

Midland District Health Boards

Midland Cancer Network

Progress Report – October - December 2007

Executive Summary

This is the Midland Cancer Network's (MCN) progress report covering the quarter two period 1 October 2007 – 31 December 2007. This report builds on the quarter one report and summarises the background to the formation of the MCN and reports on progress to date on:

- development of the MCN
- progress on key MCN projects
- national engagement and developments.

Summary of key achievements from quarter one and two include:

Network Executive Group

- Stakeholder representation on the Network is strengthening, there are some areas of representation still in progress, these are discussed;
- Waikato General Manager Maori services is a member on the MCN and will provide the link to the Midland regional forum
- Manager and Clinical Director meet with NZ Royal College of General Practitioners to discuss opportunities for primary engagement, now need to discuss with primary stakeholders and agree on a way forward
- Midland Maori GM forum recommended that MCN utilise current Iwi Governance structure to inform and discuss issues
- The MCN Executive group consumer advocate unfortunately had to resign as representative and project officer for the MCN consumer advocate project. Recruitment has commenced. The NZ Regional Cancer Networks (RCN) has agreed that there needs to be a consistent approach and framework for engagement and recognition of the value of consumers. Work will occur in 2008
- The Network work streams developed include; service improvement groups (NSCT, Care Co-ordinators, Oncology Nurse Group); population focus groups (AYA OHS); site specific groups (Breast)
- The Executive group meet monthly- usually for 1 hour via teleconference; with 3 meetings per year for half day face to face and plan to hold an annual MCN day for stakeholders to share learnings

MCN Management Infrastructure

- Clinical Director sole focus is MCN following realignment of Regional Cancer Centre (RCC) clinical director positions
- Patient mapping manager confirmed in full time position
- Part time PA/administrator appointed
- MCN management team link in with the national governance structure – Manager member of the NZ Cancer Control Steering Group and Clinical Director member of the NZ Cancer Treatment Working Party and both are members of the NZ Regional Cancer Network forum

Breast

- Midland breast cancer mapping report of findings and action plan first draft is complete and consultation commenced. Final draft scheduled for February 2008
- Breast Cancer Work Group terms of reference developed, discussions are occurring on appointment of a clinical chair and planning has commenced for the first meeting to be scheduled in 2008

Patient Mapping Work Programme

- Work programme in progress for lung, colorectal, prostate and ovarian
- NZ RCN agreed to adopt the Victorian Patient Management Framework to guide a consistent approach to patient / service mapping work programmes

Non-Surgical Cancer Treatment Operations Network

- Update of terms of reference in progress
- Radiation Wait Time compliant with national target – 15 – 20 days
- RCC new single linac replacement plans to be operational early 2008
- Waikato employed 4th Haematologist (while position has non-malignant focus this additional position will assist the cancer burden)
- Clinical supervision of Thames Hospital oncology nurses implemented
- Scoping feasibility of Thames district nurses obtaining access to oncology clinical notes
- Lakes DHB chemotherapy access is supplied by Baxters based at RCC. Quality improvement initiatives introduced with use of vincristine, access to clinical protocols and nurse education
- A register of clinicians competent to administer pharmaceutical cancer treatments introduced
- Whakatane cancer centre opened

BOP Resident Medical Oncology / Haematology Service

- Resident Medical Oncology / Haematology Service in Tauranga business case work in progress, due for final draft in quarter 3

Adolescent / Young Adult Oncology / Haematology Service

- Establishment of Adolescent / Young Adult Oncology / Haematology Service (AYA OHS) commenced with appointment of clinical nurse specialist and project officer (until 30 June 2008)
- Terms of reference for AYA OHS work group developed and second meeting planned for early 2008
- Stock take of services and providers sent out for consultation
- Analysis of services against service specifications and NZ CC Action Plan
- Commenced development of AYA OHS model of care
- Service commenced in Waikato Hospital Wards 52 (paediatrics) and 25 (oncology)

Palliative Care

- Outreach Specialist Palliative Care Services based at Lakes proposal for change endorsed by Midland GM Planning and Funding
- Midland meeting held in December to discuss collaborative opportunities for new service components; end of life programmes; education for generalists; 24/7 telephone advice and support for generalists (medical and nurse). Awaiting CFA to fully understand requirements
- Terms of reference to be developed
- Waikato appointed third palliative care specialist to provide an integrated service between Hospice Waikato and Waikato provider arm
- Waikato appointed a locum fourth palliative care specialist November 2007 – March 2008
- Waikato developed an End of Life Implementation Plan and is the first in NZ to implement in a tertiary hospital, Hospice, a rural hospital, GP, rest homes and community settings

Gynae-Oncology

- Midland Gynae-Oncology Service proposal for change to develop a regional model of care and service framework. Proposal for Change was endorsed by the Midland GM Planning and Funding forum
- Data collection and patient flow analysis commenced, will be a delay due to lack of analytical resource, working on possible solutions
- Following the recent national colposcopy audit, Waikato has employed a colposcopy nurse. Lean Thinking has been applied to referral process and waste removed from system. Aim to implement patient experience based design in 2008¹
- Waikato has approved funding for a Gynae-Oncology nurse co-ordinator

