

# **PROGRESS TOWARDS A NEW ZEALAND CANCER CONTROL STRATEGY**

A BACKGROUND PAPER PREPARED BY THE  
NEW ZEALAND CANCER CONTROL TRUST FOR  
THE PUBLIC HEALTH DIRECTORATE OF THE  
NEW ZEALAND MINISTRY OF HEALTH

by

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# FOREWORD

The New Zealand Cancer Control Trust is a consortium of organisations committed to the development of a New Zealand Cancer Control Strategy (NZCCS). The current impetus to develop a NZCCS was provided by the 1999 Cancer Control Workshop. The widely representative workshop participants unanimously called for the development of a strategy by a network of relevant organisations with a commitment to cancer control. The New Zealand Cancer Control Trust was formed in February 2001 in response to this directive and with funding support from the Cancer Society of New Zealand and the Child Cancer Foundation.

This paper is one of two produced by the Trust under contract to the Public Health Directorate of the Ministry of Health. It reviews the burden of cancer and trends in New Zealand, overseas approaches to reducing the incidence and impact of cancer through comprehensive national cancer control strategies, and existing work that could form part of the New Zealand strategy. The companion document, *The Development of a National Cancer Control Strategy for New Zealand*, provides a plan for the development of a NZCCS.

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# 1. SUMMARY

In developed countries cancer is the second most common cause of death, and evidence points to the emergence of a similar trend in developing countries. The principal factors contributing to this pattern are: the increasing proportion of older people in whom cancer is more prevalent, the greater ability of medical science to control once-fatal communicable diseases; and the rising incidence of certain forms of cancer, notably lung cancer resulting from tobacco use (WHO, 1995). Thus, cancer is an increasingly important item on every country's health agenda, and many are responding to the increasing incidence and burden of cancer by developing national cancer control strategies.

Cancer control is defined as an organised approach to the reduction of cancer incidence, morbidity and mortality. A cancer control strategy provides a framework for an integrated set of activities covering: primary prevention, screening and early diagnosis; treatment and symptom control; rehabilitation and support, and palliative care.

Medical knowledge is now sufficiently advanced to allow the prevention of at least one-third of all cancers, the cure of a further one-third (provided that there is early diagnosis), and adequate symptom control (palliative care) of the remainder. However, putting this knowledge into effect for the control of cancer requires the establishment of systematic nationally based programmes (WHO, 1995). By 1995 more than 40 countries had instituted a national cancer control strategy (NCCS); this number was expected to exceed a hundred by the year 2000.

The present report is a background paper that defines the cancer burden in New Zealand (section 4) and reviews the strategies other countries have adopted to deal with similar challenges (section 6). A companion paper, *The Development of a Cancer Control Strategy for New Zealand* (Gavin *et al*, 2001), recommends how a comprehensive national strategy can be developed, building upon the considerable amount of work already done on the various components of cancer control (section 3).

About 16 000 people develop cancer and 7500 die from it each year in New Zealand (section 4). Incidence is rising and it is predicted that in the year 2006 about 21 500 people will develop cancer and 9800 will die from it in the year 2006. However, many cancers are preventable, some can be detected early, and effective treatment is available for most. In 1997 cancer patients comprised 6.6 percent of all public hospital inpatient and day patient discharges and 15 percent of all hospitalisations for chronic diseases. About 70 percent of patients with cancer are admitted to hospital and their treatment is often expensive. Cancer is a significant cause of disability and lost years of life. From 1960 onwards, New Zealand's cancer mortality rate has been increasing considerably faster than those of Australia, Canada, the USA, and the UK: the cancer mortality rate increased 30 percent for men and 12 percent for women between 1960 and 1995 in New Zealand. Some, but not all, potentially modifiable factors to reduce the cancer burden have been recognised by the Government.

In New Zealand there are non-governmental and governmental imperatives for a NCCS, and currently there is a high level of public expectation that the ways in which the various aspects of cancer are managed and coordinated will be improved (section 3). In 1999 a widely representative workshop unanimously concluded that a national cancer control plan should be established, and *The New Zealand Health Strategy* (King, 2000) includes, as one of its objectives, a reduction in the incidence and impact of cancer. This statement provides an overall goal for a New Zealand NCCS.

The national cancer control strategies of most countries also have similar primary goals. Examples are:

- *USA*: to increase quality and length of life and eliminate disparities among population groups
- *England*: to increase the number of years people spend free from cancer and improve the health of the worst-off members of the population
- *Sweden*: to reduce cancer-related mortality and improve the quality of life of people with cancer
- *Japan*: to pursue a strong research-orientated strategy
- *Italy*: to promote cancer prevention-related lifestyles
- *Ireland*: to establish an equitable, uniform, high quality, integrated national cancer service
- *Germany*: to improve cancer prevention, detection, patient care, research and education
- *Australia*: to improve the continuum of cancer care in prevention, treatment and management.

The national cancer control strategies, frameworks and/or plans that are being developed and implemented overseas (section 6) were developed for reasons that currently apply in New Zealand:

- Resources are limited and cooperative effort will reduce duplication.
- Cancer control cannot be achieved by any single organisation or by government alone.
- The public expects, irrespective of where they live, that there will be reasonable access to current high-quality care.
- Organisations can show leadership by cooperation and partnership.
- A NCCS will provide the focused ongoing attention and leadership that is difficult to achieve otherwise due to high turnover among top-level health leadership.
- The objective of a reduced cancer burden can only occur through cooperation and leadership at the national level.
- A NCCS provides the environment in which prevention can be given the level of priority appropriate to its potential impact.

The reasons why cancer control strategies should be developed now also apply to New Zealand.

These are:

- There is public and government acceptance of the need to re-equip the health system to meet the challenges of an ageing population.
- It is important to act now, before the full impact of the ageing population is felt by the health-care system.
- There is recognition among stakeholders in cancer control that cooperative efforts are the most effective way that individual and common goals can be achieved.
- There is the potential that a NCCS will develop and strengthen alliances among stakeholders, providers, centres, constituents and collaborators.

- There are public concerns about geographic variations in the quality of care available to cancer patients, and, indeed, significant actual variations in care are evident.

The process of developing a NCCS involves a series of stages. These are:

- *Impetus:* In those countries where governments have officially recognised the need for a NCCS, the underlying impetus is usually attributed to the influence of one or more national non-governmental organisations (NGO), which, in many cases, has already developed the nascent infrastructure that will be used and improved by government initiatives and involvement.

In New Zealand, the 1999 Cancer Control Workshop initiated by the Cancer Society of New Zealand provided impetus and *The New Zealand Health Strategy* (King, 2000) clearly indicates the Government's commitment to cancer control.

- *Development:* Extensive consideration by, and consultation with, stakeholders is essential. This is required within each component of cancer control—primary prevention, screening and early diagnosis, treatment, rehabilitation and support, and palliative care—to determine the cost-effectiveness and priorities of the various initiatives that could be taken. Careful discussion is then required among the component sectors to identify overall priorities and agree on targets for the NCCS. This process increases understanding and provides the cohesion necessary for the NCCS to have maximum benefit. The development phase is usually the responsibility of a cancer control strategy development committee, to which sector advisory sub-committees report. All committees should include members drawn from key government and non-governmental organisations. Following the consultation process, the development committee prepares a draft NCCS for approval by the Ministry of Health and the Minister of Health. *The Development of a Cancer Control Strategy for New Zealand* (Gavin et al, 2001) describes how such committees might be established and function.

In New Zealand, considerable work has already been done in cancer prevention, cancer treatment services have been extensively reviewed recently (Ministry of Health 2001c), and a strategy for palliative care already exists (King, 2001b). These would be integrated into a NCCS for New Zealand.

- *Implementation:* Once a NCCS is developed, the Ministry of Health usually assumes responsibility for the implementation, funding and success of the programme. The United Kingdom has appointed a cancer task force headed by the National Cancer Director to oversee the implementation of the NHS cancer plan.
- *Monitoring and review:* Regular and systematic monitoring should be an integral part of the strategy, along with realistic targets. Essential to effective monitoring is availability of adequate data to allow the effectiveness of the strategy's various components to be assessed. The types of data required, and the times required to evaluate effectiveness, will depend on the particular objectives defined by the strategy. The results of monitoring of services and outcomes, periodic review, and new knowledge arising from research on any aspect of cancer control must be used to modify the NCCS. For monitoring and review, there should be a NCCS monitoring and review committee made up of members drawn from both government and non-governmental organisations, and it should report to the Minister of Health.

The New Zealand Health Information Service includes the Cancer Registry, which was empowered by the Cancer Registry Act 1993, and which could, perhaps with additional external contracting and/or collaboration, provide the data base for monitoring. The sources and deficiencies of current data are reviewed in section 5.

The objectives of a NCCS have to be realistic, and set in relation to the increasing incidence of cancer and to particular cancers as well as cancer overall. Appropriate data need to be collected. Because the data needed to demonstrate progress toward each objective require different time periods, the monitoring and review mechanisms need to allow for this. Improved screening, diagnosis and treatment may be evident in survival data within five years, but it may take decades for improved prevention to be reflected in reduced incidence and mortality. Unrealistically optimistic goals may encourage the adoption of a NCCS, but they may lead to it being prematurely discredited.

- The incidence of cancer is rising and, as more people develop cancer, continuation of the status quo only guarantees that the need and demand for services will increase, leading to greater competition for existing resources among the agencies concerned with the various aspects of cancer control from prevention to palliative care.
- Countries similar to New Zealand have developed or are developing comprehensive national cancer control strategies to meet these realities.
- New Zealand is now in a position to build on work already carried out to fully develop its own comprehensive strategy.
- A national cancer control strategy not only would contribute to the improvement in health status and reduction of health inequality which are general goals of *The New Zealand Health Strategy* (King, 2000), but also would provide the necessary focus for achieving one if its highlighted specific objectives, reduction in the incidence and impact of cancer.

## 2. INTRODUCTION

The New Zealand Health Strategy (King, 2000) sets out the Government's platform for action on health. The strategy identifies seven fundamental principles that should be reflected across the health sector and that should be evident in any new strategies or developments. Of particular relevance to the way a cancer control strategy would be implemented are the principles of cross-sector collaborative health promotion and disease and injury prevention. This over-arching strategy highlights 13 population health objectives on which the Ministry of Health and district health boards should focus in the short to medium term. One of these objectives is to reduce the incidence and impact of cancer.

This background paper discusses how a national cancer control strategy (NCCS) could provide the necessary focus for achieving this objective.

