

SUMMARY
Mapping Progress:

THE FIRST TWO YEARS OF THE CANCER CONTROL STRATEGY ACTION PLAN 2005-2010



CANCER CONTROL COUNCIL
OF NEW ZEALAND

Te Kaunihera Whakahaere Mate Pukupuku o Aotearoa

SUMMARY

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THE FIRST TWO YEARS OF THE CANCER CONTROL STRATEGY ACTION PLAN 2005–2010

acknowledgements

The Cancer Control Council of New Zealand would like to thank the many individuals and groups who have contributed to this report by taking part in the questionnaire sent to stakeholders in the cancer control community. In particular, we acknowledge the work of the Council's Evaluation and Monitoring Working Group (Professor Tony Blakely, Chair, Professor John Gavin, Ms Helen Glasgow, Dr John Childs, Dr Garry Forgeson, Dr Beverley Lawton) and the staff of the Secretariat (Craig Tamblyn, Mary Clare Tracey, Matt Soeberg, Anna Smith, Katie Phillips and Scott Trainor) for making this report a reality.

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foreword



Dame Catherine Tizard



Professor Tony Blakely

This summary report presents the key findings of the first evaluation and monitoring report of the Cancer Control Strategy Action Plan 2005–2010. The report is an important milestone in the Cancer Control Council’s work. It is two years since the many organisations involved in controlling cancer in New Zealand started work to put the Action Plan into operation. It is now time to look at how far we have come and what more needs to be done.

The report does a number of things. First, it provides the Council with information about how all of us in the field of cancer control have achieved or worked towards implementing the wide range of milestones outlined for Phase 1 of the Action Plan.

This progress has been made by the whole cancer control community which includes non-government organisations, district health boards, the Ministry of Health and professional bodies.

Second, the report will guide the way in which the Council works with the cancer control community. It highlights areas where the Council needs to provide further leadership and engagement if we are to meet the targets in the Action Plan. Overall, we have made steady progress but there are areas where further effort is needed.

Third, the report provides information to the many cancer control agencies about how their work has contributed to reducing the incidence and impact of cancer in New Zealand. Seeing the wider picture of cancer control activities in New Zealand helps us to understand where we have been, where we are now and where we need to next focus our efforts.

Finally, the report will provide invaluable information for how we approach the review of the current Action Plan and develop its successor over the next two to three years.

One of the key developments in the past year has been the establishment of four regional cancer networks. These networks are formalising collaboration across cancer control and will work to ensure cancer services are co-ordinated across health providers. Over time they will become an important engine room for achieving the goals of the Cancer Control Strategy, especially for Goals 3, 4 and 5.

The report contains the results of a high level review of how these networks have developed and identifies issues that need to be addressed for the future. The Council will continue to evaluate the networks’ progress to ensure they succeed.

We would like to thank the many organisations and individuals who have made a vital contribution to this report by responding to our request for information. The material we received was rich with details about successful initiatives being undertaken across cancer control in New Zealand. We would greatly appreciate feedback on any aspects of this report so we can improve our evaluation and monitoring.

We look forward to continuing to work with you as we now implement Phase 2 of the Cancer Control Strategy Action Plan 2005–2010.

A handwritten signature in blue ink that reads "Catherine Tizard".

Dame Catherine Tizard
Chair, Cancer Control Council

A handwritten signature in blue ink that reads "Tony Blakely".

Professor Tony Blakely
Chair, Evaluation and Monitoring Working Group,
Cancer Control Council

background

Cancer control is an organised approach to reducing the burden of cancer. It includes prevention, screening and early detection, treatment, support and rehabilitation, palliative care, and surveillance and research. Successful cancer control builds on co-operation between groups and organisations providing services across the spectrum of cancer control.

This summary report presents the key findings of the Cancer Control Council's first evaluation and monitoring report of the Cancer Control Strategy Action Plan 2005–2010.

The Council undertakes monitoring, evaluation and review at three different levels of the Cancer Control Strategy.

- 1| Monitoring at the **individual action level** involves assessing the progress of specific actions (milestones) in the Cancer Control Strategy Action Plan 2005–2010.
- 2| Evaluation at the **Action Plan level** involves selecting a few high priority questions or issues to evaluate each year.
- 3| Review at the **Strategy level** is linked to the five-yearly process of generating the next Action Plan (2010–2015).

Purpose of report

The purpose of the evaluation and monitoring report is twofold:

- 1| to gather and analyse information on Phase 1 cancer control activities in New Zealand in order to
 - identify successes, work in progress and areas of delay
 - identify opportunities for collaboration and streamlining
- 2| to assist the Cancer Control Council and other stakeholders in identifying and prioritising activities planned for Phase 2 of the Cancer Control Strategy Action Plan 2005–2010.