Care Co-ordination

¹ Based on NHS Institute of Innovation and Improvement

- Formation of a Midland Care Co-ordinators forum established, terms of reference in progress. Oncology Nurse group established
- Systematic literature review completed and MCN care co-ordination model of care and framework developed and out for consultation
- Waikato has approved funding and recruitment will commence in 2008 for: Colorectal nurse co-ordinator (1.0 fte); Gynae-Oncology nurse co-ordinator (0.5 fte); MDT co-ordinator (1.0 fte)
- BOP has appointed: Cancer CNS for Tauranga and Whakatane chemotherapy
- Lakes has appointed: Maori Cancer Nurse Specialist (1.0 fte)
- Waikato care co-ordination database project is a quality initiative to improve care, timeliness and monitor waiting times to standards has completed phase 1 and in progress with phase 2

Regional Strategic Plan

- MCN has endorsed framework and interim plan (A proposal for establishing the Midland cancer network 2006) this has been updated
- Agreed strategic cancer control plan framework with Ministry of Health
- The Northern Network has contracted a consultant to consult with stakeholders and develop a regional cancer control strategic process plan. Northern have agreed to share this work and MCN will adapt to local situation
- Requested Midland Planning and Funding services to have consistent approach to presenting cancer health needs assessment information (due February 2008)
- World Cancer Research Fund published Food, Nutrition, Physical Activity and the Prevention of Cancer: a global perspective. This provides a comprehensive scientific review of the evidence and presents a set of policy and personal recommendations for the prevention of cancer

Other

- Advance notification for additional MCN funding for addressing inequalities and resource support from PHI for next 3 years, effective 1 January 2008 (awaiting further information)
- Ministry funded pilot project for a community based Maori Cancer Support Service funded at Lakes – Te Kahui Hauora Trust and Hunga Manaaki
- Participation with the Cancer Control Council (CCC) evaluation of DHB and regional cancer network establishment – refer to Mapping Progress: the first two years of the cancer control strategy action plan 2005-2010. Participation in CCC stakeholders feedback and planning session
- Review and comment on the National Laboratory Screening Unit proposal via DHB planning and funding services. Review and comment of the national draft Adolescent / Young Adult Service Specifications and Specialist Palliative Care Service Specifications via DHB planning and funding services
- NZ Cancer Control 2 day conference focus was on consumer participation, reducing inequalities and care co-ordination.

Introduction

This is the Midland Cancer Network's progress report covering the quarter two period 1 October 2007 – 31 December 2007. This report builds on quarter one report, and summarises the background to the formation of the MCN and reports on progress to date on:

- structure development of the MCN
- progress on key MCN projects
- national engagement and developments.

Background

The Cancer Control Strategy Action Plan 2005-2010 (Action Plan) identified a number of priorities, including the continued development of regional cancer networks to enhance co-operation and collaboration of organisations involved with / or contributing to cancer control. The structures, scope and functions of regional networks are evolving in New Zealand. Regional networks are complex organisational and service delivery structures that work across organisational boundaries; they bring together key stakeholders to plan and deliver a set of comprehensive and integrated cancer services, that are co-ordinated across patient care pathways through a multidisciplinary team approach, for a given population area (region). Regional networks can increase access to comprehensive cancer services by sharing knowledge and promoting a collaborative approach to care planning and delivery.

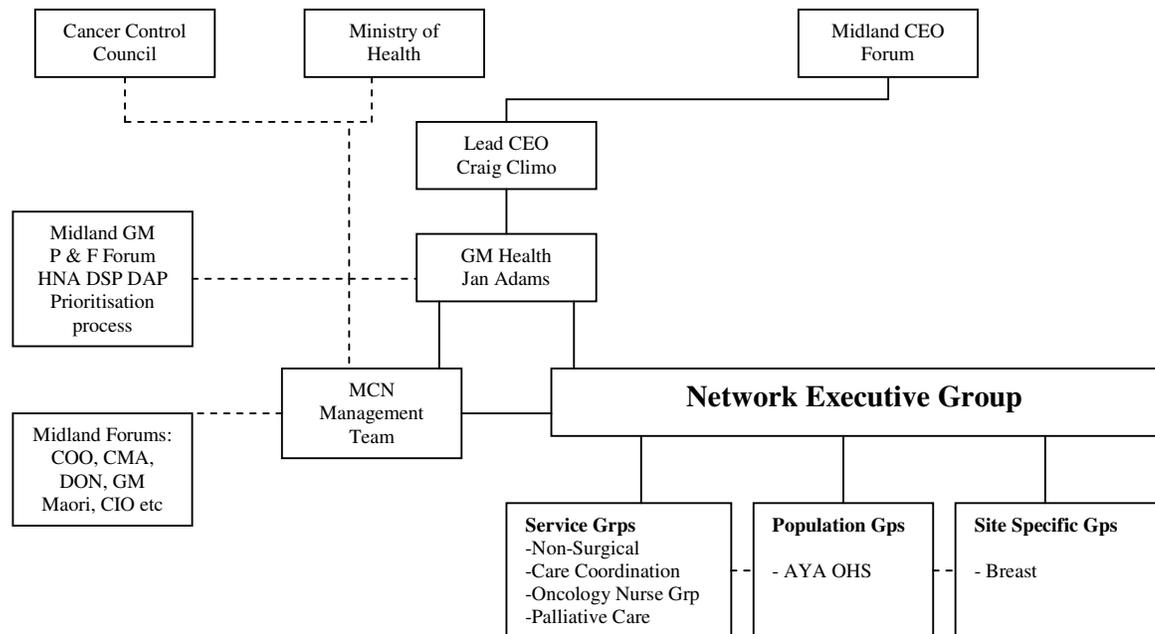
The Ministry of Health funded the establishment of the regional cancer networks through a lead DHB via the eighth omnibus variation to the 2004/05 Crown Funding Agreement (CFA). The CFA provides resource to support the network management infrastructure that will provide leadership, co-ordination and facilitation to assist constituents of the network to develop and achieve the regional strategic cancer control plan.

