations and general practitioners where required.

Challenges and Risk

The key challenges relate to getting the breast cancer work group established and achieving effective relationships amongst its membership, participating DHBs and organisations, effective participation by stakeholders, as well as ensuring that the work group is able to deliver on implementing the action plan and the relevant sectors of the health community are kept informed of activity and successes.

Key risk and mitigation strategies for implementation of the action plan for early stage breast cancer

Risk	Mitigation Strategy	Responsibility
Lack of engagement by breast cancer team	<ul style="list-style-type: none"> • Agreement with participating DHBs and other organisations to provide appropriate resourcing to enable staff to participate. • Provide orientation and support as indicated. • Membership covers breadth of breast cancer team and regional representation. 	Midland Cancer Network DHBs and other stakeholders organisations
Lack of infrastructure to support work group	<ul style="list-style-type: none"> • Appointment of the project officer (within allocated resource) • Support from Midland Cancer Network 	Midland Cancer Network DHBs and other stakeholder organisations
Lack of resources and funding	<ul style="list-style-type: none"> • Identify resources and potential sources • Proposals developed 	Midland Cancer Network DHBs and other stakeholder organisations
Work programme too ambitious	<ul style="list-style-type: none"> • Prioritisation process • Provide a watching brief and monitor • Regular reporting • Promote simple innovations and solutions 	Breast Cancer Work Group Midland Cancer Network Participating DHBs and other stakeholder organisations

Risk	Mitigation Strategy	Responsibility
Relevant sectors of health community uninformed of activity and successes	<ul style="list-style-type: none"> • Stakeholder involvement is sought as required • Communication plan in place 	Midland Cancer Network
Initiatives do not meet needs of Māori and Pacific women	<ul style="list-style-type: none"> • Māori and Pacific involvement • Apply HEAT Tool 	Midland Cancer Network DHBs and other organisations Māori Health Services Māori representatives Pacific expertise

Implementation Plan

The breast cancer work group will work with the Midland Cancer Network and participating DHBs and organisations to carry out the implementation of the plan over the next three years.

An approach for phased implementation from 2007/2008 to 2010/2011 is in Appendix Three to this report. The implementation plan will be reviewed by the breast cancer work group. Specific actions identified for implementation in the short term that are in progress or delayed as at end of June 2008 will be carried across to the medium term 2008/2009.

Link with New Zealand Cancer Control Strategy Action Plan

The Ministry of Health, DHBs and the four regional cancer networks are working to implement actions identified in the New Zealand Cancer Control Strategy Action Plan 2005 – 2010. The cancer control action plan comprises six goals with objectives listed under each of the goals.

Work on implementation of phase one (the first two years) of the cancer control action plan commenced in 2005. One of the key developments of phase one was the establishment of the four regional cancer networks. Key findings of the evaluation and monitoring report for phase one were that Goals 1 (Primary Prevention of Cancer) and 2 (Effective Screening and Early Detection) are proceeding most rapidly, whereas progress was patchy in relation to Goals 3 to 6.

Work on implementing phase two of the Cancer Control Strategy Action Plan 2005 – 2010 got underway in 2007. The Midland Cancer Network's action plan for early stage breast cancer has been designed to contribute to the goals of the cancer control action plan with particular emphasis on activities identified for phase two. The table below shows how the specified actions in the action plan for early stage breast cancer align with phase two of the cancer control strategy actions:

Goal	Objective	Specified Phase 2 Cancer Control Actions	Specified Early Stage Breast Cancer Actions
2	Effective Screening	On-going high level oversight of cancer screening Strategies used to ensure ongoing reduction in breast cancer mortality	Support BreastScreen Midland initiatives to increase breast screening coverage to 70% by 2008/2009
3	Optimal Treatment	Improved access for groups with recognised disadvantage Regional and national consistency of diagnosis and treatment Appropriate access to multidisciplinary approach	Adopt guidelines to promote the consistent management of Early Stage Breast Cancer. Developing a Midland multidisciplinary model for breast cancer. Support developments to improve multidisciplinary care in breast cancer.
3	Patient-centred, integrated care	Co-ordinated and seamless patient journeys Patients empowered to make informed choices	Developing a breast cancer model of care co-ordination. Support and promotion of the breast/cancer care co-ordination service. Support the development of care co-ordinator led services.
4	Access to appropriate resources for support and rehabilitation	Assessment of current policy and development of new policy	Adopt guidelines to promote optimal supportive care. Scope/develop feasibility of a Midland psycho-oncology service.
	High-quality information on treatment and care, including complementary and alternative medicine	Database of information established. Approved standard for cancer-related information. Quality information available in a clinical setting.	Develop a strategy to address gaps in patient/carer information
5	Workforce	Annual monitoring of the cancer control workforce. Increasing radiotherapy, nursing, palliative care and rehabilitation workforce capacity and capability.	Monitor breast cancer workforce including identifying shortages and strategies for overcoming. Developing multidisciplinary teams.
6	Services accessible to Māori	Case management approach for Māori. Focus on Māori priorities and reducing inequalities, including funding and policy decisions and monitoring. Improved communication with and for Māori.	Further work to identify variations in access, transit times and pathways. Developing strategies to reduce inequalities in the breast cancer treatment pathway. Support targeted cancer-related initiatives.

SECTION SEVEN

BREAST CANCER STATISTICS

This section contains an overview of incidence and mortality rates for breast cancer, breast screening coverage rates and cancer waiting time target. Refer to Appendix Four for more in-depth information on the breast cancer statistics.

In New Zealand, breast cancer is the most common cancer registered for both Māori and non-Māori females.

OVERVIEW

Incidence

From a national and regional perspective, the incidence of breast cancer has been increasing. Some of the increase in incidence can be attributed to the introduction of the national screening programme, as early undiagnosed cancers are now detected. For both Lakes and Waikato DHBs breast cancer is the second highest leading cause of cancer registrations. However, for Bay of Plenty DHB breast cancer is the third highest leading cause of cancer registrations. There is geographical variation in breast cancer incidence, with the highest rate (213 new cases per 100,000) in Waikato DHB area and the lowest rate (180 new cases per 100,000) in Bay of Plenty DHB area. The breast cancer incidence rate for Bay of Plenty DHB area decreased over the observation period, which is a departure from national, regional and individual DHB breast cancer incidence trends.

Mortality

Breast cancer is the second highest leading cancer killer across all ethnic groups in the Midland region. Breast cancer mortality rates have fallen over the observation period. The greatest breast cancer mortality rate declines were in the 65+ and 45 to 64 age groups at national and regional level. The reduction in breast cancer mortality is likely to be due to several different causes, including screening, increasing specialisation of care, and the widespread adoption of hormone therapy. There is geographical variation in breast cancer mortality with the highest rate (51 deaths per 100,000) in Lakes DHB area and the lowest rate (44 deaths per 100,000) in Waikato DHB region. For Lakes DHB area, breast cancer mortality is decreasing in the 65+ age group and increasing in the 45 to 64 age group, which represents a departure from national, regional and DHB breast cancer mortality trends.

Ethnicity

Māori females have a breast cancer registration rate around 1.3 times that of non-Māori and a breast cancer mortality rate around twice that of non-Māori females. There are geographical variations in breast cancer incidence and mortality rate between Māori and non-Māori across the Midland region. The variations are more apparent for breast cancer mortality rates. The proportion of Māori in the Lakes DHB population is significantly higher than in the national population (35% compared with 15% nationally) and this is a possible reason for the geographical variations.

Breast cancer is the second highest leading killer among Midland region Māori and Other. However, among Pacific people, it is the leading cause of mortality. Breast cancer mortality rate trends for Māori are higher in Lakes DHB area and lower for Māori in Waikato and Bay of Plenty DHBs. In Lakes in 2005, 55% of deaths from breast cancer were Māori and the mortality standardised rate ratio was around 2.3. In Waikato and Bay of Plenty, around 20% of deaths from breast cancer were Māori and the mortality standardised rate ratio was just over 1. In Lakes in 2005, 36% of the new cases of breast cancer were in Māori women, compared with around 16% of new cases in Bay of Plenty and Waikato DHBs.

A recent monitoring report on health inequality in New Zealand (Ministry of Health, 2007) indicates that ethnic inequalities in breast cancer mortality rates increased markedly from the mid - 1980s to the mid - 1990s. The increase in inequality is understood to have possibly peaked during the late - 1990s to early - 2000s.

Screening Coverage

BreastScreen Aotearoa reported a 54% coverage of eligible women aged 45 to 69 within Bay of Plenty DHB area, 51% coverage with Lakes DHB and 58% coverage within Waikato DHB for the two-year period July 2005 to June 2007. Current national coverage rate is 57% and the national target is 70%. Coverage rates for Māori and Pacific women are around 20% lower than the DHB area rates.

Cancer Waiting Time Target

Nationally, around 95% of all cancer cases are treated within the target timeframe of eight weeks from first specialist assessment to start of radiotherapy. For the Midland region in September 2007 93% of patients waited less than four weeks for their treatment and 5% waited between four and eight weeks. The Midland region includes Waikato, Bay of Plenty, Lakes, Tairāwhiti and Taranaki DHBs (all Midland DHBs) in this particular instance. The cancer waiting times target relates to all cancers, it is not tumour specific.

As at February 2008 the waiting time for patients with breast cancer between referral to oncology and first assessment by an oncologist is around four weeks for radiation oncology and eight to ten weeks for medical oncology. A patient with breast cancer could then have to wait for around three weeks to start radiation treatment. For chemotherapy there is no waiting list at this time. (Source: communication with Oncology Booking Clerk, February 2008).

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APPENDIX ONE SUPPLEMENTARY INFORMATION

The following is a list of additional information and documents related to the patient mapping work programme for early stage breast cancer which are referred to within the report and/or have been authorised for release.

1.	Flowcharts detailing the care pathways for early stage breast cancer: <ul style="list-style-type: none"> • Waikato DHB • Bay of Plenty DHB (versions for both Tauranga Hospital and Whakatane Hospital) • Lakes DHB (Can be supplied as either electronic or hard copy. VISIO reader required for electronic copies).
2.	Flowchart detailing the view of just the patient processes for symptomatic and screening-detected (asymptomatic) patients – hypothetical journey (Can be supplied as either electronic or hard copy. VISIO reader required for electronic copies).
3.	Midland Cancer Network Patient Mapping Project. Report on early stage breast cancer for DHB workshops. The patient's breast cancer journey and what we know about the system. April 2007.
4.	Complaints and patient satisfaction survey data (Judy Fitness).
5.	Report on breast cancer focus groups and interviews (Judy Fitness).
6.	Understanding the breast cancer journey: Thematic analysis of Interviews and Focus Groups Report (Anna Whitehead).
7.	Report on Waikato DHB early stage breast cancer patient's pathway: Waiting times at key stages (Marcus Ghuman, February 2007).
8.	Regional high level report on audit of waiting times across key stages of the breast cancer journey (Loryn Scanlan, April 2007).
9.	Access to breast cancer services for Māori.
10.	File notes of the three workshops held at each of the participating DHBs.
11.	Draft Terms of Reference - Breast Cancer Work Group.
12.	Midland District Health Boards. Midland Region Cancer Control Project on Patient Mapping. June 2006.

APPENDIX TWO MIDLAND EARLY STAGE BREAST CANCER ACTION PLAN

KEY ATTENTION AREA 1: ESTABLISHMENT OF THE BREAST CANCER WORK GROUP

Specific Actions	Stakeholders	Milestone/Measures	Timeframe	Resources/Funding	Comments
Membership of the Midland Breast Cancer Work Group determined	Midland Cancer Network Breast surgeons Breast physicians Medical oncologists Radiation oncologists Breast radiologists Pathologist BreastScreen Midland Breast/cancer co-ordinators DHBs/organisations Māori Health Service Māori / Pacific representation Consumer perspective PHOs/general practice NGOs/Community	Membership of the breast cancer work group appointed and promulgated. Members understand their role and function within the work group.	July 2007 – June 2008	Existing	It is anticipated that the work group would be established by June 2008.
Appointment of a lead clinician responsible for co-ordinating breast cancer work group	Midland Cancer Network Breast cancer work group DHBs/organisations	Chairperson of breast cancer work group appointed and promulgated.	July 2007 – June 2008	Existing	
Formalised structure in place to support the operations of breast cancer work group	Midland Cancer Network Breast cancer work group DHBs/organisations	Terms of reference agreed. Project officer appointed.	July 2007 – June 2008 April 2008 – June 2009	Existing Additional through prioritisation.	Project officer position will depend on the prioritisation of Midland Cancer Network infrastructure funding.
Review and prioritisation of recommendations in the early stage breast cancer action plan	Breast cancer work group	Annual work programme developed. Annual work programme agreed and endorsed by Midland Cancer Network.	July 2008 – June 2009 and for each year thereafter	Existing	
Monitor and report on progress with implementing work programme	Breast cancer work group	Contribute to annual progress report of Midland Cancer Network.	June 2009 and each year thereafter	Existing	Project officer will assist with implementing work programme.
Publicise and promote early stage breast cancer work programme	Breast cancer work group Midland Cancer Network DHBs/organisations	Copies of work programme sent to all participating DHBs and other interested parties.	July 2008 – June 2009	Existing	

KEY ATTENTION AREA 2: REDUCING INEQUALITIES AND IMPROVING OUTCOMES FOR MAORI AND PACIFIC WOMEN WITH BREAST CANCER

Investigate Māori and Pacific women's access to and through breast cancer treatment pathways

Specific Actions	Stakeholders	Milestone/Measure	Timeframe	Resource/Funding	Comments
Detailed analysis of individual Māori and Pacific women's breast cancer journeys	Breast cancer work group Midland Cancer Network DHBs/organisations Māori Health Service Māori and Pacific representation Breast/cancer co-ordinators BreastScreen Midland	Maps of individual journeys completed.	July 2008 – December 2008 (to be confirmed)	Existing + additional funding (if required) through prioritisation of Midland Cancer Network inequalities funding.	Work collaboratively with Māori and Pacific expertise from participating DHBs to plan and undertake this area of work.
Identify variations in access, transit times and pathways together with reasons for variations	Breast cancer work group Midland Cancer Network DHBs/organisations Māori Health Service Māori and Pacific representation Breast/cancer co-ordinators BreastScreen Midland	Analysis of individual patient journeys completed and presented to breast cancer work group and Midland Cancer Network.	July 2008 – December 2008 (to be confirmed)	Existing + additional funding (if required) through prioritisation of Midland Cancer Network inequalities funding.	In collaboration with Māori and Pacific expertise from participating DHBs/organisations.
Develop strategies to address and reduce inequalities in the breast cancer treatment pathway	Breast cancer work group Midland Cancer Network DHBs/organisations Māori Health Service Māori and Pacific representation Breast/cancer co-ordinators BreastScreen Midland	Proposal developed and submitted for approval of Midland Cancer Network and DHBs. Proposal discussed with breast cancer work group. Implementation of strategy and actions as agreed.	July 2008 – June 2009 (to be confirmed)	Existing + additional funding (if required) through prioritisation of Midland Cancer Network inequalities funding.	In collaboration with Māori and Pacific expertise from participating DHBs/organisations.
Investigate and support targeted cancer-related initiatives to address inequalities for Māori and Pacific women with breast cancer	Breast cancer work group Midland Cancer Network DHBs/organisations Māori Health Service Māori and Pacific representation Breast/cancer co-ordinators BreastScreen Midland	Proposal developed and submitted for approval by Midland Cancer Network. Proposal discussed with breast cancer work group.	July 2008 – June 2009 (to be confirmed)	Existing + additional funding through prioritisation of Midland Cancer Network inequalities funding.	In collaboration with Māori and Pacific expertise from participating DHBs/organisations.

