Access to cancer services for Māori

A report prepared for the Ministry of Health

FINAL REPORT

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FOREWORD

Cancer is a leading cause of illness and death in New Zealand that touches most people during their life, either directly or through friends and family. The *New Zealand Cancer Control Strategy* aims to reduce the impact of cancer and to reduce inequalities with respect to cancer. This is consistent with broader goals of reducing inequalities in health outcomes for Māori and non-Māori, as well as with obligations under the Treaty of Waitangi to ensure equity of access and outcome for Māori.

Cancer has a disproportionate impact on Māori. The Crown and its agencies have obligations to meet Māori rights – human, indigenous, and Treaty of Waitangi rights. The significant disparities in cancer outcomes indicate a breach of those rights that needs to be addressed with urgency and genuine commitment.

The aim of this project is to provide baseline information and data to enable a better understanding of issues surrounding access to cancer services for Māori and highlight interventions to address barriers to access and facilitate timely and appropriate access to cancer services across the cancer care continuum.

This project was contracted by the Ministry of Health as part of the implementation phase of the New Zealand Cancer Control Strategy. This report is intended to inform strategies to reduce inequalities and ensure the equitable and timely access to cancer services that all cancer patients and their whānau deserve.

ACKNOWLEDGEMENTS

Tënei te mihi whānui atu ki a koutou katoa e pāngia nā e te mate pukupuku, ki a koutou e ngana tonu ana ki te whakamatua i te kaha aweawe o taua mate i roto i ō koutou ora, ki a rātou kua mutu i a rātou te whawhai ki taua momo mate taumaha, ā, kua rūpeke atu ki tua o te arai, ki ngā whānau katoa o rātou e pāngia ana e te mate pukupuku, o rātou kua hemo kë atu ko te mate pukupuku te putake, tēnā koutou, tēnā koutou, tēnā ra koutou katoa.

This project was a collaboration between researchers at Te Rōpū Rangahau Hauora a Eru Pōmare and the Department of Public Health at the Wellington School of Medicine and Health Sciences, and the Division of Public Health and Psychosocial Studies, Auckland University of Technology. It was contracted by the Ministry of Health as part of the implementation phase of the *New Zealand Cancer Control Strategy.*

We would like to thank the many individuals and organisations that contributed to the report by providing information, time and expertise. We would also like to thank the peer reviewers of the report and our colleagues for their guidance and support.

We acknowledge those who are working to improve access to cancer services for Māori. Most importantly, we acknowledge the Māori individuals, whānau and communities that have been affected by cancer – ngā mihi ki a koutou katoa.

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INTRODUCTION

In 2003, the Ministry of Health and the New Zealand Cancer Control Trust released the *New Zealand Cancer Control Strategy*. The overall purposes of the Strategy are reducing the incidence and impact of cancer and reducing inequalities with respect to cancer (Ministry of Health, 2003). As part of the development and implementation of a comprehensive cancer control programme in New Zealand, the Ministry of Health has undertaken further work to identify directions and priorities for cancer control. This project has been contracted by the Ministry of Health to provide information on access to cancer services for Māori.

Cancer is a leading cause of disability and death in New Zealand. Māori experience a disproportionate impact of cancer, and inequalities in terms of cancer risk, incidence and outcome are well documented. In addition, recent research has demonstrated a widening of inequalities in cancer death rates between Māori and non-Māori and an increase in the contribution of cancer to inequalities in life expectancy.

This report aims to contribute to a better understanding of the extent and nature of disparities in access to cancer services for Māori that is necessary to the elimination of inequalities in cancer outcomes.

APPROACH

The project was informed by a kaupapa Māori framework that recognises the structural causes of inequality, such as unequal power structures, colonisation and institutional racism. It takes a broad multi-level approach to access and centralises Māori. A multi-methods approach was employed that incorporated a literature review, review of data, and interviews with providers and stakeholders. This approach was designed to deliver a more comprehensive understanding of issues relevant to access to cancer services for Māori and intends to be broad rather than exhaustive. Further work, particularly that incorporating Māori patient, whānau and community voices, is vital.

KEY FINDINGS

Data review

In order to provide context to discussions of access to cancer services for Māori, routinely collected data on deaths and cancer registrations for the 6-year period between 1 January 1996 and 31 December 2001 were mapped and assessed by major cancer site in relation to the completeness and quality of ethnicity and staging data for Māori and non-Māori. In addition, findings from analyses relating to disparities in cancer incidence, mortality, survival and stage at diagnosis were reported.

In terms of ethnicity data quality, it was estimated that for this period Māori cancer registrations were undercounted by approximately 17% and Māori deaths by approximately 6%. Using the 'ever Māori' method of ethnicity classification produced estimates of Māori cancer registrations and deaths accurate to within 1%.

Leading cancer types differ for Māori and non-Māori and priorities may therefore differ. Some cancers are more common amongst Māori than non-Māori (e.g. lung, stomach, cervix, testis, liver), while others are less common (e.g. colorectal, melanoma, prostate, bladder, brain).

Overall, Māori are 18% more likely to be diagnosed with cancer than non-Māori, but nearly twice as likely as non-Māori to die from cancer. Māori: non-Māori age-standardised mortality ratios are higher than incidence ratios for most types of cancer. Cancer-specific survival is lower for Māori than non-Māori for most types of cancer, (e.g. breast, cervix, prostate, colorectal, lung, uterus, kidney, leukaemia, non-Hodgkin's lymphoma) (adjusted for age at diagnosis).

Māori cancer registrations are less likely than non-Māori to have stage at diagnosis recorded for cancers of the lung, breast cervix, colon, rectum, stomach, uterus, testis, oesophagus, and brain (adjusted for age at diagnosis). Among those staged, Māori are more likely than non-Māori to be diagnosed at a later stage of disease spread for cancers of the breast, lung, colon and rectum, cervix, prostate, testis, kidney, lip, oral cavity & pharynx, and melanoma. Among those diagnosed with stomach cancer, Māori are more likely than non-Māori to be diagnosed at localised stage (adjusted for age at diagnosis).

Differential stage at diagnosis accounts for part but not all of the cancer-specific survival disparity between Māori and non-Māori for some cancers (e.g. lung (18%), breast (30%), cervix (20%), colorectal (49%), prostate (47%) (adjusted for age at diagnosis). However, at each stage (localised, regional, distant, unknown), Māori cancer-specific mortality after diagnosis is higher than non-Māori for many cancers (adjusted for age at diagnosis).

These findings indicate the likely existence of disparities between Māori and non-Māori in timely access to definitive diagnostic procedures, staging procedures, and optimal treatment or management of cancer.

Access to cancer care

Discussions of access to care have tended to focus on utilisation aspects of access, particularly in terms of gaining entry into services. More recent models of access have been broadened to include process and outcome aspects.

Access to cancer care is complex and multidimensional - there are a range of key factors potentially associated with access operating at a number of levels, including health system factors, health care process factors, and patient-level factors. Some factors have influence across all phases of cancer care, while other factors have particular relevance at certain points of the cancer care pathway. In this project, factors seen to be associated with Māori access to cancer services were identified through the literature and through providers, stakeholders and key informants.

Health system level factors identified in this study include the focus of the cancer care system and services, funding and resources, service configuration and location, workforce, availability of information and resources, and expense. Factors associated with health care processes study include the way that services operate and work with other services, characteristics of physicians/providers such as training, competence, perceptions and biases, and patient-provider interaction. At a patient level, factors identified were socioeconomic position (including deprivation, employment conditions, and insurance status), transportation and patient context.

Although there are a number of issues that are raised consistently in regard to access to cancer services for Māori, there is limited detailed information on the range of factors potentially influencing access and the ways in which these may function differently in varied contexts. There is also limited information on access from the point of view of Māori with cancer and their whānau, which is vital to developing effective policies and interventions to address access.

Interventions to address access

A stocktake of interventions to improve access to cancer services for Māori with cancer and their whānau was undertaken. The scope of the project meant that it was not possible to talk to all services or organisations that may be providing interventions, particularly outside of specific cancer care services (for example, interventions offered through Māori providers or in other sectors). Very few interventions specifically addressing Māori access to cancer services were identified. The only dedicated Māori cancer service identified was a Māori cancer support group in Rotorua, that provides information on cancer and cancer services to Māori patients and their whānau, raises public awareness of cancer, offers emotional support to facilitate service access, and provides travel assistance.

A number of Māori providers were offering cancer-specific interventions. These included working in local communities to raise awareness of cancer and cancer service options, hosting a cancer control continuum workshop, maintaining patient and whānau contact and providing support throughout the cancer pathway, and Māori women's support team which supported women pre- and post-operatively. Māori providers were contributing indirectly to improving Māori access to cancer services through health promotion, primary health care, and support and rehabilitation, which was cancer-related (although cancer was not the primary focus).

Some mainstream providers identified interventions designed to enhance service responsiveness to Māori such as working with Māori advisors and kaumātua, developing close links with local Māori providers to support Māori patients, and formulating cultural safety policy. Some mainstream providers also identified plans to develop interventions, including publishing existing cancer resources in the Māori language and delivering workshops about cancer and cancer services.

Among mainstream providers, such as cancer treatment centres, hospices, and NGOs, the majority of initiatives to facilitate or enhance access to cancer services were focused on the total population. This included providing information and support about cancer and cancer services to patients and their families, organising workshops and seminars in both clinical and community settings, and developing information resources to encourage patients and their families to seek advice and utilise services related to cancer.

There was a lack of comprehensive interventions, current or planned, to specifically address Māori access to cancer services. Those interventions that were identified were limited and isolated. There were a number of universal activities and initiatives within the cancer sector to facilitate access to cancer services and enhance the care journey for cancer patients and their families. The extent to which universal policies are delivering for Māori in cancer care is not known, however, the interviews with providers and key informants suggest major gaps in service delivery for Māori.

DISCUSSION

There are significant and consistent disparities in cancer outcomes between Māori and non-Māori that require urgent attention. There is also a pressing need to go beyond describing disparities in cancer outcomes between Māori and non-Māori to examine the underlying causes of these disparities. Access to services for Māori along the cancer care continuum has a role in disparities in cancer outcomes. The report findings highlight the complex, multilevel nature of access to cancer services for Māori and their whānau, and the need for broad approaches to intervention that address factors at the health system, health care process, and patient/population level.

Māori with cancer and their whānau deserve excellence in cancer care, including access to timely, appropriate and high quality cancer services. This requires ongoing work to identify and address access issues. Addressing disparities in access to cancer services also necessitates recognition of, and a commitment to, addressing the fundamental drivers of the differential distribution in New Zealand of the factors associated with access, such as racism and unequal power relations.

The current environment in cancer control in New Zealand provides opportunities for a strong and committed response to the stark disparities in cancer outcomes between Māori and non-Māori. Indeed, there are ethical, moral and human rights imperatives, obligations under the Treaty of Waitangi, and legislative and policy drivers, to support the development of policy and interventions to effect change.

RECOMMENDATIONS

There are key areas for action under which recommendations fall:

Cancer control governance and structures

- Determine in partnership with Māori the extent and nature of Māori participation in any established or proposed cancer control bodies (such as working groups and taskforces), and Māori priorities for these bodies.

- Evaluate established and proposed cancer control bodies in respect of their ability to address Māori rights and reduce inequalities.

- Adequately resource and support effective Māori participation in cancer control bodies, as determined by Māori.

Cancer control policy and funding decisions

- Strengthen the inequalities focus of cancer control policies, better integrate the principle of reducing inequalities throughout cancer control strategies and policies, and clearly reflect the dual focus of the cancer control strategy in all decisions (that is reducing the incidence and impact of cancer **and** reducing inequalities).

- Ensure Māori input into cancer control policy development and funding decisions.

- Assess policy and funding decisions (established and proposed) for differential effect discrimination and/or the potential to contribute to or reduce inequalities (this may include the use of tools such as the HEAT tool).

- Encourage a planned approach to the development of interventions to address access to cancer services for Māori.

Cancer control guidelines, standards and priorities

- Prioritise the development of guidelines or standards that will address Māori priorities for cancer control.

- Take into account the need to monitor for inequality and service responsiveness to Māori in the development of national standards.

Cancer workforce

- Increase awareness among those involved in cancer care provision of inequalities in cancer and the role of system and health workforce factors in creating and perpetuating inequalities.

- Support and resource comprehensive and ongoing training of the cancer care workforce to provide for culturally safe and responsive service provision to Māori.

- Provide incentives and funding to encourage Māori workforce development in cancer care at all levels and in a variety of roles. This includes supporting and meeting the training and professional development needs of those Māori already within the cancer care workforce.

- Recognise and support the valuable contribution of the Māori provider workforce to enhancing access to cancer care for Māori through adequate, on-going funding.

Service orientation and development

- Involve Māori expertise and the range of relevant Māori services and providers in multidisciplinary teams and networks.
- Prioritise Māori in the piloting of developments or initiatives in service delivery in order to address the high level principle of reducing inequalities.
- Support and adequately fund Māori led initiatives in cancer control.
- Support and encourage Māori participation in cancer services at the governance level, and mechanisms to ensure Māori expert advice at service policy levels.
- Require that providers demonstrate planning to address inequalities, with associated strategies, timeframes, and measurable indicators.

Monitoring and evaluation

- Institute systems for the routine monitoring and reporting on equity of access to cancer services for Māori across the cancer control continuum.
- Routinely collect and publish data by ethnicity (in line with the Ministry of Health protocols) to reflect the goal of reducing inequalities and allow for monitoring of ethnic inequalities.

Research

- Prioritise research with Māori cancer patients, their whānau and communities to reflect the high level goal of reducing inequalities.
- Investigate the reasons why the NZCR records higher rates of unstaged disease for Māori than for non-Māori for most cancers.
- Explore the extent to which delays in access to cancer services contribute to inequalities in cancer outcome between Māori and non-Māori (including delays in primary prevention, screening and early detection, diagnosis, staging, treatment, support and rehabilitation, and palliative care).
- Investigate the role of Māori patient advocates, navigators, or other interventions to enhance the patient journey for Māori with cancer and their whānau.
- Explore Māori perspectives of barriers and facilitators to access of cancer services, and preferences and priorities for interventions to address access issues.
- Consider the role of differential access to timely and appropriate cancer services in inequalities in cancer outcome between Māori and non-Māori.

Resources

- Encourage and fund the development of high quality Māori-specific resource material about cancer and cancer service options for individuals, whānau and communities.

- Develop tools to assist services and health professionals to communicate effectively about cancer and cancer care with Māori patients and their whānau.

Addressing structural barriers

- Collaborate with other sectors to address fundamental drivers of disparities in cancer access and outcomes for Māori.

- Advocate for Māori human, indigenous and Treaty of Waitangi rights in all work in the health sector.

- Fulfil obligations under the Treaty of Waitangi.

- Operationalise governmental commitments and obligations under the International Convention on the Elimination of All Forms of Racial Discrimination (CERD) within the health sector.

INTRODUCTION

In 2003, the Ministry of Health and the New Zealand Cancer Control Trust released the *New Zealand Cancer Control Strategy* (CCS(NZ)). The overall purposes of the Strategy are reducing the incidence and impact of cancer and reducing inequalities with respect to cancer (Ministry of Health, 2003). As part of the development and implementation of a comprehensive cancer control programme in New Zealand, the Ministry of Health has undertaken further work to identify directions and priorities for cancer control. In line with the purposes, principles and goals of the CCS(NZ), this project has been contracted by the Ministry of Health to provide information on access to cancer services for Māori.

Cancer is a leading cause of disability and death in New Zealand. Māori experience a disproportionate impact from cancer and inequalities in terms of cancer risk, incidence and outcome are well documented in New Zealand. In addition, recent research indicates an increase in Māori cancer mortality rates during the 1980s and 1990s for all cancers combined and for lung, breast, prostate and colorectal cancer. In contrast, non-Māori non-Pacific cancer mortality rates steadily declined during this period, resulting in a widening of the gap in cancer death rates between Māori and non-Māori (Ajwani, Blakely, Robson, Tobias, & Bonne, 2003; Blakely, Ajwani, Robson, Tobias, & Bonne, 2004).

The contribution of cancer to inequalities in life expectancy between Māori and non-Māori also increased during this period. Cancer accounts for more than a fifth of the difference in life expectancy at birth between Māori and non-Māori males, and approximately a third of the difference among females (Ajwani et al., 2003). Māori:non-Māori mortality ratios for all adult cancer are higher than the same ratios for cancer incidence. Combined with evidence of lower relative survival rates for Māori, this suggests disparities in access to early diagnosis and effective treatments for cancer (Ajwani et al., 2003, Jeffreys, 2004).

Differential access to timely and effective cancer care is likely to contribute to disparities in cancer outcomes for Māori and non-Māori. In order to reduce inequalities, it is necessary to have a better understanding of the extent and nature of disparities in access to cancer services for Māori. Previous work has commented on barriers to access for Māori with known diabetes and recommended interventions to reduce these barriers (Baxter, 2002). Further investigation of interventions to address access to cancer services for Māori is required. It is reasonable to assume that interventions at all four levels of the Ministry of Health's framework to reduce inequalities (i.e. structural, intermediary, health service and impact levels) (Ministry of Health, 2002) will be necessary.

AIMS OF THE PROJECT

The overall aim of the project is to enable a better understanding of issues in access to cancer services for Māori. Project findings are intended to contribute to future cancer control policy direction and implementation and to inform the development of interventions to improve Māori access to cancer care and reduce inequalities in cancer outcomes for Māori. In order to achieve this, the project will also:

- map and assess the available data on cancer by ethnicity in terms of quality and completeness, with a particular focus on stage;
- identify findings relating to the stage of cancer at diagnosis for Māori and non-Māori; and,
- identify and assess existing or planned interventions to address barriers to Māori access to cancer services.

SCOPE OF THE PROJECT

The primary focus of this project is access to cancer services for Māori across the continuum of cancer care. The project includes consideration of publicly funded cancer services, as well as private cancer services and NGO organisations that have a role in the provision of services.

Cancer care services are defined in the CCS(NZ) as services "…for those with cancer, their family and whānau to assist in meeting their total needs; ie, physical, social, psychological, sexual, nutritional, information and spiritual needs" (Ministry of Health, 2003): 67). As such, this project generally excludes the primary prevention phase of the cancer spectrum. However, where it enhances discussion, primary prevention has been included.

For the purposes of this report, 'cancer services' do not include breast and cervical cancer services, as Breast Screen Aotearoa and the Cervical Screening Programme are currently researching these areas. Where there are common or relevant issues, breast and cervical cancer services may be included in the discussion.

The scope of the project did not allow for the systematic incorporation of consumer voices in the report. The research team is cognisant of the need for research with Māori with cancer and their whānau to both identify issues in access to cancer services that they see as key and to determine the level of agreement with issues that have been identified in the literature and by cancer care providers.

THEORETICAL APPROACH

The project was informed by a kaupapa Māori framework that recognises the structural causes of inequality, such as unequal power structures, colonisation and institutional racism. In regards to access to cancer services for Māori, the project took an anti-deficit model approach, incorporating a broad multi-level view of access that acknowledged the role of environment, systems, institutions and individuals. In considering facilitators to effective care as well as barriers to access, the project aimed to not only focus on those who are disadvantaged by the system, but also those whom the system advantages.

The project was influenced by a rights-based approach to health, which recognises Māori human, indigenous and Treaty of Waitangi rights.

METHODS

Multi-methods were employed by the research team, including a review of the literature, mapping and assessment of routinely collected data, a stocktake of interventions, interviews with providers, and consultation with key informants and experts. This approach was to facilitate an understanding of issues relevant to access to cancer services for Māori that was broad rather than exhaustive.

Literature review

Literature relating to access to cancer services for Māori was searched and reviewed. A specific search strategy was developed to define the scope of the literature search, outline a framework for searching the literature, and identify key search terms. This was then used as a guide to search databases, catalogues, review bibliographies of published research, conference proceedings, websites, and consult with key informants.

The following primary search questions were formulated:

- *What are the issues in regard to access to cancer services for Māori?*
- *What interventions are there to address access to cancer services for Māori?*

Further to this, a number of related, overarching topic areas were searched to identify key literature that would provide background and context to the report. The most relevant literature was that which related specifically to Māori, however New Zealand, indigenous, and racial/ethnic disparities literature was also searched to identify key supplementary material. Further detail on the literature search is appended (Appendix One).

Data review

In order to provide a context for discussions of access to cancer services for Māori, routinely collected data on deaths and cancer registrations for the 6-year period between 1 January 1996 and 31 December 2001 from the New Zealand Health Information Service (NZHIS) were mapped and assessed by major cancer site in relation to the completeness and quality of ethnicity and staging data for Māori and non-Māori. In addition, findings of analyses of cancer data being undertaken by Te Rōpū Rangahau Hauora a Eru Pōmare in relation to disparities in cancer incidence, mortality, survival and stage at diagnosis, were reported [1]. This included:

- Māori and non-Māori age-standardised and age-specific rates of cancer registration and mortality (total, female and male).
- Māori and non-Māori distributions of stage at diagnosis (localised, regional, distant, unstaged).
- Regression analysis of unstaged data, including by ethnicity, age, and deprivation.
- Hazard ratios adjusted for age and stage at diagnosis.

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[1] Te Rōpū Rangahau Hauora a Eru Pōmare are currently undertaking a range of analyses for the production of *Hauora IV*, a compendium of Māori health statistics. This includes analyses of routinely collected data on cancer registrations and deaths.

Further detailed discussions of the data review methods are included in Appendices Two and Three.

Discussions with providers and key informants

A stocktake was undertaken to identify provider views on access to cancer services for Māori and to gather baseline data on the range of current and planned interventions to address access issues. This involved preliminary contact with a wide range of providers and subsequent discussions with thirty-nine cancer services and providers, including Māori health providers that deliver to people with cancer and/or their whānau. In addition, meetings were held with a number of key informants and stakeholders. Key issues were then identified from the discussions. Further detail of the stocktake methods is included in Appendix Four.

BACKGROUND

CANCER CONTROL POLICY

In recent years, there has been increasing recognition of the need for systematic and organised approaches to cancer control. The World Health Organisation (WHO) has defined a national cancer control programme as:

> a public health programme designed to reduce cancer incidence and mortality and improve quality of life of cancer patients, through the systematic and equitable implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment, and palliation, making the best use of available resources (World Health Organisation, 2002).

Several countries, including Australia, the United States of America, Canada and New Zealand have developed cancer control strategies to address the cancer burden within their populations and to provide cancer care in a more integrated and co-ordinated way.

Reducing the incidence and impact of cancer was identified as one of the 13 priority population health objectives in the *New Zealand Health Strategy* released in 2000. However, progress towards the development of a national cancer control strategy has been ongoing in New Zealand for a number of years. The Cancer Society of New Zealand formed a working group in 1997 to investigate the need for a national strategy for cancer control. This was followed by a Workshop on Cancer Control in 1999, at which it was recommended that a cancer control strategy be developed.

In early 2001, the New Zealand Cancer Control Trust was formed with funding from the Cancer Society of New Zealand and the Child Cancer Foundation. Two key background reports were produced for the Ministry of Health: *Progress towards a New Zealand Cancer Control Strategy* and *The development of a national cancer control strategy for New Zealand.* Later that year, a Cancer Control Steering Group was established to guide development of a strategy and as part of the process, five expert working groups (primary prevention, early detection and screening, support and rehabilitation, treatment, and palliative care) were also formed to provide advice to the Steering Group.

A discussion document entitled '*Towards a cancer control strategy for New Zealand Marihi Tauporo'* was released for public consultation in 2002. Following the submission and consultation process, the *New Zealand Cancer Control Strategy* (CCS(NZ)) was released in August 2003.