'Cancer control' is defined as an organised approach to the reduction of cancer incidence, morbidity and mortality, and 'cancer control strategy' as a process that leads to the development of an organised approach to cancer control. The strategy provides a framework for an integrated set of activities covering primary prevention; screening and early diagnosis where this has been shown to be effective; treatment and symptom control; rehabilitation and support; and palliative care. It operates with appropriate allocation of available resources and helps ensure careful planning. The strategy also identifies appropriate priorities and defines the responsibilities of various agencies in implementing the strategy.

The World Health Organisation (1995) has identified four basic steps in establishing a NCCS. These are:

- assessing the magnitude of the cancer problem
- setting measurable cancer control objectives
- evaluating possible cancer control strategies
- choosing priorities for initial cancer control activities.

The goals of a NCCS are to:

- prevent future cancers
- diagnose cancers early
- provide curative therapy
- ensure freedom from suffering
- reach all members of the population.

This background paper describes the size of the cancer burden in New Zealand (section 4) and the relevant data available (section 5), reviews cancer control strategies in countries similar to New Zealand (section 6), and concludes that work already carried out on aspects of cancer control should be built upon to develop a cancer control strategy for New Zealand. A companion paper, *The Development of a National Cancer Control Strategy for New Zealand* (Gavin *et al*, 2001), describes ways in which a NCCS could be developed.



A New Zealand NCCS would be aligned with other government strategies including those set out in *The New Zealand Disability Strategy* (Dalziel, 2001), *The New Zealand Primary Health Care Strategy* (King, 2001a), *The New Zealand Palliative Care Strategy* (King, 2001b), *He Korowai Oranga* (King, 2001c) and '*The Pacific Health Action Plan*' (currently being developed). It would also acknowledge the Government's commitment to fulfilling its obligations to Māori under the Treaty of Waitangi, addressing the dual goals of reducing disparities in health for Māori and ensuring Māori development in health. The NCCS would be an over-arching strategy, embracing specific existing cancer control policies, guidelines, standards and strategies (Appendix 1).

### **3. WHY A CANCER CONTROL STRATEGY IS NECESSARY FOR NEW ZEALAND**

#### **INTERNATIONAL DEVELOPMENTS**

Cancer causes 5 million deaths throughout the world every year. In developed countries it is the second most common cause of death, and evidence points to the emergence of a similar trend in developing countries. The principal factors contributing to this pattern are the increasing proportion of older people (in whom cancer is more prevalent), the greater ability of medical science to control once-fatal communicable diseases, and the rising incidence of certain forms of cancer, notably lung cancer resulting from tobacco use (WHO, 1995).

Therefore, cancer is an increasingly important item on the health agenda of all developed countries. Medical knowledge is now sufficiently advanced to allow the prevention of at least one-third of all cancers, the cure of a further one-third (provided that there is early diagnosis), and adequate symptom control (palliative care) for the remainder. However putting this knowledge into effect for the control of cancer requires the establishment of systematic nationally-based programmes (WHO, 1995). This WHO report states that NCCSs offer the best means of reconciling what is possible with what is achievable in particular circumstances. In 1995, more than 40 countries had instituted, or were in the process of instituting, NCCSs, and the target number of countries was over a hundred by the year 2000.

Progress with NCCSs in other countries is reviewed in more detail in section 6 and summarised for Australia, Canada, England and New Zealand in Appendix 2. The commentary that follows indicates that considerable progress has already been made toward developing a NCCS for New Zealand.

#### **THE MANDATE OF THE NEW ZEALAND HEALTH STRATEGY**

In the discussion of its objective to reduce the incidence and impact of cancer, *The New Zealand Health Strategy* (King, 2000) reports that cancer is the second leading cause of death (27%) and a major cause of hospitalisation (7%) in New Zealand. There are about 17 000 new registrations of cancer each year, with the highest rates in the middle (46-64 yrs) and older (65 and over) age groups. Further details of the cancer burden in New Zealand is given in section 4. King states that 'to address this priority, a co-ordinated approach is being developed across prevention activities, early detection (particularly screening), treatment and rehabilitation'. This is a clear statement of Government commitment to the development of a NCCS. Reducing the incidence and impact of cancer would be the primary aim of a New Zealand NCCS.

#### **PREVIOUS ACTIVITIES RELATING TO CANCER CONTROL**

In 1997 the Cancer Society of New Zealand formed a small working group to review the need for a NCCS in New Zealand. In a 1999 editorial in the *New Zealand Medical Journal*, that group summarised efforts to date in achieving a co-ordinated approach to cancer, some of which occurred during the 1940s, 1970s and 1980s (Cox *et al*, 1999).

Progress during the 1990s included the following:

- A 1993 survey of specialists involved in cancer treatment sought information about regional services, resources and types of treatment protocols. The majority of respondents were supportive of a national cancer control programme in promoting a co-ordinated approach integrating treatment with prevention, screening and research (Middleton et al, 1994).
- In 1994 an advisory group to the Ministry of Health on a national cancer control programme unanimously agreed that such a plan would minimise duplication and wastage of resources, and improve the quality and effectiveness of existing cancer control services, and that, furthermore, it would provide direction for policy-makers, purchasers and providers across the spectrum of cancer prevention, screening and early detection, treatment and palliative care (National Advisory Group on a National Cancer Control Programme, 1994).
- The 1995 publication of *Cancer Control Services in New Zealand: Developing a National Implementation Strategy* (Ministry of Health, 1995), a report prepared by Coopers and Lybrand, 'to outline the most appropriate process for developing a national cancer control plan and to outline the objectives and the relevant responsibilities to be allocated to particular agencies that would need to be involved in the establishment of a national cancer control plan.'

During the 1990s the control of specific cancers was also addressed in a series of documents produced by the Public Health Commission, including *A Strategic Direction to Improve and Protect the Public Health* (Public Health Commission, 1994a). Published three years later, *Strengthening Public Health Action: The strategic direction to improve, promote and protect public health* (Ministry of Health, 1997) extended the earlier document. Both included specific national objectives with targets and public health strategies for cervical cancer, melanoma, breast cancer and lung cancer. Annual Progress on Health Outcome Targets reports have monitored progress towards these targets.

Other, more recent documents relating to cancer control, including policies, guidelines, standards and strategies, are referred to in Appendix 1. Most of these relate to primary prevention (tobacco control, sun protection, nutrition and physical activity) and early diagnosis/screening (relating to cancers of the cervix, breast, bowel and prostate). The work already done on these aspects of cancer control would contribute substantially to the development of a New Zealand NCCS.

## **THE 1999 CANCER CONTROL WORKSHOP**

On the advice of its 1997 working group, the Cancer Society of New Zealand appointed the National Cancer Control Steering Committee to organise a national workshop in Wellington on 5-6 August 1999, with the purpose of developing a process by which a cancer control strategy could be developed for New Zealand. The workshop was supported and sponsored by the Cancer Society of New Zealand, the Child Cancer Foundation, the Health Funding Authority, the National Health Committee and the Ministry of Health. The 110 invited workshop participants represented a wide range of organisations, interests and expertise, including non-governmental organisations, government agencies, consumer groups and health professionals from throughout New Zealand. They were provided with considerable background reading, including *Systematic Approach to Cancer Needed* (Cox, 1998) and the background paper *Further Information on Cancer Trends, Country Comparisons and Ethnic Differences* (Cox, 1999).

The aims of the workshop were to:

- define the current state of cancer control in New Zealand
- identify what could be achieved in New Zealand by a NCCS
- establish a commitment to, and a process by which, such a strategy could be achieved in New Zealand.

Prior to attending the workshop, participants were sent a questionnaire asking about their areas of expertise, for examples of planned approaches in their sector, where a planned approach was lacking, and how a cancer control strategy could overcome any problems.

Key issues identified and included in the report of the workshop were as follows:

- A cancer control process-involving the four basic steps of assessing the magnitude of the problem, setting the agendas, developing strategies and prioritising control activities-is needed to improve cancer control activities in New Zealand.
- Identifying relevant data and information and using an evidence-based approach are important.
- If it is to succeed, a national cancer control plan must have relevance to the quality of life of patients and the wider community, and must involve the public.
- Political will, and appropriate tactics and resources are required to implement the strategy.
- Realistic targets must be set within the resources available, and information needs to be gathered to shape the plan.
- The methods of monitoring and evaluating the strategy will need to be planned from the outset.
- Cancer control initiatives need to be integrated with other health initiatives so that the wider context of improving health status is not forgotten.
- Because of the geographic spread of the New Zealand population, decisions have to be made about the care available at primary, secondary and tertiary levels.
- The geographic spread of the population also impacts on the provision of accessible sub-specialty care, such as cancer care for children and adolescents.
- A specific-issue targeted approach has been used already by the Ministry of Health, particularly in areas such as tobacco control, healthy eating, reducing alcohol consumption, reducing UV exposure, immunisation against hepatitis B and the breast and cervical screening programmes; however, many other components of a national cancer control plan still need to be addressed.
- Which agencies are responsible for which steps in cancer control need to be identified so that gaps and areas requiring attention can be identified and resolved.
- Māori need to be involved in the development of the national cancer control plan so that appropriate representation, involvement of Māori expertise, use of data, and commitment to the Treaty of Waitangi, are fully considered.
- The strategy would need to cover areas of familial cancer and cancer genetics, palliative care, and child and adolescent cancer.

At the workshop various options for developing a more systematic approach and increased co-ordination of activities were explored. The option that was unanimously favoured was the development of a consortium of agencies to fund a secretariat, which would liaise with the various organisations and the public in the development of a NCCS. As highlighted in the report, 'the secretariat's success would depend on its interface with the government agencies responsible for policy, purchasing and regulation.'

At the conclusion of the workshop, participants unanimously approved the following recommendations:

1. A national cancer control plan for New Zealand should be established.
2. The National Cancer Control Strategy Steering Committee should continue, and co-opt additional members where necessary.
3. The Steering Committee should establish a taskforce to drive this initiative, work to establish a representative national network of relevant organisations with a commitment to cancer control, and develop terms of reference for the taskforce and the network (Members of the National Cancer Control Steering Committee, 2000).

## **THE NEW ZEALAND CANCER CONTROL TRUST**

In response to the unanimous call by the workshop for a consortium of member organisations committed to the development of a national cancer control strategy, the New Zealand Cancer Control Trust was formed in February 2001. The trustees and members of the Expert Advisory Panel, which served as a reference group in the preparation of this background paper, are listed in section 9 of this report. Personnel of the Trust prepared this paper and its companion scoping plan in consultation with, and under contract to, the Ministry of Health.

