

THE DEVELOPMENT OF A NATIONAL CANCER CONTROL STRATEGY FOR NEW ZEALAND

A SCOPING PLAN PREPARED BY THE
NEW ZEALAND CANCER CONTROL TRUST FOR
THE PUBLIC HEALTH DIRECTORATE OF THE
NEW ZEALAND MINISTRY OF HEALTH

by

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FOREWORD

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

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

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1. EXECUTIVE SUMMARY

There is a significant opportunity for New Zealand to develop and implement a National Cancer Control Strategy (NZCCS). This opportunity arises now due to:

- positive stakeholder momentum and ownership
- availability of international experience and models for cancer control
- the priority given to cancer control in *The New Zealand Health Strategy* (King, 2000).

A NZCCS is necessary now because of:

- the evidence of an increasing cancer burden in New Zealand; and,
- the ongoing risks of a fragmented approach to cancer control in prevention, detection, treatment, rehabilitation and palliative care services.

To be successful the NZCCS must:

- focus on health gains for New Zealand
- maintain a vision and direction for cancer control
- lead and facilitate collective action
- identify the risks and pathways to manage those risks
- be independent from health structures and restructuring
- be robust and sustainable in the medium to long term
- be based on current and evolving evidence
- uphold the principles of the Treaty of Waitangi in responding to the needs and expectations of Māori.

Because cancer control cannot be achieved by any single organisation, its development should be consortium-based, involving partnerships of consumer and professional organisations and government and non-government organisations. To provide the necessary expertise as well as buy-in, the development of a successful NZCCS requires high-level, widely respected leadership as well as the involvement of major stakeholders through appropriate consultation.

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

There are four phases to cancer control: impetus, development, implementation and review. This report presents a scoping plan for the development phase of a national cancer control strategy for New Zealand.

The rate at which a NZCCS can be developed, and the extent to which expert advice is available to inform the process, will depend on the resources that may be available from the various directorates within the Ministry of Health and perhaps also from the non-government sector.

It has been assumed that most of the salary costs for developing the NZCCS will be covered by the Ministry of Health, the New Zealand Cancer Control Trust and by other employers. Estimated minimal additional costs for the first year (Section 9) will allow the preparation of a draft NZCCS suitable for consultation. Because the candidate priority actions have yet to be identified, it is not yet possible to estimate the costs of reviewing evidence and economic and health gain analyses. The budget for the second year will need to cover the costs of the consultation process and the publication of the New Zealand Cancer Control Strategy.

This plan outlines the history of cancer control strategy development in New Zealand and the people and materials that have contributed to the development of the plan. It describes the key components of a national cancer control strategy and the guiding principles on which it should be based. Options and approaches for developing the full plan, and the organisational structures required for its development, are set out. The plan includes costings and timelines.

In summary, the New Zealand Cancer Control Trust (NZCT) recommends that:

- the leadership of the NZCCS and its development be at the highest level
- a NZCCS steering group be appointed as a partnership between the Ministry of Health and the NZCCT to oversee the development, implementation and ongoing review of the strategy
- issue-specific expert advisory groups be resourced to utilise the significant New Zealand expertise base in developing the strategy
- a representative stakeholder reference group be established to advise the steering group and to maintain sector-wide commitment
- a small secretariat be established to maintain communication, provide support and implement decisions made by the steering group
- a draft strategy be completed in year one, and consultation on the draft take place in year two, followed by finalisation and implementation of the strategy and ongoing monitoring and review.

Adoption of this development plan would advance the objective in *The New Zealand Health Strategy* (King, 2000) of reducing the incidence and impact of cancer.

2. INTRODUCTION

The New Zealand Health Strategy (King, 2000) states that cancer is the second leading cause of death (27%) and a major cause of hospitalisation (7%) in New Zealand. There are about 17 000 new registrations of cancer each year, with the highest rates in the middle and older age groups. Furthermore, the incidence of cancer is expected to increase by about 40 percent in 2005 relative to 1990, placing strain on assessment, treatment, palliative care, rehabilitation and support services (Cox, 1995). *The New Zealand Health Strategy* defines, as a population health objective for the Ministry of Health and District Health Boards, the reduction of the incidence and impact of cancer; to address this objective, a co-ordinated approach is being developed across prevention activities, early detection (particularly screening), treatment and rehabilitation.

As identified in a recent review, *Progress Towards a New Zealand Cancer Control Strategy* (Gavin et al, 2001), like New Zealand, many overseas countries are developing comprehensive national cancer control strategies in response to the challenge of cancer.

Cancer control is defined as an organised approach to the reduction of cancer incidence, morbidity and mortality (WHO, 1995). A national cancer control strategy (NCCS) is a framework for an integrated, comprehensive set of activities covering primary prevention, screening and early diagnosis, treatment and symptom control, rehabilitation and support, and palliative care. It should also address equity of access to services, workforce development, and the need for relevant research as well as monitoring, analysis and data collection. By providing a framework for the control of cancer in a systematic and coordinated way, a cancer control strategy helps ensure careful planning and appropriate priorities, making the best use of existing resources.

The need for a national cancer control strategy for New Zealand (NZCCS) has been considered over the last decade. This was clearly identified at a widely representative workshop in 1999. In response to the unanimous call by the workshop for a consortium of member organisations committed to the development of a NCCS, the New Zealand Cancer Control Trust (NZCCT) was formed in February 2001. Under contract to the Public Health Directorate of the Ministry of Health, the Trust has undertaken a comprehensive review of the cancer burden in New Zealand and of overseas cancer control strategies. That background paper, *Progress Towards a New Zealand Cancer Control Strategy* (Gavin et al, 2001), also summarises the considerable amount of work already done on various aspects of cancer control that could form the basis of a NZCCS. The present report provides a plan for the **development** of the strategy. Work undertaken in the development phase will in turn address the subsequent phases of **implementation, monitoring** and **review**.

The development phase of a NZCCS is particularly challenging because:

- cancer includes a wide variety of diseases involving many different organs and treatment modalities
- cancer involves a wide range of methods for prevention, screening, early detection, diagnosis, treatment, symptom control, rehabilitation, support and palliative care
- cancer control could involve various approaches, including those based on population groups, cancer site, cancer services, clinical pathways and/or professional groups
- cancer control involves a wide spectrum of both government and non-government stakeholders.
- A comprehensive NZCCS will involve almost all directorates of the Ministry of Health.