Develop a culturally responsive method of care co-ordination for breast cancer

Specific Actions	Stakeholders	Milestone/Measure	Timeframe	Resource/Funding	Comments
Develop a culturally responsive model of care co-ordination for early stage breast cancer for the Midland region	Breast cancer work group Midland Cancer Network DHBs/organisations Māori Health Service Māori and Pacific representation Breast/cancer co-ordinators	Proposal developed and discussed with breast cancer work group. Proposal submitted for approval by Midland Cancer Network.	July 2008 – June 2009	Existing + additional funding (if required) through prioritisation. Project officer	
Develop process for implementation and proceed with implementation of strategies	Breast cancer work group Midland Cancer Network DHBs/organisations Māori Health Service Māori and Pacific representation Breast/cancer co-ordinators	Strategies implemented.	July 2008 – June 2009 ongoing	Existing + additional funding (if required) through prioritisation. Project officer	

KEY ATTENTION AREA 3: IMPROVING ACCESS TO CLINICAL SERVICES AND REDUCING VARIATIONS IN SERVICE PROVISION

Specific Actions	Stakeholders	Milestone/Measure	Timeframe	Resource/Funding	Comments
Establish appropriate service waiting times for critical points in the pathway and implement monthly monitoring	Breast cancer work group DHBs/organisations Regional Cancer Centre Breast/cancer co-ordinators	Service waiting times agreed. Reporting template and frequency agreed.	July 2008 - June 2009	Existing + additional funding (if required) through prioritisation. If additional funding is required to implement performance measures then it will need to be determined.	Existing targets include relevant BreastScreen Aotearoa evaluation targets and Ministry of Health waiting time indicator for radiation treatment.
Review current waiting times for surgery at Lakes and Waikato DHBs and develop specific strategies that are sustainable to bring waiting times into line with currently acceptable service waiting times	Breast cancer work group DHBs	Waiting times for surgery at Lakes and Waikato DHBs in line with currently agreed service waiting time of four weeks.	July 2008 – June 2009	Existing DHB funding + additional funding (if required) through DHBs prioritisation processes. If additional funding is required then it will need to be determined.	
In-depth mapping of the interval between surgery and initial oncology assessment for all participating DHBs. Develop strategies to reduce waiting time between surgery and initial oncology assessment.	Midland Cancer Network DHBs/organisations Regional Cancer Centre	Review completed and outcome discussed by breast cancer work group. Discussion paper for Midland Cancer Network.	July 2008 – June 2009	Existing DHB funding.	Link with breast/cancer care co-ordination service initiatives (nurse-led clinics were implemented at Waikato DHB in 2008).
Develop/adopt guidelines to promote consistent management of early stage breast cancer	Breast cancer work group DHBs/organisations Regional Cancer Centre Ministry of Health New Zealand Guideline Group	National and regional guidelines and standards are in place for the management of patients with breast cancer.	July 2008 – June 2010	Existing + additional funding (if required) through prioritisation. If additional funding is required to implement the guidelines then it will need to be determined.	Await outcome of nationally-led project on management of patients with breast cancer. Anticipated release date is 2009.
Review volumes and existing arrangements for stereotactic biopsies across the participating Midland region and investigate sustainable strategies to improve access to stereotactic biopsies across the region.	Breast cancer work group DHBs Private radiology services contracted to DHBs (if relevant) BreastScreen Midland	Review completed and outcome discussed by breast cancer work group. Strategies developed for discussion by Midland Cancer Network and DHBs.	July 2008– June 2009	Existing + additional funding through DHB prioritisation processes. If additional funding if required it will need to be determined.	

Specific Actions	Stakeholders	Milestone/Measure	Timeframe	Resource/Funding	Comments
Support investigating the establishment of a breast cancer risk assessment service within the Midland region	Midland Cancer Network Breast cancer work group DHBs/organisations Regional Cancer Centre Māori Health Services Māori and Pacific representation Consumer perspective PHOs/general practice Northern Region Genetic Service	Proposal developed and submitted for approval.	July 2008 – June 2009	Additional through prioritisation processes.	Applicable to other tumour streams.
Support improving access to clinical trials and maintain a watching brief on research directly related to breast cancer	Breast cancer work group DHBs/organisations Midland Cancer Network Māori Health service Clinical Trials (Regional Cancer Centre)	Discussion paper presented to Midland Cancer Network as required.	July 2008 - ongoing	Existing + additional funding through DHB prioritisation processes.	

KEY ATTENTION AREA 4: IMPROVING MULTIDISCIPLINARY CARE

Specific Actions	Stakeholders	Milestone/Measure	Timeframe	Resource/Funding	Comments
Develop and implement a Midland region multidisciplinary model for breast cancer service delivery	Breast cancer work group Midland Cancer Network DHBs/organisations BreastScreen Midland Breast/cancer co-ordinators Māori Health Service Māori and Pacific representation Consumer perspective General practitioners Co-ordinator, multidisciplinary team meetings, cancer care	Model of multidisciplinary care for breast cancer agreed. Multidisciplinary framework and standards developed and implemented for breast cancer.	July 2008 – June 2009 July 2008 – July 2009	Existing	Model must be culturally effective and in line within Midland Cancer Network multidisciplinary care framework (once it has been developed). Note: Multidisciplinary framework links with continuity of care/ co-ordination framework.
Support developments to improve multidisciplinary care in breast cancer	Breast cancer work group Midland Cancer Network DHBs/organisations Māori Health Service Māori and Pacific representation Consumer perspective Breast/cancer co-ordinators General practitioners	Tools and resources are developed. All participating DHBs have implemented breast cancer multidisciplinary model.	July 2008 – June 2009	Existing DHB funding.	

KEY ATTENTION AREA 5: IMPROVING CARE CO-ORDINATION

Improving Care Co-ordination

Specific Actions	Stakeholders	Milestone/Measure	Timeframe	Resource/Funding	Comments
Develop a breast cancer model of care co-ordination	Breast cancer work group DHBs/organisations Māori Health Service Māori and Pacific representation Consumer perspective Breast/cancer co-ordinators	Model of care co-ordination for breast cancer agreed.	July 2007 – June 2008	Existing Project support	In progress. Model must be culturally effective and in line within Midland Cancer Network care co-ordination framework and the New Zealand version of the Patient Management Framework (once it has been developed).
Support promotion of the Breast/cancer co-ordination Service	Breast cancer work group DHBs/organisations BreastScreen Midland Māori Health Service Māori and Pacific representation Consumer perspective Breast/cancer co-ordinators PHOs/general practice NGOs	Breast/cancer co-ordination service embedded.	July 2008 – June 2009 ongoing	Existing	
Support the development of breast/cancer care co-ordinator-led service initiatives	Breast cancer work group Midland Cancer Network DHBs Regional Cancer Centre Breast/Cancer Co-ordinators Māori Health Service Māori and Pacific representation Consumer perspective PHOs/general practice NGOs	Proposals developed and submitted for approval.	July 2008 – June 2009 ongoing	Existing	Links with nurse-led clinics pilot at Breast Care Centre and care co-ordination database (Waikato DHB only).

Improving access to Patient Cancer Information

Specific Actions	Stakeholders	Milestone/Measure	Timeframe	Resource/Funding	Comments
Mapping of local patient information delivery pathways for breast cancer	Breast cancer work group Midland Cancer Network DHBs Regional Cancer Centre BreastScreen Midland Breast/cancer co-ordinators General practice NGOs Consumer perspective	Patient information pathway for breast cancer completed.	July 2008 – June 2009	Existing + additional funding (if required) through prioritisation. Project support	
Stocktake and review of resources, support and entitlement arrangements available to patients with breast cancer	Breast cancer work group Midland Cancer Network DHBs NGOs Other agencies (WINZ) General practice	Stocktake completed.	July 2008 – June 2009	Existing + additional funding (if required) through prioritisation. Project support	Applicable to all tumour streams. Links with supportive care activities.
Develop a strategy to address gaps in patient/carer information	Breast cancer work group Midland Cancer Network DHBs Regional Cancer Centre BreastScreen Midland Breast/cancer co-ordinators Māori Health Service Māori and Pacific representation Consumer perspective General practice NGOs	Proposal developed and submitted for approval.	July 2009 - June 2010	Existing + additional funding (if required) through prioritisation. Project support	Await outcome of nationally-led project on information and support for people with cancer. Links with development of a supportive care directory for the Midland region.

KEY ATTENTION AREA 6: IMPROVING COMMUNICATIONS ACROSS BREAST CANCER CARE COMMUNITY

Specific Actions	Stakeholders	Milestone/Measure	Timeframe	Resource/Funding	Comments
Review local referral and acknowledgement processes and communication links	Breast cancer work group Midland Cancer Network DHBs/organisations Regional Cancer Centre Breast/cancer co-ordinators Private specialists General practitioners	Review completed.	July 2008 – June 2009	Existing	
Review communications and communication points with community and primary healthcare services (district nurses and general practitioners)	Breast cancer work group Midland Cancer Network DHBs Regional Cancer Centre Breast/cancer co-ordinators District nurses General practitioners	Review completed.	July 2008 – June 2009	Existing	
Develop better guidance for all referrers referring patients with breast cancer or symptoms suggestive of breast cancer for diagnostics, assessment or treatment	Breast cancer work group Midland Cancer Network DHBs Regional Cancer Centre BreastScreen Midland Māori Health Service Māori and Pacific representation Breast/cancer co-ordinators General practitioners District nurses Consumer perspective	Guidelines adopted	July 2008 – June 2009	Existing	Await the outcome of nationally-led project. Anticipated release date is July 2008.

KEY ATTENTION AREA 7: IMPROVING ACCESS TO SUPPORTIVE CARE

Specific Actions	Stakeholders	Milestone/Measure	Timeframe	Resource/Funding	Comments
Support the scoping and development of a psycho-oncology service within the Midland region	Midland Cancer Network Breast cancer work group DHBs/organisations Regional Cancer Centre Breast/cancer co-ordinators Māori Health Service Māori and Pacific representation Consumer perspective NGOs Community PHO/general practice	Proposal developed and submitted for approval. Proposal aligns with national supportive care guidelines.	July 2008 – June 2009	Additional through DHB prioritisation processes.	Applicable to all tumour groups. National supportive care guidelines will be available in 2008.
Support the development of a supportive care service directory	Midland Cancer Network Breast cancer work group Regional Cancer Centre DHBs/organisations Breast / Cancer Care Co-ordinators Māori Health Service Māori and Pacific representation Consumer perspective NGOs Community PHO/general practice	Directory developed and submitted for approval. Directory promulgated.	July 2008 – July 2009	Existing + additional funding (if required) through prioritisation.	Most support services will be applicable to all tumour groups but there are some support services which are specific to breast cancer. Links with initiatives related to improving information for patients with cancer (see key attention area 5).
Collaborate with NGOs to develop strategies to improve community-based breast cancer support services for Māori, Pacific and rural cancer patients	Midland Cancer Network Breast cancer work group Regional Cancer Centre DHBs/organisations Breast/cancer co-ordinators Māori Health Service Māori and Pacific representation Consumer perspective NGOs Community PHO/general practice	Proposal developed and submitted for approval.	July 2008 – June 2009 ongoing	Existing + Additional funding (if required) through prioritisation.	Applicable to all tumour groups.

Specific Actions	Stakeholders	Milestone/Measure	Timeframe	Resource/Funding	Comments
Collaborate with NGOs to develop strategies to improve community-based support services for breast cancer survivors	Midland Cancer Network Breast cancer work group Regional Cancer Centre DHBs/organisation Breast/cancer co-ordinators Māori Health Service Māori and Pacific expertise Consumer perspective NGOs Community PHO/general practice	Proposal developed and submitted for approval.	July 2008– June 2009 ongoing	Existing	Focus is after the completion of treatment. Link to psycho-oncology service.

KEY ATTENTION AREA 8: WORKFORCE MONITORING

Specific Actions	Stakeholders	Milestone/Measure	Timeframe	Resource/Funding	Comments
Monitor breast cancer workforce including identifying shortages and issues, strategies for overcoming, promoting training and continuing professional development	Breast cancer work group Midland Cancer Network DHBs/organisations Regional Cancer Centre BreastScreen Midland	Paper on issues for discussion by Midland Cancer Network (as required). Input into Midland Cancer Network workforce plan.	July 2008 - June 2009 ongoing	Existing	Shortages identified were with the diagnostic radiology (MRTs, sonographers and radiologists), surgical and supportive care workforce.

KEY ATTENTION AREA 9: SERVICE PLANNING AND TECHNOLOGY ASSESSMENT

Specific Actions	Stakeholders	Milestone/Measure	Timeframe	Resource/Funding	Comments
Advice and future planning of diagnostic and treatment services for breast cancer on a regional basis including identification of issues, recommendations and options for managing future demand	Breast cancer work group Midland Cancer Network DHBs/organisations Regional Cancer Centre BreastScreen Midland	Paper on issues for discussion by Midland Cancer Network (as required). Input into regional service plans.	July 2008 and June 2009 ongoing	Existing	Issues identified include access to specialised imaging services (stereotactic imaging and breast MRIs).
Provide regional guidance on new/existing treatments and procedures to ensure standardised care across the region	Breast cancer work group Midland Cancer Network DHBs/organisations Regional Cancer Centre BreastScreen Midland				Issues identified include techniques for identification of sentinel nodes.

KEY ATTENTION AREA 10: IMPROVING BREAST SCREENING COVERAGE AND REDUCING INEQUALITIES IN BREAST SCREENING PROGRAMMES ACROSS MIDLAND REGION

Specific Actions	Stakeholders	Milestone/Measure	Timeframe	Resource/Funding	Comments
Support BreastScreen Midland initiatives to reduce inequalities and increase breast screening coverage to 70% by 2008	Breast cancer work group Midland Cancer Network DHBs/organisations BreastScreen Midland Māori Health Services Māori and Pacific representation Consumer perspective PHO/general practice	Increased coverage and reduced inequalities.	June 2007 – July 2008 ongoing	Existing	
Propose a change to BreastScreen Aotearoa consent and notification of results processes	Breast cancer work group Midland Cancer Network BreastScreen Midland PHOs/general practice	Letter from Midland Cancer Network or breast cancer work group to BreastScreen Aotearoa.	July 2007 – June 2008	Existing	Change consent requirements from “opt on” to “opt off”.
Propose a review of diagnostic and treatment services subsidised by BreastScreen Aotearoa for screening-detected patients	Breast cancer work group Midland Cancer Network BreastScreen Midland	Letter from Midland Cancer Network or breast cancer work group to BreastScreen Aotearoa.	July 2007 – June 2008	Existing	MRIs currently not subsidised by BreastScreen Aotearoa for screening-detected women.

Note: The specific actions, milestones in the action plan are ambitious and are dependent on supporting resource being available and services'/organisations' ability to allocate/align their current resources to support service improvements.