## **PARALLEL DEVELOPMENTS IN OTHER COUNTRIES**

As section 6 and Appendix 2 indicate, national cancer control strategies, frameworks or plans are also being developed in many other countries that face similar challenges to New Zealand. Although the overall goals set by the NCCSs of the various countries may differ in emphasis, the reasons for developing national strategies are surprisingly similar, and apply equally to New Zealand. As expressed in the *Canadian Draft Synthesis Report* (Canadian Strategy for Cancer Control, 2001), these are:

- *Resources are limited:* Cooperative effort will reduce duplication.
- *Collective action:* Cancer control cannot be achieved by any single organisation or government alone.
- *Equity:* The public expects, irrespective of where they live, that there will be reasonable access to care of current high quality.
- *Leadership:* Organisations can show leadership by cooperation and partnership. A national cancer control plan will provide the focused ongoing attention and leadership that is otherwise difficult to achieve due to high turnover among health leadership.

- *Vision:* The ideal of a reduced cancer burden can only occur through cooperation and leadership at the national level. A national cancer control plan provides the environment in which prevention can be given a level of priority in keeping with its potential impact. A national population database is needed to demonstrate impact of strategies.

The Canadian report goes on to outline the reasons why national cancer control strategies should be developed now:

- There is public and government acceptance of the need to re-equip health systems to meet the challenge of an ageing population.
- It is important to act now, before the full impact of the ageing population is felt by the health care system.
- There is recognition among stakeholders in cancer control that cooperative efforts are the most effective way that individual and common goals can be achieved.
- There is the potential that a national cancer control plan will develop and strengthen alliances among stakeholders, providers, centres, constituents and collaborators.
- There are public concerns about geographic variations in the quality of care available to cancer patients, and, indeed, significant actual variations in care are evident.

## **PARTICULAR CONSIDERATIONS FOR CANCER CONTROL IN NEW ZEALAND**

New Zealand is in a position to take advantage of the other countries' experiences in developing national cancer control strategies, with some countries providing useful models of both process and outcome.

However, a national strategy will reflect the unique and specific needs of this country, identifying priorities for action within the New Zealand context.

The National Cancer Control Strategy will acknowledge the Treaty of Waitangi as New Zealand's founding document and the Government's commitment to fulfilling its obligations as Treaty partner. It will also acknowledge the 'special relationship' between the Crown and Māori and the basic premise that Māori should continue to live as Māori in Aotearoa (King, 2000). In the health and disability sectors this relationship has been based on three key principles (Royal Commission on Social Policy, 1998), which are:

- *Participation* at all levels
- *Partnership* in service delivery
- *Protection* and improvement of Māori health status.

The National Cancer Control Strategy will address the dual goals (Cunningham, 2000) of reducing disparities in health for Māori and ensuring Māori development in health (King, 2000).

In line with The New Zealand Health Strategy (King, 2000) and the 'Pacific Health Action Plan' (under development), the NCCS also will address such issues as access to services and the provision of culturally appropriate services for Pacific Islands peoples.

- Government and non-government groups knowledgeable about aspects of cancer control have concluded that New Zealand needs a NCCS.
- Extensive work, which could contribute to or form part of a New Zealand NCCS, has already been done.
- The reasons that have led other countries to develop NCCSs apply equally to New Zealand and are:
  - The incidence of cancer is rising and, as more people develop cancer, continuation of the status quo only guarantees that the need and demand for services will increase, leading to greater competition for existing resources among the agencies concerned with the various aspects of cancer control from prevention to palliative care.
  - As the population ages, more money will be spent on cancer: the question a national strategy addresses clearly and effectively is how best to use these resources.
  - The public expect, and deserve nothing less than, full cooperation and coordination among government and community-based organisations to ensure access to the services they need across the continuum of cancer control.

## 4. THE CANCER BURDEN IN NEW ZEALAND

About 16 000 people develop cancer, and 7500 die from it each year in New Zealand (New Zealand Health Information Service, 2000). About 21 500 people are forecast to develop cancer and 9800 to die from cancer annually in the time period 2002-06 (Cox, 1995). However, many cancers are preventable, some can be detected early, and effective treatment is available for most. In 1997 cancer patients comprised 6.6 percent of all public hospital inpatient and day-patient discharges and 15 percent of all hospitalisations for chronic diseases (New Zealand Health Information Service, 2000). About 70 percent of patients with cancer are admitted to hospital and their treatment is often expensive. Cancer is a significant cause of disability and lost years of life (Ministry of Health, 2001a). From 1960 onwards, New Zealand's cancer mortality rate has been increasing considerably faster than those of Australia, Canada, the USA, and the United Kingdom (Ministry of Health, 1999). The cancer mortality rate increased 30 percent for men and 12 percent for women between 1960 and 1995 in New Zealand. Some, but not all, potentially modifiable factors to reduce the cancer burden have been recognised by the Government (Ministry of Health, 2001b).

Tables 1 and 2 contain summaries of cancer mortality and incidence, and show the relative contribution of different cancer sites to the cancer burden in New Zealand. The 1989-93 time period has been used for the comparison of incidence rates because the breast and prostate cancer incidence have recently been inflated by detection bias, respectively from mammography screening and the use of PSA tests. Reported melanoma incidence, in particular, has increased since 1994, due to the introduction of statutory notification of cancer.

The cumulative incidence and mortality rates shown in Tables 1 and 2 can be interpreted as the chance of a newborn baby developing, or dying from, cancer before its 75th birthday. For example, the cumulative mortality rate for all malignant neoplasms (all cancers) before age 75 years was 188.4 per 1000 newborns—that is, about 19 percent of newborns will die of cancer before they reach the age of 75.

**Table 1. Cumulative mortality and incidence rates per 1000 (0-74 years) and average annual number of deaths and cases for cancers in New Zealand men.**

Site	Average annual number of deaths	Cumulative mortality rate 1991-95	Average annual number of cases	Cumulative incidence rate 1989-93
All malignant neoplasms (except non-melanoma skin)	3741	188.4	6098	329.5
Lung	881	48.8	1023	60.7
Colon	337	17.9	632	36.2
Prostate	487	16.2	946	42.4
Stomach	156	7.8	238	12.7
Rectum	219	11.8	399	23.5
Pancreas	138	7.2	149	8.3
Brain and other nervous system	107	6.2	129	7.3
Oesophagus	125	6.9	123	7.3
Melanoma	112	5.6	464	25.5
Leukaemia	132	6.1	214	10.2
Kidney & other urinary organs	83	4.5	154	9.0
Bladder	103	4.0	296	15.1
Non-Hodgkin's lymphomas	117	6.0	211	11.5
Liver and biliary passages	78	4.3	98	5.6
Multiple myeloma	58	2.9	83	4.2
Larynx	28	1.7	77	5.0

Source: New Zealand Health Information Service, 2000.



In the 1991-95 time period, the five cancer sites with the highest mortality rates for men were: lung, colon, prostate, stomach and rectum (Table 1).

In the 1991-95 time period the five cancer sites with the highest mortality rates in women were: breast, lung, colon, ovary, and rectum (see Table 2 below).

**Table 2. Cumulative mortality and incidence rates per 1000 (0-74 years) and average annual number of deaths and cases for cancers in New Zealand women.**

Site	Average annual number of deaths	Cumulative mortality rate 1991-95	Average annual number of cases	Cumulative incidence rate 1989-93
All malignant neoplasms (except non-melanoma skin)	3281	140.0	6225	297.4
Breast	580	27.4	1605	83.1
Lung	424	21.2	502	27.2
Colon	372	14.5	735	32.9
Ovary	166	8.0	241	12.2
Rectum	151	6.1	282	13.2
Cervix uteri	83	4.0	240	11.9
Stomach	97	3.0	138	5.2
Pancreas	130	4.8	133	5.4
Brain & other nervous system	87	4.5	98	5.2
Leukaemia	101	3.6	167	6.2
Non-Hodgkin's lymphomas	110	4.3	182	8.2
Corpus uteri	55	2.3	213	11.4
Melanoma	77	3.3	522	25.8
Liver and biliary passages	88	3.4	76	3.2
Multiple myeloma	52	2.1	73	3.5
Oesophagus	67	2.1	73	2.7

Source: New Zealand Health Information Service, 2000.

- About 16 000 people develop cancer, and 7500 die from it each year in New Zealand. This will increase considerably over the next two decades.
- About 70 percent of patients with cancer in New Zealand are admitted to hospital.
- From 1960 onwards, New Zealand's cancer mortality rate has been increasing considerably faster than those of Australia, Canada, the USA, and the United Kingdom.

## CHANGE IN RATES OVER TIME

Improvements in the completeness of cancer registration, particularly from about 1970 to 1980, have contributed to increases in recorded incidence rates of cancer (Foster, 1976). This has affected reported rates for some cancer sites more than others. Those cancer sites for which treatment or diagnosis at a public hospital is required are least likely to have been affected, particularly if patients require radiotherapy. For other cancer sites, the improvements in cancer registration will have altered trends in incidence: in particular, trends in incidence rates for cancers of breast, colon, rectum, bladder, ovary, corpus uteri, melanoma, leukaemia, lymphomas, and multiple myeloma are likely to be affected by improved registration from private hospitals and private treatment facilities over time.

Prior to 1972, registration of cancer was not made from death certificates (Foster and Fraser, 1982). More recently, statutory reporting of cancer from pathology laboratories has been instituted and registrations are expected to be almost complete for all sites from 1995 onwards. For these reasons, both changes in incidence and mortality should be considered together and greater reliance given to changes in mortality when assessing underlying trends in cancer in New Zealand. Some reductions in mortality for some cancer sites are likely to be the result of improvements in therapy; this has been dramatic in the case of paediatric cancers, lymphomas and germ-cell tumours.

Annual publications of the Cancer Registry provide information on the annual numbers of men and women diagnosed with, and the numbers who have died from, cancer in New Zealand for each five-year age group. The information in these publications and tables of the annual mean population of New Zealand have been used to calculate both cumulative and age-standardised mortality and incidence rates of cancer in New Zealand.

Overall, male cancer mortality increased 30 percent over the past 35 years (Ministry of Health, 1999). Reductions in mortality among men occurred for cancer of the stomach and, to a lesser degree, for cancer of the pancreas and leukaemia. Male mortality for the smoking-related cancers of the lung and larynx did not increase during the time period examined, although rates initially increased markedly and then fell. Large increases in male mortality were observed for melanoma, cancers of the oesophagus, kidney and urinary organs, non-Hodgkin's lymphomas, prostate and rectum, with smaller increases in mortality for multiple myeloma and cancers of the colon, brain and nervous system, liver and biliary passages and bladder.

In general, changes in male incidence have been similar to mortality, but with an additional effect from increased completeness of registration over time. For prostate cancer, a marked increase in the number of registrations has occurred in recent years, due to increased detection through the use of PSA tests.