Goals of the Cancer Control Strategy

- 1| Reduce the incidence of cancer through primary prevention.
- 2| Ensure effective screening and early detection to reduce cancer incidence and mortality.
- 3| Ensure effective diagnosis and treatment of cancer to reduce morbidity and mortality.
- 4| Improve the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care.
- 5| Improve the delivery of services across the continuum of cancer control.
- 6| Improve the effectiveness of cancer control in New Zealand through research and surveillance.

The focus of this report is on Phase 1 milestones in the Cancer Control Strategy Action Plan 2005–2010. At the Action Plan level, we also report on the establishment of regional cancer networks and the initiation of an adult cancer care experiences survey.

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Results of the Phase 1 monitoring of the Cancer Control Strategy Action Plan 2005–2010

High level overview

The Action Plan lists objectives under each of the six goals of the Cancer Control Strategy. These objectives are then broken down into outcomes/results and specific actions, against which there are milestones for monitoring.

There are 152 milestones for Phase 1 (the first two years of the five-year Action Plan), of which:

- 23 have been achieved (15 percent)
- 85 are in progress (56 percent)
- 33 are delayed (22 percent)
- 11 could not be assessed due to insufficient information (7 percent).

Overall, Goals 1 and 2 are proceeding most rapidly and thoroughly, whereas progress under Goals 3, 4, 5 and 6 is patchy and less systematic.

The establishment of regional cancer networks will be critical to advancing Goals 4 and 5 and especially Goal 3. The Council is keen to facilitate and support the networks as much as possible, working in collaboration with non-governmental organisations (NGOs), the Ministry of Health and district health boards (DHBs). It may be that the establishment of networks will require actions and milestones under these goals to be reformulated before the next Action Plan for 2010–2015 is developed.

The recent establishment of a supportive care expert advisory group, and its subsequent work plan, will be essential to making good progress under Goals 3 and 4. This group will, among other things, adapt overseas guidelines and standards for application in New Zealand. The Council is keen to support and facilitate this process and welcomes the involvement of lead non-governmental organisations, such as the Cancer Society of New Zealand.

	MONITORING AGAINST ALL MILESTONES				
	Achieved	In progress	Delayed	Insufficient information available for monitoring	Goal total
Goal 1 Primary prevention of cancer	9	29	4	3	45
Goal 2 Effective screening and early detection	4	3	3		10
Goal 3 Effective diagnosis and treatment	4	18	5	4	31
Goal 4 Improve the quality of life for those with cancer	4	14	10		28
Goal 5 Improve the delivery of cancer control services	1	15	11	2	29
Goal 6 Cancer control research and surveillance	1	6		2	9
TOTAL	23 (15%)	85 (56%)	33 (22%)	11 (7%)	152

Progress against Phase 1 milestones that aim to address cancer-related inequalities

The Cancer Control Council has identified specific actions and milestones in Phase 1 of the Action Plan that aim to address cancer-specific inequalities. Overall, most of these milestones are in progress (64 percent). However, much of the progress

reported against milestones in the evaluation and monitoring report relates to specific activities at a district or regional level, rather than a systematic approach to addressing inequalities. The Council will undertake further work to investigate the progress made on the outcomes and actions relating to cancer-related inequalities.

	MONITORING AGAINST INEQUALITIES-RELATED MILESTONES*				
	Achieved	In progress	Delayed	Insufficient information available for monitoring	Milestones in Phase 1 relating to cancer-specific inequalities *
Goal 1 Primary prevention of cancer	5	11	1	1	18
Goal 2 Effective screening and early detection		3		2	5
Goal 3 Effective diagnosis and treatment	2	6		3	11
Goal 4 Improve the quality of life for those with cancer	1	3	1		5
Goal 5 Improve the delivery of cancer control services		10	3		13
Goal 6 Cancer control research and surveillance		2		1	3
TOTAL	8 (15%)	35 (64%)	5 (9%)	7 (13%)	55

* Milestones have been included in this table if they refer to ethnicity (particularly Māori or Pacific peoples), rurality, socioeconomic status and/or vulnerable or high-risk populations (such as children and young people).

GOAL 1: Reduce the incidence of cancer through primary prevention

Introduction

This goal is based on seven potential cancer risk areas: tobacco, physical inactivity, poor nutrition, ultraviolet (UV) radiation, infectious diseases, alcohol and occupational risks. Primary prevention approaches aim to reduce exposure to these risk factors and offer the greatest health gains and most cost-effective forms of cancer control. Public health policies and programmes are needed to encourage and promote healthy social environments and to support people to make healthy lifestyle choices.