APPENDIX THREE IMPLEMENTATION PLAN

Key Attention Areas	Short Term 2007/2008	Medium Term 2008/2009	Long Term 2009 and onwards
1. <i>Establishment of the Breast cancer work group</i>	<ul style="list-style-type: none"> • Determining membership • Appointment of lead clinician • Structure in place to support operations of work group 	<ul style="list-style-type: none"> • Review of breast cancer pathways and models of care • Prioritisation of recommendations in action plan • Develop 2008/2009 work programme 	<ul style="list-style-type: none"> • Publicise and promote work programme and progress • Monitor and report on progress with implementing work plan
2. <i>Reducing inequalities and improving outcomes for Māori and Pacific women with breast cancer</i>		<ul style="list-style-type: none"> • Detailed analysis of individual Māori and Pacific women's journeys • Identify variations in access, transit times and pathways and reasons for variations • Investigate and support targeted cancer-related initiatives for Māori and Pacific women 	<ul style="list-style-type: none"> • Develop a culturally responsive model of care co-ordination for Māori and Pacific women with breast cancer • Develop strategies to address and reduce inequalities in the breast cancer treatment pathway • Investigate and support targeted cancer-related initiatives for Māori and Pacific women

Key Attention Areas	Short Term 2007/2008	Medium Term 2008/2009	Long Term 2009 onwards
3. <i>Improve access to services and reduce variations in service provision</i>		<ul style="list-style-type: none"> • Review current waiting times for surgery • Develop strategies to reduce/ align current waiting times at Lakes and Waikato DHB with currently acceptable service waiting times • Establish appropriate service waiting times for critical points in the journey and implement monthly monitoring • In-depth mapping of the interval between surgery and initial oncology assessment for all DHBs • Develop strategies to reduce waiting time between surgery and initial oncology assessment • Review volumes, arrangements for stereotactic biopsies and develop framework for future provision 	<ul style="list-style-type: none"> • Develop/adopt guidelines to promote consistent management of breast cancer • Support the investigation of breast cancer risk assessment service within Midland region • Support improving access to clinical trials and maintain watching brief on research directly related to breast cancer
4. <i>Improving multidisciplinary care</i>		<ul style="list-style-type: none"> • Develop and implement a Midland multidisciplinary model for breast cancer service delivery 	<ul style="list-style-type: none"> • Support developments to improve multidisciplinary care in breast cancer
5. <i>Improving care co-ordination</i>		<ul style="list-style-type: none"> • Develop a Midland region model of care co-ordination for breast cancer • Map local patient information delivery pathways • Stocktake and review resources, support and entitlement arrangements available to patients with breast cancer 	<ul style="list-style-type: none"> • Support the development of breast/cancer co-ordination-led service initiatives • Develop a strategy to address gaps in patient/carer information

Key Attention Areas	Short Term 2007/2008	Medium Term 2008/2009	Long Term 2009 onwards
6. <i>Improving communications across the breast cancer care community</i>		<ul style="list-style-type: none"> Review local referral and acknowledgement processes and communication links between participating Midland DHBs/organisations Review communications and communication points with community, primary and private providers Develop better guidance for all referrers referring patients with cancer or symptoms suggestive of cancer for diagnostic assessment or treatment 	
7. <i>Improving access to supportive care</i>		<ul style="list-style-type: none"> Support the establishment of psycho-oncology service within the Midland region Support the development of a directory of supportive care services for the Midland region 	<ul style="list-style-type: none"> Collaborate with NGOs to develop strategies to improve community-based breast cancer support services for Māori, Pacific and rural cancer patients Collaborate with NGOs to develop strategies to improve community-based breast cancer support services for breast cancer survivors
8. <i>Workforce</i>		<ul style="list-style-type: none"> Monitor breast cancer workforce including identifying shortages, issues, strategies for overcoming 	<ul style="list-style-type: none"> ongoing
9. <i>Service planning and technology assessment</i>		<ul style="list-style-type: none"> Advice and future planning of diagnostic and treatment services for breast cancer 	<ul style="list-style-type: none"> ongoing

Key Attention Areas	Short Term 2007/2008	Medium Term 2008/2009	Long Term 2009 onwards
10. <i>Improving breast screening coverage and reducing inequalities in breast screening programmes across Midland region</i>	<ul style="list-style-type: none"> • Support BreastScreen Midland initiatives to reduce inequalities and increase breast screening coverage to 70% • Propose a change to BreastScreen Aotearoa consent and notification of results processes • Propose a review of diagnostic and treatment services subsidised by BreastScreen Aotearoa 	<ul style="list-style-type: none"> • Support BreastScreen Midland initiatives to reduce inequalities and increase breast screening coverage to 70% 	<ul style="list-style-type: none"> • ongoing

APPENDIX FOUR

BREAST CANCER STATISTICS

The following information concentrates on breast cancer incidence and mortality statistics, breast screening coverage and cancer waiting time information. The information for the analysis has been obtained from TAS Health Needs Assessment 2007 CD-Rom, BreastScreen Aotearoa, the Health Targets Quarter One Report November 2007 and from staff at the Regional Cancer Centre, Waikato Hospital.

For this particular analysis ethnicities have been categorised as Māori, Pacific or Other. In this case everyone who is not Māori or Pacific is referred to as 'Other'. The ethnicity categorisation used in this section is not the same as the ethnicity categorisation used for the audit of waiting times.

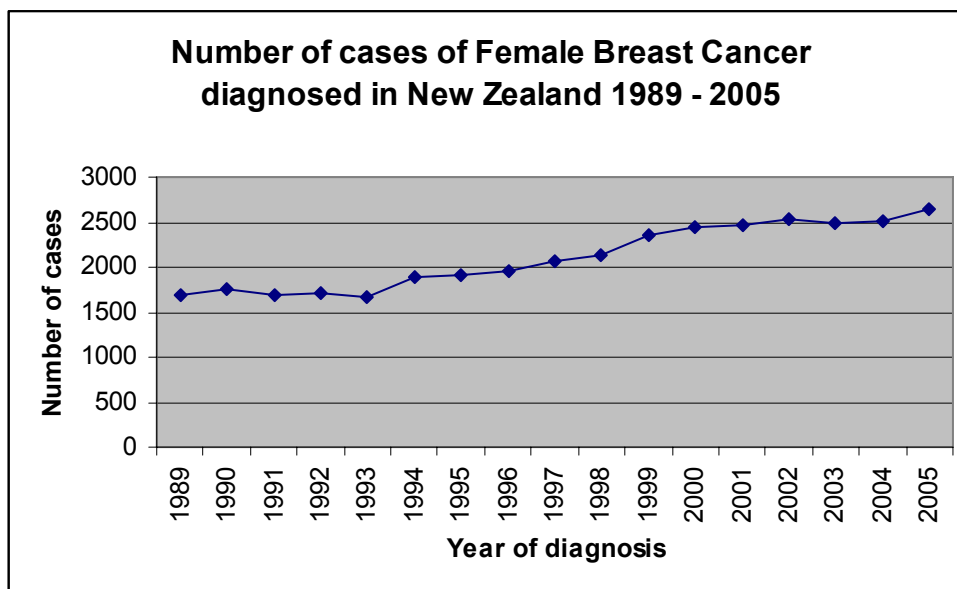
National Trends

This section concentrates on national female breast cancer incidence and mortality statistics.

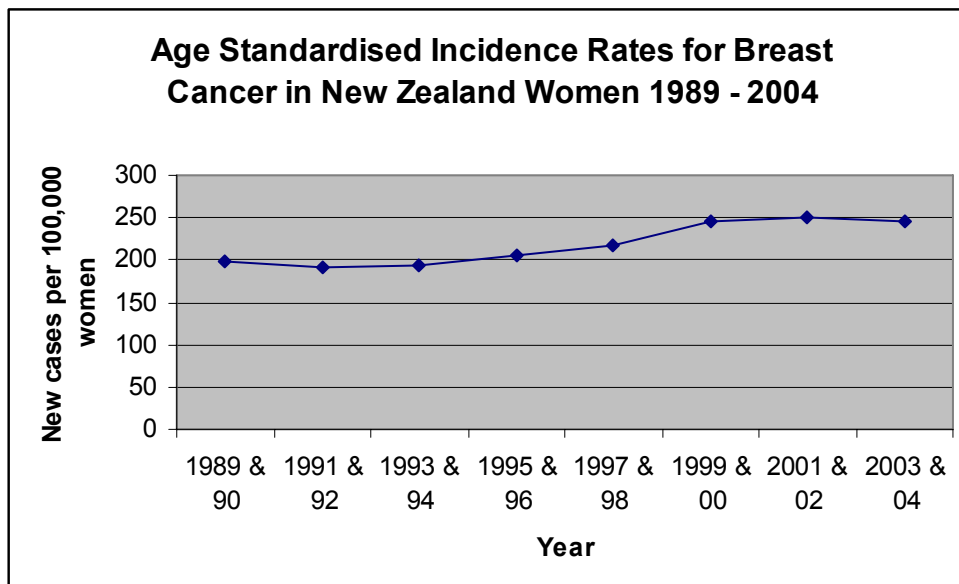
In 2005 (the most recent year numbers are available) 2,637 women were diagnosed with breast cancer in New Zealand.

In 2004 (the most recent year numbers are available) 447 women died from breast cancer in New Zealand.

Incidence



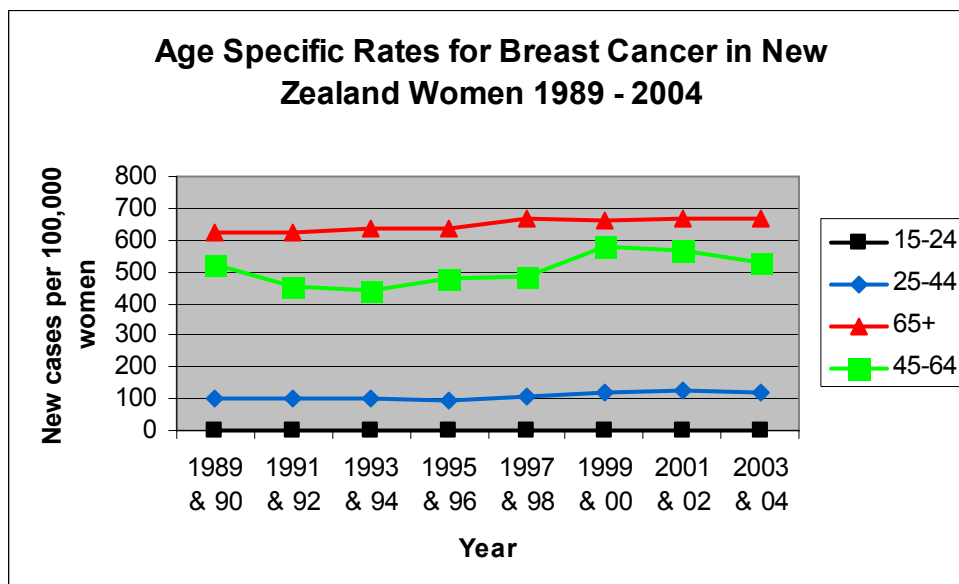
The number of women diagnosed with breast cancer in New Zealand increased from 1,679 in 1989 to 2,637 in 2005.



The age-standardised incidence of breast cancer increased from 197 per 100,000 population in 1989/90 to 251 per 100,000 in 2001/2002 and 245 per 100,000 in 2003/2004. The above graph appears to indicate that the age-standardised incidence rate may be decreasing or stabilising.

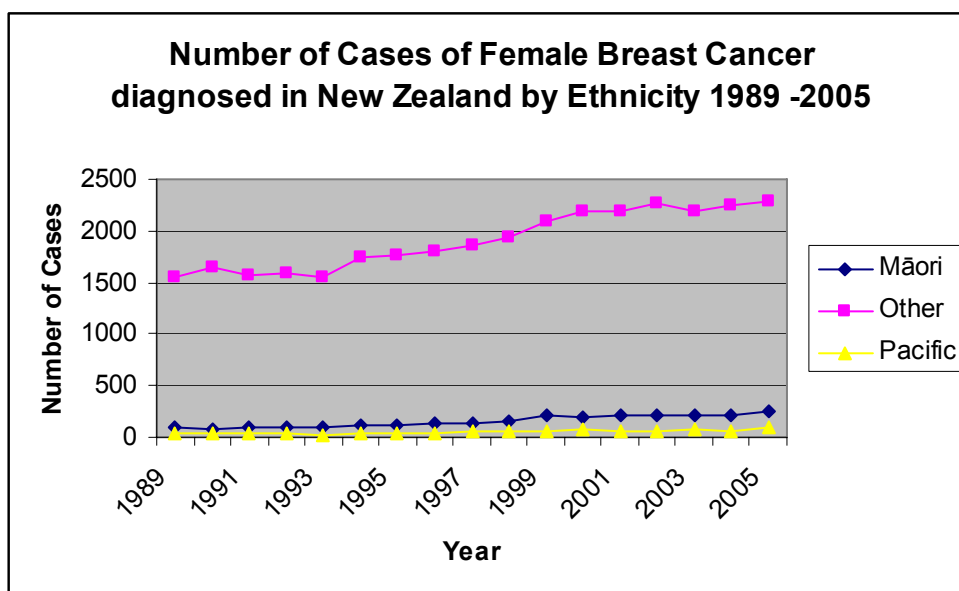
BreastScreen Aotearoa, the national breast screening programme, was launched in December 1998 with services offered progressively throughout the country. At that time, screening mammography was free for women in New Zealand aged 50 to 64 years who had no symptoms. In July 2004 the eligible age-range for publicly funded screening mammograms was extended to women aged 45 to 49 years and 65 to 69 years.

The rise in incidence in the mid to late 1990s is due to asymptomatic women with breast cancer who were diagnosed through breast screening programmes who would not otherwise have been identified until symptoms emerged.



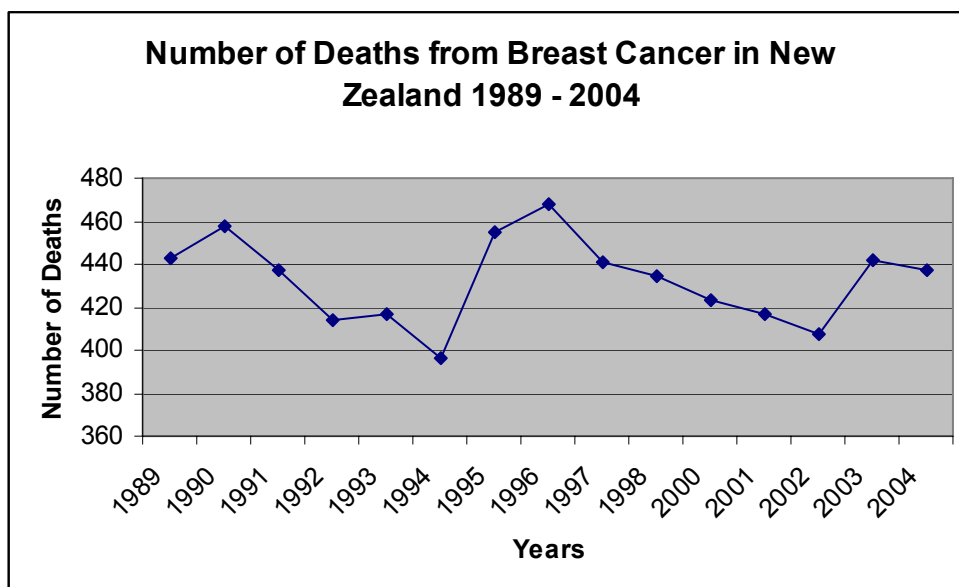
Since the introduction of the BreastScreen Aotearoa there has been a considerable increase in the incidence rate in the screening target age groups of 45 to 64 years and 65+ years. There has also been an increase in the 25 to 44 age group from around 95 cases per 100,000 population in 1995/1996 to 120 per 100,000 in 2003/2004. In 2003/2004 there were around 2 new cases per 100,000 for women aged 15 to 24, 120 new cases per 100,000 for women 25 to 44, 529 new cases per 100,000 for women 45 to 64 and 670 new cases per 100,000 for women 65 + years. From the graph above it appears that incidence rate for the 45 to 64 age group has peaked and is now following a downward trend which tends to suggest that increase in breast cancer incidence due to the introduction of breast screening programme may be transient.

