

The New Zealand Cancer Control Strategy

Cover:

Hutia te rito o te harakeke,
Kei hea te kōmako e kō kī mai ki ahau?
He aha te mea nui o te ao?
Māku e kī atu, he tāngata, he tāngata, he tāngata.

If you remove the heart of the flax bush,
From where will the bellbird sing to me?
What is the most important thing in this world?
I say to you, it is people, people, people.

Cover photo:

Flax (*Phormium* sp.) flowers heads
at Cape Turakirae; Wellington. © Rob Suisted

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Foreword

Cancer is a leading cause of death in New Zealand (29 percent) and the number of people developing and dying from cancer is predicted to continue to increase steadily both in New Zealand and worldwide. We know that at least one-third of cancer can be prevented and early detection and effective treatment of a further third is also possible. Our ability to achieve what we know is possible depends to a great extent on our taking a more planned approach involving all activities and services related to cancer.



The World Health Organization advocates the development of national cancer control programmes as the best means of reducing the incidence and impact of cancer and improving the quality of life of those with cancer within available resources. This involves a comprehensive, planned approach that will identify and implement priorities for action from cancer prevention activities through treatment, rehabilitation and palliative care to research.

Reducing the incidence and impact of cancer is one of the Government's 13 population health objectives identified in the New Zealand Health Strategy. Growing concern about cancer is also reflected in the public domain by the activities of the many cancer-related organisations. Commitment of the non-government sector to this objective is reflected in the formation of the New Zealand Cancer Control Trust (funded by the Cancer Society of New Zealand and the Child Cancer Foundation) to facilitate and work in partnership with the Ministry of Health in developing this Strategy.

Cancer touches us all at some point in our lives, if not directly as a patient, then as the relative, friend or workmate of someone who develops cancer. The development of this Strategy reflects a shared commitment to reducing the incidence of cancer and improving the quality of life of those who develop cancer.

I would like to thank the many individuals who contributed to this Strategy, either by participating in working groups, providing comment and peer review or by participating in consultation through meetings, hui, fono and individual submission.

The next step is the implementation plan to turn this strategy into a reality. I look forward to working with you all.

A handwritten signature in black ink that reads "Annette King". The signature is written in a cursive, flowing style.

Hon Annette King
Minister of Health

Acknowledgements

The development of this strategy has involved valued input from a wide range of individuals, groups and organisations. The advice and assistance from the following are particularly acknowledged:

- the Cancer Control Steering Group (for membership see Appendix 1)
- the Expert Working Groups (for membership see Appendix 3)
- the Australian National Cancer Control Initiative
- the Canadian Strategy for Cancer Control
- Professor Mike Richards, National Cancer Director for England
- Professor Roy West, National Cancer Institute of Canada
- Dr Neil Berman, Health Canada
- Cancer Control Secretariat (for membership see Appendix 2).

Contents

Foreword	III
Acknowledgements	IV
The Strategy in Summary	1
Overall purposes of the New Zealand Cancer Control Strategy	1
The principles of the New Zealand Cancer Control Strategy	1
The goals of the New Zealand Cancer Control Strategy	1
Introduction	3
Overview	3
What is cancer?	4
What is cancer control?	5
Why do we need a cancer control strategy?	5
Māori and the New Zealand Cancer Control Strategy	7
Strategy development process	8
The strategy in context	9
Implementation of the strategy	9
The Burden of Cancer in New Zealand	11
Cancer incidence, mortality rates and trends in New Zealand	11
Inequalities and health	12
The Cancer Control Continuum	15
Prevention	15
Early detection and cancer screening	15
Diagnosis and treatment	16
Support and rehabilitation	16
Palliative care	17
Cancer control continuum and Māori	17
Cancer control surveillance	18
Cancer control research	18
The High-level Framework to Guide Existing and Future Actions	19
Overall purposes of the strategy	19
The principles of the New Zealand Cancer Control Strategy	19
The goals of the New Zealand Cancer Control Strategy	21

Objectives to Meet the Goals	23
Goal 1: Reduce the incidence of cancer through primary prevention	24
Goal 2: Ensure effective screening and early detection to reduce cancer incidence and mortality	30
Goal 3: Ensure effective diagnosis and treatment of cancer to reduce morbidity and mortality	34
Goal 4: Improve the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care	39
Goal 5: Improve the delivery of services across the continuum of cancer control through effective planning, co-ordination and integration of resources and activity, monitoring and evaluation	47
Goal 6: Improve the effectiveness of cancer control in New Zealand through research and surveillance	52
Appendix 1: The New Zealand Cancer Control Steering Group Membership	56
Appendix 2: The New Zealand Cancer Control Strategy Secretariat Members	57
Appendix 3: Expert Working Group Members	58
Appendix 4: The Strategy in Context	59
Appendix 5: WHO Definitions of Palliative Care	60
Appendix 6: Intervention Framework to Improve Health and Reduce Inequalities	61
Appendix 7: Health Equity Assessment Tool	62
Appendix 8: Consultation	63
Glossary	67
References	72

The Strategy in Summary

The New Zealand Cancer Control Strategy is the first phase in the development and implementation of a comprehensive and co-ordinated programme to control cancer in New Zealand. The strategy includes purposes, principles and goals to guide existing and future actions to control cancer. It also includes objectives and broad areas for action. The next phase will involve identifying priorities for action, planning implementation, and defining processes to manage, monitor and review implementation.

Overall purposes of the New Zealand Cancer Control Strategy

The overall purposes of the New Zealand Cancer Control Strategy are to:

- reduce the incidence and impact of cancer
- reduce inequalities with respect to cancer.

The principles of the New Zealand Cancer Control Strategy

All activities undertaken to meet these purposes should:

- work within the framework of the Treaty of Waitangi to address issues for Māori
- reduce health inequalities among different population groups
- ensure timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay
- be of high quality
- be sustainable
- use an evidence-based approach
- reflect a person-centred approach
- actively involve consumers and communities
- recognise and respect cultural diversity
- be undertaken within the context of a planned, co-ordinated and integrated approach.

The goals of the New Zealand Cancer Control Strategy

The goals of the New Zealand Cancer Control Strategy are to:

- 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 to reduce cancer 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 through effective planning, co-ordination and integration of resources and activity, monitoring and evaluation
- 6 improve the effectiveness of cancer control in New Zealand through research and surveillance.

Introduction

Overview

Cancer affects most of us at some point in our lives. We may be diagnosed with cancer ourselves or have relatives, friends or neighbours with the disease. More so than many other diseases, cancer conjures up deep fear and anxiety in most people in New Zealand. Many are unaware how much can be done to reduce the risk of developing cancer and to successfully treat and care for those who develop the disease.

At present we have enough knowledge to prevent at least one-third of cancers. Depending on the availability of resources, early detection and effective treatment of a further third of cancers are also possible. And when cancer cannot be cured, or held in remission, prevention and relief of suffering can greatly improve the quality of life of people with cancer and their families and whānau.

The whole field of cancer is complex, and achieving what is possible poses significant challenges. Cancer includes over a hundred diseases with different causes and treatment methods. It can arise in any organ and at any age. Also, there is a wide range of organisations and health professionals, both government and non-government, involved in the many aspects of cancer prevention, detection, diagnosis, treatment and care.

Along with many other countries, New Zealand has an increasing number of people who are developing cancer, mainly because of population growth and ageing. At present about 16,000 people develop cancer each year; recent forecasts suggest that by 2011 this number will increase to 22,000. This will cause increasing strain on already stretched health resources.

Cancer is now a leading cause of death in New Zealand, accounting for 29 percent of deaths from all causes. About 7500 people die from cancer each year, with the number expected to increase to about 9000 by 2012. Research has shown that between 1963 and 1993 our cancer death rate increased at a faster rate, and is now higher, than that of comparable countries such as Australia, Canada, the United States and Britain (Gavin et al 2001).

The *New Zealand Health Strategy* (Minister of Health 2000) includes *reducing the incidence and impact of cancer* as one of the population health goals chosen for implementation in the short to medium term. Along with Australia, Norway, Canada, Britain and most European countries, we have accepted the conclusion of the World Health Organization (WHO) that development and implementation of a national cancer control strategy is the most effective way of reducing the incidence and impact of cancer.

The New Zealand Cancer Control Strategy is the first phase in the development and implementation of a comprehensive cancer control programme for New Zealand. The strategy includes purposes, principles and goals to guide existing and future actions to control cancer. It also includes objectives and broad areas for action that should be subject to ongoing monitoring and periodic review. Systematic review of objectives and actions will ensure that the strategy is achieving the desired effect, and also will allow new objectives to be added or substituted as researchers identify more effective ways of reducing the incidence and impact of cancer.

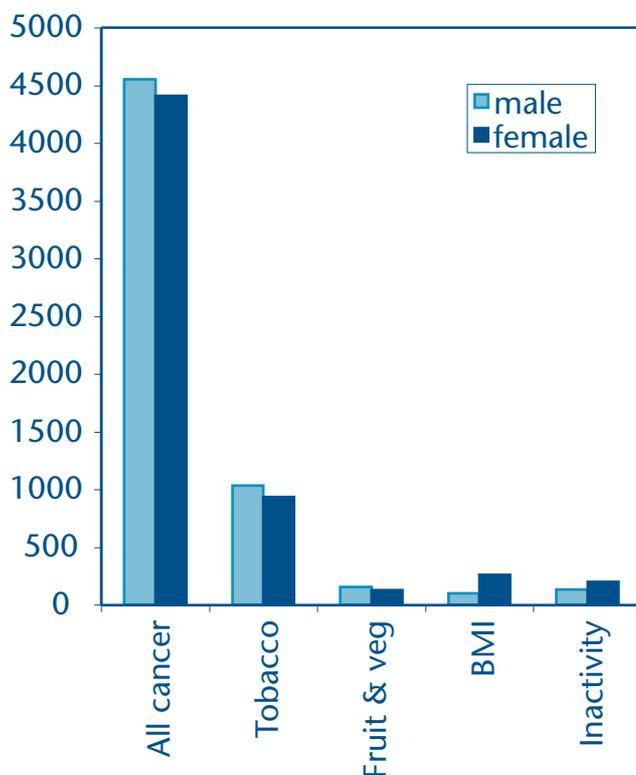
What is cancer?

'Cancer' is a generic term used to describe a group of over a hundred diseases that occur when malignant forms of abnormal cell growth develop in one or more body organs. These cancer cells continue to divide and grow to produce tumours. Cancer cells can invade adjacent structures and spread via the lymph or blood to distant organs. Some of the biological mechanisms that change a normal cell into a cancer cell are known; others are not. Cancer differs from most other diseases in that it can develop at any stage in life and in any body organ.

No two cancers behave exactly alike. Some may follow an aggressive course, with the cancer growing rapidly. Other types grow slowly or may remain dormant for years. Very high cure rates can be achieved for some types of cancers, but for others the cure rates are disappointingly low and await improved methods of detection and treatment. The wide range of cancer treatments and associated services reflects the biological diversity of cancer.

It is estimated that about 80 percent of cancers are due to environment or lifestyle, and therefore are potentially preventable (Doll and Peto 1981). The risk factors for some cancers have been clearly identified, but for others further research is needed. Based on current evidence, at least 30 percent of future cancer cases are preventable by comprehensive and carefully considered action, taken now (WHO 1995).

Figure 1: Numbers of cancer deaths attributable to selected risk factors, projected to 2012



What is cancer control?

Cancer control is an organised approach to reducing the burden of cancer in our community. It recognises that the disease cannot be completely eradicated in the foreseeable future, but that its effects can be reduced. The aims of cancer control are to reduce the number of people who develop cancer and the number who die from cancer, and to ensure a better quality of life for those who do develop the disease.

The control of cancer requires a planned, systematic and co-ordinated approach. It also requires resources, which are always likely to be limited. With careful planning and appropriate priorities, the New Zealand Cancer Control Strategy offers the most rational means of achieving the maximum degree of cancer control, even when resources are constrained.

The areas to be covered by a cancer control strategy encompass all aspects of cancer: prevention, screening (where appropriate), early detection, diagnosis, treatment, rehabilitation and support, and palliative care. It also means addressing problems associated with equity of access to services, workforce development and the need for relevant research, monitoring and evaluation of services, and data collection and analysis. Thus, a wide range of government and non-government organisations will need to make a real and enthusiastic commitment to make the strategy effective.

Why do we need a cancer control strategy?

Although the standard of cancer services in New Zealand is high by international standards, the largely piecemeal way they have developed has led to gaps in and fragmentation of service provision and delivery. A lack of foresight in co-ordinated workforce development over the last decade has resulted in serious gaps and shortages, exacerbated by limited specialist training in some areas. This situation, coupled with limited resources, has resulted in unacceptable waiting times for some people requiring treatment for their cancers. It has also resulted in inequitable access to services for socially disadvantaged and geographically isolated groups, who are unable to afford the travel and related costs involved in travelling to cancer treatment centres.

Gaps also exist in health promotion activities directed at reducing the number of people who develop the disease. Although many initiatives reflect the close collaboration of agencies and community groups (eg, in some tobacco control-related activities), more effort and resources are needed to improve overall co-ordination and integration.

In summary, New Zealand requires a cancer control strategy because:

- increasing numbers of people in New Zealand are developing cancer and dying from cancer
- our cancer death rate has increased at a faster rate, and is now higher, than that of comparable countries
- people in New Zealand expect that, irrespective of where they live, there will be reasonable access to high-quality care

- cancer control is unique in its complexity, involving a range of diseases and a diversity of service providers – it cannot be achieved by any single organisation or by government alone
- effective and efficient use of limited resources is crucial
- establishing an alliance of organisations and health professionals, both government and non-government, is critical if action is to be cost-effective
- it is important to act now, before the full impact of the ageing population is felt by the health care system.

The general aim of the strategy is to provide an overarching framework to guide existing and future activities with a view to:

- reducing the overall incidence and impact of cancer on the New Zealand population
- reducing health inequalities relating to cancer
- strengthening health promotion so that as many of the population as possible enjoy cancer-free lives
- ensuring timely diagnosis for those with cancer and timely access to high-quality care throughout their experience of cancer
- assisting those with cancer, their families and whānau to fully participate in all decision-making related to their treatment and care
- reducing barriers to cancer services for those who experience them, such as Māori, Pacific peoples and the socially disadvantaged
- ensuring careful planning and appropriate priorities, by making the best use of existing resources and identifying where additional resources are needed
- ensuring the effectiveness of cancer control in this country through New Zealand-based research
- furthering the development of the cancer control workforce and increasing specialist training opportunities
- regularly monitoring cancer control activities to ensure they are effective and remain effective.

Who is the strategy for?

