

**Towards a Cancer Control
Strategy for New Zealand
Marihi Tauporo**
A Discussion Document

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<http://www.cancercontrol.org.nz>



MANATŪ HAUORA

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Foreword

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 has 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. The first, *Progress Towards a New Zealand Cancer Control Strategy* (Gavin, Marshall and Cox 2001), reviewed trends in cancer incidence and efforts to develop national cancer control strategies both here and overseas. The second, *The Development of a National Cancer Control Strategy for New Zealand* (Gavin, Marshall and Cunningham 2001), was a plan for developing a cancer control strategy for New Zealand. Both documents are available at the New Zealand Cancer Control Trust website (www.cancercontrol.org.nz).

Following a commitment from the Minister of Health, the Cancer Control Steering Group was formed to oversee development of the strategy. Members of the Steering Group have expertise in the various aspects of cancer control, and there is a secretariat that reflects the ongoing partnership between the Ministry of Health and the New Zealand Cancer Control Trust. The Ministry of Health and the Trust (the Cancer Society and the Child Cancer Foundation) are funding ongoing development of the strategy.

Five expert working groups were established to advise the Steering Group and to recommend objectives for the draft strategy. These groups covered prevention, screening and early detection, treatment, support and rehabilitation, and palliative care. Their reports on candidate proposed objectives for the strategy are available on the Ministry of Health website (www.moh.govt.nz/cancercontrol) 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 have also been particularly helpful.

The present discussion document provides the basis for consultation with the New Zealand public and with the many government, charitable and professional stakeholders in cancer control. The results of this consultation will contribute to the development of the definitive New Zealand Cancer Control Strategy to be introduced in mid-2003.

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Acknowledgements

The development of the discussion document 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 2)
- 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.

How to Have Your Say

This discussion document is available to the public and has been circulated to key stakeholder groups involved in the delivery of cancer control services. You are invited to submit your comments and ideas on the practicality and workability of the goals and proposed objectives, and to identify any issues that the Cancer Control Steering Group may not have addressed.

You can make a submission as an individual or as a group. There are some key questions we would like you to think about and comment on as you read the document. These questions are in the submission booklet, which is enclosed and found on the Ministry of Health web site (www.moh.govt.nz/cancercontrol).

Feedback on the discussion document can be made in any of the following ways.

1. Complete the submission form on the internet (www.moh.govt.nz/cancercontrol). This sends your submission directly to the Ministry of Health.
2. Complete the submission form as a Word document, which can be found at the above web site and either email it to the Ministry of Health (cancercontrol@moh.govt.nz) or print it off and send it by post to the Ministry of Health (see below for postal address).
3. Write your comments on the submission booklet enclosed in this document and send it to the Ministry of Health by post.
4. Write your comments as a letter or an email and send them to the Ministry of Health by post or email.
5. Attend a consultation meeting, hui or fono, where your comments will be recorded manually (timetable of consultation meetings to be advised).

If you send your submission by post, the address is:

Towards a Cancer Control Strategy for New Zealand
Submissions
Ministry of Health
PO Box 5013
Wellington.

Once the closing date for the submissions is reached, all submissions will be analysed and a strategy finalised on the basis of the submissions.

All submissions are due by **5pm Friday 14 March 2003**.

If you require additional copies of this document, contact:

Wickliffe Press
PO Box 932
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What Happens Next?

After the strategy has been finalised, the next step will be the development of an implementation plan, which will translate the goals and objectives of the strategy into actions. The implementation plan will identify the actions needed by government and non-government service funders, planners and providers to achieve the overarching goals of the strategy.

It will not be possible to do everything at once and a phased introduction of the implementation plan may be required. It may be possible to implement some actions very early, whereas others will take longer to plan and carry out.

The implementation plan will be developed with government and non-government agencies, health professionals and consumers involved with all aspects of cancer control.

The Structure of the New Zealand Cancer Control Strategy

The New Zealand Cancer Control Strategy will be in two parts. The first part is intended to be enduring and will provide a high-level framework, including a purpose, principles and goals to guide existing and future actions to control cancer in the long term.

The second part will include a series of evidence-based objectives that will be subject to ongoing monitoring and periodic review. Systematic review of these objectives every three years will ensure that they are achieving the desired effect and that they remain cost-effective, and also will allow new objectives to be added or substituted as research identifies new and more effective ways of reducing the incidence and impact of cancer.

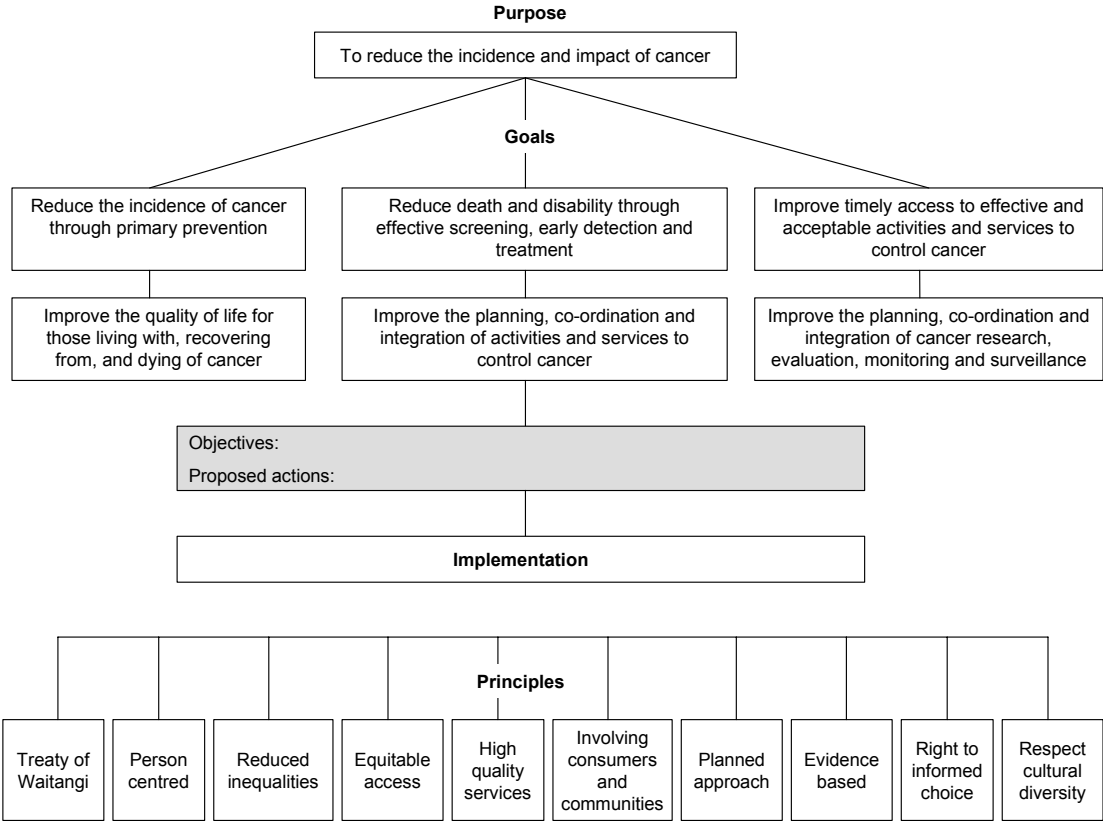
This discussion document includes all of the proposed objectives developed by the expert working groups, and refers to others being developed. The Steering Group will decide, following the consultation process, which proposed objectives should be included in the strategy. The objectives selected will:

- be the most effective
- be able to be implemented in an acceptable timeframe
- be able to be implemented within the resources likely to be available
- have data collection mechanisms available or able to be developed that will allow their effectiveness to be measured.

Ideally the objectives should span the continuum of cancer control so that all the government and non-government agencies involved in cancer control can participate in implementing the strategy. The reality is that initial inclusion of too many objectives could compromise their effectiveness.