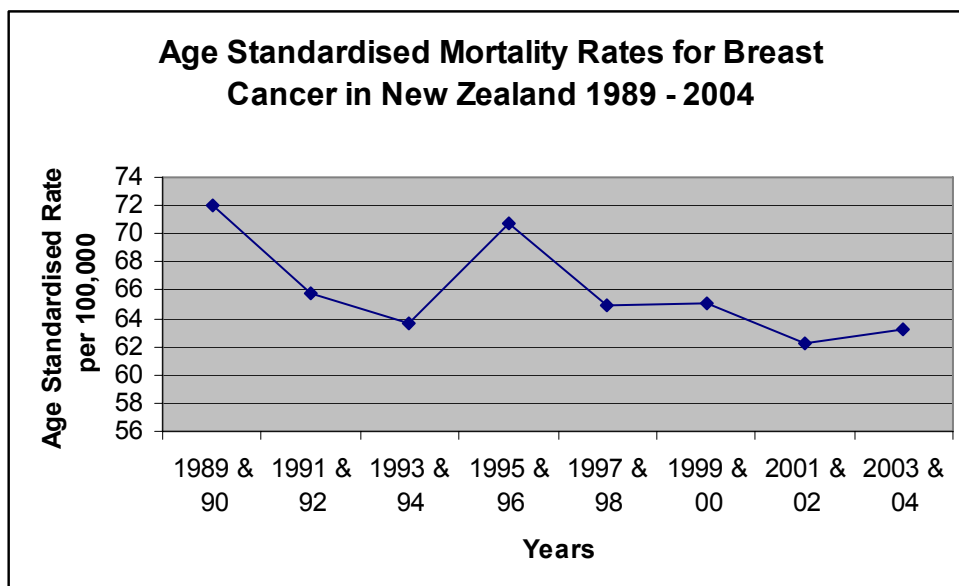
Ethnicity



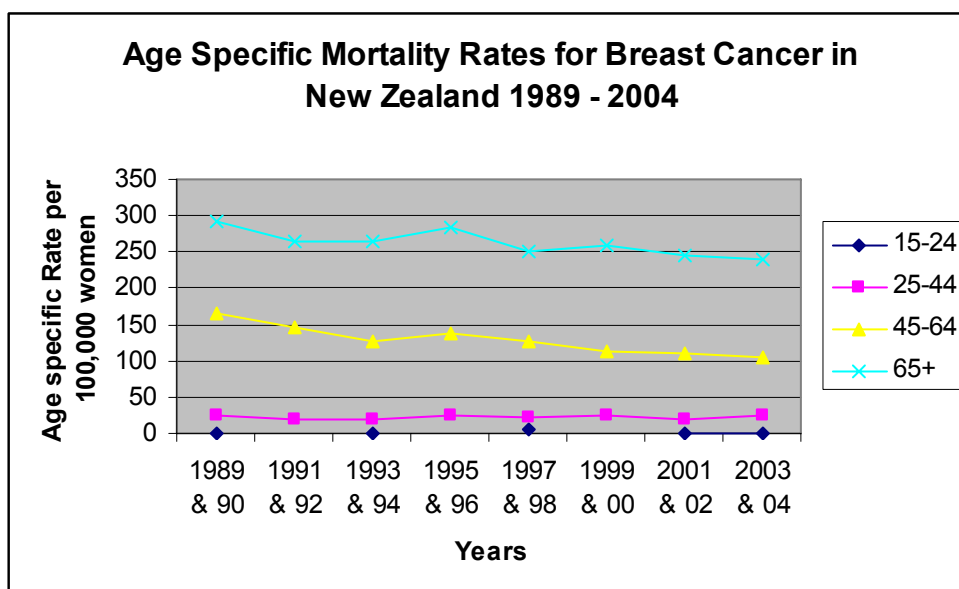
In 2005 of the total of 2,637 registrations for breast cancer, 255 were Māori, 93 were Pacific and 2,289 were Other.

Mortality



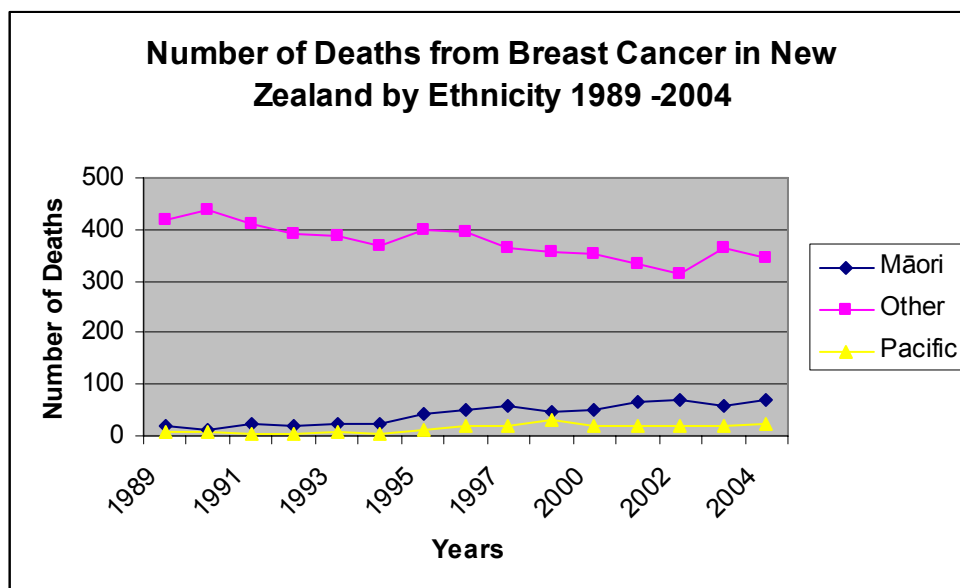


The age-standardised rate of death due to breast cancer among women has fallen markedly, from 72 deaths per 100,000 in 1989/90 to 63 deaths per 100,000 females in 2003/2004.



Mortality rates are highest in the older age groups. In 2003/2004 women 65+ had an age-specific mortality rate of 241 deaths per 100,000, women 45 to 64 years had an age specific mortality rate of 105 deaths per 100,000 and women 25 to 44 years had an age-specific mortality rate of 24 deaths per 100,000. Deaths in women aged 24 years and younger are very rare. In 2003/2004 there was less than 1 death per 100,000 females due to breast cancer in women less than 25 years.

Ethnicity



In 2004 (the most recent year numbers are available) of the total 437 deaths attributable to breast cancer, 71 were Māori, 22 were Pacific and 344 were Other.

Regional Trends

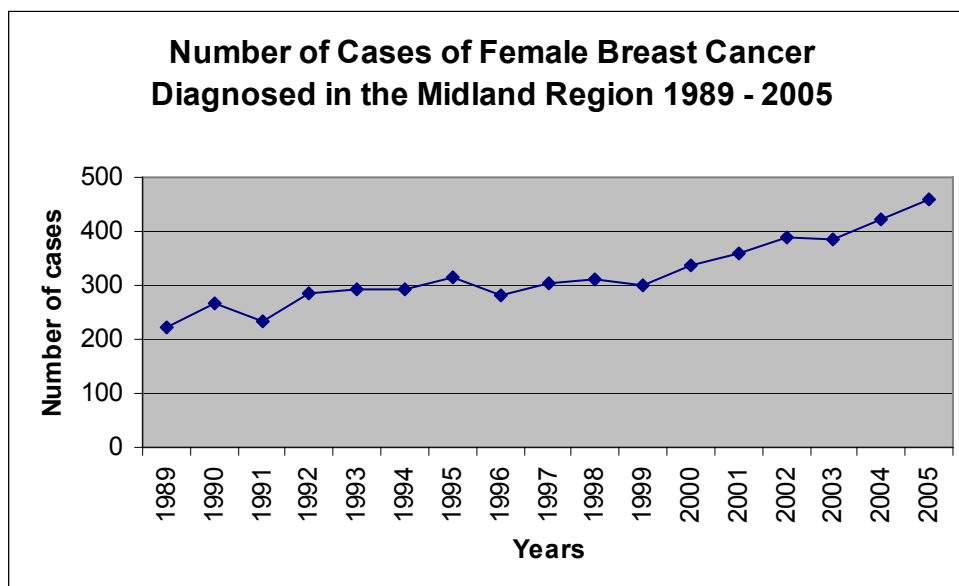
This section concentrates on breast cancer statistics for the Midland region which comprises the three participating DHBs - Bay of Plenty, Lakes and Waikato DHB.

In 2005 (the most recent year numbers are available) 461 women were diagnosed with breast cancer in the Midland region.

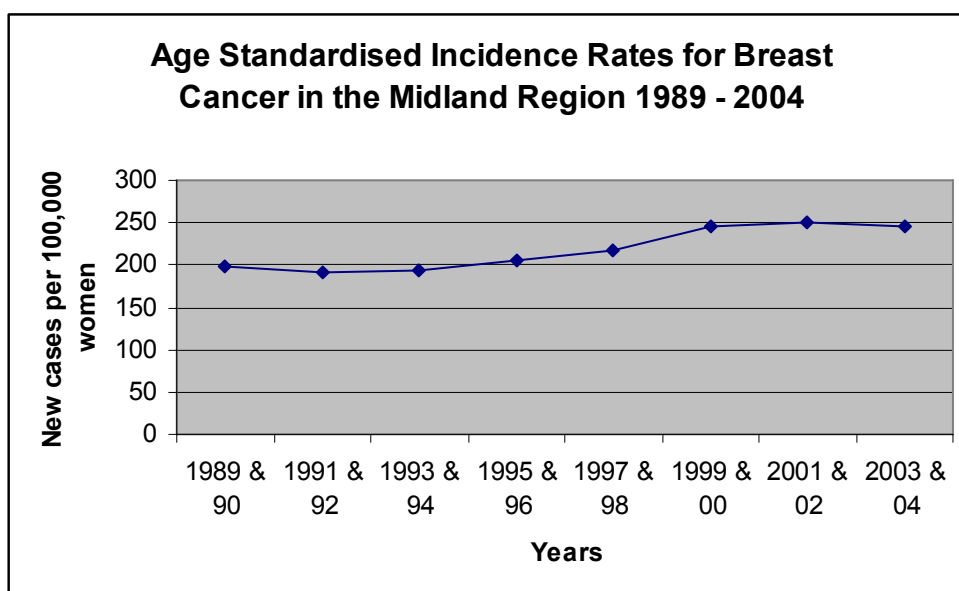
In 2004 (the most recent year numbers are available) 74 women died from breast cancer in the Midland Region.

Incidence

For both Lakes and Waikato DHBs breast cancer is the second leading cause of cancer registrations. However, for Bay of Plenty DHB breast cancer is the third leading cause of cancer registrations.



The number of women diagnosed with breast cancer in the Midland region increased from 223 in 1989 to 461 in 2005.



The age-standardised incidence of breast cancer increased from 197 new cases per 100,000 in 1989/90 to 245 new cases per 100,000 in 2003/2004. The rates for the Midland region are similar to the national rates. The rise in incidence in the late 1990s is due to the introduction of the breast screening programmes.

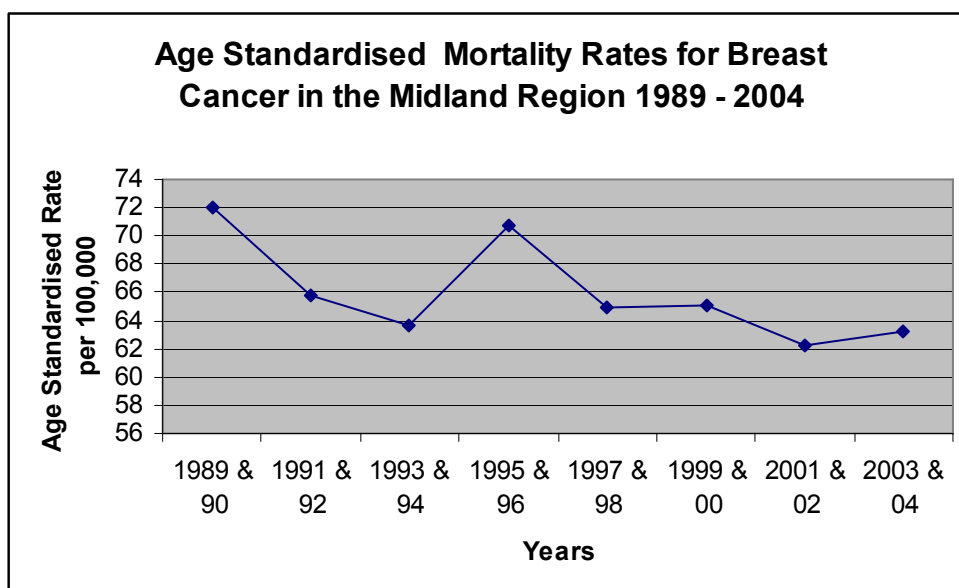
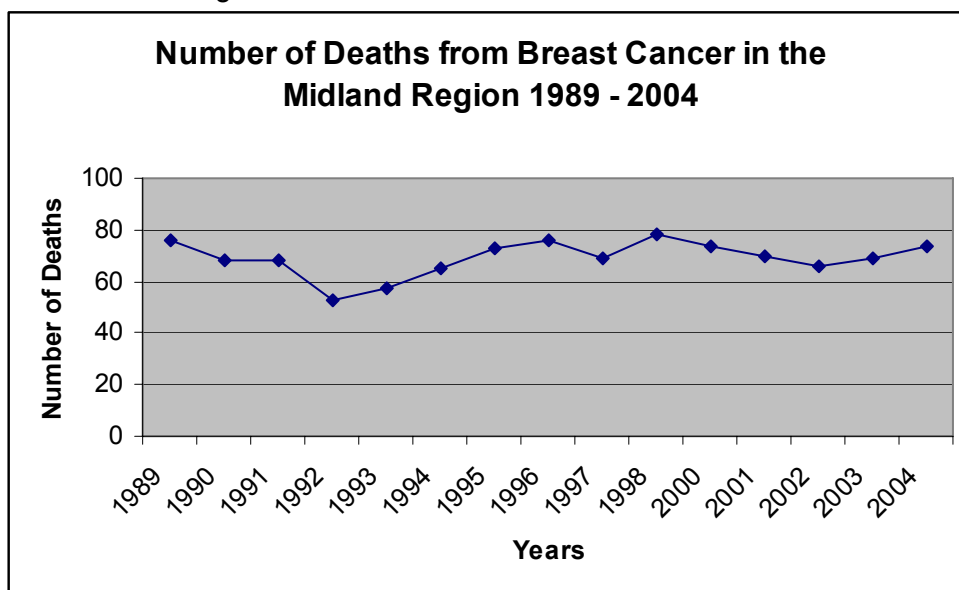
There is no age specific analysis available at a regional level for just the three Midland DHBs that have participated in this particular work programme.

Ethnicity

In 2005, of the total of 461 registrations for breast cancer in the Midland region, 83 were Māori, 9 were Pacific and 369 were Other.

Mortality

Breast cancer is the leading cause or second highest leading cancer killer across all ethnic groups in the Midland region.