The New Zealand Cancer Control Strategy is for all those living in New Zealand, but it will have particular relevance to government and non-government agencies whose work impacts on the delivery of services across the spectrum of cancer control, the wide range of individuals involved in the management and delivery of services across the spectrum of cancer control, and those with cancer and their family and whānau.

By promoting an integrated approach to the control of cancer in New Zealand, the strategy will encourage and assist government and non-government service providers to work more closely together and enable all providers to have a common understanding of where they fit in the overall spectrum of cancer control.

Māori and the New Zealand Cancer Control Strategy

This strategy has been designed to be consistent with Māori needs and expectations, and to enable the dual goals of Māori development and improving Māori health. This requires:

- acknowledging the Treaty of Waitangi
- action to reduce inequalities
- the explicit use of Māori concepts of hauora, whānau, and whānau ora.

The Treaty of Waitangi and cancer control

The Treaty of Waitangi is New Zealand's founding document and is fundamental to the relationship between Māori and the Crown. The Treaty underpins the New Zealand Cancer Control Strategy and informs all activity across the cancer control continuum to address the diverse needs of Māori. The Treaty relationship is based on the following three principles:

- *partnership* – working with iwi, hapū, whānau and Māori communities to develop strategies for Māori health gain and appropriate health and disability services
- *participation* – involving Māori at all levels of the sector in the planning, development and delivery of health and disability services
- *protection* – ensuring Māori enjoy at least the same level of health as non-Māori and safeguarding Māori cultural concepts, values and principles (Minister of Health and Associate Minister of Health 2002a).

The above principles have guided the development of the New Zealand Cancer Control Strategy and must be an integral component of implementation of the strategy.

Reducing inequalities

Māori are disproportionately affected by the cancer burden compared to non-Māori. Achieving equitable outcomes for Māori across the spectrum of cancer control is an explicit goal for this strategy.

Although Māori have an important role in implementing a cancer control strategy for Māori, responsibility for improving the quality of service delivery to Māori does not just lie with Māori service providers. Mainstream service providers must also make serious efforts to improve the acceptability and accessibility of health services and their responsiveness to the needs of Māori and their whānau in order to contribute to a reduction in the incidence and impact of cancer for Māori. In addition, support for the continuing development of Māori providers is necessary.

Hauora, whānau and whānau ora

The Māori concept of hauora is central to the lives of many Māori, and this strategy acknowledges that cancer control activities in New Zealand need to be consistent with this broad, holistic view of health.

Māori in the context of their whānau can be expected to contribute to, and benefit from, this strategy. To achieve this, cancer control for Māori must be consistent with the stated priority of whānau ora as described in the *He Korowai Oranga: Māori Health Strategy* and *Whakatātaka: Māori health action plan 2002–2005* (Minister of Health and Associate Minister of Health 2002a, 2002b).

Strategy development process

Preliminary planning phase

Work on a strategy to control cancer has been gathering momentum for a number of years. In 1999 a wide range of groups met in Wellington to address concerns that the death rate in New Zealand from cancer had been increasing at a faster rate than in comparable countries. The meeting called for a cancer control strategy to be developed by government and non-government agencies working together. The New Zealand Cancer Control Trust was established in February 2001 (with funding from the Cancer Society of New Zealand and the Child Cancer Foundation) as a mechanism by which the non-government sector could facilitate the development of a cancer control strategy.

The New Zealand Cancer Control Trust subsequently prepared two background reports for the Ministry of Health to inform the development of the strategy. *Progress Towards a New Zealand Cancer Control Strategy* (Gavin et al 2001) reviewed trends in cancer incidence and efforts to develop national cancer control strategies both here and overseas. *The Development of a National Cancer Control Strategy for New Zealand* (Gavin et al 2001) was a plan for developing a cancer control strategy for New Zealand. Both documents are available on the New Zealand Cancer Control Trust website (www.cancercontrol.org.nz).

Formation of the Cancer Control Steering Group

Following a commitment from the Minister of Health, the Cancer Control Steering Group, with expertise in the various aspects of cancer control, was formed in October 2001 to oversee development of the strategy. The Ministry of Health and the Trust (the Cancer Society and the Child Cancer Foundation) have funded the development of the strategy.

Five expert working groups were established to advise the Steering Group and to recommend priorities for the strategy. Their reports are available on the Ministry of Health website (www.moh.govt.nz) and the New Zealand Cancer Control Trust website (www.cancercontrol.org.nz). People involved in developing cancer control strategies in Australia, England, Canada and Norway were also particularly helpful.

Consultation on the discussion document

On 5 December 2002 Health Minister Annette King released for consultation the discussion document *Towards a Cancer Control Strategy for New Zealand: Marihi Tauporo* (Cancer Control Steering Group 2002). Consultation on the document, which took place between 5 December 2002 and 14 March 2003, included public forums, along with written submissions from individuals and key stakeholders with an interest and involvement in the control of cancer. Its

aim was to seek informed comment, highlight any gaps and identify which organisations should be actively involved in implementing the strategy. The analysis of consultation feedback, available on the Ministry of Health website, has informed the final development of the New Zealand Cancer Control Strategy.

The strategy in context

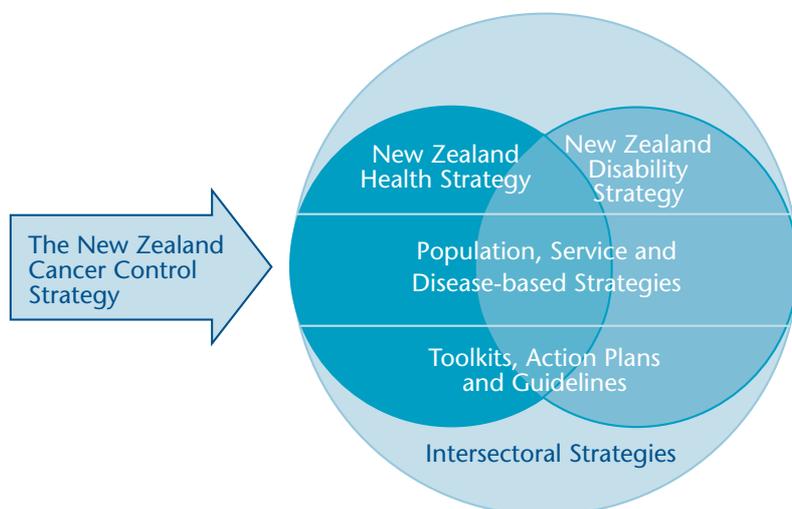
The New Zealand Cancer Control Strategy derives its mandate directly from the overarching *New Zealand Health Strategy* (Minister of Health 2000), one of the population health objectives of which is to reduce the incidence and impact of cancer.

The development of the New Zealand Cancer Control Strategy builds on considerable work already undertaken by a number of agencies, committees and working parties. The reports they have produced are summarised in *Stocktake of Strategies and Other Key Policy Documents for Cancer Control in New Zealand* (Ministry of Health 2002e) and in *Progress Towards a New Zealand Cancer Control Strategy* (Gavin et al 2001).

A number of toolkits were developed to assist the District Health Boards in implementing the population health objectives of the *New Zealand Health Strategy* (Minister of Health 2000). The aim of the *DHB Toolkit: Cancer control* (Ministry of Health 2001b) is to identify essential services and activities and identify areas where intervention can be improved. The toolkit will be amended to reflect the recommendations and approaches of the New Zealand Cancer Control Strategy.

Improving Non-Surgical Cancer Treatment Services in New Zealand (Ministry of Health 2001c) anticipates the development of a New Zealand Cancer Control Strategy. The New Zealand Cancer Treatment Working Party and the Paediatric Oncology Steering Group are currently active, and the Ministry of Health has announced its intention to review surgical cancer services with the Royal Australasian College of Surgeons. The New Zealand Cancer Control Strategy also builds on the New Zealand Palliative Care Strategy which was released in 2001 and is currently being implemented.

Figure 2: The New Zealand Cancer Control Strategy in relation to the New Zealand Health Strategy and related policies



Source: Health and Independence Report 2002. Ministry of Health

The key health and disability strategies linked with the New Zealand Cancer Control Strategy are listed in Appendix 4.

Implementation of the strategy

The New Zealand Cancer Control Strategy includes 25 objectives to support the six goals, along with broad areas for action to achieve the objectives. The next phase will include the development of an implementation plan that identifies evidence-based priorities for action, who is responsible for action in the government and non-government sectors, what can be undertaken with existing resources, and where additional resources will be needed. Stakeholder input will be an integral part of this process. Implementation planning will also involve defining the processes to manage, monitor and review the implementation process.

The Burden of Cancer in New Zealand

Cancer incidence, mortality rates and trends in New Zealand

As documented in *Cancer in New Zealand: Trends and projections* (Ministry of Health 2002a), the age-standardised incidence rate of all adult cancer increased steeply from the mid-1950s to the early 1980s and has increased more slowly since then. It is expected that this trend will continue for both genders over at least the next 15 years. By contrast, the age-standardised death rate of all adult cancer remained essentially stable throughout the 1970s and began to decrease in the 1980s and 1990s. It is expected that this trend will continue due to improved survival for some cancers, earlier diagnosis of others, and reduction in incidence of others through prevention.

The cancer burden reflects not only trends in risk but also the impact of demographic factors. As the population has grown, so the number of adult cancer registrations or deaths has increased steadily over the past three decades, and this increase in burden is projected to continue for the next 15 years. The ageing of the population – reflected in longer life expectancy – will also have an increasing effect.

In 1998 cancer was a leading cause of death for New Zealanders, accounting for 29 percent of all deaths (NZHIS 2002). The most common causes of cancer deaths in females were breast, bowel and lung cancers. For males the most common causes of cancer deaths were lung cancer, bowel cancer and prostate cancer.

The death rates of some types of cancers are high in this country by international standards. Compared with other OECD¹ countries, New Zealand has the highest death rate for large bowel cancer, the fifth highest rates for cancers of the prostate and cervix, and the sixth highest for female breast cancer (NZHIS 2001). Incidence and mortality rates for melanoma in New Zealand are among the highest in the world, with New Zealand having the highest death rate among OECD countries (IARC 2001).

Although in 1998 the overall rates of cancer registrations for Māori and non-Māori were similar, mortality from cancer was 51 percent higher for Māori males and 78 percent higher for Māori females than for non-Māori. In part this is due to a greater incidence in Māori of cancers with poorer survival, such as lung cancer, which was the leading cause of cancer death for Māori in 1998 (NZHIS 2002). Māori have markedly higher registration rates than non-Māori for cancers of the liver, stomach, lung, cervix uteri and testis.

For Pacific men, incidence was highest for cancers of the lung, prostate, stomach, and colon and rectum. For Pacific women, incidence was highest for cancers of the breast, colon and rectum, cervix, lung, ovary and corpus uteri (Gavin et al 2001).

¹ Organization for Economic Cooperation and Development (see Glossary for a list of OECD countries).

Although children with cancer represent only 1 percent of the overall incidence of the disease, the successful treatment of cancers occurring in young people results in considerable saving of years of life. Cancer incidence in the 0–14 years age group in New Zealand is comparable with other OECD countries. Seventy percent of childhood cancers are cured, but one-half of the survivors have long-term sequelae. Adolescents with cancer have poorer survival than children with cancer.

Inequalities and health

One of the Government's key goals, which guide public sector policy and performance, is to reduce inequalities in education, employment, housing and health for all disadvantaged groups. Reducing inequalities in health is also a goal of the *New Zealand Health Strategy* (Minister of Health 2000). DHBs have a statutory responsibility for reducing health inequalities (New Zealand Public Health and Disability Act 2000), which is reinforced through their main accountability documents – the Crown Funding Agreements.

In New Zealand, as elsewhere, health inequalities exist between socioeconomic groups, ethnic groups, males and females and people living in different geographical areas. These inequalities are not random and can be seen in the distribution of the cancer burden in New Zealand. People who are less well off have greater exposure to health risks, poorer access to health services, and are more likely to develop, and die of, cancer. The reasons for health inequalities are complex and based on the unequal distribution of the wider determinants of health, rather than just the biomedical causal pathways.

In colonised countries, such as New Zealand, indigenous people have poorer health status than others: Māori are more likely to develop and die from some cancers than non-Māori. Cancer is the leading cause of death for Māori women and the second most frequent cause of death for Māori men. Reducing inequalities for Māori is a Treaty of Waitangi obligation and a priority for the Government.

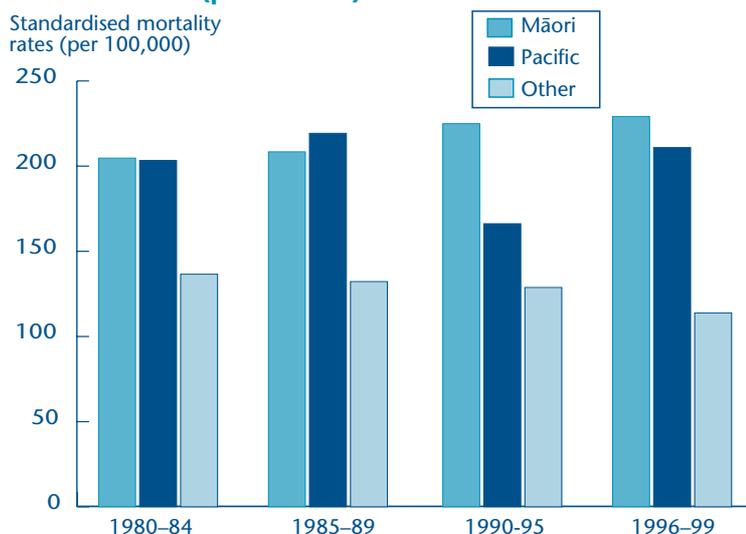
Cancer mortality is making an increasing contribution to the life expectancy gap for both Māori and Pacific peoples. Overall cancer mortality rates have increased over time among Māori compared to a steady decrease among non-Māori and non-Pacific people (Ajwani et al 2003).

Interventions to improve health inequalities should tackle the underlying determinants as well as directly addressing the risk factors themselves. Ethnic disparities in health arise from differential access to the political, social, environmental, economic and behavioural determinants of health resulting in differential incidence of disease. Differential incidence is then compounded by differential access to health care and differential quality of care leading to differential mortality (Ajwani et al 2003).