The MCN was formed in October 2006 following endorsement of the Midland Region Cancer Control Project report - A Proposal for Establishing the Midland Cancer Network (Hewitt J. 2006). This report included an interim work plan. Waikato DHB, the lead DHB, will ensure the establishment of the regional network and will manage the regional network on behalf of the three designated DHBs (Lakes, Bay of Plenty and Waikato). MCN has an open invitation to Tairāwhiti and Taranaki DHBs.

A key requirement of the MCN during the establishment phase is to work collaboratively to develop a Regional Cancer Control Strategic Plan agreed by the local DHBs.

MCN Organisational Framework

The MCN structure builds on current structures and forums within the Midland DHBs. The structural framework is not intended to be an additional management hierarchy and does not replace the responsibilities or accountabilities of individuals, services or organisations within the network for decision making or service provision.



The above structure diagram highlights the MCN workstreams development to date.

MCN Management Infrastructure

The Network management team provides clinical and managerial leadership and includes:

- Clinical Director Dr Jeremy Long (0.2 fte)
- Manager Jan Hewitt (1.0 fte)
- Patient Mapping Manager Loryn Scanlan (1.0 fte)
- Administration support / PA² Jana Rowlands (0.5fte)
- AYA OHS Project Officer³ Mariah Hudler (1.0 fte)

Dr Jeremy Long has resigned from the position of Clinical Director: Waikato Regional Cancer Centre to focus on the MCN Clinical Director role.

Loryn Scanlan has been appointed permanently full time to the Patient Mapping role.

The MCN staff are geographically scattered across the Waikato DHB campus. Plans are in progress to relocate MCN management team off site to Pembroke Street by June 2008.

The Manager attended Lean Thinking training. The five principles of lean thinking to enhances the quality of healthcare by improving flow in the patient journey and eliminating waste, specify value, identify the value stream of the patient journey,

² Commenced 1 October 2007

³ Adolescent / Young Adult Oncology Haematology Service project officer fixed term until 30 June 2008.

make the process and value flow, let the customer pull and pursue perfection. This is further discussed in the gynae-oncology section.

Quarter one report indicated additional MCN funding and CFA service requirements, and awaiting Crown Funding Agreement via the DHB planning and funding service to understand these requirements.

MCN Work Programme

This section summarises progress of the MCN annual work programme initiatives including;

- Patient mapping work programme
- Non-Surgical Cancer Treatment Operations Network
- BOP Resident Medical Oncology / Haematology Service
- Adolescent Young Adult Oncology Haematology Service (AYA OHS)
- Specialist palliative care outreach
- Gynae-Oncology services
- Development of Regional Cancer Control Strategic Plan
- Care Co-ordination work group and database project
- Primary engagement and participation
- Consumer engagement and participation
- Maori engagement and participation & Lakes Maori Cancer Support Service Pilot
- National engagements and developments

Patient Mapping Work Programme

Patient journey and parallel process mapping is completed for early stage breast cancer and in progress for:

- Lung
- Colorectal
- Prostate
- Ovarian

In addition to the mapping the following is being completed for each tumour stream:

- Log of staff issues
- Consumer perspective i.e. focus groups, review of compliments / complaints
- Variation analysis of each hospital map
- High level health needs analysis for each tumour group
- Analysis of waiting time between key stages of the journey
- Inequalities analysis
- Regional report of findings and action plan for each tumour stream

- Establishment of a regional site specific group.

The Midland Breast Cancer Mapping Report and Action Plan first draft is complete and consultation has commenced. The final draft is scheduled for February 2008.

The Breast Cancer Work Group terms of reference have been developed, discussions are occurring on appointment of a clinical chair and planning has commenced for the first meeting to be scheduled in 2008.

This information is being shared with other NZ Regional Cancer Networks (RCN).

Midland Non-Surgical Cancer Treatment Operations Network

The MRNSCT Operations Network now meets quarterly and the primary focus is on the recent health target for: radiotherapy waiting time, workforce, equipment, contract volumes and chemotherapy outreach. The terms of reference will be adapted to reflect the establishment of the MCN and structural framework. It was also agreed that a stocktake of the implementation plan for the MRNSCT be completed.