A collaborative approach between non-governmental organisations (for example the Cancer Society of New Zealand, Te Hotu Manawa Māori, The Quit Group, Action on Smoking and Health, the National Heart Foundation), Crown agencies (such as SPARC, the Health Sponsorship Council, ALAC and the district health boards) and central government agencies, for example the ministries of health and education, is critical to the success of this goal.

Overall progress

This wide-ranging goal details 45 milestones to be actioned during the first two years of the Action Plan. Nine of these have been achieved in the areas of tobacco control, inactivity, nutrition and UV radiation. A further 29 milestones (64 percent) are in progress. Four milestones have been delayed, but work has started in three areas which will feed into these milestones.

Comments from the Cancer Control Council

Rapid and thorough progress has been made in this goal over the past two years. Two notable reasons for this good progress are the existence of a long-standing tobacco control programme of work and the recent push on the Healthy Eating, Healthy Action Strategy. Work planned by stakeholders for the coming year will address the few delayed milestones.

Achievements

- The number of smokefree homes has increased and exposure to second-hand smoke has decreased.
- The Framework for Reducing Smoking Initiation in Aotearoa has been launched.
- The Aukati Kai Paipa Programme, which focuses on Māori women and their whānau, has been extended to every district health board region.
- The Mission-On programme, which provides initiatives to improve nutrition and physical activity among young New Zealanders, has been implemented.
- The Fruit in Schools initiative started in late 2005 and around 271 schools now take part.
- National guidelines setting out healthy food options were distributed to all schools in June 2007.
- A baseline survey of sun protection policies and practices in primary schools has been completed. This survey can be used to track progress in implementing national sun safety policies.

The Council was not able to assess three milestones, one in tobacco control and two relating to infectious disease, and will follow these up with the relevant stakeholders.

The Council has identified tobacco control as a priority area for its work programme over the next one to three years.

Find out more: The Cancer Control Council's full report, *Mapping Progress: The First Two Years of the Cancer Control Strategy Action Plan 2005–2010*, is available at <http://www.cancercontrolcouncil.govt.nz>

GOAL 2: Ensure effective screening and early detection to reduce cancer incidence and mortality

Introduction

Screening is the process of examining asymptomatic or well people in order to classify them as unlikely or likely to have a disease. Screening has the potential to identify a high proportion of people in the early stages of a disease. Early detection aims to detect cancer as early in its development as possible, when the options for treatment are greatest. Increased efforts should be focused on those cancers where early detection has been shown to reduce cancer mortality or morbidity.

Stakeholders involved in this goal include: primary health organisations, the Cancer Society of New Zealand, the National Screening Advisory Committee, professional societies such as the Royal New Zealand College of General Practitioners and the New Zealand Dermatological Society, tertiary education institutes, district health boards, the Health Sponsorship Council, the National Screening Unit (within the Ministry of Health) and the Ministry's public health and clinical services directorates.

Overall progress

This goal details 10 milestones, focused on screening and early detection, to be actioned during the first two years of the Action Plan. Four of these have been achieved, two each in the areas of screening and early detection. A further three milestones (30 percent) are in progress. Three milestones, relating to early detection, have been delayed. The Cancer Control Implementation Steering Group within the Ministry of Health is considering how these milestones should be prioritised in the context of other screening and early detection work.

Comments from the Cancer Control Council

Progress has been satisfactory in this goal over the past two years. This has been helped by the long-standing existence of the National Screening Unit and the more recent

Achievements

- The National Screening Advisory Committee has been set up.
- Advice on establishing a colorectal screening programme has been developed and delivered to the Minister of Health.
- A review of cancers suitable for early diagnosis efforts showed that outcomes from breast, cervical and colorectal cancers benefit from screening programmes.
- Effective strategies for early detection of melanoma have been identified along with areas for ongoing monitoring and research for skin cancers.

establishment of the National Screening Advisory Committee. However, progress on improving breast cancer screening rates for Māori and Pacific women is poor and worrying. Strategies to address this have been identified, through the National Screening Unit's Quality Framework, but these have yet to be reflected in increased coverage of BreastScreen Aotearoa or in reported reductions in breast cancer mortality.

The Council plans to work closely with the National Screening Unit in developing a feasibility study for a colorectal screening programme, continue to monitor coverage rates of BreastScreen Aotearoa and maintain links with the community to ensure milestones for screening and early detection are prioritised and implemented.