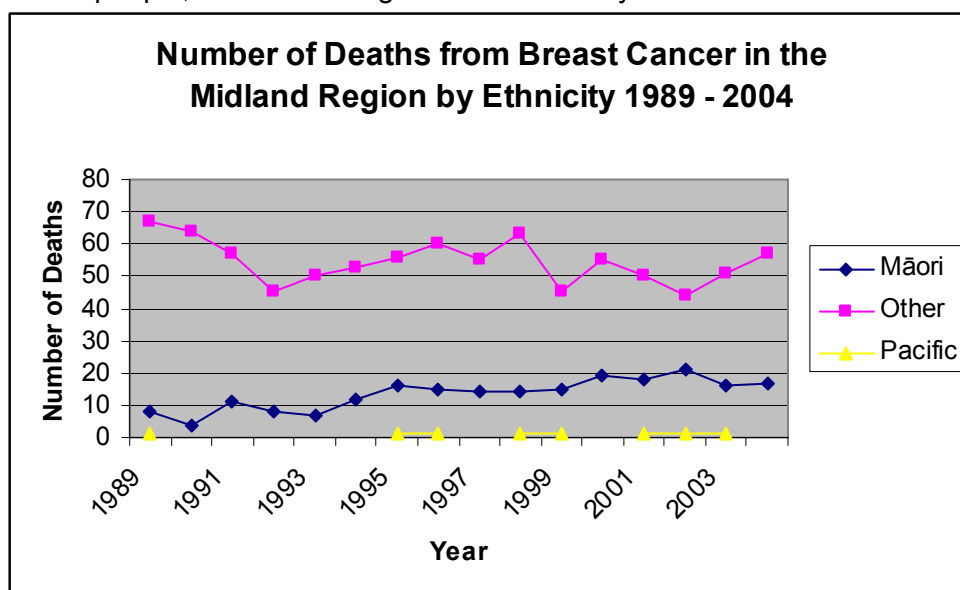


In line with national trends the age-standardised rate for death due to breast cancer among women in the Midland Region has fallen markedly. In 2003/2004 there were around 63 deaths per 100,000 females.

There is no age specific analysis available at Midland region level.

Ethnicity

Breast cancer is the second leading killer among Midland region Māori and Other. However, among Pacific people, it is the leading cause of mortality.



Out of the 74 deaths attributed to breast cancer in the Midland region for 2004, 17 were Māori and 57 were Other.

Individual DHB Trends

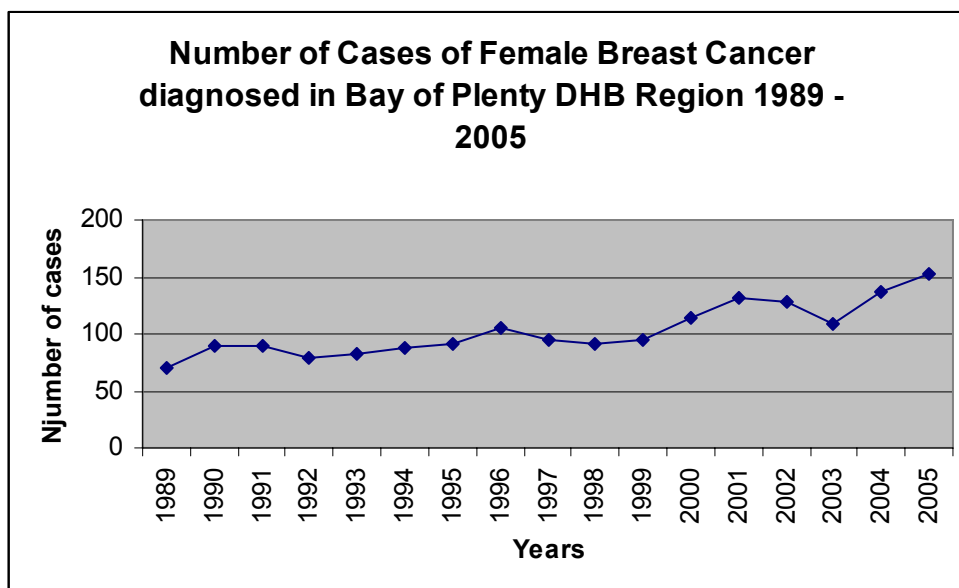
This section concentrates on breast cancer statistics at DHB level.

Bay of Plenty

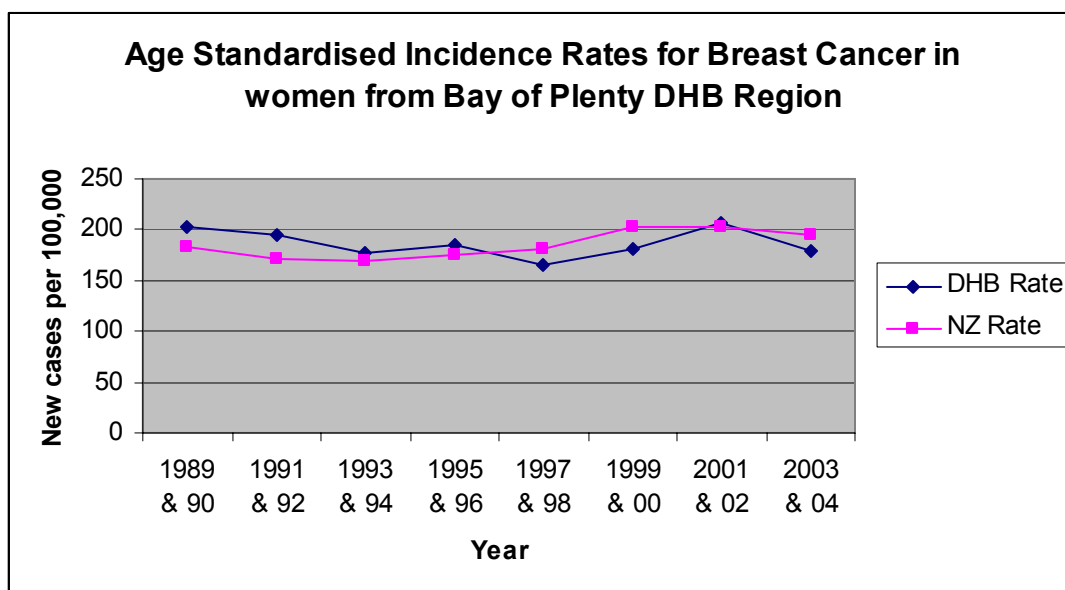
In 2005 (the most recent year numbers are available) 152 women were diagnosed with breast cancer in the Bay of Plenty DHB region.

In 2004 (the most recent year numbers are available) 25 women died from breast cancer in the Bay of Plenty DHB region.

Incidence

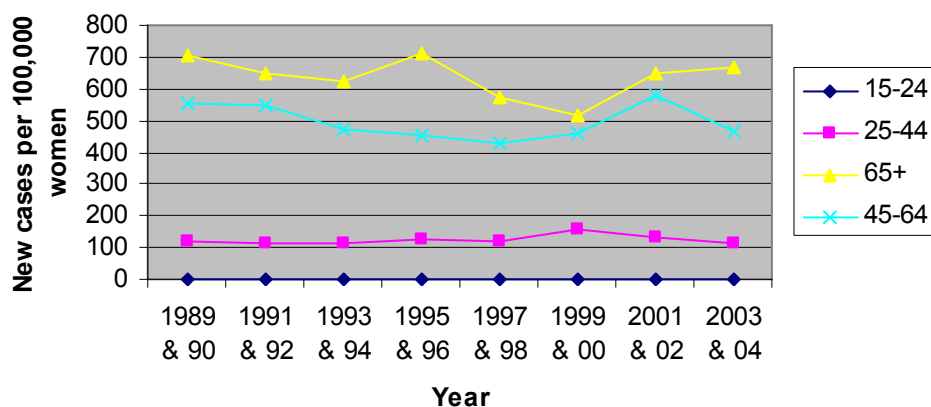


The number of women diagnosed with breast cancer in the Bay of Plenty DHB region increased from 71 in 1989 to 152 in 2005.



The age-standardised incidence of breast cancer in the Bay of Plenty DHB region decreased from 202 new cases per 100,000 women in 1989/90 to around 180 new cases per 100,000 in 2003/2004 which is a departure from national, regional and other DHBs. The age-standardised incidence rate for breast cancer in the Bay of Plenty DHB region is slightly lower than the New Zealand age-standardised rate at this time.

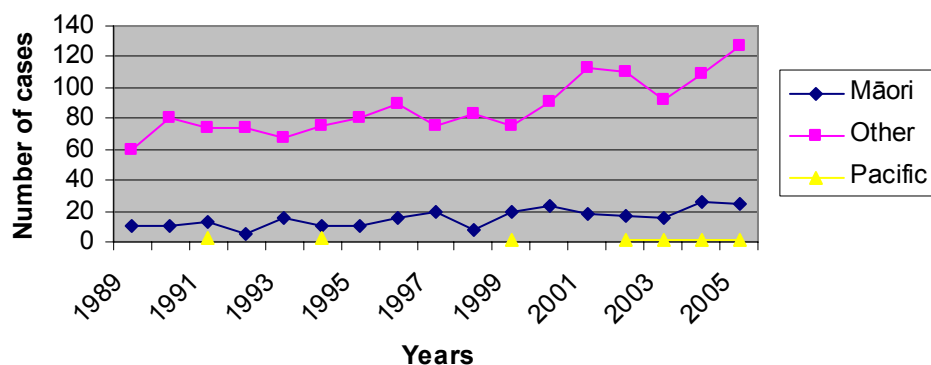
Age Specific Rates for Breast Cancer in Women from Bay of Plenty DHB 1989 - 2004



In 2003/2004 there were 113 new cases per 100,000 for women aged 25 to 44 years, 465 new cases per 100,000 for women 45 to 64 years and 667 new cases per 100,000 for women 65+ years.

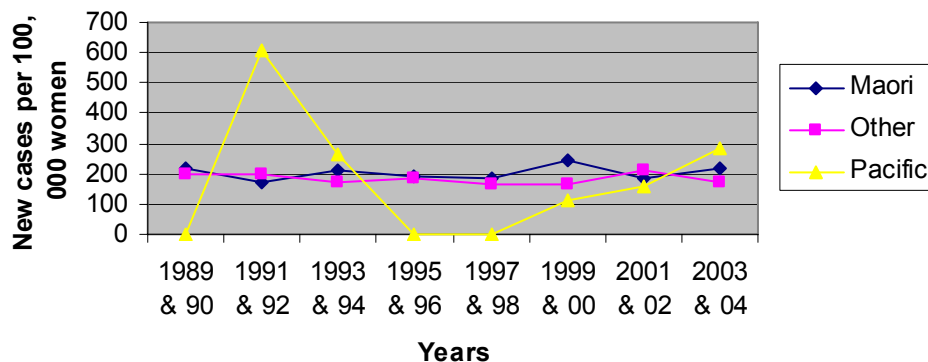
Ethnicity

Number of cases of Breast Cancer Diagnosed in Bay of Plenty DHB Region by Ethnicity 1989 - 2005



In 2005, of the total of 152 registrations for breast cancer in the Bay of Plenty DHB region, 24 were Māori, 1 was Pacific and 127 were Other.

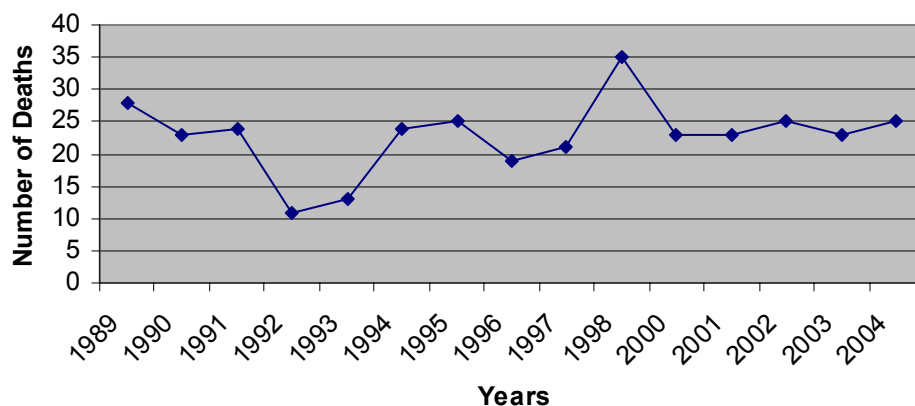
Age Standardised Incidence Rates by Ethnicity for Breast Cancer for Women in the Bay of Plenty DHB Region



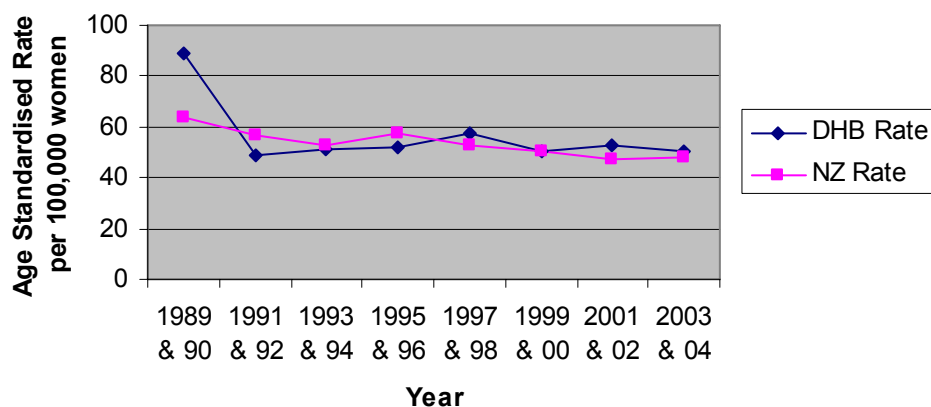
In 2003/2004 the age-standardised rate in Bay of Plenty DHB region was 216 new cases per 100,000 women for Māori, 281 for Pacific and 174 for Other. Age-standardised rates for Māori have often been higher than the rates for Other over the last fifteen years.

Mortality

Number of Deaths from Breast Cancer in the Bay of Plenty Region 1989 - 2004

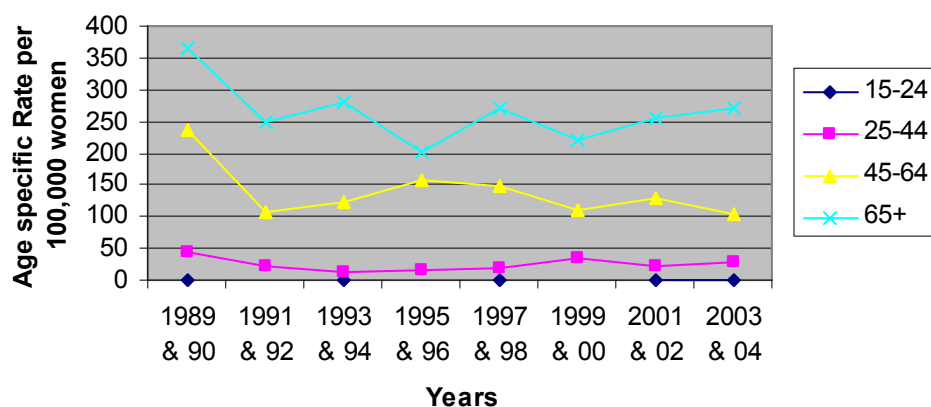


Age Standardised Mortality Rates for Breast Cancer in the Bay of Plenty DHB Region

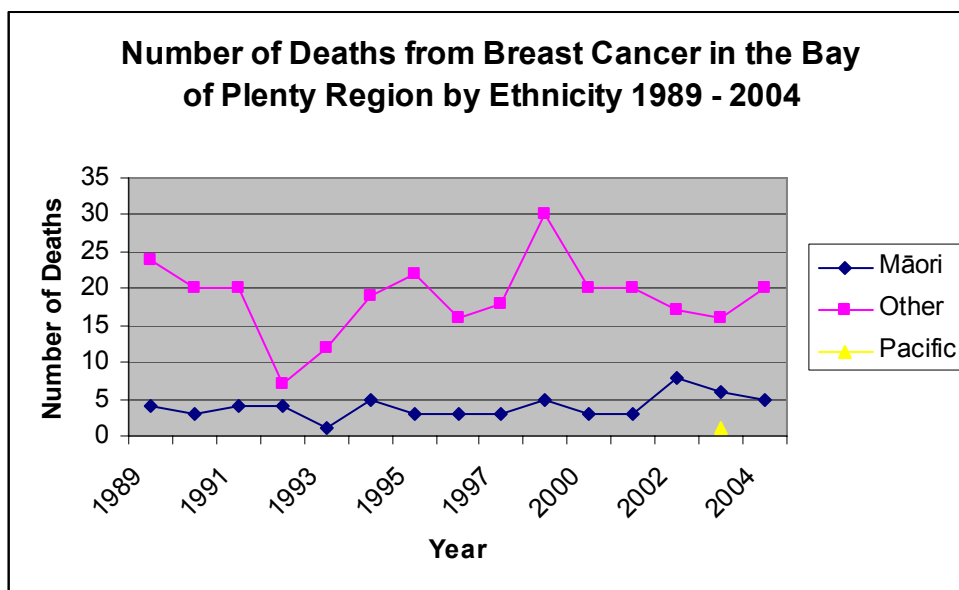


In line with national trends the age-standardised rate for death due to breast cancer among women in the Bay of Plenty region has fallen markedly from 89 deaths per 100,000 women in 1989/90 to 50 deaths per 100,000 women in 2003/2004.

