

# Report of the 2003 Cancer Control Workshop

## **From Policy to Action – Working Together to Implement the New Zealand Cancer Control Strategy**

**Wellington  
29–30 September 2003**

*The Genesis Oncology Trust was the premier sponsor of the workshop. Other sponsors were the Ministry of Health, the New Zealand Cancer Control Trust, the Cancer Society of New Zealand and the Child Cancer Foundation*

# Contents

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Summary of the Event	1
Background	1
The workshop	1
The Strategy as a basis for a national cancer control programme	2
Key themes and messages	4
Generic Issues	5
Collaboration and co-operation	5
Workforce	5
Research	6
Leadership	6
Summation and Conclusion	7
Workshop Summaries – Goal 1: Reduce the incidence of cancer through primary prevention	8
Workshop A	8
Workshop F	11
Workshop G	13
Workshop Summaries – Goal 2: Ensuring effective screening and early detection	15
Group B1	15
Group B2	17
Workshop Summaries – Goal 3: Care and treatment of those with cancer	18
Workshop C	18
Workshop H	21
Workshop Summaries – Goal 4: Improve quality of life through support, rehabilitation and palliative care	24
Workshop D	24
Workshop I	28
Workshop Summaries – Goal 5: Improving the delivery of services	33
Workshop E	33
Workshop Summaries – Goal 6: Research and surveillance	37
Workshop J	37

*(This draft, incorporating feedback from the Ministry of Health and plenary/keynote speakers, completed 24 November 2003.)*

# Summary of the Event

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## Background

Work on a strategy to control cancer in New Zealand has been gathering momentum for a number of years. In 1999 a widely-representative group met in Wellington and recommended that a cancer control strategy be developed by government and non-government agencies working together.<sup>1</sup> The New Zealand Cancer Control Trust (NZCCT) was established in February 2001, with funding from the Cancer Society of New Zealand (CSNZ) and the Child Cancer Foundation, as a mechanism by which the non-government sector could facilitate the development of a cancer control strategy.

Following a commitment from the Minister of Health, the Hon Annette King, the Cancer Control Steering Group, with expertise in the various aspects of cancer control, was formed in October 2001 to oversee development of the strategy. The work was undertaken by a partnership between the Ministry of Health and the NZCCT. Public consultation on a discussion document, *Towards a Cancer Control Strategy for New Zealand – Marihi Tauporo*, informed the final development of *The New Zealand Cancer Control Strategy* which was launched by the Minister on 25 August 2003.

## The workshop

Recognising that the effectiveness of the New Zealand Cancer Control Strategy will be crucially dependent on its enthusiastic acceptance and involvement by the wide range of organisations and individuals responsible for its implementation, the NZCCT initiated planning for the workshop with a grant from the Genesis Oncology Trust. Other funders were the Ministry of Health, the NZCCT, the CSNZ and the Child Cancer Foundation. The workshop was held in Wellington on 30 September 2003.

Entitled *From Policy to Action: Working Together to Implement the Cancer Control Strategy*, the event was organised by a workshop advisory group on behalf of the Cancer Control Steering Group. The 190 participants, including 13 speakers, were invited because of their expertise related to the goals and objectives of the strategy, because of their position to influence implementation, and/or because of their experience in successful implementation of other New Zealand health initiatives.

In officially opening the workshop, the Minister of Health introduced the 11 members of the newly formed Cancer Control Taskforce responsible for developing a plan to implement the strategy.

Thus the workshop marked the transition from policy development to planning for the Strategy's implementation. It provided an opportunity for those with expertise and responsibility in various aspects of cancer control, to identify what was needed to ensure effective and ongoing implementation of the Strategy, and to contribute to the development of an implementation plan.

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<sup>1</sup> Members of the National Cancer Control Steering Committee, Report of the Cancer Control Workshop '99, *New Zealand Medical Journal*, 11 August 2000, pp. 341–2.