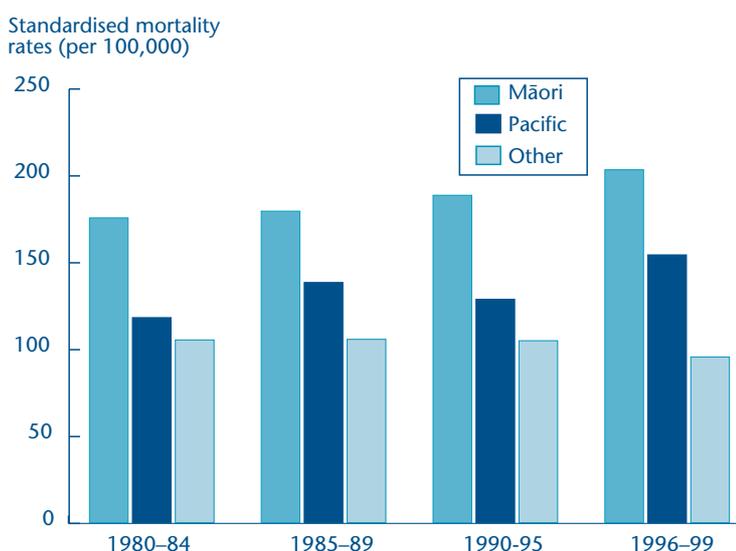
In response to the Government's clear direction to reduce inequalities in health, the Ministry of Health has developed an Intervention Framework (Appendix 6) to assist the health sector in the development and implementation of comprehensive strategies to improve health and reduce health inequalities. This framework is set out in the document *Reducing Inequalities in Health* (Ministry of Health 2002f), and should be used in conjunction with the Health Equity Assessment Tool (Appendix 7) to assist in changing the cancer sector's activities in order to reduce health inequalities.

Figure 3: Standardised mortality rates, ages 1–74 years, all cancer (prioritised series)*

Cancer Males (prioritised)



Cancer Females (prioritised)



* In the report *Decades of Disparity: Ethnic mortality trends in New Zealand 1980–1999* the prioritised ethnic group was assigned as Māori if one of the three possible self-identified ethnicity responses recorded on the 1986, 1991 or 1996 censuses was Māori. Therefore, for Māori, the prioritised ethnic group represents the total Māori ethnic group (MEG). For those not allocated as Māori, the prioritised ethnic group was assigned as Pacific if one of the self-identified ethnic groups as Pacific. The remainder were assigned as non-Māori non- Pacific.

The Cancer Control Continuum

Reducing the incidence and impact of cancer in New Zealand will require a planned, systematic and co-ordinated approach to myriad activities within what is known as the 'cancer control continuum'. Cancer control activities and services are undertaken by a wide range of government and non-government agencies and involve both a paid and a volunteer workforce. Their activities range from reducing our risk of developing cancer, to the care of those of us who will ultimately die from the disease.

Prevention

According to the WHO (2002), cancer prevention should be a key element in all cancer control programmes. Cancer prevention focuses not only on factors that increase a person's chances of developing cancer (such as smoking), but also on protective factors such as a healthy diet and physical activity.

Prevention services include the use of health protection, health promotion and disease-prevention strategies to alert the population to cancer risks, promote healthier lifestyles and create healthier environments that aim to reduce potential cancer risks. The prevention workforce, which involves both government and non-government personnel, includes public health, research, health promotion, primary health care and community providers.

Because people's exposure to risk factors is generally the result of a complex range of behavioural, social, economic, environmental and cultural factors that are not easy to change, efforts to reduce the incidence of these lifestyle-related cancers require a comprehensive approach, such as that described in the Ottawa Charter for Health Promotion (WHO, Health and Welfare Canada, Canadian Public Health Association 1986). Overseas experience shows that the effectiveness of such approaches depends on their being implemented widely over a substantial period of time, with adequate resources, leadership and a sound research base (Cancer Council Australia 2001).

Early detection and cancer screening

Early detection means detecting cancer prior to the development of symptoms or as soon as is practicable after the development of symptoms. Its aim is to detect the cancer when it is localised to the body organ of origin, before it has time to spread to other parts of the body. Because early detection is only part of a wider strategy including diagnosis, treatment and follow-up, its effectiveness is dependent on the sustainability of other services along the cancer control continuum (WHO 2002).

Early detection of cancer can involve strategies to promote early presentation, including education about signs and symptoms and improved access to primary care. Such strategies may also include endeavours to dispel myths, fears and negativity about cancer that may influence the likelihood of seeking medical advice.

Early detection of cancer prior to the development of symptoms occurs through screening, which is a process whereby people who have no symptoms are invited (either directly or through publicity) to undergo a test or procedure, usually at regular intervals. In some instances, the purpose of screening is to detect cancer at an early stage of development; in others, cancer screening identifies precursors of cancer, the treatment for which can reduce the risk of cancer developing. Although a number of cancer screening tests have been developed, only a few have been proven effective and therefore recommended for defined populations. To be considered effective, a screening test must meet a number of requirements established by the WHO and more recently by the National Health Committee (2003).

Diagnosis and treatment

The WHO (2002) describes cancer diagnosis as the first step to cancer management. It involves a combination of clinical assessment and a range of investigations, such as endoscopy, imaging, histopathology, cytology and laboratory studies. Diagnostic tests are also important in identifying the extent to which the cancer may have spread (known as 'staging'). Cancer staging is necessary for determining options for treatment and assessing likely prognosis.

Treatment of cancer is complex, involving a range of therapies. These include surgery, radiation, chemotherapy or hormonal therapy, or a combination of these. The aim of treatment is to cure (ie, to result in normal life expectancy), or to prolong and improve the quality of the life of those with cancer (WHO 2002).

Support and rehabilitation

When someone develops cancer, its impact extends beyond the physical effects of the disease to include psychological, social, economic, sexual and spiritual consequences. Coping with the disease and its treatment involves a range of issues, which impact on those with cancer as well as their families and whānau.

Supportive care and rehabilitation is defined as:

the provision of the necessary services, as determined by those living with or affected by cancer, to meet their physical, social, emotional, nutritional, informational, psychological, sexual, spiritual and practical needs throughout the spectrum of the cancer experience (Canadian Strategy for Cancer Control 2002).

These needs may occur during diagnosis, treatment or follow-up after treatment, and include issues of survivorship, recurrence of the disease and, in some cases, death.

There is growing evidence that supportive care and rehabilitation can buffer cancer patients and their caregivers from psychiatric, psychological and social morbidity. Furthermore, for those who go on to develop intrusive or more severe problems, a range of psychological and social interventions have been found to have a variety of benefits, including improved quality of life and illness adaptation, reduced psychological distress, and reduced rates of clinical

syndromes. Internationally, it is accepted that supportive care and rehabilitation are desirable at every stage along the continuum of care.

Palliative care

As further detailed in Appendix 5, palliative care is:

‘An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’ (WHO 2002).

As outlined in the *New Zealand Palliative Care Strategy* (Minister of Health 2001b), palliative care:

- affirms life and regards dying as a normal process
- aims neither to hasten nor to postpone death
- aims to provide relief from distressing symptoms
- integrates physical (tinana), social (whānau), emotional (hinengaro) and spiritual (wairua) aspects of care to help the dying person and their family and whānau attain an acceptable quality of life
- offers help to the family, whānau and carers during the person’s illness and their bereavement.

Palliative care for children represents a special field – albeit closely related to adult palliative care – whose principles also apply to other paediatric chronic disorders (WHO 2002) (Appendix 5).

Cancer control continuum and Māori

Ensuring that the cancer control continuum addresses Māori needs and expectations is a priority for the New Zealand Cancer Control Strategy.

A number of specific Māori health frameworks have been developed to provide a structure for addressing the quality of service delivery to Māori in the areas of health promotion, screening, support and rehabilitation services, treatment services, and palliative care provision (Ratima 2002). These frameworks, listed below, all emphasise the need to acknowledge Māori cultural values and beliefs, and the importance of whānau:

- *Hui Whakamārama: Report of a consensus hui concerning screening amongst Māori* (Te Manawa Hauora 1993)
- *Kia Whai te Māramatanga: The effectiveness of health messages for Māori* (Ministry of Health 1994)
- *He Taura Tīeke: Measuring effectiveness of health services for Māori* (Ministry of Health 1995)
- *He Anga Whakamana: A framework for the delivery of disability support services for Māori* (Ratima et al 1995).

Cancer control surveillance

Cancer control surveillance involves the routine and continuous collection of information on the incidence, prevalence, mortality, diagnostic methods, stage distribution and survival of those with cancer and aspects of the care received. Surveillance is a fundamental element of the New Zealand Cancer Control Strategy. The data collection required for surveillance requires the collaboration of service providers and, where necessary, continuing legislative support. A fully functioning and dedicated cancer registry with appropriate expertise is a cornerstone of cancer-control surveillance. Improvement in the collection and interpretation of ethnicity data is important for increasing our knowledge about cancer among Māori and Pacific populations, and to enable interventions focused on these populations.

Cancer control research

Cancer control research seeks to identify and evaluate the means of reducing cancer morbidity and mortality and of improving the quality of life of people living with, recovering from or dying of cancer. Research is needed across the spectrum of cancer control to provide the basis for continual improvement.

As identified by the WHO (2002), the major categories of research are:

- laboratory (eg, biological mechanisms underlying cancer)
- epidemiological (environmental or human behavioural factors)
- clinical (determining the most effective treatment)
- psychosocial and behavioural (eg, factors impacting on prevention, the response to screening, and the impact of diagnosis and treatment)
- health systems and health policies (eg, how services can best be implemented and organised).

As in other areas of cancer control, research involves the use of multidisciplinary approaches.

The High-level Framework to Guide Existing and Future Actions

Overall purposes of the strategy

The overall purposes of the strategy are to:

- reduce the incidence and impact of cancer
- reduce inequalities with respect to cancer.

The principles of the New Zealand Cancer Control Strategy

Achieving the overall purposes of the New Zealand Cancer Control Strategy is a society-wide responsibility, requiring a collaborative approach among many agencies and individuals. All activities undertaken to meet these purposes should be guided by the following principles.² They should:

- **work within the framework of the Treaty of Waitangi to address issues for Māori**
As New Zealand's founding document, the Treaty of Waitangi should underpin actions to address the diverse needs of Māori. Within the context of cancer control, these actions should reflect the Treaty and follow the three principles of partnership in service delivery: participation at all levels of the health sector; protection and improvement of Māori health status; and the safeguarding of Māori cultural concepts, values and practices.
- **reduce health inequalities among different population groups**
Significant health inequalities exist among different groups in New Zealand and can be seen in the distribution of the cancer burden: cancer mortality rates for Māori are higher than for others in New Zealand. Actions to reduce Māori mortality also recognise the Treaty of Waitangi obligations of the Crown. Pacific peoples also have higher cancer mortality rates than non-Māori. Gender and geographic inequalities are other important areas for action.
- **ensure timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay**
This principle acknowledges the need to address, in a fair way, factors that impact on the ability of people to access services across the continuum of cancer control in sufficient time to be of benefit.

² Some of these principles draw on the principles of the *New Zealand Health Strategy* and the *Health of Older People Strategy* and threads of *He Korowai Oranga: Māori Health Strategy*. The New Zealand Public Health and Disability Act (2000), which governs the structure of the New Zealand health care system, mandates a population-based approach to health (Ministry of Health 2002c).

- **be of high quality**

This principle identifies the importance of developing standards and guidelines, monitoring performance, and evaluating outcome to ensure high quality.

- **be sustainable**

This principle identifies the importance of having the adequate resources, including human resources, required over a period of time to ensure a high standard of performance.

- **use an evidence-based approach**

This principle acknowledges the need for actions to be based on best practice, which is supported by a systematic review of scientific knowledge and includes ongoing research and development.

- **reflect a person-centred approach**

This principle recognises a person's total wellbeing, including her or his physical, emotional, spiritual, social and practical needs within the context of family and whānau. For Māori, this means recognising and responding appropriately to a Māori holistic view of health.³ It also recognises people's autonomy and dignity and their right to make informed choices.⁴

- **actively involve consumers and communities**

This principle identifies the need to have consumers and communities involved in the decisions that affect them and to provide opportunities for consumer participation. It also means that services should reflect the needs of individuals and communities.

- **recognise and respect cultural diversity**

This principle recognises the importance of actions being culturally appropriate; that is, responsive to, and respectful of, the history, traditions and cultural values of the different ethnic groups in New Zealand.

- **be undertaken within the context of a planned, co-ordinated and integrated approach**

This principle underscores the importance of adopting a systematic and co-ordinated approach to ensure effectiveness and that resources are used efficiently. It also acknowledges that activities to control cancer should be part of a population-based approach to health.

³ There are several models that characterise a holistic Māori view of health. A frequently used framework is based on four dimensions of health and wellbeing: taha wairua (spiritual health), taha tinana (physical health), taha hinengaro (emotional, psychological health) and taha whānau (family health) (Durie 1998).

⁴ The rights of people to make informed choices should be respected in a manner that is consistent with consumers' rights and providers' obligations under the Code of Health and Disability Services Consumers' Rights 1996, a regulation under the Health and Disability Commissioner Act 1994.

The goals of the New Zealand Cancer Control Strategy

The goals of the New Zealand Cancer Control Strategy are to:

- 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 to reduce cancer 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 through effective planning, co-ordination and integration of resources and activity, monitoring and evaluation
- 6 improve the effectiveness of cancer control in New Zealand through research and surveillance.

Objectives to Meet the Goals

The following sections outline objectives and broad areas for action for the next three to five years to achieve the purposes and goals of the New Zealand Cancer Control Strategy. These were developed by five expert working groups (identified in Appendix 3).⁵

The purposes and goals of the strategy are enduring; the objectives (and associated areas for action) are priorities in the short to medium term. Ongoing monitoring and periodic review will help to ensure that they are achieving the desired effects and allow new objectives to be added or substituted as research identifies effective ways of reducing both the incidence and impact of cancer and health inequalities. Specific actions to achieve the objectives – and those who will assume key responsibility for them – will be identified during the strategy implementation planning phase.

The objectives have been organised under each goal, although there is some overlap because action in any of these areas does not occur in isolation.

⁵ Background papers of the groups, providing additional rationale and support for these objectives, are available on the Ministry of Health and New Zealand Cancer Control Trust websites: www.moh.govt.nz/cancercontrol and www.cancercontrol.org.nz.

Goal 1: Reduce the incidence of cancer through primary prevention

Primary prevention approaches that aim to reduce exposure to cancer-causing risk factors offer the greatest health gain and most cost-effective form of cancer control. The WHO suggests that, based on what we already know about potential cancer risks and risk-reduction interventions, it is possible to prevent at least one-third of all cancers (WHO 2002).

The *New Zealand Health Strategy* (Minister of Health 2000) includes in its listed priority population health objectives: reducing smoking, improving nutrition, reducing obesity, improving the level of physical activity, and minimising the harm caused by alcohol and illicit drug use to individuals and the community. Work undertaken in these areas will link with, and feed into, Goal 1 of the New Zealand Cancer Control Strategy.