To provide the necessary expertise as well as buy-in, the development of a successful NZCCS requires high-level, widely respected leadership; as well it requires the involvement of all major stakeholders through extensive consultation, which will require both time and resources.

The rate at which the NZCCS can be developed, and the extent to which expert advice is available, will depend on the resources available from the various directorates within the Ministry of Health and perhaps also from the non-government sector. The potential risks that apply to the development phase are outlined in Section 10.

Those who have contributed towards the development of this plan are listed in Appendix 1.

There are four key phases to the production of a NCCS. These are:

- impetus
- development
- implementation
- monitoring and review.

The impetus for a NZCCS is evidenced by:

- Sector-wide commitment to the development of a strategy in 1999 by the 1999 Cancer Control Workshop (Members of the National Cancer Control Steering Committee, 2000).
- Government commitment in *The New Zealand Health Strategy* (King, 2000) to reducing the incidence and impact of cancer.
- Government commitment to reducing disparities in health for all New Zealanders, including Māori and Pacific peoples, and ensuring development in health (King, 2000) and to addressing the specific priorities for Māori of smoking cessation and cancer reduction (King, 2001a).
- The background review paper *Progress Towards a New Zealand Cancer Control Strategy* (Gavin *et al*, 2001) which concluded that:
 - The incidence, morbidity and mortality due to cancer are increasing internationally.
 - Since 1960, New Zealand's cancer mortality rates have been increasing faster than those of Australia, Canada, the USA and the United Kingdom.
 - Increasing numbers of New Zealanders are likely to suffer from cancer over the next two decades.
 - There are public concerns about geographic variations in the quality of care available to cancer patients, and significant actual variations in care are evident.
 - Comprehensive national cancer control strategies are being developed in countries similar to New Zealand to cope with the increasing incidence of cancer.
 - The processes involved in developing various national cancer control strategies are remarkably similar and should involve both government and non-government agencies and extensive consultation.

- A comprehensive national cancer control strategy involves not only the various components of cancer control - prevention, screening and early diagnosis, treatment, rehabilitation and support, and palliative care - but also equity of access to services, workforce development and ongoing relevant research.
- A national cancer control strategy needs to have realistic goals, agreed priorities for action, effective mechanisms for monitoring services and outcomes, and mechanisms for periodic review and refinement of the strategy.
- There is substantial government and non-government commitment to the development of a national cancer control strategy for New Zealand.
- Overseas experience and contacts developed during the preparation of the background paper will be helpful in the development of a cancer control strategy for New Zealand.
- A widely representative workshop in 1999 recommended that a consortium-based approach be used in the development of a national cancer control strategy in New Zealand.
- A national strategy should reflect the unique and specific needs of this country, identifying priorities for action within the New Zealand context.
- Substantial work has already been completed on related policies, plans and strategies with which a national cancer control strategy for New Zealand will interdigitate.

Adoption of this development plan will allow the present momentum to be maintained, and would provide additional evidence of the government's commitment to reducing the incidence and impact of cancer (King, 2000).

3. DEVELOPMENT OF THE PLAN

A group of individuals from government and non-government agencies with expertise in various aspects of cancer control met in Wellington on 11 May 2001. They discussed the draft of the background paper (Gavin *et al*, 2001) and considered the most efficient way to complete the development of a NZCCS. They identified the concepts embodied in this plan and defined the guiding principles for the development of a NZCCS (Section 4.3) and the characteristics for the completed strategy (Section 4.2). A draft development plan was then circulated for comment to those who attended the 11 May meeting and to members of the Board and the Expert Advisory Panel of the New Zealand Cancer Control Trust. The members of these reference groups are listed in Appendix 1.

In developing this scoping plan, the New Zealand Cancer Control Trust has therefore drawn upon:

- Recommendations of the World Health Organization (WHO, 1995)
- Recommendations of the 1999 Cancer Control Workshop (Members of the National Cancer Control Steering Committee, 2000).
- Knowledge of cancer control strategies being developed or implemented by similar countries overseas as outlined in the background paper (Gavin *et al*, 2001). A summary of the key features of these plans and their development is provided in Appendix 2.
- Discussions and conclusions from the 11 May meeting.
- Comments from those to whom the draft was circulated.

This scoping plan is the next major step forward, moving the NZCCS into a development phase.

4. KEY COMPONENTS OF A NATIONAL CANCER CONTROL STRATEGY

4.1 THE AIMS OF A NCCS

As defined by the World Health Organization in 1995, the aim of a NCCS is to provide a framework for an integrated, comprehensive set of activities covering primary prevention, screening and early diagnosis, treatment and symptom control, rehabilitation and support and palliative care. By providing a framework for the control of cancer in a systematic and coordinated way, a cancer control strategy helps ensure careful planning and appropriate priorities and, thus, makes the best use of existing resources (WHO, 1995).

The New Zealand Health Strategy (King, 2000) includes, as one of its objectives, a reduction in the incidence and impact of cancer. This statement provides an overall goal for a NZCCS.

4.2 THE CHARACTERISTICS OF A NCCS

A national cancer control strategy should:

- Present a high-level framework, including a goal, objectives and principles for cancer control, which is intended to guide existing and future action and should remain relevant indefinitely.
- Propose a set of evidence-based, cost-effective priority actions for the short term, which reflect the objectives and principles in the framework, and these priorities should be reviewed every three to five years.
- Recommend action with respect to all components of cancer control-*ie*, prevention, screening and early diagnosis, treatment and symptom control, support and rehabilitation, and palliative care.
- Provide realistic initial goals for reducing the incidence and impact of cancer.
- Provide a sense of direction or vision and foster understanding and common purpose among those involved in the various aspects of cancer control.
- Establish initial and ongoing priorities for action, according to defined criteria based on maximum health benefit and gain.
- Identify and involve key stakeholders and providers.
- Include robust mechanisms and measures for monitoring and review.
- Define responsibilities for implementation, monitoring and review.
- Link with The New Zealand Health Strategy (King, 2000) and with other related health strategies.
- Give expression to the public and political expectation that more can-and should-be done to reduce the incidence and impact of cancer.