The purpose of the consultation process is to seek feedback on the discussion document, in particular the proposed objectives and identify others that may be missing.

Cancer Control Strategy Structure



Part One: The High-Level Framework to Guide Existing and Future Actions

Introduction

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. Cancer, unlike many other diseases, conjures up deep fear and anxiety in most New Zealanders. Many people are unaware how much can be done to prevent, cure and care for those with cancer.

At present we have enough knowledge to prevent at least one-third of cancers. Where resources are available, 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 a significant challenge. For example, cancer includes over a hundred diseases with different causes and treatment methods. Cancer can arise in any organ and at any age. There are also a wide range of organisations and health professionals, both government and non-government, involved in the many aspects of cancer prevention, detection, treatment and care.

New Zealand, along with many other countries, has an increasing number of people who are developing cancer mainly due to population growth and ageing. At present about 16,000 people develop cancer each year, and 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. At present about 7500 people die from cancer each year, with the number expected to increase to about 9000 by 2012. Research has also shown that 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 the United Kingdom.

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, Great Britain and most European countries, we have accepted the conclusion of the World Health Organization (WHO) that development of a national cancer control strategy is the most effective way of reducing the incidence and impact of cancer.

The aim of this discussion document is to inform you about progress in developing a New Zealand cancer control strategy and to seek comment on work in progress.

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 minimised. The aims of cancer control are to reduce the number of people who develop and die from cancer and 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 establishment of 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, treatment, rehabilitation and support, and palliative care are all included. Also to be addressed are equity of access to services, workforce development and the need for relevant research, as well as monitoring, analysis and data collection. This means a wide range of government and non-government organisations will need to make a real and enthusiastic commitment to make the strategy effective. A glossy document that is not acted upon will have little effect on cancer in New Zealand. Stakeholder input and long-term involvement are essential to the success of this important initiative.

Why do we need a cancer control strategy?

While the standard of cancer control services in New Zealand is high by international standards, the largely ad hoc nature of development has led to gaps and fragmentation of service provision and delivery. A lack of co-ordinated foresight in workforce development over the last decade has resulted in chronic 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 unable to afford the travel and related costs to cancer treatment centres.

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 increased at a faster rate, and is now higher than that of comparable countries
- New Zealanders expect that, irrespective of where they live, there will be reasonable access to high-quality care
- effective and efficient use of limited resources is crucial
- cancer control cannot be achieved by any single organisation or by government alone

- the strategy will develop and strengthen alliances among organisations and health professionals, both government and non-government, involved in the many aspects of cancer control
- it will provide a mechanism by which cancer control activities can be systematically monitored and improved
- it is important to act now, before the full impact of the ageing population is felt by the health care system.

Thus, the general aim of the strategy will be 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
- preventing cancer so that as many of the population as possible enjoy cancer-free lives
- detecting cancer and providing treatment as early as possible
- ensuring that once a diagnosis is made those affected have prompt access to high-quality care throughout their experience of cancer
- assisting people, and their families/whānau, experiencing cancer to fully participate in all decision-making related to their treatment and care
- reducing barriers to cancer services for socially disadvantaged groups, such as Māori and Pacific peoples
- co-ordinating cancer 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 New Zealanders, but it will have particular relevance to:

- government and non-government agencies whose work impacts on the delivery of cancer services and activities
- the wide range of individuals involved in the management and delivery of cancer activities and services
- those people affected by cancer.

By promoting an integrated approach to the provision of cancer control activities and services, the strategy will:

- encourage and assist government and non-government service providers to work more closely together
- provide a common understanding of where they fit in the overall spectrum of cancer control.

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 of Waitangi will underpin the New Zealand Cancer Control Strategy and will need to inform the development of activities and services 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 (Ministry of Health 2001c).

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

Māori will 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 services must also make serious efforts to improve the acceptability, accessibility and responsiveness to the needs of Māori living with, recovering from and dying of cancer as well as those of their whānau in order to contribute to a reduction in the incidence and impact of cancer for Māori.

The strategy in context

The New Zealand Cancer Control Strategy will derive 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 have been reviewed in *Stocktake of Strategies and Other Key Policy Documents for Cancer Control in New Zealand* (Ministry of Health 2002d) and in *Progress Towards a New Zealand Cancer Control Strategy* (Gavin, Marshall and Cox 2001). *Improving Non-Surgical Cancer Treatment Services in New Zealand* (Ministry of Health 2001c) anticipates the New Zealand Cancer Control Strategy. A Ministry of Health Cancer Treatment Services Working Group and the Paediatric Oncology Steering Group are currently active.

The strategy will also draw on and link with other key health and disability strategies. These include:

- the *Primary Health Care Strategy* (Minister of Health 2001a)
- 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* (Associate Minister of Health and Minister for Disability Issues 2002)
- *Healthy Eating – Healthy Action; Oranga Kai – Oranga Pūmau* (Ministry of Health 2002b)
- *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 2002).

The burden of cancer in New Zealand

What is cancer?

‘Cancer’ is a generic term used to describe a group of over 100 diseases that occur when malignant forms of abnormal cell growth develop in one or more body organs. These cancer cells continue to divide 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, while 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 such that the cancer grows rapidly. Other types grow slowly or may remain dormant for years. Very high cure rates can be achieved for some types of cancers, while 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.

Differences in incidence of the many types of cancer between countries, after migration and over time have led to the conclusion that the great majority of cancers are caused by factors in our lifestyle or environment. Hence, reducing the exposure of populations to these factors has the potential to reduce the number of people who develop cancer.

Currently it is estimated that about 80 percent of cancers are due to our environment or lifestyle and therefore are potentially preventable (Doll and Peto 1981). For some cancers the risk factors have been clearly identified, while 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).

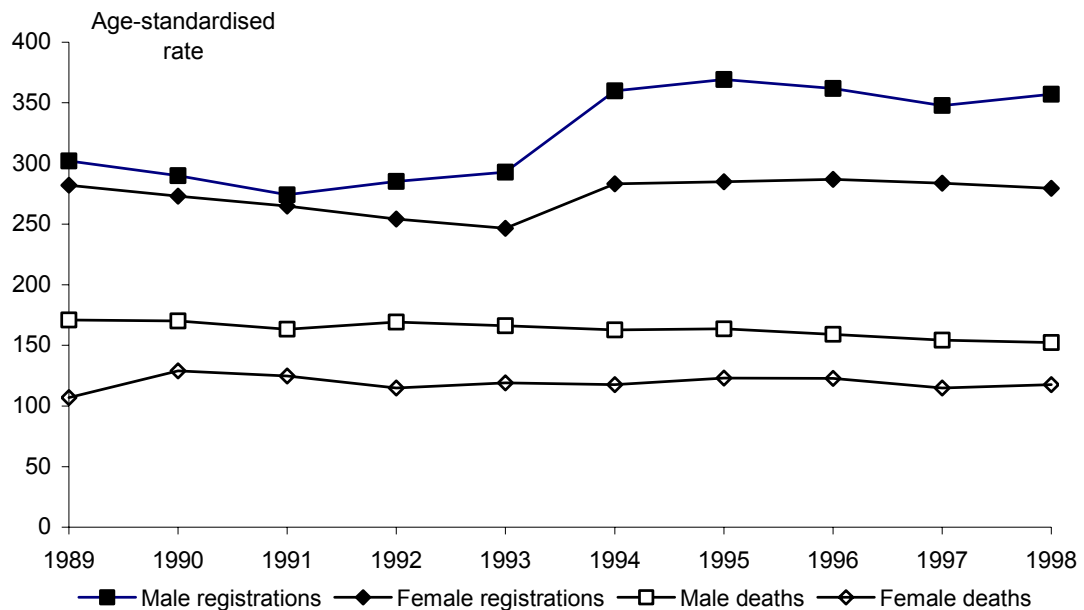
In New Zealand the most significant and modifiable risk factors for common cancers are smoking, sun exposure, poor nutrition, alcohol consumption, obesity and physical inactivity.