Simply educating people to adopt healthy lifestyles does not by itself get people to change risk-taking behaviours such as smoking or over-eating. Co-ordinated public health policies and multi-faceted comprehensive interventions are needed to encourage and promote healthy social environments, and to support people to make healthy lifestyle choices (eg, supporting smokers to quit smoking). These policies and interventions need to occur at national, regional and local level.

The Ottawa Charter for Health Promotion provides a comprehensive approach to improving the health of populations and individuals (WHO, Health and Welfare Canada, Canadian Public Health Association 1986). This approach is one of a number of useful planning models and provides a framework that demonstrates the need to look wider than just providing health services. It stresses the need to build healthy public policy, to encourage community action, develop personal skills, create supportive environments and reorient health services in order to ensure effective public health actions. The Ottawa Charter for Health Promotion is used in New Zealand as a framework for planning public health strategies. In practical terms this means that a wide range of organisations, agencies and providers is involved in achieving an effective approach.

In order to ensure Māori receive the same benefits as non-Māori in the area of primary prevention, it is important to collect accurate ethnicity data relating to risk factors and to use Treaty-based health promotion practices to address lifestyle risk factors (Ratima 2002).

Goal 1 encompasses seven potential cancer risk areas, requiring multi-faceted approaches that aim to reach the whole of the population.

Objective 1: Reduce the number of people who develop cancers due to tobacco use and second-hand smoke

Exposure to tobacco smoke increases the risk of developing lung cancer and many other types of cancers. Tobacco use is responsible for about 25 percent of all cancer deaths in New Zealand. Lung cancer is a significant cause of illness and death in all New Zealanders, particularly among Māori. Māori lung cancer mortality rates are currently three times higher than non-Māori rates.

Government policy approaches to tobacco control include legislation and taxation. A clear policy direction has been set out in *Clearing the Smoke: A five year plan for tobacco control in New Zealand* (2003–2007) (Ministry of Health 2002b). In 1999 The National Health Committee published its *Guidelines for Smoking Cessation*, which were designed principally for primary care providers to determine appropriate advice for smokers.

The prevalence of tobacco use is socially patterned, with a strong correlation between smoking prevalence and deprivation for both males and females, and at most ages. In New Zealand and internationally the decline in smoking prevalence has been greatest among the socially advantaged.

Rates of tobacco use are disproportionately high among Māori. Public health initiatives to reduce smoking rates have not resulted in the same benefits for Māori as for the general population.

Broad areas for action

Broad areas for action include:

- possible further legislation
- monitoring effectiveness of programmes
- increases in health promotion activities, advocacy, smoking cessation services
- normalising of smokefree environments
- further research.

Objective 2: Reduce the number of people developing physical inactivity and obesity-related cancers

In 1997 overweight (35%) and obesity (17%) combined affected more than half of New Zealand adults. More and more people are becoming obese in the New Zealand, particularly among some populations.

For example, Māori rates of obesity are approximately twice those of Pākehā (Russell et al 1999). People who are obese are more likely to develop certain types of cancer, including bowel, breast (post-menopausal) and oesophageal cancer.

One in three people in New Zealand do less than 2.5 hours per week of moderate to hard physical activity. People who are physically active are less likely to develop cancers of the bowel, breast, prostate, lung and uterus.

This objective links with *Healthy Eating – Health Action* (Ministry of Health 2003a) and the earlier joint report of the Hillary Commission and the National Health Committee *Active for Life: A call for action: The health benefits of physical activity* (National Health Committee 1998). It is expected that work undertaken by SPARC (Sport and Recreation New Zealand) on physical activity will continue to link in to the implementation of this section of the New Zealand Cancer Control Strategy.

Broad areas for action

Broad areas for action in this objective include actions that:

- support lifestyle change
- foster an increase in physical activity through safer accessible environments
- involve comprehensive media campaigns
- promote green prescriptions
- encourage action to prevent the development of obesity in children
- increase rates of physical activity for all New Zealanders, and in particular Māori, Pacific peoples and those on low incomes.

Objective 3: Reduce the number of people developing nutrition-related cancers

There is evidence that links bowel cancers (cancers of the colon and rectum) with a number of food and dietary habits. The composition of diet is considered important, in that fruit and vegetables, increased fibre and reduced fat intake may decrease the risk of certain types of cancers, including oral, stomach and bowel cancers (Ministry of Health 2003b). The *Healthy Eating – Health Action* strategy (Ministry of Health 2003a) and the *New Zealand Food and Nutrition Guidelines for Healthy Adults* (Ministry of Health 2003b) advocate the following key messages:

- eat a variety of healthy foods
- eat fewer fatty, salty and sugary foods
- eat more vegetables and fruit
- fully breastfeed infants for at least six months.

Broad areas for action

Broad areas for action in this objective include:

- improving access to acceptable and affordable healthy foods
- reducing the promotion of unhealthy food choices to children
- raising awareness for healthy food choices
- research into emerging nutrition issues.

Objective 4: Reduce the number of people developing skin cancer due to UV radiation exposure

The New Zealand population is exposed to relatively high levels of ultraviolet (UV) radiation, particularly UV radiation from sunlight. Excessive exposure to sunlight causes all forms of skin cancers, including melanoma. Skin cancers are the most common forms of cancer experienced in New Zealand. The mortality rate from melanoma in this country is among the highest in the world. People with fair hair, fair skin and who are prone to excessive freckling and burning on exposure to the sun are most at risk. The Cancer Society of New Zealand and the Health Sponsorship Council have undertaken a considerable amount of health promotion development in this area.

Broad areas for action

Broad areas for action include:

- supporting health promotion campaigns
- encouraging the provision of environmental sun protection
- supporting international efforts to protect the ozone layer.

Objective 5: Reduce the number of people developing infectious disease-related cancers

The presence of some infectious diseases has been associated with the development of liver cancer, cervical cancer and stomach cancer. For example, people who have had hepatitis B and C are more likely to develop liver cancer, and the presence of the human papillomavirus is a contributing factor in the development of cervical cancer. These cancers are unequally distributed throughout the population. Māori, Pacific and Asian people in New Zealand more often carry the virus that causes liver cancer, so it is more common in these populations compared with the European/Pākehā population. Likewise, Māori women have higher cervical cancer incidence and death rates than non-Māori women.

An Integrated Approach to Infectious Diseases: Priorities for action 2002–2006 (Ministry of Health 2000) carries specific recommendations for risk reduction in sexually transmitted infections, and hepatitis B and C.

Broad areas for action

Broad areas for action include:

- increasing health promotion around infectious disease-related cancers
- effective targeted screening for hepatitis B in high-prevalence populations
- promoting hepatitis B vaccination
- raising awareness of the risks associated with intravenous drug use.

Objective 6: Reduce the number of people developing alcohol-related cancers

The *National Alcohol Strategy 2000–2003* (Minister of Health 2001a) indicates that over 80 percent of New Zealand's adult population drink alcohol. While the total alcohol consumption has declined over the past 10–15 years, there is considerable variation in the amount consumed by individuals. It is estimated that 10 percent of drinkers consume almost half of the total alcohol consumed. Young people who drink are drinking more heavily, more often, and start drinking at an earlier age. While a lower proportion of Māori drink, young Māori appear to engage in heavier and riskier drinking, so their cancer risk is likely to be even higher. Young Māori are also likely to be more responsive to the promotion and advertising of alcohol, as is shown by increasing alcohol consumption among this age group (Pōmare et al 1995).

There is strong evidence that consumption of alcohol increases the risk of cancers of the oral cavity, pharynx, oesophagus and larynx. It probably also increases the risk of cancers of the stomach, bowel, rectum, liver, breast and ovary.

The New Zealand Government has adopted an intersectoral National Drug Policy covering alcohol, illicit and other drugs as well as tobacco. The *National Alcohol Strategy 2000–2003* (Minister of Health 2001a) is part of this policy and provides recommendations that will contribute to the implementation of this objective of the New Zealand Cancer Control Strategy.

Broad areas for action

Broad areas for action include:

- raising awareness of the harmful effects of alcohol
- reducing exposure to alcohol advertising
- increasing taxation
- considering the impact of age legislation on drinking patterns.

Objective 7: Reduce the number of people developing occupational-related cancers

An estimated 600 cases of occupational cancer occur each year in New Zealand, most of which are preventable. Regulations are in place to protect workers against many known carcinogens. The Occupational Safety and Health Service (OSH) is responsible for ensuring that the legislative protection for workers is upheld in workplaces. Further efforts and actions are required to identify other potential occupational carcinogens and cancer sites, develop strategies to reduce workers' exposure, and hence reduce the incidence of occupational cancers in the future.

The planning of actions to support this objective should involve collaboration with organisations such as OSH.

Broad areas for action

Broad areas for action could include:

- strengthening the legal framework to protect workers
- reducing exposure to, and raising awareness of, carcinogenic compounds in the workplace
- supporting OSH research into occupational exposures
- improving the reporting of occupational cancers.

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

Screening is the examination of asymptomatic or well people in order to classify them as unlikely or likely to have a disease. In a screening programme, everyone in a target group – defined by age, gender, locality, etc – is invited to participate. It is a process aimed at reducing the risk of developing cancer or its complications through early detection and treatment. Screening has the potential to identify a high proportion of people with early disease in a population, but this proportion is dependent on the uptake of screening and the sensitivity of the screening test.

Well-established principles apply to this public health activity (Wilson and Jungner 1968; Miller 1992). The main underlying principle is to do the least harm to achieve the greatest measurable benefit for the population. There may be adverse effects of screening for some people. Because such people would not have experienced the adverse effects had they not been invited to take part in screening, it is very important that there is good evidence of benefit from screening, and that screening tests and follow-up investigations carry low risks.

Primary-care providers often administer screening tests or follow up and advise people with positive screening tests. They may also assist in identifying the target population of screening programmes.

Familial risk assessment involves investigating those with a reported family history of cancer – including relatives of those who develop cancer at a much younger age than is usual for the type of cancer – to assess their risk of developing the disease and monitoring them on an ongoing basis (known as surveillance). Part of the familial risk assessment may involve genetic testing for the presence of specific gene mutations. Access to preventive treatments, such as prophylactic surgery, may be important for people with a very high risk of cancer due to genetic susceptibility.

In principle, it is important to educate people to recognise the early signs and symptoms of cancer in order to encourage early presentation, and thus early treatment. However, although some cancers have early warning signs that are easily identified, many do not. Furthermore, detection of a cancer before it appears to have spread does not always lead to an improved outcome. Therefore, early detection efforts should be focused on those cancers where this has been shown to reduce cancer mortality and morbidity.

Objective 1:

At a national level, provide a strategic approach to cancer screening, and the assessment and surveillance of those with familial risk, to ensure quality, acceptability and effectiveness

Cancer screening in New Zealand occurs in two ways: through organised screening programmes and in an opportunistic fashion (ie, outside organised programmes). The key feature distinguishing these two approaches is the lack of a quality process – including routine monitoring and evaluation – in the opportunistic screening of individuals (National Health Committee 2003). Appropriate, high-quality, organised screening programmes are among the most powerful cancer control strategies available (Screening Working Group 2002). By contrast, opportunistic screening is resource-intensive, carries real, but frequently unacknowledged, risks and is less likely to provide benefits at a population level or be cost-effective (Expert Working Group on Cancer Screening and Early Detection 2003).

New Zealand has two national cancer screening programmes: the National Cervical Screening Programme and BreastScreen Aotearoa. Both are overseen at a national level by the National Screening Unit within the Ministry of Health, which is dedicated to ongoing management of all operational aspects of the programmes. Opportunistic screening of individuals also occurs in New Zealand, in some cases despite acknowledged risks and a lack of proven effectiveness; for example, screening for prostate cancer (National Health Committee 2003).

In New Zealand, high-level cancer screening recommendations have been made by different working parties at different times. This work has frequently been undertaken as the result of external requests from special interest groups rather than as part of an organised, ongoing approach. Furthermore, once the working parties have provided their advice, they have been disbanded, leaving no group responsible for ongoing monitoring of related issues.

It is important to have a clear process for reviewing high-level recommendations regarding cancer screening in New Zealand. This should include assessment of potential new screening programmes, regular review of current screening programme recommendations, and ongoing oversight of implementation of the recommendations. Currently, the National Screening Unit undertakes the latter two roles for the breast and cervical screening programmes, but does not assess other potential cancer screening nor address issues relating to familial risk assessment. Currently, there is no single body with specific responsibility for providing advice and recommendations on cancer screening and for ensuring that all the necessary elements are in place to support existing and future programmes.

There are also issues for Māori and Pacific peoples in relation to current and future screening programmes that need to be addressed at a strategic level. For example, despite a particular effort by the National Cervical Screening Programme to ensure the participation of Māori and Pacific women in the programme for over a decade, there remain inequities in coverage.

Screening programmes need to consider and respond to specific cultural issues unique to Māori in order to increase Māori participation and thus reduce their higher morbidity and

mortality rates from cancer. An effective screening programme for Māori needs to be delivered within a responsive framework, which addresses Treaty of Waitangi, workforce and ownership of information issues (National Health Committee 2003). Screening programmes must also address the needs of the diverse range of cultural groups in New Zealand.

Familial cancer risk assessment involves counselling, confirmation of family history and, whenever clinically indicated, genetic testing. In New Zealand, access to familial risk assessment services is not equitable and referrals have tended to come mainly from urban centres. National guidelines specifying who should be referred to these services are needed, as is a strategic approach to the development of guidelines for the ongoing assessment (surveillance) of those at increased risk.

High-level strategic oversight of existing and potential cancer screening programmes, and of the assessment and surveillance of those with familial risk, is needed to ensure:

- improved assessment and decision-making relating to screening programmes and activities
- optimum effectiveness and cost-effectiveness of cancer screening and familial cancer risk assessment
- culturally appropriate screening services, including familial risk assessment
- increased Māori participation in cervical and breast-screening programmes
- improved understanding of cancer screening and familial cancer risk assessment
- reduced cancer morbidity and mortality from well-organised, high-quality, acceptable evidence-based cancer screening and familial cancer risk assessment.

Broad areas for action

An effective national mechanism, such as a national cancer screening committee, is needed to provide high-level strategic oversight of existing and potential cancer screening, and of the assessment and surveillance of those with familial risk.

Objective 2: Establish a process to assess the value of early detection of cancer other than that obtained through organised screening

There is evidence that survival from some cancers (eg, melanoma and certain breast cancers) may be improved by early symptom identification and treatment, and that delays in presentation remain common among some population groups in New Zealand (Lawes et al 1999; Newman et al 1992). Early cancer detection by individuals and health-care workers, coupled with timely referral for specialist assessment and investigation, is an important component of cancer control.