- Reflect the special relationship between the Crown and Māori which, in the health and disability sector, is based on the principles of participation, partnership and protection of Māori health status
- Be evolutionary and use iterative processes in development, implementation and review.
- Identify needs for further research and be able to incorporate new knowledge into the strategy.

4.3 GUIDING PRINCIPLES FOR THE DEVELOPMENT OF A NZCCS

The process of developing a national cancer control strategy should be guided by the following principles:

- Be consortium-based, involving partnerships of consumer and professional organisations and government and non-government organisations. This is because cancer control cannot be achieved by any single organisation.
- To provide the necessary expertise as well as buy-in, the development of a successful NCCS requires high-level, widely respected leadership; as well it requires the involvement of all major stakeholders through extensive consultation, which will require both time and resources. Appendix 3 describes participatory approaches to the development of a NZCCS.
- Ensure roles and responsibilities in the development process are agreed and understood. This is because cancer control requires co-operation and partnership among many government and non-government organisations.
- Build on progress to date and upon the considerable knowledge and research base of various components of cancer control. Gavin et al (2001) summarises the large amount of work already done toward a NZCCS.
- Acknowledge the 'special relationship' between the Crown and Māori and the basic premise that Māori should continue to live as Māori in Aotearoa; the relationship should be based on the key principles of participation, partnership and protection.
- Acknowledge and utilise appropriate expertise.
- Follow an orderly sequence of stages that is transparent to stakeholders.
- Acknowledge the need for a balance between urgency for action and the need for buy-in by multiple interests.
- Be sensitive and realistic to resource opportunities and constraints.
- Be sustainable in the long term by including monitoring and review and incorporation of new knowledge.

5. STEPS IN DEVELOPING A NATIONAL CANCER CONTROL STRATEGY

The World Health Organization (1995) envisages 13 steps in the establishment of a NCCS. These are listed below, with comment on how these have already been achieved, or the ways proposed in the present plan for them to be addressed as the NZCCS is developed. Section 7 and Appendix 5 describe the steering group and advisory groups proposed for developing a NZCCS. Section 8 presents detail of key deliverables and time frames.

- **Launching the NCCS with a workshop.** In 1999 a sector-wide Cancer Control Workshop (Members of the National Cancer Control Steering Committee, 2000) unanimously supported the development of a NCCS for New Zealand.
- **Developing a communication strategy.** It is proposed that this will be developed by the Cancer Control Steering Group (CCSG) advised by the Stakeholder Reference Group and will lead to extensive consultation on the draft NZCCS. Appendix 3 describes participatory approaches to developing the strategy.
- **Recruiting leaders.** This will occur as the membership of the CCSG and its advisory groups is determined.
- **Consideration of existing health care systems.** This will be considered by the CCSG as it identifies initial priority actions for inclusion in the draft NZCCS.
- **Consultation with non-governmental organisations.** This has already occurred through the 1999 Cancer Control Workshop and through the involvement of NZCCT in the preparation of this development plan. It will continue through the consortium-based approach proposed for the development of the NZCCS, through the Stakeholder Reference Group, and through consultation on the draft NZCCS.
- **Ensuring community involvement.** This will occur through the proposed consultation on the draft NZCCS.
- **Preparing a draft national cancer control plan.** This is the primary function of the CCSG.
- **Organising a national conference.** This is an option to be considered by the CCSG and Stakeholder Reference Group as they plan consultation on the draft NZCCS.
- **Changing legislation.** This is unlikely to be necessary.
- **Identifying resources for the NCCS.** A budget has been allocated by the Public Health Directorate of the Ministry of Health for the development phase (2001-2002), and some funding may be available from the non-government sector. Resources required for the implementation, monitoring and review phases (2003 and beyond) will depend on the specific priority actions included in the NZCCS.
- **Reviewing the role of existing organisations in cancer control.** This will occur as priority actions are being considered for inclusion in the draft NZCCS.

- **Identifying the systems that already exist.** This will occur as priority actions are being considered for inclusion in the draft NZCCS.
- **Drawing up a budget for cancer control.** This will occur when the initial priority actions for inclusion in the NZCCS are identified and accepted.

It can be seen that progress has already been made, and that the present plan for the development of a NZCCS deals with the preparation of, and consultation on, a draft NZCCS. This development phase will be led by the Cancer Control Steering Group (CCSG), which will consider and recommend not only the options and priority actions for the NZCCS but also the mechanisms for monitoring progress towards targets and for periodic review of the priority actions once the NZCCS has been implemented.

6. OPTIONS FOR THE FORM OF THE NZCCS

In its review of cancer control strategies in other jurisdictions, the background paper *Progress Towards a New Zealand Cancer Control Strategy* (Gavin *et al*, 2001) discusses the approaches taken by various countries in developing their national cancer control initiatives. Appendix 2 summarises and compares progress toward a NCCS in Australia, Canada, England and New Zealand.

In Australia consultation is nearly complete on *Priorities for Action in Cancer Control 2001-2003* (Cancer Strategies Working Group, 2001). This includes a high-level framework, including the goal, objectives and principles for cancer control, which is intended to guide existing and future action and should remain relevant indefinitely. Its second component is a set of 13 evidence-based, cost-effective priority actions for the short term; these reflect the objectives and principles in the framework, and should be reviewed every three to five years. This is a comprehensive approach with 13 priority actions related to improving services in each of the five components of cancer control (prevention, screening and early detection, treatment, support and palliative care). These actions will address more than two-thirds of the potentially fatal cancers that are diagnosed in Australia and all non-melanotic skin cancer. For seven of the 13 options, an evidence-based marginal economical analysis found them to be cost-effective, with some generating cost savings as well as health gain.

Because responsibilities for various components of cancer control involve, in different measures, the commonwealth and state governments and NGOs, some priority actions may be more difficult to implement than others. This is particularly so with treatment-based priorities. In New Zealand there may be similar issues coordinating action on priorities among the District Health Boards.

