

# **Cancer Screening and Early Detection**

**Report of the Cancer Screening  
and Early Detection**

**Expert Working Group to the Cancer  
Control Steering Group**

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# Introduction

This document outlines the work of the screening and early detection expert working group and provides supporting documentation that sets out the rationale for these recommendations.

## Process

The Screening and Early Detection Expert Working Group met on four occasions over the period April–September 2002: two face-to-face meetings and two teleconferences. The group was chaired by Dr Brian Cox and supported by Betsy Marshall from the New Zealand Cancer Control Trust and Bridget Caird from the Ministry of Health.

The purpose of the first meeting, held on 19 April 2002, was to identify potential Candidate Priority Actions for screening and early detection. The aim of the subsequent teleconference was to confirm the minutes from the meeting and to provide comments on a first draft of the report from the Expert Working Group.

The purpose of the second face-to-face meeting and subsequent teleconference was to finalise the group's report and Candidate Priority Actions. This report and the attached templates are the results of the deliberations and work of the Cancer Screening and Early Detection Expert Working Group.

## Definitions

### Screening programmes

A public health service in which members of a defined population, who do not necessarily perceive they are at risk of, or are already affected by, a disease or its complications, are asked a question or offered a test to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of disease or its complications (UK National Screening Committee 2000).

### Cancer screening

Cancer screening is the early detection of cancer, or precursors of cancer, in individuals who do not have symptoms of cancer. These interventions are often directed to entire populations or to large and easily identifiable groups within the population.

### Opportunistic or ad hoc screening

Opportunistic screening refers to screening tests that are applied to individuals outside of an organised screening programme. In this situation the risks and benefits of testing are borne by the individual undergoing the test, as opposed to a defined population. Opportunistic screening is resource intensive, carries real, but frequently unacknowledged, risks and is unlikely to provide benefits at a population level or be cost-effective.

## **Surveillance**

The ongoing assessment of an individual for the purpose of instituting appropriate intervention to reduce their risk of death from a specific cancer.

## **Familial cancer risk assessment**

Familial cancer risk assessment is the investigation of:

- a reported family history of cancer
- an individual with no family history who develops cancer at a much younger age than is usual for the type of cancer

to assess cancer risk for individuals and members of their family. It includes the development of a clinical management plan to reduce their risk where possible without undue harm or anxiety. This may involve testing for specific genetic traits linked to an evidence-based management plan.

## **Early detection**

The detection of cancer prior to the development of symptoms or as soon as is practicable after the development of symptoms.

# Candidate Priority Action One: Provide at a National Level a Systematic Approach to Cancer Screening, Familial Risk Assessment and Surveillance to Ensure their Quality, Acceptability and Effectiveness

## Current status

In New Zealand, high-level cancer screening recommendations have been made by different groups at different times (Skegg et al 1985; Skegg et al 1988, Elwood et al 1988; Paul et al 1991; National Health Committee 1996; Members of the Working Party on Cervical Screening 1997; Members of the Breast Cancer Screening Policy Advisory Group 1998; Working Party on Screening for Colorectal Cancer 1998; Te Manawa Hauora 1993).

This work has frequently been undertaken as a result of external requests and lobbying rather than as part of an organised, ongoing approach. Furthermore, once the groups have provided their advice, they have been disbanded with no ongoing oversight of implementation.

There is a need for clarity regarding roles and responsibilities for this work. The National Health Committee has a role but it has a very broad mandate and is not able to provide the continuous, ongoing oversight required. The National Screening Unit within the Ministry of Health is dedicated to ongoing national management of all operational aspects of New Zealand's two existing cancer screening programmes. Its mandate does not include other areas of cancer screening and its focus, appropriately, is not on broader, strategic cancer screening issues.

There is no established process to review the appropriateness of cancer screening programmes and policies, and no single body has specific responsibility for developing guidelines and recommendations for cancer screening, or for monitoring their implementation. This has led to an ad hoc approach and one where there have been one-off reports and recommendations but no ongoing strategic oversight.

## Objectives

- The establishment of an effective national mechanism, such as a national cancer screening committee, would serve to maximise the health benefit from our investments in cancer screening in New Zealand. It would ensure there was a systematic approach to the establishment and delivery of cancer screening and familial risk assessment resulting in effective and efficient programmes appropriate to the New Zealand setting. For example, a mechanism of this sort would likely have advised on the deficiencies in the New Zealand National Cervical Screening Programme (NCSP) at a much earlier stage enabling corrective action to be taken. Further, advice from a national mechanism, such as a national cancer screening committee, might lead to a reduction in ad hoc primary care based screening (for example, prostate-specific antigen or PSA

testing) which is resource intensive but at the current time not cost-effective and of limited benefit.

- A national mechanism of this sort should be able to influence both decision-making processes and clinical practice through the distribution of a well-considered annual report that provides clear recommendations on specific cancer screening issues. By providing a high-level oversight of cancer screening and familial cancer risk assessment, a national structure will be able to highlight issues and challenges confronting existing programmes and services thereby working to reduce gaps in service provision.
- The establishment of a national mechanism, such as a national cancer screening committee, provides for potential co-ordination and integration with other services and strategies, including those specifically developed for Māori. For example, such a committee would be linked with the wider cancer control network, cancer epidemiology units, academic units doing primary research, and the National Screening Unit as well as any other relevant national committee that might be established in the future.