Currently, it is not known to what extent delays in presentation are contributing to New Zealand's high cancer mortality rates, particularly among Māori and Pacific peoples, and there is no process established to determine this. It is also unclear which interventions to promote early presentation of symptoms, and thus referral for diagnosis and treatment of those with cancer, have the potential to improve survival and quality of life.

Broad areas for action

A process is needed to:

- identify if the early detection of specific cancers reduces mortality and morbidity
- recommend strategies to increase early detection where that has proven to be advantageous. These strategies would include:
 - a formal assessment of the reasons for delays in early detection of these cancers in New Zealand, focusing on who is affected and why
 - the implementation of programmes to overcome the delays, and the evaluation of their effectiveness
 - programmes designed to encourage earlier presentation of Māori and Pacific people with cancer.

Goal 3:

Ensure effective diagnosis and treatment of cancer to reduce morbidity and mortality

The diagnosis of cancer covers a breadth of activity, from presentation or identification of signs and symptoms, to confirmation (or elimination) of a cancer diagnosis. For those with cancer, their family and whānau, the definitive diagnosis of cancer is the beginning of a journey, the duration of which can extend from months, to years, to a lifetime. Of prime importance is the timeliness of diagnosis. An excessive delay between the presentation or identification of initial symptoms and the definitive diagnosis can have a significant psychological effect on those with cancer, their family and whānau. This, along with a further delay to definitive treatment, can have an impact on the likely effectiveness of treatment.

Because cancer treatments are continually improving, many people are living longer with the disease. For them, cancer is now regarded as a chronic, or long-term, disease for which treatment (which includes a wide range of therapies) may be complex. At one time treatment was sequential: patients were referred to a specialist, usually a surgeon, and then to other cancer specialists for treatment. Now treatment includes combined modalities, with input from more than one discipline. In addition, many patients seek complementary and alternative therapies outside the medical system. As identified in Goal 4 (see below), support, rehabilitation and/or palliative care (referred to as 'care' in this strategy), which are essential in meeting the total needs of those with cancer, their family and whānau throughout the cancer journey, are an integral part of treatment.

Cancer diagnosis, treatment and care involve a wide range of providers. Of particular importance is the primary-care provider, especially because cancer is increasingly being treated in community settings (Clinical Oncological Society of Australia, The Cancer Council Australia, the National Cancer Control Initiative 2003). The need for a more integrated approach to treatment and care, with the patient as the focus, is recognised as critical for those with cancer, their families and whānau.

Objective 1:

Provide optimal treatment for those with cancer

Optimising survival and the quality of life for those with cancer means having access to treatments that, on the basis of current evidence, are known to provide the best outcomes. New Zealand has traditionally provided a high standard of treatment for cancer, but currently there is insufficient resource capacity (funding and staff) to cope with the demand for services. This has led to delays in access to some technologies essential for optimal treatment, resulting, for example, in some cancer patients having to travel to Australia for radiation treatment.

Cancer is a complex disease, and its diagnosis, treatment and follow-up require the collaboration of a number of health disciplines. Close collaboration between disciplines – or multidisciplinary management – is thought to have led to more appropriate diagnosis and

better selection of patients for treatment, particularly surgery, and has been shown to provide better outcomes (Department of Health [London] 1995). It is important that surgery and post-operative care take place under the care of skilled and experienced practitioners, in hospitals equipped to support these difficult problems.

Multidisciplinary teams and specialised treatment centres, which have developed in some centres for some cancers, are not necessarily essential for the management of all cancers. Optimal management requires different levels of service to function in a co-ordinated way. Effective liaison within a clinical group can be achieved by regular discussion through face-to-face meetings or other forms of communication. The benefits of some specific cancers being treated at a specialised unit need to be explored. Among the issues likely to impact on the establishment of such units is funding to facilitate inter-regional patient flows and the impact on the patient, family and whānau of having to travel to other regions.

Establishing what is optimal treatment requires an ongoing and systematic process for evaluating and introducing new drug treatments and technologies when evidence emerges to support their use. Pharmac is currently evolving such a process to assess new chemotherapy drugs, but this process does not deal with other treatment technologies. One model for consideration in New Zealand is the Australian Safety and Efficacy Register of New Interventional Procedures. It is important that any process established to assess new cancer treatment technologies includes the capacity to compare the additional benefits gained from these treatments with benefits from existing treatments. This process should involve close collaboration with professional colleges and societies.

Broad areas for action

Broad areas for action include:

- ensuring timely access to treatment currently recognised as providing optimal outcomes
- expanding the use of multidisciplinary management
- exploring the establishment of specialised units for the treatment of some specific cancers
- systematically assessing new treatment approaches.

Objective 2: Develop defined standards for diagnosis, treatment and care for those with cancer

Everyone with cancer needs access to a consistent standard of diagnosis, treatment and care throughout his or her cancer journey in order to achieve the best possible outcomes. Various approaches to achieve consistent standards include the use of national and regional guidelines and protocols, and interdisciplinary management through multidisciplinary clinics or teams. All of these require continuous monitoring against key performance measures to determine whether diagnosis, treatment and care reach recommended standards.

The application of guidelines and protocols in this country is variable. Although some systems exist for monitoring standards and guidelines (eg, those for the breast and cervical screening programmes), there are few systems in place to monitor the use and effectiveness of guidelines and protocols relating to cancer diagnosis, treatment and care. More people with cancer should be offered the opportunity to take part in clinical trials, which are governed by defined protocols, and there is a need to set in place appropriate standards for timeliness of assessment, diagnosis and treatment. Protocols are also needed for the translation of research findings into practice (eg, for using genetic testing in diagnosis, prognosis and treatment).

Broad areas for action

Broad areas for action to ensure those with cancer have a consistent standard of care include:

- the development, implementation and ongoing refinement of national and regional standards, guidelines and protocols
- multidisciplinary approaches to treatment and care
- the development of a minimal data set to measure performance and outcome.

The potential for unnecessary duplication and the resourcing implications of these actions will need to be addressed.

Objective 3: Ensure patient-centred and integrated care for those with cancer, their family and whānau

To improve health outcomes and quality of care, cancer services need to be patient-centred. Patient-centred care includes giving careful attention to individual needs and concerns and, where appropriate, offering choice with full information. It also means meeting patient needs as a whole, and requires professionals to work well together (Commission for Health Improvement / Audit Commission 2001).

One of the key challenges to ensuring patient-centred care is the increasing complexity of cancer management and the potential for fragmented care. Because many of the services across the cancer control continuum have developed in a piecemeal way, service provision is uneven and fragmented. As a result, people accessing diagnosis, treatment and care have to negotiate their way through many different services. Often they 'slip between the cracks' of services and may be lost before and after treatment.

Improving the integration of cancer care services would help to improve people's access to the full range and combination of services and would also improve quality of life and satisfaction with care. Improving integration would also improve access for particular population groups currently experiencing difficulties in accessing appropriate care, such as Māori and Pacific peoples. Integration needs to occur from initial diagnosis, through

secondary care (hospital) services, to tertiary cancer treatment and management centres, and back through to community support services once initial treatment has been completed. It needs to cover the full spectrum of needs of the patient, family and whānau, including psychosocial support, rehabilitation and palliative care. Linking to the new direction of the Primary Health Care Strategy (Ministry of Health 2001c) provides opportunities for better co-ordination of primary care services.

To achieve this level of integration will require considerable improvement of existing systems and adequate funding resources. Although there is limited evidence to establish how fragmentation and treatment delays affect patient outcomes, patients and providers clearly support timeliness and continuity of care.

Concerns about Māori health development include the effective delivery of conventional, mainstream health services to Māori. Most Māori treatment needs will be met within the usual professional settings, but innovation, flexibility and choice have not been strong features of the health system, at least for Māori, and they are generally welcomed. Treatment services need to integrate Māori concepts of hauora (Ratima 2002).

Broad areas for action

Broad areas for action include:

- the evaluation of different systems of care co-ordination (eg, by assigning responsibility for co-ordination and oversight of care to specific people or services)
- the creation of a seamless process for those with cancer and their families and whānau. This action will require enhancing relationships between the community, community agencies, primary and secondary care providers and cancer centres. Primary care providers have a key role within this process and need to be kept fully informed of what is happening to patients enrolled at their practice.

Objective 4: Improve the quality of care delivered to adolescents with cancer and their family and whānau

In New Zealand there is no consistent, equitable pattern of referral and management for adolescents with cancer. Instead they 'fall into the gaps', receiving treatment in either paediatric or adult oncology units, the environments of which are unsuitable. Referral is often dependent on the interest of the oncologist, a judgement about the maturity of the patient and the nature of the cancer.

Special problems for carers of adolescents with cancer include:

- psychosocial and emotional problems faced by adolescents
- types of cancers that straddle paediatric and adult age groups

- absence of a clear, widely accepted definition of adolescence
- responsibility for consent varying over time and among patients (ranging from almost complete dependence on adults to autonomy)
- relatively small number of cancers in this age group compared with adults
- lack of recognition of the need for peer support.

Broad areas for action

Areas for action include the development of an infrastructure comparable to that for paediatric oncology, based around designated adolescent care areas in specified oncology centres. These centres would require dedicated multidisciplinary teams to co-ordinate care in a manner that ensures minimal psychosocial disruption and includes shared care with outlying centres. This adolescent cancer service should:

- define adolescence based on developmental state, not age
- address their challenging psychosocial needs
- ensure that the most appropriate medical personnel treat a designated cancer
- ensure maximal entry in age-appropriate clinical trials
- minimise disruption to family dynamics and financial impact
- ensure prospective collection of data on adolescent cancer incidence, treatment and outcome in New Zealand
- recognise and encourage entitlement to peer support, continued education and support for the family at large.

Goal 4: Improve the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care

Quality of life, when referring to health, means the extent to which a person's usual or expected physical, emotional and social wellbeing is affected by a medical condition or its treatment (Cella 1998). Evidence shows that when people experiencing cancer receive good social and psychological support, their quality of life improves. In order to achieve the best possible outcome for those with cancer, every aspect of their treatment and care must recognise their total needs. Their physical, social, psychological, nutritional, information and spiritual needs are all equally important.

In some cases, their quality of life is affected by physical impairments due to cancer; in such cases, assistance may be needed to enable them to perform everyday activities and live as independently as possible. The extent to which physical, psychological and social rehabilitation is required depends on the type and severity of the impairment and the type and magnitude of the treatment provided (WHO 2002).

The purpose of palliative care is to maintain and improve quality of life, especially for those who are diagnosed with cancers that are life threatening, and those for whom cancer treatment is no longer effective. In palliative care services, there should be a focus not only on effective symptom control and physical factors (tinana) but also on the emotional (hinengaro), spiritual (wairua), cultural and social (whānau) aspects that impact on the person, family and whānau. Support for the family and whānau extends beyond the person's life; it also acknowledges bereavement.

Objective 1: Establish integrated programmes of supportive care and rehabilitation with defined leadership

All those associated with cancer care potentially contribute to the processes and practices of supportive care and rehabilitation. However, some health professionals (cancer nurses and specialists), disciplines (eg, social work, occupational therapy, psychology, psychiatry and pastoral care) and organisations (eg, Cancer Society and DHBs) are more likely to be involved in delivering such services.

Across New Zealand cancer centres there is uneven provision and access to supportive care and rehabilitation. Some centres have such services clearly integrated and embedded within routine service delivery; others may activate or, where possible, contract in such services only when it is apparent that problems are directly affecting treatment. This piecemeal service delivery is indicative of the absence of a national policy for supportive care/rehabilitation.

Furthermore, support and rehabilitation services have traditionally been monocultural (Moore 1995). Although little research has been conducted to examine Māori access to support and rehabilitation services, it can be assumed that the same trends of inequity experienced in other areas of the cancer control continuum are likely to occur, and that significant gaps in service provision exist.

Broad areas for action

Broad areas for action include:

- the development and implementation of guidelines to assess and address the psychosocial and cultural needs of all people with cancer
- the development of training opportunities in supportive care and psycho-oncology
- the development of integrated programmes of supportive care and rehabilitation for Māori and Pacific peoples.

Objective 2:

Ensure all people with cancer and their families and whānau are able to access the appropriate resources for support and rehabilitation that they need

An informal review of resource provision in different parts of New Zealand indicates that access to necessary resources for support and rehabilitation from both the government and non-government sectors varies according to local arrangements and the age at which cancer is diagnosed. In some situations, even within the same region, the availability of assistance is dependent on the 'local knowledge' of health professionals. This clearly creates inequity of access to resources for support and rehabilitation.

A key issue of concern over many years has been the inequitable funding of travel and accommodation costs for those with cancer (and the families of children with cancer) who must travel outside their region for specialist care and support. Although efforts have been undertaken by regional health authorities, the Health Funding Authority and the Ministry of Health, in consultation with the non-government sector, to develop a national policy on adult travel and accommodation, the matter continues unresolved. Furthermore, persistent efforts and report recommendations relating to the special circumstances of families of children and adolescents with cancer have yet to be addressed.

At present, centrally provided government funding for disability support services (DSS) is only available to people who meet the definition of a 'person with a disability' and people with cancer are usually excluded on the basis of their having a 'personal health' condition. Disparities exist, for example, between a child who loses a leg as the result of an accident (and who receives assistance through ACC) and one who has limb surgery for osteogenic sarcoma; the latter requires access to rehabilitation services and resources, but is often

denied assistance. There have historically been unclear boundaries between funding streams for services for people with cancer who have long-term disabling effects.

The current lack of an integrated approach to resources for support and rehabilitation may well result in financially disadvantaging individuals, families and whānau and unnecessarily prolonging use of public hospital beds when other solutions are available. Also, it is clear that the difficulties relating to access of resources by Māori and Pacific peoples and their families and whānau are often unacknowledged and, as a consequence, some needs may be largely unmet.

Broad areas for action

Broad areas for action include:

- assessing the current problems relating to access to support and rehabilitation resources:
 - identifying the process by which these could be addressed
 - identifying the responsibilities of the government and non-government sectors in this process
- addressing the funding implications of meeting service gaps, and of the growing demand for these services due to the increase in numbers of those with cancer.

Objective 3: Ensure all survivors of childhood and adolescent cancer receive timely and ongoing support and rehabilitation, including early identification of, and intervention in, late effects

Although remarkable survival rates in malignancies of childhood have been achieved over the last 30 years, there is emerging evidence of major physical and psychological sequelae which, if not identified early and addressed by intervention strategies, can result in serious loss of quality of life. The impact of such late effects of the disease or its treatment will, without a planned intervention programme, inevitably result in escalating utilisation of other social and health services in New Zealand.