In late 2004, the Minister of Health announced the establishment of an ongoing independent Cancer Control Council that will have a role in monitoring the implementation of the CCS(NZ) and encouraging increased collaboration and co-ordination in cancer control. The *New Zealand Cancer Control Strategy Action Plan: 2005-2010,* outlining how the goals and objectives in this strategy will be implemented over the next five years, is due for public release in March 2005.

CANCER CARE SERVICES

The complex and varied nature of cancer means that there are a wide range of services and providers involved in cancer care. This includes services that are available through the public and private sectors, as well as the NGO sector, which has an important role in the provision of cancer care services. Care pathways are often complex and differ depending on, among other things, the type and site of cancer. The CCS(NZ) outlines a cancer control continuum that includes the following phases of cancer care:

Prevention	Early detection and screening	Diagnosis and treatment	Support and rehabilitation	Palliative care

In addition, the CCS(NZ) identifies cancer control research and cancer control surveillance as important components of the cancer care trajectory (Ministry of Health, 2003).

Prevention

Primary prevention is concerned with preventing the occurrence of cancer through the reduction of risk factors and the encouragement of protective factors. In New Zealand, prevention involves various health promotion and protection activities and a diverse range of organisations and personnel, both governmental and non-governmental. Services involved in primary prevention of cancer include primary care practitioners, nurses, and Māori providers who may be providing health promotion and primary prevention information and interventions, such as smoking cessation.

Early detection and cancer screening

Early detection and cancer screening aim to detect cancer at as early stage of development as possible, when options for treatment are greatest. National screening programmes for asymptomatic populations exist in New Zealand for breast and cervical cancer. Guidelines have also been produced for the screening of individuals at high risk of colorectal cancer. Screening for the early detection of cancers in asymptomatic individuals may occur in primary care in an opportunistic or ad hoc manner, such as through prostate screening or melanoma checks. For symptomatic populations, early detection usually involves access to primary care, although this may occur in other settings.

Diagnosis and treatment of cancer

Cancer diagnosis, including staging, is important in determining appropriate care pathways for patients. There are a number of services involved in the diagnosis of cancer, many of which are not particular to cancer, such as pathology and radiology. Some of these can be accessed through primary care, while others involve a referral to secondary care.

Cancer treatments can be both surgical and medical and provided by specialist cancer providers or by non-cancer specific providers. New Zealand has six regional cancer treatment centres (Auckland, Waikato, Palmerston North, Wellington, Christchurch and Dunedin) that offer medical oncology, radiation oncology and haematology services across the 21 District Health Boards (DHBs). Some treatments such as chemotherapy and haematology are also available through secondary hospitals (Ministry of Health, 2001).

Support and rehabilitation

Support and rehabilitation services for patients with cancer and their families involve cancer-specific services, such as the support services provided by the Cancer Society of New Zealand, the Child Cancer Foundation, Canteen and other NGOs, and specialist support provided within cancer treatment centres, hospices and so on. Support and rehabilitation can also include non-cancer specific services, such as rehabilitation services that may be necessary after surgery or treatment, or financial assistance for home help or carer relief. Support and rehabilitation is important at all phases of the cancer care pathway.

Palliative care

In New Zealand, palliative care delivery can involve a range of providers including hospices, hospitals, general practitioners and community health services. Hospice service provision varies across the country in terms of availability and the way the service is provided (in-patient or home-based, respite care, counselling). In areas where hospice services are not available, some care is provided by hospitals and health services, primarily through district nurses (Minister of Health, 2001).

MAPPING CANCER DISPARITES

Significant disparities in cancer risk, incidence and outcome exist between Māori and non-Māori. However, detailed information on Māori cancer, such as stage at diagnosis and survival rates, is not routinely available and the picture of cancer for Māori is therefore incomplete. In addition, there are issues with the quality and completeness of cancer data for Māori and non-Māori. As a background to discussions of access to cancer services for Māori, this section maps the routinely collected data on cancer deaths and registrations for the period 1996 to 2001 (inclusive) in relation to the completeness of ethnicity and staging data. It also describes Māori cancer incidence, mortality and survival, and reports findings of analysis undertaken to further investigate hypotheses about stage at diagnosis and the contribution of late diagnosis to disparities in cancer outcomes.

ETHNICITY DATA

It is essential that ethnicity data is accurately, comprehensively, consistently and continuously recorded, in order to monitor the performance of the health system in meeting Māori needs. Accurate ethnicity data is also a fundamental requirement for monitoring disparities in health care and outcomes. Issues with undercounting of Māori in official health data sets have previously been identified (Te Röpü Rangahau Hauora a Eru Pömare, 2000). It was not possible to conduct a full audit of the quality of ethnicity data on the New Zealand Cancer Registry (NZCR) within the scope of this project. Nevertheless, utilising the results from the New Zealand Census-Mortality Study, in combination with data from the National Minimum Data Set (cancer registrations, deaths and hospital discharges) and National Health Index, it was possible to estimate that for the period 1996-2001 (inclusive), Māori cancer registrations were undercounted by approximately 17% and Māori deaths were undercounted by approximately 6%. The process for determining these estimates is described in more detail in Appendix Two.

Using the 'ever Māori' method of analysis (by which individuals are classified as Māori if Māori was coded as one of the ethnic groups in any ethnicity field of the death event record, the NHI, any other cancer registration, or any hospitalisation during this period) produces estimates of Māori cancer registrations and deaths accurate to within 1%. This method of classifying ethnicity data is used in the data analyses reported below.

CANCER INCIDENCE AND MORTALITY

During the period 1996-2001, there were around 1,200 new Māori cancer registrations a year on average (660 females and 570 males) and 15,700 new non-Māori registrations (7,300 females and 8,400 males). The age-standardised rate for all-sites cancer was 220.9 per 100,000 among Māori, eighteen percent higher than the non-Māori rate of 187.8 per 100,000.

Deaths from cancer numbered around 700 a year among Māori (365 females and 360 males) and nearly 6,900 a year among non-Māori (3,200 females and 3,700 males). The age-standardised Māori cancer mortality rate was 127.9 per 100,000, nearly twice that of non-Māori at 66.3 per 100,000.

Leading sites for Māori and non-Māori

Māori and non-Māori had different leading cancer sites in terms of both cancer incidence and mortality for the period 1996-2001 (inclusive).

Registrations

When ranked by number of registrations, the leading sites among Māori (total population) were lung, female breast, prostate, colorectal and stomach (55% of all cancers). However, when ranked by age-standardised rates, the leading sites were female breast, lung, prostate, colorectal, and cervical cancer replaces stomach cancer as the 5th highest.

Among non-Māori the highest numbers of registrations were for prostate, colorectal, female breast, melanoma and lung cancer (62% of all cancers). When ranked by age-standardised rate, the leading sites remained the same, although breast cancer becomes the leading site.

Deaths

The five leading sites of cancer death among Māori were lung, breast, colorectal, stomach and prostate cancer, with lung cancer comprising a third of all cancer deaths. Breast cancer contributed 9% of the total, colorectal and stomach 7% each, and prostate cancer 4%. In total these sites made up 58% of all Māori cancer deaths.

Among non-Māori, the most common causes of cancer death were lung, colorectal, breast and prostate cancer, and non-Hodgkin's lymphoma. Lung cancer and colorectal cancer each constituted around 16% of all cancer deaths, breast and prostate around 8% each, and non-Hodgkin's lymphoma 4%, totalling 53% of all non-Māori cancer deaths.

Leading sites for males and females

Registrations

Among Māori females, breast, lung, cervix, colorectal, uterus and ovary were the most common cancers, representing 57% of all registrations. Breast cancer, colorectal cancer, melanoma, and lung cancer made up 61% of all non-Māori female registrations (Table 1).

Leading registration sites among Māori males were lung, prostate, colorectal, stomach, and testicular cancers (58% of all registrations). Among non-Māori males, prostate, colorectal, lung cancer and melanoma constituted 64% of all registrations (Table 2).

Deaths

The leading causes of cancer death among Māori females were lung, breast, colorectal, cervical, and stomach cancer, forming 60% of all cancer deaths. Among non-Māori females, the major causes of cancer death were breast, colorectal, and lung cancer (56% of all cancer deaths) (Table 3).

For Māori males, lung, prostate, stomach, colorectal, and liver cancer were the leading causes, constituting 63% of cancer deaths. Among non-Māori males, lung, colorectal, and prostate cancer were the primary causes of cancer death, comprising 45% (Table 4).

Priority sites

Lung, breast, prostate, and colorectal cancer were leading sites for both Māori and non-Māori, in both registrations and deaths. However, for Māori, stomach, cervical, and liver cancer were also important causes of cancer death.

Testicular cancer was common among Māori registrations although not a leading cause of cancer death. Melanoma was common among non-Māori cancer registrations but also not a leading cause of cancer death.

Lung, breast, prostate and colorectal cancer are clear priorities for both Māori and non-Māori. However, to meet Māori needs, priority should also be given to stomach, cervical, and liver cancers. Testicular, uterine, ovarian and pancreatic cancers could also be considered.

Table 1. Female leading cancer registration sites 1996-2001

	Māori			non-Māori		
Rank	**Site**	**Number**	**%**	**Site**	**Number**	**%**
	All sites	3,953	100	All sites	43,688	100
1	Breast	1,177	29.0	Breast	11,762	26.9
2	Trachea, bronchus & lung	708	17.9	Colorectal	7,149	16.4
				Colon	*5,157*	*11.8*
				Rectum	*1,992*	*4.6*
3	Cervix uteri	250	6.3	Melanoma	4,637	10.6
4	Colorectal	221	5.6	Trachea, bronchus & lung	2,976	6.8
	Colon	*134*	*3.4*			
	Rectum	*87*	*2.2*			
5	Uterus	175	4.4	Ovary	1,571	3.6
6	Ovary	163	4.1	Uterus	1,570	3.6
7	Stomach	147	3.7	Non-Hodgkin's lymphoma	1,545	3.5
8	Leukaemia	109	2.8	Leukaemia	1,318	3.0
9	Non-Hodgkin's lymphoma	107	2.7	Cervix uteri	985	2.3
10	Thyroid	97	2.5	Bladder	873	2.0
11	Pancreas	86	2.2	Pancreas	868	2.0
12	Melanoma	66	1.7	Stomach	760	1.7
13	Brain	58	1.5	Kidney	693	1.6
14	Kidney	48	1.2	Multiple myeloma	600	1.4
15	Multiple myeloma	48	1.2	Thyroid	586	1.3

Table 2. Male leading cancer registration sites 1996-2001

	Māori			non-Māori		
Rank	**Site**	**Number**	**%**	**Site**	**Number**	**%**
	All sites	3,457	100	All sites	50,596	100
1	Trachea, bronchus & lung	729	21.1	Prostate	15,324	30.3
2	Prostate	632	18.3	Colorectal	7,261	14.4
				Colon	*4,450*	*8.8*
				Rectum	*2,811*	*5.6*
3	Colorectal	293	8.5	Trachea, bronchus & lung	4,999	9.9
	Colon	*163*	*4.7*			
	Rectum	*130*	*3.8*			
4	Stomach	182	5.3	Melanoma	4,735	9.4
5	Testis	174	5.0	Bladder	2,411	4.8
6	Leukaemia	167	4.8	Leukaemia	1,815	3.6
7	Liver	149	4.3	Non-Hodgkin's lymphoma	1,711	3.4
8	Non-Hodgkin's lymphoma	125	3.6	Stomach	1,259	2.5
9	Kidney	90	2.6	Kidney	1,142	2.3
10	Pancreas	90	2.6	Lip, oral cavity & pharynx	1,025	2.0
11	Multiple myeloma	81	2.3	Pancreas	867	1.7
12	Lip, oral cavity & pharynx	79	2.3	Brain	842	1.7
13	Oesophagus	67	1.9	Multiple myeloma	764	1.5
14	Brain	61	1.8	Oesophagus	727	1.4
15	Bladder	58	1.7	Mesothelial & soft tissue	685	1.4

Table 3. Female leading cancer deaths 1996-2001

	Māori			non-Māori		
Rank	**Site**	**Number**	**%**	**Site**	**Number**	**%**
	All sites	2,152	100.0	All sites	19,329	100.0
1	Trachea, bronchus & lung	676	31.4	Breast	3,435	17.8
2	Breast	383	17.8	Colorectal	3,177	16.4
				Colon	*2,263*	*11.7*
				Rectum	*914*	*4.7*
3	Colorectal	129	6.0	Trachea, bronchus & lung	2,588	13.4
	Colon	*73*	*3.4*			
	Rectum	*56*	*2.6*			
4	Cervix uteri	116	5.4	Ovary	964	5.0
5	Stomach	110	5.1	Pancreas	847	4.4
6	Pancreas	83	3.9	Non-Hodgkin's lymphoma	774	4.0
7	Ovary	69	3.2	Stomach	602	3.1
8	Leukaemias	58	2.7	Leukaemias	594	3.1
9	Non-Hodgkin's lymphoma	52	2.4	Melanoma	530	2.7
10	Uterus	49	2.3	Brain	496	2.6
11	Brain	41	1.9	Uterus	410	2.1
12	Liver	29	1.3	Multiple myeloma	387	2.0
13	Mesothelial & soft tissue	26	1.2	Oesophagus	364	1.9
14	Multiple myeloma	25	1.2	Bladder	331	1.7
15	Kidney	24	1.1	Kidney	321	1.7

Table 4. Male leading cancer deaths 1996-2001

	Māori			non-Māori		
Rank	**Site**	**Number**	**%**	**Site**	**Number**	**%**
	All sites	2133	100.0	All sites	21,867	100.0
1	Trachea, bronchus & lung	694	33.4	Trachea, bronchus & lung	4,519	20.7
2	Prostate	178	8.3	Colorectal	3,325	15.2
				Colon	*2,047*	*9.4*
				Rectum	*1,278*	*5.8*
3	Stomach	167	7.8	Prostate	3,111	14.2
4	Colorectal	163	7.6	Stomach	935	4.3
	Colon	*85*	*4.0*			
	Rectum	*78*	*3.7*			
5	Liver	124	5.8	Non-Hodgkin's lymphoma	882	4.0
6	Pancreas	85	4.0	Melanoma	822	3.8
7	Leukaemias	79	3.7	Pancreas	804	3.7
8	Oesophagus	63	3.0	Leukaemias	798	3.6
9	Non-Hodgkin's lymphoma	59	2.8	Brain	678	3.1
10	Brain	54	2.5	Oesophagus	675	3.1
11	Lip, oral cavity & pharynx	50	2.3	Bladder	649	3.0
12	Kidney	49	2.3	Kidney	480	2.2
13	Multiple myeloma	49	2.3	Multiple myeloma	447	2.0
14	Mesothelial & soft tissue	31	1.5	Mesothelial & soft tissue	409	1.9
15	Gallbladder	19	0.9	Lip, oral cavity & pharynx	401	1.8

CANCER INCIDENCE AND MORTALITY DISPARITIES

Cancer incidence disparities

During the period 1996-2001, the rate of cancer incidence was 220.9 per 100,000 among Māori; 18% higher than the non-Māori rate of 187.8 per 100,000 (relative risk 1.18; 95% CI 1.15-1.21) (Table 5).

Table 5. Cancer registrations and deaths 1996-2001, numbers, age-standardised rates† & Māori/non-Māori rate ratios (ranked by Māori incidence)

	Registrations					Deaths				
	Māori		non-Māori			Māori		non-Māori		
	Number	Rate	Number	Rate	Ratio	Number	Rate	Number	Rate	Ratio
All sites	**7,410**	**220.9**	**94,284**	**187.8**	**1.18**	**4,285**	**127.9**	**41,184**	**66.3**	**1.93**
Female breast*	1,147	65.1	11,762	53.9	1.21	383	21.6	3,435	12.8	1.68
Trachea, bronchus & lung	1,437	42.8	7,975	12.9	3.31	1,370	40.7	7,107	11.0	3.70
Prostate*	632	41.2	15,324	49.3	0.84	178	12.1	3,111	7.5	1.61
Colorectal	514	15.5	14,410	24.1	0.64	292	8.8	6,502	9.8	0.90
Colon	297	8.9	9,607	15.4	0.58	158	4.8	4,310	6.3	0.76
Rectum & anus	217	6.6	4,803	8.7	0.76	134	4.15	2,192	3.5	1.17
Cervix uteri*	250	14.2	985	6.3	2.27	116	6.6	317	1.4	4.85
Testis*	174	10.9	618	5.9	1.84	14	0.9	27	0.2	4.25
Ill-defined & unspecified	348	10.4	3,440	5.5	1.90	260	7.8	2,739	3.9	2.00
Uterus*	175	9.9	1,570	6.1	1.61	49	2.7	410	1.2	2.28
Stomach	329	9.8	2,019	3.2	3.08	277	8.3	1,537	2.3	3.69
Ovary*	163	9.3	1,571	7.3	1.28	69	3.9	964	3.3	1.17
Leukaemias	276	8.4	3,133	7.7	1.09	137	4.1	1,392	2.8	1.46
Non-Hodgkin's lymphoma	232	6.9	3,256	6.8	1.02	111	3.3	1,656	2.8	1.18
Liver & intrahep bile ducts	183	5.6	698	1.4	3.86	153	4.7	588	1.1	4.33
Pancreas	176	5.2	1,735	2.7	1.96	168	5.0	1,651	2.4	2.06
Kidney	138	4.1	1,835	3.9	1.05	73	2.2	801	1.3	1.64
Multiple myeloma	129	3.9	1,364	2.1	1.89	74	2.2	834	1.1	2.03
Thyroid gland	126	3.7	787	2.6	1.39	12	0.3	97	0.1	2.34
Lip, oral cavity & pharynx	120	3.6	1,575	3.4	1.06	62	1.9	595	1.0	1.81
Brain	119	3.5	1,402	4.5	0.79	95	2.8	1,174	3.1	0.93
Melanoma of skin	100	2.9	9,372	23.9	0.12	15	0.4	1,352	2.8	0.15
Mesothelial & soft tissue	97	2.9	1,066	2.5	1.15	57	1.7	592	1.2	1.41
Oesophagus	91	2.8	1,126	1.7	1.64	86	2.6	1,039	1.5	1.78
Bladder	85	2.6	3,284	5.2	0.51	36	1.1	980	1.2	0.91
Gallbladder & biliary tract	44	1.3	405	0.6	2.22	35	1.1	306	0.4	2.57
Hodgkin's disease	36	1.1	393	1.7	0.61	11	0.3	72	0.2	1.87
Bone & joints	29	0.9	203	0.9	1.01	16	0.5	104	0.4	1.18

*sex-specific rates

† age-standardised per 100,000 to the Māori population

(See Appendix for confidence intervals on rates and ratios)

The largest risk differences between Māori and non-Māori were for cancers of the lung (an extra 30 per 100,000 among Māori compared to non-Māori), breast (11 per 100,000), cervix (8 per 100,000), stomach (7 per 100,000), testis (5 per 100,000) and liver (4 per 100,000).

The highest disparities in terms of relative risks were for cancers of the lung, stomach and liver (3 or more times higher among Māori than non-Māori), and cervix (more than twice as high). Other cancers significantly more common among Māori included cancers of the testis and multiple myeloma (over 80% higher), cancers of the uterus and oesophagus (over 60% higher), thyroid (40% higher), ovary and breast (over 20% higher).

Cancers for which Māori had significantly lower rates than non-Māori included melanoma of the skin (one-eighth the non-Māori rate), bladder cancer (half as high), colorectal (two-thirds as high), brain, and prostate cancers (both four-fifths the non-Māori rate). Māori and non-Māori had similar rates of leukaemia, non-Hodgkin's lymphoma, cancers of the lip, oral cavity and pharynx, kidney, and mesothelial and soft tissue.

Figures 1 and 2 show rates of new cancer registrations for selected cancer types, by sex.

Figure 1. Female cancer registrations 1996-2001

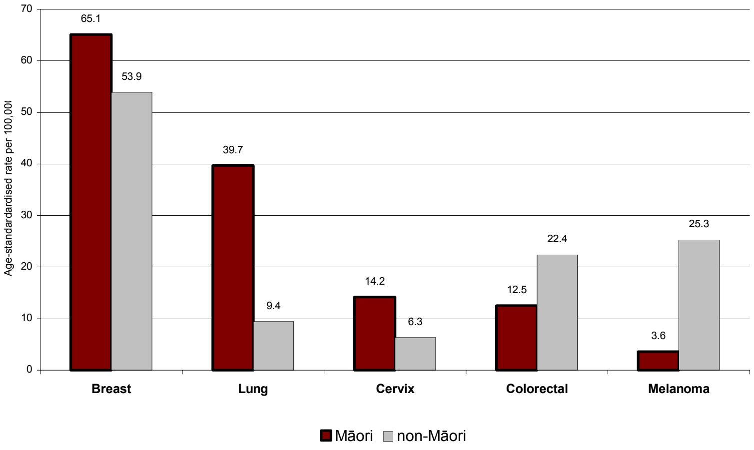
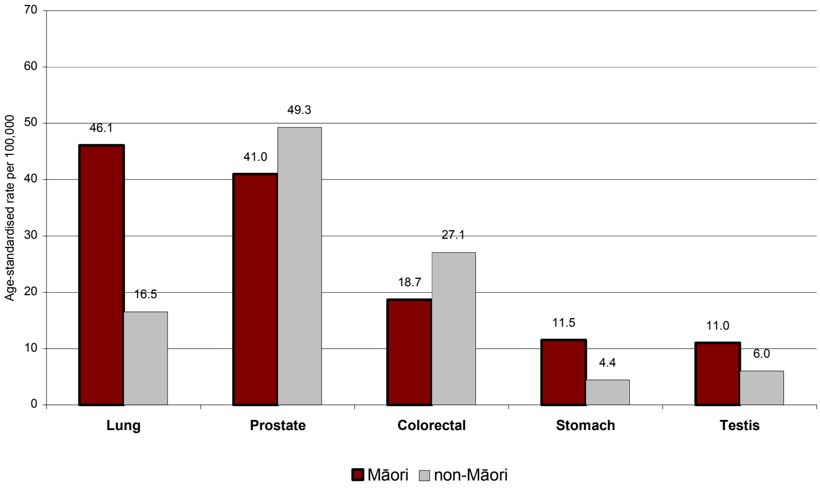


Figure 2. Male cancer registrations 1996-2001



Cancer mortality disparities

During the period 1996-2001, the cancer mortality rate was 127.9 per 100,000 among Māori, nearly twice the non-Māori rate of 66.3 per 100,000 (relative risk 1.93; 95% CI 1.87-1.99), giving a risk difference of 61.6 deaths per 100,000. Among Māori the average number of cancer deaths was 58% of the number of registrations, while among non-Māori it was 44%.

Death rates were significantly higher among Māori than non-Māori for many types of cancer. The largest risk differences were for deaths from lung cancer (30 deaths per 100,000), breast cancer (9 per 100,000), stomach (6 per 100,000), cervix and prostate (5 per 100,00) and liver (4 per 100,00). The most extreme risk ratio was for deaths from cervical cancer - nearly five times higher among Māori than non-Māori (RR=4.85; 95% CI 3.87-6.06), while the incidence rate was two and a quarter times higher (RR=2.27; 95% CI 1.97-2.62). Substantial disparities also exist for deaths from cancer of the liver and testis – both over four times higher among Māori than non-Māori. Lung and stomach cancer death rates were more than three times higher among Māori.

Deaths from cancer of the pancreas, uterus, multiple myeloma, gallbladder, and thyroid were more than twice the non-Māori rates. Deaths from cancers of the breast, prostate, oesophagus, kidney, lip oral cavity & pharynx were over 50% higher among Māori than non-Māori; leukaemia and mesothelial & soft tissue cancers 40% higher.