Overall, for women, all cancer mortality increased 12 percent over the past 35 years (Ministry of Health, 1999). The greatest reductions in mortality were seen for cancers of the stomach, cervix uteri and corpus uteri, with lesser reductions for leukaemia, cancers of the liver and biliary passages, and ovary. Colon cancer decreased slightly over the period examined. Improved accuracy in the classification of cancers of the liver may have led to lower liver cancer mortality rates. The largest increases in female mortality rates were from lung cancer, melanoma, multiple myeloma, non-Hodgkin's lymphoma and cancers of the brain and nervous system and rectum. Changes in diagnosis over time may have contributed to increased mortality rates of lymphomas, melanoma, and multiple myeloma.

In general, the changes in female incidence rates were similar to changes in mortality rates, but were often of much greater magnitude mainly due to more complete cancer registration over time. The opposite trend of reduced mortality and incidence of leukaemia for both women and men was probably due to improvements in treatment over the time period studied.

- Male cancer mortality in New Zealand has increased 30 percent over the past 35 years.
- Cancer mortality in New Zealand women has increased 12 percent over the past 35 years.

## COMPARISON WITH SIMILAR COUNTRIES

Because New Zealand cancer registration has improved since statutory notification was introduced, and few other nationwide cancer registries exist, the comparison below with other countries is restricted to mortality rates. Differences in cancer mortality among countries are due to differences in the prevalence of cancer-causing behaviours (such as cigarette smoking), the effectiveness of cancer prevention, effective early detection, and/or the use of effective treatment of cancer.

Out of 175 countries studied, New Zealand women have the sixth highest cancer mortality rate in the world, and men have the 33rd highest cancer mortality (Ferlay *et al*, 1998).

Table 3 shows the age-standardised cancer mortality rates for the 1963-67 time period and 1996 and the percentage change in rates compared with the average rate between the two time periods for men and women for selected countries. Trends between the 1963-67 time period (Aoki *et al*, 1992) and 1996 (WHO, 2001) are presented to summarise the historical change in cancer mortality in New Zealand compared with Australia, the USA, Canada, and England/Wales. These populations have been chosen because they are countries with which we traditionally compare ourselves. Due to the availability of published age-standardised rates for the particular cancer sites assessed, the 1963-67 time period and 1996 were compared. The world standard population was used to calculate age-standardised rates.

New Zealand had the greatest increase in male and female cancer mortality over the 30 years. It would appear that the other countries listed have achieved greater progress than New Zealand in preventing cancer, effective early detection or treatment over several decades.

- Compared with the USA, Canada, England and Wales, New Zealand had the greatest increase in male and female cancer mortality over the 30 years from 1963.

**Table 3. Trends in age standardised cancer mortality rates between 1963-67 and 1996.**

	Male			Female		
	1963-67	1996**	% change†	1963-67	1996**	% change†
New Zealand	146.5	158.4	8.1	111.7	122.4	9.6
Australia	144.0	152.2	5.7	99.1	97.0	-2.1
USA	147.6	155.0	5.0	107.4	107.8	0.4
Canada	143.8	154.9	7.7	112.7	108.1	-4.1
England & Wales	182.6	160.3	-12.2	116.3	113.9	-2.1

\*Rate for 1964 used for the USA

\*\* Only rate for 1995 available for Australia

† Change expressed as a percentage of the average rate for the two time periods

Sources: Aoki *et al*, 1992; WHO, 2001.

## COUNTRY COMPARISON OF THREE MAJOR CANCERS

### Trachea, bronchus, and lung

Each year in New Zealand 1000 men are diagnosed with cancer of the trachea, bronchus, and lung, and it causes the death of about 900 men. Also, at least 470 women die from and at least 550 women are diagnosed with this cancer annually. Over 90 percent of these cancers are due to the smoking of cigarettes. Table 4 shows the change in age-standardised mortality rates for cancer of the trachea, bronchus, and lung over a 30-year period for selected countries. Mortality decreased among men in New Zealand compared with Canada, the USA and Australia. New Zealand did not achieve the reduction seen in England/Wales. Among women the increase in mortality from cancer of the trachea, bronchus, and lung was not as great as seen in Canada and the USA.

**Table 4. Lung cancer: trends in age-standardised mortality rates between 1963-67 and 1996.**

	Male			Female		
	1963-67*	1996**	% change†	1963-67*	1996**	% change†
New Zealand	37.3	37.1	-0.5	5.3	17.8	235.8
Australia	36.2	37.4	3.3	4.4	13.6	209.1
USA	37.3	51.9	39.3	5.7	26.6	365.6
Canada	33.0	49.1	48.8	5.3	24.6	364.2
England & Wales	70.0	44.2	-36.9	10.2	19.6	92.2

\*Rate for 1964 used for the USA

\*\* Only rate for 1995 available for Australia

† Change expressed as a percentage of the average rate for the two time periods

Sources: Aoki et al, 1992; WHO, 2001.

Māori have higher mortality rates of lung cancer than non-Māori. As cigarette consumption in men has fallen among successive generations, lung cancer rates have finally begun to fall. As a result a 35 percent reduction in lung cancer mortality among men is expected over the next 20 years (Cox, 1995). However, some lung cancers may be induced through the smoking of cannabis and this may ameliorate the expected reduction in lung cancer.

### Stomach

About 150 men die from, and about 230 are diagnosed with, stomach cancer each year in New Zealand. Among women, about 100 die and 140 are diagnosed with it each year. Stomach cancer mortality has been declining rapidly over many decades in most affluent countries with predominantly European populations. The reason for this is not known. Although New Zealand has followed this trend, reductions in both male and female stomach cancer mortality rates were not as pronounced as in the other comparative countries (see Table 5 next page). In many countries the incidence of cancer of part of the stomach (the cardia) and the lower third of the oesophagus is increasing, despite the overall reduction in stomach cancer rates. The reason for this is unknown.

It has been estimated that the cause of up to 60 percent of stomach cancer may be a chronic infection of the stomach by the *Helicobacter pylori* bacteria. This infection appears to be largely

acquired in childhood and for many people is asymptomatic and chronic. For a small minority of those infected, stomach cancer occurs. Māori have higher incidence and mortality rates of stomach cancer than non-Māori.

**Table 5. Cancer of the stomach: trends in age-standardised mortality rates between 1963-67 and 1996.**

	Male			Female		
	1963-67*	1996**	% change†	1963-67*	1996**	% change†
New Zealand	16.9	7.2	-57.4	8.2	3.7	-54.9
Australia	16.1	6.4	-60.2	8.1	2.7	-66.7
USA	16.3	4.3	-73.7	19.9	2.0	-89.9
Canada	17.5	6.1	-65.1	8.1	2.8	-65.4
England & Wales	23.8	9.3	-60.9	11.6	3.4	-70.7

\* Rate for 1964 used for the USA

\*\* Only rate for 1995 available for Australia

† Change expressed as a percentage of the average rate for the two time periods

Sources: Aoki et al, 1992; WHO, 2001.

## Breast

About 600 women die from, and at least 1700 are diagnosed with, breast cancer each year in New Zealand. The number of registrations of breast cancer has increased recently due to the increased detection of breast cancer among women aged 50 to 64 participating in the National Breast Screening Programme. Historically, compared with the countries listed in Table 6, New Zealand has experienced a small increase in breast cancer mortality. The reasons for this are unknown.

**Table 6. Cancer of the breast in women: trends in age-standardised mortality rates between 1963-67 and 1996.**

	1963-67*	1996**	% change†
New Zealand	23.5	25.0	6.4
Australia	19.5	19.3	-1.0
USA	21.9	19.8	-9.6
Canada	24.0	21.1	-12.1
England & Wales	24.8	23.8	-4.0

\* Rate for 1964 used for the USA

\*\* Only rate for 1995 available for Australia

† Change expressed as a percentage of the average rate for the two time periods

Sources: Aoki et al, 1992; WHO, 2001.

## Ovary

About 170 women die from, and about 260 are diagnosed with, cancer of the ovary each year in New Zealand. Use of the contraceptive pill for three or more months appears to reduce the life-time risk of ovarian cancer. The reason for this is unknown. As a consequence, generations of women with high use of the contraceptive pill have experienced lower rates of ovarian cancer. Mortality from cancer of the ovary has been reduced in many countries and further reduction in ovarian cancer mortality is predicted (Cox, 1995).

## Liver and biliary passages

About 80 men die from cancer of the liver and biliary passages and about 100 are diagnosed with it each year in New Zealand. Annual figures for women are about 80 deaths and 80 diagnoses. Māori have higher liver cancer incidence and mortality. Liver cancer incidence and mortality is lower in the South Island than the North Island, among both Māori and non-Māori populations. Liver cancer rates among men have been predicted to increase over the next two decades.

A significant proportion of liver cancer is caused by chronic infection with the hepatitis B virus. National immunisation of children against hepatitis B virus may reduce liver cancer incidence and mortality in decades to come (Cox, 1995).

## Māori and non-Māori incidence rates of cancer

Despite the known difficulties with the recording of ethnicity in national information systems it is still worth making some comparisons of incidence rates by recorded ethnicity.

In general, Māori incidence rates are believed to be underestimated by about 25 percent in Cancer Registry data. Ethnicity coded by the Cancer Registry has been recorded with varying accuracy at hospital admission. Table 7 shows Māori and non-Māori rates separately for the 1988-92 time period published by the International Agency for Research on Cancer (IARC, 1997).

Overall, cancer incidence was higher in Māori compared with non-Māori. Much of this excess came from differences in smoking-related cancers such as cancer of the lung, reflecting historical differences in smoking prevalence between ethnic groups. The relatively high Māori smoking prevalence is being reduced through health promotion action. For cancers of the colon, rectum, brain and nervous system, bladder, non-Hodgkin's lymphoma and melanoma, incidence rates were lower among Māori.

**Table 7. Māori and non-Māori age-standardised cancer incidence rates (per 100 000), 1988-92**

Site	Male		Female	
	Māori	Non-Māori	Māori	Non-Māori
All cancers (except non-melanoma skin)	359.7	290.3	339.7	274.6
Lung	99.7	46.5	72.9	18.2
Stomach	27.9	11.0	13.7	4.8
Colon	21.5	31.2	16.0	29.6
Rectum	12.8	20.1	9.2	11.2
Prostate	44.4	37.8		
Breast			77.1	77.2
Ovary			12.2	11.0
Cervix uteri			32.2	11.9
Corpus uteri			15.8	9.4
Pancreas	9.8	7.3	6.7	4.6
Liver and biliary passages	15.2	4.2	4.8	2.7
Brain and other nervous system	5.2	7.4	4.0	5.1
Kidney and other urinary organs	7.6	7.1	3.5	4.4
Bladder	10.5	14.0	2.2	4.1
Multiple myeloma	5.7	4.1	5.8	2.7
Leukaemia	12.2	10.7	7.9	7.1
Non-Hodgkin's lymphomas	8.1	10.3	6.7	7.5
Melanoma	5.1	25.0	3.4	29.8
Larynx	3.1	4.0	1.2	0.6

Source: IARC, 1997.