The workshop had three components. A plenary session introduced the strategy as the basis for a national cancer control programme. Following this were two sets of facilitated small group discussions that generated recommendations for implementing the 25 objectives of the strategy. The final session received feedback from the small groups, considered generic issues such as workforce, research, partnership and leadership and heard a final summation. The workshop also received reports from a pre-workshop hui. Fono are planned as part of the follow-up.

## The Strategy as a basis for a national cancer control programme

The Strategy notes that cancer is now a leading cause of death, accounting for 29% of deaths from all causes. Its first aim is to reduce the incidence and impact of cancer. New Zealand has a higher cumulative mortality rate for ages 0–75 years than Australia, England and Wales, and the USA. Associate Professor Chris Atkinson of Christchurch told the first plenary session that New Zealand's increase in cancer rates is broadly similar to world rates, but we have disproportionately high rates of stomach cancer (some with a genetic cause) and cancers (such as primary liver cancer) related to infectious diseases.

New Zealand's cancer death rate is sixth out of 175 countries for women, and 33rd for men, according to Dr Brian Cox, director of the Hugh Adam Cancer Epidemiology Research Unit at Otago University. He noted that only in cervical cancer has our death rate dropped below the base rate set in the mid-1960s, yet it has not dropped as much as in Australia, UK, Canada or the USA. While we have done as well as other countries in leukemia and Hodgkin's disease, our prostate and breast cancer mortality have increased more than in countries with whom we like to compare ourselves. But New Zealand still has the highest colorectal cancer ratio of these countries and the gap is not closing.

The second purpose of the strategy is to reduce inequalities with respect to cancer. Maori mortality for all cancers combined is higher than for non-Maori in both males and females, and the difference over the last two decades is increasing,<sup>2</sup> said public health physician Dr Ruth Richards of the Ministry of Health. She said that in implementing the Strategy, we must make sure that inequalities between population groups – particularly Maori, Pacific peoples, people who live in rural areas and those of lower socioeconomic status are not increased, and are actively decreased.

Questions need to be asked about why Maori and Pacific people present with their cancer later than others. Primary care has to take a variety of approaches to be suitable to all population groups. Systems issues, such as scheduling and sites, need to be considered when a patient doesn't show up for an outpatient appointment or radio-therapy treatment, rather than simply blaming the person. She urged the use of the health equity assessment tool (HEAT)<sup>3</sup> to make sure that the continuum of efforts in cancer control contributes to reducing inequalities in cancer outcomes.

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<sup>2</sup> Ministry of Health. 2001. *Decades of Disparity: Ethnic mortality trends in New Zealand 1980–99*, pp. 35–36.

<sup>3</sup> Ministry of Health and Wellington School of Medicine and Health Sciences, University of Otago. *Tackling Inequalities: Moving theory into action*. Workshop documentation, Wellington, 2003.

Michelle Mako, senior advisor in Maori Public Health, also noted the inequitable cancer burden for Maori, with the death rate from the disease 51 percent higher than for non-Maori. She reported that the pre-workshop hui for Maori had identified the need to build on He Korowai Oranga (the Maori Health Strategy),<sup>4</sup> to improve support for whanau to manage the impact of cancer, increase Maori community involvement, address barriers to access for Maori and improve prevention (especially for tobacco-related cancer) and research. Maori had expressed concern about having a single Maori member on the 11-strong Cancer Control Taskforce, and suggested either explicit support mechanisms for that person or (the preferred option) a separate cancer control implementation taskforce for Maori. She stressed the need to build Treaty principles into all stages of the cancer control continuum, and to make explicit use of Maori concepts of hauora, whanau and whanau ora.

From a Pacific perspective, Dr Debbie Ryan of the Ministry of Health also noted the need for cultural recognition. She said that cancer control must start with an understanding of Pacific world views, operating within a series of personal and community obligations, and that illness results from not meeting those obligations. She noted that for Pacific people resident in New Zealand, life expectancy had actually dropped for both men and women since 1995. The Pacific colorectal cancer risk began in 1980 at one-third of that for other New Zealanders and was now about equal.