Cancer incidence, mortality rates and trends in New Zealand

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 males were lung cancer, bowel cancer and prostate cancer. For females the most common cancers were breast, bowel and lung cancers.

The rates of some types of cancers are high in this country by international standards. Compared to 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).

Figure 1: Registration and death rates for all cancers by sex, 1989–98



¹ Organisation for Economic Co-operation and Development (see glossary for a list of OECD countries).

Although in 1998 the overall rate of cancer registrations for Māori and non-Māori was 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 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. It is likely that current data on Māori cancer rates under-represent the true prevalence due to difficulties in collecting standardised ethnicity data in the health sector (Pōmare et al 1995).

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, Marshall and Cox 2001).

Although children with cancer represent only 1 percent of the overall incidence of the disease, the prevention and cure of cancers occurring in young people result in considerable saving of years of life. Cancer incidence in the 0–14 years age group in New Zealand is comparable to other OECD countries, although the incidence of lymphoblastic leukaemia (the most common type of childhood cancer) is increasing in New Zealand (Dockerty, Becroft and Lewis 1996). Seventy percent of childhood cancers are cured, but one-half of the survivors of childhood cancer have long-term sequelae. Adolescents with cancer have poorer survival than children with cancer.

The cancer control continuum

Reducing the incidence and impact of cancer in New Zealand will require a planned, systematic and co-ordinated approach to a myriad of 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 involving both a paid and a volunteer workforce. Their activities extend 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 tobacco), 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, that involves both government and non-government personnel, includes public health, 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 and cultural factors that are not easy to change, efforts to reduce the incidence of these lifestyle-related cancers require a comprehensive approach. 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).

Screening and early detection

Screening for cancer is an organised process aimed at reducing the incidence or mortality from cancer. People who have no symptoms are invited (either directly or through publicity) to undergo a test or procedure, usually at regular intervals. Although a number of cancer screening tests have been developed, only a few have been proven effective. To be considered effective a screening test must meet a number of requirements established by the WHO and others.

Early detection is the detection of 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. While some cancers have early warning signs that are easily identified, many do not. Furthermore, detection of a cancer when it appears to be localised does not always lead to an improved outcome. As identified by the Screening and Early Detection Expert Working Group, early detection efforts should be focused on those cancers where this has been shown to reduce cancer mortality and morbidity.

Diagnosis and treatment

The WHO (2002) describes cancer diagnosis and treatment services as typically starting with recognition of an abnormality, followed by consultation, then referral to appropriate services that may involve, radiology, pathology, surgery, radiation, chemotherapy or hormonal therapy, or a combination of these. The aim of these services is to cure or prolong and improve the quality of the lives of those affected by cancer.

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, 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.

As identified by the Support and Rehabilitation Expert Working Group, there is growing evidence that supportive care and rehabilitation approaches 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. These include 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

Palliative care is the total care of people who are dying from active, progressive diseases or other conditions when curative or disease-modifying treatment has come to an end. Palliative care services are usually provided by multidisciplinary teams who work with people dying from cancer, providing support and care for them and their families and whānau. 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 (Minister of Health 2001b).

Cancer control monitoring and surveillance

Cancer control monitoring and surveillance involve the routine and continuous collection of cancer-related information on the incidence, prevalence, mortality, diagnostic methods, stage distribution, and survival of those with cancer and aspects of the care received. Monitoring of known risk factors such as tobacco smoking and the prevalence of population exposure to those risk factors is also part of cancer control surveillance.

Surveillance will be a fundamental element of the New Zealand Cancer Control Strategy. The data collection required for surveillance involves 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. Furthermore, improvement in the collection and interpretation of ethnicity data will be important in increasing our knowledge about cancer among Māori and Pacific populations.

Cancer control research

Cancer 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 should be carried out across the spectrum of cancer control and provide the basis for continual improvement.

Cancer control continuum and Māori

Ensuring that the cancer control continuum is responsive to 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 quality 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, provided below, all emphasise the need to acknowledge Māori cultural values and beliefs, and the importance of whānau:

- *Hui Whakamarama: Report of a consensus hui concerning screening amongst Maori* (Te Manawa Hauora 1993)
- *Kia Whai te Maramatanga: The effectiveness of health messages for Māori* (Ministry of Health 1994)
- *He Taura Tieke: Measuring effectiveness of health services for Māori* (Ministry of Health 1995)
- *He Anga Whakamana: A framework for the delivery of disability support services for Maori* (Ratima , Durie, Allan,1995).

Overall purpose of the strategy

To reduce the incidence and impact of cancer.

The principles of the New Zealand Cancer Control Strategy

All actions undertaken to reduce the incidence and impact of cancer should be guided by the following principles. The actions should:

- acknowledge the special relationship between Māori and the Crown under the Treaty of Waitangi
- maintain a person-centred approach that strives to maintain people's autonomy and dignity and is sensitive to the total needs of the individual and their family and whānau
- reduce inequalities that currently exist between different population groups
- provide timely and equitable access for all New Zealanders to cancer prevention, detection, treatment and care, regardless of their ability to pay
- provide high-quality services that inspire confidence at all levels
- actively involve consumers and communities at all levels
- provide a planned, co-ordinated and collaborative approach
- use an evidenced-based approach

- respect the rights of people to make informed choices about their care
- recognise and respect cultural diversity.

The goals

The goals of the New Zealand Cancer Control Strategy are:

- 1 to reduce the incidence of cancer through prevention
- 2 to reduce death and disability through effective screening, early detection and treatment
- 3 to improve timely access to effective and acceptable activities and services to control cancer
- 4 to improve the quality of life for those living with, recovering from, and dying of cancer
- 5 to improve the planning, co-ordination and integration of activities and services to control cancer
- 6 to improve the planning, integration and co-ordination of cancer research, evaluation, monitoring and surveillance.

Part Two: Proposed Objectives and Actions to Meet the Goals

Part 2 of the strategy will identify the objectives that were developed by the expert working groups to achieve the goals of the New Zealand Cancer Control Strategy. The background papers, developed by the groups and identifying these objectives, are available on the Ministry of Health and New Zealand Cancer Control Trust web sites (www.moh.govt.nz/cancercontrol and www.cancercontrol.org.nz). 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.

Possible actions have been identified under each objective. These are not comprehensive lists and will be further fleshed out following feedback from consultation and during the implementation phase.

Reducing inequalities: a central and underpinning theme for all proposed objectives

The New Zealand Cancer Control Strategy will set out to reduce inequalities in health in the first instance. Where this is not possible, in the short term it will strive to increase people's control over their lives, favour the least advantaged, foster social inclusion and minimise stigmatisation, and endeavour not to make inequalities in health worse.

One of the Government's key priorities is to reduce inequalities in health. Inequalities exist among socio-economic groups, ethnic groups, people living in different geographical areas, the young and the old, and males and females. These inequalities are not random and can be seen in the distribution of the cancer burden in New Zealand. Socially disadvantaged people have greater exposure to health risks and poorer access to health services, and experience a greater cancer burden.

A history of colonisation and urbanisation has impacted strongly on Māori development and the socio-economic position of Māori in today's society (Pōmare, Keefe, Ormsby and Pearce, 1995). It is well known that Māori are more likely than non-Māori to live in the most deprived socio-economic circumstances, and are likely to experience worse health outcomes than non-Māori who experience the same level of social and economic deprivation (Reid, Robson and Jones, 2000). This is supported by evidence showing that 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. Pacific people are also more likely to experience ill health as a result of poorer socioeconomic status (Ministry of Health 201d).

The Ministry of Health has developed an intervention framework (Appendix 3) to assist the health sector in the development and implementation of comprehensive strategies to improve health and reduce health inequalities. Differential access to health care services and differences in care for those receiving services have a considerable impact on health status and mortality and are particularly relevant to the provision of cancer services.

These issues will be taken into consideration in each of the following goals, objectives and possible actions.

Goal 1: To reduce the incidence of cancer through prevention

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 also 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).