- Overall, the incidence of cancer is higher in Māori than non-Māori, with much of this excess due to smoking-related cancers.

### Pacific Islands people living in New Zealand

Cancer incidence rates among Pacific Islands people living in New Zealand have been published for the 1987-91 time period (Public Health Commission, 1994b). These rates are useful for assessing the relative importance of cancer for Pacific Islands people and approximate annual rates calculated from the publication are shown in Table 8. The relative importance of the different cancers has not changed dramatically since the 1978-82 time period (IARC, 1987).

**Table 8.** Approximate annual age-standardised cancer incidence rates for Pacific Islands people in New Zealand (per 100 000), 1987-91

Site	Male	Female
All cancers (except non-melanoma skin)	354	266
Lung	70	18
Stomach	26	12
Colon and rectum	24	28
Prostate	48	
Breast		58
Ovary		18
Cervix uteri		26
Corpus uteri		18
Pancreas	10	ng
Liver and biliary passages	20	6
Brain and other nervous system	6	ng
Bladder	10	ng
Multiple myeloma	6	ng
Leukaemia	14	12

ng = not given

Source: Public Health Commission, 1994b.

For Pacific Islands men, incidence was highest for cancers of the lung, prostate, stomach, and colon and rectum. For women, incidence was highest for cancers of the breast, colon and rectum, cervix, lung, ovary, and corpus uteri.

### Cancer in children and adolescents

Considering the number of person-years of potential life at risk, childhood cancers rank third (behind breast and lung cancer) among all malignancies in the USA (Bleyer, 1990). Although children with cancer represent only 1 percent of the overall incidence of the disease, cancers in the 0-14 age group rank second only to breast cancer in the number of years of potential life saved. The incidence of cancer in this age group in New Zealand is comparable to that in other OECD countries; 131 per million person-years (Dockerty *et al*, 1997). International data indicate that the incidence rate for cancer in children is increasing by about 1 percent per annum (Kosary *et al*, 1995). In New Zealand, the incidence of acute lymphoblastic leukaemia, the most common type of childhood cancer, is increasing (Dockerty *et al*, 1996). The cause for this is not known. Acute lymphoblastic leukaemia is

less common in Māori but when it occurs is associated with poorer survival compared with European children (Ridgway *et al*, 1991).

It is estimated that between one in 600 and one in 1000 adults will be survivors of childhood cancer, amounting to 1 percent of the young workforce (Bleyer, 1990). About 50 percent of survivors of childhood cancer suffer permanent side-effects from the cancer and its treatment. Identification and treatment of these effects present an increasing challenge to oncologists in New Zealand. Presently about 70 percent of childhood cancers are cured, and a national infrastructure is being developed by the paediatric oncology steering group to coordinate child cancer care in New Zealand. There is a need to provide a similar service for adolescents with cancer. Half the survivors of cancer in childhood suffer long-term physical and psychological sequelae and, thus, there is a need for coordinated treatment and follow up for these patients.

Cancer in adolescents (15-19 years) exceeds 200 per million person-years. In the USA, the incidence of adolescent cancer has increased 30 percent over the period 1973-96. Improvement in cure rates for childhood cancer is due to treatment in cooperative clinical trials in specialised child cancer units. Adolescents with cancer have an inferior survival compared to children (<15 year-olds). Adolescents are not treated in dedicated units and few are entered into clinical trials (Barr, 1999).

- Cancers in children rank second only to breast cancer in the number of years of potential life at risk.
- Seventy percent of childhood cancers are cured.
- Half the survivors of childhood cancer have long-term sequelae and there is a need for coordinated follow up and treatment.
- Adolescents with cancer have poorer survival than children with cancer.



## **5. THE SOURCES OF DATA AND DEFICIENCIES IN EXISTING DATA**

### **BACKGROUND**

The New Zealand Health Information Service (NZHIS), a group within the Ministry of Health, is responsible for maintenance of both the New Zealand Cancer Registry and the New Zealand Mortality Registry. The Cancer Registry, one of the oldest in the world, was established by the Medical Statistics Branch of the Department of Health and the British Empire Cancer Campaign Society in 1948.

The Cancer Registry's operations were independently reviewed in 1988 and 1991; both review reports recommended, among other things, that legislation was required to support the operation of the Registry. The 1988 review was recommended by the National Health Statistics Centre and the Cancer Society of New Zealand.

In 1993, Parliament passed the Cancer Registry Act, which became law on 1 July 1994. It required that persons in charge of laboratories report all diagnoses of cancer to the Registry. Total cancer registrations in 1994 were over 20 percent higher than in 1993 and registrations of malignant melanoma of the skin increased by 45 percent.

Previously, there had been issues with incomplete and untimely cancer registration information. This empowering legislation resolved some of these issues. The New Zealand Cancer Registry is now well placed to support the proposed NCCS. The efficiency of processing will be further enhanced with the development of a new computer system, which is expected to be operational by September/October 2001.

The Registry has limited resources available for analysis and interpretation of data. However, recently the Public Health Intelligence Section of the Public Health Directorate of the Ministry of Health has expressed interest in joint project arrangements to enable greater analysis and dissemination of cancer information.

### **DATA AVAILABILITY**

The hard-copy publication on 1997 registrations is currently in final draft, 1998 data processing is complete and provisional summary statistics will be published on the NZHIS web page shortly.

Data on malignant melanoma of the skin, colorectal cancers, and cancers of the breast, cervix and prostate are treated as priorities for processing and all available cases are processed up to the end of the year 2000. In total, these cases represent over 50 percent of the expected registrations each year.

The Public Health Intelligence Section is currently involved in work on several major areas of cancer:

- Production of an atlas of cancer mortality and registrations by census area units, which will include a comparison with the findings from the previous cancer mortality atlas produced in the early 1980s; to be completed by June 2001.
- Publication of time trends for male and female cancer mortality since 1980; to be completed by June 2001.
- Forecasting the cancer burden in New Zealand; to be completed during 2001/02.

## **THE DATABASE**

Most registrations of cancer since mid-1994 have been based on laboratory reports that are supplied as paper copies. This information is supplemented with information from public and private hospital discharge reports, and death certificate and autopsy reports.

The present computer system that supports the Registry's operations is part of a larger system that supports all the NZHIS core statistical collections. The present design has some drawbacks and the planning for a new computer system is well advanced. It is expected that a new stand-alone computer system will be operational by September/October 2001.

The Registry is also consulting with laboratories with the objective of eliminating paper-based reporting in favour of reporting by electronic means. However, because information about stage or the spread of cancer is often not available from pathology reports, staging information is often not available. Multiple streams of information can often result in the need for time-consuming checking of records to establish whether greater or more relevant information is available than is already recorded by the Cancer Registry.

## **CANCER CLASSIFICATION SYSTEMS**

Information about site of disease (topography) is classified on the Registry according to the International Classification of Diseases (ICD). Morphology is classified according to the International Classification of Diseases for Oncology (ICD-O); the ICD-O morphology classification is almost identical to the SNOMED classification used by most laboratories.

## **DATA QUALITY**

The Registry has enlisted the support of a small group of honorary clinical advisers, who assist in resolving classification problems, provide advice on maintaining good relationships with healthcare providers, and conduct training seminars for Registry staff.

The Registry's basic data-site, morphology, age and sex-required for routine analysis of incidence are believed to be of very high quality; however, apart from the review of registration of childhood cancers (Dockerty et al, 1997), no independent audit of the completeness and accuracy of the individual records has been carried out. Dockerty et al concluded that overall the New Zealand Cancer Registry had good completeness for childhood cancers, but the number of unconfirmed registrations was larger than expected. It would seem timely for a comprehensive audit to be carried out so that the effects of any NCCS can be accurately measured.

The data contained in the Cancer Registry should provide the incidence benchmarks that will be essential in measuring the effectiveness of a NCCS.

## **SURVIVAL DATA**

There has not been a comprehensive analysis of survival data carried out since 1984. However, when the mortality statistics processing for 1999 is completed (estimated June 2001), the NZHIS will embark on an analysis of the survival of cases registered in the years 1994 to 1996 employing

methodologies and computer software developed by the Finnish Cancer Registry. This methodology was used to analyse survival in the recent Eurocare study, which compared survival rates of cancers in different countries in Europe (but it was not possible to adjust for the stage of cancer at presentation in the analysis). For comparison of survival rates between treatment centres in New Zealand staging information will be required so that some adjustment for the severity of disease can be carried out. As some carcinoma-in-situ cases, or those where the histology is equivocal, are inadvertently registered as invasive cancers, review of the histology reports by trained personnel will be required for at least some cancer sites.

Survival analysis processing will be carried out following the completion of 1999 cause of death statistics processing after June 2001.

The Registry has limited resources available to interpret the results of the survival analysis and expects to enter into collaborative arrangements for the preparation of reports. The Public Health Intelligence Section in the Ministry of Health has expressed interest in being involved.

The results of this analysis will provide a set of benchmarks for future measurement of the success of a NCCS.

## **MORTALITY DATA**

The NZHIS is responsible for compiling New Zealand's cause of death statistics. Copies of all certificates of cause of death, some autopsy reports and all coroners' findings are supplied to NZHIS. This information is supplemented with information from hospital discharge reports and Cancer Registry records.

Mortality records are routinely linked with Cancer Registry data for the purposes of ascertaining dates of death and to enable registration of the very small proportion of cases where the only information about cancer diagnoses may have been the death certificates.

Time trend statistics of mortality from cancer are routinely published in the NZHIS annual reports of Mortality and Demographic Data. Data are also published on the NZHIS website. International comparisons of cancer mortality are also compiled and published on an occasional basis.

- The Cancer Registry has a major role in a NCCS.
- The results from analyses of geographical differences in cancer incidence, time trends, projections, and the accurate calculation of survival after diagnosis will be important measures of performance of a NCCS.
- Analysis should include an adequate assessment of time trends and survival for childhood cancers.
- Differences between ethnic groups in these measures of performance should be assessed.

## 6. CANCER CONTROL STRATEGIES IN OTHER JURISDICTIONS

### INTERNATIONAL PERSPECTIVE

In 1995 the World Health Organisation published *National Cancer Control Programmes: Policies and Managerial Guidelines*, work initiated in 1991 (WHO, 1995). This handbook outlines the scientific knowledge that forms the basis for national cancer control programmes and offers extensive guidance on their establishment and organisation. Much of its content was derived from experience gained in various countries that had already instituted their own NCCSs.