Other key points to note are:

- **Radiation Wait Times** – For October 2006 the waiting time for medical oncology was around 27.5 days (midpoint). It had increased to around 37 days over June and July. For October 2007 the waiting time for radiation therapy was around 17.5 days (mid-point). It had increased to 35 days in August. The radiation waiting time was estimated to be between 15 – 20 days for the majority of patients at this time. This means most patients are being seen within the Ministry of Health target of eight weeks. The Regional cancer Centre has been providing treatment to some patients from Palmerston North. However treatment of out of area patients would be stopped over the holiday period due to consultants on leave.
- The Regional Cancer Centre new single energy linac replacement should be operational in early 2008.
- The Regional Cancer Centre has commenced the process to appoint a clinical director for medical oncology, radiation oncology, haematology and palliative care (Waikato only). The Regional Cancer Centre clinical director will be a rotated position shared between the clinical directors of the four services.
- Waikato's third palliative care specialist has commenced. This will enable an integrated service between Hospice Waikato and Waikato provider arm. A locum fourth palliative care specialist employed for period November 2007-March 2008.
- Waikato's employed a fourth haematologist (while a specialist for haemophilia / coagulation, the position will assist the cancer population through additional resource) commenced in December 2007. A business case is in progress for a 5th haematologist and CNS haematology.
- Waikato's Clinical Nurse Educator Oncology Outreach reported introduction of clinical supervision of oncology nurses at Thames Hospital. It will involve a monthly session facilitated by the Practice Development Unit at Waikato DHB. The oncology nurses and medical staff at Thames Hospital responded

very well to a patient who had suffered a severe anaphylactic reaction to the first dose of a pharmaceutical cancer treatment. Investigating obtaining access to oncology notes by District Nurses at Thames Hospital. The nurses are seeing community based oncology patients with portacaths and from time to time the nurse may be required to access the portacath.

- Chemotherapy for Lakes DHB is now being supplied by Baxter's based at Waikato. There was an issue with vincristine being supplied in syringes. It is not for intrathecal use so should be supplied in a minibag. The situation has now been remedied with appropriate education and copying of protocols to pharmacy staff at Lakes DHB. New nurses (with limited oncology experience) are starting with the Chemotherapy Unit at Lakes DHB in the New Year and will require support.
- A register of clinicians who are competent to administer pharmaceutical cancer treatments intrathecally is being introduced. To be included in the register clinicians must have undertaken a competency assessment which consists of reading a protocol, watching a DVD and being witnessed carrying out a procedure. The register is for regional staff and will be kept in electronic format on a shared drive. Lakes DHB will need to have at least one clinician on the register in order for chemotherapy to be administered via intrathecal route at Rotorua Hospital.
- Whakatane Hospital new cancer centre has opened. The centre is operating three days a week. Dr Richard Sorrenson (consultant physician at Whakatane Hospital until October 2008) is providing clinical oversight for oncology nurses at Whakatane Hospital and patients in the Whakatane area who are currently undergoing treatment. He has a special interest in haematology.
- New Cancer CNS for Bay of Plenty DHB - Rosemary Davis has been appointed to the position of Cancer CNS for Bay of Plenty DHB. She is responsible for chemotherapy suites at Tauranga and Whakatane Hospitals. It is expected that the Cancer CNS at Bay of Plenty DHB would work closely with Clinical Nurse Educator Oncology Outreach at Waikato DHB
- Lakes DHB has appointed a Maori Cancer Nurse Specialist. The nurse will work as a care co-ordinator specifically with Maori patients. It was noted that the cancer care co-ordinators title has been changed to CNS in accordance with a remit from the New Zealand Nursing Organisation.

BOP Resident Medical Oncology/Haematology Service Business Case

The business case for development of a resident medical oncology / haematology service based in Tauranga, Bay of Plenty DHB is in progress. BOPDHB is the lead for development of this business case in partnership with Waikato DHB and the MCN. BOP aim to have the business case out for wider consultation in quarter three. A working draft is available.

The medical oncologist Dr Richard North is due to commence at BOPDHB in January 2008.

Adolescent / Young Adult Oncology / Haematology Service

Since quarter one report the following initiatives are in progress and out for consultation with key stakeholders:

- Final draft stock take of services and providers
- Requested and awaiting Health Needs Assessment information requirements from Planning and Funding
- Audit of New Zealand Cancer Control Strategy Action Plan 2005 – 2010 phase one and two activities
- Analysis against current services against draft AYA OHS service specifications
- Commenced developing an AYA OHS model of care
- Initialisation of AYA OHS CNS service at Waikato Hospital Wards 25 and 52
- Participating in weekly telephone conference meeting with representatives of AYA teams from other DHBs
- Establishing youth health focus group.

Unfortunately the MCN was not able to co-ordinate the New Zealand AYA OHS Advisory Group to present and share learnings to the MCN Executive Group in October. A national forum for AYA OHS is being held in February 2008 in Wellington.