## Recommendations

### Goal

To contribute to cancer prevention and a reduction in cancer mortality and morbidity by ensuring a systematic approach to the review, introduction, delivery and evaluation of cancer screening and familial risk assessment in New Zealand through the establishment of an ongoing national mechanism, such as a national cancer screening committee. Such a mechanism would publish an annual report which would be widely distributed to the sector and available to the public.

### Target

A national mechanism, such as a national cancer screening committee, with appropriate secretariat support, should be established by December 2003.

### Actions

The establishment of a national mechanism will require the following actions:

- set up of required structure, accountability, funding and reporting arrangements
- set up of dedicated secretariat
- appointment of experts.

The Expert Working Group considered three options for the structural relationships of a national committee, which is one example of a potentially effective national-level mechanism. These include a national cancer screening committee as a:

1. sub-group of a future national screening committee
2. part of a future cancer control structure

3. subgroup of the existing National Advisory Committee on Health and Disability (NHC).

Long term, the group's preference was for option 2 and members would see this as the ultimate goal. However, in recognition of the fact that such a structure does not currently exist and considering the importance of the issue, the group considered that option 3 would be acceptable as an interim measure. The group recognised that there may be legislative implications and that these would need to be assessed.

However, because a committee would be providing independent advice to the Government on a wide variety of cancer screening activities and would have a role in monitoring the uptake of this advice, it is essential that it is independent of the Ministry of Health.

### Expected outcomes

- Improved assessment and decision-making processes relating to potential and/or proposed screening programmes and screening activities.
- Improved effectiveness and cost-effectiveness of cancer screening and familial cancer risk assessment.
- Improved understanding of cancer screening and familial cancer risk assessment at all levels of the health sector through a widely distributed annual report and provision of other expert advice.
- Reduced cancer morbidity and mortality from well-organised, high-quality, acceptable evidence-based cancer screening and familial cancer risk assessment services.
- Culturally appropriate screening services, including familial risk assessment.
- A reduction in ad hoc screening and in inequalities between Māori and non-Māori participation in breast and cervical screening programmes.
- Guidelines, policies and monitoring of treatment of patients and their outcomes will improve the quality of treatment services beyond just those for patients identified by screening.

# Candidate Priority Action Two: Establish a Process to Assess the Value of Early Detection of Cancer Other than that Obtained through Organised Screening

## Current status

Overall cancer survival rates in New Zealand appear relatively poor and are worse for Māori than for non-Māori (Skegg and McCredie 2002).

There is evidence that survival from some cancers may be improved by early detection and treatment and that delays in detection and treatment do occur in some population groups in New Zealand (Lawes et al 1999).

Currently, in New Zealand it is not known to what extent delays in diagnosis and treatment are contributing to our apparently high cancer mortality rates and there is no process established to determine this. This information is essential prior to any consideration of strategies promoting early detection outside of organised screening programmes.

## Objective

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

## Recommendations

### Goal

To contribute to a reduction in both cancer mortality and morbidity among New Zealanders as a whole, and inequalities between Māori and non-Māori in cancer mortality and morbidity, through the implementation of strategies that facilitate early detection and treatment of cancers for which early detection is both possible and cost-effective.

### Target

To establish at a national level a process to assess the value of early detection of cancer by 30 June 2005.

### Actions

The initial actions would be to:

- identify an appropriate sponsor for this work (a national structure, such as a national cancer screening committee)

- secure a budget for the research
- identify and prioritise the research required
- identify the agency that would develop the research methodology.

### **Expected outcomes**

- Identification of those cancers for which early detection and treatment is both feasible and cost-effective.
- Improved understanding amongst the public and health professionals of the role of early detection in reducing morbidity and mortality from selected cancers.
- Reduced time between onset of symptoms and diagnosis for specific cancers (reduced stage).
- Reduced mortality and morbidity from selected cancers over time.
- Reduction in the inequalities between Māori and non-Māori in mortality and morbidity from selected cancers.

# Current Status of Cancer Screening and Early Detection in New Zealand

Cancer screening occurs in New Zealand as part of both organised screening programmes, and in an opportunistic fashion.

## Existing cancer screening programmes

New Zealand has two national cancer screening programmes, overseen at a national level by the National Screening Unit (NSU) within the Public Health Directorate of the Ministry of Health.

### National Cervical Screening Programme

The National Cervical Screening Programme (NCSP) was the first national cancer screening programme established in New Zealand and was piloted in Marlborough (1989) and Whanganui (1990) before being progressively implemented in each of the Area Health Boards in 1990 and 1991. The programme is targeted at women aged 20–69 years and promotes a three-yearly cervical smear test (or more often if this is clinically recommended) and provides for the reading of the smear and any follow-up that is required. Guidelines for the management of abnormalities detected have been propagated (Jones et al 2000). The aim of the programme is to reduce the incidence of, and mortality and disability from, squamous cell cancer of the cervix by detecting precancerous changes in the cervix. The NCSP incorporates: health promotion; smear-taking services including recall and referral; laboratory services including reading of all cervical cytology and histology samples relating to cervical screening; colposcopy services including biopsy and treatment of pre-cancerous lesions; national management and co-ordination; regional co-ordination; information management; and monitoring and evaluation.

In the last few years the programme has benefited from an improved approach to national co-ordination, the introduction of detailed operational policy and quality standards, ongoing monitoring and evaluation and a nationally consistent approach to health promotion. An independent monitoring group provides ongoing quantitative monitoring of the Programme and a Ministry-based team is conducting an audit of cases of invasive cervical cancer with support from epidemiologists at the University of Auckland.