The Canadian *Draft Synthesis Report* (Canadian Strategy for Cancer Control, 2000) includes 53 recommendations with a focus on: prevention; screening, diagnosis and treatment; supportive and palliative care; and research. This 'service-based' approach includes both short (1-5 years) and longer term (10 years and beyond) goals.

Priority actions that lie predominantly within 'services', such as prevention or early detection or rehabilitation, are likely to be easier to coordinate than priorities based on target cancers (a 'site' approach), such as breast cancer, which span early detection, treatment and rehabilitation. Selection of particular cancer sites for priority action would be on the basis of their present impact and potential for health gain. No doubt those non-governmental organisations associated with cancers of the selected and non-selected sites would have opposing reactions to the priority actions.

Population-based choices for priority action might also be considered by the CCSG. For example, cancer in children and adolescents might be selected because of the prospect of improved long-term survival; Maori and/or Pacific groups might also be shown by health gain analysis to be important foci for attention.

In England the *NHS Cancer Plan* (Department of Health, 2000b) sets out how cancer services will benefit from increased investment, how investment in staff will respond to shortages in key specialities and enable services to expand, and how investment in new equipment will enable faster access to diagnosis and treatment. The accompanying reform requires new ways of working to streamline cancer services around the needs of the cancer patient: through extending the roles of staff, and through guidance to ensure high standards of treatment and care are in place right across the country. In addition, targets for the reduction of smoking in adults, reductions in waiting times for diagnosis and

treatment, and additional investment in hospices and specialist palliative care are included. This is a 'service based' and 'patient focused' strategy.

The Director of the *NHS Cancer Plan* (Department of Health, 2000b) believes that this plan is now a comprehensive national strategy. However, it is widely thought that the plan's strong treatment-based focus is because of the terms of reference given to the expert advisory group on cancer services, which was commissioned in 1995 to provide guidance to purchasers and providers of cancer services. That review of cancer services has similarities to the *Improving Cancer Services* (Ministry of Health 2001) review recently undertaken in New Zealand. Treatment-based priority actions could have the advantage of simpler funding streams than initiatives involving the whole spectrum of cancer control.

All three of these overseas models incorporate initial priorities selected on the basis of reviewing evidence of health benefit with modulation by appropriate expertise. They indicate that relatively rapid progress could be made in New Zealand by defining a high-level framework then identifying possible initial short-term priorities for evaluation.

If the NZCCS is to be comprehensive, its candidate priority actions are likely to include several approaches, including target cancers arising at particular sites, particular populations and particular services. In choosing, a matrix analysis, an example of which is provided in Appendix 4, provides a framework for systematic initial evaluation of current and potential cancer control activities. The matrix approach was found to be particularly useful by participants of the 1999 Cancer Control Workshop.

Monitoring and periodic review of the NZCCS once implemented also require clearly defined mechanisms, responsibilities and timeframes. Many of the priority actions will involve the Cancer Registry as provider of baseline and new data relevant to the defined target reductions in incidence and mortality and improvements in survival. The sources and deficiencies of existing cancer data were reviewed in the background paper (Gavin et al, 2001). Other sources and types of data will be necessary to monitor improvements in such activities as prevention, support and palliative care.

7. MECHANISMS FOR THE DEVELOPMENT OF THE NZCCS

Because of the complexity and public concern about cancer, and the political consequences of failure to develop and implement a satisfactory, respected and effective strategy (Section 10), it is essential that those responsible for the development of the NZCCS are widely respected and possess the necessary expertise. Furthermore, the group responsible for the development of the strategy should report at the highest possible level. The New Zealand Cancer Control Trust is of the view that this should be to the Minister of Health.

7.1 A NATIONAL CANCER CONTROL STRATEGY STEERING GROUP

The Ministry of Health and the New Zealand Cancer Control Trust should appoint a national Cancer Control Steering Group (CCSG). This high-level group should be given the mandate to manage and complete the development of the NZCCS.

This group needs to be appointed urgently to maintain the sector-wide and government commitment to cancer control and to address public expectation that improvements in the control of cancer need to occur.

The CCSG should:

- draw upon the considerable expertise and wisdom available in New Zealand and ensure appropriate consultation.
- consist of members who are widely respected and capable of acting as a board of directors to provide the decision-making that the expeditious development of the strategy requires.
- draw its membership from within the Ministry of Health, Māori, Pacific and consumer groups, and from non-government sectors.
- be supported by a secretariat that administers the functions and implements the decisions of the CCSG; membership of the secretariat should be drawn from the CCSG, supplemented by staff from the Ministry of Health and the NZCCT and others with appropriate skills as required.
- be advised by expert advisory groups convened for particular purposes.

The proposed terms of reference for the CCSG and advisory groups are outlined in Appendix 5. A diagram of the proposed structure is provided in Appendix 6.

It is anticipated that the CCSG would meet eight times in the first year to complete the preparation of the draft NZCCS. In the subsequent year it would oversee the consultation process and preparation of the definitive strategy.

7.2 EXPERT GROUPS

The development of the strategy will need to draw upon the considerable expertise available on various aspects of cancer control. This is best done by the CCSG convening advisory groups of experts to address specific issues; these may include, for example, cancer prevention, childhood and adolescent cancer, cancer in specific sites or cancer treatment services. Membership of each group would be multi-disciplinary and would need to include expertise in evidence-based economic analysis.

In some areas the CCSG will be able to draw upon the substantial work that has already been done. For example, there is already a *New Zealand Palliative Care Strategy* (King, 2001b) and, there has been a recent comprehensive review of radiation therapy, medical oncology and haematological oncology services in New Zealand, *Improving Cancer Services in New Zealand* (Ministry of Health, 2001). Other examples of relevant work already completed are provided in Appendix 7.

7.3 A STAKEHOLDER REFERENCE GROUP

A stakeholder reference group will advise the CCSG on the plan of action and issues relating to stakeholder involvement. On the draft strategy, it will also provide the CCSG with commentary and advice on approaches to public consultation.

Members should be appointed from the key agencies and providers, population groups and consumer advocacy groups listed in Appendix 8. Selection of members would be the responsibility of the CCSG and would involve participatory processes as outlined in Appendix 3.