Lakes Specialist Palliative Care Business Plan

Lakes DHB and the MCN proposal for change was endorsed by the Midland GM Planning and Funding forum to scope and develop a detailed business plan for Waikato DHB to support the development of an outreach specialist palliative care service within the Lakes district. This initiative aligns with the draft national specialist palliative care service specifications.

In addition the Ministry⁴ has indicated that additional palliative care funding is available effective 1 January 2008 on a PBFF to advance three new service components:

- Last days of life programmes
- Education programmes for generalists
- Telephone advice and support for generalists.

A regional palliative care forum was held 11th December 2007 at Rotorua Community Hospice to commence discussions regarding the above service component initiatives. Representatives were there for all districts and apologies from Tairāwhiti. Outcomes from the meeting identified opportunities to collaborate on:

- Last days of life programme, utilising Waikato PCU framework, resources and lessons learnt
- Develop standardised and core education programme for generalists in conjunction with local district education initiatives

⁴ Ministry of Health letter to DHB CEOs 13 November 2007

- Expand Waikato's 24/7 medical specialist telephone advice and support to a regional service for generalists, supported by local triage nurse service
- Establish regional palliative care network. Draft terms of reference for MCN palliative care network will be developed in quarter three.

Further discussions will occur as required in quarter three when the CFA has come to the DHB planning and funding services.

Gynae-Oncology Model of Care and Framework

Following completion of the national colposcopy audit at Waikato in June 2007, there was a recommendation to have a lead colposcopy nurse specialist. April McFarlane⁵ was employed into this position. The purpose of this position is to:

- improve service to women throughout the Waikato district and;
- to meet national standards through a quality/audit approach of improvement to the systems and processes putting women at the heart of the service and;
- to redefine the service profile by gaining patient input to redesign the journey.

There is a vision to develop the service to include more of a multi agency approach to clinics to discuss domestic violence, contraception and sexual health.

Following on from the Dr Lynne Mayer presentation in quarter one Waikato plans to start patient experience based design for colposcopy and then to cascade it to other areas of gynae-oncology. Waikato has also used Lean Thinking to value map the colposcopy journey and has already benefited from removing waste from the process.

In addition Waikato has also approved appointment of a Gynae-Oncology nurse co-ordinator (0.5 fte). This position will sit within the Regional Cancer Centre with the other care co-ordinators. Planning for recruitment will commence in quarter three.

Developing a Midland Cancer Control Strategic Plan

The eighth omnibus variation to the 2004/05 Crown Funding Agreement (CFA) reporting requirements of the MCN is to provide by 31 December 2007 to the Ministry:

- Interim regional network objectives with any identified priorities
- Draft regional network work plan
- A framework and outline of the process for developing the draft and final regional strategic plans.

The primary purpose of the regional strategic cancer plan is to describe how the network will support regional stakeholders to achieve the goals of the Cancer Control Strategy, and to establish high-level objectives for the next 3 – 5 years. The Midland DHBs Cancer Control Plans align actions required for predominately phase one.

The Ministry have provided a strategic cancer plan framework and guideline for networks to follow.

⁵ Commenced 3rd December 2007

Northern Cancer Network has contracted a consultant to consult with stakeholders and develop a regional cancer control strategic process plan. Northern have agreed to share this piece of work with other networks within New Zealand to reduce duplication.

MCN has used the Northern Cancer Network report as a basis to develop a framework and outline of the process or developing the final regional strategic plan. The interim MCN objectives and identified priorities are outlined in the 'Proposal for establishing the Midland Cancer Network' (Hewitt, 2006), this document has been updated. The MCN has available on request 'A Planning Process for the Development of a Regional Cancer Strategy Plan'.

Currently all three DHBs HNA reports do not present consistency of data and information, preventing using this information to have a regional as well as local DHB HNA perspective for cancer control. A request was made in October to the Midland GM's planning and funding to coordinate consistent presentation of cancer continuum data in the current HNA across the three DHBs. This would reduce the need to contract additional resource to meet the needs of the MCN to meet CFA requirements. The MCN is awaiting DHB's planning and funding HNA for the cancer continuum. Waikato DHB unfortunately has a delay due to a major incidence where data was lost, revised timeframe is February 2008.

Primary Engagement and Participation

At the December 2007 NZ Regional Cancer Networks (RCN) meeting Karen Thomas of the Royal NZ College of General Practitioners was invited to discuss opportunities for primary engagement and participation in the RCNs. Key themes from the discussion were:

- Minimal inclusion of primary in the NZ Cancer Control Strategy Action Plan
- No alignment between the NZ CC Action Plan and the NZ Primary Health Strategy
- College has an accreditation programme in place and practices are probably in a place to move forward and interact with the Networks
- Already addressing cancer and palliative care under chronic disease management – need to look at how other chronic diseases have managed to engage primary – why hasn't it happened with cancer? There are also lessons learnt from MOH electives processes
- Need to look at role of GP in cancer early detection – access to diagnostics an opportunity area to develop
- Systems with hospitals could be better – clinical governance, education, collegial relationships, communication
- Suggestion – 1 DHB and 1 PHO per Network pilot establishing a mechanism of linkage, look at improving access to cancer diagnostics for early detection and lastly improve communication.
- NZ RCN present at Annual GP conference in July 2008.