### BreastScreen Aotearoa

BreastScreen Aotearoa (BSA) was launched nationally in December 1998 following two pilot programmes in Waikato and Otago–Southland. It offers women aged 50–64 years a two-yearly mammogram and any necessary further assessments to determine if breast cancer is present. The programme aims to reduce the mortality from breast cancer by detecting breast cancer in its early stages when early treatment provides greater health gains. The programme is delivered principally by six lead providers to nationally consistent standards and policies. Each of these providers promotes the programme, as well as providing screening mammography, follow-up multidisciplinary assessment, counselling and support, and an information system to support BSA.

An Independent Monitoring Group provides ongoing monitoring and evaluation, while the NSU conducts an ongoing process of provider compliance audits.

### **National Screening Unit**

The National Screening Unit is sited within the Ministry of Health and is responsible for national operational management and funding of the current two national cancer screening programmes. Agreement for a national structure with 33 to 35 full-time equivalent staff and an operating budget occurred in November 2000 with development of position descriptions and intensive recruitment to the unit commencing shortly thereafter. A Group Manager manages the unit alongside a Public Health Leader for Screening Programmes, and there are Clinical Leaders for each of the cervical and breast screening programmes. The unit has six teams: breast screening, cervical screening, monitoring and audit, information systems, contracts and finance, and Māori screening development.

### **Other cancer screening programmes recently considered**

The National Health Committee (NHC) has critically examined the value of screening for colorectal cancer and prostate cancer in New Zealand in the last few years. In both cases this work was undertaken by specific, dedicated working parties established to review the evidence and advise on the issue. In both cases, following extensive review and consideration of the evidence, the NHC has recommended against implementing population-based screening for these diseases.

For prostate cancer, the NHC states that to date there is no evidence that improved survival or quality of life results from screening asymptomatic men using either prostate-specific antigen (PSA) testing or digital rectal examination (DRE) (National Health Committee 1996). Evidence since 1996 is currently being reassessed by the New Zealand Guidelines Group under contract to National Health Committee and a report is due in May 2003.

For colorectal cancer, the Working Party concluded that population-based screening using faecal occult blood (FOB) tests conveys only potential modest benefits while holding a small, but real potential for harm (Working Party on Screening for Colorectal Cancer 1998). Population-based colorectal cancer screening with other methods such as flexible sigmoidoscopy, colonoscopy or double-contrast barium enema was also not recommended due to lack of evidence, from randomised control trials, of reductions in colorectal cancer mortality. The Working Party acknowledged that randomised control trials with newer faecal occult blood tests and other modalities are underway and all new evidence should be reviewed, as it becomes available.

A New Zealand Guidelines Group working party is currently defining the groups who are at higher risk of developing colorectal cancer and making surveillance recommendations for these groups. These recommendations are due for release in early 2003.

A hepatitis B carrier detection screening programme was established in two geographic areas of the North Island in 1999, following a decision not to proceed with an initial pilot study. The aim of the programme is to screen 70 percent of Māori, Asian and Pacific peoples between 15 and 45 years for hepatitis B, in order to immunise non-immune individuals and to provide surveillance for carriers. To date, it appears that screening coverage rates remain low at between 20 and 40% of the target population.

There are several issues in relation to hepatitis B carrier screening which require further discussion and where guidance is needed. These include: ethical issues; issues for particular at-risk groups (Paul and Thomas 1997); observation of carriers; relative merits of other cost-effective programmes to control the disease; and the need for further research.

### Opportunistic cancer screening

No national policies exist for the screening of many cancers (for example, melanoma, stomach, lung, liver, or testicular cancer). However, opportunistic cancer screening tests are available through primary care providers (for example, mammographic screening, prostate specific antigen testing for prostate cancer, and faecal occult blood for colorectal cancer). In some cases the screening is organised by the wider primary health care organisation with potential participants actively invited and recalled. This is particularly so for mammographic screening of women ineligible for the national programme or who are perceived to be at high risk of the disease.

### Early detection (outside of organised cancer screening programmes)

New Zealand appears to have high cancer mortality rates and within that Māori have poorer survival from cancer than do non-Māori (Skegg and McCredie 2002).

There is evidence both that early detection of some cancers (for example, melanoma, certain breast cancers, colorectal cancer in those with a genetic predisposition) has a favourable impact on patient outcomes and that the converse is also true, delayed diagnosis and treatment of cancer may adversely affect patient outcomes (Feldman et al 1983; Arbman et al 1996; Richards et al 1999). In New Zealand there is at least some evidence that delays in presentation with cancer remains common among some population groups (Lawes et al 1999, Newman et al 1992).

Early cancer detection by health care workers, coupled with timely referral for specialist assessment and investigation, is an important component to effect control of several cancers. The Cancer Society of New Zealand and the Health Sponsorship Council are reviewing the evidence in this area with a view to identifying strategies to improve the early detection of melanoma.

However, it is unclear in this country to what extent delays in diagnosis and treatment are contributing to New Zealand's apparently poor cancer survival statistics. It is also unclear which interventions to promote early presentation of symptoms, and thus referral for diagnosis and treatment of those with cancer, have the potential to improve survival and quality of life.

## **Familial risk**

About 5 percent of cancers are familial, frequently affecting predisposed individuals at young ages. With foreknowledge, the development of cancer in susceptible individuals can be prevented with the potential for years of life gained being highest for young people with a familial risk for cancer. Part of the assessment of the familial risk of cancer may involve genetic testing for genetic traits or the presence of specific genes.