Simply educating people to adopt healthy lifestyles does not on its own 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, for instance supporting smokers to quit smoking. In order to address the needs of 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 approaches that aim to reach the whole of the population.

Proposed Objective 1: Reduce the number of people who develop cancers due to tobacco use

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 rates are currently three times higher than non-Māori rates.

Public health initiatives aimed at discouraging smoking and warning people of the dangers of smoking have contributed to the decline of smoking among adults over the past two decades. However, 24 percent of the population continues to smoke. Smoking rates among young people, particularly adolescents, have changed very little over the last 10 years. Rates of tobacco use are disproportionately high among Māori, who are consequently more likely to live in a smoking environment and less likely to have a supportive environment for quitting. Māori may respond to different styles of lifestyle prevention programmes, so it is important to have culturally appropriate providers for Māori smokers wanting to quit (Ratima 2001).

Possible actions

- 1 Reduce exposure to tobacco smoke and prevent the uptake of smoking through a comprehensive tobacco control programme that includes increased health promotion, advocacy, cessation services, legislation, and support for international tobacco control efforts.
- 2 Increase and normalise smoke-free environments (this requires stronger legislation, display and sales restrictions, and restrictions on promotion of tobacco).
- 3 Support further development and implementation of strategies and activities directed towards lowering tobacco consumption among Māori.

Proposed 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 population, particularly Māori and Pacific peoples. Māori rates of obesity are approximately twice those of Pākehā (Russell, Parnell and Wilson, 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 bowel cancers, breast, prostate, lung and uterine cancers.

While Māori and non-Māori population groups were equally active, Māori who undertake insufficient levels of physical activity are more likely to be sedentary than non-Māori (20.5% to 14.7%) (National Health Committee 1998).

Possible actions

- 1 Foster increased physical activity through safe and accessible environments, active transport, workplaces, schools, communities and the mass media, and develop evidence and a rationale for interventions to address obesity as a risk factor for cancer.
- 2 Provide and support comprehensive mass media campaigns that promote physical activity, the development of safe and accessible public environments that encourage people to use more physically active means of transportation, such as walking, and advocate for and support workplaces that encourage employees to be physically active.
- 3 Encourage continued use of primary health care practitioner 'green prescriptions' (prescribed physical activity) to promote physical activity tailored to suit individual capabilities.
- 4 Further build the evidence base for interventions addressing obesity as a risk factor.
- 5 Support appropriate interventions for the prevention of obesity, and to increase rates of physical activity among Māori.

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

There is evidence that links bowel and rectal cancers 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 2002b). The *Healthy Action – Healthy Eating* strategy (Ministry of Health 2002b), and *the Food and Nutrition Guidelines for Healthy Adults* (Ministry of Health 2002c) 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.

Possible actions

- 1 Make the healthy food choice the easy choice by improving access to and availability of healthy foods.
- 2 Reduce the promotion of unhealthy food choices to children (for example, through advertising).
- 3 Support a comprehensive campaign to raise awareness of healthy food choices.
- 4 Support community-based initiatives aimed at improving nutrition among Māori and Pacific communities.

Proposed 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 skins and who are prone to excessive freckling and burning on exposure to the sun are most at risk.

Possible actions

- 1 Support health promotion campaigns that increase people's awareness of the dangers of the sun's rays, and encourage sun protection.
- 2 Encourage local bodies, employers, schools and others to provide environmental sun protection (for example, in schools and on sports fields).
- 3 Support international efforts to protect the ozone layer.

Proposed 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. 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.

Possible actions

- 1 Continue to promote safe sex practices.
- 2 Promote Hepatitis B vaccination, particularly for high-risk populations (mainly Māori, Pacific and Asian peoples).
- 3 Support the Needle and Syringe Exchange Programme and raise awareness of the risks associated with intravenous (IV) drug use.
- 4 Protect blood product supplies from all possible infectious disease contamination.

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

The National Alcohol Strategy 2000–2003 (Minister of Health 2001c) 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.

Possible actions

- 1 Raise awareness of the harmful effects of alcohol and its relationship with cancer.
- 2 Reduce exposure to alcohol advertising.
- 3 Promote health warnings on alcohol beverages about the relationship between alcohol and cancer, and support.
- 4 Increase taxation on alcohol products (preferably a tied alcohol tax).

Proposed 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 carcinogens, develop strategies to reduce workers' exposure, and hence reduce the incidence of occupational cancers in the future.

Possible actions

- 1 Strengthen and enforce the legal framework designed to protect workers against carcinogenic compounds in occupational settings and raise awareness of, and reduce exposure to, carcinogenic compounds in the workplace. This could include promoting smoke-free work plans and actions, and promoting physical activity in the workplace.
- 2 Support the OSH Cancer Panel research programme on occupational exposures, and improve the reporting of occupational cancers.

Goal 2: To reduce death and disability through effective screening, early detection and treatment

Screening for cancer is an organised process aimed at reducing the incidence or mortality of cancer. Well-established principles apply to this public health activity (Wilson and Jungner 1968). The main underlying principle of screening is to do the least harm to achieve the greatest measurable benefit for the population, because there may be adverse effects of screening for some people.

The screening test is just one aspect of screening. The organisation of the screening service and lines of accountability are also important in determining the impact of screening on the mortality or morbidity of the disease (WHO 1986; Working Group 1986). Because people screened do not have symptoms, more stringent quality assurance processes for each aspect of screening are required than often exist in clinical care (National Audit Office 1992; Committee of Public Accounts 1992; Calman and Hine 1997). The structural framework used for screening services is important (Shapiro, Coleman and Broeders, 1998) and the methods of funding can also be important in determining the effectiveness of cancer screening (Calman and Hine 1997).

Screening for genetic susceptibility is becoming more common. Prevention, including prophylactic surgery or treatment, can be important for people with a very high risk of cancer due to genetic susceptibility.

Treatment is always changing as newer therapies and better methods of diagnosis and treatment become available. The way in which care is given and the co-ordination of the necessary expertise in multidisciplinary teams for the care of patients has developed apace, and approaches to more integrated care in the New Zealand setting require further development.

Proposed Objective 1: Provide at a national level a systematic approach to cancer screening, familial risk assessment and surveillance to ensure their quality, acceptability and effectiveness

Screening for cancer in New Zealand has largely been undertaken in response to external requests and lobbying rather than as part of an organised and ongoing approach. This country currently has no established process to review the appropriateness of cancer screening programmes and policies, nor is there any single body that has specific responsibility for developing guidelines and recommendations for cancer screening, familial risk assessment and surveillance and monitoring their implementation. This has led to an ad-hoc approach, with one-off reports and recommendations but no ongoing strategic oversight.

There are also issues for Māori and Pacific peoples in relation to screening that need to be addressed at a strategic level in relation to current and future screening programmes. For example, despite a particular effort by the National Cervical Screening Programme to recruit Māori and Pacific women to the programme for over a decade, there remain inequities in coverage. Between 1997 and 1999 coverage for Māori and Pacific women was estimated to be 50% and 51% respectively as compared to 75% for other women. While the overall coverage of the breast screening programme in the last two years was reported as 59%, coverage for Māori and Pacific women was estimated to be at less than 40%.

Screening programmes need to consider and respond to specific cultural issues unique to Māori in order recruit to Māori. Māori participation in screening programmes is crucial to reducing the inequalities in the morbidity and mortality from breast cancer and cervical cancer.

About 5% of cancers are familial. Part of the assessment of the familial risk of cancer may involve genetic testing for the presence of specific gene mutations. Access to familial risk assessment services is not equitable and, to date, referrals have tended to come mainly from urban centres. No national guidelines are available specifying who should be referred to these services.

Providing high level strategic oversight of existing and potential cancer screening, familial risk assessment and surveillance would serve to provide the following benefits:

- improved assessment and decision-making relating to screening programmes and activities
- improved effectiveness and cost-effectiveness of cancer screening and familial cancer risk assessment
- culturally appropriate screening services, including familial risk assessment
- reduction in inequalities between Māori and non-Māori in 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.