Bennett *et al* (1999) extensively reviewed 11 OECD countries with respect to progress toward **national** cancer control strategies, and this review provided background information for the Canadian initiative. The survey analysed 'the success or failure of these programmes based on self-assessment documents published by federal authorities', and concluded that, at that time, some countries had not identified a national strategy (Belgium, Germany, Japan), some were identifying national strategies (Australia, France, Ireland, and Sweden), and some had initiated them (Italy, New Zealand, England and the USA). The report included a database of 129 Canadian non-governmental organisations (NGOs) involved in realising the national strategy under eleven different cancer control frameworks (prevention, screening, diagnosis, treatment, rehabilitation, palliation, research, education, surveillance, advocacy and infrastructure). Appendix 2 compares progress in Australia, Canada, England and New Zealand.

The review concludes that, in all of the countries studied, development and implementation of a NCCS are achieved only through a coordinated effort of federal, provincial, and national/regional NGOs, since no one organisation is capable of initiating and realising a NCCS on its own. In those countries where federal governments had officially recognised the need for a NCCS, invariably the underlying impetus is attributed to (a) the influence of one or more national NGO, and (b) that organisation's ability to rally regional affiliates prior to federal involvement. These NGOs often set in place the nascent infrastructure that would be used and improved by federal initiatives prior to federal involvement. Conversely, once a NCCS is initiated, the programme is not led by the national NGO responsible for its genesis but rather by the federal ministry responsible for health, which assumes responsibility for the programmes implementation, success, and funding.

According to Bennett *et al* (1999), the leading NGO becomes one of a number of stakeholders composing a national advisory committee (NAC) charged with defining the overall cancer control strategy and advising the federal government on its implementation. This committee should be made up of representatives from all major stakeholders, including: the country's ministry of health; the primary medical research funding agency; organisations involved in national screening programmes; national research and advocacy-orientated NGOs; regional government-funded hospitals; private clinics; health insurance providers; and scientific and medical experts in cancer research, cancer care, and/or epidemiological analysis. Significantly, in countries in which a strategy has been undertaken and has failed or required substantial re-evaluation, the NAC has been composed of only a few stakeholders. Once implementation is underway, the NAC is commonly reorganised to include representatives of the data collection/analysis infrastructure and clinicians.

This international comparison by Bennett et al (1999) also defined seven steps necessary in the evolution of strategies. These are:

1. *Define who is responsible:* In the most successful countries studied, the NCCS is mandated by the national ministry of health advised by a NAC, with the duties for implementation, data collection, and data analysis performed by separate steering committees/project teams overseen by the NAC, and carefully defined fiscal reporting measures are in place.
2. *Establish baseline and a respected data collection agency:* Data collection is linked to a national registry system, with success or failure of the NCCS often depending on the accuracy and honesty of this system. In Australia, the Australian Institute of Health and Welfare (AIHW) is the data collection agency; before being forwarded to AIHW, the data are monitored by the Australian Cancer Society (an NGO), which ensures consistency and reliability between different reporting sources.
3. *Establish national cancer control priorities:* Before establishing NCCSs, most countries have set a 'horizon' for cancer control, a statement of primary aims that will be addressed by specific strategies.

Examples are:

- *USA:* to increase quality and length of life and eliminate disparities among population groups
  - *England:* to increase the the number of years people spend free from cancer and improve the health of the worst-off members of the population
  - *Sweden:* to reduce cancer-related mortality and improve the quality of life of people with cancer
  - *Japan:* to pursue a strong research-orientated strategy
  - *Italy:* to promote cancer prevention-related lifestyles
  - *Ireland:* to establish an equitable, uniform, high quality, integrated national cancer service
  - *Germany:* to improve cancer prevention, detection, patient care, research and education
  - *Australia:* to improve the continuum of cancer care in prevention, treatment and management
4. *Identify target cancers:* The most successful means is a national surveillance system that collects and monitors the incidence of cancer and cancer-related mortality in the population (ie, national registries). In all the countries analysed the common target cancers are lung, skin, cervix and breast. Prostate and colon/rectal cancers are included in the Australian, French and American targets. Oral cavity/larynx/pharynx are included in the French and American targets, and in Ireland the goal is to prevent cancers for which a cause is suspected. Of all the countries surveyed, only Germany included haemopoietic cancers.

5. *Set baseline indicators and target reductions in mortality and incidence:* In each of the countries analysed, a national advisory committee accepts baseline indicators and defines target reductions in terms of percentage reductions in incidence and/or mortality within a given period of time for a defined population. Where a national data collection system is not sufficiently developed, WHO reduction targets are often adopted.
6. *Define strategies to achieve target reductions:* According to Bennett et al (1999), the Irish NCCS has developed a successful process for this. In the Irish model, a strategy group should be established by the Minister advised by the National Advisory Committee; this strategy group should be expanded when necessary by a number of working groups addressing different aspects of a cancer control framework. The working groups should consult and seek the advice of professional bodies, NGOs, cancer specialists and patients and solicit oral and written submissions from them.
7. *Monitor and refine each initiative at defined endpoints:* Once strategies are recommended, pilot studies are often conducted to determine feasibility and practical implications. Pilots permit testing of the data collection and dissemination structure, monitoring of the effectiveness of interim strategy and refining of protocols as needed.

## **AUSTRALIA**

Australia recognises that there is potential for further gains in health status. Its National Health Priority Areas Initiative (1997) identified six priority areas, of which cancer is one.

On the basis of the prevailing incidence rates at that time, it was expected that one in three men and one in four women would be directly affected by cancer in the first 75 years of their lives. Cancer accounts for approximately 28 percent of male deaths and 25 percent of female deaths in Australia. Although cancer ranks eighth in direct health system costs, it is the most common cause of premature death overall in Australia. Cancer is responsible for nearly 20 percent of the total burden of disease as measured by death and disability, and it consumes about 6 percent of the overall direct government expenditure on health (Mathers et al, 1999).

In 1997 the Government established the National Cancer Control Initiative (NCCI) as a bilateral relationship between the federal government and the Australian Cancer Society (ACS). ACS was contracted to develop and manage the NCCI, which is based in the Anti-Cancer Council of Victoria. Its role included developing policy and providing independent advice to the Government on all aspects of cancer control, as well as managing a range of projects.

There is also a Cancer Strategies Group (CSG) which is a subsidiary of the National Health Priority Action Council. It aims to develop a national approach to cancer control through a strategic partnership of the federal and state governments, health professionals, cancer organisations, the NCCI and consumers.

After an extensive consultation process, the NCCI prepared the report *Cancer Control Towards 2002: The first stage of a nationally coordinated plan for cancer control* (National Cancer Control Initiative, 1998). This defined 13 actions that were accorded priority on the basis that they would have a beneficial effect on cancer control by the year 2002. These were:

1. preventing tobacco-related cancers
2. developing faecal occult blood testing for colorectal cancer
3. rationalising prostate-specific antigen testing
4. improving diagnostic skills for the detection of skin cancer
5. implementing a national approach to treatment guidelines
6. evaluating and facilitating a multidisciplinary approach to treatment
7. filling gaps in palliative care
8. dealing with treatment uncertainties for prostate cancer
9. defining, implementing and monitoring psychosocial care
10. promoting participation in cancer control by general practitioners
11. continuing the national commitment to cancer research
12. organising education and resources for familial cancers
13. meeting urgent national needs in terms of data collection.

In January 2001, the report *Priorities for Action in Cancer Control 2001-2003* (Cancer Strategy Working Group, 2001) was released as a consultation draft. It is intended that, following consultation (submissions closed on 9 March 2001), endorsement by the National Health Priority Action Council, the Australian Health Ministers' Advisory Council and the Australian Health Ministers' Council will be sought for the report. These endorsements will form the basis for a nationally coordinated approach to the implementation of the actions.

This report has two elements:

- It presents a high-level framework, including a goal, objectives and principles for cancer control, which is intended to guide existing and future action and should remain relevant indefinitely.
- It proposes a set of evidence-based, cost-effective priority actions for the short term, which reflect the objectives and principles in the framework, and should be reviewed every three to five years.

The priority actions address more than two-thirds of the potentially fatal cancers that are diagnosed in Australia and all non-melanotic skin cancer. The seven priority cancers are: melanoma, non-melanotic skin cancer, colorectal cancer, breast cancer, prostate cancer, lung cancer (and other tobacco-caused cancers) and cervical cancer. Although non-Hodgkins lymphoma (the eighth priority cancer) is not the subject of a specific priority action, the development of clinical practice guidelines is recommended.

Setting priorities within the framework is necessary because available resources will never be able to meet all health costs of cancer. A systematic process was used to identify priority actions that reflect the objectives of the framework and build on national action in cancer control. The identification and assessment of priorities involved wide-ranging consultation by NCCI and a national workshop of major

stakeholders in cancer control as a starting point. A final set of 13 options for change was identified. Each option was assessed against a range of criteria. For seven of the options, an evidence-based marginal economic analysis was used, and all were found to be cost effective, with some generating cost savings as well as health gain (action on smoking, sun exposure, and insufficient intake of fruit and vegetables).

The 13 recommended priorities in five fields of cancer control are:

### **Prevention**

- reducing smoking prevalence through the continuation of national tobacco media campaigns
- reducing the incidence of skin cancer through the national SunSmart campaign
- increasing consumption of vegetables and fruit through the introduction of a national campaign.

### **Screening and early detection**

- improving detection of colorectal cancer through the introduction of a national coordinated population-based screening programme
- improving the efficiency of the national cervical screening programme by increasing the screening interval from two to three years
- improving the efficiency of skin cancer control through a national programme to increase the accuracy of general practitioner diagnosis of lesions that might be skin cancer
- rationalising prostate-specific antigen testing through education for general practitioners and the community about the implications of the PSA test.

### **Treatment**

- reorganising breast cancer management to ensure seamless continuity of care from screening, or first presentation with symptoms, to diagnosis, treatment, and follow-up care
- improving outcomes from ovarian and lung cancer by ensuring that all people with these cancers are assessed at a multidisciplinary specialist centre as soon as possible after diagnosis
- developing, implementing and maintaining clinical practice guidelines for cancer.

### **Support for cancer patients**

- improving the psychosocial care of women with breast cancer through provision of breast cancer nurses
- improving the psychosocial care of people with cancer through the provision of psychologists in cancer centres and clinics.

### **Palliative care**

- improving palliative care of people with advanced cancer.



Some of these priority actions are already in process, and the report seeks to reinforce and support present directions. For others the next steps will usually require collaboration between federal and state health authorities and non-governmental cancer agencies. The roles of each will need to be defined and funding sought through their respective budget processes. The monitoring and evaluation of relevant process and outcome data, and the continuing economic analysis of cancer interventions will be used to review and possibly reaffirm the existing actions as well as to propose new priority actions in cancer control in Australia beyond 2003.