Colon cancer and melanoma were the only sites with significantly lower mortality rates among Māori. No significant differences were observed for deaths from cancers of the ovary, brain, rectum and anus, bladder or non-Hodgkin's lymphoma.

Gender-specific mortality rates are shown in figures 3 and 4. They illustrate the prominence of lung cancer as the leading cause of cancer death among Māori men and women, as well as the stark disparity between Māori and non-Māori in deaths from this cancer.

Figure 3. Female cancer deaths 1996-2001

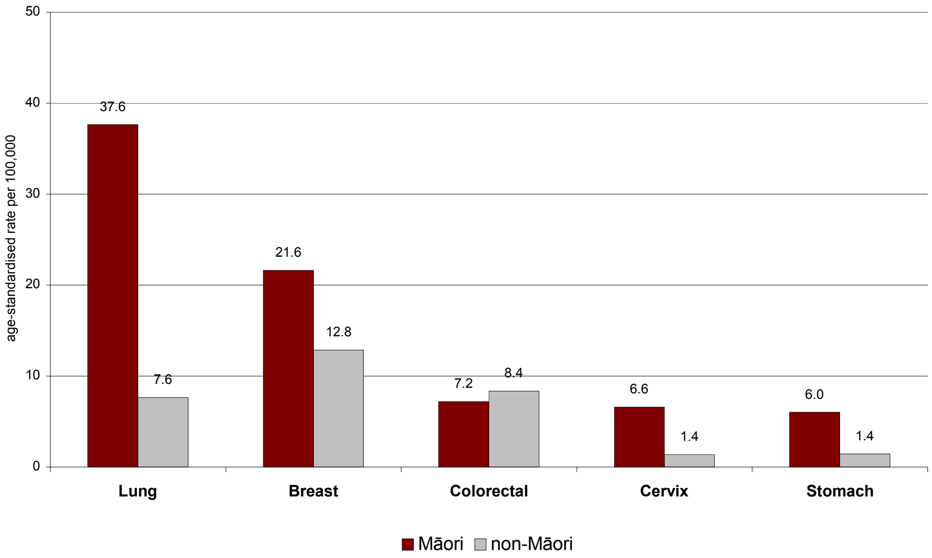
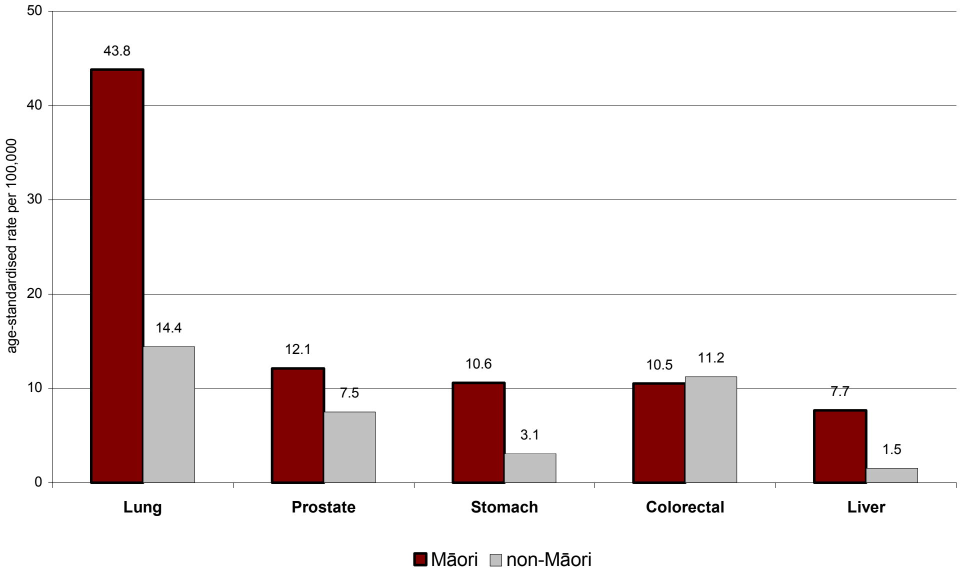


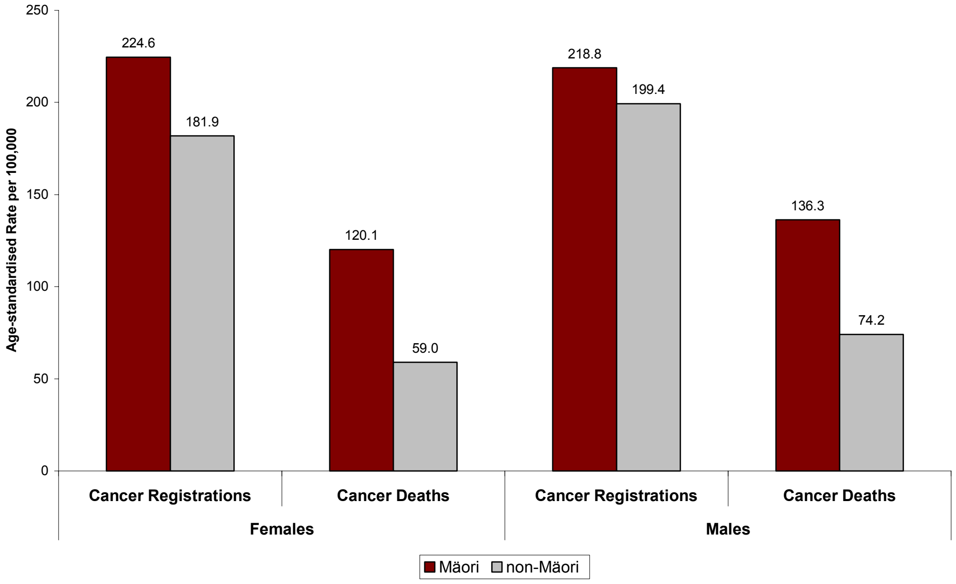
Figure 4. Male cancer deaths 1996-2001



Cancer incidence compared to cancer mortality

The cancer mortality/incidence ratio was 0.58 among Māori compared to 0.35 among non-Māori. Figure 5 shows rates of new cancer registrations and deaths for males and females. Among females, the Māori mortality rate was twice the non-Māori rate (ratio 2.04; 95% CI 1.95-2.13), while the incidence was only 23% higher (ratio 1.23; 95% CI 1.19-1.28)). Among males, deaths were 84% more common among Māori (ratio 1.84; 95% CI 1.76-1.92) while there was only a 10% difference in incidence (ratio 1.10; 95% CI 1.06-1.14).

Figure 5. All sites cancer registrations and deaths 1996-2001, by gender

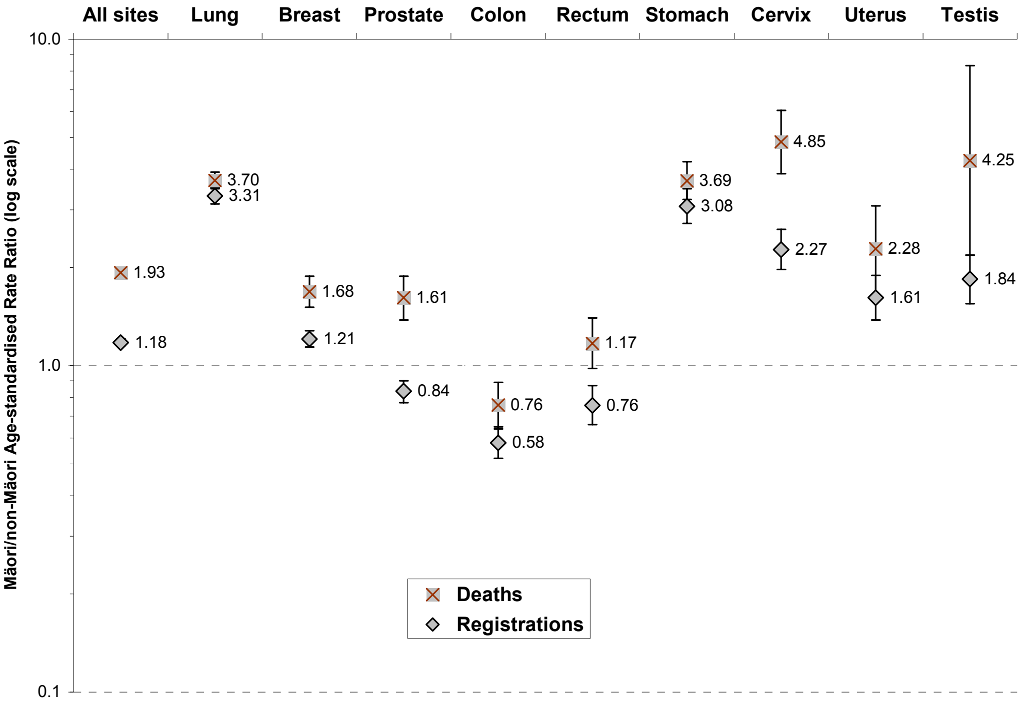


There was a consistent pattern across most cancer sites of higher Māori to non-Māori mortality ratios compared to the incidence ratios (Table 5). This indicates that Māori have a more fatal experience of cancer than non-Māori – including cancers that are less common among Māori than non-Māori such as colon, rectum and prostate cancers. Ovarian cancer was the only cancer where the Māori/non-Māori mortality rate ratio was lower than the incidence ratio.

Figure 6 shows the difference between incidence and mortality ratios for selected cancers. For most types of cancer, the mortality ratios are higher than the incidence ratios – i.e. the relative risk of death is greater than the relative risk of being diagnosed with cancer. For example, Māori men are less likely than non-Māori men to be diagnosed with prostate cancer, but 61% more likely than non-Māori to die from prostate cancer.

The largest gaps between ratios can be seen in the types of cancer with more treatment options, e.g. breast, prostate, cervix, colon and rectum. The findings on cervical cancer are particularly concerning as screening and treatments are available, yet Māori women are two and a quarter times more likely to be diagnosed with invasive cervical cancer and nearly five times more likely to die from it than non-Māori women.

Figure 6. Māori/non-Māori age-standardised cancer incidence and mortality ratios 1996-2001



Note that the log scale telescopes the high (or low) ratios closer together. Any point above 1 indicates a higher rate among Māori than among non-Māori. Conversely, any point below 1 indicates lower rates among Māori. 95% confidence limits on the ratios are represented by the bars extending out from the points. The confidence interval is narrow on the ratios for 'all sites' but wide on the mortality ratio for testicular cancer as deaths from this cancer are relatively rare.

These mortality ratios are a function of both comparative cancer incidence among the Māori and non-Māori populations, and cancer survival rates. The data indicates likely differences in survival chances between Māori and non-Māori diagnosed with cancer, and thus points to the existence of serious problems with equitable receipt of cancer services in Aotearoa. However, it does not tell us what the survival differences actually are. In order to focus more closely on potential disparities in access to timely and effective cancer care, the next section compares the risk of dying from the cancer once diagnosed among Māori cancer patients compared to non-Māori cancer patients.

CANCER SURVIVAL DISPARITIES

Table 6 presents hazard ratios adjusted for sex and age at diagnosis. Hazard ratios above 1 indicate that Māori cancer patients had a higher risk of dying from their cancer than non-Māori cancer patients of the same age. If the lower confidence limit is above 1, the difference in risk is significant at the 5% level (p-value less than 0.05).

Table 6. Māori: non-Māori relative risk of cancer-specific death after diagnosis (hazard ratios), 1996-2001, adjusted for sex and age at diagnosis.

Site	Hazard Ratio	(95% CI)	p value
Trachea, bronchus & lung	1.34	(1.26, 1.43)	**<0.0001**
Breast	1.69	(1.44, 1.99)	**<0.0001**
Prostate	2.33	(1.94, 2.79)	**<0.0001**
Colorectal	1.67	(1.45, 1.93)	**<0.0001**
Colon	1.50	(1.24, 1.82)	**<0.0001**
Rectum, rectosigmoid junction & anus	2.04	(1.65, 2.53)	**<0.0001**
Stomach	1.57	(1.35, 1.83)	**<0.0001**
Cervix	2.68	(2.00, 3.58)	**<0.0001**
Liver & intrahepatic bile ducts	1.39	(1.13, 1.70)	**0.002**
Pancreas	1.15	(0.97, 1.36)	0.12
Uterus	1.65	(1.15, 2.37)	**0.007**
Testis	3.07	(1.36, 6.95)	**0.007**
Ovary	1.02	(0.76, 1.36)	0.92
Kidney	1.52	(1.13, 2.05)	**0.006**
Thyroid	1.18	(0.56, 2.47)	0.67
Lip, oral cavity & pharynx	2.07	(1.50, 2.84)	**<0.0001**
Brain	1.16	(0.90, 1.49)	0.25
Melanoma of skin	1.19	(0.53, 2.67)	0.67
Mesothelial & soft tissue	1.66	(1.19, 2.32)	**0.003**
Oesophagus	1.74	(1.37, 2.22)	**<0.0001**
Bladder	2.37	(1.59, 3.52)	**<0.0001**
Leukaemias	1.43	(1.16, 1.77)	**0.0009**
Non-Hodgkin's lymphoma	1.42	(1.13, 1.78)	**0.002**
Multiple myeloma	1.60	(1.21, 2.12)	**0.001**

For most types of cancer, Māori cancer patients had a significantly higher risk of dying from the cancer after diagnosis, than non-Māori patients. The largest differentials were observed for cancers of the cervix, prostate, testis, rectum, and lip, oral cavity & pharynx. Māori diagnosed with these cancers were more than twice as likely to die from their cancer than non-Māori diagnosed at the same age.

Māori diagnosed with breast, colorectal, uterine, mesothelial, oesophageal, multiple myeloma, and kidney cancer had a 50-70% higher likelihood of dying from their cancer than their non-Māori counterparts.

The only cancers where the cancer-specific mortality risk was similar among Māori and non-Māori were cancers of the pancreas, ovary, brain, thyroid and melanoma of the skin.

STAGE AT DIAGNOSIS

Impact of stage at diagnosis on cancer survival

Early diagnosis can have a significant impact on cancer survival for some cancers, especially if the cancer has not spread to other parts of the body. Cancer registrations include information on the extent of disease spread or stage at diagnosis. Stage at diagnosis can be classified as localised, regional (spread to adjacent tissue or organ and/or involves regional lymph nodes), distant (spread to distant organs, tissues or to distant lymph nodes), or unknown. This schema is not applicable to leukaemias or lymphomas.

The relative importance of stage at diagnosis on survival chances for the different types of cancer was compared by estimating the cancer-specific risk of death among all patients (both Māori and non-Māori) diagnosed at regional, distant or unknown stage at diagnosis, relative to those diagnosed when their cancer was still localised. Where hazard ratios are greater than one (and lower confidence limit greater than one), the risk of death is significantly higher than for those diagnosed at localized stage. These ratios do not measure the absolute survival chances or mortality risks of patients. They estimate only the risk of death relative to those diagnosed when their cancer has not spread beyond the localised stage.

Cancers diagnosed at more advanced stages had a significantly higher risk of death than localised cancers, for all types of cancer (Table 7). The differences were most extreme at the distant stage of diagnosis, especially notable for cervical cancer, melanoma and breast cancer – cancers with good treatment options available if diagnosed at an early stage.

Patients with unstaged cancers had lower mortality risks than distant stage cancers for all types of cancer - evidence that these cancers were not predominantly patients with widespread metastatic disease. If the lack of stage data on the registration means these cancers were not staged, or were staged too late for entry onto the registration, this group may not be receiving adequate or timely access to follow-up procedures after diagnosis.

This section found that later stage diagnosis has a significant impact on cancer-specific survival for all cancers. For some cancers, early diagnosis makes a very large difference to the risk of death. In addition, those with unknown stage at diagnosis cannot be assumed to be so ill that staging would not make a difference to treatment options.

Table 7. Relative risk of cancer specific death after diagnosis (hazard ratios) for cancers diagnosed at regional, distant, and unknown stage compared to cancers diagnosed at localised stage (1996-2001), adjusted for age and sex.

	Regional: Localised		Distant: Localised		Unknown: Localised	
Site	**HR**	**(95% CI)**	**HR**	**(95% CI)**	**HR**	**(95% CI)**
Trachea, bronchus & lung	3.79	(3.20, 4.50)	9.01	(7.67, 10.59)	4.03	(3.44, 4.72)
Breast	4.14	(3.55, 4.84)	38.72	(32.63, 45.94)	4.06	(3.41, 4.82)
Prostate	4.55	(2.95, 7.03)	27.63	(18.83, 40.54)	2.61	(1.79, 3.80)
Colorectal	3.92	(3.45, 4.45)	26.24	(23.09, 29.82)	8.50	(7.38, 9.79)
Colon	*4.17*	*(3.52, 4.93)*	*29.11*	*(24.58, 34.48)*	*10.65*	*(8.82, 12.87)*
Rectum	*3.67*	*(3.01, 4.49)*	*21.71*	*(17.74, 26.57)*	*6.59*	*(5.32, 8.17)*
Stomach	2.98	(2.30, 3.84)	9.46	(7.32, 12.24)	4.46	(3.47, 5.74)
Cervix uteri	17.61	(7.26, 42.72)	138.64	(59.16, 324.87)	37.79	(16.52, 86.45)
Liver & intrahepatic bile ducts	1.70	(0.98, 2.94)	1.80	(1.22, 2.66)	1.49	(1.04, 2.13)
Pancreas	1.72	(1.16, 2.56)	4.18	(2.89, 6.05)	2.49	(1.72, 3.59)
Uterus	4.25	(3.07, 5.87)	15.88	(11.66, 21.62)	4.22	(2.98, 5.98)
Testis	4.58	(1.40, 15.01)	21.65	(8.12, 57.73)	3.58	(0.72, 17.76)
Ovary	8.04	(5.24, 12.33)	13.24	(9.25, 18.95)	8.45	(5.51, 12.95)
Kidney	4.21	(3.03, 5.84)	25.89	(19.62, 34.16)	8.30	(6.08, 11.32)
Thyroid	4.47	(1.96, 10.18)	28.24	(12.69, 62.84)	3.91	(1.55, 9.84)
Lip, oral cavity & pharynx	3.98	(2.86, 5.55)	7.66	(4.99, 11.75)	2.57	(1.85, 3.58)
Brain	3.20	(1.32, 7.76)	4.03	(2.22, 7.34)	1.13	(0.94, 1.36)
Melanoma	7.79	(6.32, 9.61)	45.56	(36.37, 57.07)	3.41	(2.45, 4.74)
Mesothelial & soft tissue	6.31	(3.82, 10.43)	11.23	(7.16, 17.62)	4.10	(2.70, 6.21)
Oesophagus	2.45	(1.51, 3.96)	6.18	(3.88, 9.84)	2.89	(1.84, 4.52)
Bladder	2.70	(1.75, 4.16)	7.43	(4.79, 11.51)	0.61	(0.41, 0.90)

Distribution of stage at diagnosis

Table 8 presents the numbers and distribution of new cancers, registered during 1996-2001, by stage at diagnosis. The percentages shown are unadjusted for age or sex.

Among both Māori and non-Māori, cancers more likely to be diagnosed at the localised stage included cancers of the uterus, testis, thyroid, brain, and melanoma. Colorectal cancer was most frequently diagnosed at regional stage.

Cancers where stage at diagnosis was unknown for the majority of registrations included lung, prostate, liver, mesothelial, oesophagus and bladder cancers. Melanoma, ovarian cancer and colon cancer had the lowest proportions of unstaged registrations.

Table 8. Distribution of cancer registrations 1996-2001 by stage at diagnosis

		Total	Localised		Regional		Distant		Unknown	
		Number	Number	%	Number	%	Number	%	Number	%
Trachea, bronchus & lung	Māori	1,437	53	3.7	132	9.2	484	33.7	768	53.4
	non-Māori	7,975	486	6.1	899	11.3	2,469	31.0	4,121	51.7
Breast	Māori	1,147	441	38.4	454	39.6	66	5.8	186	16.2
	non-Māori	11,762	5,356	45.5	3,813	32.4	480	4.1	2,113	18.0
Prostate	Māori	632	42	6.6	16	2.5	86	13.6	488	77.2
	non-Māori	15,324	1,411	9.2	650	4.2	914	6.0	12,349	80.6
Colorectal	Māori	514	86	16.7	218	42.4	130	25.3	80	15.6
	non-Māori	14,410	3,684	25.6	6,698	46.5	2,583	17.9	1,445	10.0
Colon	Māori	297	52	17.5	134	45.1	85	28.6	26	8.8
	non-Māori	9,607	2,227	23.2	4,771	49.7	1,861	19.4	748	7.8
Rectum & anus	Māori	217	34	15.7	84	38.7	45	20.7	54	24.9
	non-Māori	4,803	1,457	30.3	1,927	40.1	722	15.0	697	14.5
Stomach	Māori	329	45	13.7	83	25.2	90	27.4	111	33.7
	non-Māori	2,019	204	10.1	594	29.4	493	24.4	728	36.1
Cervix	Māori	250	106	42.4	31	12.4	24	9.6	89	35.6
	non-Māori	985	488	49.5	121	12.3	55	5.6	321	32.6
Liver & intrahepatic bile ducts	Māori	183	17	9.3	4	2.2	30	16.4	132	72.1
	non-Māori	698	51	7.3	23	3.3	148	21.2	476	68.2
Pancreas	Māori	176	6	3.4	14	8.0	78	44.3	78	44.3
	non-Māori	1,735	54	3.1	169	9.7	698	40.2	814	46.9
Uterus	Māori	175	110	62.9	18	10.3	16	9.1	31	17.7
	non-Māori	1,570	949	60.4	266	16.9	161	10.3	194	12.4
Testis	Māori	174	108	62.1	33	19.0	16	9.2	17	9.8
	non-Māori	618	464	75.1	75	12.1	46	7.4	33	5.3
Ovary	Māori	163	73	44.8	8	4.9	71	43.6	11	6.7
	non-Māori	1,571	455	29.0	113	7.2	873	55.6	130	8.3
Kidney	Māori	138	57	41.3	30	21.7	34	24.6	17	12.3
	non-Māori	1,835	830	45.2	282	15.4	429	23.4	294	16.0
Thyroid	Māori	126	78	61.9	31	24.6	7	5.6	10	7.9
	non-Māori	787	437	55.5	204	25.9	53	6.7	93	11.8
Lip, oral cavity & pharynx	Māori	120	19	15.8	50	41.7	7	5.8	44	36.7
	non-Māori	1,575	413	26.2	470	29.8	80	5.1	612	38.9
Brain	Māori	119	101	84.9	2	1.7	2	1.7	14	11.8
	non-Māori	1,402	1,247	88.9	4	0.3	11	0.8	140	10.0
Melanoma of skin	Māori	100	82	82.0	7	7.0	7	7.0	4	4.0
	non-Māori	9,372	8,321	88.8	508	5.4	237	2.5	306	3.3
Mesothelial & soft tissue	Māori	97	16	16.5	7	7.2	18	18.6	56	57.7
	non-Māori	1,066	169	15.9	68	6.4	149	14.0	680	63.8
Oesophagus	Māori	91	1	1.1	10	11.0	18	19.8	62	68.1
	non-Māori	1,126	56	5.0	145	12.9	199	17.7	726	64.5
Bladder	Māori	85	4	4.7	8	9.4	7	8.2	66	77.6
	non-Māori	3,284	118	3.6	174	5.3	111	3.4	2,881	87.7

Unknown stage at diagnosis

Access to definitive cancer staging evaluation is an important component of cancer treatment, as stage at diagnosis can determine appropriate treatment options and thus affect quality, if not quantity of life for most cancers. Definitive diagnosis and staging "…informs estimates of prognosis, physician-patient communication about disease and treatment options, and the treatment decision-making process." (Mandelblatt, Yabroff, & Kerner, 1998). Disparities in registrations with unknown stage at diagnosis may therefore signal differential access to staging procedures, with a consequent impact on receipt of optimal cancer care.