Find out more: The Cancer Control Council's full report, *Mapping Progress: The First Two Years of the Cancer Control Strategy Action Plan 2005–2010*, is available at <http://www.cancercontrolcouncil.govt.nz>

GOAL 3: Effective diagnosis and treatment of cancer to reduce morbidity and mortality

Introduction

Diagnosis of cancer covers a broad range of activity, from presentation or identification of signs and symptoms, to confirmation – or elimination – of a cancer diagnosis. Excessive delays between the presentation or identification of initial symptoms and the definitive diagnosis of cancer have a significant psychological effect on those with cancer, their family and whānau. Excessive delays can also have impacts on prognosis. Developing a more integrated approach to treatment and care, focused on the patient's needs, is critical for those with cancer, their families and whānau.

Stakeholders involved in this goal include: primary health organisations, non-governmental organisations (such as CanTeen, the Child Cancer Foundation and the Cancer Society of New Zealand), professional bodies (such as the Royal Australasian College of Surgeons, the Royal College of Pathologists of Australasia, the Royal New Zealand College of Obstetrics and Gynaecology and the Royal Australian and New Zealand College of Radiologists), advisory groups (such as the New Zealand Cancer Treatment Working Party, the Paediatric Oncology Steering Group and the New Zealand Guidelines Group) district health boards, regional cancer networks, the Ministry of Social Development and the Ministry of Health's clinical services and Māori health directorates.

Overall progress

This highly detailed goal specifies 31 milestones to be actioned during the first two years of the Action Plan. Only four of these milestones have been achieved. These are in the areas of optimal treatment for those with cancer, ensuring patient-centred care and improving the quality of care for adolescents. A further 18 milestones (58 percent) are in progress. Five milestones have been delayed, all within the area of providing optimal treatment and defining standards for diagnosis, treatment and care. These delayed milestones are mostly related to developing guidelines or accrediting services.

Achievements

- District health boards have set up case management approaches and multidisciplinary teams.
- Four DHB-led projects have studied cancer patient journeys, focusing on the patient's experiences, needs and frustrations. Recommendations from these projects are being incorporated into improved DHB planning and implementation.
- Regional adolescent oncology services have been developed and pilot programmes have been set up in three tertiary centres. Service specifications for these services are nearing completion.

Comments from the Cancer Control Council

Progress has been slow but steady in this goal, with more than 70 percent of milestones achieved or in progress. The Council specifically acknowledges the work of the New Zealand Cancer Treatment Working Party's adolescent oncology working group, CanTeen and the Child Cancer Foundation in establishing regional adolescent oncology services ahead of time – this is a Phase 2 milestone. The Council was unable to assess four milestones in the area of providing optimal treatment and defining standards for diagnosis, treatment and care. It will follow these up with the relevant stakeholders.

The Council plans to continue monitoring the development of standards and guidelines for access and referral and for diagnosis and treatment. The Council will also promote areas of effective diagnosis and treatment that will help to reduce inequalities for population groups with identified differences in health status.

Find out more: The Cancer Control Council's full report, *Mapping Progress: The First Two Years of the Cancer Control Strategy Action Plan 2005–2010*, is available at <http://www.cancercontrolcouncil.govt.nz>

GOAL 4:

Improve the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care

Introduction

Quality of life means the extent to which a medical condition or its treatment affects a person's usual or expected physical, emotional and social wellbeing. Supportive care and rehabilitation cover the essential services required to meet a person's needs throughout their experience of cancer. Palliative care is the total care of people who are dying from active, progressive diseases or other conditions when curative or disease-modifying treatment has come to an end.

Stakeholders critical to the success of this goal include: primary health organisations, non-governmental organisations (such as the Child Cancer Foundation, Hospice New Zealand, Hospital Palliative Care New Zealand, the Cancer Society of New Zealand and consumer groups), professional bodies (such as the Australia and New Zealand Society of Palliative Medicine), advisory committees (such as the Paediatric Oncology Steering Group and the New Zealand Cancer Treatment Working Party), district health boards, regional cancer networks and the Ministry of Health's clinical services and public health directorates.

Overall progress

This goal details 28 milestones to be actioned during the first two years of the Action Plan. Only four of these have been achieved. These are in the areas of support and rehabilitation for children and adolescents, and in access to high-quality information. A further 14 milestones (50 percent) are in progress. Ten milestones (36 percent) have been delayed, mainly because of the delay in setting up a supportive care expert advisory committee

Comments from the Cancer Control Council

Progress has been slow in this goal, with only 64 percent of the Phase 1 milestones achieved or in progress. However, the Council commends district health boards for consistently integrating the New Zealand Palliative Care Strategy into their strategic planning and cancer plans. The Council acknowledges specifically the Paediatric Oncology Steering Group's achievement in establishing the Late Effects Assessment Programme. However, the Council is concerned at the delay in setting up a supportive care expert advisory