It is anticipated that the reference group would meet twice in the first year to provide a stakeholder perspective on the proposed form and content of the draft strategy and subsequently on the consultation plan. In the following year it would probably only need to meet once, following the consultation process, to endorse the final strategy.

7.4 CANCER CONTROL SECRETARIAT

A secretariat will administer the functions and implement the decisions of the CCSG and provide support for the expert advisory groups. The secretariat will also be responsible for the preparation of the draft and definitive strategies, drawing upon the work of the CCSG, Stakeholder Reference Group, and expert advisory groups.

Reflecting the principle of partnership, membership of the secretariat should be defined by the Ministry of Health and the New Zealand Cancer Control Trust, and should include some members of the CCSG. The Ministry of Health and the NZCCT may contribute additional resources in terms of staff time as the strategy develops. The Secretariat should be a working team that will ensure that the project advances in a timely way.

The secretariat will need to be supported by administrative staff, who will arrange meetings, travel and accommodation as well as prepare agendas and minutes.

8. KEY DELIVERABLES AND TIMEFRAMES

- Ministry of Health and New Zealand Cancer Control Trust establish the National Cancer Control Steering Group (by 15 September 2001).
- The CCSG establishes the secretariat (by 1 October 2001).
- The CCSG agrees on approach and framework for strategy development (by 30 November 2001).
- The CCSG defines a work plan for the preparation of a draft strategy suitable for consultation within the first year (by 30 November 2001).
- The CCSG develops the goal, objectives and principles for the NZCCS (by 31 December 2001).
- The CCSG appoints the Stakeholder Reference Group using selection techniques outlined in Appendix 3 (by 31 December 2001).
- The Stakeholder Reference Group advises the CCSG following consideration of the proposed goal, objectives and principles for cancer control in New Zealand. (by 1 February 2002).
- Secretariat develops background papers for the expert advisory groups (ongoing).
- The CCSG convenes expert groups as required to review the evidence, including economic and health gain analyses, needed to inform the decisions that determine the initial priority actions for the NZCCS (as required, ongoing).
- The CCSG identifies areas of cancer control that could become initial priority actions within the strategy (by 31 March 2002).
- The CCSG completes the draft strategy (by 30 June 2002).
- The CCSG develops a consultation plan reflecting the principles outlined in Appendix 3 (by 31 July 2002).
- The Stakeholder Reference Group considers and endorses the draft strategy and advises on the proposed consultation plan (by 1 September 2002).
- Secretariat oversees the implementation of the consultation plan (between 1 September 2002 and 15 December 2002).
- The CCSG finalises the New Zealand Cancer Control Strategy (by 1 March 2003).

9. ESTIMATED COSTS

The major costs of the development of the NZCCS are in the personnel involved. It is possible that most of the salary costs of those involved in the CCSG, Secretariat, expert groups and Stakeholder Reference Group will be covered by the Ministry of Health, the New Zealand Cancer Control Trust and by other employers.

Estimated additional essential costs required to develop the NCCS in the first year are summarised as follows:

Steering Group (8 meetings of 10 members, 5 travel)	32,000
Stakeholder Reference Group (2 meetings of 12 members, 6 travel, meeting fee for 3)	12,800
Secretariat (12 meetings, 2 travel)	19,800
Consultancy fees (economic, project management, analysis, etc)	20,000
Ad hoc expert groups (per group: 3 meetings of 6-8 members, 5 travel, meeting fee for 1): Cost of one group 16,000	as budget allows

The budget for the second year will need to cover the costs of production and distribution of the draft strategy, the consultation process and the publication of the NZCCS. The budget will also need to support the CCSG and Secretariat during these stages.

10. RISKS IN THE DEVELOPMENT PHASE

There are a number of potential risks to the development project:

- Poorly defined responsibilities for development and implementation will result in inefficiency and delay.
- There is the potential for failure if all parties do not appreciate the complexities of a comprehensive NCCS.
- There is a potential that if insufficient funding is allocated for the development of the strategy it will be unable to meet the aim of a national cancer control strategy as defined by the WHO or meet New Zealand's needs.
- There is a potential risk that the resource constraints in the health sector, combined with competing priorities, may give rise to conflict and delay.
- The timeframes indicated in this plan are optimistic. Any unexpected requirements or delays will result in unacceptable pressure to achieve the deliverables in the expected timeframes.
- There is a potential for both insufficient funding and tight timeframes to result in insufficient stakeholder involvement. The involvement of all major stakeholders in cancer control is a critical factor in the successful development of a cancer control strategy (Bennett et al., 1999).
- Failure to involve those with sufficient and appropriate expertise will not only slow progress but will also compromise the quality of the strategy.

11. CONCLUSIONS

1. There is substantial impetus, both in New Zealand and overseas, for the development of a national cancer control strategy.
2. By providing a framework for the control of cancer in a systematic and coordinated way, a NZCCS will help to ensure careful planning and appropriate priorities, and thus make the best use of resources.
3. The plan outlined in this paper describes how progress can be made with the **development** of a comprehensive national cancer control strategy for New Zealand.
4. The NZCCS will be an important step in reducing the incidence and impact of cancer which is a population health objective of *The New Zealand Health Strategy* (King, 2000).
5. The NZCCS can build upon, and link with, the relevant work already done on several aspects of cancer control, including *New Zealand Palliative Care Strategy* (King, 2001b) and the recent review of cancer treatment services (Ministry of Health, 2001).
6. The development of the NZCCS should be consortium-based and involve both government and non-government agencies.
7. The New Zealand Cancer Control Trust recommends that the development should be led by a highly respected Cancer Control Steering Group which should report at the highest level.
8. In the first year the CCSG should produce a draft strategy ready for consultation.
9. The draft strategy should include: a framework including a goal, objectives and principles for cancer control; a set of evidence-based, cost-effective priority actions for the short term; and mechanisms for monitoring progress toward targets and for periodic review and modification of priorities.
10. In the second year consultation on the draft strategy should occur and the final strategy should be prepared for the Minister of Health.
11. The rate of progress and the quality of decisions made in the preparation of the strategy will depend on the budget available.
12. Funds in addition to those likely to be provided by the Public Health Directorate may be available to ensure that the NCCS is comprehensive and its priorities are based on robust analysis.
13. Adoption of this development plan would advance the objective in *The New Zealand Health Strategy* (King, 2001) of reducing the incidence and impact of cancer.