Possible action

- 1 Establish an effective national structure, such as a national cancer screening committee, to ensure a systematic approach to cancer screening, risk assessment and surveillance in New Zealand.

Proposed 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 may be improved by early detection and treatment and that delays in detection and treatment do occur in some population groups in New Zealand. Currently, in New Zealand it is not known to what extent delays in diagnosis and treatment are contributing to our apparently high cancer mortality rates, particularly among Māori and Pacific people, and there is no process established to determine this.

A process is needed to identify where early detection of a cancer reduces cancer mortality and morbidity and to recommend strategies to increase early detection in those circumstances contributing to:

- a determination of which cancers might benefit from early detection and treatment
- a formal assessment of the reasons for delays in early detection of these cancers in New Zealand, focusing on who is affected and why
- implementation of some deliberate strategies to overcome the delays with evaluation of their effectiveness
- earlier presentation of cancer among Māori and Pacific peoples.

Possible actions

- 1 To identify and implement strategies to reduce delays in diagnosis and treatment where these are shown to be effective in reducing mortality and morbidity from selected cancers.
- 2 To identify and implement Māori specific strategies to reduce delays in diagnosis and treatment where these are shown to be effective in reducing mortality and morbidity from selected cancers.

Proposed Objective 3: Develop defined standards of integrated care for the treatment of people with cancer

Everyone receiving treatment for cancer needs access to a consistent standard of care to achieve the best possible outcomes. Integrated cancer care approaches include the use of national and regional guidelines, protocols, clinical treatment trials and multidisciplinary clinics. All of these approaches require continuous monitoring against key performance measures to determine whether the care received by people accessing cancer services reaches recommended standards.

Application of guidelines and protocols in this country is variable. There is no system in place to monitor the use and effectiveness of guidelines and protocols. There is a need to offer people with cancer more choice for entry into clinical trials, which are governed by protocols.

Māori health development concerns include the effective delivery of conventional, mainstream health services to Māori. Most Māori treatment needs will be met within the usual professional settings. 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 holistic wellbeing that encompass all dimensions of health, including the physical, spiritual, mental and whānau aspects of health (Ratima 2002).

Possible actions

- 1 Promote quality of care for people with cancer through the development and implementation of nationally and locally agreed cancer treatment and management guidelines and local protocols.
- 2 Encourage the use of multidisciplinary approaches for managing the treatment and care of people with cancer (for example, multidisciplinary clinics, multidisciplinary conferencing).
- 3 Develop a minimal clinical data set that will facilitate the development of treatment performance measures and outcomes.

Proposed Objective 4: Provide people experiencing cancers access to the best available drugs, surgery and treatment procedures

Optimising survival and the quality of life for people living with cancer means having access to treatments that, on the basis of current evidence, are known to provide the best outcomes. Cancer treatment technologies include procedures for diagnosis and staging (radiology and pathology), surgery, radiation treatment, chemotherapy, other drug therapies, and other more complex treatments such as bone marrow transplantation.

While New Zealand has traditionally provided a high standard of treatment for cancer, currently there is insufficient resource capacity (funding and staff) to cope with the demand for services. This situation has led to delays in access to some treatment technologies, and recently some cancer patients have had to travel to Australia for radiation treatment.

There is a need to establish a process for evaluating and allowing the introduction of newer drug treatments and technologies, when evidence emerges to support their use. PHARMAC is currently evolving such a process to assess new chemotherapy drugs. That process, however, only addresses drugs and does not deal with other treatment technologies. Close collaboration should be encouraged with professional colleges.

Many of the newly developed treatments being used in some countries are considerably more expensive than those currently used in New Zealand. Funding restraints have precluded their use here. 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 against existing treatments.

Possible actions

- 1 Develop a nationally co-ordinated and consistent process for introducing new treatment technologies and drugs for cancer treatment.
- 2 Develop a process to prioritise management of specific cancers with new treatment approaches.
- 3 Continue to develop standards for the utilisation, replacement and addition of radiation oncology equipment.
- 4 Establish speciality surgical oncology networks for patients through regional oncology programmes.
- 5 Establish an expert working group of surgeons, including gynaecologists, to identify the major areas of surgical management which require discussion with a view to producing recommendations for surgical management.

Goal 3: To improve timely access to effective and acceptable activities and services to control cancer

The chances of developing cancer, having it detected and treated according to best practice, receiving support and rehabilitation, having relief from unnecessary pain and suffering, and dying from cancer should not depend on where a person lives, their ethnicity or cultural background, their socioeconomic status, their age or their gender. Inequity of access to effective and acceptable services throughout the continuum of cancer control translates into inequities in cancer incidence, morbidity and mortality.

Equitable access does not mean all services will be provided everywhere. It does mean that everyone in New Zealand will have reasonable access to effective and acceptable cancer prevention, screening, diagnosis, treatment and care, if and when they require it, without financial hardship.

Addressing inequities in access, a fundamental principle of the New Zealand Cancer Control Strategy, aligns with the *New Zealand Health Strategy* (Minister of Health 2000) principle of timely and equitable access to care to ensure that New Zealanders with similar health conditions are able to achieve similar outcomes. Similarly, the active involvement of consumers and communities at all levels – a key factor in acceptability – is a fundamental principle of both strategies.

Proposed Objective 1: Ensure that all cancer treatment providers follow principles of patient-centred and co-ordinated care

Cancer management has become increasingly complex and demanding for health service providers and for those using cancer services. Much of the service development across the cancer control continuum has been ad hoc, leading to uneven and geographically fragmented service provision. People accessing treatment and support throughout their experience with cancer have to negotiate their way through a network of highly variable (in terms of availability) services.

Improving the integration of cancer care services would improve people's access to the full range and combination of cancer treatment services and would also improve their quality of life and survival. Improving co-ordination similarly would serve to improve access for particular population groups currently experiencing difficulties in accessing appropriate care, such as Māori and Pacific peoples. This needs to occur from initial diagnosis through to secondary care (hospital) services, tertiary cancer treatment and management centres, and back through to community support services once initial treatment is completed.

To achieve this level of co-ordination 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.

Possible actions

- 1 Ensure resources to permit co-ordination of patient care through their cancer treatment to avoid unnecessary delays and provide treatment within achievable clinically acceptable timeframes.
- 2 Optimise the communication between care providers and develop networks between cancer centres, secondary care providers (for example, hospital-based specialities such as surgery) and primary care providers (for example, general practitioners, district nurses and Māori health providers) identifying clear roles and responsibilities in the pathway of care.
- 3 Improve access of patients to information about cancer care in New Zealand (for example, develop aids to guide patients through the cancer care process).
- 4 Respect patients' rights to pursue complementary and alternative health care and promote co-operative management between the care providers and people with cancer.

Proposed Objective 2: Ensure all people with cancer and their families and whānau are able to access the appropriate support and rehabilitation resources that they need

An informal review of resource provision in different parts of New Zealand indicates that access to necessary support and rehabilitation resources 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 some health professionals. This clearly creates inequity of access to support and rehabilitation. An example is the provision of equipment, personal care and funding to allow patients to remain in their own homes when they might otherwise be in hospital. Interpretation of existing eligibility criteria for both disability and health-related needs is variable, with indications that these are becoming increasingly restricted as funders look to more effectively manage their budgets.

The current lack of an integrated approach to accessing support and rehabilitation services may well result in financial disadvantage for families and whānau and unnecessarily prolonged 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. As a consequence, some needs may be largely unmet.

Possible actions

- 1 Assess current issues relating to access to support and rehabilitation resources. This would include:
 - defining the population groups
 - identifying current services being accessed, and from what sources
 - identifying gaps and those groups that are most disadvantaged

- defining the likely services needed over time
 - identifying the differences between resources available to those with cancer and those available for other conditions, illnesses and disabilities.
- 2 Identify the process by which the above issues will be addressed by both the government and non-government sectors.
 - 3 Identify the responsibilities of the government and non-government sectors in this process.