Achievements

- The Late Effects Assessment Programme (LEAP) for young people has been set up. The programme, a Paediatric Oncology Steering Group initiative, reviews all young people who have completed treatment for childhood cancer. LEAP is a nationally co-ordinated programme funded by the Child Cancer Foundation, CanTeen and the Ministry of Health. It provides long-term follow-up and care for all children and young people up to the age of 20 or, for older adolescents and young adults, up to five years after the end of chemotherapy. The programme involves regular health follow-up as well as psychosocial assessment and, when needed, extensive neuro-cognitive assessment. A LEAP database captures long-term data and is linked to the New Zealand Child Cancer Registry.
- A stocktake of cancer information resources available in New Zealand has been published. It recommends a tool to use when reviewing or developing new resources and a set of principles to guide those producing and reviewing cancer information resources.

group, which has led to delays in seven other milestones. The Council is also aware of the delay in establishing a national body for palliative care, which has impacted on a range of actions under this goal.

The Council plans to monitor the establishment of the supportive care expert advisory committee and collaborate with it. It also plans to work with the cancer control community to ensure the diversity of populations needing palliative care is recognised when palliative care interventions are being planned and provided.

Find out more: The Cancer Control Council's full report, *Mapping Progress: The First Two Years of the Cancer Control Strategy Action Plan 2005–2010*, is available at <http://www.cancercontrolcouncil.govt.nz>

GOAL 5: Improve the delivery of services across the continuum of cancer control

Introduction

The focus of this goal is on improving the delivery of all cancer services throughout the country and across the continuum of cancer control. Some issues, such as developing the workforce and addressing health inequalities for Māori and Pacific peoples, are common to all areas. This means the cancer control community can work on them collectively and collaboratively. Conversely, some of the technical issues facing various types of services need to be dealt with at an individual service level.

A collective and co-ordinated approach is needed to create greater cohesion among the various agencies involved in cancer control and to ensure relatively scarce resources are used fairly, efficiently and effectively. Stakeholders responsible for this approach include: non-governmental organisations (such as the Cancer Society of New Zealand and consumer groups), primary health organisations, tertiary education providers, Crown agencies (such as the Tertiary Education Commission, the Clinical Training Agency, the Health Research Council and district health boards), professional bodies (such as the New Zealand Nurses Organisation, the Royal College of Pathologists of Australasia and the Australia and New Zealand Society of Palliative Medicine), regional cancer networks and the Ministry of Health.

Overall progress

This cross-cutting goal details 29 milestones to be actioned during the first two years of the Action Plan. Only one of these milestones has been achieved, with a further 15 (53 percent) in progress. Eleven milestones have been delayed. These relate to a national cancer workforce plan, increased training awards, and active involvement of consumer representatives.

Comments from the Cancer Control Council

This goal cuts across all other goals of the Cancer Control Strategy. It has specific objectives relating to workforce development, accessibility of programmes and services to Māori and consumer representation. Progress has been slow in this goal, with only 55 percent of the Phase 1 milestones

Achievements

- Specifications for palliative care specialist services have been developed.
- Funding has been established for new post-entry positions for palliative care doctors.
- A cancer and palliative care nursing work group has been set up within the New Zealand Cancer Treatment Working Party.
- District health boards have introduced case management and patient navigator approaches.
- Initiatives to create formal governance or relationships between Māori and district health boards have been developed.
- An agenda has been developed for Māori cancer research.

achieved or in progress. Workforce issues are a vexing matter across the health sector, particularly in cancer control. Many new initiatives in the Cancer Control Strategy relate to Māori, and vigilance is needed to ensure these initiatives lead to improved outcomes. Activity to enhance consumer representation is underway.

The Council plans to strengthen monitoring of actions specifically relating to accessibility of programmes and services to Māori, engage with relevant agencies to ensure progress is made in implementing a national cancer workforce strategy, and engage and lead the cancer control community in achieving the outcomes and objectives for consumer involvement and representation.

Find out more: The Cancer Control Council's full report, *Mapping Progress: The First Two Years of the Cancer Control Strategy Action Plan 2005–2010*, is available at <http://www.cancercontrolcouncil.govt.nz>

GOAL 6: Improve the effectiveness of cancer control in New Zealand through research and surveillance

Introduction

Cancer control research and surveillance seeks to identify and evaluate ways to reduce cancer morbidity and mortality and to improve the quality of life of people living with, recovering from or dying from cancer. Research directly related to cancer control in New Zealand is essential to improve the quality and cost-benefit ratio of cancer control services and activities.

Close collaboration between stakeholders is essential for the success of this goal. Stakeholders critical to its success include: the research community (organisations that fund or take part in research related to cancer control), public and private health providers, Crown agencies (such as the Health Research Council and district health boards), the New Zealand Health Information Service, the New Zealand Cancer Registry and the Ministry of Health.