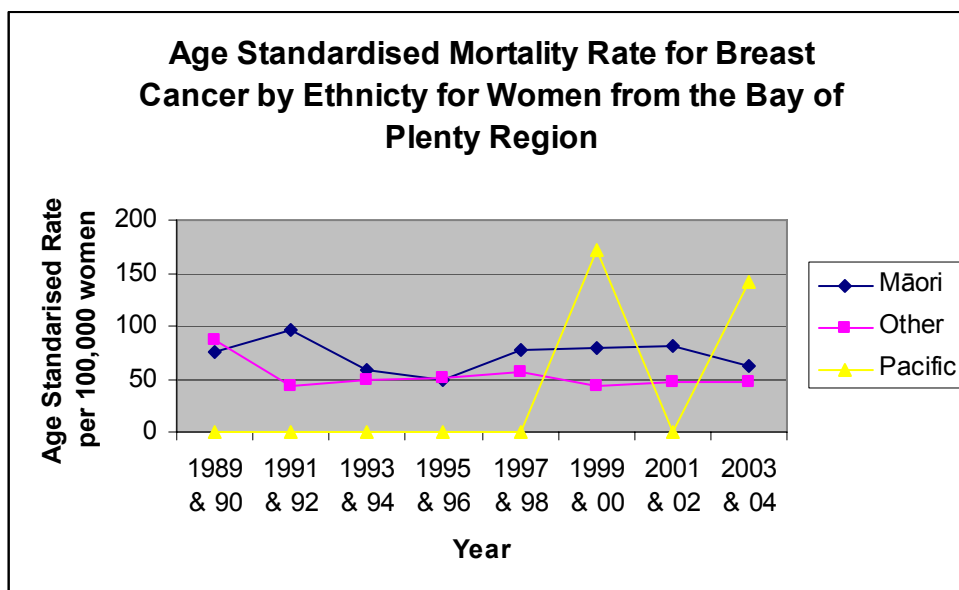
Age specific mortality Rates for Breast Cancer in the Bay of Plenty DHB Region



In 2003/2004 women from the Bay of Plenty DHB region 65+ had an age-specific mortality rate of 271 deaths per 100,000, women 45 to 64 years had an age-specific mortality rate of 102 deaths per 100,000 and women 25 to 44 years had an age-specific mortality rate of 27 deaths per 100,000.



In 2004 (the most recent year numbers are available) of the total 25 deaths attributable to breast cancer 5 were Māori and 20 were Other.



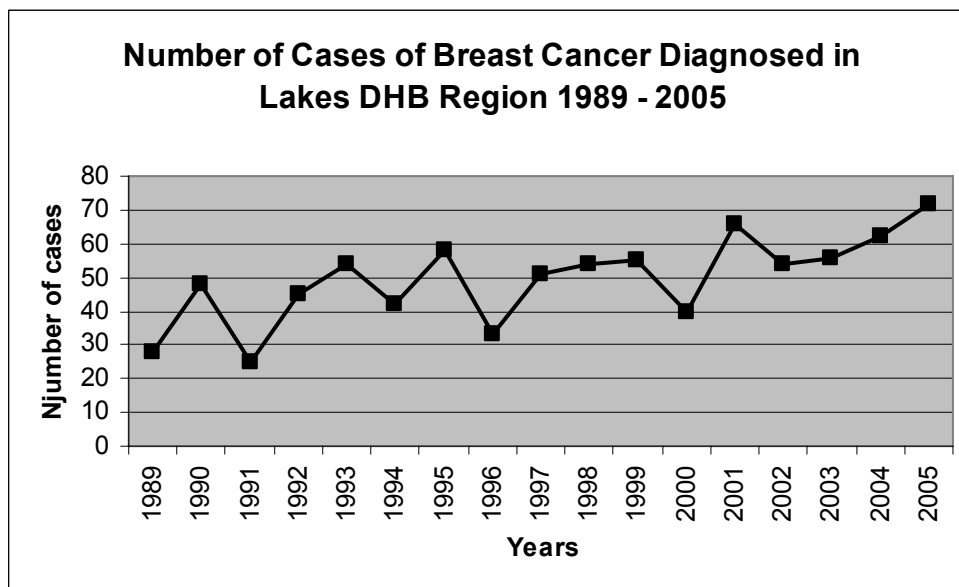
In 2003/2004 the age-standardised mortality rate for Māori was 50 deaths per 100,000 women and for Other the age-standardised mortality rate was around 48 deaths per 100,000. As a general guide age-standardised mortality rates for Māori have been higher than that of Other over the last 15 years in the Bay of Plenty DHB region.

Lakes DHB

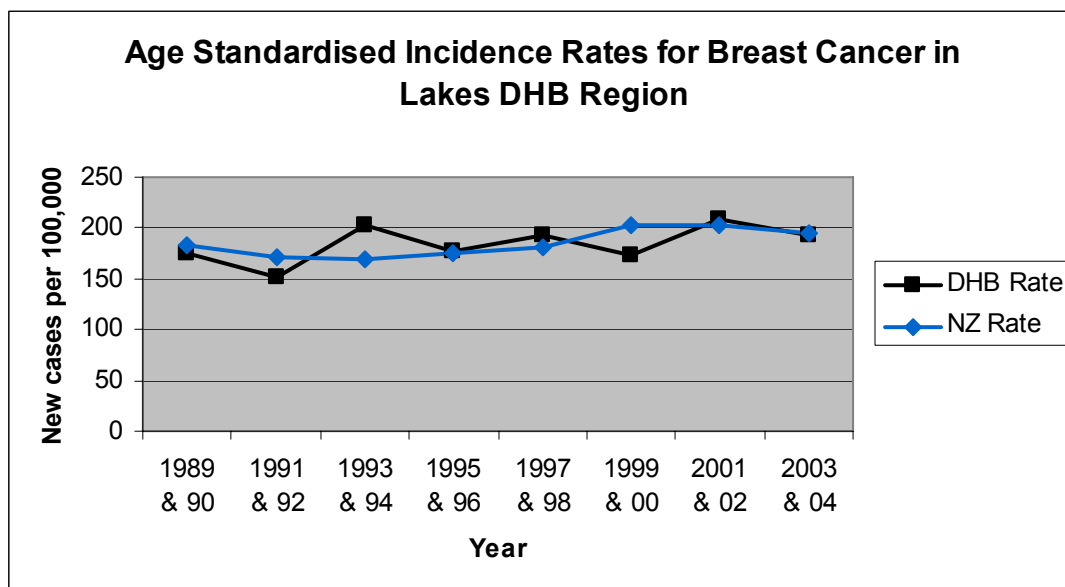
In 2005 (the most recent year numbers are available) 72 women were diagnosed with breast cancer in Lakes DHB region.

In 2004 (the most recent year numbers are available) 13 women died from breast cancer in Lakes DHB region.

Incidence

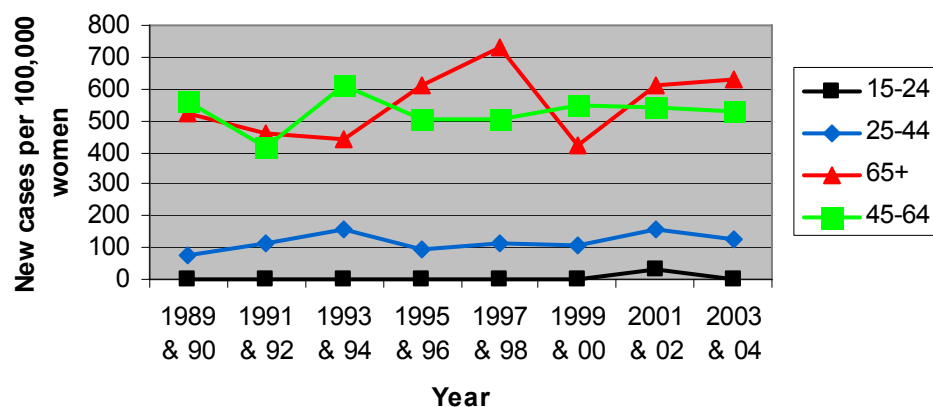


The number of women diagnosed with breast cancer in Lakes DHB region increased from 28 in 1989 to 72 in 2005.



The age-standardised incidence of breast cancer increased from 176 cases per 100,000 in 1989/90 to 193 cases per 100,000 in 2003/2004. The age-standardised rate for breast cancer in Lakes DHB region aligns with the New Zealand rate at this time.

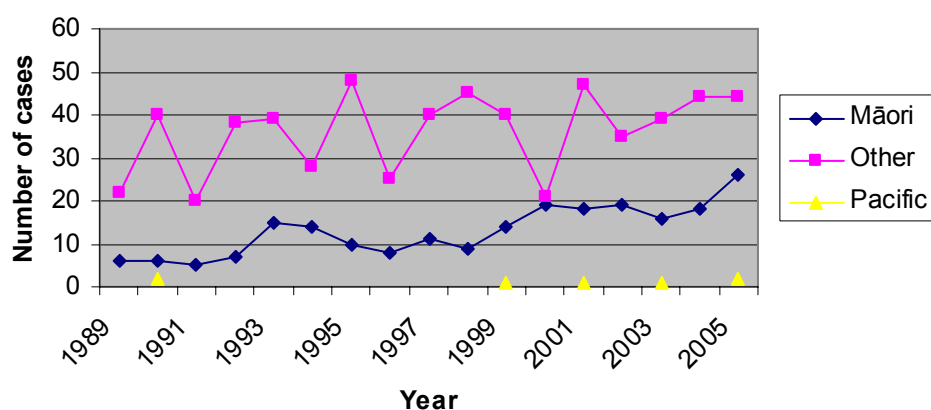
Age Specific Rates for Breast Cancer in Lakes DHB Region 1989 - 2004



In 2003/2004 there were 123 new cases per 100,000 for women aged 25 to 44 years, 531 new cases per 100,000 for women aged 45 to 64 years and 632 new cases per 100,000 for women aged 65+ years. These rates align with the New Zealand age-specific rates for breast cancer. The rate for 45 to 64 years category has been higher than the rate for 65+ category at times during the last fifteen years, which is a deviation from national, regional and other individual DHB age specific rate trends.

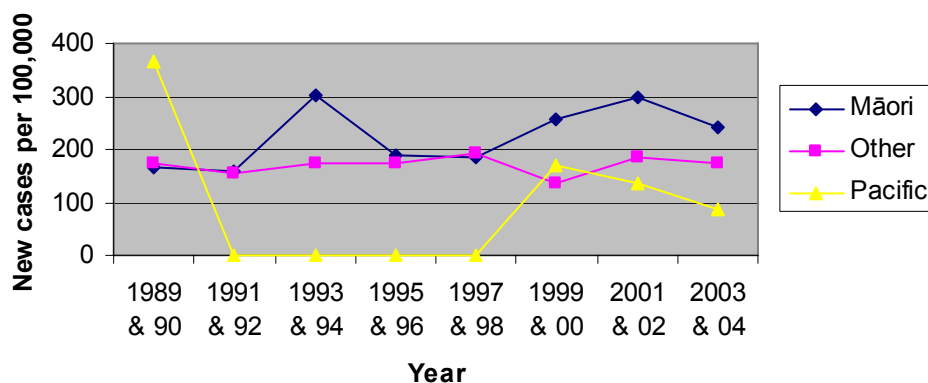
Ethnicity

Number of cases of Breast Cancer Diagnosed in Lakes DHB Region by Ethnicity 1989 - 2005



In 2005, of the 72 registrations for breast cancer, 26 were Māori, 2 were Pacific and 44 were Other.

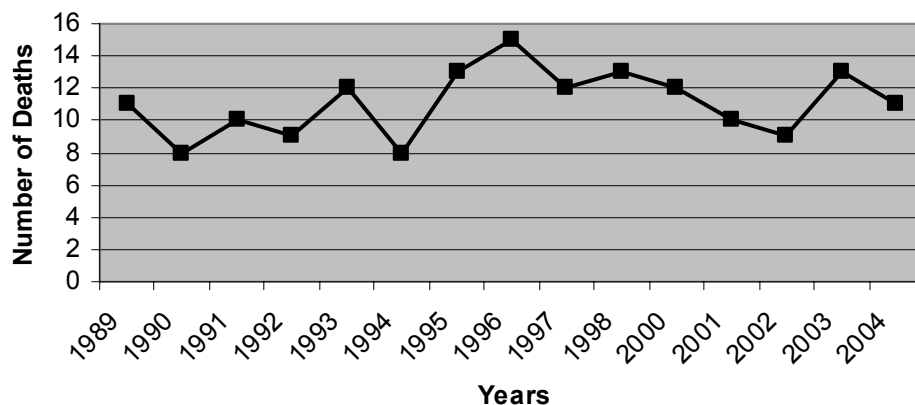
Age Standardised Incidence Rates by Ethnicity for Breast Cancer in Lakes DHB Region 1989 - 2004

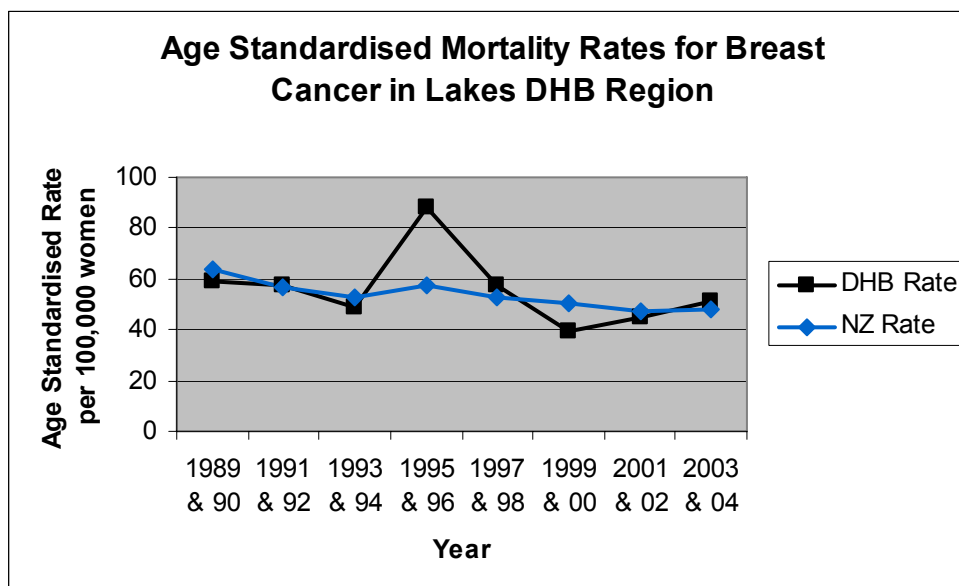


In 2203/2004 the age-standardised incidence rate in the Lakes DHB region was 242 new cases per 100,000 women for Māori, 86 for Pacific and 172 for Other. Age-standardised rates for Māori have often been significantly higher than age-standardised rates for Other over the last fifteen years.