Proposed Objective 3: Continue to improve access to essential palliative care services which provide appropriate symptom relief and emotional, spiritual, cultural and social support for the person 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. Nearly 50 percent of people diagnosed with cancer in New Zealand die from the disease.

The need to set in place 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 were 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.

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 for Palliative Care (2002) identified a number of remaining barriers that prevent people receiving appropriate care. These include:

- 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
- cultural barriers to access, especially for Māori and Pacific peoples
- a lack of services designed for children and young people.

Possible actions

- 1 There will be a continued commitment to ensuring that each region has at least one local palliative care service which provides access to assessment, care co-ordination, clinical care and support care. These services will build on existing services, including primary care.

- 2 Those groups identified as having limited or difficult access (for example, Māori and Pacific peoples, children and rural New Zealanders) will have access to appropriate care.
- 3 Clinical staff working in hospitals and the community will be able to access specialist palliative care services which can assist those dying of cancer.
- 4 Information will be made available to the public about palliative care services.

Proposed Objective 4: Provide people experiencing cancer with information so that they can make better-informed choices about complementary and alternative therapies

People with cancer need high quality and comprehensive information to make well-informed choices about complementary and alternative therapies. A complementary therapy is one that adds benefit to orthodox or conventional evidence-based therapies. An alternative therapy is one that is used instead of an orthodox treatment. Alternative medicine is not a single entity, nor is it clearly distinguishable from orthodox medicine. In practice there is a broad grey zone between the two.

Belief in and the use of complementary and alternative therapies for cancer are steadily increasing. Factors responsible for this include the rising prevalence of chronic disease, increased public access to health information of variable veracity, reduced tolerance of paternalism, an increased sense of entitlement to quality of life, declining faith that scientific breakthroughs will in the short term have relevance to the personal treatment of disease, an increased interest in personal spirituality, and, in particular, the wish of cancer patients to consider and choose from the full range of therapies that may be helpful to them.

Current relevant developments include recognition of traditional healing methods by some hospitals, proposals to modify the legislation on therapeutic products, the Ministerial Advisory Committee on Complementary and Alternative Health, and the development by the Ministry of Health of an internet database on complementary and alternative medicines.

Better integration of complementary and alternative therapies would allow the positive involvement of people with cancer, their friends, family and whānau in cancer care, reduce the risks of ineffective treatments and therapies that compromise conventional treatment, and allow cancer patients maximum opportunity to select the treatment regime most appropriate for them.

Possible actions

- 1 Ensure that the Ministry of Health's internet database on complementary and alternative medicines includes high-quality and comprehensive information about the known benefits and lack of benefits of therapies related to cancer.

Proposed Objective 5: Ensure supportive and 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.

Under-utilisation of primary and tertiary care services and late presentation of cancer have a profound effect on health outcomes for Māori and contribute to the disparities in health status between Māori and non-Māori. *Hauora: Māori Standards of Health III* (Pōmare et al 1995) notes that a number of barriers to accessing services need to be overcome in order to improve Māori health outcomes. These barriers are cost; location of services, particularly in relation to travelling distances; acceptability of the service in terms of legal, ethical, physical and cultural safety; and attitudes towards services, including reluctance to attend general practice clinics, and whakamā (embarrassment). Barriers to access tend to be multi-dimensional and closely interrelated, so they need to be addressed as a whole, rather than as a number of separate issues.

Differential access to health services is therefore an important issue. Further, the predominant monocultural mode of ‘one fits all’ is inadequate. For example, kaupātua services to Māori are limited and often not recognised. 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 (Pōmare et al 1995), Te Pae Mahutonga, or the Southern Cross (Durie 1999), and Te Wheke, the Octopus (Pōmare et al 1995), to name just a few. Services being delivered to Māori need to reflect an understanding of hauora Māori and approaches that appropriately address Māori health needs.

Kaupapa Māori, or ‘by-Māori, for-Māori’, services are being increasingly integrated into the mix of health and disability services in New Zealand. Kaupapa 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 usually also accessible 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. Durie’s report, *Cultural Competence and Medical Practice in New Zealand* (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*, and provides a framework and specific priority action areas to improve Māori health outcomes. There are 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.

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. However, this will require commitment from all sectors involved in cancer control.

Possible actions

- 1 Implement the four pathways as outlined in *Whakatātaka* (Minister of Health 2002b).
- 2 Ensure that treatment services have policies in place that recognise the specific needs of Māori, and that these are implemented and monitored.
- 3 Develop culturally appropriate practices and procedures as an integral requirement in the purchase and provision of support and rehabilitation services for Māori.
- 4 Ensure that palliative care services have policies in place that are specific to addressing the needs of Māori, and that these policies are implemented and monitored.
- 5 Improve linkages between palliative care providers and Māori development organisations to assist in meeting the specific needs of Māori.
- 6 Further develop and maintain Māori health providers, and improve the accountability of mainstream providers for Māori health outcomes.

Proposed Objective 6: Ensure the active involvement of consumer representatives across the spectrum of cancer control activities and services

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 in 1988, the implementation of consumer input has been piecemeal and ad hoc. At present, there are very few consumers involved as representatives in cancer control activities, and this is only in some activities and only 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. 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 what strategies would be appropriate.

A systematic approach is required to the use of consumer representatives in cancer control activities and services. Well-resourced initiatives in countries such as Australia and the United Kingdom provide working examples of what can be achieved with appropriate training, support and sufficient funding.

Possible actions

- 1 The organisation responsible for cancer control will:
 - advise and assist groups working within the cancer control umbrella to make sure they have a policy and/or terms of reference that will adequately address consumer representation
 - ensure that it has established formal links with relevant consumer organisations that have an interest in cancer control
 - investigate progress on planned New Zealand consumer training initiatives and liaise with the organisations involved to establish whether the proposed training is likely to meet the needs of those planning to work as consumer representatives in cancer control
 - review, in conjunction with relevant consumer organisations, existing guidelines developed by consumers to provide practical advice and guidance on consumer representation to ensure all necessary areas are covered
 - provide advice as well as practical assistance to groups in finding appropriate consumer representatives.

Goal 4: To improve the quality of life for those living with, recovering from and dying of cancer

Quality of life, with reference to health, refers to 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 people living, recovering from, or dying of cancer, every aspect of their cancer treatment and care must recognise that person's total needs. Their physical, social, psychological, nutritional, information and spiritual needs are all equally important.

Proposed Objective 1: Improve return to work and quality of life of cancer patients 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, many of them of working age. Many will want to pursue a career or job for economic reasons or for personal satisfaction. Many will carry over residual effects of malignancy, or of the treatment, or both, which may affect them at work. These may be physical effects, or indirect psychological or social effects, which contribute to discrimination as a latent sequel of chronic disease. As such, those who have been treated for cancer may encounter outright or subtle discrimination in the workplace, and may encounter other workplace or physical barriers to the return to work. Many of these damaging effects could be avoided or minimised if addressed in a more timely manner as an integral part of an individual management plan.

Possible actions

- 1 Develop materials on provisions of the Health and Disability Act and human rights legislation with a focus on people with cancer.
- 2 Develop initial screening tool with 'triggers' to assess the vocational rehabilitation needs of cancer patients.
- 3 Develop a vocational plan that includes realistic goals, timelines and outcomes for all participants.
- 4 Undertake a campaign of public education and dissemination of information to address issues relating to discrimination and other potential barriers to return to work.

Proposed Objective 2: Ensure all survivors of childhood cancer receive timely and ongoing support and rehabilitation, including early identification of and intervention in late effects

It has been estimated that by the year 2000 one in every 900 young adults would be a survivor of childhood cancer. 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. Such 'late effects' can range in severity and are highly dependent on the specific cancer, the treatment received and the age of the child during therapy. Examples include problems with growth and cognitive abilities, learning difficulties, and endocrine complications resulting, for example, in infertility. Survivors of childhood cancer are also at risk of discrimination. The impact of such late effects of the disease or its treatment will result in escalating demand for other social services in New Zealand, such as education, employment and welfare.