Familial cancer risk assessment involves counselling, confirmation of family history and, where clinically indicated, genetic testing. This mainly occurs for the assessment of the risk of breast, ovarian and colorectal cancer. At-risk individuals are identified when those with a strong family history or those who are diagnosed at a young age are referred to specialist genetic clinics by their general practitioners for assessment (and, in some cases, by self-referral). Currently the National Cancer Registry is not involved with the identification of families at significantly increased risk of cancer.

Familial cancer risk assessment is an ethically and technically complex area requiring a nationally co-ordinated response to ensure safe, high-quality, nationally consistent and equitable services.

Currently there are two regional familial risk assessment services operating in New Zealand. These are based in Auckland and Wellington. The Wellington service covers the lower part of the North Island as far north as Hawkes Bay, and the entire South Island. The Auckland-based service covers Northland, Auckland and as far south as Tairāwhiti. Individuals and families can be referred by their regular health professional, but self-referrals are also accepted. Access to services is not equitable and to date referrals have tended to come mainly from urban centres. However, an attempt is being made to communicate the availability of the service to rural communities. No national guidelines are available specifying who should be referred to these services.

# Current Issues

## Requirement for strategic oversight of cancer screening issues

Appropriate, high-quality, organised, cancer screening programmes are among the most powerful cancer control strategies available (Screening Working Group 2002). Currently in New Zealand however, there is no single national body with specific ongoing oversight of all the strategic aspects of cancer screening including familial cancer risk assessment. There is no established review process for current strategic cancer screening policies and no single body has specific responsibility for providing advice and recommendations for cancer screening and ensuring all the required elements are in place to support existing and future programmes.

Recommendations for cancer screening have been made by different groups and organisations at different times, frequently by expert groups convened for a single purpose, and subsequently disbanded (for example, Skegg et al 1985; Skegg et al 1988; Elwood et al 1988; Paul et al 1991; National Health Committee 1996; Members of the Working Party on Cervical Screening 1997; Members of the Breast Cancer Screening Policy Advisory Group 1998; Working Party on Screening for Colorectal Cancer 1998; Te Manawa Hauora 1993).

The work outlined above has frequently been undertaken in response to external requests and lobbying rather than as part of any ongoing approach and appropriate action has not always resulted. For example, despite expert advice in 1985 urging the establishment of an organised cervical cancer screening programme in New Zealand, the decision to advance this only really gained momentum subsequent to the release of the Cartwright report (Cartwright 1988). Moreover, although pilot breast-screening programmes were established in 1991, the decision to establish a national programme was made by the then Minister of Health prior to results from the final pilot evaluations becoming available and considered, and prior to the establishment of a Breast Cancer Screening Policy Advisory Group (BCSPAG) to determine high-level programme policy.

In addition, an ongoing process is required for review of cancer screening recommendations, development of policies and advice on key screening issues, and potential new technologies. For example, participation by Māori women in both the breast and cervical screening programmes has been relatively poor since the inception of both programmes, but no strategic review of this issue has occurred. When work by Gotzsche and Olsen (2000; Olsen and Gotzsche 2001) questioned the benefits of breast screening it was not clear who in the sector was responsible for critically reviewing this and advising what, if any, action was required.<sup>1</sup> In addition, guidance on the appropriate surveillance of women deemed to be at high risk of developing breast cancer was identified as an urgent requirement but has not been developed. Further, a number of new technologies that will demand consideration are on the horizon (new screening modalities for breast screening; human papilloma virus testing in cervical cancer and spiral computerised tomography

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<sup>1</sup> The Ministry of Health and Health Funding Authority did collaborate to ensure a review of the initial work was commissioned.

screening for lung cancer). Currently, there is no dedicated mechanism for ongoing oversight of these issues.<sup>2</sup>

This situation ensures that New Zealand's response to developments in cancer screening remains ad hoc and discontinuous. Some of the risks of this approach have been graphically illustrated in the situation that arose in the National Cervical Screening Programme, and have been fully described in the report of the Gisborne Inquiry (Duffy et al 2001).

## **Requirement for systematic follow-up of recommendations**

The National Health Committee has sponsored work on colorectal screening in New Zealand following the need for this being brought to its attention by the Cancer Society of New Zealand. At present the Committee's advice is not to establish an organised national programme. However, it recommended that this decision be reviewed when new evidence becomes available. It is unclear who is responsible for monitoring such evidence and identifying the timing of such a review.

A working group to develop advice on surveillance recommendations for groups identified to be at increased risk of colorectal cancer is due to report its findings in late 2002. However, it is not at all clear how the group's recommendations will be implemented and no body exists that is dedicated to maintaining a watching brief of the implementation process to ensure this occurs in a planned and consistent manner throughout the country.<sup>3</sup> District Health Boards are not sufficiently resourced to implement organised screening programmes, which in a country the size of New Zealand, should be centralised.

A further example of the need for systematic follow-up relates to extension of the national breast screening programme to women aged 65–69 years. Although the advice from BCSPAG was to establish a programme for women aged 50–69 years, the government of the time determined that a programme would be established for women aged 50–64 years inclusive, and also stated that the age range would be reviewed when the programme was 'up and running well'. However, in the absence of a clear mechanism for reviewing the original advice and the status of the current programme, no clear path exists for advising the government on this issue. Currently, all advice would come from the National Screening Unit – a unit charged with predominantly operational issues and not necessarily well positioned to provide this strategic advice.