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APPENDIX 1

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APPENDIX 2:

PROGRESS TOWARDS A NATIONAL CANCER CONTROL STRATEGY

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

NGO = Non-government organisation

APPENDIX 3:

PARTICIPATORY APPROACHES IN DEVELOPING THE DRAFT STRATEGY

PARTICIPATION

For those with specific cancer care and control expertise, those representing consumer interests and knowledge, and those with the responsibility for public policy considerations, the ideal process of involvement and participation is based on active engagement in thinking, analysing, planning and setting priorities. Such participation identifies key characteristics for effective engagement in strategising and decision-making as including people:

- having elbow-room for decision-making
- learning - including setting goals and getting feedback
- mutual support and respect
- meaningfulness
- the idea of there being a desirable future for those involved.

A range of techniques and approaches can be used for effective engagement but the key underlying elements include that:

- The structures adopted for developing the strategy will ideally reflect the desired processes of engagement. As a result partnership arrangements are often ideal.
- Those involved know that they can be truly engaged with the range of other groups/interests also engaged rather than simply being asked for limited (and therefore limiting) input.
- The management/overview structure facilitates involvement and engagement rather than controls information and access to information, perspectives and expertise.
- The processes are iterative and allow for multiple rounds of discussion and dialogue to produce the clarity and agreement on thinking, planning and priority setting required.
- The processes can be adapted or added to.
- The processes build on existing material, involvement and commitment. They are designed to enhance rather than destroy and to acknowledge past achievements rather than ignore.
- The processes for developing the key directions for the strategy contribute to and connect with the later, more formal public and community consultation approaches.

Some NCCS frameworks (Abed et al, 2000) talk about processes of partnership, consultation, co-ordination and cooperation allied with stages of strategy development .

The early stages of the development of a New Zealand Cancer Control Strategy have been based on partnership and collaborative approaches in identifying the value of having a national cancer control strategy in the first instance. The national collaborative workshop in 1999 is one clear example of this. The formation of the Trust representing a number of the key stakeholders is another.

The proposed development of the draft strategy suggests a number of expert groups and a stakeholder reference group under a partnership-based management/overview group. These are designed for maximum effective and efficient engagement.

The establishment phase of the groups will be a useful time for those key elements of effective participation to be discussed and used as checklists for development of the draft strategy. Using checklists such as these is likely to provide the opportunity to ensure that the development of the draft strategy is participative and, where the processes used may be adapted, based on the need to clarify issues, consolidate agreements or explore other options. It is planned that consumers are to be part of the groups of experts.

As well, a separate stakeholder group representing a range of interests and perspectives is proposed. Selecting such stakeholder reference groups can be fraught. A social science research technique called the “snowball” technique is particularly relevant under these circumstances. In research contexts, it is most often adopted when seeking focused input from a broad-based range of informants where random sampling is very unlikely to ensure the full range of key views. The technique is simple and participatory. It is based on seeking, from a number of key informants, the names of those considered to be the most relevant and suitable contributors from any given, defined communities or groups. The most frequently mentioned names are then selected and turned to for advice, information and input.

FORMAL CONSULTATION

Health and disability legislation requires consultation. In many ways formal consultation with the public and communities is more formalised, operating to clear guidelines developed by the lead agency(ies) in accordance with legal requirements.

A 1992 Court decision¹ has provided the basis for much of the guidelines developed around consultation. Key principles for the design of consultation arising from this decision include:

- consultation does not require agreement
- consulting does not mean negotiation
- consultation is more than mere notification
- there must be sufficient information to actually inform
- due notice must be taken, and shown to be taken, by those leading the consultation of what is said
- those leading the consultation must wait until other parties have had their say before reaching decisions
- that is, the decisions are taken after consultation.

1. Wellington International Airport Ltd v Airlines (1992) under the Wellington Airport Act 1990.

For the development of the NZCCS an important consideration is that the process of engagement and participation in developing the draft strategy connects with and influences the design and implementation of the more formal consultation process.

The Stakeholder Reference Group is ideally placed to design an appropriate approach to formal consultation that will provide the opportunity to ensure:

- key communities of interest and geographical communities are involved
- those who participate in the design of the draft strategy are available to discuss the draft during the formal consultation
- the consultation is undertaken in a manner which appropriate and effective for Māori and non-Māori
- active steps are taken to ensure that the views of particular at-risk or vulnerable groups, such as Pacific Islands peoples, are sought and heard.

APPENDIX 4

A MATRIX OF THE STEPS IN CANCER CONTROL IN NEW ZEALAND: BREAST CANCER

	Primary Prevention	Screening	Early Diagnosis	Treatment	Rehabilitation & Support	Palliative care
Basic research	overseas	overseas	overseas	overseas and in main treatment centres	overseas and ?	none
Development of interventions	none	NZ pilots & overseas	overseas	guidelines developed	none?	none
Evaluation of interventions	none	NZ pilots & overseas	overseas	guidelines not evaluated?	none?	none
Situations analysis	none	Working group report	College of GPs?	none?	none?	NZ Palliative Care Strategy
Community involvement and advocacy	none	Cancer Society and BCF	Cancer Society and BCF	RACS, oncologists and consumer groups	Cancer Society & Breast Cancer Support Services	Hospice movement
Commitment to action	none	Ministry of Health	College of GPs?	none?	none?	?
Programme planning	none	Ministry of Health	none?	none?	none?	?
Programme implementation	none	Ministry of Health	none?	none?	none?	none?
Programme monitoring	none	Independent Monitoring Group	none?	none?	none	none
Future planning	none	Ministry of Health	none?	none?	none	none

APPENDIX 5

PROPOSED TERMS OF REFERENCE FOR THE STEERING GROUP AND SUBGROUPS

1. CANCER CONTROL STEERING GROUP

Proposed Terms of Reference:

To hold the kaupapa, ie, to drive the initiative and ensure progress continues to made in the development of a NZCCS.

To implement the development plan.

To be responsible for the development of a draft NZCCS using consultative processes.