By July 2004 the District Health Boards will have almost all health funding devolved to them, and only a few services such as public health will be operating nationally, said Dr Jan White of Waikato DHB. She pointed out that they have 13 population health objectives, and most have identified four or five as their priorities. Cancer does not rate highly in these. Furthermore the Cancer Control Strategy is but one of nearly 50 strategies competing for attention.

As keys to implementation of the strategy, she identified co-ordination and better use of current resources (including rationalisation of current providers) and 'building in' elements of the strategy into current contracts. This might require thinking laterally – lifestyle education for young people, for example, would need to involve the education sector. The complexities of operating through 21 DHBs could be overcome by co-operation on a regional basis for services and programmes.

Professor John Gavin of the New Zealand Cancer Control Trust discussed the distinctions between a strategy document and an implementation plan, and advocated using the World Health Organization (2002)<sup>5</sup> recommendations to plan and implement a national cancer control programme. He stressed that the functional relationships between the cancer control strategy and its implementation and the other health-related strategies related to cancer control will need to be determined.

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<sup>4</sup> Ministry of Health. 2002. *He Korowai Oranga: Maori Health Strategy*.

<sup>5</sup> World Health Organization. 2002. *National Cancer Control Programmes Policies and Managerial Guidelines*. 2nd edition. Geneva: WHO, pp. 113–129.

## Key themes and messages

The morning plenary was followed by two workshop sessions to address implementation of the 25 objectives in the Strategy. Participants chose which to participate in, identifying those objectives for which they had expertise, experience and/or responsibility. All groups were asked to consider questions relating to implementation and to identify three key issues to be addressed by the Cancer Control Taskforce in relation to each objective.

In considering possible actions, groups were asked to reflect on how these actions would contribute to the overall purposes of the strategy: to reduce the incidence and impact of cancer and to reduce inequalities with respect to cancer. Documentation from each workshop session has been compiled into a separate report for the Cancer Control Taskforce.

There was a strong call for a structure/process/national vehicle (independent but inclusive of all key stakeholders) having a range of responsibilities. Some of these were to:

- ❖ provide strategic leadership
- ❖ provide a national co-ordinated approach, involving collaboration across local and national government (ministries) and the NGO sector
- ❖ identify key components of effective models
- ❖ develop and set national standards for cancer services and be responsible for ongoing monitoring of their delivery
- ❖ ensure consistency of services, identifying gaps and inequities
- ❖ ensure the Strategy is adequately funded
- ❖ ensure implementation is nationally promulgated, regionally delivered and locally responsive.

Other recurring themes included the following needs:

- ❖ an intersectoral (involving both government and NGO sectors), collaborative and co-ordinated approach to cancer control to minimise duplication, to ensure use of existing models and to ensure the best use of existing resources
- ❖ to identify approaches to reduce disparities, including workforce training relating to health determinants
- ❖ to operationalise the Treaty of Waitangi
- ❖ to increase recruitment and training of Maori across the spectrum of cancer control
- ❖ enhanced cancer data monitor regional and national activities
- ❖ evidence-based/research-driven approaches across the cancer control continuum
- ❖ stocktakes in a number of areas including workforce, research and activity across the spectrum of cancer control
- ❖ national and regional co-ordination and planning
- ❖ timely and equitable access to services
- ❖ minimum standards of best practice
- ❖ national service specifications to ensure consistency of services throughout the country
- ❖ local and well-focused community-based practice taking account of cultural, personal characteristics, age groups and local facilities.

## Generic Issues

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The afternoon plenary reported back summaries from the workshops and also featured speakers dealing with some of the generic issues. Many of the issues raised by these speakers had also been identified by workshop participants during the small group sessions.