This section compares the odds of being registered with unknown stage at diagnosis for Māori and non-Māori diagnosed between 1996 and 2001. Because age is positively associated with unknown stage at diagnosis (i.e. the older the age at diagnosis, the higher the chance of being registered with unknown stage), the odds ratios are adjusted for sex and age at diagnosis.

Table 10. Māori: non-Māori odds ratios for unknown stage at diagnosis 1996-2001

	Age-sex adjusted			
	OR	**(95% CI)**		**p value**
Trachea, bronchus & lung	1.41	(1.25,	1.58)	**<0.0001**
Breast (female)	1.29	(1.09,	1.53)	**0.004**
Prostate	0.90	(0.74,	1.09)	0.30
Colorectal	2.19	(1.70,	2.81)	**<0.0001**
Colon	1.71	(1.12,	2.60)	**0.01**
Rectum & anus	2.36	(1.70,	3.26)	**<0.0001**
Stomach	1.63	(1.24,	2.14)	**<0.001**
Cervix uteri	1.86	(1.34,	2.57)	**<0.001**
Liver & intrahepatic bile ducts	1.29	(0.88,	1.87)	0.19
Pancreas	1.31	(0.94,	1.82)	0.11
Uterus	2.13	(1.37,	3.29)	**<0.001**
Testis	1.98	(1.06,	3.72)	**0.033**
Ovary	1.01	(0.52,	1.94)	0.98
Kidney	1.40	(0.81,	2.44)	0.23
Thyroid gland	0.73	(0.37,	1.46)	0.38
Lip, oral cavity & pharynx	1.04	(0.70,	1.54)	0.85
Brain	1.90	(1.03,	3.51)	**0.041**
Melanoma of skin	1.30	(0.47,	3.55)	0.61
Mesothelial & soft tissue	0.91	(0.59,	1.42)	0.69
Oesophagus	1.79	(1.10,	2.91)	**0.02**
Bladder	0.52	(0.30,	0.87)	**0.014**

Among cancers registered during 1996-2001, Māori were significantly less likely than non-Māori to have stage recorded for cancers of the trachea, bronchus & lung, breast, colon, rectum & anus, stomach, cervix, uterus, testis, brain and oesophagus (Table 10). Bladder cancer was the only type for which non-Māori were more likely to be unstaged. Controlling for rurality and area deprivation made very little difference to these results.

For some cancers, controlling for age provided a different picture to the unadjusted proportions in Table 8. For example, using the unadjusted data, the proportion of Māori breast cancer registrations with no staging data (16%) was slightly lower than the non-Māori proportion (18%). Yet, after adjusting for age, Māori were 29% more likely than non-Māori to be unstaged, (odds ratio of 1.29). This reflects the higher proportion of non-Māori women whose breast cancer was diagnosed at age 65 years and over (38%) (the age group less likely to be staged) compared to the proportion of Māori (19%). Māori women diagnosed with breast cancer at younger ages appear less likely to be staged than their non-Māori counterparts of similar age.

Stage disparities

Table 9 compares the odds of being diagnosed at a localised or distant stage, among Māori and non-Māori whose cancer was staged on registration. Because there is an association between age and stage at diagnosis, the odds ratios are adjusted for age and sex.

Localised stage

Among cancers that were staged, Māori were significantly less likely than non-Māori to be diagnosed at a localised stage for cancers of the trachea bronchus & lung, breast, prostate, rectum & anus, cervix, testis, kidney, lip, oral cavity & pharynx, and melanoma.

Among those diagnosed with stomach cancer, Māori were more likely than non-Māori to be diagnosed at localised stage. No significant differences were evident for cancers of the liver, pancreas, uterus, ovary, thyroid, brain, mesothelial & soft tissue, oesophagus, or bladder.

Distant stage

Among those staged, Māori had significantly higher odds of being diagnosed at a distant stage of disease spread than non-Māori for cancers of the lung, breast, prostate, colon, rectum & anus, cervix, and melanoma.

There were no cancers where Māori were significantly less likely than non-Māori to be diagnosed at distant stage.

Table 9. Māori: non-Māori odds ratios for localised or distant stage at diagnosis, adjusted for age and sex, cancer registrations 1996-2001 (staged cancers only)

	Localised				Distant			
	OR	(95% CI)		p value	OR	(95% CI)		p value
Trachea, bronchus & lung	0.54	(0.40,	0.73)	**<0.0001**	1.63	(1.35,	1.96)	**<0.0001**
Breast (female)	0.71	0.62,	0.81)	**<0.0001**	1.89	1.44,	2.49)	**<0.0001**
Prostate	0.38	(0.26,	0.56)	**<0.0001**	5.89	(3.98,	8.72)	**<0.0001**
Colorectal	0.63	0.50,	0.81)	**<0.001**	1.66	1.34,	2.05)	**<0.0001**
Colon	0.74	(0.54,	1.00)	0.053	1.59	(1.22,	2.07)	**<0.001**
Rectum & anus	0.49	0.33,	0.72)	**<0.001**	1.80	1.26,	2.57)	**0.001**
Stomach	1.55	(1.05,	2.27)	**0.026**	1.15	(0.85,	1.57)	0.36
Cervix uteri	0.58	0.40,	0.86)	**0.006**	2.65	1.52,	4.62)	**<0.001**
Liver & intrahepatic bile ducts	1.57	(0.79,	3.09)	0.20	0.83	(0.43,	1.57)	0.56
Pancreas	0.75	0.30,	1.84)	0.53	1.69	0.99,	2.89)	0.055
Uterus	1.37	(0.91,	2.06)	0.13	0.99	(0.57,	1.73)	0.97
Testis	0.57	0.38,	0.86)	**0.007**	1.36	0.74,	2.51)	0.33
Ovary	1.29	(0.90,	1.85)	0.16	0.87	(0.61,	1.24)	0.43
Kidney	0.66	0.45,	0.97)	**0.033**	1.20	0.78,	1.82)	0.41
Thyroid	1.14	(0.75,	1.74)	0.54	0.96	(0.41,	2.20)	0.91
Lip, oral cavity & pharynx	0.44	0.25,	0.75)	**0.003**	1.15	0.51,	2.62)	0.74
Brain	0.54	(0.17,	1.77)	0.31	1.39	(0.28,	6.79)	0.68
Melanoma of skin	0.44	0.24,	0.78)	**0.005**	3.40	1.55,	7.46)	**0.002**
Mesothelial & soft tissue	0.64	(0.32,	1.31)	0.22	1.31	(0.65,	2.63)	0.45
Oesophagus	0.22	0.03,	1.66)	0.14	1.76	0.80,	3.85)	0.16
Bladder	0.56	(0.18,	1.74)	0.31	1.95	(0.72,	5.28)	0.19

For most cancers, stage at diagnosis has a major impact on chances of survival after diagnosis. Patients registered with unknown stage at diagnosis had higher mortality rates than those diagnosed at localised stage, but lower rates of death than those diagnosed when the disease had spread to distant organs or lymph nodes.

Māori cancer patients were less likely than non-Māori to have stage at diagnosis (or extent of disease) recorded on their cancer registrations. Knowledge of stage of disease spread is vital for deciding treatment options for many cancers. If Māori are less likely to have their cancer staged or have delays in staging, there is an urgent need to investigate how this is happening, how it may contribute to differential quality of care or pathways through care, and any consequent disparities in duration and/or quality of life.

Among those who received definitive cancer staging, the odds of being diagnosed at a late stage of disease was higher among Māori than non-Māori for many cancers, including those for which there are good screening and treatment options. These differences signal unequal access to screening, timely follow-up of abnormal findings, definitive diagnostic procedures and expertise. The next section considers the extent to which differential stage at diagnosis contributes to disparities between Māori and non-Māori in the risk of dying from the cancer once diagnosed.

STAGE AT DIAGNOSIS & CANCER SURVIVAL DISPARITIES

To estimate the impact of differential access to early diagnosis on cancer survival disparities between Māori and non-Māori we compared age-adjusted hazard ratios with hazard ratios also adjusted for stage at diagnosis (localised, regional, distant, unknown) (Table 11). The amount of reduction in the hazard ratio provides an estimate of the degree to which differential stage at diagnosis contributes to the higher Māori mortality risk.

Table 11. Relative risk of dying from cancer after diagnosis among Māori compared to non-Māori, cancer-specific hazard ratios 1996-2001

	Adjusted for age and sex		Adjusted for age, sex, & stage (including unstaged)		% reduction*
Site	**HR (95% CI)**	**p value**	**HR (95% CI)**	**p value**	
Trachea, bronchus & lung	1.34 (1.26, 1.43)	<0.0001	1.28 (1.20, 1.37)	<0.0001	18%
Breast	1.69 (1.44, 1.99)	<0.0001	1.48 (1.26, 1.73)	<0.0001	30%
Prostate	2.33 (1.94, 2.79)	<0.0001	1.7 (1.41, 2.04)	<0.0001	47%
Colorectal	1.67 (1.45, 1.93)	<0.0001	1.34 (1.16, 1.54)	<0.0001	49%
Colon	1.5 (1.24, 1.82)	<0.0001	1.24 (1.03, 1.51)	0.025	52%
Rectum & anus	2.04 (1.65, 2.53)	<0.0001	1.58 (1.28, 1.96)	<0.0001	44%
Stomach	1.57 (1.35, 1.83)	<0.0001	1.73 (1.49, 2.01)	<0.0001	-28%
Cervix	2.68 (2.00, 3.58)	<0.0001	2.34 (1.74, 3.15)	<0.0001	20%
Liver & intrahepatic bile ducts	1.39 (1.13, 1.70)	0.002	1.43 (1.16, 1.76)	0.0007	-10%
Pancreas	1.15 (0.97, 1.36)	0.12	1.14 (0.96, 1.36)	0.12	7%
Uterus	1.65 (1.15, 2.37)	0.007	1.85 (1.28, 2.67)	0.001	-30%
Testis	3.07 (1.36, 6.95)	0.007	3.16 (1.36, 7.38)	0.008	-4%
Ovary	1.02 (0.76, 1.36)	0.92	1.18 (0.88, 1.59)	0.26	-800%
Kidney	1.52 (1.13, 2.05)	0.006	1.36 (1.01, 1.84)	0.046	31%
Thyroid	1.18 (0.56, 2.47)	0.67	1.07 (0.51, 2.26)	0.86	61%
Lip, oral cavity & pharynx	2.07 (1.50, 2.84)	<0.0001	1.78 (1.30, 2.45)	0.0004	27%
Brain	1.16 (0.90, 1.49)	0.25	1.14 (0.89, 1.46)	0.31	13%
Melanoma of skin	1.19 (0.53, 2.67)	0.67	0.86 (0.38, 1.93)	0.72	174%
Mesothelial & soft tissue	1.66 (1.19, 2.32)	0.003	1.68 (1.20, 2.36)	0.003	-3%
Oesophagus	1.74 (1.37, 2.22)	<0.0001	1.67 (1.31, 2.13)	<0.0001	10%
Bladder	2.37 (1.59, 3.52)	<0.0001	1.95 (1.31, 2.90)	0.001	31%

* reduction was calculated as follows: (age-adjusted HR – age & stage-adjusted HR) / (age-adjusted HR-1). Negative values indicate that adjusting for stage increased the hazard ratio.

Even after adjusting for stage, the excess cancer-specific mortality risk among Māori patients compared to non-Māori cancer patients remained significant for most types of cancer (lung, breast, prostate, colorectal, stomach, cervix, liver, uterus, testis, kidney, oral cancers, mesothelial, oesophagus and bladder). This implies that improving access to early detection alone will not be enough to eliminate mortality disparities.

Nevertheless, differential stage at diagnosis does contribute to some cancer disparities. In particular, adjusting for stage **reduced** the hazard ratios for cancers of the lung, breast, prostate, colon, rectum, cervix, kidney, lip, oral cavity & pharynx, and bladder.

For some cancers adjusting for stage at diagnosis **increased** the hazard ratios. These included cancers of the stomach, liver, uterus, and testis. Apart from testicular cancer, these are cancers where Māori had a favourable distribution of stage at diagnosis compared to non-Māori. Therefore, for these particular cancers, stage at diagnosis is not contributing to the excess mortality disparities for Māori.

There was **no significant difference** between Māori and non-Māori in the risk of cancer-specific mortality for cancers of the pancreas, ovary, brain, thyroid and melanoma, in either the age-adjusted or stage-adjusted ratios.

Staged cancers only

Restricting the analysis to those whose registration included stage at diagnosis resulted in generally similar findings, although the reductions or increases from adjusting for stage were generally larger than those observed when unknown stage was included as a stage category.

For some cancers, stage at diagnosis accounted for quite substantial proportions of the excess Māori mortality risk – around three-quarters of the prostate cancer survival disparity, half of the colorectal, and around 40% of the lung and breast cancer differentials. Other cancers that showed a decrease in hazard ratios include pancreas, lip, oral cavity & pharynx, oesophagus, and bladder.

Adjusting for stage increased the relative risks for cancers of the stomach, liver, cervix, uterus and ovary, and made no difference for cancers of the pancreas, brain or mesothelial and soft tissue.

It should be noted that this analysis includes a substantially smaller group of people – especially for the cancers with a high proportion of unstaged registrations (e.g. prostate, lung, liver). Because only those who received access to staging procedures are represented in this table, the findings will not necessarily reflect the experience of the whole group of cancer patients.

However, as noted above, adjusting for stage among this smaller group of staged cancers only partially reduced the inequalities in mortality after diagnosis.

Table 12. Māori/non-Māori Hazard Ratios adjusted for sex and age at diagnosis, and for stage (staged cancers only)

	adjusted for age and sex			adjusted for age, sex & stage			%
Site	HR	(95% CI)	P value	HR	(95% CI)	p value	reduction
Trachea, bronchus & lung	1.48	(1.34, 1.62)	<0.0001	1.28	(1.17, 1.41)	<0.0001	42%
Breast	1.61	(1.34, 1.92)	<0.0001	1.37	(1.15, 1.64)	0.0006	39%
Prostate	2.25	(1.74, 2.92)	<0.0001	1.33	(1.02, 1.73)	0.034	74%
Colorectal	1.61	(1.37, 1.88)	<0.0001	1.27	(1.08, 1.48)	0.003	56%
Colon	1.48	(1.21, 1.82)	0.0002	1.21	(0.99, 1.49)	0.066	56%
Rectum & anus	1.98	(1.54, 2.55)	<0.0001	1.48	(1.15, 1.90)	0.002	51%
Stomach	1.49	(1.24, 1.80)	<0.0001	1.8	(1.49, 2.18)	<0.0001	-63%
Cervix	2.9	(1.85, 4.54)	<0.0001	3.1	(1.93, 4.99)	<0.0001	-11%
Liver & intrahepatic bile ducts	1.52	(1.03, 2.26)	0.037	1.73	(1.15, 2.60)	0.009	-40%
Pancreas	1.32	(1.04, 1.66)	0.02	1.27	(1.01, 1.61)	0.04	16%
Uterus	1.52	(1.00, 2.31)	0.051	1.96	(1.28, 2.99)	0.002	-85%
Testis	3.35	(1.43, 7.86)	0.005	3.41	(1.41, 8.26)	0.007	-3%
Ovary	1.05	(0.78, 1.42)	0.73	1.28	(0.95, 1.72)	0.11	-460%
Kidney	1.37	(0.99, 1.92)	0.061	1.23	(0.88, 1.73)	0.22	38%
Thyroid	1.33	(0.63, 2.82)	0.46	1.18	(0.55, 2.53)	0.67	45%
Lip, oral cavity & pharynx	2.37	(1.62, 3.46)	<0.0001	1.95	(1.33, 2.85)	0.0006	31%
Brain	1.11	(0.84, 1.46)	0.45	1.1	(0.83, 1.45)	0.51	9%
Melanoma	1.07	(0.44, 2.58)	0.88	0.76	(0.32, 1.85)	0.55	443%
Mesothelial & soft tissue	1.71	(1.04, 2.83)	0.036	1.69	(1.00, 2.87)	0.051	3%
Oesophagus	2.88	(1.94, 4.28)	<0.0001	2.22	(1.49, 3.30)	<0.0001	35%
Bladder	1.97	(1.07, 3.65)	0.031	1.64	(0.88, 3.04)	0.12	34%

* reduction was calculated as follows: (age-adjusted HR – age & stage-adjusted HR) / (age-adjusted HR-1). Negative values indicate that adjusting for stage increased the hazard ratio.

Hazard ratios by stage at diagnosis

The hazard ratios presented above are a weighted average of the relative risk of death of Māori patients compared to non-Māori patients, across stage categories. They are affected by the relative distribution of stage at diagnosis, as well as the relative risk of death in each stage category. The stage-group with the highest number of deaths (usually the distant stage category) contributes the most weight to the overall hazard ratio (rather than the stage-group with the largest number of people). In order to examine differences in outcomes between Māori and non-Māori within each stage category, we calculated Māori/non-Māori hazard ratios separately for each stage at diagnosis, adjusted for sex and age at diagnosis (Table 13).

The overall pattern is one of higher case fatality among Māori at each stage compared to non-Māori at the same stage. However, the hazard ratios are generally more accurate for the group diagnosed at distant stage of disease spread (with the narrowest confidence intervals) and less accurate for the localised stage group, where the number of deaths is relatively low resulting in wide variance on the hazard ratio.

Table 13. Māori:non-Māori Hazard Ratios 1996-2001 (relative risk of death after diagnosis) by stage of disease spread at diagnosis (adjusted for sex and age at diagnosis)

	Localised			Regional			Distant			Unknown Stage		
	HR	(95% CI)	p value	HR	(95% CI)	p value	HR	(95% CI)	p value	HR	(95% CI)	p value
Trachea, bronchus & lung	1.95	(1.20, 3.16)	0.007	1.67	(1.35, 2.07)	<0.0001	1.20	(1.07, 1.33)	0.001	1.30	(1.18, 1.42)	<0.0001
Breast	1.76	(1.16, 2.68)	0.008	1.35	(1.05, 1.73)	0.021	1.26	(0.90, 1.75)	0.17	1.97	(1.39, 2.80)	0.0002
Prostate	0.46	(0.06, 3.59)	0.46	1.26	(0.31, 5.18)	0.75	1.30	(0.99, 1.72)	0.061	2.05	(1.58, 2.65)	<0.0001
Colorectal	2.49	(1.27, 4.87)	0.008	1.51	(1.18, 1.93)	0.001	1.08	(0.87, 1.33)	0.50	1.80	(1.30, 2.50)	0.0004
Colon	2.94	(1.29, 6.74)	0.011	1.37	(0.98, 1.92)	0.063	1.06	(0.81, 1.40)	0.65	1.48	(0.86, 2.56)	0.16
Rectum & anus	1.96	(0.62, 6.20)	0.25	1.83	(1.27, 2.65)	0.001	1.18	(0.82, 1.69)	0.38	2.28	(1.50, 3.47)	0.0001
Stomach	2.51	(1.37, 4.60)	0.003	1.67	(1.24, 2.25)	0.0007	1.65	(1.26, 2.15)	0.0003	1.75	(1.35, 2.27)	<0.0001
Cervix	4.27	(0.66, 27.52)	0.13	2.05	(0.89, 4.76)	0.094	3.21	(1.71, 6.01)	0.0003	2.11	(1.42, 3.13)	0.0002
Liver & intrahepatic bile ducts	1.30	(0.56, 3.05)	0.54	4.73	(0.76, 29.46)	0.096	1.67	(0.98, 2.85)	0.061	1.34	(1.05, 1.70)	0.019
Pancreas	1.29	(0.14, 12.08)	0.82	1.40	(0.74, 2.67)	0.30	1.31	(1.02, 1.69)	0.034	1.04	(0.80, 1.35)	0.79
Uterus	1.64	(0.79, 3.39)	0.19	2.63	(1.22, 5.69)	0.014	1.41	(0.68, 2.92)	0.36	2.14	(1.01, 4.53)	0.048
Testis	6.17	(1.05, 36.32)	0.044	1.70	(0.23, 12.90)	0.61	6.42	(1.38, 29.80)	0.018			
Ovary	1.02	(0.30, 3.45)	0.97	0.87	(0.26, 2.87)	0.82	1.37	(1.00, 1.89)	0.053	0.71	(0.17, 3.01)	0.65
Kidney	1.91	(0.74, 4.90)	0.18	1.43	(0.71, 2.90)	0.32	1.06	(0.70, 1.61)	0.79	3.16	(1.56, 6.43)	0.001
Thyroid gland	1.81	(0.20, 16.70)	0.60	1.32	(0.36, 4.86)	0.68	1.57	(0.46, 5.39)	0.47			
Lip, oral cavity & pharynx	5.29	(2.00, 14.03)	0.0008	1.62	(1.02, 2.57)	0.040	2.64	(0.97, 7.16)	0.056	1.72	(0.94, 3.14)	0.079
Brain	1.11	(0.83, 1.48)	0.47				6.67	(0.40, 111.24)	0.19	1.74	(0.90, 3.36)	0.10
Melanoma	0.40	(0.06, 2.85)	0.36	3.15	(0.76, 13.01)	0.11	0.50	(0.12, 2.06)	0.34	3.32	(0.43, 25.69)	0.25
Mesothelial & soft tissue	1.50	(0.45, 4.96)	0.51	3.80	(1.11, 12.97)	0.033	1.54	(0.76, 3.12)	0.23	1.80	(1.14, 2.85)	0.012
Oesophagus	29.89	(2.23, 399.97)	0.010	5.20	(2.55, 10.60)	<0.0001	1.62	(0.99, 2.66)	0.055	1.38	(1.01, 1.89)	0.043
Bladder	3.50	(0.78, 15.71)	0.10	2.89	(0.95, 8.77)	0.062	1.36	(0.52, 3.54)	0.53	2.45	(1.45, 4.12)	0.0008

Among those diagnosed at localised stage, the risk of death was significantly higher among Māori for cancers of the lung, breast, colon, testis, stomach, lip, oral cavity & pharynx, and oesophagus. Although we cannot say that the hazard ratios are significantly different between stages, for many of these cancers, the hazard ratio was highest for the localised stage-group. This raises the possibility that disparities in pathways through care are having a cumulative effect – such that non-Māori diagnosed at localised stage may have a more timely, more effective treatment pathway than Māori diagnosed at an early stage.

The hazard ratios appear to be high at each stage, even the localised stage, particularly for those cancers with good treatment options. Thus improving early detection will assist in reducing cancer outcome disparities, but if it is the sole focus of intervention, cannot eliminate them. The entire treatment pathway requires serious attention.

SUMMARY

Data on Māori cancer has previously not been comprehensive or complete. Issues with the quality of ethnicity data on cancer registrations and deaths have been addressed in this project through using an 'ever Māori' method of ethnicity classification. The analysis presented in this section demonstrates differences in the leading sites for cancer incidence and mortality between Māori and non-Māori that may affect cancer priorities. In addition, the data shows that while Māori are 18% more likely to be diagnosed with cancer than non-Māori overall, they are almost twice as likely to die from cancer. Cancer-specific survival is also lower for Māori than non-Māori for most cancer sites.

The assessment of staging data highlights differences between Māori and non-Māori in stage distribution, including higher likelihood for Māori to have unstaged cancer registrations for a number of cancers. Although stage does account for some of the cancer-specific survival disparity, Māori cancer-specific mortality after diagnosis is higher for Māori at each stage for many cancers. This suggests the likely existence of disparities between Māori and non-Māori in timely access to definitive diagnostic procedures, staging procedures and optimal treatment or management of cancer.

ACCESS TO HEALTH SERVICES

CONCEPTUALISING ACCESS TO SERVICES

> The process of gaining access to care represents dynamic interactions of diverse individuals in their social context interfacing with health care providers, who, in turn, are operating in a variety of changing, and often constrained medical care structures and environments (Mandelblatt et al 1999: 3).