Overall progress

This focused goal details nine milestones to be actioned during the first two years of the Action Plan. One milestone has been achieved, relating to a forum of cancer research funders. A further six milestones (67 percent) are in progress. No milestones in this goal have been delayed, but the Council was unable to assess two milestones because insufficient information was available.

Comments from the Cancer Control Council

Considerable progress has been made in this goal, with 78 percent of the Phase 1 milestones achieved or in progress. A stocktake of cancer research in New Zealand has been undertaken and the Council is now engaging with research funders to develop a rolling plan for cancer research.

Achievements

- A forum for cancer research funders has been held, providing opportunities for networking and discussion of next steps for developing a strategic and regular process for facilitating research relevant to cancer control.
- The Cancer Control Council has published *Developing a Strategic Plan for Cancer Control Research in New Zealand*. This report describes the findings of a stocktake of cancer control research, development and evaluation projects in New Zealand and summarises the forum held for agencies that fund cancer control research.
- The Ministry of Health and the Health Research Council have developed a joint venture in the primary prevention of cancer and other chronic diseases.

Improvements to the New Zealand Cancer Registry and development of a National Cancer Management Dataview are both critical to the long-term success of the Cancer Control Strategy.

The Council plans to liaise with the cancer control community on developing a strategic approach for cancer control research and monitor the development and maintenance of Māori research capacity.

Find out more: The Cancer Control Council's full report, *Mapping Progress: The First Two Years of the Cancer Control Strategy Action Plan 2005–2010*, is available at <http://www.cancercontrolcouncil.govt.nz>

Results of the two evaluations of the Cancer Control Strategy Action Plan 2005–2010

Regional cancer networks review

Regional cancer networks are being established in New Zealand to ensure services are co-ordinated across the cancer control continuum. Similar networks have been set up in the United Kingdom and Australia.

As part of the evaluation and monitoring report, the Council commissioned the first stage of an independent review to evaluate progress with implementing regional cancer networks. The objective was to identify key areas for continuing network development that would develop a way of working across the cancer control continuum to achieve the goals of reducing inequalities with respect to cancer and reducing the incidence and impact of cancer.

The four networks are in the early stages of development, with each having started at a considerably different point. They are complex structures that need to work across traditional organisational boundaries with district health boards and also to engage the wider cancer control community. The district health boards have successfully formed themselves into four regional networks that now face the challenge of working with all the relevant groups and organisations that are involved throughout the cancer control continuum within each region.

All networks appear to be adopting broadly the same model but with some key differences in makeup and focus. As they develop, particularly if they work closely together at a national level, it is expected that they will evolve into very similar entities while appropriately reflecting their regional uniqueness.

Indications are that the networks understand the need to actively involve consumers and NGOs. However, there appear to be varying interpretations of the Action Plan's requirement that the wider cancer control community be an integral part of network planning and decision-making.

Some networks have advanced further than others towards sharing network governance with the wider community. Each network acknowledges the concept of partnership but, as most have yet to fully establish their processes, it is too early to determine how extensive this engagement will be. If the intentions of the Strategy and the Action Plan are to be realised, all networks will need to ensure there is real and effective partnership with the wider cancer control community.

The review uncovered a lack of clarity within the cancer control community about the respective roles and responsibilities of the Ministry of Health and the Cancer Control Council, and its Secretariat, in implementing the Cancer Control Strategy and Action Plan. The respective roles and working relationships among the Council, the Ministry and the regional cancer networks need to be fully scoped and

agreed. Clear definitions of roles and accountabilities are needed to ensure good communication and co-ordination. A documented national framework, collectively owned by regional networks, the Ministry and the Council, would support this development.

Establishing a national collective of regional networks would also enable networks to formally work with the Council and the Ministry to share experiences as the networks develop, learn from one another and take collective responsibility for implementing the Cancer Control Strategy.

The successful development of networks requires continued effort and commitment to building relationships and refining processes. The networks need time to evolve. If they are pushed to implement too quickly, beyond the capacity of available resources, there is a risk of failure. Conversely, if implementation does not continue at an acceptable pace, the current momentum will be lost and successful implementation of key components of the Cancer Control Strategy will be put at risk. A long-term commitment by the Council, the Ministry and the networks, with a focus on innovation and improvement, is needed for long-term sustainability.

2007/08 New Zealand Adult Cancer Care Experiences Survey (ACCESS)

The 2007/08 New Zealand Adult Cancer Care Experiences Survey (ACCESS) is underway. This project aims to measure cancer care by examining various dimensions of the cancer care journey from the patient's perspective. A postal questionnaire of at least 2,000 cancer patients is proposed. The first data set will be a benchmark for national population-based patient-centred results. Public Health Intelligence (PHI) has been commissioned to manage this project on behalf of the Cancer Control Council.