### Collaboration and co-operation

Partnership, participation and protection are principles in the Treaty of Waitangi and are also elements of international health frameworks, said Teresa Wall of the Ministry of Health. She said co-ordination and collaboration are embedded in the Ottawa Charter, the Jakarta Declaration on Health Promotion and the WHO (2002)<sup>6</sup> guidelines for developing national cancer control programmes. These require them to be goal oriented, have systematic decision-making processes, take a systemic and comprehensive approach, show leadership and partnership, and expect continual improvement, innovation and creativity. In implementing the New Zealand Cancer Control Strategy, Ms Wall identified three 'Ps' – partnership, participation and protection. Partnership, she said, can be expressed by working together with iwi, hapu, whanau and Maori communities, participation by involving Maori at all levels in the sector, and protection by working to ensure Maori have at least the same level of health as non-Maori.

### Workforce

Implementing change and achieving improvements in the quality of health services depends on the availability of an appropriately trained workforce. In the cancer field this includes a large and important component of unpaid volunteer workers.

Furthermore, equity of access to training is critical for boosting Maori and Pacific worker participation. Professor Andrew Hornblow, chair of the Health Workforce Advisory Committee (HWAC), addressed some of these issues. He outlined HWAC's task and its recent comprehensive stocktake of the health workforce and the Committee's recent recommendations to the Minister which provide a framework for workforce development.

Educating a responsive health workforce means reviewing current postgraduate and vocational training so that future needs can be met, he said. The health and education sectors have to work together.

Cancer and diabetes have been identified as two disease entities that will be the focus of further work by the medical reference group set up by HWAC.

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<sup>6</sup> World Health Organization. 2002. *National Cancer Control Programmes Policies and Managerial Guidelines*. 2nd edition. Geneva: WHO, pp. 113–129.

## Research

Cancer research has received about \$18.1 million (for expenditure over three years) through 28 contracts with the Health Research Council over the last two years, Chief Executive Dr Bruce Scoggins, said. The HRC funded about one-third of the proposals received for cancer research, twice the normal funding rate for health research projects. Most cancer research comes into the non-communicable disease portfolio, with a mix of biomedical, clinical and public health research, but some comes from the determinants of health area. Programmes funded include research into cancer genomics, University of Otago; vaccines and cell biology, Malaghan Institute; and anti-cancer drug design, University of Auckland; and some work is linked to biotechnology companies ProActa and Pacific Edge Biotechnology.

The Strategy also refers to research needs at the applied end of the research spectrum and in the social, behavioural and psychological aspects of cancer, said Dr Scoggins. It recommends extending and enhancing research across the continuum of cancer control as a basis for continuous improvement.

## Leadership

Leadership in cancer control starts with the Minister of Health and she set the scene well in her introduction to the Strategy, said Mike Findlay Professor of Oncology at the University of Auckland. She has put a lot of effort into the Strategy, but its implementation will require team effort and that has not always been evident. Australia, on the other hand, has done well with cancer control and it provides a lead we should be looking at. Professor Findlay referred to WHO policies and managerial guidelines for cancer control, particularly the need for 'leadership that creates clarity and unity of purpose, that encourages team-building, broad participation, ownership of the process, continuous learning and mutual recognition of efforts made'.

All stakeholders in the New Zealand Cancer Control Strategy are individually and collectively accountable, with individual leadership responsibilities and a collective responsibility to determine and support the overall leadership. Leadership requirements, he said, include credibility, accountability and being in touch with the purposes, principles and goals of the New Zealand Cancer Control Strategy.

## Summation and Conclusion

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Summing up the day's proceedings, Palmerston North oncologist Dr Simon Allan stressed that the implementation plan for cancer control must stand out from the crowd of other strategies, while not being so complex or ambitious that it looks irrelevant to the community. Clear, definite and simple objectives will help its visibility, he said, and he believed that a few good early outcomes would help ensure that the Strategy endures and is effective in the long term. Flexibility, and creative ways of moving across the 'silos' of national activity while involving the local and regional agencies, must be found.

Dr Allan said this can be done by applying good models, such as the 'three Ps' outlined by Teresa Wall, and also the concept of whanau ora, which is at heart of palliative care and extends right through into health promotion. We need an intersectoral modus operandi – changing values, learning new behaviours, and working together across the cancer control continuum.