## **CANADA**

In 1999 the National Cancer Institute of Canada and the Canadian Cancer Society entered into discussions with the Canadian Association of Provincial Cancer Agencies and Health Canada about how to work together in the fight against cancer. It was acknowledged that the challenge posed by cancer would require greater resources than those provided by any one organisation, and that therefore a comprehensive Canadian NCCS was needed. A steering committee of the Canadian Strategy for Cancer Control formed from representatives of the above institutions is guiding a participative process, with the goal of having a NCCS in place before the end of 2001. The Steering Committee is located in the Population Health Directorate of Health Canada.

In January 2000 the Canadian Strategy for Cancer Control published a Draft Synthesis Report (Canadian Strategy for Cancer Control, 2000). This report notes that one in three Canadians will develop cancer and half of these will become long-term cancer survivors. Due to the growth and ageing of the population, the incidence of cancer will more than double in the next 15 years. It concludes that, given the projected rise in incidence and the consequential pressures on treatment and support services, coordinated strategies are required. Furthermore, the implementation of strategies to deal with these immediate issues must be accomplished at the same time as prevention and screening strategies needed to reduce the burden of cancer in the future are being developed. It is strongly believed that a national strategy has the potential to achieve the sustained, coordinated, comprehensive and collaborative cancer control that is needed to meet these challenges.

The vision of the Canadian Cancer Control Strategy includes:

- reductions in morbidity and mortality rates through improved screening, diagnosis and treatment strategies in one to five years
- improved quality of life through increased access to supportive and palliative care
- reductions in incidence rates in the longer term (10 years and beyond) through preventive strategies
- progressive improvements in the outcomes of cancer control strategies in the medium term (5-10 years) through research
- decreasing incidence and morbidity will reduce direct and indirect costs to individuals and society, alleviating the economic and personal burden of cancer.

Actions to be taken include the formation of a coalition of cancer stakeholders (to ensure coordination) and the development of national advisory groups (to identify key areas for potential action).

The *Draft Synthesis Report* summarises the work of 250 individuals and 12 working groups who examined particular areas of cancer control over 12 months. This planning process was characterised by consultation, multi-jurisdictional participation, timeliness and survivor perspective. The analytic framework has been internationally recognised to encapsulate the elements and processes of cancer control (Hiatt and Rimer, 1999).

The reasons for developing a NCCS strategy for Canada are:

- *Resources are limited:* Cooperative effort will reduce duplication.
- *Collective action:* Cancer control cannot be achieved by any single organisation or government alone.
- *Equity:* The public expects, irrespective of where they live, that there will be reasonable access to care of current high quality.
- *Leadership:* Organisations can show leadership by cooperation and partnership. A NCCS will provide the focused ongoing attention and leadership that is otherwise difficult to achieve due to high turnover among health leadership.
- *Vision:* The ideal of a reduced cancer burden can only occur through cooperation and leadership at the national level. A NCCS provides the environment in which prevention can be given a level of priority in keeping with its potential impact. A national population database is needed to demonstrate impact of strategies.

Why now?

- There is public and government acceptance of the need to re-equip health systems to meet the challenge of an ageing population.
- It is important to act now, before the full impact of the ageing population is felt by the health care system.
- There is recognition among stakeholders in cancer control that cooperative efforts are the most effective way that individual and common goals can be achieved.
- There is the potential that a NCCS will develop and strengthen alliances among stakeholders, providers, centres, constituents and collaborators.
- There are public concerns about geographic variations in the quality of care available to cancer patients, and, indeed, significant actual variations in care are evident.

The main themes and 53 recommendations include: re-balancing the focus with a greater emphasis on prevention; more research into best prevention strategies; how best to deliver cancer care services, how best to ease pain and suffering; how to integrate care across institutional and community settings; moves towards seamless, integrated care; tackling the human resource deficit that threatens to defeat cancer control efforts at all levels; more socio-behavioural and health services research; better education about cancer control; the development of standards against which 'evaluation,'equity', 'best practices' and 'evidence-based' claims can be tested; and the development of effective mechanisms to monitor progress and enable accountability.

The overarching recommendation is that all interested stakeholders form a coalition to provide leadership and direction, set priorities and coordinate the implementation of a cancer control strategy.

The conclusions of the Draft Synthesis Report are that as more Canadians develop cancer, continuation of the status quo only guarantees that the need and demand for services will increase, leading to greater competition for existing resources among the various agencies concerned with providing care to cancer patients. More money will be spent on cancer-the issue the strategy addresses clearly and effectively is how best to use these resources. The Canadian public expect and deserve nothing less than the full cooperation and coordination among governments, institutions, and community-based organisations to ensure their access to the services they need across the continuum of cancer control.

## **SCANDINAVIA**

The five Nordic countries each have fairly homogeneous populations, high levels of literacy and knowledge about cancer, democratic health-care systems, high expectations of prompt treatment for cancer, a number of cancer screening programmes, and excellent cancer registries. The high quality of data from the registries has allowed progress with cancer control to be monitored. Finland, for example, has had a nationwide population-based cancer registry since 1952 and its first cancer control committee was formed and its first national cancer control plan published in 1954. Since then, there has been more or less constant health-care planning, and the Finnish Cancer Society is an important lobbying group and participant. Denmark, Norway and Sweden also have functioning cancer control plans.

In 1996 the Norwegian parliament asked for a cancer control plan, which was delivered to the Minister of Health in 1997, and commitments were made to a five-year plan funded from 1998 (Kvinnslund, 1999).

A combined Nordic cancer control plan, which was published in 1991 (Elovainio, 1999), was developed jointly by the five governments and the NGO cancer leagues. The plan defined a need for more data on incidence, prevalence, avoidability and detectability of cancers, as well as forward predictions.

Although this multinational cooperation led to much sharing of information, the Nordic Plan was disrupted when the governments withdrew their support. This may have been partly due to a perceived failure of the plan to achieve its stated goal, which was a reduction in cancer mortality by 2000. The male cancer mortality rates are increasing in Denmark, Iceland and Norway, are stable in Sweden and decreasing (by about 10%) only in Finland (Elovainio, 1999); the Finnish decrease is

believed to be due to a particularly effective anti-smoking campaign in that country. The female mortality rates are still increasing in all the Nordic countries.

Clearly, the goals of cancer control strategies have to be realistic, and set in relation to the increasing incidence of cancer and to particular cancers, as well as cancer overall. They should also be set in relation to each element of the strategy, and should recognise the different time periods needed to accumulate sufficient data to demonstrate the effectiveness of different objectives. Improved screening, diagnosis and treatment may be reflected in survival data within five years, but it may take decades for improved prevention to be reflected in reduced mortality. Unrealistic goals may encourage the adoption of a NCCS, but may lead to it being prematurely discredited.

## **ENGLAND**

In 1995 the 14-member Expert Advisory Group on Cancer (EAGC) published a report entitled *A Policy Framework for Commissioning Cancer Services* (Expert Advisory Group on Cancer, 1995), known as the Calman/Hine Report. Its purpose was to provide guidance to purchasers and providers of cancer services. It referred to 'The Health of the Nation' white paper, which had identified the potential for reducing deaths from cancer by prevention and screening, had noted the concern expressed by many health carers about the increased burden of cancer if the disease is advanced at initial presentation or recurrence, and pointed out geographic variations in the recorded outcomes of treatment and in the methods of data registration.

The Calman/Hine Report built on previous work, some going back over 20 years, and referred to six reports, 31 publications and over 300 responses received from professional bodies, the National Health Service, related charities and community health councils. The EAGC especially noted the 'patient centred' approach taken in *The Protocol for Health Gain* which had been developed by the Welsh Office, and reviewed the recent improvements in the management of cancer and the international literature on cancer survival in relation to patterns of care. It was noted that improved outcomes are associated with specialised care for uncommon cancers, and that many studies suggest that this association also applies for the common cancers. The committee concluded that it was timely to review cancer services to ensure that these benefits are made available to all cancer patients.

The report defined seven principles that should govern the provision of cancer care. In summary these are:

1. All patients should have access to uniformly high-quality care in the community or hospital wherever they may live. Care should be provided as close to the patient's home as is compatible with high-quality, safe and effective treatment.
2. Public and professional education to help early recognition of symptoms of cancer and the availability of national screening programmes are vital parts of a comprehensive programme for cancer care.
3. Patients, families and carers should be given clear information and assistance about treatment options and outcomes at all stages, from diagnosis onwards.
4. The development of cancer services should be patient centred and should take account of patients', families' and carers' views, as well as those of professionals involved in cancer care.

5. The primary-care team is a central and continuing element in cancer care for both the patient and his or her family from primary prevention, presymptomatic screening, initial diagnosis, through care and follow up or, in some cases death and bereavement. Effective communication between sectors is imperative in achieving the best possible care.
6. In recognition of the impact that screening, diagnosis and treatment of cancer have, psychosocial aspects of cancer care should be considered at all stages.
7. Cancer registration and careful monitoring of treatment and outcomes are essential.

The Calman/Hine Report recommended a new structure for cancer services based on a network of expertise in cancer care-reaching from primary care through cancer units in district hospitals to cancer centres-the aim of which is to deliver a uniform standard of high-quality care to all patients. Three levels of care were proposed:

- Primary care was seen as the focus of care.
- Designated cancer units in many district hospitals and of sufficient size to support clinical teams with sufficient expertise and facilities to manage commoner cancers.
- Designated cancer centres, which should provide expertise in the management of all cancers.

Published in July 2000, *The NHS Plan* (Department of Health, 2000a) outlines the British Government's plan for investment and reform right across the National Health Service (NHS) to develop a health service for the 21st century. This overall plan identified cancer services as a high priority. More than one in three people in England will develop cancer, and one in four will die of cancer, and progress on cancer prevention, on research and on improved access to services was promised. In September 2000 the *NHS Cancer Plan* (Department of Health, 2000b) was released, with a foreword by the Secretary of State for Health.

The Cancer Plan sets out the first comprehensive national cancer programme for England. It has four aims:

- to save more lives
- to ensure that people with cancer get the right professional support and care as well as the best treatments
- to tackle the inequalities in health that mean that unskilled workers are twice as likely to die from cancer as professionals
- to build for the future through investment in the cancer workforce, through strong research and thorough preparation for the genetics revolution, so that the NHS never falls behind in cancer care again.

This plan provided the first comprehensive strategy for bringing together prevention, screening, diagnosis, treatment and care for cancer, and the investment needed to deliver these services in terms of improved staffing, equipment, drugs, treatments and information systems.

The *NHS Cancer Plan* (Department of Health, 2000b) sets out: how cancer services will benefit from increased investment; how investment in staff will respond to shortages in key specialties and enable services to expand; and how investment in new equipment will enable faster access to diagnosis and treatment. The accompanying reform requires new ways of working to streamline cancer services around the needs of the patient: through extending the roles of radiographers, nurses and other staff, and through guidance to ensure high standards of treatment and care are in place right across the country. It defines actions and milestones that, it is claimed, will deliver the fastest improvement in cancer services anywhere in Europe over the next five years. By 2010 it is anticipated that the British five-year survival rates for cancer will compare with the best in Europe.