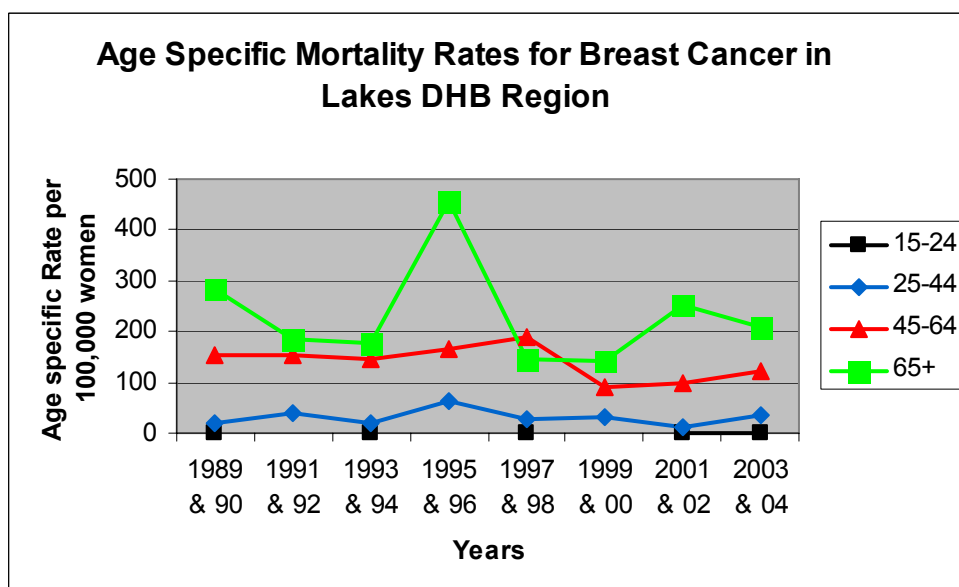
Mortality

Number of Deaths from Breast Cancer in Lakes DHB Region 1989 - 2004

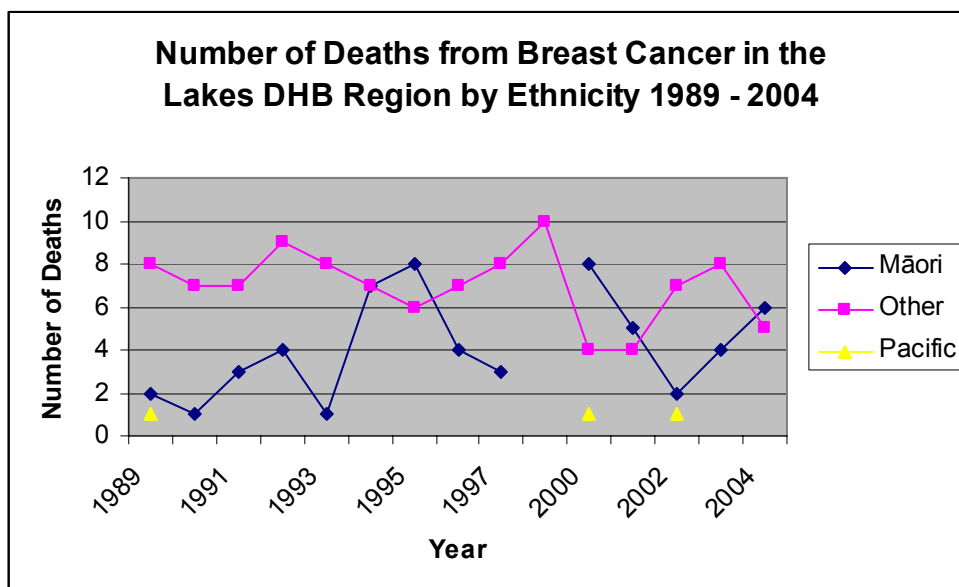




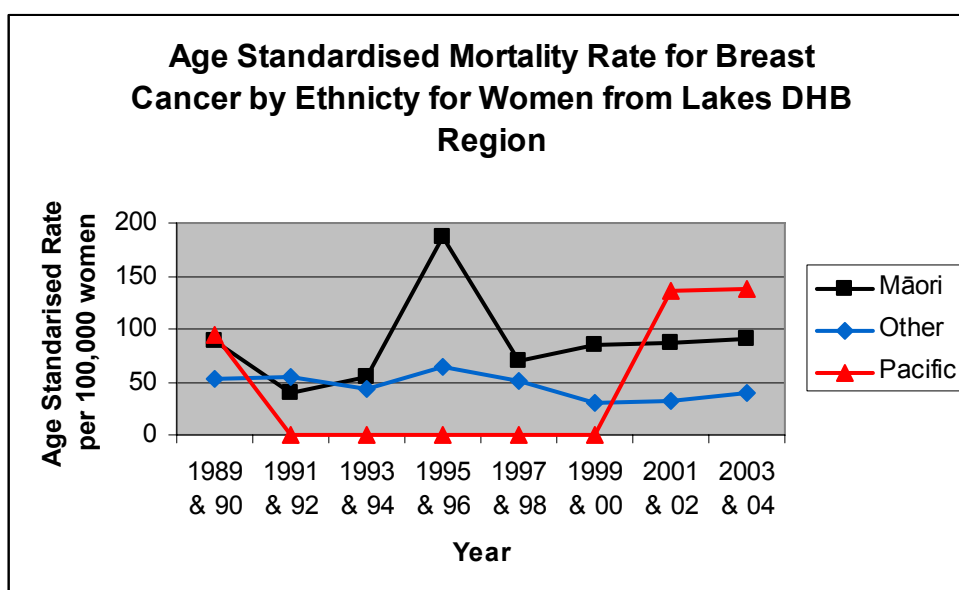
The age-standardised rate for death due to breast cancer among women in Lakes DHB region has fallen from 59 deaths per 100,000 women in 1989/90 to 51 deaths per 100,000 women in 2003/2004.



In 2003/2004 women from Lakes DHB 65+ years had an age-specific mortality rate of 209 deaths per 100,000, women 45 to 64 years had an age-specific mortality rate of 122 deaths per 100,000 and women 25 to 44 years had an age-specific mortality rate of 35 deaths per 100,000.



Out of the 11 deaths attributable to breast cancer in the Lakes DHB region in 2004, 6 were Māori and 5 were Other.



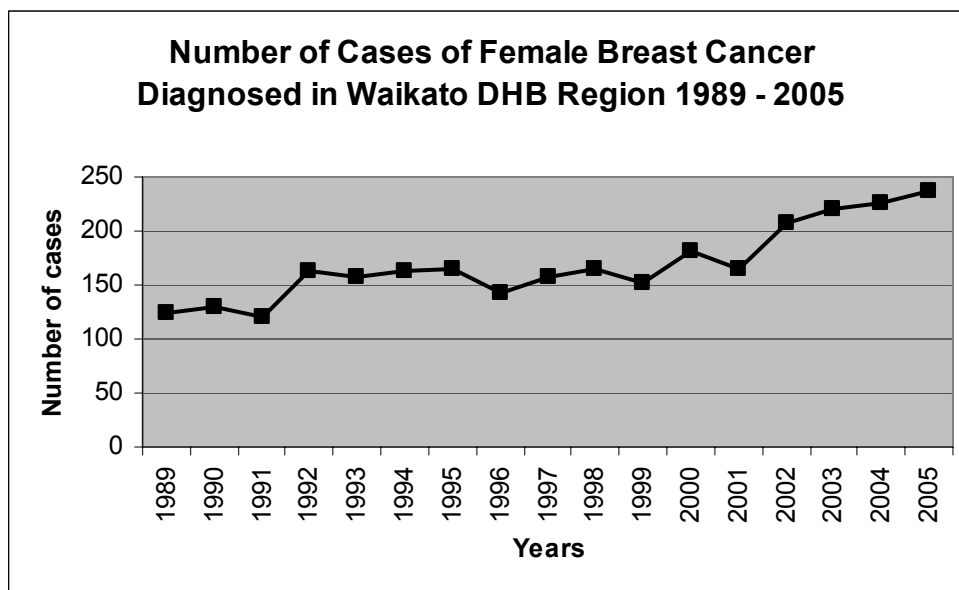
In 2003/2004 the age-standardised mortality rate for Māori was 92 deaths per 100,000, for Other it was 39 deaths per 100,000 and for Pacific it was 137 deaths per 100,000.

Waikato DHB

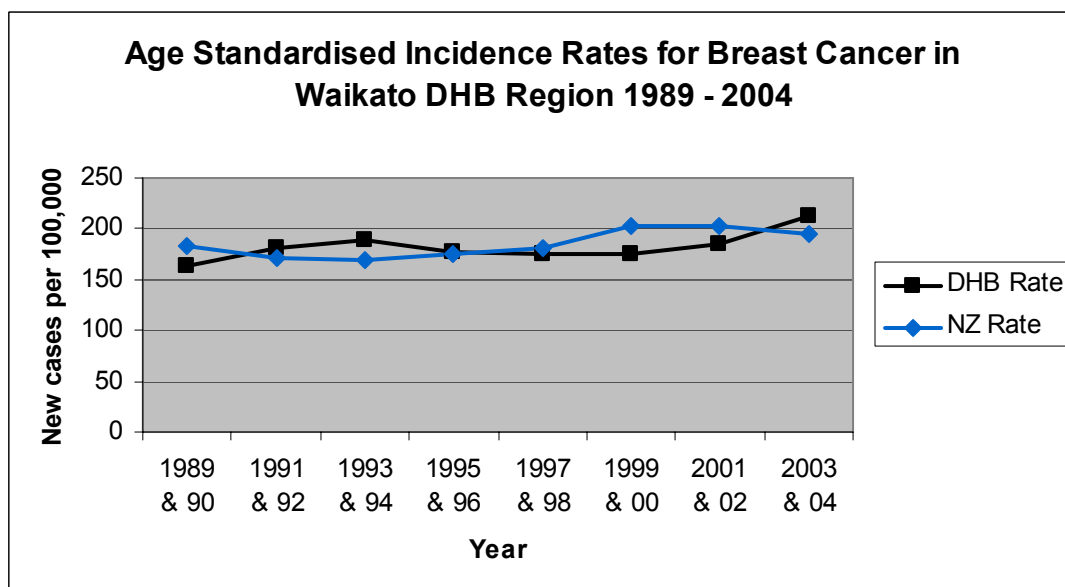
In 2005 (the most recent year numbers are available) 237 women were diagnosed with breast cancer in the Waikato DHB region.

In 2004 (the most recent year numbers are available) 38 women died from breast cancer in the Waikato DHB region.

Incidence

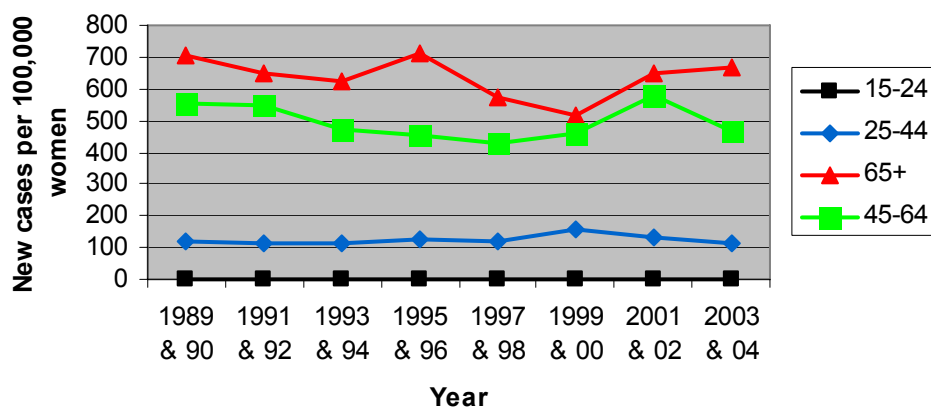


The number of women diagnosed with breast cancer in the Waikato DHB region increased from 124 in 1989 to 237 in 2005.



The age-standardised incidence of breast cancer in Waikato DHB region has increased from 164 cases per 100,000 women in 1989/1990 to 213 cases per 100,000 in 2003/2004.

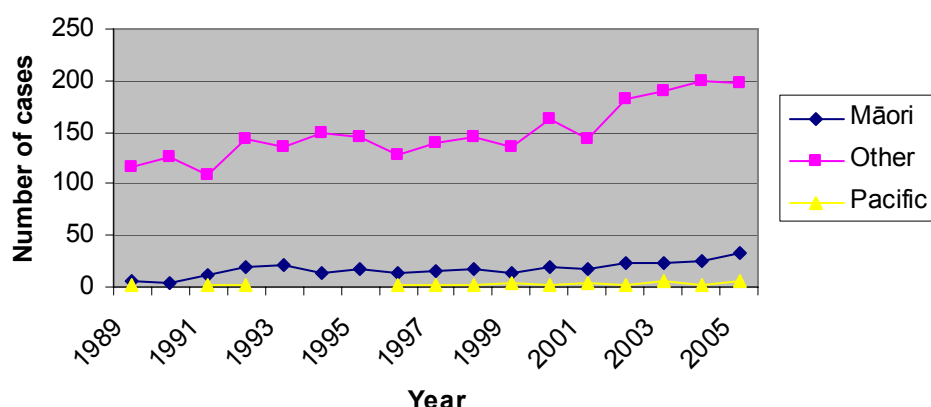
Age Specific Rates for Breast Cancer in Women from Waikato DHB 1989 - 2004



In 2003/2004 there were 134 new cases per 100,000 for 25 to 44 years, 567 new cases per 100,000 for women 45 to 64 years and 749 new cases per 100,000 for women 65+ years.

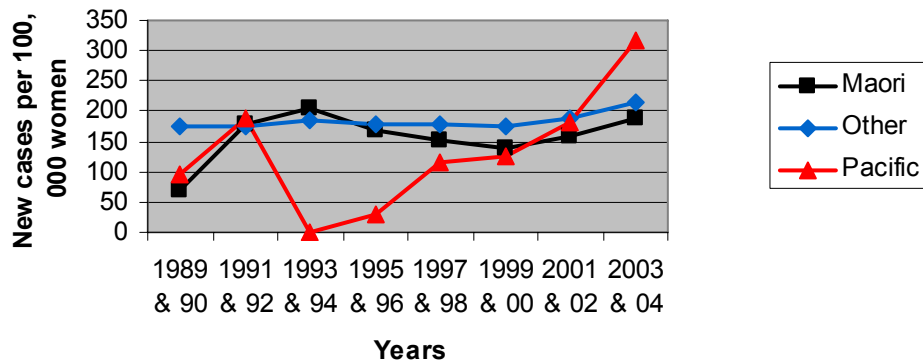
Ethnicity

Number of Cases of Breast Cancer Diagnosed in Waikato DHB Region by Ethnicity 1989 - 2005



In 2005, of the total of 237 registrations for breast cancer in the Waikato DHB region, 33 were Māori, 6 were Pacific and 198 were Other.