Late effects can range in severity and are highly dependent on the specific cancer, the type(s) of treatment received and the age of the child during therapy. An example is impairment of cognitive function, which may subsequently manifest in declined intellectual and academic ability. Endocrine complications of cancer treatment may include ovarian or testicular damage resulting in infertility, impaired growth, and other dysfunction. Survivors of childhood and adolescent cancer have also been shown to be at risk of permanent unemployment (Mostow et al 1991) and of discrimination based on their medical history (Li

et al 1984; Yebby et al 1989). Such discrimination impacts very negatively on their mental wellbeing and their efforts to become independent and productive members of society.

Children and adolescents who survive cancer with significant impairments may be regarded as having lifelong disability acquired early in life, and therefore should be considered as eligible for government-funded support services. However, some late effects may take a long time to be identified, and currently there is no clear responsibility as to who should fund the needs of these survivors.

Broad areas for action

Collaborative action, involving the Ministries of Health and Education and the Paediatric Oncology Steering Group, is needed to oversee:

- the development and implementation of national guidelines for the support and rehabilitation of all children and adolescents with cancer
- a comprehensive late-effects programme for survivors of childhood cancer.

Objective 4: Ensure that those with cancer and their family and whānau have access to high-quality information on treatment and care, including complementary and alternative medicine

People with cancer need high-quality and comprehensive information to make well-informed choices about treatment, including complementary and alternative medicine (CAM).⁶ According to a recent review in Britain, among the beneficial effects of providing information are anxiety reduction, enhanced satisfaction, adherence to treatment and improved self-care (Commission for Health Improvement / Audit Commission 2001b). In New Zealand, lack of information has been identified as a barrier to utilisation of cancer services, particularly for Māori, Pacific and Asian peoples.

Belief in, and the use of, CAM for cancer is steadily increasing (O'Brien 2002). In New Zealand a wide range of therapies is available, including diet and nutrition, meditation, massage, rongoā Māori and Chinese herbal remedies. Some people choose these therapies because they consider, and some evidence suggests, that they may sustain and improve health. However, more information is needed about what therapies are safe and effective.

⁶ According to the definition adopted by the Ministerial Advisory Committee on Complementary and Alternative Health, 'Complementary and alternative medicine (CAM) is a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting health and well-being' (Ministerial Advisory Committee on Complementary and Alternative Health 2003).

Current developments in New Zealand relating to CAM include recognition of traditional healing methods by some hospitals, proposals for new legislation on regulating therapeutic products, and the establishment by the Ministry of Health of an evidence-based website on complementary and alternative medicines. The growing interest in CAM is also reflected in the establishment of advisory structures to assist the Minister of Health on such matters as regulation, consumer information needs, research, and efficacy and integration. Policy advice with regard to traditional Māori healing is being addressed by the Ministry of Health's Māori Health directorate in the context of implementing *He Korowai Oranga: Māori Health Strategy* (Minister and Associate Minister of Health 2002a) . These developments will help to ensure the positive involvement of people with cancer, their family and whānau in cancer treatment and care and reduce the risks of ineffective therapies that compromise conventional treatment.

Broad areas for action

Broad areas for action include:

- ensuring comprehensive, reliable and objective information, including that from the Ministry of Health database on CAM research, is easily accessible and understandable to patients, their families and whānau
- making sure the information is available in different forms and in different languages
- training in communication skills and ensuring that information is communicated in a way that meets varying needs, recognising that many people prefer information to be delivered face to face.

Objective 5: Ensure optimal independence and function for those with cancer through systematic assessment and appropriate multidisciplinary intervention for their social and vocational needs

Over 50 percent of people with cancer will be long-term survivors, and many of them will be of working age (Berry and Catanzaro 1992). Many will carry residual effects of malignancy, or of cancer treatment, or both, which may affect their ability to work or pursue everyday activities. These may be physical effects, or indirect psychological or social effects, which also may contribute to discrimination – a latent sequel of chronic disease (Corner 2000). This could be in the form of outright or subtle discrimination in the workplace or in social interaction. Those seeking to work may also encounter workplace or physical barriers to their return to work. Many of these damaging effects could be avoided or minimised if addressed in a timelier manner as an integral part of an individual management plan.

Broad areas for action

Broad areas for action include the development of:

- materials on the rights of people with cancer, focusing on provisions of the Health and Disability Code and human rights legislation
- an initial screening tool with 'triggers' to assess the social, vocational and rehabilitation needs of cancer patients
- a vocational plan that includes realistic goals, timelines and outcomes for patients
- strategies to address issues relating to discrimination and other potential barriers to everyday life, including return to work.

Objective 6: Continue to improve access to essential palliative care services that provide appropriate symptom relief and emotional, spiritual, cultural and social support for those with cancer and their family and whānau

The WHO (2002) holds that not only should palliative care be a central feature of all good clinical practice, but it should also be given priority status within public health and disease-control programmes. There is now widespread recognition that the principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness.

The need to establish a systematic and informed approach to funding and providing palliative care in New Zealand has already been acknowledged. The *New Zealand Palliative Care Strategy* (Minister of Health 2001b) outlines nine strategies that are to be implemented over a five- to ten-year period. The first priorities are to ensure that essential palliative care services are available for all dying people and that at least one local palliative care service is available in each DHB area. Essential palliative care services are defined as: assessment (initial and ongoing), care co-ordination, clinical care (community-based nursing and medical management), inpatient care, bereavement and spiritual care, and support care (in the home or in long-term residential care).

The first stage of the implementation of the *New Zealand Palliative Care Strategy* has gone some way to increasing access to palliative care services. The Expert Working Group on Palliative Care (2003) identified a number of remaining barriers that prevent people receiving appropriate care, including:

- the lack of a palliative care approach by some cancer service providers, leading either to no referral or late referral to palliative care services
- uneven distribution of palliative care services throughout the country, resulting in service gaps, particularly in rural areas

- barriers to access, especially for Māori and Pacific peoples
- a lack of services specifically designed for children and adolescents.

There is a continuing need to ensure that those short-term and medium-term strategies that have already been identified are enacted.

Broad areas for action

Broad areas for action include:

- ensuring each region has at least one local palliative care service
- building on existing services, including primary care services
- developing appropriate support services
- improving access for those with limited or difficult access (eg, Māori and Pacific peoples, children and those living in rural areas)
- providing equality of access to hospital-based palliative care teams
- ensuring equality of access to a specialist palliative care service
- ensuring information on available services is widely available.

Objective 7: Ensure an integrated and comprehensive service is provided to all those with cancer who require palliative care and their family and whānau

A review by the Health Funding Authority (1999) identified that there was very little co-ordination and integration of palliative care services. Since the introduction of the *New Zealand Palliative Care Strategy* (Minister of Health 2001b), some DHBs have been working to improve this situation. However, there is still some way to go.

Lack of co-ordination and inflexibility of services can result in:

- people not being able to access the full range of palliative care services
- inappropriate care (eg, hospital care when hospice or community care may be more appropriate and desirable)
- repeated acute admissions to hospital for some people in their last few months of life
- inefficient delivery of services (eg, some people have been visited by more than four providers in a single day (Health Funding Authority 1999)), including fragmentation and duplication of services
- an inability to provide flexible packages of care that are specific to an individual's (or family's and whānau's) needs
- older people and people living alone having problems accessing services.

Broad areas for action

DHBs need to continue to work on co-ordinating and integrating the broad range of professionals and services involved in the care of a person with cancer. These services include:

- primary care
- hospital services, such as oncology, surgical services and hospital palliative care teams
- community-based services, including district nursing and allied health services
- hospice services (community and inpatient)
- Māori and Pacific peoples' services and groups
- long-term residential care and support services
- social support services provided by voluntary agencies.

Goal 5: Improve the delivery of services across the continuum of cancer control through effective planning, co-ordination and integration of resources and activity, monitoring and evaluation

The focus of this goal is to improve the delivery of all cancer control services throughout the country and across the continuum of cancer control. Some of the technical issues facing various types of services will need to be dealt with at an individual service level. Other issues are common to all areas and can be worked on collectively and collaboratively; for example, workforce development and addressing health inequalities in cancer that exist for Māori and Pacific peoples.

A collective and co-ordinated approach would create greater cohesion among the various agencies involved in cancer control and ensure that relatively scarce resources are used fairly, efficiently and effectively. Collaboration across the sectors would also serve to promote continual improvement, innovation and creativity among cancer service providers, as well as maximising performance in delivering services that fit the diversity of cultural and social needs of New Zealand's population.

Evaluation is essential in supporting decision-making processes (including planning, implementation and outcome evaluation) relating to cancer control activities and services. Continuous evaluation of standards and monitoring processes is also essential for assessing progress and enhancing effectiveness. Monitoring the effectiveness of services is crucial.

Influential and respected leadership will be needed to bring the various and diverse stakeholders together, to promote effective working relationships, and to share knowledge, skills, expertise and responsibilities in areas of common concern.

Objective 1: Develop a co-ordinated national cancer workforce strategy

The human resources devoted to cancer control include both the paid and – particularly in the non-government sector – unpaid workforce. Many of the issues being addressed by the Health Workforce Advisory Committee (HWAC) (2002) are common to those of the cancer workforce. This committee has defined six priority areas for development, including addressing workforce implications for the Primary Health Care Strategy and building capacity in the Māori, Pacific and disability-related health workforces. However, it has not considered the present and future needs of the cancer control workforce.

Recruitment, training and retention are major problems for cancer control in New Zealand. At present, shortages of specialist professional staff in many areas of cancer care are affecting our ability to provide appropriate treatment and support for people and their families and whānau experiencing cancer. Some of these workforce shortages have been well documented – particularly those in radiation oncology services (radiation oncologists, radiation therapists and physicists), and current capacity in these areas has been described as marginal and barely meeting demands (Ministry of Health 2001c). There are also deficiencies in other cancer treatment disciplines, including anatomic pathology and medical oncology, and shortages of trained oncology nurses and pharmacists. Gaps in other workforce groups who contribute significantly to cancer control (eg, radiologists, surgeons, general practitioners, health promoters and community health workers) are less well documented, and further work is needed to quantify the needs and determine their impact on cancer service provision in these areas. The planned approach to the development of a screening workforce undertaken by the National Screening Unit may offer useful guidance for other areas of cancer control.

There are also problems relating to the planning and development of the palliative care workforce, along with the provision of a culturally representative workforce, and the development of national requirements and sources of training support for palliative medicine and other multidisciplinary professionals. There is a need for increased training for clinicians to ensure that palliative care principles and the palliative care approach are offered as an option to people with life-threatening cancer.

The cancer control workforce contains relatively few Māori workers at all levels. Educational programmes related to cancer need to target Māori, who should be encouraged to train as doctors, nurses, counsellors, chaplains and allied health professionals. The training of the general cancer control workforce needs to include specific learning to ensure that non-Māori health professionals understand, and are responsive to, the needs of Māori (Ratima 2002). The workforce development plan for cancer control needs to ensure that sufficient numbers of trained Māori and Pacific cancer control professionals are available to provide appropriate care for these population groups.

As the demand for cancer control services and activities continues to rise with population growth and an ageing population, there will be a pressing need to develop and implement a nationally co-ordinated cancer control human resources plan. Implementation of the workforce development plan will require collaborative and co-operative effort involving the Ministry of Health, DHBs and other cancer service providers involved in screening, rehabilitation, community support and palliative care services, and the tertiary institutions and other providers of workforce education and continuing professional development.

Broad areas for action

Broad areas for action include:

- a comprehensive stocktake of the present workforce and workforce requirements across the continuum of cancer control
- a workforce development plan aimed at correcting current deficits and meeting future needs
- increased involvement of Māori and Pacific health professionals in cancer control
- ensure consistency with HWAC recommendations.

Objective 2: Ensure appropriate programmes and services are accessible to Māori across the cancer control continuum

Cancer is a leading cause of morbidity and mortality among Māori and there are significant disparities between Māori and non-Māori in relation to the incidence of cancer, cancer mortality rates and utilisation of cancer services.

Differential access to health services is a primary concern; it has had a profound effect on health outcomes for Māori and contributes to the disparities in health status between Māori and non-Māori. Further, the predominant monocultural mode of 'one size fits all' is inadequate, although there are some indications that access to hospice services is improving for Māori.

Māori approaches to health are primarily based on the view that hauora, or holistic health, is the product of wellbeing at the physical, spiritual, psychological and social levels. There are many Māori models of health in use that encompass this approach, including Te Whare Tapa Whā, or the four corner posts of health (Durie 1994), Te Pae Mahutonga, or the Southern Cross (Durie 1999), and Te Wheke, the Octopus (Pere 1984). Services being delivered to Māori need to reflect an understanding of hauora Māori and approaches that appropriately address Māori health needs.

Māori-provided services are being increasingly integrated into the mix of health and disability services in New Zealand. Māori health services are those that are planned and delivered by Māori health workers and professionals using cultural concepts and values. While the target audience for these services is Māori and their whānau, they are also used by other members of the community at large.

In addition to services specifically developed within a Māori cultural framework, there is a need to ensure that all services delivered to Māori demonstrate a level of cultural competency. *Cultural Competence and Medical Practice in New Zealand* (Durie 2001) notes the need to ensure that treatment and service delivery in New Zealand are based on the 'cultural competence or capacity of health workers to improve health status by integrating culture into the clinical context'.

Whakatātaka: Māori Health Action Plan 2002–2005 (Minister of Health and Associate Minister of Health 2002b) is the implementation plan for *He Korowai Oranga* (Minister of Health and Associate Minister of Health 2002a), and provides a framework and specific priority action areas to improve Māori health outcomes. It identifies four pathways that need to be addressed:

- development of whānau, iwi and Māori communities
- Māori participation in the health and disability sector – active participation by Māori at all levels of the health and disability sector
- effective health and disability services – timely, high-quality, effective and culturally appropriate services to improve health and reduce inequalities
- intersectoral – with the health and disability sector taking a leadership role across government sectors and government agencies to achieve whānau ora by addressing the broader determinants of health.

Broad areas for action

While full implementation of *Whakatātaka* has the potential to address many of the issues faced by the health and other sectors that impact on Māori health status generally, addressing the inequalities in cancer that exist for Māori requires a change in the way in which the sector plans, funds and provides cancer services for Māori. The Intervention Framework (Appendix 6) and the Health Equity Assessment Tool (Appendix 7) are useful tools for changing the cancer sector's activities in order to address health inequalities.

Other areas for action include:

- ensuring that services across the spectrum of cancer control have policies in place that recognise the specific needs of Māori, and that these are implemented and monitored
- improving links between providers and Māori development organisations to assist in meeting the specific needs of Māori
- further developing and maintaining Māori health providers
- improving the accountability of mainstream providers for Māori health outcomes.