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<sup>2</sup> In the United Kingdom the National Screening Committee has an ongoing role in ensuring constant surveillance of all manner of issues relating to screening.

<sup>3</sup> While it is possible that this work may fall to the National Screening Unit, this new organisation would require significant additional workforce, budget and guidance to enable successful implementation.

## Addressing inequalities and ensuring high-quality, accessible, appropriate screening for Māori

Despite the particular efforts of the National Cervical Screening Programme and BreastScreen Aotearoa to recruit and screen Māori women, coverage for Māori within both programmes remains lower than that for non-Māori women. This is a continuing source of health inequalities as Māori women cannot benefit from the programme to the same extent as non-Māori while their coverage rates remain so low.

National Māori consensus is that the Treaty of Waitangi is central to screening. Māori want screening programmes that are integrated within the health service and accessible through primary care, where this is feasible. Māori consider that screening programmes need to be developed comprehensively and implementation should occur only when downstream services are in place. Barriers to access need to be addressed, and screening needs to be linked into other existing wellness tools. Information relating to Māori, held by a screening programme, needs to be managed and used sensitively. In addition to these requirements Māori agree that each of the 10 requirements of the World Health Organization for an effective screening programme need to be met (Te Manawa Hauora 1993).

## Inappropriate use of scarce resources

There is a need for a body charged with ensuring the rationale for decisions about implementing organised screening programmes is communicated to all health professionals and the public. The lack of such a resource means that opportunistic screening frequently occurs with little benefit and, as such, results in a diversion of resources away from effective screening activities. A recent article in the *New Zealand Doctor* highlighted the poor general understanding of screening among the health workforce and the need for ongoing, readily available, evidence-based advice to the health sector and consumers (St John 2002). General practitioners in particular, need to be able to discuss these issues with patients and the sector requires this information to enable appropriate funding and operational policy decisions to be taken.

For example, although organised screening for prostate cancer is not currently recommended, a great deal of ad hoc prostate specific antigen screening tests are being carried out with dubious benefit and known harm. Similarly, much ad hoc screening of breast cancer in young women is occurring and yet there is a lack of clear national guidance on this issue. In some parts of New Zealand, community service organisations promote faecal occult blood testing by providing test kits and arranging for samples to be sent to a local laboratory for reading. In the past, local Cancer Societies organised annual 'spot test' days for melanoma so the public could have their skin checked by skin specialists or general practitioners. Although no longer endorsed by the Cancer Society such services do continue in some parts of New Zealand, either at public venues or general practice surgeries.

## Assessment of flow-on effects of screening required

Cancer screening programmes also create flow-on effects for individuals and health services external to the programme itself.

For example, the establishment of the national breast screening programme has led to pressure on breast cancer treatment services and has raised questions about the management of women at high risk of developing breast cancer who are ineligible for the programme. Similarly, the surge in prostate-specific antigen testing is increasing demand for diagnostic and treatment services.

There are workforce implications when screening programmes are introduced both for the workforces involved in delivering the programme and those involved in treating individuals who are diagnosed through the programme. There has been evidence of this stress on the radiotherapy workforce with the introduction of BreastScreening Aotearoa. While acknowledging the significant work the National Screening Unit has done in developing and commencing implementation of a workforce strategy for breast and cervical cancer screening, this strategy cannot address the flow-on effects of those screening programmes to treatment services.

Again, there has been no dedicated body with responsibility for ensuring that such issues are recognised at an early stage and addressed before crises arise.

# Role of a National Mechanism for Cancer Screening

As an example of a national mechanism, a national cancer screening committee would enable many of the above-mentioned issues to be addressed proactively by setting the strategic goals of cancer screening programmes, recommending what cancer screening programmes should proceed and what structures and processes are necessary for their development. Such a committee would also be responsible for maintaining a watching brief on existing New Zealand cancer screening programmes and overseas developments in screening for cancer.

## National Cancer Screening Committee draft terms of reference

A national cancer screening committee would:

- be an independent multidisciplinary group of experts, which would include appropriate Māori representation
- meet quarterly
- advise on:
  - the case for and against implementing new population cancer screening programmes within New Zealand and, where recommended, the process and resources required to ensure optimal implementation
  - the case for continuing, modifying or withdrawing existing population cancer screening programmes; in particular, programmes inadequately evaluated or of doubtful effectiveness, quality, or value
  - the case for implementing various familial risk assessment services
  - screening technologies of proven effectiveness but which require controlled and well-managed introduction
- be evidence-based in its approach and would also take into account the particular characteristics of the New Zealand health service when formulating its advice
- recognise the commitment of the government to the Treaty of Waitangi and the particular needs of Māori when formulating its advice
- develop a conceptual framework identifying the criteria and principles for cancer screening and familial cancer risk assessment in New Zealand
- maintain a high-level oversight of all aspects of cancer screening and familial cancer risk assessment programmes focusing in particular on: ensuring key programmatic elements are in place (including access to high-quality treatment services); effectiveness and cost-effectiveness of programmes; and quality assurance
- establish multidisciplinary working groups (including those with relevant clinical expertise) to address specific issues requiring detailed review
- receive reports and meeting minutes from Advisory Committees for specific cancer screening programmes

- report annually
- produce an annual report that would be widely distributed within the health sector and available to the public.

## **Canadian strategy on cancer control: Draft operating principles of a national cancer screening committee**

The following provides some level of detail as to the desired operating principles of a National Cancer Screening Committee.