PHI aims to complete the final report for this project by July 2009. The Cancer Control Council is working towards a multifaceted cancer care experiences collection system. This system will include this initial ACCESS survey and follow-up surveys to help identify how well government priorities identified in the Cancer Control Strategy and Action Plan are being achieved over the next five to ten years.

This research project has a number of goals.

- Actively involve consumers in monitoring and evaluating the implementation and progress of the Cancer Control Strategy.
- Provide a stimulus for quality improvement in the cancer control community.
- Develop a stronger evidence base for the Cancer Control Council's independent strategic advice to the Minister of Health and wider cancer control community.

Next steps for the Cancer Control Council

The table below synthesises the next steps that the Cancer Control Council believes emerge from this report. We encourage comment and feedback from the cancer control

community on these. The Council plans to implement those steps marked with an asterisk (*) in the 2007/08 fiscal year.

Council role	All goals	Goal 1 Primary prevention of cancer	Goal 2 Effective screening and early detection	Goal 3 Effective diagnosis and treatment	Goal 4 Improve the quality of life for those with cancer	Goal 5 Improve the delivery of cancer control services	Goal 6 Cancer control research and surveillance
Evaluation, monitoring and review	<ul style="list-style-type: none"> Continue to map progress towards achieving the Phase 1 milestones of the Cancer Control Strategy Action Plan 2005–2010.* Lead the mapping of progress against Phase 2 of the Action Plan, following possible rationalisation and further prioritisation of actions and milestones.* Lead the overall review of the Action Plan.* Continue to evaluate specific projects under the Action Plan, for example the regional cancer networks.* 	<ul style="list-style-type: none"> Monitor the progress of DHBs in developing a district tobacco control plan.* Monitor the extent to which DHBs, primary health organisations and other services record smoking status of their patients. 	<ul style="list-style-type: none"> Continue to monitor progress in the rates of coverage of BreastScreen Aotearoa, with particular reference to rates for Māori and Pacific women. Monitor implementation of the recommendations of the Early Detection Advisory Group on melanoma. 	<ul style="list-style-type: none"> Monitor the development and implementation of standards and guidelines for access and referral and for diagnosis and treatment. Consider whether the activities currently underway are on target to achieve the specified outcomes/results. Monitor the current strategies in place to address outstanding workforce issues, which may impact significantly on achieving this goal. 	<ul style="list-style-type: none"> Monitor and support the establishment of a national supportive care committee and consequent Action Plan Outcomes 60–65. Evaluate ongoing measures to establish national standards for developing and disseminating consumer information.* 	<ul style="list-style-type: none"> Continue and strengthen monitoring of the outcomes and specific actions for Objective 2 relating to accessibility of programmes and services to Māori.* 	<ul style="list-style-type: none"> Continue to monitor the development and maintenance of Māori research capacity.* Continue to monitor the development of the National Cancer Management Dataview.
Independent strategic advice	<ul style="list-style-type: none"> Scope and develop cancer-specific advice about the implementation of new technologies such as medications and interventions in cancer control.* 	<ul style="list-style-type: none"> Support the Minister of Health and Director-General of Health on the Ministry of Health's prioritisation of tobacco control.* Provide strategic independent advice on the desirability of an ongoing tobacco taxation policy.* 	<ul style="list-style-type: none"> Provide advice to the Minister of Health on strategies for early detection and diagnosis of cancers. 	<ul style="list-style-type: none"> Provide advice to the Minister of Health on issues regarding support, rehabilitation and palliative care, as they arise. 			<ul style="list-style-type: none"> Provide advice to the Minister of Health on the development of a strategic approach for cancer control research in New Zealand.*