Objective 3: Ensure the active involvement of consumer representatives across the spectrum of cancer control

Although the importance of consumer involvement and the role of consumer representatives have become widely recognised in New Zealand, particularly since the release of the Cartwright Report (Cartwright 1988), implementing consumer input has been piecemeal. At present, there are very few consumers involved as representatives in cancer control activities, and this only in some activities and at some levels. Consumer voices and concerns are not actively sought in many areas; for instance, in assessing, guiding and formulating the requirements for support and rehabilitation services, or in the development and monitoring of standards. There is no organised approach to make sure that people most represented in the health statistics have a say, on an ongoing basis, on what the key issues are and which strategies would be appropriate.

A systematic approach is required to facilitate the use of consumer representatives in cancer control activities and services. Well-resourced initiatives in countries such as Australia and Britain provide working examples of what can be achieved with organised consumer networks that provide appropriate training, support and sufficient funding. The Ministry of Consumer Affairs' *Guidelines for Consumer Representation: Guidelines for officials* (Ministry of Consumer Affairs 2003) may provide a useful guide for involving consumers. Women's Health Action, a consumer advocacy group, also provides guidelines on consumer participation and representation.

Broad areas for action

Broad areas for action include the development of a mechanism to:

- provide advice and assistance to organisations and groups on how to adequately address consumer representation
- investigate and assess consumer-training initiatives
- provide advice, as well as practical assistance to groups in finding appropriate consumer representatives
- increase Māori and Pacific peoples' consumer representation.

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

The knowledge required for effective cancer control originates in three broad types of knowledge-generating activities: fundamental research, intervention research and surveillance (Canadian Strategy for Cancer Control 1999).

Fundamental research allows us to better answer the questions: *What are the causes of different types of cancer and how can they be prevented? How does cancer start and how does it progress? and What is its impact on people's lives?* This type of research includes biomedical research (on the biological mechanisms underlying cancer), epidemiology (identifying the factors that increase or decrease the risk of developing cancer), public health, social sciences and economics.

Intervention research assesses the efficacy and effectiveness of actions designed to achieve cancer control. This includes testing strategies and methods relating to prevention, early detection, treatment, support and rehabilitation, and palliative care. It addresses the question, *What works?*

Surveillance is the collection, analysis and review of cancer-related data, and the dissemination of findings on prevalence, morbidity, survival and mortality. It provides information about practices that prevent cancer, facilitate screening, and improve care and the quality of life. It provides answers to the following: *What population subgroups have higher cancer risks? Which types of cancer have greater impact? How well are we preventing cancer incidence and controlling cancer progression?*

These three activities are the key inputs to knowledge synthesis, and the production of the evidence needed for effective prevention and control of cancer. Knowledge synthesis helps to answer: *What actions are needed now?* Thus, research allows the development of evidence-based priorities for cancer control.

Objective 1: Extend and enhance research across the continuum of cancer control

Some research is currently being conducted in New Zealand in most fields of cancer control, but the effort is somewhat unco-ordinated and unevenly distributed, and varies greatly in quality and quantity. Although overseas research findings are an important source of new knowledge, there is much vital information that can only be obtained by New Zealand-based research; for example, the reasons for significant disparities in the incidence of, and survival from, some forms of cancer between New Zealand and similar countries, and between population groups within New Zealand.

The Health Research Council is the largest source of funds for cancer research, followed by the Cancer Society of New Zealand and the other cancer-related charities. Most of the research funded by these agencies is on topics chosen by the investigators. Currently, about three-quarters of this funding supports laboratory-based biomedical research, about 10 percent goes towards clinical research, and about 6 percent is for epidemiological studies. The biomedical cancer research conducted in New Zealand is of high international quality – especially in the fields of cellular biology, cancer genetics and anti-cancer drug development – and this national strength should be maintained. However, additional clinical, public health and epidemiological research is required to inform planning related to cancer control. A greater involvement of health-care providers in research would improve the quality of clinical practice (eg, through participation in clinical trials, which is a fundamental way to provide and evaluate new treatments).

There is a particular need for increased social, behavioural, environmental, psychological and health services research to determine and evaluate better methods of preventing cancer; encouraging timely access to screening, diagnosis, treatment and palliative care services; and improving rehabilitation and support activities. Such research has great potential to substantially reduce the incidence and impact of cancer in New Zealand.

The current research workforce has talents that reflect the current distribution of investigator-initiated research. Therefore, training as well as funding will be needed to stimulate research in fields that are presently under-investigated. In order to address this imbalance, the Health Research Council has developed the Partnerships for Evidence Based Public Policy and Services programme, which is designed to facilitate co-operation with other funding agencies, such as the Ministry of Health, in collaborative research projects on defined topics.

There is a need for high-quality and comprehensive research into Māori health and cancer. This needs to include the broader aspects of whānau ora, which are important determinants of Māori health status (Minister of Health and Associate Minister of Health 2002a).

At present there is no single body responsible for identifying and remedying gaps in the spectrum of cancer research in New Zealand. Thus, there is a need to establish a strategic and continuing process for overseeing and facilitating cancer research, to provide a ‘from research to policy practice’ perspective (Canadian Strategy for Cancer Control 2001) for this New Zealand Cancer Control Strategy. There is also a need to identify areas where specific research is needed, as provided, for example, by the Tobacco Control Research Strategy (Tobacco Control Research Steering Group 2003).

Broad areas for action

Key areas for action are:

- the development of a strategic and regular process for facilitating research relevant to cancer control in New Zealand
- the development and maintenance of Māori research capacity.

Objective 2: Improve the use, efficiency and scope of national data collection and reporting

Determining the effectiveness of the actions required to implement this strategy will require the collecting, analysing and reporting on national cancer data related to each of these actions. Such information is also essential evidence for the periodic review and modification of the strategy's objectives. Together with improved collaboration among the various stakeholders in cancer control, this will significantly increase the range of data collected and provide an increased emphasis on the analysis and interpretation of cancer-related information.

Essential to this objective is the development of an agreed, nationally consistent minimum data set and the efficient and collaborative management of cancer data. This requires the effective use of information technology, including using standard data sets, agreed data definitions and appropriate networking mechanisms to link databases and health record systems across New Zealand. A more comprehensive national cancer data set would enhance surveillance at both the population and individual levels. Population cancer trends could be monitored and the information linked to treatments provided, allowing comparisons and reporting on patterns of care and outcomes.

Standardised collection of ethnicity data is necessary to form an accurate picture of the cancer situation in New Zealand's various sub-populations. Ethnicity data tend to be poorly collected, inaccurate or not collected at all in the health sector. Differences in the way ethnicity has been defined and measured over time, and across agencies, make it difficult to form an accurate picture of the disparities between Māori and non-Māori. Additional data on ethnicity would also identify important differences that may exist with respect to the growing Pacific and Asian populations.

New Zealand has a dedicated Cancer Registry, which was established in 1948. Part of the New Zealand Health Information Service (NZHIS) situated in the Ministry of Health, it collects the histopathological diagnosis on all people with cancer and limited stage information on some cancers, and provides information on cancer incidence and survival. However, its resources are limited, and there are inefficiencies with data collection. At present, data do not always include detail of the stage of cancer at the time of diagnosis, the treatment received or the length of survival following treatment. The Cancer Registry should be a central core of cancer control activities.

Although substantial cancer-related data are already being collected in New Zealand, they require more focused analysis and interpretation. The six cancer centres (in Auckland, Hamilton, Palmerston North, Wellington, Christchurch and Dunedin) are attempting to develop regional clinical databases, but most are not comprehensive nor well co-ordinated and thus are of limited utility in informing the national cancer strategy. Links to other databases, such as those used in palliative care and primary care, could assist to further our understanding of the continuum of cancer care; for example, clinical information systems could be appropriately linked to the Cancer Registry; data from pathology laboratories could

be electronically transferred to the Registry; and information on waiting times and survival would identify any geographic and ethnic differences with respect to access to or effectiveness of treatment.

The Cancer Registry has the potential for receiving and processing the considerably expanded range of information required to underpin the Cancer Control Strategy. Its role could be further extended if it were involved in developing more detailed data sets for cancers identified to have particular significance in New Zealand. To achieve such objectives, the enhanced Registry will need to be provided with medical and scientific strength to assist with the timely analysis and interpretation of cancer-related data.

Broad areas for action

Broad areas for action include:

- developing and collecting a standardised national data set
- expanding and standardising the collection of ethnicity data
- defining the role of the Cancer Registry and the essential links it needs to collect the information most effective in cancer control
- linking the Cancer Registry with the appropriate clinical, pathology and palliative care databases
- developing national data sets for cancers that have particular significance in New Zealand
- facilitating ongoing monitoring and cancer control research through an enhanced Cancer Registry.

Appendix 1: The New Zealand Cancer Control Steering Group Membership

Dr Colin Tukuitonga (Chair)	Director of Public Health, Ministry of Health
Assoc Prof Chris Atkinson (Deputy Chair)	Chair, Oncology, Haematology and Palliative Care, Canterbury District Health Board
Glenys Baldick	Chief Executive Officer, Nelson–Marlborough District Health Board
Dr John Childs	Clinical Director, Auckland Oncology Service; Chair, New Zealand Cancer Treatment Working Party
Assoc Prof John Collins	Head of the Breast Cancer Service, Middlemore Hospital
Dr Rob Corbett	Medical Director, South Island Child Cancer Service
Dr Brian Cox	Director, Hugh Adam Cancer Epidemiology Unit, University of Otago
Dr Chris Cunningham	Director, Health Research, School of Māori Studies, Massey University
Dr Colin Feek	Deputy Director-General, Clinical Services Directorate, Ministry of Health
Prof John Gavin	Executive Director, New Zealand Cancer Control Trust
Helen Glasgow	Executive Director, Quit Group
Dr Colleen Lewis	General practitioner, Dunedin
Cynthia Maling	Manager, Public Health Policy Group, Ministry of Health
Betsy Marshall	Project Manager, New Zealand Cancer Control Trust
Jan Nichols	Executive Manager, St Joseph's Mercy Hospice
Dr Keri Ratima	General practitioner, Māori Medical Practitioners' Association member
Dr Tony Ruakere	General practitioner, Te Ati Awa Medical Service, Taranaki

Appendix 2: The New Zealand Cancer Control Strategy Secretariat Members

Andrea Bland	Administration, Ministry of Health
Bridget Caird	Analyst, Ministry of Health
Prof John Gavin	Executive Director, New Zealand Cancer Control Trust
Emma Hindson	Senior Analyst, Ministry of Health
Laura Lambie	Clinical Advisor, Ministry of Health
Jane Lyon	Clinical Advisor, Ministry of Health
Michelle Mako	Senior Advisor, Ministry of Health
Cynthia Maling	Manager, Public Health Policy Group, Ministry of Health
Betsy Marshall	Project Manager, New Zealand Cancer Control Trust
Marjan van Waardenberg	Senior Analyst, Project Leader, Cancer Control Strategy, Ministry of Health

Appendix 3: Expert Working Group Members

Group	Members
Primary prevention Chair: Cynthia Maling Co-ordinator: Marjan van Waardenberg	Helen Glasgow Alistair Harray Dr Colleen Lewis Dr Tony Reeder Anaru Waa Carolyn Watts Prof Alistair Woodward
Screening and early detection Chair: Dr Brian Cox Co-ordinator: Betsy Marshall	Dr Linda Cameron Dr Julia Peters Dr Keri Ratima Anne Allan-Moetaua Judi Strid Assoc Prof Ingrid Winship
Treatment Chair: Assoc Prof John Collins Co-ordinator: Jane Lyon	John Booth Dr Hilary Blacklock Dr John Childs Dr Robin Corbett Prof Brett Delahunt Dr Vernon Harvey Natalie James Dr Juliet Walker Colleen Winera
Support and rehabilitation Chair: Assoc Prof Chris Atkinson Co-ordinator: Betsy Marshall	Marilyn Barclay Janet Bernard Kay Morris Fiona Pearson Dr Tony Ruakere Doug Sexton Dr Lois Surgenor
Palliative care Chair: Jan Nichols Co-ordinator: Laura Lambie	Maggie Barry Peter Buckland Dr Ross Drake Dr Kate Grundy Dr Mark Jeffrey Dr Graham Kidd Dr Rod McLeod Debbie Sorensen Janice Wenn

Appendix 4: The Strategy in Context

The New Zealand Cancer Control Strategy draws on and links with other key health and disability strategies. These include:

- the *New Zealand Health Strategy* (Minister of Health 2000)
- the *Primary Health Care Strategy* (Minister of Health 2001c)
- the *New Zealand Palliative Care Strategy* (Minister of Health 2001b)
- the *New Zealand Disability Strategy* (Minister for Disability Issues 2000)
- *He Korowai Oranga: Māori Health Strategy* (Minister of Health and Associate Minister of Health 2002a)
- *Whakatātaka: Māori Health Action Plan 2002–2005* (Minister of Health and Associate Minister of Health 2002b)
- *Health of Older People Strategy: Health sector action to 2010 to support positive ageing* (Associate Minister of Health and Minister for Disability Issues 2002a)
- *Healthy Eating – Healthy Action: Oranga Kai – Oranga Pumau: A strategic framework* (Ministry of Health 2003a)
- *Making a Pacific Difference: Strategic initiatives for the health of Pacific people in New Zealand* (Ministry of Health 1997)
- the *Pacific Health and Disability Action Plan* (Minister of Health 2002d)
- *New Zealand Health and Disability System Quality Improvement Strategy* (draft) (Ministry of Health 2003c)
- *Clearing the Smoke: A five-year plan for tobacco control in New Zealand (2003–2007)* (preliminary discussion document) (Ministry of Health 2002b)
- *An Integrated Approach to Infectious Disease: Priorities for action 2002–06* (Ministry of Health 2002)
- *Improving Non-Surgical Cancer Treatment Services in New Zealand* (Ministry of Health 2001c)
- *Reducing Inequalities in Health* (Ministry of Health 2002e)
- *National Alcohol Strategy 2000–2003* (Ministry of Health 2001d).