Definitions of access to health care have often emphasised utilisation of health services by individuals and population groups. For example, the glossary of the CCS(NZ) refers to access as "…the ability of people to reach or use health services. Barriers to access may be influenced by: (1) a person's locality, income or knowledge of services available; (2) the availability or acceptability of existing services" (Ministry of Health, 2003). Access has been further defined as the "…timely use of personal health services to achieve the best possible health outcomes" (Millman, 1993). This definition from the Institute of Medicine broadens the concept of access to incorporate timeliness and outcomes, as well as the process of obtaining care in itself. Access has also been conceptualised in terms of 'levels of access' – primary, secondary, and tertiary - that incorporates the idea of access through, as well as access to, health care services (Bierman, Silverman Magari, Jette, Splaine, & Wasson, 1998). In this framework, primary access represents gaining entry to the system, while secondary access refers to navigating through the system and its structural barriers. The third aspect, tertiary access, relates to the "ability of the providers and of the system to understand and address specific needs" (Bierman et al., 1998). A number of other frameworks and models of access to care have also been developed in recent decades (Andersen, 1995; Lurie, 2002; Millman, 1993).

For the purposes of this report, access is conceptualised as multidimensional and multilevel. That is, access is about obtaining entry into **and** through health services, and encompasses the timeliness and quality of both the process and the outcomes (i.e. how health services were used and what was achieved).

Health care often involves multiple care pathways and is provided by a wide range of individuals, organisations and services. This is particularly the case for cancer care. Identifying the factors influencing access to services, and the various points of the cancer care continuum at which they impact, is therefore relatively complex. Contributing factors can be analysed at three broad levels: health system level, health care process level, and at the level of the patient or population and context (Mandelblatt et al., 1998; Panel on Racial and Ethnic Disparities in Medical Care, 2003; Shavers & Brown, 2002; Smedley, Stith, & Nelson, 2002; Zapka & Lemon, 2004).

Health system factors include those associated with the medical care system in the broader sense, as well as specific health institutions. A number of health system-level factors have been identified in the literature as contributing to access to cancer services, including funding policies, resources, service organisation and configuration, physical accessibility of services, waiting times, and cost (Mandelblatt et al., 1998; Mandelblatt, Yabroff, & Kerner, 1999; President's Cancer Panel, 2001). In New Zealand, the cultural appropriateness of services, the 'universal' focus of the health system, and workforce issues have also been identified as system level factors that influence access to health care for Māori (Baxter, 2002).

At the *health care process* level, factors influencing access may include the way in which services and providers operate and how they work together and communicate with each other. In addition, the characteristics of physicians or providers themselves, such as age, gender, training and competence, communication skills, values, attitudes and biases, have been identified as being associated with access (Mandelblatt et al., 1998). Physician/provider factors play an important role in the recommendations that are made about cancer care for their patients, which have been consistently shown to be associated with receipt of cancer services for patients (Mandelblatt et al., 1998). A further important part of the *health care process* is patient-provider interaction. This interaction has the potential to affect not only the quality and extent of information sharing and therefore decision-making and recommendations, but can have influence beyond the consultation itself.

Patient-level factors that have been associated with access include demographic characteristics, socioeconomic position, access to transportation, knowledge, attitudes and beliefs, patient resources and context, and patient decision-making/preferences (Baxter, 2002; Mandelblatt et al., 1999; Shavers & Brown, 2002). Patient-level characteristics may represent the cumulative effects of discrimination from multiple areas (B Robson & Reid, 2001), or conversely, cumulative privilege. Discussions of access have often tended to concentrate on patient or population level attributes.

At each level, factors can potentially function as barriers or facilitators. Furthermore, at any one time it is possible for a number of these factors to be operating to influence access, or combining to mediate and/or compound barriers.

The implication of a multi-dimensional view of access for discussing Māori access to cancer care services is that it allows for a more comprehensive understanding of issues and the way in which factors interact to impact on access. It also encourages a concept of access that does not simply focus on attributes of individuals and communities, thereby moving away from deficit or 'victim-blame' discourses of access.

DISPARITIES IN ACCESS TO HEALTH SERVICES

Access to high quality, timely, affordable and appropriate health care is vital, especially for populations with less than optimum health status. Ensuring "timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay" is a principle of both the *New Zealand Health Strategy* and the *New Zealand Cancer Control Strategy* (Ministry of Health, 2003).

Inequities in access to health care can manifest as systematic differential experiences and health outcomes among population groups (Millman, 1993). In New Zealand, the systematic disparities in health outcomes between Māori and non-Māori suggest persistent inequities in access to health care. However, while there is substantial international evidence of disparities, work on unequal access to health care in New Zealand is relatively new and not yet comprehensive. Nevertheless, disparities in access to health care between Māori and non-Māori have been demonstrated across the health care sector, in terms of both gaining entry into services and differential experience of services (including quality, appropriateness and timeliness of care).

Although information on access to primary health care by ethnicity has been incomplete, there is some research indicating different patterns of utilisation of primary health services (Davis, Lay-Yee, Sinclair, & Gribben, 1997; Ministry of Health, 2004c). This includes results from the 2002/03 New Zealand Health Survey that showed Māori males were significantly less likely to report having visited a general practitioner in the last 12 months compared with European/Other males, and that report of unmet need was significantly higher in Māori females than European/Other females (Ministry of Health, 2004c). The Commonwealth Fund 2001 International Health Policy Survey also found higher report of problems with access to health care for Māori than Europeans that persisted after controlling for income (Schoen et al., 2002).

A number of barriers to access to primary care for Māori have been identified (Crengle, 2000). The development and success of Māori providers has in part been in response to inequalities in access to mainstream primary care services (in terms of utilisation, appropriateness, quality and outcomes).

In secondary care, differential access is reflected in disparate rates of hospitalisation, access to specialists and access to procedures or interventions. For example, European/Other males and females were significantly more likely than other groups, including Māori, to report visiting a specialist in the last 12 months (Ministry of Health, 2004c). Differences in receipt of interventions for heart disease have been identified in New Zealand. Tukuitonga et al found that Māori were less likely to receive coronary artery revascularisation in the 1990s, in spite of higher rates of morbidity and mortality from coronary artery disease (Tukuitonga & Bindman, 2002). Westbrooke et al also found lower rates of intervention for Māori, in contrast to high rates of hospitalisation for heart failure (Westbrooke, Baxter, & Hogan, 2001). Recent research has reported that Māori are more likely to be admitted to hospitals without cardiac interventional facilities, which is in turn associated with receiving less investigations and interventions (Ellis et al., 2004).

The relationship of socio-economic status with access to health care in New Zealand has also been documented (Schoen et al., 2002; Schoen et al., 2004). For example, cost has been reported as an issue in gaining access to primary care. The Commonwealth Fund Primary Health Care Survey found that 28% of New Zealand respondents reporting not getting medical care, not getting recommended 'medical test, treatment, or follow-up' (20%), or not filling a prescription/skipping doses (11%), because of cost (Schoen et al., 2004). However, the interaction of socioeconomic status and ethnicity is complex, and disparities persist even when socio-economic position has been taken into account (Howden-Chapman & Tobias, 2000; Reid, Robson, & Jones, 2000; Williams, 1997).

The Ministry of Health's Intervention Framework for Reducing Inequalities posits that policies that impact differentially on the Māori and non-Māori populations at the structural level (e.g. labour market policy, tax policy, welfare policy) produce inequalities in the distribution of intermediary factors (e.g. income, education, housing, employment status, occupation, physical and social environment). These in turn affect health status and the need for health care, as well as producing differential access to and quality of health service receipt (Ministry of Health, 2002). In addition, within the health sector itself, disparities in access can arise from policies and practices that directly discriminate against Māori, such as bias, stereotyping and racism, as well as through practices and policies that have a differential impact on Māori (differential effect discrimination). In this sense, policies and practices without discriminatory intent can have a discriminatory effect on Māori [2].

Disparities in access to cancer services therefore need to be viewed within the context of disparities in access to health services in general, as well as in the broader social inequalities in New Zealand that are a reflection of entrenched disparities in access to resources and power.

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[2] Differential effect discrimination has been defined as "…*treatment on the basis of inadequately justified factors other than race* that disadvantages a racial group (differential effect)" (Blank, Dabady, & Citro, 2004: 39). For example, a policy that excluded smokers from participating in a programme or treatment, where smoking was not adequately justified as a reason for exclusion, would be likely to impact disparately on Māori and non-Māori due to the different distribution of smoking within the populations.

ACCESS TO CANCER SERVICES FOR MĀORI

In terms of access to cancer services, cancer control policy and literature in New Zealand makes reference to cancer service access issues, such as cost, waiting times for treatments and geographical inequities, however, there is limited in-depth discussion of these. Further, there is a relative dearth of information relating specifically to Māori. The information on access to cancer services for Māori from the literature and from interviews with providers and key informants is summarised in the next section. The project was concerned with identifying the range of views on access to cancer services for Māori. The themes presented in this section are therefore not quantified, but are intended to give a broad overview of access issues that will inform future work and identify areas for further investigation.

Overseas work on access to cancer care has suggested that there are factors that have the potential to influence access across the full cancer care continuum, as well as factors with particular impact or relevance at one point of the cancer care pathway (Mandelblatt et al., 1998). This section firstly outlines factors impacting on access for Māori at all phases of cancer care. Access issues with particular pertinence to specific points of the cancer care continuum are then discussed. The three levels of factors previously identified (health system, health care process, and patient-level factors) as a framework to guide discussion.

HEALTH SYSTEM FACTORS

A number of key factors with the potential to influence access to cancer services for Māori that related to the system itself, both the broader health system and the more specific cancer care environment, were identified. These include the focus of the system and services, funding and resources, service configuration and location, workforce, availability of information and resources, and cost.

The focus of the cancer care system and services

The focus of the health system in New Zealand, including the cancer care environment, has tended to be on the total population. Consideration of Māori priorities and inequalities in health has been relatively recent. The importance of the development of effective cancer control policy for Māori was noted by some providers, as was the need for a cancer care system that supports a focus on Māori.

> Health services are Western-based…Pākehā middle class targeted.

Providers identified a lack of services specifically designed to meet the needs of Māori with cancer such as Kaupapa Māori cancer interventions (including Māori healing such as mirimiri and the integration of traditional medicines) and inadequate Māori-specific cancer services or service components. The need to enhance Māori specific services or service components (such as integrating Māori expertise and advice, locating services in Māori settings, and incorporating te reo Māori) and to address institutionalised racism was also identified.

> Patients can't take whānau with them to treatment…the system doesn't accommodate the whānau approach.

Concerns were also raised that currently funded mainstream cancer services do not always support a whānau-based approach to cancer care, with some providers indicating low recognition by cancer services of the important role of whānau. Services were not always seen to be geared towards providing opportunities for whānau input and participation, facilitating whānau access to appropriate information, or providing adequate support for whānau. This could be reflected in the policies and practices of services, as well as in physical facilities, such as not having enough space for whānau to accompany patients to treatment.

Cancer service funding and resources

The focus of cancer care service delivery is closely associated with the way in which services are funded and what they are contracted to provide. In publicly funded cancer care, as in other areas of the health sector, services are operating under resource and funding constraints. Some providers raised timely access to diagnosis and treatment services as an issue. Delays in access to treatment and a lack of appropriate resources (including equipment and workforce) have been particularly apparent in relation to radiotherapy in recent years. Although the Ministry of Health routinely monitors waiting times for radiotherapy, data are not reported by ethnicity and it is therefore not possible to determine the impact of delays in access to radiotherapy for Māori. Resource and funding issues have also been identified in relation to other care services (Expert Working Group on Palliative Care, 2003; Expert Working Group on Treatment, 2003; Ministry of Health, 2001).

Funding and resources to facilitate access to cancer services vary throughout the system. A number of Māori providers indicated that they were providing services that they were not funded or contracted for in order to address gaps in cancer service provision, such as providing transportation and support for cancer patients and their whānau. The un-contracted nature of this provision means that there is no guarantee of continuity for either providers or communities.

> We have no public transport to service the needs of our community. We are at least one to two hours away from cancer treatment centres…NGOs like ourselves whose focus is clients first are left to provide this service without any inclusion of transport in our current contracts. Without this service clients have stated they would be less likely to attend appointments.

The availability of entitlements and the differential access to entitlements by region were described as barriers to access. Providers related difficulties their clients had experienced in accessing financial support for travel or other service entitlements, such as home help and frustration at the time involved in obtaining resources or entitlements for patients. Entitlements often depend on particular contractual and funding arrangements within DHBs, as well as the policies of agencies outside of the health sector (such as WINZ for financial assistance, carer relief and so on). It was noted that although cancer is debilitating, it is not usually recognised by WINZ as a disability and there is therefore no disability entitlement (Ministry of Health, 2003).

The indication by some services that they would require additional funding to increase accessibility to Māori suggests that there may be a view that meeting the needs of Māori is something that is done in addition to meeting the needs of the total population (who are largely non-Māori) rather than a core component of service provision.

The configuration and location of cancer care services

> Geographical area means that patients are sometimes separated from whānau.

Decisions about the configuration of cancer services are intrinsically bound up with fiscal considerations. Geographic inequity in access to cancer services in New Zealand has been noted along the cancer care continuum (Expert Working Group on Palliative Care, 2003; Expert Working Group on Support and Rehabilitation, 2003; Ministry of Health, 2001), relating to the differential availability of resources by region as well as the concentration of cancer services in metropolitan areas. Geographic inequity has the potential to impact disparately on Māori due to differences in the geographic distribution of the Māori population. A recent study of geographical access to general practitioners found Territorial Authorities (TAs) with higher Māori populations had less access to GP services (measured by average travel times) (Brayban & Barnett, 2004).

In recent years, the configuration of services, particularly cancer treatment services, has become increasingly specialised and centralised. The geographical location of services was consistently raised as an important factor contributing to access, particularly for those living in rural or remote communities. Some providers identified a preference for local service provision, which would enable more accessible regional coverage, and concerns were raised about the extensive geographical coverage of some services, including small providers. The geographical location of services was also seen to potentially undermine a whānau-based approach to cancer service delivery.

The cancer care workforce

> Need more Māori employed within the services…bigger commitment to workforce development in terms of staffing and working with Māori.

Issues with the cancer care workforce were identified by providers and in the literature as being associated with access to cancer services for Māori (Ministry of Health, 2003; Ratima, 2002). The limited numbers of Māori working in all areas of cancer care and the perceived inability of the current cancer care workforce to respond adequately and competently to Māori patients and their whānau were described. Some providers raised concerns that the cancer workforce was not culturally safe or culturally competent in general and strongly emphasised the need for enhanced workforce responsiveness. In addition, the need to actively develop the Māori cancer workforce and to ensure Māori participation at all levels, including the governance level, was noted. There was also a concern regarding the pressure on Māori working within cancer care, particularly in terms of taking on responsibility for Māori issues. These issues are in line with concerns regarding the health sector workforce in general.

Availability of information

The availability of cancer information, and in particular, information designed to meet the needs of Māori patients and their whānau, was consistently noted as an issue. The need for appropriate information on cancer and treatment options for patients and their whānau, as well as information on the range of entitlements and services available, was identified by providers and in the literature. A 1999 study of the information and support needs of Māori affected by cancer identified a desire for improved information that was comprehensive, practical and appropriate, including information on complementary treatment options such as rongoa and mirimiri. The need for the information to be appropriately delivered was also noted (Kokiri Seaview Marae, 1999). Issues with the availability, relevance and appropriateness of information for Māori were also raised in the 2002 Patiki Report for the Cancer Society (Patiki Associates, 2002) and in provider and key informant comments. Some providers also expressed concern over negative connotations in some of the information aimed specifically at Māori.

In addition to information provided through public sector health services, NGO organisations often have an important role in the provision of cancer information. Access to and quality of information is therefore likely to vary by region, as well as by other factors, such as cancer type and profile.

Expense of cancer care

The cost of cancer-related travel, accommodation, and family expenses were identified by providers as major generic barriers to service access. The significant financial burden of childhood cancer has been previously reported in New Zealand (Dockerty, Skegg, & Williams, 2003). Treatment can often involve travel to regional cancer centres, which has a number of associated costs particularly for those living in provincial or rural areas. Although there is some availability of funding for travel, the arrangements tend to vary by region and/or organisation. In many cases, travel expenses are addressed by partial reimbursement. This means that cancer patients and whānau are met with up-front costs, which can often be significant. There is also variable availability of financial support for accommodation and other cancer-associated costs. At times, this is dependent on gaining access to NGO organisations.

Regional differences in availability of cancer services can mean that whānau pick up the cost of care that would be covered in other regions, such as where in-patient hospice services are available. There is also concern that caring for family at home involves significant expense for whānau that is not adequately recognised or addressed through current reimbursement or entitlement arrangements.

In addition, the direct costs of cancer services, such as cervical smears offered through primary care, or private services for early detection and treatment, can influence access. Results from the Commonwealth Fund International Health Policy Survey 2004 have indicated that cost is a factor that can influence access to consultations, recommended tests, treatments or follow-ups, and medication in primary care (Schoen et al., 2004). There may also be perceptions that free services, such as hospice services, have a cost associated with them.

HEALTH CARE PROCESS FACTORS

The way that services operate and work with other services, characteristics of physicians/providers such as training, competence, perceptions and biases, and patient-provider communication, are factors with the potential to impact on access to cancer services for Māori identified in this project.

The processes and practices of services

The cancer care pathway often involves multiple providers and organisations. This increases the potential for duplication and/or gaps in service provision. Efficient cancer care requires effective communication and coordination between services. The timeliness and adequacy of information sharing between services was identified by some providers as an issue. Services could experience delays in receiving information about patients undergoing investigation or treatment in other services or regions.

Issues with 'care coordination' in New Zealand in general have been identified in the Commonwealth Fund Survey of sicker adults. Care co-ordination concerns included respondents reporting medical records or test results not reaching the doctors' office in time for an appointment (16%), being sent for duplicate tests or procedures (17%) or receiving conflicting advice (23%) from different professionals (Blendon, Schoen, DesRoches, Osborn, & Zapert, 2003). In a similar survey of adults conducted by the Commonwealth Fund in 2004, the figures were 13%, 7% and 14% respectively (Schoen et al., 2004).

> Lack of good discharge planning to ensure that the client receives the best quality follow-up care, both clinical and support…when they come home

The need for comprehensive discharge planning, taking into consideration whānau, relevant support services, and links with Māori providers (both iwi and Māori community based) was seen to be important to access for Māori. Processes for referral to treatment and support services, including NGOs and hospices, varied between providers. Informalised procedures for referral may increase the potential for inequities in information about, and access to, services and entitlements, as decisions can become discretionary rather than routine.

Training and socio-cultural competence

Access for patients and their whānau can be influenced by the training and competence of those involved in the delivery of cancer services (Mandelblatt et al., 1999). In terms of Māori access, this could include training relating to cancer control, Māori health, and health inequalities. The training and competence of those working in cancer care was seen by some providers to influence Māori access to cancer services. In particular, a number of providers identified the cultural competency and safety of those involved in delivering cancer services as an issue, including inadequate training and a lack of understanding. These concerns were closely related to those expressed about the cancer workforce in general, as well as to concerns about the training and socio-cultural competence of the 'mainstream' health workforce.

Provider perceptions and biases

Provider perceptions and biases have the potential to impact upon access for patients to a range of services (Mandelblatt et al., 1999). There is some evidence of stereotypes about Māori held by health professionals (Johnstone & Read, 2000; McCreanor & Nairn, 2002; McLeod et al., 2004) including stereotypes around late presentation, non-compliance and treatment preferences. These perceptions have the potential influence patient-provider interactions and provider recommendations for treatment and care. For example, perceptions of Māori preferences regarding palliative care and dying at home may influence access for Māori patients to hospice services. A concern that assumptions may be being made about Māori wanting to be cared for by whānau was identified in the Patiki report (Patiki Associates, 2002).

Communication and patient-provider interaction

> Make sure there is communication between doctors, community nurses, patients and whānau. More public awareness so people can be in control of their own outcome. Patient and whānau need to have control over what is going on

In talking with providers, the level of public knowledge of cancer and cancer services was seen as a key factor influencing access in general. In part, this was seen to be related to poor communication on the part of cancer services and providers, which could in turn contribute to fear of cancer and inadequate information on care and service options. There were issues with both the adequacy and appropriateness of information provided to cancer patients and their whānau, as well as the way in which the information was provided. The need for strategies to improve communication between providers and patients was emphasised, including providing more effective cancer and cancer service related information to Māori.

Some providers expressed the view that Māori are the most effective 'messengers' for delivering cancer-related information to Māori, and the need to work with whānau and communities in effective information provision was noted. Some responses also indicated that the availability of specialised Māori advice would be important to ensure that cultural issues that have the potential to impact on patient-provider communication were addressed.

PATIENT-LEVEL FACTORS

At the patient level, there are a number of factors that can influence access to care. This is the level at which discussions of access to health care for Māori have often focused. Factors identified in the literature and from providers as being related to Māori access to cancer services at a patient or population level are discussed below.

Socioeconomic position

> Poverty makes transport difficult…hard to get time off work

The relationship of socioeconomic position with access to cancer services is consistently identified by providers and in the literature, often alongside other inter-related factors such as cost, transportation, accommodation and travel requirements. Socioeconomic deprivation in New Zealand is strongly associated with ethnicity, with Māori distribution skewed towards the most deprived. The association of socioeconomic deprivation with access to cancer care services is therefore likely to discriminate against Māori through differential impact.

Employment is a related factor that has the potential to influence access to cancer services. For example, leave entitlements and flexibility in working hours and conditions may impact upon a person's ability to attend screening appointments or undertake treatment regimes (which can often involve concentrated periods of time) as well as their family members' abilities to provide support and care, including when travel is required for treatment. Māori and non-Māori in New Zealand have differential distribution within the workforce. In addition, there is evidence of lower Māori incomes (Robson, 2004).

Insurance status is associated with the ability to access services through the private sector that may provide for more timely access to cancer services or increased choice in terms of the provider and institution. Māori have lower rates of health insurance than non-Māori, across all age groups and labour force status groups (Te Puni Kōkiri, 2000). This in turn impacts on the ability to access services privately across the cancer continuum. Other insurances, such as income protection insurance and life insurance/living assurance may also be important in influencing access to cancer services, as some policies have provisions for pay out on diagnosis of certain conditions.

Transportation and travel

> People don't have cars or warrants and registrations … can't get to the doctor.

Transportation is consistently identified as a barrier to access of cancer services. This is in terms of both access to a vehicle as well as the availability and affordability of public transportation. Providers identified that even when services were located in the same city transport can remain a barrier, particularly for those of lower socioeconomic groups. Transportation is closely associated with other barriers of cost and geographic isolation, which compound each other and are inter-linked. Transportation issues may be mediated by service policies and components, such as providing travel grants, reimbursing travel costs, and supplying drivers. Transportation and travel arrangements vary by service and region. Where policies are based on reimbursement, patients are required to pay up-front costs, which may be substantial. Māori access to drivers, grants and other forms of travel assistance provided through NGOs is not known.

Patient values, preferences and context

Patient values, preferences and context have been identified as being associated with access to cancer services in general. For example, access may be influenced by the extent to which patient values or preferences are reflected in services or treatment options available to them. Perceptions and previous experiences of cancer and cancer services, or of the health system in general, also have the potential to influence access, as do the resources and support networks available to individuals (e.g. having help to care for children while attending appointments).

ACCESS ISSUES AT KEY PHASES OF THE CONTINUUM

In addition to the factors already discussed, there are some specific issues relating to accessing services at particular phases of the cancer care pathway that were identified in this study.