1. **Ensure an evidence-based process is undertaken for considering new, and evaluating the case for continuing, modifying or withdrawing existing cancer screening programmes and cancer screening guidelines**

Adherence to the established principles of screening (Wilson and Jungner 1968) is required when evaluating screening programmes. These principles have been recently adapted (Screening Working Group 2002) and are recommended by the Expert Working Group as the principles to be used in New Zealand when assessing cancer screening programmes and guidelines.

- The target cancer should be appropriate for screening.
- The objectives of screening must be clearly identified.
- There should be an appropriate screening test.
- There should be agreement on the appropriate management of people with positive results on the screening test.
- There must be sound evidence that screening impacts favourably on its intended objectives. This evidence must deal effectively with critical potential biases, including length, lead time, over-diagnosis and selection bias. Randomised controlled trial (RCT) evidence should be of the required standard, wherever possible, for new screening strategies.
- Screening should do more good than harm.
- The health care system should be capable of supporting all necessary elements of screening, including diagnosis and treatment.
- Screening should be endorsed only if it is provided in a continuous manner in conjunction with the necessary quality assurance and programmatic elements.

In addition, the planning and implementation of cancer screening should be in keeping with the Treaty of Waitangi principles of partnership, protection and participation.

More detail can be found in Appendix 2 of this report.

**2. Provide ongoing high-level oversight to ensure the key elements are in place for both new and existing organised cancer screening programmes**

Effective population cancer screening requires specific structures and processes. Managerial aspects of programmes have been identified as important in determining the effectiveness of screening programmes (World Health Organization 1995). Failure to incorporate these key elements can waste resources and lives. It is therefore important that there is oversight of existing cancer screening programmes.

The following summary of the key elements of cancer screening programmes has, with minor modification, been reproduced from the draft report of the Screening Working Group of the Canadian Strategy for Cancer Control. It is envisaged that the National Cancer Screening Committee will use this list to assess New Zealand cancer screening programmes at a high level to ensure they provide an effective and efficient service to the New Zealand population.

- Screening must be comprehensive and culturally appropriate, including recruitment, recall, follow-up and timely assessment of people with positive tests. Accurate information about eligible individuals, particularly their current address, is an invaluable adjunct to a screening programme. In addition, privacy legislation should allow the appropriate use of this information to support cancer screening programmes.
- The necessary workforce required for screening programmes needs to be developed before screening programmes are implemented (including at a national level). Appropriate training and education for those involved in screening programmes is required. The workforce needs to reflect the cultural diversity of New Zealand.
- Screening must be supported by public education, including education about primary prevention when applicable. Public education must address the cultural and linguistic diversity of the population and the unique needs of hard-to-reach groups.
- Screening must be supported by education of health care providers. The participation of primary care providers is essential to the success of any population cancer screening programme. Primary care providers must understand all aspects of the screening programme so that they can counsel their patients appropriately and assist in linking them to the different elements of the screening programme.
- All eligible people should have reasonable access to screening, diagnostic assessment and treatment, in keeping with the principles of equity and distributive justice. This may have important implications for the choice of screening test and the organisation of the programme.
- Participation in a screening programme should be on the basis of a realistic understanding of the harms and benefits of screening and the manner in which health information will be managed. Participation should be voluntary with the ability to opt out at any time.
- All aspects of the screening programme must be of high quality, supported by minimum standards, evidence-based guidelines and promotion of best practice.

- All aspects of the screening programme must be subject to continuous monitoring and evaluation. The results of this monitoring and evaluation should be available to the public. The programme must ensure that it at least meets to performance standards of the randomised clinical trials on which it is based. The programme must have the capacity to change its programmatic elements based on the results of evaluation.
  - Screening programmes must adopt a culture of continually striving to increase the benefits and minimise the harms of screening.
  - The programme must have the capacity to modify screening standards, guidelines and best practices based on new scientific evidence.
  - The programme must be supported by an effective and efficient computerised information system designed to accommodate the needs for confidentiality and information sharing. Data elements should be consistent across and between district health board regions to facilitate surveillance, evaluation and research.
  - There must be the provision of adequate resources (financial, physical, human and informational) to support all aspects of screening.
  - Screening programmes must include a consumer perspective in all aspects of their planning and operations.
3. Provide a process for planning services and the development of guidelines for the management of familial risks of cancer, including genetic testing where clinically indicated

Gains in our ability to understand the genetic basis of cancer and the public desire to know their genetic risk underpins the need for a national process for planning services and developing guidelines for the management of patients with significant familial risks of cancer.

A co-ordinated national service to assess familial risk of cancer and the development of regionally consistent management plans for those with a strong family history would need to address the following issues:

- multi-factorial cancers
- variability in hereditary risks
- geographic variability in access
- co-ordinated national access to laboratories, here or overseas, for rare or specialised testing.

The key issues that need to be addressed are the training of geneticists and genetic counsellors. The role of medical and surgical oncologists in familial cancer risk assessment and cancer genetics needs to be defined to ensure consistency of practice and continuity of care. Their activities need to be integrated with other services involved in the assessment of familial cancer risk. In addition, other health professionals need better information and education on the nature of familial cancer risk assessment and what it entails.

Ethical issues in familial cancer risk assessment and genetic testing are complex and need to be clearly understood by those providing these services. Genetic testing must remain an option not a 'given' part of the assessment process and the right 'not to know' must always be respected.