How this is to be achieved is not yet decided, Dr Allan said. There has to be a 'vehicle' – be it an agency, co-ordinating body, or monitoring mechanism – to ensure the implementation maintains momentum, 'bite' and traction as well as accountability. The nature of the vehicle was critical and has yet to be determined. He would prefer a functional, well-designed and adequately-powered utility to a fashionable, resource-hungry, over-powered 4WD.

Cancer Control Taskforce chair Associate Professor Chris Atkinson concluded the workshop by thanking all those present who had contributed their time, enthusiasm and wisdom to moving cancer control from policy into action. He reviewed work done since 1994 and said that the sector had become much more collaborative and co-operative since then. The workshop proceedings would be made available to the Taskforce, which now faces a daunting timeline. 'It must have an implementation package ready by about June 2004 to have some impact on funding for the 2005 year.'

# Workshop Summaries – Goal 1: Reduce the incidence of cancer through primary prevention

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The summaries below include the objectives for discussion listed in the programme for Workshop Groups A (morning), F (afternoon) and G (afternoon). They include the key issues identified and the proposed actions. They record the raw data but do not include the initial 'brainstorming' material or any very broad statements of principle; the recurring themes throughout both of these will be integrated, however, into the final workshop report. Where there was more than one group, responses from each are listed separately.

Sometimes the relationship between objectives and actions was not explicit, and often the relationship between *What should be done* and the implementation process (in columns 2–5) was not at all clear in the scribing. Where links were not identified in the workshop report, some effort has been made to make the connections between these. The initial wording was taken verbatim from the recording sheets. To ensure the accuracy of workshop documentation, drafts were sent to all relevant workshop facilitators and scribes for review and correction. All suggested additions and/or changes submitted thus far have been incorporated.

## Workshop A

### Objectives

- ❖ Reduce the number of people developing nutrition-related cancers.
- ❖ Reduce the number of people developing physical inactivity and obesity-related cancer.
- ❖ Reduce the number of people developing alcohol-related cancers.

### Group A1

#### Priorities

1. Recognise that many cancers are preventable through lifestyle change and give prevention strategies the highest priority. Strategies should be based on a health promotion model.
2. Support a societal change through facilitation of a collaborative and co-operative approach that involves all key sectors.
3. Identify approaches to reduce disparities and target resources appropriately.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
For all objectives – community groups important to push ideas along and stimulate public interest and concern.				
Find out receptivity of population to change.	Put resources into groups that are ready to change, targeting appropriately. Look at incubator model used in business to recognise success and transfer it to others			
Take a long-term view – recruit and train now.	Look beyond what can happen now to what might work in future.			
Identify barriers to lifestyle change. Recognise this is about social change movement and identify the most effective way of changing behaviour.	Robust social/behavioural research.			
Objective 1: Smaller plate sizes/portions.				
Objective 2: Restrictions on advertising to children. Safe environments – not just physical, also economic – for equity reasons.	Intersectoral collaboration and co-ordination.			
Take a comprehensive approach. Advocacy groups must be supported.	Funding sustainability for all groups involved and for the process.	DHBs need policies to facilitate collaboration.		
Involve other partners.	Education, especially health promoting schools Transport Fashion industry Entertainment industry Food industry Advertisers Employers	Local government, consumers, event managers, social agencies, churches in some communities, PHOs, urban planners, architects.		
Objective 3: Pricing and cost issues for addressing inequalities.				
Evaluation, research into what works.				
Implement HEHA.	Fund adequately		First things to do follow below.	
Assess level of knowledge/leadership/ research in each area.	Tailor mechanisms to the level each area is at.			
Put across healthy lifestyle message.	Comprehensive approach, recognise connections and use them.	National communication of what is happening in local areas.		Design evaluation in at the beginning.