Primary prevention

Effective primary prevention is important in reducing the incidence of cancer as well as reducing inequalities in respect of cancer. Some providers perceived that the lack of a culturally safe and culturally competent primary prevention cancer workforce undermines efforts to improve Māori knowledge of cancer and cancer services. The appropriateness of primary prevention initiatives and materials has also been identified as important in terms of access, in particular the focus and design of health promotion materials. The need for health promotion activities to be relevant and appropriate was discussed, including embedding health promotion within Māori contexts.

The Ministry have noted that gaps exist in terms of primary prevention for cancer (Ministry of Health, 2004b: 121). Primary prevention that does not take into consideration the differential exposure of Māori to both risk and protective factors, as well as the structural factors driving this differential exposure, is likely to have limited success.

Early detection and screening

In New Zealand, national screening programmes exist for breast and cervical cancer. To date, the programmes have failed to achieve adequate or equitable coverage for Māori women (Expert Working Group on Cancer Screening and Early Detection, 2003). The recently released Cervical Cancer Audit indicated that the National Cervical Screening Programme (NCSP) also identified important differences in screening by age groups (Sadler, Priest, Peters, Crengle, & Jackson, 2004).

The need for greater attention to improving Māori access to early detection services was emphasised by providers. As early detection outside of systematic screening programmes is most likely to occur within primary care, access to quality primary care and a focus on early detection becomes very important to Māori access. The often opportunistic and ad-hoc nature of early detection and screening in primary care makes it more difficult to measure. The impact of different patterns of primary care utilisation for Māori and non-Māori on screening and early detection, as well as the effect of recent changes to primary care service provision and organisation, need to be further investigated.

Diagnosis and treatment

Reports on cancer treatment in New Zealand refer to inequitable access to treatment services, including inequity in access to drugs and specialist cancer treatment services (Ministry of Health, 2001). Delays in radiotherapy have also been well publicised. However, references to access for Māori to cancer diagnosis and treatment tend to be general. There is no routinely produced information on stage at diagnosis or access to treatment services and only limited reference to differences in treatment in the literature. However, the Cervical Cancer Audit identified that Māori women with a high-grade smear were more likely to experience delays in obtaining timely investigation and diagnosis. Māori women were more likely than non-Māori women with cervical cancer to wait for more than the recommended 12 weeks between first high-grade smear and colposcopy, for more than six months between first high-grade smear and diagnosis, and for more than two months between high-grade biopsy and diagnosis (Sadler et al., 2004). Furthermore, there is strong international evidence of disparities in the receipt of investigations and treatment by ethnicity (Haynes & Smedley, 1999; Shavers & Brown, 2002; Smedley et al., 2002).

Providers identified a lack of culturally responsive services and culturally competent health professionals as a barrier to access of treatment services in some areas. Issues were also raised in relation to the way Māori treatment modalities are integrated into treatment service provision. Offering Māori treatment modalities was seen as a facilitator to access. The importance of access to accurate and comprehensive information about treatment options was also mentioned.

Providers indicated that Māori with cancer and their whānau experienced difficulties in negotiate the treatment system, and several providers also discussed the possibility of having individuals such as patient advocates or patient navigators to assist Māori to navigate the system.

Support and rehabilitation

There are a wide range of support and rehabilitation services for cancer patients and their whānau, such as counselling, social workers, support groups, provision of support aids, and so on. Provision is through both cancer specific and non-cancer specific services and organisations and has been noted to be uneven across regions (Expert Working Group on Support and Rehabilitation, 2003).

In terms of access to cancer support and rehabilitation services for Māori, there is little published with the exception of internal Cancer Society reports, which suggest issues with access for Māori to the support and rehabilitation services offered through their organisation (Kokiri Seaview Marae, 1999; Patiki Associates, 2002). The NGO sector has an important role in support and rehabilitation for cancer patients and their whānau. The extent to which the government relies on NGOs to provide important cancer services for Māori, in the absence of monitoring for equity or ensuring Māori needs and rights are being met, potentially impacts on Māori access to cancer services.

Access to appropriate home help and carer entitlements have been identified as an area of particular concern. Disparities in terms of receipt of entitlements in other areas, such as access to special benefits, have previously been identified. In relation to special benefits, data from 2002 showed that for similar levels of need, Māori were 60% less likely to obtain a special benefit than Pākehā. This disparity varied by region (Hackwell & Howell, 2002). Access to support and rehabilitation services for Māori with cancer and their whānau is likely to be uneven, due to the differential availability of services as well as differential interpretation or application of eligibility criteria. The Expert Working Group on support and rehabilitation noted in their report that eligibility criteria can be interpreted in different ways (Expert Working Group on Support and Rehabilitation, 2003).

The importance of support for whānau has been noted (Kokiri Seaview Marae, 1999). The demands on family and the requirement for emotional support, health information, and financial help were raised. The need for Māori advocates to aid in connecting people with services and providing information and support was also expressed. Whānau often have a significant role in caring for and supporting Māori with cancer. The differential rates of carer entitlement by which 'strangers' are paid at a higher rate than whānau members were noted as a concern. This can be seen to endorse 'stranger' care rather than supporting a whānau ora approach to cancer care. In addition, supporting and caring for whānau at home should not result in 'cost-shifting' to whānau, who are often already financially pressured, of the significant expense of cancer care.

Palliative care

> Māori are the latest of the late referrals

Inequities in access to palliative care in New Zealand have been reported, including differential distribution of resources and geographical inequities. Māori access to palliative care services, including hospices, has been identified as an issue (Minister of Health, 2001). As ethnicity data is not routinely collected and/or palliative care service utilisation is not routinely analysed by ethnicity, it is not possible to have an overview of service use for Māori. However, reference has been made in the literature to differential utilisation of palliative care services, and it is a consistent theme from providers. Hospices identified late referrals as a key concern for Māori, the implication being that Māori involvement with services tended to be at the imminent death stage and therefore earlier requirements (e.g. equipment and support) were not met and there was less opportunity for patients to be familiar and comfortable with staff and hospice facilities.

Low Māori use of services has been attributed by providers and in the literature to preference in some instances. The New Zealand Palliative Care Strategy reported figures from 1996 on place of death that found that there was a higher proportion of Māori with cancer that died at home (53.2%) compared with Pacific peoples (41.5%) and nonMāori nonPacific (30.8%). Over one-quarter of nonMāori nonPacific peoples (29.4%) were noted to have died in private hospital or other institutions, including hospices and rest homes. These figures on place of death may therefore also be a reflection of increased nonMāori access to hospice services and rest homes, rather than a preference per se (Minister of Health, 2001).

Other providers indicated that the lack of a culturally competent and representative palliative care workforce contributed to Māori under-utilisation of palliative care services. Providers also felt there were low levels of awareness of palliative care options and the roles of hospices, as well as some 'myths' about hospices among providers and communities.

Some palliative care providers indicated that additional resources will be required if hospice services are to be developed beyond what is already provided. However, palliative care services are already funded to meet the needs of Māori alongside the needs of other New Zealanders.

SUMMARY

Access to cancer services for Māori is complex and multidimensional. Although there are key issues that are raised consistently in regard to access to cancer services for Māori, there has tended to be limited detailed information on the range of factors potentially influencing access and the ways in which these may function differently in different contexts. There is also limited information on access from the point of view of Māori with cancer and their whānau, which is vital to developing effective policies and interventions to address access.

This study identified a number of factors with the potential to influence Māori access to cancer services, including health system, health care process and patient-level factors. Many of these factors operate across the cancer care continuum to influence access. In addition, there are factors with particular relevance to different phases of cancer care. Findings indicate that incorporating a clear Māori focus (as opposed to a primarily total population focus) across the cancer continuum will be important to improving access. This focus would be reflected in service configurations and processes, workforce profiles and levels, and resources that meet the distinctive needs and priorities of Māori. Further, the approach would be multilevel and comprehensive, and take into account not only what happens in terms of gaining entry to a health service, but also progress through the service and the quality and timeliness of the process.

INTERVENTIONS TO ADDRESS ACCESS

As part of the study, a stocktake was undertaken to identify current or planned interventions to address access to cancer services for Māori. The scope of the project meant that it was not possible to talk to all services or organisations that may be providing interventions, particularly outside of specific cancer care services (for example, interventions offered through Māori providers or in other sectors). This section outlines interventions specifically focused on facilitating access to cancer services for Māori that were identified in this project from the literature and from discussions with providers and stakeholders.

IMPROVING MĀORI ACCESS TO CANCER SERVICES

The stocktake identified very few interventions that had a specific focus on Māori access to cancer services. The only dedicated Māori cancer service identified was a Māori cancer support group that has been operating in Rotorua for over three years. The intervention was originally initiated by a Māori health provider, but is now wholly a consumer group that is voluntary in nature and generates its resources through donations and fundraising activities. The group provides information on cancer and cancer services to Māori patients and their whānau, raises public awareness of cancer, offers emotional support to facilitate service access, and provides travel assistance (including petrol vouchers and transport for treatment-related travel).

Cancer-specific interventions were reported as being offered by some Māori providers. These included activities such as working in local communities to raise awareness of cancer and cancer service options, hosting cancer control workshops for staff, having a Māori women's support team to support women pre- and post-operatively, and maintaining contact and providing support to patients and whānau following a cancer diagnosis.

There was a lack of comprehensive initiatives to facilitate or enhance Māori access to 'mainstream' cancer services, such as cancer treatment centres and hospices, which were identified by the stocktake or through the literature. However, some providers reported activities designed to enhance service responsiveness to Māori or indicated that they were considering ways to improve Māori access. This included initiatives such as having a Māori advisor working alongside the hospice palliative care team, employing a nurse to liaise with patients in hospital, having the services of a kaumātua available to accompany nurses when meeting with Māori, developing close links with local Māori providers to support Māori patients as part of an inequality initiative, and developing a cultural safety policy. One of the providers referred to the intervention of another hospice that employed dedicated kaimahi whose role was to facilitate continuity of care for Māori.

Some NGO organisations had undertaken activities in the area, including the facilitation of hui to discuss cancer and targeted health promotion activities. There were also some references to planned interventions, namely the publication of existing cancer resources in the Māori language and the delivery of workshops for Māori providers about cancer and cancer services. For some providers, it was perceived that the involvement of an individual Māori staff or board member in the services (although their role was not necessarily Māori-specific) would facilitate access for Māori.

Māori providers were also contributing indirectly to improving Māori access to cancer services through non-cancer specific health promotion, primary health care, and support and rehabilitation activities. For example, provision of advocacy and health information, outreach clinics, general practitioners services (including low cost access), and employment of a Māori disease state management nurse. Support and rehabilitation services being undertaken by Māori providers, such as Māori disability needs assessments, comprehensive health care planning for individuals and whānau, home care services, day programmes, hospital visits, provision of transport to health-related appointments, and treatment-related financial assistance and accommodation, were also seen to have the potential to improve access to cancer services. Some providers reported that they accompanied patients to appointments or employed a staff member to follow up with patients on missed appointments and to assist them in making appointments.

IMPROVING ACCESS TO CANCER SERVICES IN GENERAL

Among mainstream providers, such as cancer treatment centres, hospices, and NGOs, the majority of initiatives to facilitate or enhance access to cancer services were focused on the total population. A number of activities relating to access to cancer services were being undertaken, including the provision of information about cancer and cancer services to patients and their families, organisation of workshops and seminars in both clinical and community settings, and development of information resources to encourage patients and their families to seek advice and utilise services related to cancer. Services also offered support to cancer patients and their families considered important in facilitating access to cancer services.

Assistance with treatment-related travel and accommodation, and with expenses such as medications, was available from some providers and organisations. Travel assistance activities included the provision of drivers, taxi chits, petrol vouchers, financial support for travel, and a taxi-booking scheme. Accommodation for patients and/or their whānau was also provided in some regions (for example, the Child Cancer Foundation partnership with Ronald Macdonald House to accommodate whānau that live outside treatment areas). Other strategies to improve access included providing short-term childcare where this is required for patients to attend treatment sessions or funding counselling sessions if patients are not able to access this service through the hospital or if their entitlement has been exhausted.

The Cancer Society has cancer liaison nurses that work in the community and visit newly diagnosed patients in their homes to provide information and support to access treatment, including referrals to social support services, so that assistance can be sought with financial and other matters. One provider employed a ‘support person’ whose designated role is to accompany patients to treatment sessions and to help them understand information and processes. Some other providers offered this support, though there was no specifically dedicated staff member.

The Cancer Society was identified as a key provider of information resources available free of charge to providers and patients, including an 0800 number that has been set up by the Society to allow people to discuss cancer and treatment service options with qualified cancer nurses. The Cancer Society also organises presentations to community groups regarding all aspects of cancer from early detection to palliative care, and cancer support groups that provide a mechanism for information dissemination about cancer and service options, including the sharing of personal experiences for people who may need support in making decisions regarding service options.

PROPOSED INTERVENTIONS TO IMPROVE MĀORI ACCESS

In the interviews with providers, a range of interventions and strategies were identified as necessary to improve Māori access to cancer services. These focused primarily on developing or enhancing Māori specific services or service components, as well as improving the cancer workforce capacity in terms of responsiveness to Māori. Suggestions included the incorporation of service options within mainstream services, as well as development of Māori specific service providers.

> …make sure patients coming to a safe, friendly environment, offer options…

A number of providers emphasised the need for a whānau-based approach that would recognise the importance of whānau as support and would provide opportunities for whānau input into decision-making.

The need for enhanced workforce responsiveness was strongly emphasised by providers. This had three main aspects: addressing the needs of the current cancer workforce; developing the cancer workforce and extending the number and range of Māori health professionals at all levels including the governance; and, establishing patient 'navigators' or guides to help with presenting information and options and facilitating Māori access to services across the cancer continuum.

> …need process around getting support when getting and understanding diagnosis and treatment options…

General comments were also made about the need for interventions to reduce cost, fund transportation, target resources, and develop more effective relationships. A range of strategies to improve the information and also the quality of patient/provider communication and interactions were also proposed, including better information at grass roots levels.

> Make sure there is communication between doctors, community nurses, patients and whānau. More public awareness so people can be in control of their own outcome. Patient and whānau need to have control over what is going on

At a structural level, the location of services and the development of community-based and outreach cancer services were considered as important in addressing geographical barriers to access. Some providers recommended that processes for Māori-led policy development be put in place (e.g. partnerships with Māori such as a Māori taskforce group to lead Māori policy) and that cancer services incorporate a strengthened health promotion focus. Other recommendations focused on the need for improved service co-ordination and discharge planning, targeting of at risk groups, increased resources for providers, and research regarding access issues.

OTHER WORK TO IMPROVE ACCESS

In an overseas review of literature on access to cancer services, Mandleblatt and colleagues reported that the majority of interventions to address access to cancer services have tended to focus on patient/population level factors in relation to breast and cervical screening (Mandelblatt et al., 1999). They also found that there was some evidence of interventions to improve screening targeted at providers, but little information on interventions to address access to other phases of care, and a lack of interventions targeted at systems and structures. There is work being done internationally to improve access to cancer care, including the development of policies, programmes and interventions. However, it is not clear the extent to which this work is focused on addressing inequalities and/or targeting specific populations.

Literature on targeted interventions to address access to cancer services for indigenous peoples was also limited. However, there is evidence of a range of activities underway overseas designed to facilitate access and enhance the journey of care for patients with cancer and their families, including patient navigator programmes, support groups and the development of resources. In addition, there is related work in New Zealand on improving access to health services for Māori, such as the diabetes interventions outlined in the Baxter report (Baxter, 2002). The relevance of this work to interventions aimed at improving Māori access to cancer services requires further attention.

SUMMARY

There is a lack of comprehensive interventions, current or planned, to specifically address Māori access to cancer services. Those interventions that do exist tend to be isolated. There is little indication that cancer services are developing specific interventions or considering developing interventions in the future. While there are a number of strategies and initiatives within the cancer sector to facilitate access to cancer services and enhance the care pathway for cancer patients and their whānau, the majority of these are 'universal' interventions with a total population focus. The absence of ethnicity data and routine monitoring for inequalities means that it is difficult to identify the extent to which universal policies are delivering for Māori. The interviews with providers and key informants would suggest that there are significant gaps in service delivery for Māori and that organisations are at different stages in terms of their ability and/or willingness to address access to cancer services for Māori.

Interventions to address cancer services that were identified tended to focus on intervening at the patient level, and addressing the surface causes of barriers to access (such as providing drivers or travel reimbursement), rather than at the root causes of disparities in access. This is consistent with interventions overseas to address access to cancer services, which are reported to tend to focus on patient level factors, particularly in the areas of breast and cervical screening (Mandelblatt et al., 1999). While addressing surface causes is important, there is the need for interventions that also address fundamental drivers.

Further research on interventions that will reduce the impact and incidence of cancer for Māori is necessary. It is important to consider not only the ability of interventions to reduce inequalities, but also the potential for interventions, particularly universal interventions, to maintain or increase disparities. The use of tools such as the HEAT tool may be useful in this area.

DISCUSSION

There are significant and consistent disparities in cancer outcomes between Māori and non-Māori that require urgent attention. Findings of this report highlight the need for comprehensive and detailed information on Māori cancer in order to provide a more complete understanding of cancer trends and disparities. This includes data on stage, histology, survival, and access to cancer services. Although some of this data is available in national datasets, it is not routinely published by ethnicity. Comprehensive and accurate data is vital to the development of effective and responsive cancer control policy and interventions, and issues in terms of the quality and completeness of the datasets currently available will need to be addressed.

There is also a pressing need to go beyond describing disparities in cancer outcomes between Māori and non-Māori to examine the underlying causes of these disparities. Access to cancer services along the cancer care continuum have a role in disparities in both cancer incidence and outcome. The information on access to cancer services provided in this report, from the literature and consultation with providers and key informants, highlights a range of factors with the potential to influence access to cancer services, both positively and negatively. In addition to those relating to the patient or community context, which are the factors most frequently acknowledged, a number of health system-level and health care process factors were also described. The responsiveness of the cancer care system in general, and cancer services in particular, to Māori with cancer and their whānau, therefore needs to be carefully considered. The potential for resource constraints to have a disparate impact on Māori access to cancer services or for differential discrimination through cancer control policy and practice warrants further investigation.

The report findings highlight the complex and multilevel nature of access to cancer services for Māori with cancer and their whānau and the resultant need for broad approaches to addressing access issues. A range of activities and initiatives to enhance access to cancer services within the public and NGO sectors were identified. These were often targeted at the patient/population-level and tended to address surface (rather than structural) causes of inequality. Within mainstream services and organisations, activities also tended to have a universal approach to intervention that centred the total population. It is essential that there is recognition that universal interventions will not necessarily address Māori cancer priorities, which may differ from priorities for the total population as is demonstrated in the statistical data presented in this report. Universal interventions are essentially a form of targeted intervention in that values and assumptions are embedded within their design (e.g. delivering 'universal' interventions in the English language) or in the sense that they are targeted in their effect (that is, they are more effective for some population groups than others). The stark disparities in cancer incidence, experience, and outcomes are a strong impetus for the development of policies and services that target Māori priorities. The persistence of disparities in health outcomes, and the experience of Māori in other sectors, suggest that total population strategies and approaches will be inadequate in addressing Māori cancer needs or reducing Māori/non-Māori inequalities in cancer. Therefore, Māori specific strategies and initiatives will be required in both Māori and mainstream settings.

There is a lack of comprehensive interventions identified, either currently in existence or planned, to specifically address access to cancer services for Māori, although there are some isolated initiatives and Māori provider organisations are facilitating access to cancer services for Māori indirectly. Māori providers have already undertaken significant work to address barriers to access of health services. The role of Māori provider organisations in facilitating access to cancer services for Māori with cancer and their whānau needs to be appropriately recognised and supported, alongside the role of mainstream services in providing equitable and appropriate care for all.

Mainstream cancer services seem to be at different stages in terms of recognising and addressing access for Māori with cancer and their whānau. This includes their readiness and/or ability to monitor service utilisation and quality for Māori. The Ministry of Health *Ethnicity Data Protocols* may contribute to more complete and accurate ethnicity data within the health sector, which in turn has the potential to facilitate the monitoring of disparities in access to cancer services.

The NGO sector also has a significant role in facilitating access to cancer services, particularly in relation to providing important information and addressing support needs for cancer patients and their whānau. As with mainstream cancer services, NGOs are at different places in terms of their willingness and capacity to deliver responsive, appropriate services equitably to Māori. The role of government in ensuring NGOs are delivering services that reduce the incidence and impact of cancer **and** reduce inequalities is unclear. It is also not clear the extent to which there is reliance on NGOs to meet gaps in service provision within the public sector, without systems for the monitoring of whether those services are being delivered equitably or are contributing to disparities.

There are several limitations to this project. As work is ongoing in breast and cervical cancer, these areas were generally excluded from consideration. Information on access from the point of view of Māori with cancer and their whānau was outside of the scope of the current project. However, this information is critical in identifying key access issues and developing appropriate policies and interventions to improve access. It was also not possible to identify the full range of interventions that are being offered in relation to access to cancer services for Māori, particularly those within Māori provider and community organisations as well as within other non-cancer specific organisations. A more comprehensive evaluation of overseas interventions to improve access to cancer services in terms of their relevance to Māori, as well as initiatives in other non-cancer specific areas in New Zealand, is also important.

The study however does find that there is substantial work to be done to address access to cancer services for Māori. This includes the need for improvements in the depth and breadth of information available on Māori cancer and routine monitoring of datasets for disparities in access to cancer services. It also includes the need for interventions that are comprehensive in nature and have a broad approach to access, in line with the Ministry of Health's Intervention framework. Addressing factors at the patient/population level will be important, and providers can take measures immediately. However, it is important to also focus on the institutional and structural levels, where significant gains can be made.

Significant work has been done to progress a cancer control programme in New Zealand. This includes the release of a national Cancer Control Strategy, the announcement of the establishment of an ongoing independent cancer control body (the Cancer Control

Council), and the imminent release of the *New Zealand Cancer Control Strategy Action Plan: 2005-2010*. However, this co-ordinated and systematic approach to addressing cancer control is relatively recent. Cancer services have historically tended to develop in a fragmented and uneven way, which has contributed to gaps and inequalities in service provision. Recognition of the Treaty of Waitangi and the inclusion of goals relating to the reduction of inequalities in health policy, is also comparatively recent. Cancer policy and service development has tended to be organised around and focused on total population needs. The result in cancer care is a system that does not centre Māori priorities or needs and has not routinely measured or addressed inequalities in health outcome. It is imperative that Māori benefit equally from the current cancer control environment and from any future developments.

The CCS(NZ) outlines high-level dual goals of reducing the incidence and impact of cancer **and** reducing inequalities in cancer. However, the findings of this report indicate that the inequalities goal has yet to be fully integrated throughout cancer control policy and practice. It should be recognised that within some contexts, these two high-level goals may be in competition and that to achieve gains the goal of reducing inequalities may need to be prioritised.

Māori with cancer and their whānau deserve excellence in cancer care. This includes access to timely, appropriate and high quality cancer services. Delivering ideal cancer care would require that the system is able to "…identify barriers to the practice and receipt of quality care and target interventions to overcome these barriers" (Hewitt & Simone, 1999). Therefore, it is important that research into access issues and interventions continues. In addition, ensuring excellence in cancer care for Māori necessitates a commitment to addressing both the surface level and fundamental causes of disparities in New Zealand. Access to cancer services cannot be viewed outside the societal context within which health services, providers and communities exist. Addressing disparities in access to cancer services requires addressing fundamental drivers of the differential distribution of the factors associated with access, such as racism and unequal power relations.