To ensure linkages with other strategies.

To ensure public consultation on the draft strategy.

To appoint members of, and manage the relationship with the stakeholder reference group and groups of experts.

To ensure the development of a communication strategy.

Membership:

To be appointed by the Ministry of Health and the New Zealand Cancer Control Trust

2. EXPERT GROUPS

Proposed Terms of Reference:

To contribute to a New Zealand Cancer Control Strategy in relation to specific components or issues

To prepare reports for the Steering Group which will:

- review the evidence
- summarise progress to date
- estimate costs and cost-benefits
- establish linkages with other strategies and sub-strategies
- identify opportunities
- identify constraints, eg, workforce and equity of access
- identify data base requirements
- address Treaty-related issues
- identify priorities for incorporation into the NZCCS.

To participate in setting the overall priorities for the NZCCS.

To identify key stakeholder groups.

Membership:

To be selected by the Cancer Control Steering Group on the basis of relevant expertise and experience and to include Māori, Pacific and consumer perspectives.

3. STAKEHOLDER REFERENCE GROUP

Proposed Terms of Reference:

To advise the Steering Group on the plan of action and issues relating to stakeholder involvement.

To comment on work in progress.

To provide commentary to the Steering Group on the draft strategy.

To advise the Steering Group on approaches to public consultation on the draft strategy.

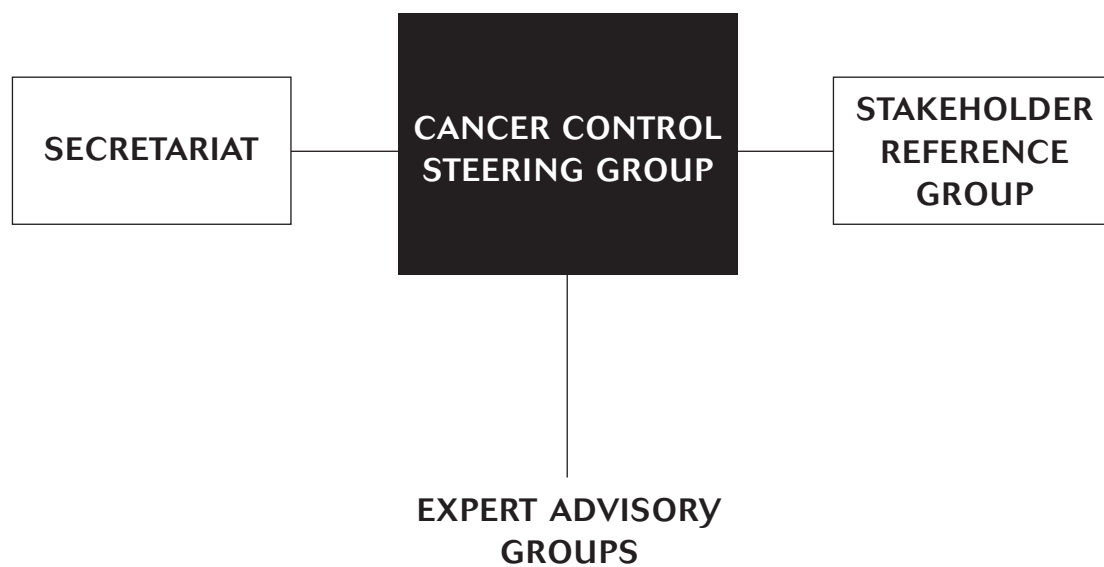
Membership:

Members drawn from key stakeholder interests, eg,

- Māori and Pacific Islands peoples
- Professional groups
- Large NGOs
- Public health groups
- Consumer advocacy groups
- District Health Boards
- Private providers
- Hospices
- Research funding agencies
- Tertiary training institutions

APPENDIX 6

DIAGRAM OF GROUPS AND RELATIONSHIPS



APPENDIX 7

CANCER CONTROL POLICIES, GUIDELINES, STANDARDS AND STRATEGIES

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

APPENDIX 8

STAKEHOLDERS WITH A DIRECT INVOLVEMENT OR INTEREST IN ASPECTS OF CANCER CONTROL

- Participants of the 1999 Cancer Control Workshop

- Government agencies
 - Minister of Health, Hon Annette King
 - Health, Social Services, Cabinet Education and Health Committees
 - Ministry of Health
 - Public Health Directorate, including National Screening Unit
 - Māori Health
 - Pacific Health
 - Personal and Family Health
 - Sector Support Funding
 - Sector Policy
 - Those responsible for strategy development, e.g. cancer services strategy, childhood cancer strategy, health of older people strategy, palliative care strategy
 - Pharmac
 - National Health Committee
 - New Zealand Health Information Service
 - Health and Disability Commissioner
 - Patient Advocacy Services
 - Te Puni Kōkiri
 - Health Sponsorship Council
 - Health Research Council
 - Work and Income New Zealand
 - Hillary Commission
 - Ministry of the Environment
 - Ministry of Education
 - Ministry of Women's Affairs
 - National Radiation Laboratory

- Ministry of Pacific Island Affairs
- The Ministry of Youth Affairs
- Medsafe
- Environmental Risk Management Authority
- OSH - Occupational Safety and Health Service
- The Office of Privacy Commissioner
- Office of the Commissioner for Children
- District Health Boards

Members of District Health Boards

Regional public health units

Diagnosis and treatment services

Genetic services (Northern Regional Genetic Services & Central Regional Genetic Services - Wellington Hospital and Christchurch Hospital)

Social work services

District nursing services

Public health nursing services

Physiotherapy and occupational therapy services

■ Māori organisations

- Māori health providers
- Māori Women's Welfare League
- Māori Women's Health League.
- Te Puni Kokiri database of contacts
- Te Hotu Manawa Māori
- Kimihauora Health & Research Unit (Tauranga)
- Te Ora (Māori Medical Practitioner's Association)
- National Council of Māori Nurses
- Women's Health League
- Aparangi Tautoko Auahi Kore - ATAK (Māori Smokefree Coalition)