The following key questions need to be addressed to improve the co-ordination of familial cancer risk assessment services.

- Who gets referred and how?
- Who gets tested?
- What tests are done?
- Who does the tests?
- Who pays for the tests?
- Who is responsible for quality control of the tests and quality assurance of the service provided?
- Patent issues (who owns the test)?

# Options for the Structure of a National Cancer Screening Committee

The following options have been considered by the Expert Working Group in formulating the recommendation for an effective national mechanism, such as a national cancer screening committee.

Because such a committee would be providing independent advice to the Government on a wide variety of cancer screening activities and would have a role in monitoring the up-take of this advice, it must be independent of the Ministry of Health. Therefore, only options that provide this level of independence have been considered.

A secretariat would be required for any of the following options. Like the National Health Committee, the secretariat could be physically located within the Ministry of Health even though the Committee itself is independent.

## Option One: A national cancer screening committee as part of a national screening committee

In this option a national cancer screening committee would be a sub-group of a national screening committee, which would have responsibility for strategic oversight of all screening issues in New Zealand (including antenatal and child screening and other medical screening).

Advantages	Disadvantages
Focused on screening issues	Potential to be disconnected from broader cancer control issues
Screening programmes share many common issues and challenges	Potential for cancer screening programmes to remain disconnected from their flow-on effects to other cancer services, in particular treatment services
Maintains cancer screening as part of public health prevention framework	Familial risk assessment unlikely to fit into this framework

## Option Two: A national cancer screening committee as part of a cancer control agency structure

In this option a national cancer screening committee would form part of a wider cancer control agency structure.

Advantages	Disadvantages
Focused on cancer issues	Operating outside generic public health prevention framework
Operating within cancer control framework	
Independent	

## Option Three: Create a dedicated sub-group of the National Health Committee

In this option, a subcommittee of the National Health Committee would take on this role in a more formal fashion. The National Advisory Committee on Health and Disability (NHC) is established under Section 11 of the Public Health and Disability Act 2000, to provide independent advice to the Minister of Health on:

- the quality and mix of health services that should, in the committee's opinion, be publicly funded, within the context of the *New Zealand Health Strategy (2000)*
- measures that would deliver the greatest benefit to the health of the population, with particular emphasis on those at risk or currently disadvantaged.

The committee's brief would include core services, disability services, public health and public health matters. To a considerable degree, the committee would set its own work programme although the Minister may request specific advice.

Advantages	Disadvantages
Independent Already established in statute	Much broader mandate than cancer screening No mechanisms to ensure appropriate action on its advice May require legislative change to enable sub-committee to be established Not connected to any specific framework, public health prevention or cancer control

## **Appendix 1: Screening and Early Detection Expert Working Group Members**

<b>Dr Brian Cox (Chair)</b>	<b>Epidemiologist and Public Health Physician</b>
<b>Betsy Marshall (Co-ordinator)</b>	<b>New Zealand Cancer Control Trust</b>
<b>Dr Julia Peters</b>	<b>Public Health Physician</b>
<b>Dr Keri Ratima</b>	<b>General Practitioner and Member of the Māori Medical Practitioner's Association</b>
<b>Dr Linda Cameron</b>	<b>Senior Lecturer, Department of Psychology, University of Auckland</b>
<b>Dr Ingrid Winship</b>	<b>Associate Professor in Clinical Genetics, University of Auckland</b>
<b>Judi Strid, Consumer</b>	<b>Women's Health Action, Auckland</b>
<b>Anne Allan-Moetaua</b>	<b>Senior Analyst, National Screening Unit, Ministry of Health</b>

## Appendix 2: Principles of Screening

The following summary of the principles of screening has, with minor modification, been reproduced from the draft report of the Screening Working Group (2002).

**The target cancer should be appropriate for screening.**

The cancer should be an important health problem. This criterion is best viewed as a balance between the disease incidence and its prognosis. This issue should be considered from both an individual and a community perspective. Most cancers are uncommon events from an individual perspective but many are very important from a community perspective.

The natural history of the cancer, cancer precursor or susceptibility should be understood. Specifically, there should be a good understanding of the likelihood of the asymptomatic cancer, precursor or susceptibility progressing to the stage that it impacts on the parameters identified as the purpose of screening (for example, mortality).

The cancer should have an identifiable susceptibility, precursor or pre-symptomatic stage.

**The objectives of screening must be clearly identified.**

The usual objective of population cancer screening is to reduce mortality. Cancer screening may also reduce morbidity (for example, increased rate of breast conserving surgery), improve quality of life and reduce health care costs. Screening for susceptibility to cancer may produce other benefits related to decision-making about medical and life choices.

In general, a mortality reduction should be a necessary objective of population cancer screening because of the magnitude of the effort required and because of the inherent harms of screening. The two widely accepted screening strategies, for breast and cervical cancer, all demonstrably reduce mortality.

This criterion allows for the possibility of considering objectives other than mortality reduction as the basis for population cancer screening. It is very unlikely, however, that a population cancer screening strategy could be supported in the absence of evidence of a substantial reduction in mortality.

**There should be an appropriate screening test.**

The screening test should be capable of detecting the susceptibility, precursor or pre-symptomatic cancer with reasonable sensitivity and specificity. Sensitivity should be sufficient to support a substantial impact on the disease from a population perspective. Specificity should be sufficiently high to produce a reasonable predictive power of a positive test. This is important because of harms, including psychological harms that result from falsely positive screening tests.