The current environment in cancer control in New Zealand provides opportunities for a strong and committed response to the stark disparities in cancer outcome between Māori and non-Māori, including the development of policy and cancer services that reduce inequalities in cancer, reduce the incidence and impact of cancer, and deliver excellence in cancer care for Māori with cancer and their whānau. Indeed, there are ethical, moral and human rights imperatives, obligations under the Treaty of Waitangi, and legislative and policy drivers, to support the development of policy and interventions to effect change.

RECOMMENDATIONS

This section outlines a number of recommendations organised under key areas for action. These recommendations were informed through the literature and data reviews and discussions with providers and key informants, and build on the recommendations identified in the Baxter report in relation to diabetes care. However, they are preliminary and require wider consultation. In particular, it is important that the voices of Māori with cancer and their whānau are incorporated.

Cancer control governance and structures

Appropriate and effective governance models and structures in cancer control are a necessary part of recognising Treaty of Waitangi obligations and Māori priorities for cancer control, and reducing inequalities. Negotiated and meaningful Māori participation is vital in any established or proposed cancer control structures. To this end it is necessary to:

- Determine in partnership with Māori the extent and nature of Māori participation in any established or proposed cancer control bodies (such as working groups and taskforces), and Māori priorities for these bodies.
- Evaluate established and proposed cancer control bodies in respect of their ability to address Māori rights and reduce inequalities.
- Adequately resource and support effective Māori participation in cancer control bodies, as determined by Māori.

Cancer control policy and funding decisions

Decisions about policy and funding need to address cancer inequalities and be in line with Māori priorities for cancer control. Structural factors such as policy and funding decisions have been identified as having a significant influence on access to cancer services for Māori, and the potential for contributing to the reduction of inequalities in cancer is therefore considerable. In relation to policy and funding, decisions should:

- Strengthen the inequalities focus of cancer control policies, better integrate the principle of reducing inequalities throughout cancer control strategies and policies, and clearly reflect the dual focus of the cancer control strategy in all decisions (that is reducing the incidence and impact of cancer **and** reducing inequalities).
- Ensure Māori input into cancer control policy development and funding decisions.
- Assess policy and funding decisions (established and proposed) for differential effect discrimination and/or the potential to contribute to or reduce inequalities (this may include the use of tools such as the HEAT tool).
- Encourage a planned approach to the development of interventions to address access to cancer services for Māori.

Cancer control guidelines, standards and priorities

The data in this report shows differences in leading sites of cancer incidence and mortality, as well as differences in rates, relative risk and survival. Māori cancer priorities may differ from those of the total population and this will need to be recognised in the development of national guidelines, standards and priorities. To this end:

- Prioritise the development of guidelines or standards that will address Māori priorities for cancer control.
- Take into account the need to monitor for inequality and service responsiveness to Māori in the development of national standards.

Cancer workforce

The cancer care workforce is consistently raised as a significant issue in terms of access to cancer services for Māori. There is a range of workforce issues that needs to be addressed, many of which are also applicable to the health workforce in general. This includes work to:

- Increase awareness among those involved in cancer care provision of inequalities in cancer and the role of system and health workforce factors in creating and perpetuating inequalities.
- Support and resource comprehensive and ongoing training of the cancer care workforce to provide for culturally safe and responsive service provision to Māori.
- Provide incentives and funding to encourage Māori workforce development in cancer care at all levels and in a variety of roles. This includes supporting and meeting the training and professional development needs of those Māori already within the cancer care workforce.
- Recognise and support the valuable contribution of the Māori provider workforce to enhancing access to cancer care for Māori through adequate, on-going funding.

Service orientation and development

In order to meet Māori needs and reduce inequalities, cancer care services need to be focused on Māori priorities. This may involve the reorientation of existing services, the development of new services or initiatives, as well as strengthening the role of effective service delivery models.

- Involve Māori expertise and the range of relevant Māori services and providers in multidisciplinary teams and networks.
- Prioritise Māori in the piloting of developments or initiatives in service delivery in order to address the high level principle of reducing inequalities.
- Support and adequately fund Māori led initiatives in cancer control.
- Support and encourage Māori participation in cancer services at the governance level, and mechanisms to ensure Māori expert advice at service policy levels.

- Require that providers demonstrate planning to address inequalities, with associated strategies, timeframes, and measurable indicators.

Monitoring and evaluation

There is limited data on access to cancer services for Māori. Monitoring and evaluation is crucial in assessing Māori access to cancer services and measuring inequalities between Māori and non-Māori. This requires commitment and action from policymakers, services and the health workforce. In some cases it involves better use of existing data, while in other cases it may require the collection of new datasets.

- Institute systems for the routine monitoring and reporting on equity of access to cancer services for Māori across the cancer control continuum.

- Routinely collect and publish data by ethnicity (in line with the Ministry of Health protocols) to reflect the goal of reducing inequalities and allow for monitoring of ethnic inequalities.

Research

One of the key findings of the project was the limited information on access to cancer services for Māori, including the discussion of interventions. As such, there are several areas that arise from the project as priorities for further research.

- Prioritise research with Māori cancer patients, their whānau and communities to reflect the high level goal of reducing inequalities.

- Investigate the reasons why the NZCR records higher rates of unstaged disease for Māori than for non-Māori for most cancers.

- Explore the extent to which delays in access to cancer services contribute to inequalities in cancer outcome between Māori and non-Māori (including delays in primary prevention, screening and early detection, diagnosis, staging, treatment, support and rehabilitation, and palliative care).

- Investigate the role of Māori patient advocates, navigators, or other interventions to enhance the patient journey for Māori with cancer and their whānau.

- Explore Māori perspectives of barriers and facilitators to access of cancer services, and preferences and priorities for interventions to address access issues.

- Consider the role of differential access to timely and appropriate cancer services in inequalities in cancer outcome between Māori and non-Māori.

Resources

The need for appropriate resources, including information about cancer and cancer services, was identified as a key access issue in this study. Although some organisations indicated there were activities underway or planned in this area, it remains important to:

- Encourage and fund the development of high quality Māori-specific resource material about cancer and cancer service options for individuals, whānau and communities.

- Develop tools to assist services and health professionals to communicate effectively about cancer and cancer care with Māori patients and their whānau.

Addressing structural barriers

In addition to the above areas for action, substantial work needs to be done to address structural barriers to access and the fundamental drivers of inequality in New Zealand. Access to cancer services for Māori needs to be viewed within the context of pervasive disparities in access to the goods and opportunities of society that have resulted from historical and contemporary processes of colonisation, racism and unequal power. There are a number of ways in which the health sector can contribute to addressing structural barriers and root causes of inequality.

- Collaborate with other sectors to address fundamental drivers of disparities in cancer access and outcomes for Māori.

- Advocate for Māori human, indigenous and Treaty of Waitangi rights in all work in the health sector.

- Fulfil obligations under the Treaty of Waitangi.

- Operationalise governmental commitments and obligations under the International Convention on the Elimination of All Forms of Racial Discrimination (CERD) within the health sector.

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APPENDIX ONE: LITERATURE SEARCH

Search strategy
Combinations of the following key search terms were used to search the literature. Some of these may have varied depending on the thesaurus of a particular database.

Māori; Cancer/Neoplasms; Access; New Zealand; Indigenous; Ethnic/racial; Prevention; Screening; Diagnosis; Treatment; Services; Care; Palliative; Support; Rehabilitation; Cancer Control; Intervention; Initiative; Strategy

The following sources of literature were searched:

Electronic databases
- Medline 1966 to July Week 5 2004
- Cochrane Library
- Embase
- AMED (Allied and Complementary Medicine)
- Cinahl
- Current Contents/All
- Web of Science
- CancerLit
- Index New Zealand (INNZ)
- PubMed

Internet search
The World Wide Web was searched, with a particular emphasis on major subject-related sites, relevant governmental sites (domestic and international), professional and national associations, and consumer websites. Web-sites were visited to identify relevant content and literature.

Bibliographies of published research
Bibliographies of relevant literature retrieved were reviewed to identify any further sources of information not previously identified through database and internet searching.

Other sources

Other literature, such as unpublished reports and papers, were identified through key informants.

APPENDIX TWO: ETHNICITY DATA REVIEW

INTRODUCTION

The right to be counted as Māori is fundamental to our rights of self-determination. High quality Māori health information is essential to enable us to monitor our own health trends, to strategise for a healthy future for our mokopuna, and to evaluate whose interests the Crown is primarily serving.

Disparities in health signal differential access to the goods, services and opportunities of society. They represent unequal access to political, economic, social, and environmental determinants of health and to timely, effective, appropriate, high quality health care (Jones, 2000; Smedley et al., 2002). Disparities therefore result from historical and contemporary breaches of the rights of Māori – human, civil, political, and social, and the rights of indigenous peoples (Human Rights Commission, 1998).

Official health data undercounts Māori cancer registrations, hospital admissions and deaths (Te Röpü Rangahau Hauora a Eru Pömare, 2000). This denies our right to self-identify our own ethnicity and suppresses the true extent of health disparities between tangata whenua and tauiwi in Aotearoa. The need to improve ethnicity data is evident and the Ministry of Health has recently established a protocol for standardizing the collection and recording of ethnicity data across all health information systems.

This paper reports our estimates of the size of undercount of Māori cancer registrations and deaths for the period 1996-2001. We also report the impact of the 'ever Māori' method of ethnicity classification on the estimated undercount. This method counts as Māori anyone ever recorded as Māori in any cancer registration, hospital admission, death registration or on the National Health Index (NHI) during the period of analysis.

WHICH MĀORI POPULATION?

Three Māori populations are produced from current census information: the Māori descent or ancestry group; the Māori ethnic group comprising those who indicated Māori as at least one of their ethnic affiliations; and the sole-Māori group that indicated Māori as their only ethnic affiliation. While the sole-Māori group is a subgroup of the Māori ethnic group, there is some evidence that it is particularly important in the monitoring of disparities as its members have more risks associated with breaches of social, economic and civil rights, including socio-economic deprivation and discrimination in a colour-conscious society (Salmond & Crampton, 2000; Te Ropu Rangahau Hauora a Eru Pomare, 2000) and higher death rates than the total Māori ethnic group (Ajwani et al., 2003). Therefore, in addition to monitoring the health status of the total Māori ethnic group, it is important to monitor health determinants, service receipt and outcomes for the sole Māori population, the group most affected by the forces that create disparities. However, this would require ethnicity data in health datasets to be routinely collected and recorded in exactly the same way as in the population census. The data held by New Zealand Health Information Service (NZHIS) show that this is not the case.

The proportion of Māori recorded as sole Māori in cancer registrations, hospital admissions, death registrations and on the NHI, is unrealistically high (90% or more) when compared to Census data (under 60% for 1996 & 2001). This implies that a single ethnicity recording system is still being implemented, despite official policy that ethnicity data should allow the recording of multiple ethnic groups since July 1996. Once the standard ethnicity data protocols for the whole health sector (Ministry of Health, 2004a) have been fully implemented it may be possible to track health trends among both sole Māori and the total Māori ethnic group. At this stage however, it is only possible to report data for the total Māori ethnic group.

Further limitations include our lack of ability to monitor Crown performance for people with Māori ancestry, and for iwi, hapü and whānau. There are significant issues to be resolved to enable such data collection and analysis to be safely done – including how to collect such data, who should collect it, who should control it and own it, and how should it be reported and disseminated (B Robson & Reid, 2001). Given the aspirations, needs and rights of iwi and hapü to receive and to provide effective health services for their communities, this area requires further research and consultation with relevant Māori communities.

Due to the limitations described above, this assessment of ethnicity data focused only on the total Māori ethnic group.

METHODS

Cancer registrations and deaths from 1995-2001 (any cause) and hospital admissions from 1996-2003 were obtained from NZHIS. Each event has three ethnicity fields associated with it, as well as the three associated with that person's NHI data (name, address, data of birth and ethnicity). Using encrypted NHI numbers to identify anonymous individuals, each event was assigned an ethnicity using data from successive additions of datasets. This enabled us to examine the difference made by each data source.

A study of ethnicity data in Wellington Hospital in 1999 reported that an unrealistically high proportion of admissions were being coded as "Other, not further defined (code 54)"[3] (Moala, 1999). This suggests that the 54 code may have been used as a default entry when coders were having difficulty categorising ethnicity (possibly multiple ethnic groups stated, or "New Zealander" type responses) or perhaps as a default entry for 'not stated'. We therefore examined the proportion of deaths, hospital admissions and cancer registrations that were coded as 54 and not stated (99), along with the codes for Māori (21) and all other specific non-Māori codes grouped together.

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[3] Code 54 at Level 2 of the Standard Classification of Ethnicity (Ministry of Health 2004a).

Deaths

Table i. Deaths 1996-2001, Numbers (%) in each ethnic category by method of categorisation

Ethnicity (in priority order)	On death registration only	On death registration or NHI	On death, NHI or cancer registrations	On death, NHI, cancer registration or hospital admission
Māori Ethnic Group	15,526 (9.4%)	16,228 (9.80%)	16,271 (9.83%)	16,475 (9.95%)
Non-Māori	148,336 (89.6%)	148,895 (89.95%)	148,888 (89.94%)	148,763 (89.87%)
Other not further defined (54)	70 (0.04%)	330 (0.2%)	303 (0.18%)	244 (0.15%)
Not stated (99)	1,602 (1.0%)	81 (0.05%)	72 (0.04%)	52 (0.03%)
TOTAL	165,534 (100%)	165,534 (100%)	165,534 (100%)	165,534 (100%)

The 'ever Māori' method increased the number of deaths classified as Māori during 1996-2001 from 15,526 (9.4% of all deaths) to 16,475 (9.95% of all deaths) - an increase of 6%. The number of deaths specifically coded as non-Māori also increased using this method, and the proportion with no ethnicity assigned decreased considerably.

The increase in Māori deaths using the 'ever Māori method' is very close to the 7% undercount identified for the 1996-1999 period by the New Zealand Census Mortality Study which probabilistically matched death registrations and census data (Ajwani et al. 2003a; 2003b). This lead us to be reasonably confident of our estimates of mortality rates for Māori using the 'ever Māori' method. Therefore, we took the deaths classified as Māori by this method as the gold standard for estimating the undercount in cancer registrations and hospital admissions.

Cancer registrations

Table ii. Malignant Cancer Registrations 1996-2001, numbers (%) in each ethnic category by method of categorisation

Ethnicity (in priority order)	On cancer registration only	On cancer registration or NHI	On any cancer registration or NHI	On any cancer registration, NHI or hospital admission	On any cancer registration, NHI, hospital admission or death registration
Māori Ethnic Group	6,353 (6.3%)	6,859 (6.7%)	6,871 (6.8%)	7,083 (7.0%)	7,410 (7.3%)
Non-Māori	86,979 (85.5%)	90,770 (89.3%)	90,840 (89.3%)	90,992 (89.5%)	91,088 (89.6%)
Other not further defined (54)	237 (0.2%)	1,753 (1.7%)	1,720 (1.7%)	1,715 (1.7%)	1,432 (1.4%)
Not stated (99)	8,125 (8.0%)	2,306 (2.3%)	2,263 (2.2%)	1,904 (1.9%)	1,764 (1.7%)
TOTAL	101,694 (100%)	101,694 (100%)	101,694 (100%)	101,694 (100%)	101,694 (100%)

The 'ever Māori' method increased the number of malignant cancers registered between 1996 and 2001 classified as Māori from 6,353 (6.3% of the total) to 7,410 (7.3% of the total) – an increase of 16.6% (table 3). The inclusion of ethnicity from the NHI in addition to the cancer registrations added 8% to the Māori registrations. Other cancer registrations added another 0.2%. Hospital admissions added a further 3.1%, and death registrations an additional 4.6%. The number of registrations with missing ethnicity data decreased by 78%, and non-Māori registrations increased by 5%.

Table iii. Māori malignant cancer registrations 1996-2001, with and without a death registration

	No Death Registration (Group A)		Death registered between 1996-2001 (Group B)	
Ethnicity Source	**Cancer Registration**	**'Ever Māori'**	**Cancer Registration**	**'Ever Māori'**
Number of Māori registrations	3,031	3,515	3,322	3,895
% increase using 'Ever Māori'	16.0%		17.2%	

To estimate the total undercount of Māori cancer registrations, and any residual undercount after applying the 'ever Māori' classification, we compared the results for people who also had a death registered between 1996 and 2001, with those who didn't. The 'ever Māori' method increased the number of Māori registrations by 16.0% among those without a death registration (Group A) and by 17.2% among those with a death registration (Group B) (Table 3). This difference indicates there may be a small residual undercount of Māori among those without a death registration. An increase of 17.2% in Group A would result in 3,554 Māori registrations without a death registration, and increase the total number of 'ever Māori' cancer registrations by another 0.5% to 7,449.

Thus, we estimate that the use of ethnicity data from cancer registrations undercounts Māori by around 17% for 1996-2001. The 'ever Māori' method of classification increases the number of Māori cancer registrations by 16.6% and reduces the undercount to less than 1%. This result is reassuring as it means that differential misclassification bias in analyses that combine registration and mortality data (e.g. survival analysis or hazard ratios) is likely to be small.

SUMMARY

In summary, we estimate that official datasets underestimate Māori deaths by around 6% and Māori cancer registrations by approximately 17%. Until improvements in ethnicity data collection are fully implemented, the 'ever Māori' method of ethnicity classification can be used to produce reasonable estimates of cancer incidence and mortality for the Māori ethnic group for data from 1996 onwards.

APPENDIX THREE: STATISTICAL REVIEW METHODS

DATA SOURCES

Deaths and cancer registrations registered between 1 January 1996 and 31 December 2001 were obtained from the New Zealand Health Information Service (NZHIS). Cancer registrations were classified according to ICD-10-AM for the whole 6 year period. For the years 1996-1999, deaths were classified according to the ICD-9-CM, but changed to ICD-10-AM for the year 2000. We recoded all deaths into the ICD-10-AM classification groupings. ICD codes used are listed in the Appendix.

Registrations flagged as 'multiple' were excluded. For the survival analysis (hazard ratios) where there was more than one registration for a person within a site or site group, the first was included and subsequent registrations excluded.

Age-sex-ethnicity-specific population estimates from 1996-2001 served as denominators for computing cancer incidence and mortality rates. They were obtained from the Statistics New Zealand's revised estimates of mid-year resident Māori Ethnic Group population for 1991 - 2001. These estimates include adjustments for: missing response to the ethnicity question; the estimated net undercount at the 2001 Census as measured by the 2001 Post-enumeration Survey; the estimated number of Māori residents temporarily overseas on census night, estimated external migration, births and deaths. New ethnicity questions on birth registrations and death registrations were introduced in September 1995, resulting in significant increases in the number of births and deaths registered as Māori (around double those registered as Māori in 1994). The population estimates for the December quarter 1995 onwards on are based on births and deaths compiled using the new questions (Statistics NZ technical notes on population estimates). Denominators for the non-Māori rates were constructed by subtracting the Māori population estimates from the total New Zealand population estimates for each year.

ETHNICITY CLASSIFICATION

Deaths and cancer registrations were classified as Māori if Māori was coded as one of the ethnic groups in any ethnicity field of the death event, the NHI, any other cancer registration or any hospitalisation during this period. Otherwise they were classified as non-Māori. This method of classifying ethnicity was used to minimise the known undercount of Māori cancer registrations and deaths. It increased the number of cancer registrations classified as Māori by 16.6% and deaths by 6%. This method appears to give reasonable estimates for both registrations and deaths during our period of analysis. (See Appendix Two for detailed description).

STATISTICAL ANALYSIS

Incidence rate

The cancer incidence rate is the number of new cancers of a specific site/type occurring in a specified population during a year, usually expressed as the number of cancers per 100,000 per year. That is,

Incidence Rate = (New Cancers / Population) x 100,000

The *numerator* of the incidence rate is the number of new cancers; the *denominator* of the incidence rate is the size of the population. The population used depends on the rate to be calculated. For example, for cancer sites that occur in only one sex (e.g. cervical cancer), the sex-specific population is used (e.g. females). The number of new cancers may include multiple primary cancers occurring in one patient.

Mortality rate

The cancer mortality rate is the number of deaths with cancer given as the underlying cause of deaths occurring in a specified population during a year, usually expressed as the number of deaths due to cancer per 100,000 population per year. That is,

Mortality Rate = (Cancer Deaths / Population) x 100,000

The *numerator* of the mortality rate is the number of deaths; the *denominator* of the mortality rate is the size of the population.

Age-standardised rates

Differences in the age-structure of the Māori population (relatively young) and the non-Māori population (relatively old) make it necessary to adjust for age when comparing health outcomes. Direct standardisation applies age-specific rates to a standard population structure. The results are affected by the age-distribution of events (e.g. deaths) in each population and the relative differences across age groups (the age-specific rate ratios). If these vary between the populations being compared, the selection of standard population can affect the magnitude of rates and ratios, relative ranking of causes, and trends in rates and ratios.

In this report rates have been adjusted for age by standardising to the average Māori population for 1996-2000, as these rates reflect more closely the crude rates for Māori, and thus better reflect the experience of the Māori population. Standardising to Segi's world population or the WHO population produces rates of higher magnitude (as these standard populations are older and place greater weight on events at older ages), and in some instances also produce different rate ratios. See section on standard populations below for registration and death rates standardised to Segi's and the WHO populations.

Confidence intervals

95% confidence intervals for crude and adjusted rates and rate ratios were calculated using the log-transformation method (Clayton and Hills 1993).

Stage of disease at diagnosis

Extent of disease information determines stage of disease at diagnosis. Cancer stage was determined by the extent of cancer spread from the site of origin at initial diagnosis. (National Cancer Institute: SEER Cancer Statistics Review 1975-2000)

The Summary Staging Classification

The localised-regional-distant summary staging scheme is used in descriptive and statistical analyses of cancer registry data, and is defined (from Singh et al 2003) as:

Localised: An invasive malignant neoplasm confined entirely to the organ of origin with no lymph node involvement.

Regional: A malignant neoplasm that (1) has extended beyond the limits of the organ of origin directly into surrounding organs or tissues; or (2) involves regional lymph nodes by way of the lymphatic system; or (3) has both regional extension and involvement of regional lymph nodes.

Distant: A malignant neoplasm that has spread to parts of the body remote from the primary tumour either by direct extension or by discontinuous metastasis (e.g., implantation or seeding) to distant organs, tissues, or via the lymphatic system to distant lymph nodes.

Unstaged: When information is not sufficient to assign a stage, a neoplasm is said to be unstaged.

Prior to 1999, the NZ Cancer Registry data, the stage of cancer disease was classified as:

- In situ
- Localised
- Regional or node involvement
- Remote or diffuse metastases
- Not stated
- Not applicable (lymphomas/leukaemias)

For cancers registered from 1999 on, the “regional or node involvement” stage was divided into two categories, and the classification changed to:

- In situ
- Localised to organ of origin
- Invasion of adjacent tissue or organ
- Regional lymph nodes
- Distant
- Not known
- Not applicable

In this report, regional-stage disease includes any cancers classified with ‘regional or node involvement’, ‘invasion of adjacent tissue or organ’, or ‘regional lymph nodes’. Distant-stage disease includes cancers classified as ‘remote or diffuse metastases’ or ‘distant’. Data is presented on invasive neoplasms only. In situ tumours are not included. The staging classification is not applicable to lymphomas and leukaemias.

The stage distribution of new cases (percentage of cases diagnosed at localized, regional, distant and stage unknown) was calculated for Māori and non-Māori. To give some indication of access to diagnostic and staging evaluation, logistic regression analysis was used to compare the odds of being registered with unknown stage at diagnosis for Māori compared to non-Māori. We also calculated Māori/non-Māori odds ratios for being diagnosed at a localized or distant stage among staged cancers only. Odds ratios were calculated using the Logistic procedure of SAS version 9.1.