Possible actions

- 1 The Ministries of Health and Education, in collaboration with the Paediatric Oncology Steering Group, should work co-operatively to oversee the development of national guidelines for the support and rehabilitation of children and adolescents with cancer.
- 2 DHBs and appropriate educational and non-government services should implement these guidelines.
- 3 The Ministries of Health and Education, in collaboration with the Paediatric Oncology Steering Group, should work co-operatively to establish a comprehensive late effects programme for survivors of childhood cancer.
- 4 DHBs and appropriate educational services should implement the programme.

Proposed Objective 3: Improve the quality of life of people with life-threatening cancer and those for whom treatment is no longer effective

Palliative care focuses on maintaining and improving quality of life. This is especially important for those people who are diagnosed with cancers that are life threatening, and those for whom cancer treatment is no longer effective. When people access palliative care services there should be a focus not only on effective symptom control but also on the emotional, spiritual, cultural and social factors that impact on the person and their family/whānau. Support for the family and whānau extends beyond the person's life. It also acknowledges bereavement.

Possible actions

For proposed actions, refer to Goal 3, Proposed Objective 4.

Goal 5: To Improve the planning, co-ordination and integration of activities and services to control cancer

The focus of this goal is to ensure that all cancer control activities and services throughout the country and across the continuum of cancer control are well co-ordinated, consistent and integrated. Some of the technical issues facing various services will need to be dealt with at an individual service level. Other issues are common to all service areas and can be worked on collectively and collaboratively, including workforce development, research and evaluation, monitoring and surveillance.

By adopting a collective and co-ordinated approach there is the potential to create greater cohesion between the various agencies involved in cancer control activities 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 everyone's performance in delivering services that fit the diversity of cultural and social needs of this country's population.

Strong leadership will also be needed to bring all the various and diverse stakeholders together, to promote effective working relationships, and to share knowledge, skills, expertise and responsibilities in areas such as workforce development, establishing research priorities and promoting better links between services.

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

There is a pressing need to develop and implement a nationally co-ordinated cancer control human resources plan in this country. Currently, there are significant gaps in the cancer control workforce and a planned approach is required to enhance the preliminary work that has recently commenced on workforce planning. The planning and implementation for workforce development requires a collaborative and co-operative approach between the Ministry of Health, DHBs and all other cancer service providers involved in screening, rehabilitation, community support and palliative care services.

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 gaps and shortages have been well documented, particularly those in radiation oncology services (radiation oncologists, radiation therapists and physicists). Current capacity in these areas has been described as marginal and barely meeting current demand (Ministry of Health 2001c).

There are also gaps in other cancer treatment disciplines such as in anatomic pathology and medical oncology, where there are shortages of trained oncology nurses and pharmacists. Gaps in other workforce groups that contribute significantly to cancer care are less well quantified; for instance, there are shortages of pathologists, radiologists, surgeons, general practitioners and community health workers. Further work is needed to identify the problems in these areas and their impact on cancer service provision.

There are still some issues to be resolved relating to the planning and development of the palliative care workforce. These include a culturally representative workforce and appropriate training for multidisciplinary team members, including counsellors, chaplains, social workers, physiotherapists, occupational therapists and art therapists. An analysis of the palliative care workforce has been undertaken recently. Following this the Ministry of Health and the sector will work together to establish national palliative medicine requirements and funding support for training. A fully funded postgraduate certificate in palliative care has been developed for nurses in response to workforce issues identified in *The New Zealand Palliative Care Strategy*. Training and raising the awareness of oncology, primary care and long-term care health professionals involved in palliative care is another important issue.

The demand for cancer treatment will increase because of population growth and the ageing population. It is imperative that a co-ordinated and comprehensive strategic approach is taken to quantify gaps across current cancer control services, determine future staffing requirements and ensure that education and training resources are there to match those needs.

In addition, many Māori have emphasised the importance of the health workforce reflecting the health care needs of the New Zealand population. The cancer control workforce has a paucity of Māori workers at all levels, which is a generic problem over all areas of the health workforce. Future workforce recruitment needs to target Māori to train as doctors, nurses, counsellors, chaplains and other allied health professionals. The training of the cancer control workforce also needs to include specific learning to ensure that non-Māori health professionals understand, and are responsive to, the needs of Māori (Ratima 2002). Any workforce development plan for cancer control needs to ensure that sufficient numbers of trained Māori and Pacific cancer control professionals are there to assist the needs of these population groups.

Possible actions

- 1 Conduct a comprehensive stocktake of workforce requirements across the continuum of cancer control services.
- 2 Develop a strategy for workforce development to correct current deficits and meet future needs.
- 3 Increase the involvement of Māori and Pacific health professionals in cancer services. (For further detail see Expert Working Group on Palliative Care 2002: priority objective 3.)

Proposed Objective 2: Ensure that a seamless service is provided for patients with cancer who require palliative care, no matter where they live

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 on improving integration and co-ordination of palliative care services. 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 (for example, 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 (for example, some people may be visited by more than four providers in a single day (Health Funding Authority 1999))
- fragmentation and duplication of services
- an inability to provide flexible packages of care that are specific to an individual's or their family's and whānau's needs
- older people and people living alone having problems accessing services.

DHBs need to continue to work further on co-ordination and integration of the broad range of people and services involved in the care of a person with cancer. These services include primary care; hospital services such as oncology and surgical services; community-based services, including district nursing; hospice services; Māori and Pacific peoples' services and groups; long-term support services; and voluntary agencies providing social support.

Possible actions

As stated in *The New Zealand Palliative Care Strategy* (Ministry of Health 2001b), each DHB will ensure that:

- a palliative care referral, assessment and co-ordination system is in place
- local palliative care services will form regional palliative care networks that ensure the provision of specialist support and utilise the strengths of varying services so that the needs of people with cancer complications are met
- local palliative care services will form regional palliative care networks, established for the provision of specialist support, reflecting the population they serve.

Proposed Objective 3: Establish integrated programmes of supportive care and rehabilitation with defined leadership

All those associated with cancer care potentially contribute to processes and practices of supportive care and rehabilitation. However, some health professionals, disciplines and organisations are more likely to be involved in delivering such services. Across New Zealand cancer centres there is uneven provision and access to these resources. Some centres have such resources clearly integrated and embedded within routine service delivery. Other centres may activate or, where possible, 'contract in' such resources only when it is apparent that problems are directly affecting treatment. In the absence of a national policy regarding supportive care/rehabilitation, cancer care providers have developed in this ad hoc way. Furthermore, support and rehabilitation services have traditionally been monocultural (Moore 1995). While little research has been conducted to examine Māori access to services promoting rehabilitation, it could be assumed that the same trends of inequity experienced in other areas of the cancer control continuum are likely to occur. It is reasonable to conclude, therefore, that significant gaps in service

provision exist and that integrated programmes of supportive care/rehabilitation are needed.

Possible actions

- 1 Guidelines should be developed to assess and address the psychosocial and cultural needs of all people with cancer.
- 2 Organisations centrally involved in cancer care should adopt the framed guidelines.
- 3 These guidelines should be distributed to, and endorsed by, key stakeholders.
- 4 Relevant education providers should develop training opportunities in supportive care and psycho-oncology.

Goal 6: To improve the planning, co-ordination and integration of cancer research, evaluation, monitoring and surveillance

A commitment to build and sustain a strong foundation for research is vital for the effective control of cancer, and a strong research culture is required to permit the New Zealand Cancer Control Strategy to respond strategically to new knowledge and new technologies. Research is therefore essential not only to generate new knowledge about cancer, but also to allow the New Zealand Cancer Control Strategy to evolve and continually improve. Basic research, treatment and prevention of cancer are incremental and interdependent processes.