At the heart of the plan are three new commitments. These are:

- In addition to the existing target of reducing smoking in adults from 28 percent to 24 percent by 2010, two additional national and local targets, which address the gap between socio-economic groups in smoking rates and the resulting risks of cancer and heart disease targets, have been defined. These are to:
  - reduce smoking rates among manual groups from 32 percent in 1998 to 26 percent by 2010
  - set local targets making explicit what this means for the 20 health authorities with the highest smoking rates .
- New goals and targets to reduce waiting times for diagnosis and treatment so that: the ultimate goal is that no one should wait longer than one month from an urgent referral for suspected cancer to the beginning of treatment (except for good clinical reason or through patient choice). For some uncommon cancers such as acute leukaemia, children's cancers and testicular cancer, most patients already experience a maximum one-month wait; for others, milestones have been set. By 2005 there will be a maximum one-month wait from diagnosis to treatment of all cancers and a maximum two-month wait from urgent GP referral to treatment for all cancers.
- An extra £50 million annual investment in hospices and specialist palliative care by 2004, to improve access to services across the country. For the first time NHS investment in specialist palliative care will match that of the voluntary sector.

The plan notes that over the past three decades, there has been important progress in reducing the impact of cancer. Death rates from cancer have fallen as rates of smoking have declined. Deaths from breast cancer and cervical cancer have fallen with the introduction of national screening programmes and of new and better treatments. Survival rates for some cancers have improved dramatically; now, almost two-thirds of children with cancer are cured, as are over 90 percent of men with testicular tumours.

But there is much that needs to be improved. There are real inequalities in terms of who gets cancer, and what happens to them when they do. In the early 1990s, deaths from lung cancer among men were nearly five times higher among unskilled workers than among professional groups. Cancer patients in England often have poorer survival prospects than those in other European countries. For breast and bowel cancer this is partly because patients tend to have a more advanced stage of disease at the time they are treated. Although many cancer patients receive excellent treatment, services are patchy. Too much equipment is out of date and inadequate, and there are too few cancer specialists of every type. Thus, patients in different parts of the country receive varying quality and quantity of treatment: the 'postcode lottery' of care. The Plan states that these delays and variation in cancer care are unacceptable in a 21st century National Health Service.

The British Government has focused money and energy on improving the quality of cancer services. Targeted resources totalling £80 million a year are being invested to improve standards and cut patient waiting times. The biggest ever programme to replace and update equipment for screening, diagnosis and treatment has begun.

The British approach to measuring effectiveness relies heavily on structure and process measures, as well as on outcome measures. Over the past six years cancer site-specific service guidance documents have been developed, and these are now available for breast, colorectal, lung, gynaecological and upper gastrointestinal cancer. Reports on urological, haematological and head and neck cancers are in preparation. These guidance reports have been used to derive standards, and a manual of cancer service standards was published in January 2001.

Implementation of the NHS Cancer Plan is being led by a new cancer task force headed by Professor Mike Richards, the National Cancer Director. Bringing together cancer clinicians, GPs, patients, and managers, and drawing on a wealth of expertise from across and beyond the NHS, it will reflect the partnership needed at all levels to drive forward its implementation.

## **UNITED STATES OF AMERICA**

More than 25 years ago, President Nixon launched a war against cancer. However, cancer remains the second leading cause of death (one in four) in the USA, and the overall costs of cancer are estimated at \$107 billion annually (Centers for Disease Control, 2000). Although public health efforts to combat cancer are long standing and well established, agencies have struggled to reach growing at-risk populations with screening services, health promotion and education and to eliminate barriers.

In most states, the infrastructure supporting such efforts has remained unchanged. In addition, the various activities have been driven by separate funding streams, resulting in duplication of effort, missed opportunities for prevention and control and competition for limited resources. The states and the stakeholders now believe that improved coordination is needed and the Centers for Disease Control and Prevention (CDC) are now advocating building the knowledge base for comprehensive cancer control. It is acknowledged that comprehensive cancer control requires a complex organisational change involving the commitment of many groups of stakeholders. In a series of meetings begun in 1994, the Division of Cancer Prevention and Control of CDC has been working with state cancer control staff and with stakeholders to develop an integrated comprehensive approach to cancer control.

This process has been described in detail by Abed et al. (2000a,b). A graphic model was developed from stakeholder comment and literature review. Phases of this model include setting optimal objectives (data driven), determining optimal strategies (science driven), establishing feasible priorities (capacity driven), and implementing effective strategies (outcome driven) (Abed et al., 2000a).

This model is currently being validated through case studies of state-level cancer frameworks in six states and CDC has provided funds also to five other states and one tribal organisation that have cancer plans ready to implement (Lee, 2000).



## 7. CONCLUSIONS

This background paper has established that:

1. The incidence, morbidity and mortality due to cancer are increasing internationally.
2. Since 1960, New Zealand's cancer mortality rates have been increasing faster than those of Australia, Canada, the USA and the United Kingdom.
3. Increasing numbers of New Zealanders are likely to suffer from cancer over the next two decades.
4. There are public concerns about geographic variations in the quality of care available to cancer patients, and, indeed, significant actual variations in care are evident.
5. Comprehensive national cancer control strategies are being developed in countries similar to New Zealand to cope with the increasing incidence of cancer.
6. The processes involved in developing various national cancer control strategies are remarkably similar and should involve both government and non-government agencies and extensive consultation.
7. A comprehensive national cancer control strategy involves not only the various components of cancer control - prevention, screening and early diagnosis, treatment, rehabilitation and support, and palliative care - but also equity of access to services, workforce development and ongoing relevant research.
8. A national cancer control strategy needs to have realistic goals, agreed priorities for action, effective mechanisms for monitoring services and outcomes, and mechanisms for periodic review and refinement of the strategy.
9. There is substantial government and non-government commitment to the development of a national cancer control strategy for New Zealand.
10. Overseas experience and contacts developed during the preparation of this background paper will be helpful in the development of a cancer control strategy for New Zealand.
11. A widely representative workshop in 1999 recommended that a consortium-based approach be used in the development of a national cancer control strategy in New Zealand.
12. A national strategy should reflect the unique and specific needs of this country, identifying priorities for action within the New Zealand context.
13. Substantial work has already been completed on related policies, plans and strategies with which a New Zealand National Cancer Control Strategy will interdigitate.
14. A companion paper *The Development of a National Cancer Control Strategy for New Zealand* (Gavin *et al*, 2001) describes in more detail ways in which the national cancer control strategy could be developed.

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## APPENDIX 1:

# SELECTED CANCER CONTROL POLICIES, GUIDELINES, STANDARDS AND STRATEGIES

Prevention	Early diagnosis & screening	Treatment & symptom control	Rehabilitation & support	Palliative care
<p>Toward a Tobacco-free New Zealand: A Five-Year Plan for HFA Funding for Tobacco Control (Health Funding Authority, 1999)</p> <p>Investment Plan for Tobacco Control (Smokefree Coalition, 2000)</p> <p>Active for Life: A call for action. The health benefits of physical activity (National Health Committee, 1998a)</p> <p>The Costs of Skin Cancer to New Zealand (O'Dea, 2000)</p> <p>Under Cover: Guidelines for shade planning and design (Cancer Society of New Zealand, 2000)</p> <p>The Social, Cultural and Economic Determinants of Health in New Zealand: Action to Improve Health (National Health Committee, 1998b)</p> <p>A National Drug Policy for New Zealand (Ministry of Health, 1998)</p> <p>Guidelines for Smoking Cessation (National Health Committee, 1999)</p> <p>Social Inequalities in Health: New Zealand 1999 (Ministry of Health, 2000)</p>	<p>Population Screening for Colorectal Cancer (Working Party on Screening for Colorectal Cancer, 1998)</p> <p>Screening for Cancer of the Prostate. Information for Health Professionals (National Health Committee, 1996)</p> <p>Recommendations for Cervical Screening 1997 (Members of the Working Party on Cervical Screening, 1998)</p> <p>Operational Policy and Quality Standards for the National Cervical Screening Programme (Health Funding Authority, 2000c)</p> <p>Population-based Breast Cancer Screening: Policy Advice for a New Zealand Screening Programme (Members of the Breast Cancer Screening Policy Advisory Group, 1998)</p> <p>Early Detection of Breast Cancer. Guidelines for Primary Care Providers (Royal New Zealand College of General Practitioners, 1999)</p> <p>Interim National Quality Standards. New Zealand's breast cancer screening programme (Ministry of Health, 1996)</p>	<p>Guidelines for the Surgical Management of Breast Cancer (Royal Australasian College of Surgeons, 1997)</p> <p>Cervical Screening: Guidelines for the Management of Women with Abnormal Cervical Smears (Health Funding Authority, 1998)</p> <p>Improving Cancer Services in New Zealand (Ministry of Health, 2001c)</p>	<p>Consultation Document on a Nationally Consistent Travel and Accommodation Assistance Policy for Users of Health and Disability Services (Health Funding Authority, 2000a)</p> <p>Travel and Accommodation Assistance for Users of Health and Disability Services. A Summary of Community Feedback to the HFA Consultation (Health Funding Authority, 2000b)</p> <p>Picking Up the Pieces: Review of Special Education 2000 (Wylie, 2000)</p>	<p>The New Zealand Palliative Care Strategy (King, 2001b)</p>

## APPENDIX 2:

# PROGRESS TOWARDS A NATIONAL CANCER CONTROL STRATEGY

	Australia	Canada	England	New Zealand
<b>Overarching strategy</b>	National Health Priority Areas Initiative (1997)	No	The NHS Plan 2000	The New Zealand Health Strategy 2000
<b>Impetus</b>	NGO & government	NGO	Prime Minister, Secretary of State for Health, Department of Health	Cancer Control Workshop 1999
<b>Early wide consultation</b>	Yes	Yes	No	-
<b>Late wide consultation</b>	Yes	Yes	Informal	-
<b>High level framework</b>	Yes	Yes	Yes	-
<b>Priority actions/goals</b>	13 actions in 5 components of cancer control	53 recommendations in 5 components of cancer control, plus research	Prevention, screening, early diagnosis, research and development, treatment/care services	To be decided
<b>Approach/form</b>	Evidence-based and economically-evaluated improvements in services	Improvements in services and broadening focus beyond treatment	Improvements in services, particularly treatment and palliative care	To be decided
<b>Stage of development</b>	Final consultation almost complete	Consultation ongoing with partial implementation	Published; implementation ongoing	Early development

NGO = Non-government organisation