Hazard ratios

Hazard ratios represent the relative risk of dying from the cancer once diagnosed, for Māori compared to non-Māori. Cancers registered at death or on autopsy do not contribute to the hazard ratio.

Mortality data from 1996-2001 was searched for matching encrypted NHIs of patients registered with cancer during the same period, and treated as a cancer-specific death if the death was coded to the same ICD grouping as the cancer registration. Patients dying of a different cancer or of ill-defined cancers were treated as dying of other causes under the assumption that deaths from the underlying cancer were independent of deaths from other causes. Survival times were measured in days, and were censored at the date of death from causes other than the underlying cancer, or on 31 December 2001 (whichever occurred first). Active follow-up was not conducted and therefore we cannot account for any cancer patients who may have died outside of Aotearoa. However, we expect any impact of differential migration to be minor.

Cancer-specific hazard ratios and confidence intervals were calculated using the proportional hazards procedure (PHREG) of SAS version 9.1 (SAS Institute Inc, Cary, NC). The proportional hazards model assumes the relative risk of death between Māori and non-Māori remains constant over time. The assumption of proportionality for ethnicity was checked using the graphical and numerical methods of Lin, Wei, and Ying (1993).

Māori to non-Māori hazard ratios were calculated for selected sites, adjusted for sex and age at diagnosis (as a categorical variable). Because the assumption of proportionality did not hold when the age was treated as a continuous variable, or with 5 year age groups, age categories were constructed separately for each cancer, by dividing the total number of registrations for that cancer site into quintiles with equal numbers of registrations. However, the method of age adjustment made very little difference to the resulting hazard ratios.

To examine the relative importance of stage at diagnosis for each site (in terms of survival), hazard ratios were calculated for all patients diagnosed at regional, distant or unknown stage of spread, compared to patients diagnosed at localised stage. These were adjusted for sex and age at diagnosis.

To estimate the contribution of stage at diagnosis to the disparities between Māori and non-Māori, we also calculated hazard ratios adjusted for stage at diagnosis. These were calculated in two ways. Firstly, registrations with unknown stage at diagnosis were included as a stage category, and secondly restricted to staged cancers only. Finally we calculated hazard ratios for Māori compared to non-Māori at each stage of cancer spread at diagnosis, including unknown stage.

Table iv. ICD codes used in this report

	ICD-10-AM	ICD-9-CM
II: Neoplasms	C00-D48	140-239, 258.0, 273.1, 273.3 excluding 237.7
Bladder	C67	188
Bone & articular cartilage	C40-C41	170
Brain	C71	191
Breast	C50 & female	174
Cervix uteri	C53	180
Colorectal	C18-C21	153-154
- Colon	C18	153
- Rectum, rectosigmoid junction & anus	C19-C21	154
Gallbladder, other & unspecified parts of biliary tract	C23-C24	156
Hodgkin's disease	C81	201
Ill-defined, secondary & unspecified sites	C76-C80	195-199
Kidney	C64	189.0
Larynx	C32	161
Leukaemias	C91-C95	202.4, 204-208
Lip, oral cavity & pharynx	C00-C14	140-149
Liver & intrahepatic bile ducts	C22	155
Melanoma of skin	C43	172
Mesothelial & soft tissue	C45-C49	158, 163, 171, 176
Multiple myeloma & other immunoproliferative diseases & plasma cell neoplasms	C88, C90	203, 238.6, 273.3
Non-Hodgkin's lymphoma	C82-C85	200, 202.0-202.2, 202.8
Oesophagus	C15	150 excluding 150.8
Ovary	C56	183.0
Pancreas	C25	157
Prostate	C61	185
Stomach	C16	151
Testis	C62	186
Thyroid gland	C73	193
Trachea, bronchus & lung	C33-C34	162
Uterus	C54-C55	179, 182

STANDARD POPULATIONS

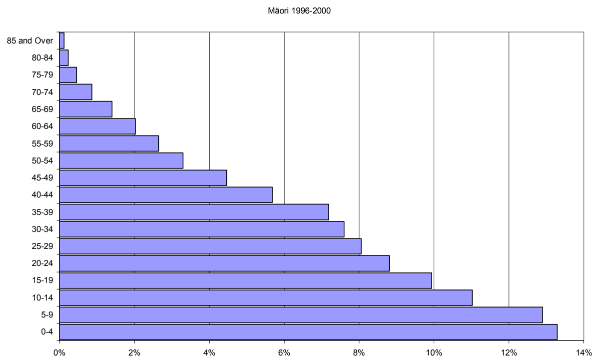
The Māori population has the youngest age distribution and the non-Māori population has the oldest. Segi's world population has a higher proportion of young people than the WHO world population and is somewhat closer to the age distribution of the Māori population.

Table v. Age-distribution of Māori & non-Māori populations 1996-2000, Segi's world population (circa 1950), WHO world population 2000-2025

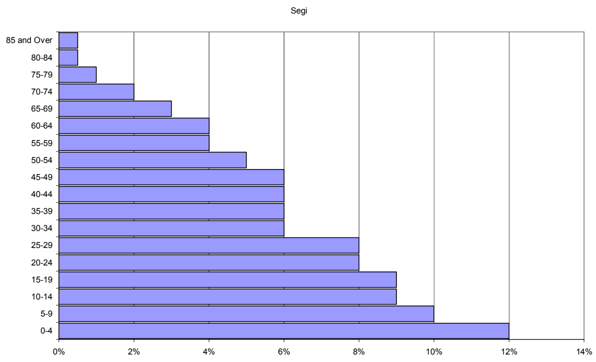
Agegroup	Māori 1996-2000	non-Māori 1996-2000	Segi's world	WHO world 2000-2025
0-4 years	13.288%	6.637%	12.000%	8.857%
5-14 years	23.921%	13.870%	19.000%	17.285%
15-24 years	18.748%	13.358%	17.000%	16.685%
25-34 years	15.653%	15.095%	14.000%	15.535%
35-44 years	12.868%	15.820%	12.000%	13.736%
45-54 years	7.765%	13.131%	11.000%	11.407%
55-64 years	4.678%	9.023%	8.000%	8.268%
65-74 years	2.267%	7.330%	5.000%	5.168%
75-84 years	0.688%	4.423%	1.500%	2.429%
85 years & over	0.123%	1.314%	0.500%	0.630%

Figure i. Age-distribution of standard populations

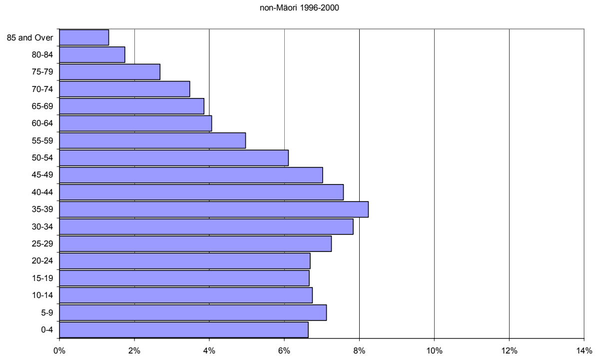
Māori population 1996-2000



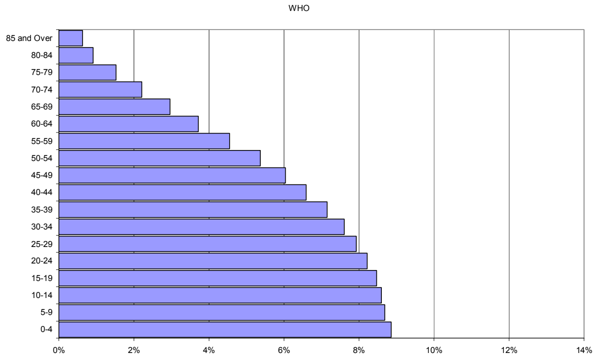
Segi's world population (~1950)



non-Māori population 1996-2000



WHO world population (2000-2025)



Impact of choice of standard on rates & ratios

Across all sites, the age-standardised rates generally increase as the age-distribution of the standard population increases, from the younger Māori population standard to the older WHO standard (see table below). The rate ratios remain fairly similar, with most sites showing a slight decrease in the rate ratios when the older standard populations are used. However, risk differences vary considerably according to the standard used – as expected given the higher rates using the WHO standard.

Table vi. Cancer registrations 1996-2001, numbers, rates per 100,000 standardised to Māori, Segi's & WHO standard populations, and rate ratios.

	Māori				non-Māori				Māori/non-Māori rate ratios		
		Rate standardised to:				Rate standardised to:					
	Number	Māori	Segi	WHO	Number	Māori	Segi	WHO	Māori	Segi	WHO
All Sites	7,410	220.9	378.4	425.0	94,284	187.8	319.2	359.1	1.18	1.19	1.18
Trachea, bronchus & lung	1,437	42.8	81.7	90.6	7,975	12.9	25.6	29.3	3.31	3.20	3.09
Female breast*	1,147	65.1	98.1	106.5	11,762	53.9	82.6	90.0	1.21	1.19	1.18
Prostate*	632	41.2	89.1	106.3	15,324	49.3	103.4	119.2	0.84	0.86	0.89
Colorectal	514	15.5	29.0	33.4	14,410	24.1	45.9	52.0	0.64	0.63	0.64
Colon	297	8.9	16.5	18.9	9,607	15.4	29.7	34.0	0.58	0.56	0.56
Rectum & anus	217	6.6	12.5	14.5	4,803	8.7	16.2	18.0	0.76	0.77	0.80
Stomach	329	9.8	17.3	19.9	2,019	3.2	6.2	7.2	3.08	2.81	2.76
Leukaemias	276	8.4	13.0	14.7	3,133	7.7	11.3	12.3	1.09	1.16	1.19
Cervix uteri*	250	14.2	17.5	19.1	985	6.3	7.5	8.3	2.27	2.33	2.30
Non-Hodgkin's lymphoma	232	6.9	11.1	12.6	3,256	6.8	11.0	12.4	1.02	1.00	1.02
Liver/intrahepatic bile ducts	183	5.6	9.4	10.1	698	1.4	2.4	2.7	3.86	3.90	3.78
Pancreas	176	5.2	9.8	11.4	1,735	2.7	5.2	6.0	1.96	1.88	1.90
Uterus*	175	9.9	16.6	17.9	1,570	6.1	10.6	11.5	1.61	1.57	1.56
Testis*	174	10.9	10.3	11.3	618	5.9	5.8	6.3	1.84	1.79	1.80
Ovary*	163	9.3	13.0	14.2	1,571	7.3	10.8	11.9	1.28	1.20	1.19
Kidney	138	4.1	6.5	7.0	1,835	3.9	6.5	7.2	1.05	1.00	0.98
Multiple myeloma	129	3.9	7.5	8.9	1,364	2.1	4.1	4.8	1.89	1.83	1.85
Thyroid gland	126	3.7	4.7	5.2	787	2.6	3.2	3.5	1.39	1.47	1.51
Lip, oral cavity & pharynx	120	3.6	5.7	6.1	1,575	3.4	5.5	6.1	1.06	1.03	1.00
Brain	119	3.5	4.7	4.8	1,402	4.5	5.8	6.1	0.79	0.80	0.79
Melanoma of skin	100	2.9	4.7	5.4	9,372	23.9	34.4	38.1	0.12	0.14	0.14
Mesothelial & soft tissue	97	2.9	3.9	4.3	1,066	2.5	3.9	4.3	1.15	1.02	0.99
Oesophagus	91	2.8	5.5	6.4	1,126	1.7	3.4	4.0	1.64	1.64	1.62
Bladder	85	2.6	5.0	5.9	3,284	5.2	10.2	12.0	0.51	0.49	0.49

Table vii. Cancer deaths 1996-2001, numbers, rates per 100,000 standardised to Māori, Segi's & WHO standard populations, and rate ratios.

	Māori				non-Māori				Māori/non-Māori rate ratios		
		Rate standardised to:				Rate standardised to:					
	Number	Māori	Segi	WHO	Number	Māori	Segi	WHO	Māori	Segi	WHO
All-sites	4,285	127.9	238.2	272.7	41,184	66.3	126.6	147.5	1.93	1.88	1.85
Trachea, bronchus & lung	1,370	40.7	79.3	88.7	7,107	11.0	22.3	25.8	3.70	3.56	3.44
Female breast*	383	21.6	33.6	37.5	3,435	12.8	21.2	23.7	1.68	1.59	1.58
Colorectal	292	8.8	17.4	20.3	6,502	9.8	19.6	22.6	0.90	0.89	0.90
Colon	158	4.8	9.3	10.9	4,310	6.3	12.8	14.8	0.76	0.73	0.74
Rectum, rectosigmoid junction & anus	134	4.1	8.1	9.4	2,192	3.5	6.8	7.8	1.17	1.19	1.20
Stomach	277	8.3	15.1	17.7	1,537	2.3	4.5	5.3	3.69	3.35	3.32
Prostate*	178	12.1	28.8	36.8	3,111	7.5	18.2	23.4	1.61	1.58	1.58
Pancreas	168	5.0	9.7	11.6	1,651	2.4	4.8	5.7	2.06	2.01	2.05
Liver & intrahepatic bile ducts	153	4.7	8.0	8.7	588	1.1	1.9	2.2	4.33	4.20	3.98
Leukaemias	137	4.1	6.7	7.6	1,392	2.8	4.5	5.2	1.46	1.50	1.47
Cervix uteri*	116	6.6	9.7	10.7	317	1.4	2.1	2.3	4.85	4.73	4.68
Non-Hodgkin's lymphoma	111	3.3	5.9	6.9	1,656	2.8	5.1	5.9	1.18	1.16	1.17
Brain	95	2.8	3.8	4.1	1,174	3.1	4.4	4.8	0.93	0.86	0.86
Oesophagus	86	2.6	5.1	5.8	1,039	1.5	3.0	3.6	1.78	1.71	1.63
Multiple myeloma	74	2.2	4.7	5.6	834	1.1	2.3	2.8	2.03	1.99	1.98
Kidney	73	2.2	3.6	3.9	801	1.3	2.5	2.9	1.64	1.41	1.35
Ovary*	69	3.9	6.6	7.4	964	3.3	5.9	6.6	1.17	1.13	1.13
Lip, oral cavity & pharynx	62	1.9	3.4	3.9	595	1.0	1.9	2.2	1.81	1.76	1.79
Mesothelial & soft tissue	57	1.7	2.5	2.7	592	1.2	2.0	2.3	1.41	1.21	1.15
Uterus*	49	2.7	5.6	6.2	410	1.2	2.2	2.6	2.28	2.48	2.40
Bladder	36	1.1	2.4	3.1	980	1.2	2.6	3.3	0.91	0.91	0.93
Melanoma of skin	15	0.4	0.8	1.0	1,352	2.8	4.6	5.2	0.15	0.17	0.20
Testis*	14	0.9	0.8	0.9	27	0.2	0.2	0.3	4.25	3.61	3.47

*sex-specific rates

CANCER REGISTRATION AND MORTALITY RATES WITH CONFIDENCE INTERVALS (AGE-STANDARDISED TO THE MĀORI POPULATION)

Table viii. Cancer Registrations 1996-2001

	Māori				non-Māori						
	Number	**Rate**	**(95% CI)**		**Number**	**Rate**	**(95% CI)**		**Ratio**	**(95% CI)**	
All sites	7,410	220.9	(215.9	226.0)	94,284	187.8	(186.3	189.2)	1.18	(1.15	1.21)
Trachea, bronchus & lung	1,437	42.8	(40.6	45.1)	7,975	12.9	(12.6	13.2)	3.31	(3.13	3.51)
Female breast*	1,147	65.1	(61.4	69.0)	11,762	53.9	(52.8	55.0)	1.21	(1.14	1.28)
Prostate*	632	41.2	(38.1	44.5)	15,324	49.3	(48.5	50.2)	0.84	(0.77	0.90)
Colorectal	514	15.5	(14.2	16.9)	14,410	24.1	(23.6	24.5)	0.64	(0.59	0.70)
Colon	297	8.9	(8.0	10.0)	9,607	15.4	(15.0	15.7)	0.58	(0.52	0.65)
Rectum	217	6.6	(5.7	7.5)	4,803	8.7	(8.4	9.0)	0.76	(0.66	0.87)
Stomach	329	9.8	(8.8	10.9)	2,019	3.2	(3.0	3.3)	3.08	(2.73	3.48)
Leukaemia	276	8.4	(7.4	9.4)	3,133	7.7	(7.3	8.1)	1.09	(0.96	1.24)
Cervix*	250	14.2	(12.6	16.1)	985	6.3	(5.9	6.7)	2.27	(1.97	2.62)
Non-Hodgkin's lymphoma	232	6.9	(6.1	7.9)	3,256	6.8	(6.5	7.1)	1.02	(0.89	1.16)
Liver	183	5.6	(4.8	6.4)	698	1.4	(1.3	1.6)	3.86	(3.25	4.59)
Pancreas	176	5.2	(4.5	6.0)	1,735	2.7	(2.5	2.8)	1.96	(1.67	2.30)
Uterus*	175	9.9	(8.5	11.5)	1,570	6.1	(5.8	6.5)	1.61	(1.38	1.89)
Testis*	174	10.9	(9.4	12.6)	618	5.9	(5.4	6.4)	1.84	(1.55	2.18)
Ovary*	163	9.3	(8.0	10.8)	1,571	7.3	(6.8	7.7)	1.28	(1.08	1.51)
Kidney	138	4.1	(3.5	4.9)	1,835	3.9	(3.7	4.2)	1.05	(0.88	1.25)
Multiple myeloma	129	3.9	(3.3	4.7)	1,364	2.1	(2.0	2.2)	1.89	(1.57	2.28)
Thyroid	126	3.7	(3.1	4.4)	787	2.6	(2.4	2.8)	1.39	(1.15	1.68)
Lip, oral cavity & pharynx	120	3.6	(3.0	4.3)	1,575	3.4	(3.2	3.6)	1.06	(0.87	1.27)
Brain	119	3.5	(3.0	4.2)	1,402	4.5	(4.2	4.8)	0.79	(0.65	0.95)
Melanoma of skin	100	2.9	(2.4	3.6)	9,372	23.9	(23.3	24.4)	0.12	(0.10	0.15)
Mesothelial & soft tissue	97	2.9	(2.4	3.6)	1,066	2.5	(2.4	2.7)	1.15	(0.93	1.42)
Oesophagus	91	2.8	(2.2	3.4)	1,126	1.7	(1.6	1.8)	1.64	(1.32	2.04)
Bladder	85	2.6	(2.1	3.2)	3,284	5.2	(5.0	5.4)	0.51	(0.41	0.63)
Ill-defined, secondary & unspecified sites	348	10.4	(9.3	11.5)	3,440	5.5	(5.2	5.7)	1.90	(1.70	2.13)

*sex-specific rates

Table ix. Cancer Deaths 1996-2001

	Māori				non-Māori						
	Number	Rate	(95% CI)		Number	Rate	(95% CI)		Ratio	(95% CI)	
All sites	4,285	127.9	(124.1	131.8)	41,184	66.3	(65.5	67.0)	1.93	(1.87	1.99)
Trachea, bronchus & lung	1,370	40.7	(38.6	42.9)	7,107	11.0	(10.7	11.3)	3.70	(3.48	3.92)
Female breast*	383	21.6	(19.6	23.9)	3,435	12.8	(12.3	13.4)	1.68	(1.51	1.88)
Prostate*	178	12.1	(10.5	14.1)	3,111	7.5	(7.2	7.8)	1.61	(1.38	1.88)
Colorectal	292	8.8	(7.9	9.9)	6,502	9.8	(9.5	10.1)	0.90	(0.80	1.02)
Colon	158	4.8	(4.1	5.6)	4,310	6.3	(6.1	6.5)	0.76	(0.64	0.89)
Rectum and anus	134	4.1	(3.4	4.8)	2,192	3.5	(3.3	3.6)	1.17	(0.98	1.40)
Stomach	277	8.3	(7.4	9.4)	1,537	2.3	(2.1	2.4)	3.69	(3.23	4.21)
Cervix*	116	6.6	(5.5	7.9)	317	1.4	(1.2	1.5)	4.85	(3.87	6.06)
Pancreas	168	5.0	(4.3	5.8)	1,651	2.4	(2.3	2.6)	2.06	(1.75	2.42)
Liver & intrahepatic bile ducts	153	4.7	(4.0	5.5)	588	1.1	(1.0	1.2)	4.33	(3.59	5.22)
Leukaemia	137	4.1	(3.5	4.9)	1,392	2.8	(2.6	3.0)	1.46	(1.22	1.76)
Ovary*	69	3.9	(3.0	4.9)	964	3.3	(3.1	3.6)	1.17	(0.91	1.50)
Non-Hodgkin's lymphoma	111	3.3	(2.7	4.0)	1,656	2.8	(2.6	2.9)	1.18	(0.97	1.44)
Brain	95	2.8	(2.3	3.5)	1,174	3.1	(2.8	3.3)	0.93	(0.75	1.15)
Uterus*	49	2.7	(2.0	3.5)	410	1.2	(1.0	1.3)	2.28	(1.68	3.09)
Oesophagus	86	2.6	(2.1	3.2)	1,039	1.5	(1.4	1.6)	1.78	(1.43	2.23)
Multiple myeloma	74	2.2	(1.8	2.8)	834	1.1	(1.0	1.2)	2.03	(1.59	2.58)
Kidney	73	2.2	(1.7	2.8)	801	1.3	(1.2	1.4)	1.64	(1.29	2.10)
Lip, oral cavity & pharynx	62	1.9	(1.5	2.4)	595	1.0	(0.9	1.1)	1.81	(1.39	2.37)
Mesothelial & soft tissue	57	1.7	(1.3	2.2)	592	1.2	(1.1	1.3)	1.41	(1.07	1.86)
Bladder	36	1.1	(0.8	1.5)	980	1.2	(1.1	1.3)	0.91	(0.65	1.28)
Gallbladder	35	1.1	(0.8	1.5)	306	0.4	(0.4	0.5)	2.57	(1.79	3.68)
Testis*	14	0.9	(0.5	1.5)	27	0.2	(0.1	0.3)	4.25	(2.18	8.31)
Melanoma	15	0.4	(0.3	0.7)	1,352	2.8	(2.6	3.0)	0.15	(0.09	0.26)
Thyroid	12	0.3	(0.2	0.6)	97	0.1	(0.1	0.2)	2.34	(1.26	4.34)
Ill-defined, secondary & unspecified sites	260	7.8	(6.9	8.8)	2,739	3.9	(3.7	4.1)	2.00	(1.75	2.28)

* sex-specific rates

APPENDIX FOUR: STOCKTAKE METHODS

Key cancer stakeholders were identified initially through the research team and advisory group networks, internet searches and provider directories. Stakeholders included iwi, Māori community groups, the Ministry of Health, District Health Boards, Primary Health Care Organisations, the Cancer Society, the Health Promotion Forum, professional bodies, Māori health providers and specialist cancer service providers. A letter was sent to 118 stakeholders nationwide, explaining the study and seeking their assistance in identifying providers of interventions to facilitate Māori access to cancer services. The letter was followed up by telephone and/or email contact after a two-week period. Stakeholders provided names and contact details for other stakeholders and potential intervention providers, which complemented contact details identified through internet searches and provider directories.

One hundred and forty potential intervention providers were contacted to discuss the study and where appropriate to invite their participation. Of those contacts, 80 providers met the criteria of providing cancer services or Māori health services that delivered to people with cancer and/or their whānau. Within the study timeframe 39 providers were interviewed. Twenty one Māori providers and eighteen mainstream providers were interviewed. Informally discussion with the 80 providers indicated that the 39 interviewees covered the range of services that provided interventions to facilitate Māori access to cancer services.

In addition, meetings were held with a number of key informants and stakeholders in cancer control and service provision.