MCN will need to consider this feedback.

Maori Engagement & Participation

Waikato General Manager Maori Services will be a member on the MCN Executive Group and provide the link to regional forum. The Midland GM Maori forum discussed options for Maori engagement and participation and recommended that MCN use each DHB Iwi Governance structure that will inform and discuss issues relating to Maori.

Currently collating the three DHBs Maori engagement structures and frameworks (to date received information from Lakes DHB).

Cancer Control Pilot

A pilot project for a community based Maori Cancer Support Service has been implemented. This is an integrate effort with Te Kahui Hauora Trust and Hunga Manaaki. The pilot has received funding from the Ministry of Health Cancer Control budget and is supported by Lakes DHB.

The aim of the pilot is to meet the needs of Maori, reduce inequalities and increase access to services. The Maori workers will provide cultural support and will work closely with the cancer care co-ordinators (refer appendix four). Maori health workers associated with the pilot have been invited to join the Midland Cancer Care Co-ordinator forum.

Consumer Engagement & Participation

The MCN Executive Group consumer advocate representative unfortunately had to resign as a representative and also as project officer for the consumer advocate project. This project was to develop a consumer advocate framework for the MCN.

Recruitment of a consumer advocate has commenced.

The New Zealand regional cancer networks have agreed that there needs to be a consistent approach and framework for engagement and recognition of the value of participation. Collectively the NZ regional cancer networks plan in 2008 to work collectively on developing this framework.

Midland Care Co-ordinators Work Group

This forum is going from strength to strength. Membership of the group has widened to include care co-ordination representatives from community NGOs', primary, Maori provider, secondary, tertiary services across the cancer continuum.

The MCN at the request of care co-ordinators has facilitated three regional meetings. From these meetings the key roles and functions of care co-ordinators has been defined, a breast care co-ordinator model of care has been developed. Draft terms of reference are to be developed.

The MCN carried out a systematic literature search and review of care co-ordination and care co-ordinator models in the context of cancer control.

A draft paper is out for consultation. This paper summarises the literature for the Midland Cancer Network on:

- A care co-ordination and continuity of care definition

- A framework that identifies and communicates a variety of care co-ordination strategies to ensure continuity of care across the continuum
- An outline of the various roles and functions of various co-ordinator positions.

This document has also been made available to other regional cancer networks.

Care Co-ordination Database Project

Patient mapping of early stage breast cancer identified significant gaps in co-ordinating care and serious issues related to obtaining relevant data along the care pathway. Across the region there are numerous database systems capturing different types of data. At no time does any organisation know where, how many, and the length of wait time of cancer patients along a specific tumour pathway. Breast cancer patients go through multiple steps (approximately 81 steps per patient and 9 handovers between services) and there are no dedicated clinical pathway guidelines for the network. These factors all contribute to difficulty in co-ordinating cancer care, sometimes this result in some patients' care falling through the cracks.

As a quality initiative Waikato is leading the scoping and feasibility, development and implementation of the pilot of a care co-ordination database for breast cancer. The aim is to have a database system for the major tumour groups for co-ordinating care, improving timeliness and care along the pathway, audit and monitor progress.

The scoping phase is completed with sign off to move to phase two - requirements analysis. Consultation of phase two has been completed and a draft software requirements specification for cancer care co-ordination system report has been received for review and comment. If sign off of this phase occurs then the project will proceed to design / development and testing / implementation phases in quarter three and four.

Nurse Care Co-ordination Positions

Waikato has approved funding and recruitment will commence in 2008 for:

- Colorectal nurse co-ordinator (1.0 fte)
- Gynae-Oncology nurse co-ordinator (0.5 fte)
- MDT co-ordinator (1.0 fte)

BOP has appointed:

- CNS Cancer for Tauranga and Whakatane chemotherapy suites (0.6 fte)

Lakes has appointed:

- Maori Cancer Nurse Specialist (1.0 fte).

National Engagement & Developments

This section summarises:

- The formation of the NZ RCN forum
- NZ Cancer Control Conference
- 2nd International Cancer Control Congress

- Update from the Ministry of Health and Cancer Control Council (CCC)
- Findings of recent international cancer prevention research.

NZ Regional Cancer Network Forum

The NZ Regional Cancer Networks (RCN) managers and clinical directors along with the Ministry of Health Cancer team and the CCC have met regularly on an informal basis to share information and learnings, this is in the process of been formalised with terms of reference. The Chair of this forum will be from within the RCNs and will be rotated, the MCN manager is Chair for the first rotation.