■ Pacific organisations

- Pacific health providers
- Pacific Heartbeat
- Pacific Health Research Centre

■ **Not-for-profit cancer organisations**

- New Zealand Cancer Control Trust
- Cancer Society of New Zealand
- Child Cancer Foundation
- Canteen
- Hospice New Zealand
- Leukaemia and Blood Foundation
- New Zealand Breast Cancer Foundation
- Look Good Feel Better Trust

■ **Cancer-specific consumer/consumer advocacy groups**

- Breast Cancer Network
- Breast Cancer Support Service
- Prostate Awareness and Support Society
- Ostomy Society NZ Federation
- Kiwi Lost Chord Society
- Lymphodema support groups
- Myeloma Australasia

■ **Public health organisations**

- Public Health Association of New Zealand
- The Public Health Sector Project (PHSP)
- New Zealand Aids Foundation
- Health Promotion Forum
- Mental Health Foundation
- Action on Smoking and Health
- Health New Zealand
- The Quit Group
- Smokefree Coalition

- Aparangi Tautoko Auahi Kore (ATAK)
 - World Smokefree Day Group
 - National Heart Foundation
 - National Smokefree Group
 - Agencies for Nutrition Action
 - Active New Zealand
 - New Zealand Sports Foundation
 - Sports New Zealand Aotearoa
 - Women's Health Action Trust
 - Age Concern New Zealand
 - New Zealand Nutrition Foundation
 - The Nutrition Society of New Zealand, Inc.
 - Alcohol Advisory Council (ALAC)
 - Pain Action in New Zealand (PAINZ)
 - Eldernet
 - Family Planning Association
 - Health Services Consumer Research
- University departments and other tertiary training institutions
- Lincoln University
 - Massey University
 - College of Education
 - Schools of Health Sciences, Health Midwifery, Nursing, Rehabilitation
 - The Institute of Food, Nutrition and Human Health
 - University of Otago
 - Children's Issues Centre
 - Consumer & Applied Sciences
 - Environment and Society
 - Environmental Policy and Management Research Centre
 - Environmental Science
 - Schools of Medicine, School of Dentistry, School of Pharmacy
 - Centre for Adverse Reactions Monitoring
 - Dunedin Multidisciplinary Health & Development Research Unit
 - Donald Beasley Institute
 - Christchurch School of Medicine
 - Wellington School of Medicine

- University of Auckland
 - Faculty of Medical and Health Sciences
 - Departments of General Practice, Community Health, Medicine, Surgery, Psychology, Radiology, Pathology, Psychiatry, Pharmacology)
- University of Waikato
- Victoria University of Wellington
- Institutes of Technology (Schools of nursing, physiotherapy, etc.)
- Auckland College of Education
- Christchurch College of Education
- Dunedin College of Education
- Wellington College of Education
- Te Wananga O Aotearoa

■ **Professional colleges and associations (medical and allied health)**

- Medical Council of New Zealand
- Royal New Zealand College of General Practitioners
- New Zealand General Practitioners Association
- New Zealand Medical Association
- Australasian Faculty of Public Health Medicine
- Australasian Faculty of Occupational Medicine
- New Zealand Society of Physiotherapists
- Royal Australasian College of Surgeons
- Royal Australasian College of Physicians
- Australia and New Zealand College of Radiologists
- Royal College of Pathologists of Australasia
- New Zealand Dermatological Society
- The Australasian College of Dermatologists
- Urological Society of Australasia
- Nursing Council of New Zealand
- New Zealand Gastroenterology Society

- College of Nurses Aotearoa (NZ)
- NZ Nurses Organisation
- National Council of Nurses
- New Zealand College of Practice Nurses
- Nursing Informatics NA Inc.
- Nurses Society of New Zealand
- Nursing Education and Research Foundation New Zealand
- Aotearoa New Zealand Association of Social Workers
- New Zealand Council of Social Services
- The National Preferred Medicines Centre Incorporated
- Clinical Leaders' Association of New Zealand
- Council of Medical Colleges in New Zealand
- NZ Branch of Australasian Faculty of Rehabilitation Medicine
- Royal Australasian and New Zealand College of Radiologists
- Royal Australian & New Zealand College of Obstetricians & Gynaecologists
- Pharmaceutical Society of New Zealand
- New Zealand Society of Anaesthetists
- New Zealand Foundation for Cosmetic Plastic Surgery
- New Zealand Charter of Health Practitioners Inc.
- New Zealand Association of Gerontology
- New Zealand Psychological Society Inc.
- New Zealand Medical Women's Association
- Independent Practitioner Associations
- New Zealand Association of Counsellors
- New Zealand Society of Translators and Interpreters Inc.
- New Zealand Speech-Language Therapists' Association
- New Zealand Society of Psychologists
- New Zealand Association of Psychotherapists
- New Zealand Association of Occupational Therapists

■ Non-government providers

- Private hospital services
New Zealand Private Hospitals Association
Private hospitals
- New Zealand Institute of Medical Laboratory Science
- New Zealand Institute of Medical Radiation Technology
- Association of Community Laboratories
- Private radiology services
- Private laboratory services
- Private nursing services
- Well Women's Nursing Service

■ Research

- Behavioural and Social Research in Cancer Group, Department of Preventive and Social Medicine, University of Otago
- Department of Preventive and Social Medicine, University of Otago
- Hugh Adam Cancer Epidemiology Unit, Department of Preventive and Social Medicine, University of Otago
- Eru Pomare Māori Health Research Centre
- Alcohol and Public Health Research Unit, University of Auckland
- Health Services Research Unit, Wellington
- Malaghan Institute
- New Zealand Health Technology Assessment Unit, Christchurch
- Auckland Cancer Society Research Centre, University of Auckland
- Cancer Genetics Research Centre, University of Otago

■ Consumer groups

- National Council of Women
- Rural Women New Zealand Inc.
- Federation of Women's Health Councils

- Grey Power Federation of New Zealand
- Regional Ethnic Councils
- Acoustic Neuroma Association of New Zealand
- Voluntary Euthanasia Society
- Alopecia Support Groups
- Asbestos Diseases Association

■ **Other agencies**

- New Zealand Health Teachers Association
- Royal New Zealand Plunket Society

■ **Local government agencies/initiatives**

- Citizen Advice Bureaux Association
- Healthy Cities initiatives