Proposed Objective 1: Co-ordinate research activities

In New Zealand research is conducted in most areas of cancer control, but most is unco-ordinated and ad hoc. A significant proportion of research has been weighted towards biomedical and clinical areas. There is a need to consider a better balance to make the best use of limited resources and ensure research efforts address commonly agreed priorities that promote effective cancer control.

The Health Research Council is the largest source of funds for cancer research, followed by the Cancer Society of New Zealand and the smaller specialised cancer charities. Most of the topics researched are chosen by investigators. At present over 75 percent of funding for projects from these sources supports laboratory-based biomedical research, about 10 percent goes towards clinical research, and about 6 percent is for epidemiological studies.

Biomedical cancer research in New Zealand is of high quality, especially in the fields of molecular biology and anti-cancer drug development, and this national strength should be maintained. Clinical and epidemiological research in New Zealand can directly inform planning related to cancer control. However, research in such fields as better methods of preventing cancer, investigating the social and behavioural factors that discourage people from seeking treatment, and psychosocial support for those with cancer is unfortunately sparse. The distribution of investigator-initiated research is at present unevenly distributed across the spectrum of cancer control activities. However, the Health Research Council does undertake joint research with the Ministry of Health to obtain an answer to specific policy and health services questions.

Research needs to capture some of the questions unique to the New Zealand environment and cannot rely only on imported findings. Areas in prevention, socio-behaviour and epidemiology can only be answered by specific New Zealand-based research. In particular, there is a need for high-quality and comprehensive research into Māori health and cancer. This should extend beyond a purely biomedical model, or one focused on morbidity and mortality, to encompass the broader aspects of whānau ora, which are important determinants of Māori health status (Minister of Health and Associate Minister of Health 2002a). However, concurrent with this there needs to be continued support to improve the involvement of care providers in biological and clinical research because this can promote and enhance quality clinical practice. For example, participation in clinical trials is a fundamental way to provide new and improved treatments.

There is currently no single body in New Zealand responsible for identifying cancer research gaps, ascertaining research priorities or determining allocation of funding. The expert working groups have all identified significant issues in cancer research and gaps across the cancer control spectrum. This supports a need to establish a strategic and continuing process for overseeing cancer research in New Zealand and to promote a 'research to policy practice' (Canadian Strategy for Cancer Control, 2001) to underpin a cancer control programme.

Possible actions

- 1 Establish a research alliance and process to begin the task of identifying and setting cancer control research priorities and determining existing research gaps.
- 2 Utilise the joint venture research procedures of the Health Research Council to balance research across the spectrum of cancer control.
- 3 Promote the value of ethically approved clinical trials to enhance and develop the quality of cancer care for people with cancer.

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

Collection, monitoring and reporting of national cancer data are essential to facilitate cancer control interventions. Management of cancer data requires the effective use of information technology tools, including standard data sets, agreed data definitions, and appropriate database and health record and networking 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 reporting on patterns of care and outcomes. Co-ordination of national cancer data could be enhanced within the legislative framework and structures.

The New Zealand Cancer Registry, which was established in 1948, is part of the New Zealand Health Information Service and is situated in the Ministry of Health. It collects the histopathological diagnosis on all people with cancer and limited stage information on some cancers, and is able to provide information on cancer incidence and survival. However, resources are limited, and there are inefficiencies with the data collection, which is not linked to more accurate staging and lacks information on treatment modality and cancer-related morbidity. Cancer centres in New Zealand are attempting to develop clinical databases, but most are not comprehensive, and many collect incomplete data and are of limited utility.

Data collected for the Cancer Registry has considerable potential for tracking the pathways of care provided by cancer services, and this could be significantly enhanced if it were linked to a clinical data set. Establishing a nationally consistent minimal data set in each cancer centre, co-ordinating this nationally and linking with the existing Cancer Registry has the potential to create an effective cancer data system that would allow the analysis of treatment and reporting of outcomes related to treatments. This could be further enhanced by developing more detailed data sets for cancers identified to have particular priority for study and monitoring in New Zealand.

Links to other databases, such as those used in palliative care and primary care, could also help to further our understanding of the continuum of cancer care.

Standardised collection of ethnicity data is necessary to form an accurate picture of the situation for Māori, including useful monitoring data such as incidence and mortality rates for various cancers. Ethnicity data tends 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 (NZHIS 2001).

Routine collection and analysis of more comprehensive cancer data could be used to assess how current policies, services and treatment programmes are impacting on cancer, and used to identify where changes should be made and to measure the impact of these changes.

Possible actions

- 1 Improve routine monitoring and reporting of cancer incidence and mortality.
- 2 Improve the Cancer Registry processes for data collection, analysis and reporting.
- 3 Develop a nationally co-ordinated minimum clinical data set that links with the Cancer Registry.
- 4 Improve the quality and accuracy of ethnicity data by reviewing current standards and systems and developing a consistent standard for use across the health and disability sector.
- 5 Develop systems for ensuring the quality and accuracy of data.
- 6 Develop performance indicators to monitor cancer and palliative care services.

Glossary

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| 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. |
| 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. |
| 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 the programme, calculated as the total number screened divided by the number of those who are eligible. |
| District Health Boards (DHBs) | The New Zealand Public Health and Disability Act 2000 established 21 District Health Boards. 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 that it does); (3) an <i>outcome</i> evaluation (an assessment of the ultimate effects of a programme). |
| Evidenced-based practice | 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. |

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| 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 whanau history to assess cancer risk for individuals and/or members of their family and whanau. |
| 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. |
| Goal | A high-level strategic action. |
| Hapū | Sub-tribe. |
| 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. |
| Incidence | The number of new cases or deaths that occur in a given period in a specified population. |
| 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 changes resulting 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. |
| Oncology | The study, diagnosis, treatment and management of cancerous tumours. |

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| Oncologist | A specialist in the treatment of cancer. |
| 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 Māori, Samoan and Tokelauan) living in New Zealand, who have migrated from those island nations or identify with them because of ancestry or heritage. |
| Pathologist | A doctor who specialises in the examination of normal and diseased tissue. |
| Palliative care | The total care of people who are dying from active, progressive, diseases (such as cancer) when curative or disease-modifying treatment has come to an end. |
| Prevalence | The level of disease or other health related condition present in the population at a given time. |
| Protocol | A defined programme for treatment. |
| Prophylactic | Use of medical procedures or treatments to prevent or defend against a disease. |
| Principle | A fundamental basis for action. |
| 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 services | Goods, services or facilities provided for the purpose of improving or promoting the health of the public. |
| 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. |
| Stage | A description of how widely a cancer has spread to adjacent lymph nodes and distant spread. |
| Stakeholders | Organisations/groups with a direct interest and involvement in aspects of cancer control. |

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| 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, 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. |

Appendix 1: The New Zealand Cancer Control Strategy Steering Group Membership

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| 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 of the 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: Expert Working Group Members

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

Appendix 3: Intervention Framework to Improve Health and Reduce Inequalities

1. Structural

Social, economic, cultural and historical factors fundamentally determine health. These include:

- economic and social policies in other sectors
 - macroeconomic policies (eg, taxation)
 - education
 - labour market (eg, occupation, income)
 - housing
- power relationships (eg, stratification, discrimination, racism)
- Treaty of Waitangi – governance, Māori as Crown partner

2. Intermediary pathways

The impact of social, economic, cultural and historical factors on health status is mediated by various factors including:

- behaviour/lifestyle
- environmental – physical and psychosocial
- access to material resources
- control – internal, empowerment

4. Impact

The impact of disability and illness on socioeconomic position can be minimised through:

- income support, eg, sickness benefit, invalids benefit, ACC
- antidiscrimination legislation
- deinstitutionalisation/ community support
- respite care/carer support

3. Health and disability services

Specifically, health and disability services can:

- improve access -distribution, availability, acceptability, affordability
- improve pathways through care for all groups
- take a population health approach by:
 - identifying population health needs
 - matching services to identified population health needs
 - health education

Interventions at each level may apply:

- nationally, regionally and locally
- taking population and individual approaches

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