NZ Cancer Control Conference

The NZ Regional Cancer Network Forum was held in Wellington over two days with the key themes:

- Consumer participation
- Care co-ordination
- Reducing inequalities

For a summary of the conference refer to appendix one, to read the presentations please refer to <http://www.moh.govt.nz/moh.nsf/indexmh/cancercontrol-regional-network-nov07>

2nd International Cancer Control Congress

The 2nd International cancer control congress was held in November over four days with six from NZ in attendance. The key themes of the conference were:

- Similarities and distinctions between controlling chronic diseases
- Cancer prevention, early detection and screening strategies - with a focus on progress to date and implementation challenges
- Novel approaches and technologies - matching renewed efforts in population based cancer control to cultural and financial benefits
- Cancer control and outcomes - use of evidence indicators
- Investing in population based cancer control
- Mobilisation of a global community of practice - building and synergising ongoing activities.

Website information www.cancercontrol2007

Ministry of Health

The Managers of the RCNs attend the NZ CC Steering Group and the Clinical Directors are members of the NZ Cancer Treatment Working Party and both will be representatives on the NZ RCN forum.

The Ministry of Health have a detailed work programme and updates refer to www.moh.govt.nz/cancercontrol

Cancer Control Council

The CCC role is to provide leadership, to monitor and review implementation of the NZCCS and to foster collaboration and co-ordination efforts of the Council, Ministry and the wider sector.

In August 2007 the CCC published the “Mapping Progress: the first two years of the cancer control strategy action plan 2005-2010” presents key findings of achievements and / or work in progress, evaluation and recommendations for the regional cancer networks (RCN) and guide for the CCC.

The CCC in partnership with the RCN have developed a website that allows networks to display their information – refer www.cancercontrolcouncil.govt.nz Note: that in 2008 the CCC are forming an independent website to that of the Ministry of Health.

The CCC General Manager presented to the MCN Executive Group meeting (October 2007) on the role and functions of the CCC and findings of the Mapping Progress Report.

Following the launch of the CCC first evaluation and monitoring report (Mapping Progress) the Council held a stakeholders feedback and planning forum in October. The MCN Manager represented the Network at this forum.

Food, Nutrition, Physical Activity and the Prevention of Cancer: a global perspective

In October 2007 the World Cancer Research Fund published the 2nd report on food, nutrition, physical activity and the prevention of cancer: a global perspective. This provides a comprehensive scientific review of the evidence and presents a set of policy and personal recommendations for the prevention of cancer. A summary of the recommendations are:

- Be as lean as possible within the normal range of body weight;
- Be physically active as part of everyday life;
- Limit consumption of energy-dense foods;
- Avoid sugary drinks;
- Eat mostly foods of plant origin;
- Limit intake of red meat and avoid processed meat;
- Limit alcoholic drinks;
- Limit consumption of salt;
- Avoid mouldy cereals (grains) or pulses (legumes);
- Aim to meet nutritional needs through diet alone rather than through supplements;
- Breastfeed children; and
- Cancer survivors are advised to follow the recommendations for cancer prevention.

For the detailed report or summary report refer to <http://www.wcrf.org/research/fnatpoc.lasso>

MCN along with HEHA project managers and other stakeholders needs to consider strategies for disseminating this information for action.

Women and Cancer Risk

A further recent study⁶ has quantified the number of cases of cancer in women caused by obesity and overweight. This study funded by Cancer Research UK is the biggest study ever undertaken to look at women and cancer risk.

Over 1 million UK women were studied during seven years. The study has found that among middle aged and older women in the UK:

- Around 5% of all cancers, 6,000 each year, are caused by being overweight or obese
- Two thirds of the additional 6,000 cancers each year due to overweight or obese are cancers of the womb or breast.

MCN along with HEHA project managers and other stakeholders needs to consider strategies for disseminating this information for action.

⁶ Reeves G., Pirie K., Beral V., Green J., Spencer E. & Bull D. (2007). *Cancer Incidence and mortality in relation to body mass index in the Million Women Study Cohort Study*. British Medical Journal

Appendix 1 – Regional Cancer Networks Forum

7 and 8 November 2007

Wellington

Summary of Proceedings

Attended by:

- Waikato DHB – Jan Hewitt, Chris Cowley, Mariah Hudler, Erena Kara, Rachel Poaneki, Ellyn Proffit and Loryn Scanlan
- Bay of Plenty DHB – Lorraine Hammersley
- Lakes DHB – David Boles

Session 1 – Consumer Perspective

Presenters:

- Dr Neil Graham – physician/patient perspective- insights from a physician's personal experience of cancer
- Denise Robbins – President of Cancer Voices NZ
- Brian Vickers – Māori Mental Health Consumer Representative with Northland DHB

Key themes

- Cancer consumer representative is someone who has cancer or cared for a cancer patient
- Needs to be formal process of selection, training and placement.
- The consumer brings a unique perspective (can only really understand it if you've done it).
- The person needs to be able to voice the consumer perspective and have knowledge about how committees operate.
- Consumers should be treated as a full member and be supported in their role including being paid for their services (expenses plus a meeting attendance fee).
- Agreement is required as to different consumer roles and the definition of roles - advocates, representatives and advisors.
- More than one representative may be required to represent needs of specific groups (paediatrics, adolescents and older people) and populations
- Need a position description: transparency, accountability and collaboration. Move away from DHB employees in Mental Health because of potential conflict of interest

- Good at creating survivors but need more resources allocated to supporting survivors. Clinicians need to be more aware about after-effects of a serious illness
- “Cancer” label sticks
- Survivorship – end of treatment and onwards
- Consumer participation is specified as an activity in Cancer Control Action Plan

Some other models of consumer participation in health

- Mental Health consumer Advisors
- National Committee of Consumer Advisors to DHBs
- Pharmac Consumer Advisory Committee
- Health and Disability Patient Advocates (statutory role).