Council role	All goals	Goal 1 Primary prevention of cancer	Goal 2 Effective screening and early detection	Goal 3 Effective diagnosis and treatment	Goal 4 Improve the quality of life for those with cancer	Goal 5 Improve the delivery of cancer control services	Goal 6 Cancer control research and surveillance
Co-operation and collaboration within the sector	<ul style="list-style-type: none"> Actively work with, and support, the regional cancer networks in becoming an important driver in delivery of the Strategy.* 	<ul style="list-style-type: none"> Foster co-operation and collaboration with DHBs and primary health organisations to increase their activity on developing tobacco control plans and to place a higher priority on health services as an opportunity to offer advice and support to smokers to quit.* Assess the effectiveness of collaborative models for tobacco control. Support discussions on more structural changes to the supply of tobacco in New Zealand.* 	<ul style="list-style-type: none"> Work with the cancer control community to ensure Phase 1 milestones for early detection of cancer are completed.* Engage with Māori and Pacific provider organisations on the process of evaluating milestones for increased coverage. Work with the cancer control community and National Screening Unit to further the goals of reducing breast cancer for Māori and Pacific peoples. Work with the National Screening Unit and the Ministry of Health to develop a feasibility study for colorectal cancer screening. 	<ul style="list-style-type: none"> Actively promote areas of effective diagnosis and treatment that will help to reduce inequalities for population groups with identified differences in health status.* 	<ul style="list-style-type: none"> Work with the cancer control community to ensure the diversity of populations in need of palliative care is recognised when planning and providing palliative care interventions.* Collaborate with and support the newly formed supportive care advisory group. 	<ul style="list-style-type: none"> Engage with relevant agencies to ensure progress is made in implementing a national cancer workforce strategy.* Engage and lead the cancer control community in achieving the outcomes and objectives for consumer involvement and representation.* 	<ul style="list-style-type: none"> Lead the research community in taking a strategic approach to cancer control research in New Zealand.*
Fostering and supporting best practice in cancer control		<ul style="list-style-type: none"> Monitor compliance with best practice in tobacco control. Profile the need for increased awareness of the association between alcohol consumption and the risks of certain cancers. 	<ul style="list-style-type: none"> Continue to support best practice by promoting guidelines and supporting their dissemination.* Communicate with the cancer control community about identified delays in diagnosis, as a basis for developing strategies for reducing delays. 	<ul style="list-style-type: none"> Regularly communicate with the cancer control community on the implementation and use of nationally consistent guidelines.* 			<ul style="list-style-type: none"> Liase with the cancer control community in developing a strategic approach to cancer control research in New Zealand.*
Linkages with overseas cancer control agencies		<ul style="list-style-type: none"> Ensure representation of the Cancer Control Council at tobacco conferences in New Zealand and Australia and maintain links with key international tobacco agencies.* 	<ul style="list-style-type: none"> Communicate with international cancer control agencies so that international knowledge of current advice regarding the benefits of screening and early detection is considered in the New Zealand context.* 	<ul style="list-style-type: none"> Showcase New Zealand's successful development of regional adolescent oncology services to relevant Australasian and international cancer control agencies. 	<ul style="list-style-type: none"> Communicate with international agencies regarding models for national oversight of supportive care and rehabilitation. 		<ul style="list-style-type: none"> Continue to maintain linkages with cancer control research and surveillance agencies in relevant overseas countries.*

Recommendations

The Cancer Control Council encourages and expects the cancer control community to continue to work together towards the goals of the Cancer Control Strategy. The Strategy and the Action Plan, district health board cancer plans, emerging regional cancer network programmes of work and many other activities demonstrate the explicit and implicit priorities of the cancer control community.

Following the inaugural evaluation and monitoring report, there are a few areas that the Council expressly wants to reinforce or recommend. We envisage that as the Council's dialogue with the community increases, future reports will include more extensive annual recommendations, including to stakeholders other than the Ministry of Health.

	All goals	Goal 1 Primary prevention of cancer	Goal 2 Effective screening and early detection	Goal 3 Effective diagnosis and treatment	Goal 4 Improve the quality of life for those with cancer	Goal 5 Improve the delivery of cancer control services	Goal 6 Cancer control research and surveillance
Ministry of Health	<ul style="list-style-type: none"> Continue to monitor progress made on the overarching purposes of the Cancer Control Strategy Action Plan 2005–2010: <ul style="list-style-type: none"> – reduce the incidence and impact of cancer – reduce inequalities with respect to cancer. 	<ul style="list-style-type: none"> Continue to develop policy, contract services and evaluate their effectiveness in tobacco control, healthy eating and activity. 	Objective 2 <ul style="list-style-type: none"> Focus resources during 2007/08 on ensuring the implementation of the actions and milestones for Outcomes 41 and 42 of the Action Plan, relating to early detection of cancer. 	Objectives 1 and 2 <ul style="list-style-type: none"> Develop methods for monitoring DHB progress on the establishment of multidisciplinary teams that support a continuum of care approach, including involvement of Māori and Pacific expertise in these teams. Objective 3 <ul style="list-style-type: none"> Continue to guide and support DHBs to establish cancer care-related navigator co-ordinator positions. Objective 4 <ul style="list-style-type: none"> Make further dedicated funding available to enhance and extend the Late Effects Assessment Programme (LEAP). 		Objective 1 <ul style="list-style-type: none"> Continue to consider workforce issues in the stocktake and needs assessment of the cancer control workforce. Objective 2 <ul style="list-style-type: none"> Undertake further work to ensure governance models to address Māori cancer-related inequalities are consistently implemented at regional and district levels. 	