Appendix 5: WHO Definitions of Palliative Care

Palliative care

'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

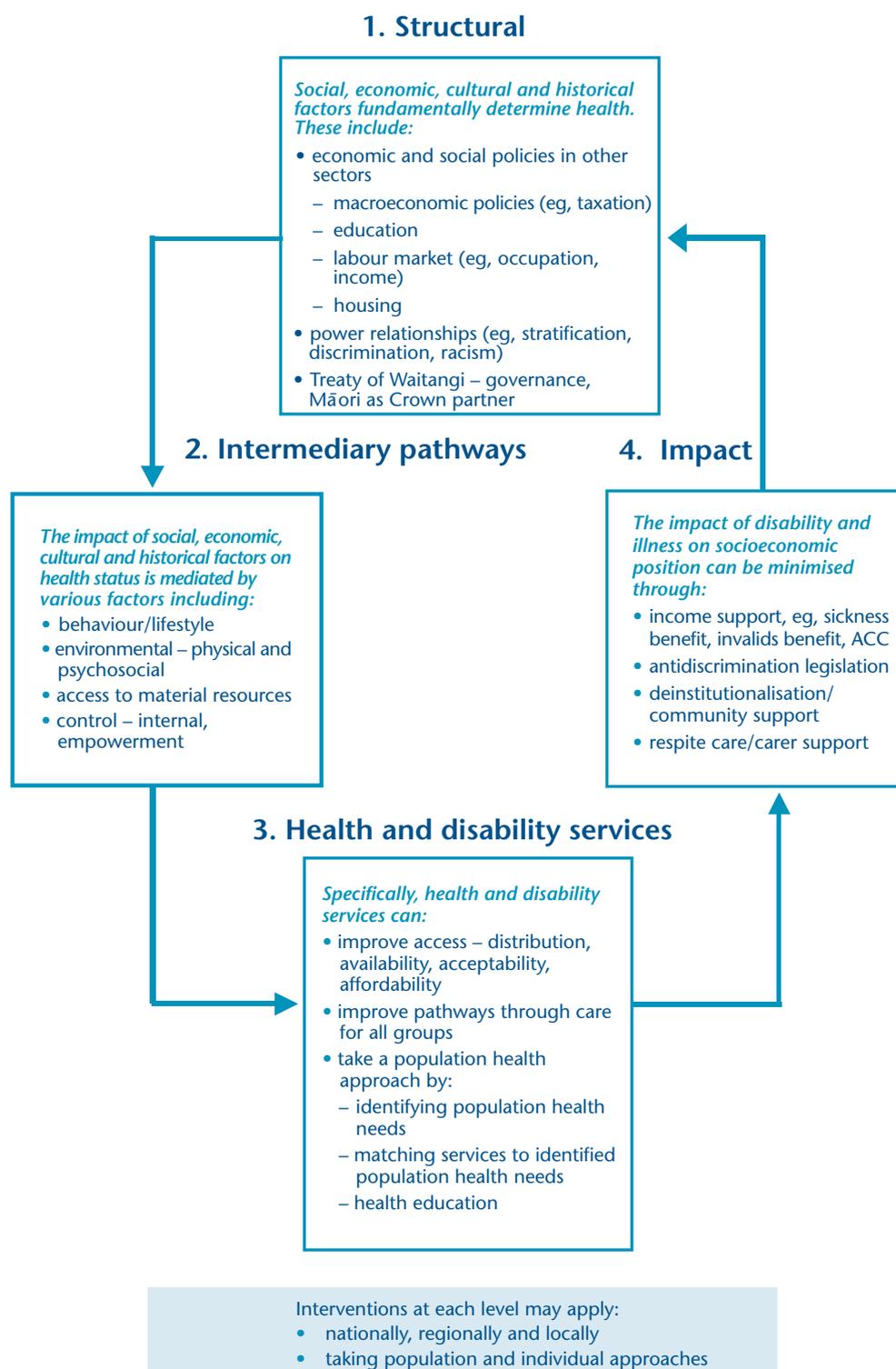
- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.'

Palliative care for children

'Palliative care for children represents a special, albeit closely related, field to adult palliative care. WHO's (1998) definition of palliative care appropriate for children and their families is as follows (the principles also apply to other paediatric chronic disorders):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.'

Appendix 6: Intervention Framework to Improve Health and Reduce Inequalities



Source: Ministry of Health 2002f

Appendix 7: Health Equity Assessment Tool

There is considerable evidence, both internationally and in New Zealand, of significant inequalities in health between socioeconomic groups, ethnic groups, people living in different geographical regions and males and females (Acheson 1998; Howden-Chapman and Tobias 2000). Research indicates that the poorer you are the worse your health. In colonised countries, such as New Zealand, indigenous people have poorer health than others. Reducing inequalities for Māori is a Treaty of Waitangi obligation and a priority for government. The New Zealand Health Strategy acknowledges the need to address health inequalities as ‘a major priority requiring ongoing commitment across the sector’ (Minister of Health 2000).

Inequalities in health are unfair and unjust. They are also not natural; they are the result of social and economic policy and practices. Therefore, inequalities in health are avoidable (Woodward and Kawachi 2000).

The following set of questions has been developed to assist you to consider how particular inequalities in health have come about, and where the effective intervention points are to tackle them. They should be used in conjunction with the Ministry of Health’s Intervention Framework (Ministry of Health 2002).

1. What health issue is the policy/programme trying to address?
2. What inequalities exist in this health area?
3. Who is most advantaged and how?
4. How did the inequality occur? (What are the mechanisms by which this inequality was created, is maintained or increased?)
5. What are the determinants of this inequality?
6. How will you address the Treaty of Waitangi?
7. Where/how will you intervene to tackle this issue? Use the Ministry of Health Intervention Framework and the Treaty of Waitangi to guide your thinking.
8. How could this intervention affect health inequalities?
9. Who will benefit most?
10. What might the unintended consequences be?
11. What will you do to make sure it does reduce/eliminate inequalities? (to manage the consequences)
12. How will you know if inequalities have been reduced/eliminated?

(Based on Bro Taf Authority. 2000. *Planning for Positive Impact: Health Inequalities Impact Assessment Tool*.)

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Appendix 8: Consultation

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Quit Group
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Christchurch Hospital Palliative Care Service
Breast Cancer Network (New Zealand) Inc
Alcohol Healthwatch
North Shore Hospice
Women's Health Action Trust
New Zealand Drug Foundation

Health by Design Ltd
Sport and Recreation New Zealand
Smokefree Central, Palmerston North
Community and Public Health, Greymouth
Canterbury

Te Puke
Reps of the NZNO Cancer Nurses Section
New Zealand Register of Holistic Aromatherapists
Public Health Association
Waikato Hospital
South Canterbury Hospice
Hastings Cranford Hospice

Leukaemia and Blood Foundation
Office for the Commissioner for Children
National Screening Unit
Sawmill Workers Against Poisons (SWAP)
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Hospital Palliative Care New Zealand
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Thames
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Craig Werner	
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Dr Peter Woolford	New Lynn Medical Centre

Addendum to list of submitters

Ann Martin

Hospice New Zealand

Schedule of consultation meetings in 2003

10 February	Whangarei, hui
11 February	Whakatane, hui
18 February	Greymouth, general
19 February	Christchurch, hui
20 February	Christchurch, fono
26 February	Southland, general
27 February	Dunedin, general
28 February	Christchurch, general
5 March	Wellington, hui
5 March	Wellington, general
6 March	Porirua, fono
7 March	Palmerston North, general
9 March	Auckland, Asian Focus Group
11 March	Auckland, hui
11 March	Auckland, general
12 March	Hamilton, general
13 March	Auckland, fono
15 March	Tauranga, hui

Glossary

Access	The ability of people to reach or use health services. Barriers to access may be influenced by: (1) a person's locality, income or knowledge of services available; (2) the availability or acceptability of existing services.
Anatomic pathology	The study and diagnosis of disease based on structural changes in cells, tissues and organs.
Cancer care services	Services for those with cancer, their family and whānau to assist in meeting their total needs; ie, physical, social, psychological, sexual, nutritional, information and spiritual needs.
Cancer control services	Services to reduce the incidence and impact of cancer, including public health, screening, diagnosis, treatment and cancer care.
Caregiver	A voluntary caregiver or carer is a person, usually a family and whānau member, who looks after a person with a disability or health problem, and who is unpaid.
Chemotherapy	The treatment or control of cancer using anti-cancer drugs.
Clinical trial	A research activity to evaluate benefit and safety among humans (eg, of a vaccine or a drug).
Community	A collective of people identified by their common values and mutual concern for the development and wellbeing of their group or geographical area.
Consumers	Users of services.
Coverage	The proportion of all eligible people screened by a programme, calculated as the total number screened divided by the number of those who are eligible.
Diagnosis	The determination of the nature of disease.
District Health Boards (DHBs)	The New Zealand Public Health and Disability Act 2000 established 21 District Health Boards (DHBs). DHBs are responsible for assessing the health and disability needs of communities in their regions, and managing resources and service delivery to best meet those needs.
Early detection	The detection of cancer prior to the development of symptoms, or as soon as practicable after the development of symptoms.
Effectiveness	The extent to which a specific intervention, procedure, regimen or service, when implemented, does what it is intended to do for a defined population.

Epidemiology	The study of the distribution and determinants of health-related states or events in specific populations.
Equity (in health)	Fairness.
Evaluation	Assessment of a service or programme against a standard. Evaluations can be: (1) <i>formative</i> (informs the development and improvement of a programme); (2) an assessment of the <i>process</i> (describes the programme and helps to explain why it produces the results it does); (3) an <i>outcome</i> evaluation (an assessment of the ultimate effects of a programme).
Evidence-based medicine	Clinical decision-making based on a systematic review of the scientific evidence of the risks, benefits and costs of alternative forms of diagnosis or treatment.
Evidence-based practice	Practice that is based on scientific evidence that demonstrates effectiveness.
Familial cancer risk assessment	The investigation of (1) a reported family and whānau history of cancer; (2) an individual who develops cancer at a young age (usually under 50 years) with no family or whānau history to assess cancer risk for individuals and/or members of their family and whānau.
Gene	A large molecule, part of a cell's DNA, that controls the production of a protein molecule and through it, some action or function of the cell.
Genetic mutation	An error in the gene caused by damage. This may result in a faulty or altered protein, or no protein being produced.
Genetic screening	Testing to detect genetic mutations that place an individual at increased risk of a disease (eg, genes that greatly increase a woman's risk of breast and ovarian cancer).
Goal	A high-level strategic action.
Green prescription	A green prescription is a health professional's written advice to a patient to be physically active, as part of the patient's health management.
Hapū	Sub-tribe.
Health inequality	Differences in health that are unnecessary, avoidable and unjust.
Health promotion	The process of enabling people to increase control over and improve their health. It is a comprehensive social and political process.
Health status	A description and/or measurement of the health of an individual or population.
Histopathological diagnosis	The determination of the nature of a disease by the microscopic examination of cells and tissues.

Incidence	The number of new cancer cases.
Incidence rate	The rate at which new cases of cancer occur.
Intervention	A programme or series of programmes.
Iwi	Tribe.
Monitoring	The performance and analysis of routine measurements aimed at detecting changes.
Morbidity	Illness.
Mortality	Death.
New Zealand Cancer Registry	The New Zealand Cancer Registry was established in the Department of Health in 1948. It maintains a register of people who develop malignant diseases. Registrations are based on single primary cancer cases that are distinguished by differences in topography or histology. Each case of cancer is registered just once, in the year the cancer is first diagnosed. Registration is required under the Cancer Registry Act 1993.
Objective	The expected results from an activity or programme.
OECD	Organisation for Economic Co-operation and Development. The 24 OECD countries are Australia, Austria, Belgium, Canada, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Japan, Luxembourg, Netherlands, New Zealand, Norway, Portugal, Spain, Sweden, Switzerland, Turkey, United Kingdom and the United States.
Oncologist	A specialist in the treatment of cancer.
Oncology	The study, diagnosis, treatment and management of cancerous tumours.
Optimal treatment	Treatment known to provide the best outcome based on current knowledge.
Outcomes	The anticipated overall effects of an intervention or programme, especially in relation to whether the overall programme goal has been achieved.
Pacific peoples	Encompasses a diverse range of peoples from the South Pacific region (eg, Tongan, Niuean, Fijian, Cook Island Maori, Samoan and Tokelauan) living in New Zealand, who have migrated from those island nations or identify with them because of ancestry or heritage.

Palliative care	‘An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’ (WHO 2002).
Pathologist	A doctor who specialises in the examination of normal and diseased tissue.
Person-centred	Recognition of a person’s total wellbeing, including their physical, emotional, spiritual, social and practical needs within the context of family and whānau. For Māori this means recognising and responding appropriately to a Māori holistic view of health.
Population-based	Relating to a general population defined by geographical boundaries.
Population health	The health of a population, measured by health status. Populations may be defined by locality, biological criteria such as age or gender, social criteria such as socioeconomic status, or cultural criteria such as whānau. A population health approach aims to maintain and improve the overall health outcomes of entire populations and reduce inequalities in health between different groups.
Prevalence	The level of disease or other health-related condition present in the population at a given time.
Principle	A fundamental basis for action.
Prophylactic	Use of medical procedures or treatments to prevent or defend against a disease.
Protocol	A defined programme for treatment.
Psycho-oncology	The study, understanding and treatment of social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer as applied across the cancer control continuum.
Public health	The science and art of promoting health, preventing disease and prolonging life through organised efforts of society.
Public health services	Services offered on a population basis. These include all programmes, interventions, policies and activities that improve and protect the health of individuals and the community. Public health services intervene at the population or group level, as distinct from individual personal health services.
Radiation oncologist	A specialist in the treatment of cancer using X-ray techniques.

Rate	In epidemiology, the frequency with which a particular type of health event (eg, cancer) occurs in a defined population.
Risk factors	An aspect of a person's condition, lifestyle or environment which increases the probability of occurrence of a disease.
Screening	Cancer screening is the early detection of cancer, or precursors of cancer, in individuals who do not have symptoms of cancer. These interventions are often directed to entire populations or to large and easily identifiable groups within the population.
Sequelae	A morbid condition(s) or symptom following a disease.
Stage	A description of how widely a cancer has spread to adjacent lymph nodes and other parts of the body.
Stakeholders	Organisations/groups with a direct interest and involvement in aspects of cancer control.
Strategy	A course of action to achieve targets.
Support and rehabilitation	At the broadest level, the provision of the essential services to meet the physical, emotional, nutritional, informational, psychological, sexual, spiritual and practical needs throughout a person's experience with cancer.
Surveillance	The ongoing assessment of an individual for the purpose of instituting appropriate intervention to reduce their risk of death from a specific cancer. Also, the continuous collection of data for public health decision-making.
Treaty of Waitangi	New Zealand's founding document. It establishes the relationship between the Crown and Māori as tangata whenua (first peoples) and requires both the Crown and Māori to act reasonably towards each other and with utmost good faith.
Whānau	Extended family and whānau, including kaumātua, pakeke, rangatahi and tamariki. The whānau is recognised as the foundation of Māori society.

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