Session Two Care Co-ordination

Presenters:

- Barry Keane – Director of Clinical Services Arohanui Hospice
- Darna Appleyard (Waitemata DHB) and Dr Peter Jansen (Mauri Ora Associates) Whanu Ora Cancer Care Co-Ordination Project
- Oriana Paewai. A study into Do Not Attend Ambulatory Service Outpatient Clinic Rates by Māori at MidCentral Health
- Jan Hewitt delivered Teresa McKenzie’s presentation on the Improving the Care of the Dying across the Waikato DHB through implementation of the Liverpool Pathway

Key themes

Palliative Care

- Integrated palliative care model recognises role and responsibility of generalist and specialist service
- Education programme, resource manual and a number of tools are used to bridge partnership between generalists and specialist arms of the service
- Averts crisis admissions and call-outs after hours
- Increases knowledge and confidence of staff
- Benchmarking of care and improve care
- Strengthens specialist-generalist link
- Integration of services maximises use of existing resources and facilitates partnership in the care of the patient rather ownership

Whanau Ora Navigation Model

- culturally responsive cancer care co-ordination model which is being piloted in Waitemata DHB

- 2 linked workers : Community health navigator located in primary care and hospital based clinical systems advocate to support culturally appropriate delivery and uptake of treatment
- A number of resources have been developed (within a kaupapa Maori framework) to support community health navigator
- Support based on whānau need
- Success factor of the model is robust engagement with Māori at all levels (Māori consumer, Māori governance) and stages of the project/pilot
- Evaluation of pilot will take place after June 2008
- Information about cancer is given to patients in an uncoordinated manner
- More materials need to be target for population groups
- Relationships and communication key concepts – Clinician’s communication sometimes lack clarity and cultural appropriateness. Rapport with clinicians is important (sensitivity and cultural understanding)

DNA Study

- Inaccuracies in DHB information - people attended appointments but were recorded as not attending. If people cancelled or changed appointment often still recorded as DNA.
- Reasons patients gave for not attending:
 - Didn’t know what to expect
 - Having to wait too long in outpatient clinics to see DR
 - Clinicians perceived to be insensitive or incompetent
 - Family emergency
 - Transport problems
 - Having to pay for parking
- System issues identified
 - DHB administrative processes
 - No reminder system
 - Possible to predict patients that are likely to DNA
 - Referrers not notified (e.g. GPs if aware could remind patients)
 - Need for more services to be provided in the community
- Enablers to attending
 - Communication
 - Whānau support and encouragement
 - Able to deal with what they are told

Session Three Reducing Inequalities

Presenters:

- Craig Tamblyn General Manager Cancer control Council
- Tony Blakely Epidemiologist Wellington School of Medicine
- Colin Tukuitonga Chief Executive of the Ministry of Pacific Island Affairs
- Michael Naera and Ray Morrison, Hunga Manaaki Cancer Support Project (NB: Lakes DHB initiative)
- Michele McCready Manager Cancer Screening National Screening Unit

Key themes

Reducing Inequalities

- Ethnic and socio-economic disparities in death rates in general population have stabilised. Improvements for Pacific people not as much as for Māori.
- Inequality in all-cancer mortality increased for Māori and Pacific people compared to European/Other
- Lung Cancer large inequalities between Māori and European. Gap is bigger than tobacco
- Colorectal Cancer, mortality rates in Māori males risen steeply
- Breast cancer inequality increased markedly for Māori compared to European. Similar increase in inequality for Pacific women. Inequality due to screening
- There are lots of reasons for inequalities including co-morbidity and later diagnosis but they only account for a small portion of the gap
- Biggest portion of inequalities gap due to differential access to and through health services
- Concerted efforts are required to try look for inequalities in health services and close health gaps
- Pacific priorities – reduce tobacco consumption, childhood obesity and improve screening rates
- Need for multiple strategies aimed at different levels and greater connection across all hospital and community sectors
- Need to education staff about inequalities and underlying drivers. Need to continue inequalities inquiry

Māori Cancer Support Service Project

- Cancer Control pilot (between MOH and Te Kahui Hauora Trust/Hunga Manaaki)
- Rationale: meet the needs of Māori, reduce inequalities and increase access to services
- Hunga Manaaki (based at Rotorua Hospital, external organisation)

- Current service focuses of inpatient part of journey. Service extended to discharge planning and patient advocacy and whānau support in community

- Services included: information resources, assist with financial and transport issues, support during clinical processes, health promotion and education

The New Minister of Health Hon. David Cunliffe closed the conference. Main objectives are to tackle major diseases through a systematic approach and address inequalities with lifting outcomes for Māori through the introduction of culturally appropriate initiatives being a major priority.