## Group A2

### Issues

1. Provide comprehensive on-going social marketing/health promotion campaigns to implement HEHA, delivering a range of message (including Maori and Pacific) and including involvement of community action, PHOs, DHBs (vertically integrated).
2. Look at the environment for children (eg, advertising to children, provision of amenities, diet especially fresh fruit and vegetables).
3. Undertake social and behavioural research strategies with particular emphasis for Maori and Pacific peoples.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Co-ordinate a social marketing strategy.	Draw all groups together. Develop overarching strategy.			
Make greater use of research across all research areas, including behavioural and social research.	Needs support especially for Maori and Pacific peoples. Opportunities for partnership between universities and people doing programmes. CC Trust could advocate for greater priority for CC research with research funders.	CC Trust		
Support implementation of HEHA (Healthy Eating – Healthy Action).	Include in Crown Funding Agreements.			Monitor its implementation.
Support evidence-based interventions to improve outcomes.	Focus on strategies addressing the needs of children – address the 'where'.			
Create regulatory environment which protects children, supported by health promotion and social marketing framework.	Strategies addressing disparities Changes to Local Government Act require greater consultation.			
Address needs of children in poverty.	Whanau ora approaches have worked well in New Zealand.			
Objectives 2, 3: Address obesogenic environment and alcohol environment.	With HEHA, support strategies which support cancer control (eg, fruit, vegetable consumption).			
Social marketing includes strategies for Maori and Pacific peoples. No public understanding of link between obesity/physical activity and cancers.	Collaboration of HP people with Maori and Pacific peoples. Targeted messages needed.	Need more Maori/Pacific workforce.		
SNAP with GPs in Australia – addressing smoking, nutrition, alcohol, physical activity.			Quickly.	
Promote breast-feeding as cancer protective for both mother and child.				
Objective 3, alcohol. Different messages for different ages, sexes.	Need consistent messages – would need considerable work.			

## Workshop F

### Objectives

- ❖ Reduce the number the people who develop cancers due to tobacco use and second-hand smoke.
- ❖ Reduce the number of people developing occupational-related cancers.

### Recommendations to task force

1. Not enough resource/workforce/commitment/leadership given to tobacco harm reduction. Budgetary emphasis – the dollars should reflect the size of the problem and the potential to improve cancer-related outcomes (ie, the investment into tobacco control should be commensurate to its health damage). Both Government and NGOs should take leadership to increase tobacco as a priority (eg, Anti-Cancer Council of Victoria).
2. Need to identify and support tobacco champion/s to systematically tackle the tobacco problem and to respond to the industry. Whole of sector approach – tobacco-related issues should be addressed through a continuum, eg prevention, an aspect of screening, of treatment etc. – focus on whanau ora including reducing the impact of second-hand smoke.
  - ❖ Explicit that all activities and strategies need to be responsive to Maori in addition to Maori-led work.
  - ❖ Needs to be built into OSH responsibilities and accountabilities.
3. How do we operationalise the Treaty (eg, recognise differential priorities for Maori)? Need to focus and resourcing towards implementing Maori smoke-free strategy and to support Maori to lead this.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Improved standards enforcement for OSH legislation.	Strengthen workforce.	More political influence exerted by professionals.		
Inclusion of second-hand smoke.	ACC needs to provide incentives to smoke-free workplaces.			
More Maori-specific research.				
Worker education.	More culturally-appropriate information. Support/empowerment to become advocates. Providing safe environment for disclosure – whistle-blowing.			
Taskforce must build on existing strategies.				
Advocate for tobacco control as a priority.	Provide leadership in tobacco control, advocate for enhanced control workforce. Greater leadership from NGOs. Increase the investment in tobacco control commensurate to the size of the problem.	Ministry of Health Cancer Society		
Alignment between CCS and national tobacco strategy, national Maori tobacco control strategy.	Maintaining funding for proven programmes (eg, road safety programme) Increase level of funding for cessation – smoking increasing. Need to ensure that activities serve to operationalise the Treaty of Waitangi.			
Legislation, taxation regime.	Further legislation needed on: fire-safe cigarettes, tobacco display in shops, regulations on cigarette toxicity and content, disclosure of roll-your-own content.			
Health promotion. Research especially on youth. Better evaluation of what is happening and the extent to which it works.	Policies for youth, more research on youth. Media and tangata whenua focus, more \$, build on evidence/research, more phone advisers, increase Pacific/Asian investment.			
Tobacco workforce including health protection/smokefree officers.	Further workforce development, co-ordination and upskilling, guidelines to advise on practice/delivery, facilitation of information flow, improved knowledge.			