The screening test should have few, if any, direct harms. Most acceptable screening tests are only minimally invasive with no direct risk of significant adverse effects.

The screening test should be acceptable to the population. People must be willing to be tested for screening to be effective. This willingness will reflect their understanding of the importance of the disease, the benefits of the screening and the nature of the test itself. The acceptability of a test may change over time, based on experience and the impact of education.

There should be agreement on the appropriate management of people with positive results on the screening test.

There should be agreement on what constitutes a positive test. There should be agreement on what is an appropriate diagnostic assessment. There should be agreement on the appropriate treatment options available to people found to have the cancer.

There must be sound evidence that screening favourably impacts on its intended objectives. This evidence must deal effectively with critical potential biases, including length, lead time, over-diagnosis and selection bias. Randomised clinical trial (RCT) evidence should be the required standard, wherever possible, for new screening strategies.

A high standard of evidence is necessary because screening is actively promoted to healthy populations and has inherent harms. The evidence should address the objectives of the screening. Randomised controlled trials have generally been considered the appropriate evidentiary standard for population cancer screening. Well-conducted RCTs deal effectively with critical potential biases, including length, lead time, over-diagnosis and selection bias. However, RCTs are difficult and expensive to organise; can take many years to produce meaningful results, particularly if mortality reduction is the objective; and generate ethical problems. There is a need to develop alternative research strategies, including the validation of surrogate endpoints.

If RCTs are in progress, then assessment of a proposed screening guideline or programme should be deferred until that evidence is available. If RCT evidence is not available and is not likely to become available, then a screening guideline or programme should only be endorsed with great caution and based on very strong evidence from other sources. Screening for cervical cancer, for example, became widely adopted before RCTs were conducted. It is generally accepted as a screening strategy based on evidence that the decline in cervical cancer mortality in different jurisdictions was closely linked to the degree of implementation of cervical screening.

There is considerable interest in the development of surrogate indicators of mortality (for example, cancer stage), to speed up the process of RCT assessment of cancer screening. Impact on surrogate indicators of mortality may, in the future, be presented as the justification for a screening strategy. Surrogate indicators should not be ignored, but they should be interpreted with great caution.

When there is already RCT evidence of mortality benefit from screening for a particular cancer, it is not generally necessary to conduct RCTs with mortality endpoints to evaluate

new screening modalities. These new modalities need to be assessed so that their test characteristics can be meaningfully compared to the modality used in the original RCTs. If, based on this assessment, a new modality has characteristics that make it a more favourable screening test then it can be considered for adoption.

**Population cancer screening should do more good than harm.**

Population cancer screening must do more good than harm at both an individual level and at a population level. A cancer screening test should always be able to demonstrate that it positively impacts on important disease parameters. This is necessary but not sufficient to recommend a screening guideline or programme. It is also necessary to compare the magnitude of the benefits of screening with the overall harms and costs of screening, including the non-economic harms.

The benefits of screening must be interpreted from the perspective of the burden of disease on the target population. Even common cancers are uncommon events in human populations. It is important to measure the absolute health benefits, taking into account the incidence of the cancer in the specific target population.

The economic costs of screening should be evaluated, including the cost of diagnostic assessment. Careful cost-effectiveness analysis is important so that the screening can be compared to other health care interventions.

The non-economic costs must also be considered. These include the inherent harms of screening, such as medicalisation of the target population and opportunity costs. The impact of false positive screens and subsequent diagnostic assessments and of false negative screens should also be taken into account.

**The health system should be capable of supporting all necessary elements of screening, including diagnosis and treatment.**

Cancer screening is part of a process that typically includes the screening procedure, analysis of the results of the screening test, diagnostic assessment and treatment. The screening test may require a primary care provider or specialised screening facility. The accessibility of the screening test to the target population is critically important.

The health system must have the capacity to provide timely and accurate assessment of screening tests. This may involve laboratory analysis or specialised medical analysis (for example, radiology). The health system must have the capacity to provide accurate and timely diagnostic assessments. This capacity is particularly important for screening tests with relatively poor specificity. Most individuals with positive screens will not have the cancer. Timely assessment is essential to minimise their anxiety.

Screening alone does not reduce mortality and morbidity. There must be access to high quality treatment to reap the appropriate benefits from screening.

An appropriately trained and stable workforce for the planning and implementation of screening programmes is required before screening programmes are implemented.

Screening should be endorsed only if it is provided in a continuous manner in conjunction with necessary quality assurance and programmatic elements

Randomised control trials of screening interventions, as a rule, provide the screening test at a high quality and in the context of programmatic elements. To apply the RCT evidence of efficacy as the rationale for justifying a screening guideline or programme, it is therefore necessary to assure that screening in practice will match to quality standards of the RCT and that the programmatic elements are in place.

The quality standards of the RCT may need to exceed the typical quality of everyday medical practice and require special attention. This is usually the case as participants are asymptomatic so the establishment of the correct diagnosis entirely depends on the screening test and subsequent investigations. The programmatic elements may include population recruitment, systematic recall, linkage to follow-up assessment, dedicated assessment centres and continuous monitoring and evaluation.

This combination of quality assurance and programmatic elements may only be possible, in most cases, through a formal organised screening programme. Many experts and consensus guidelines have endorsed an organised programme as the only acceptable method for the delivery of cancer screening.

Currently accepted population cancer screening strategies require repeated testing at regular intervals to produce a substantial mortality benefit. Population cancer screening should be regarded as a continuous process requiring regular recall of eligible people.

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