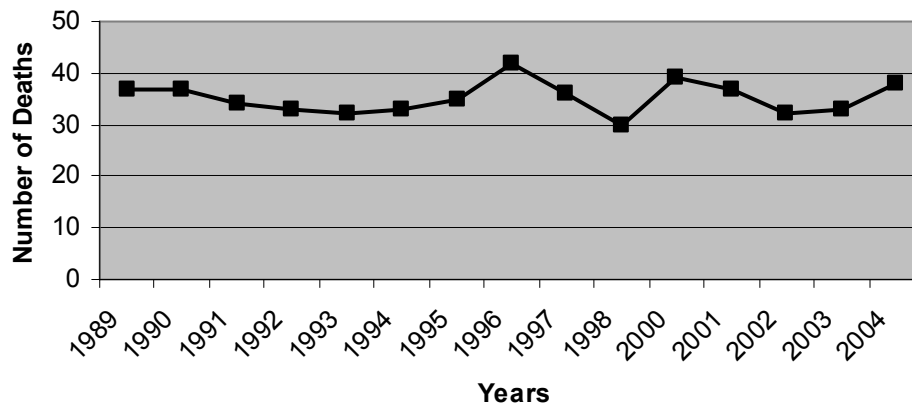
Age Standardised Incidence Rates by Ethnicity for Breast Cancer for Women in Waikato DHB Region



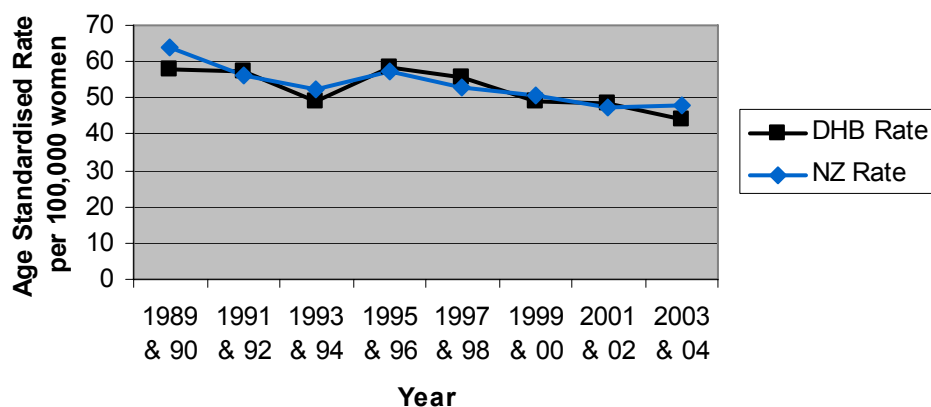
In 2003/2004 the age-standardised rate in Waikato DHB region was 188 new cases per 100,000 women for Māori, 318 new cases per 100,000 women for Pacific and 215 new cases per 100,000 women for Other. Age-standardised rates for Māori have often been lower than the rates for Other over the last fifteen years. This trend is a deviation from national, regional and individual DHB age-standardised incidence rate ethnicity analysis.

Mortality

Number of Deaths from Breast Cancer in Waikato DHB Region 1989 - 2004

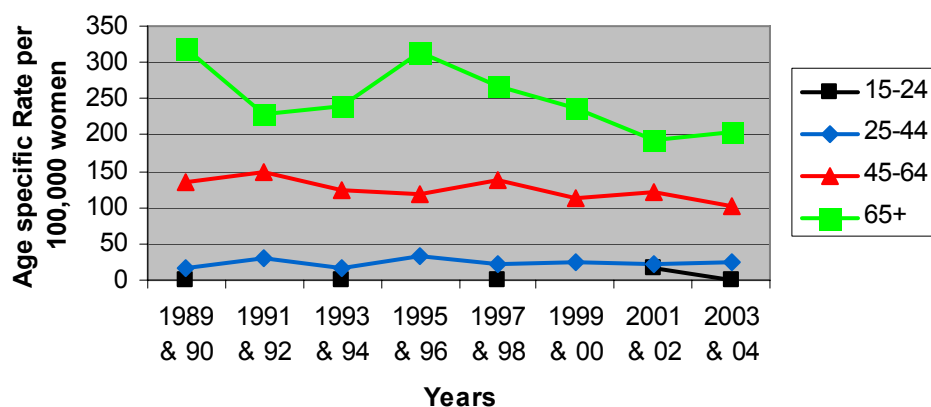


Age Standardised Mortality Rates for Breast Cancer in Waikato DHB Region 1989 - 2004

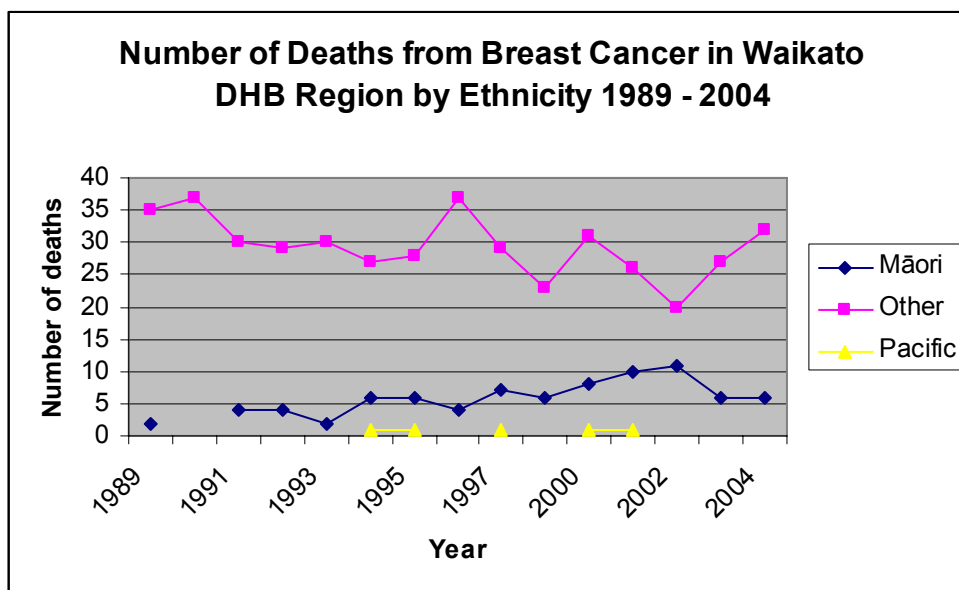


In line with national trends the age-standardised rate for death due to breast cancer among women in Waikato DHB region has fallen from 58 deaths per 100,000 women in 1989/1990 to 44 deaths per 100,000 women in 2003/2004.

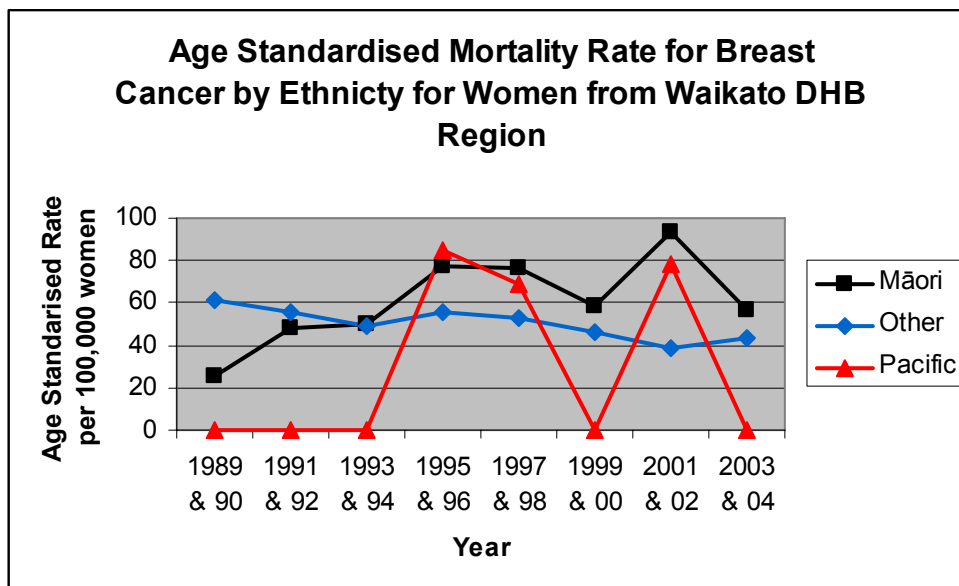
Age Specific Mortality Rates for Breast Cancer in Waikato DHB Region 1989 - 2004



In 2003/2004 in Waikato DHB region women 65+ years had an age-specific mortality rate of 203 deaths per 100,000, women 45 to 64 years had an age-specific mortality rate of 103 deaths per 100,000 and women 25 to 44 years had an age-specific mortality rate of 24 deaths per 100,000.



Out of the 38 deaths attributed to breast cancer in 2004, 6 were Māori and 32 were Other.



In 2003/2004 the age-standardised mortality rate for Māori was 56 deaths per 100,000 women and for Other was 44 deaths per 100,000. Age-standardised rates for Māori have generally been higher than that of Other over the last ten years.

Breast Screening

This section concentrates on statistics related to breast screening, both at a regional and individual DHB level.

During the last two years (July 2005 to June 2007) 93,230 of the eligible women in the Midland region were screened by BreastScreen Aotearoa.

Bay of Plenty DHB

The following table contains BreastScreen Aotearoa 24-Month screens and coverage of eligible population in Bay Of Plenty DHB area.

	Eligible Population	Screens				Coverage		
		Maori	Pacific	Other	Total	Maori	Pacific	Other
Western BOP	7280	270	12	3,219	3,502	33%	30%	50%
Tauranga	15,990	537	40	8,433	9,018	34%	50%	59%
Whakatane	4,910	606	15	2,036	2,658	39%	75%	61%
Kawerau	835	130	9	314	454	33%	180%	73%
Opotiki	1,515	303	4	480	788	43%	80%	60%
BOP DHB	30,530	1,846	80	14,482	16,420	36%	53%	57%

Coverage rate for Bay of Plenty DHB area is 54% which means a 16% shortfall in terms of the national target coverage of 70%.

The following table contains BreastScreen Aotearoa Cancers and Cancer Detection Rates in the Bay of Plenty DHB area.

	Total Screens	Cancers				Cancer Detection Rate Per 1,000			
		Maori	Pacific	Other	Total	Maori	Pacific	Other	Total
Western BOP	3,502	3	0	17	20	11	0	5	6
Tauranga	9,018	4	0	37	41	7	0	4	5
Whakatane	2,658	3	0	10	13	5	0	5	5
Kawerau	454	2	0	5	7	15	0	16	15
BOP DHB	15,632	12	0	69	81	7	0	5	5

Cancer detection rate of BreastScreen Aotearoa for the two-year period ending June 2007 was 5 per 1,000 in the Bay of Plenty DHB area. Cancer includes DCIS and invasive breast cancer. The national average detection rate was 5.77 per 1,000 for the same period.

Lakes DHB

The following table contains BreastScreen Aotearoa 24-Month screens and coverage of eligible population in Lakes DHB area.

	Eligible Population	Screens				Coverage		
		Maori	Pacific	Other	Total	Maori	Pacific	Other
Taupo District	5,000	301	16	2,100	2,417	30%	23%	53%
Rotorua District	9,530	896	47	4,106	5,050	36%	36%	60%
Lakes DHB	14,530	1,197	63	6,206	7,467	34%	32%	57%

Coverage rate for Lakes DHB area is 51% which means a 19% shortfall in terms of the national target coverage of 70%.

The following table contains BreastScreen Aotearoa cancers and cancer detection rates in Lakes DHB area.

	Total Screens	Cancers				Cancer Detection Rate Per 1,000			
		Maori	Pacific	Other	Total	Maori	Pacific	Other	Total
Taupo District	2,417	4	0	4	8	13.29	0	1.9	3.31
Rotorua District	5,050	2	1	20	23	2.23	21.28	4.87	4.55
Lakes DHB	7,467	6	1	24	31	5.01	15.87	3.87	4.15

Cancer detection rates of BreastScreen Aotearoa for the two-year period ending June 2007 was 4.15 per 1,000 in Lakes DHB area. Cancer includes DCIS and invasive breast cancer. The national average detection rate was 5.77 per 1,000 for the same period.

Waikato DHB

The following table contains BreastScreen Aotearoa 24-Month screens and coverage of eligible population in Waikato DHB area.

	Eligible Population	Screens				Coverage		
		Maori	Pacific	Other	Total	Maori	Pacific	Other
Thames-Coromandel	5,195	208	17	2,866	3,091	50%	49%	60%
Hauraki District	2,710	145	12	1,551	1,709	41%	60%	66%
Waikato District	6,080	430	11	2,705	3,148	37%	28%	55%
Matamata-Piako District	4,245	131	10	2,597	2,739	33%	67%	68%
Hamilton city	16,080	682	107	8,720	9,511	33%	40%	63%
Waipa District	6,315	168	10	3,484	3,663	26%	29%	62%
Otorohanga District	1,160	90	5	597	692	38%	0%	65%
South Waikato District	3,110	233	87	1,400	1,720	36%	38%	63%
Waitomo District	1,390	152	4	590	747	36%	40%	61%
Ruapehu District	1,885	120	4	531	655	22%	27%	40%
Waikato DHB	48,170	2,359	267	25,041	27,675	34%	40%	62%

The following table contains BreastScreen Aotearoa cancers and cancer detection rates in Waikato DHB area.

	Total Screens	Cancers				Cancer Detection Rate Per 1,000			
		Maori	Pacific	Other	Total	Maori	Pacific	Other	Total
Thames-Coromandel	3091	1	0	18	19	5	0	6	6
Hauraki District	1709	0	0	8	8	0	0	5	5
Waikato District	3148	2	0	15	17	5	0	6	5
Matamata-Piako District	2739	0	0	16	16	0	0	6	6
Hamilton city	9511	9	0	56	65	13	0	6	7
Waipa District	3663	4	0	24	28	24	0	7	8
Otorohanga District	692	2	0	2	4	22	0	3	6
South Waikato District	1720	3	0	8	11	13	0	6	6
Waitomo District	747	0	0	8	8	0	0	14	11
Ruapehu District	655	2	0	4	6	17	0	8	9
Waikato DHB	27675	23	0	159	182	10	0	6	7

Cancer detection rates of BreastScreen Aotearoa for the two-year period ending June 2007 was 7 per 1,000 in Waikato DHB area. Cancer includes DCIS and invasive breast cancer. The national average detection rate was 5.77 per 1,000 for the same period.

Cancer Waiting Times

Ten national health targets were introduced in 2007/2008 by the Minister of Health. One of the targets is aimed at improving radiation treatment capacity and ensuring all patients (except Category D patients) wait less than eight weeks between first specialist assessment and the start of radiation oncology treatment.

The Health Targets Quarter One Report (Ministry of Health, November 2007) indicates DHBs are on track to meet the cancer waiting time target for radiation treatment. Nationally, around 95% of cases are treated within the target timeframe of eight weeks. The cancer waiting times target relates to all cancers, it is not tumour specific.

In September 2007, 93% of patients waited less than four weeks for their treatment and 5% waited between four and eight weeks in the Midland Region. The Midland region includes Waikato, Bay of Plenty, Lakes, Tairāwhiti and Taranaki DHBs in this particular instance.

As at February 2008 the waiting time for patients with breast cancer between referral to oncology and first assessment by an oncologist is around four weeks for radiation oncology and eight to ten weeks for medical oncology. A patient with breast cancer could then have to wait for around three weeks to start radiation treatment. For chemotherapy there is no waiting list at this time. (Source: communication with Oncology Booking Clerk, February 2008).

Note: It is not possible to compare the current waiting time for first specialist assessment with the waiting times from the audit of waiting times that was undertaken back in 2006/2007 as part of the patient mapping work because in the audit, first specialist assessments, were not categorised according to specialty (radiation oncology or medical oncology).