## Workshop G

### Objectives

- ❖ Reduce the number of people developing skin cancers due to UV radiation exposure.
- ❖ Reduce the number of people developing infectious disease-related cancers.

### Recommendations

1. Under taskforce (cancer prevention/promotion group) specific health promotion activities required to promote health/prevention identifying causes of specific cancers/infectious diseases that may prevent cancers.
  - ❖ Comprehensive strategic approach which needs to be a priority including data collection and research (social/behavioural, epidemiological and biomedical).
  - ❖ Also appropriate objective/recommendation on skin cancer/tanning messages, including Maori/Pacific groups, social class (disparity issues).
2. More national co-ordinated structural approach involving collaboration across local and national government (ministries) and NGO sector.
3. Promote a low UV environment (schools/work) through advocacy and legislation.

### Objective: Reduce the number of people developing skin cancers due to UV radiation exposure

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
WHO framework needs to be considered.	Internationally seen as a social/structural policy issue; in New Zealand has been seen as social, voluntary rather than legislative/punitive.	Government – currently no standards, guidelines, monitoring.		
Broad areas of action required.	Messages need to be consistent across sector (eg, NZHS picture with no-one wearing hats).	Cancer Society and Health Sponsorship Council working together on health promotion.		
Regulations around school environment and workplace requirements.	Could be included in environmental legislation.	Relevant ministries.		
Not a static situation – needs to be addressed and incorporated into inequality/disparity focus.	A change in culture. Promote fake tan. Messages to Maori/Pacific groups as well as other ethnicities. Focus on skins types rather than ethnicities.			
Consider New Zealand environment – risks not necessarily associated with temperature.				

**Objective: Reduce the number of people developing infectious disease-related cancers**

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Involves four groups of cancers: ❖ Cervical (HPV) ❖ Lymphoma (HIV) ❖ Helicobacter (gastric) ❖ Liver.	❖ Can be screened. ❖ Unable to screen (consent issues). ❖ Screening modality available. ❖ Screening in place for Maori.			
Groups need to be made aware of risks.	Education, including awareness of cultural and social issues, needs to be full and frank.			
Prevention needs to be a major focus.	Linkage with other services to assist with health promotion messages. Different education requirements of public and health professionals.			
Matrix required to identify gaps in health promotion, cost effectiveness and outcomes relating to infection diseases – will help prioritise addressing of gaps.				
Diagnosis less of an issue. More education/promotion required.	Implement infectious disease strategy document re prevention/promotion.			
Hepatitis B – not good understanding of outcome and long-term implications between chronic active Hep B and liver cancer. Hep C – more education required.				
Cervical screening – tackle issues around image/perception of the programme and of screening.				
HPV prevalence – is there any purpose on health promotion on this issue?				

# Workshop Summaries – Goal 2: Ensuring effective screening and early detection

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The summaries below include the objectives for discussion listed in the programme for Workshop Group B. They include the key issues identified and the proposed actions. They record the raw data but do not include the initial ‘brainstorming’ material or any very broad statements of principle; the recurring themes throughout both of these will be integrated, however, into the final workshop report. Where there was more than one group, responses from each are listed separately.

Sometimes the relationship between objectives and actions was not explicit, and often the relationship between *What should be done* and the implementation process (in columns 2–5) was not at all clear in the scribing. Where links were not identified in the workshop report, some effort has been made to make the connections between these. The initial wording was taken verbatim from the recording sheets. To ensure the accuracy of workshop documentation, drafts were sent to all relevant workshop facilitators and scribes for review and correction. All suggested additions and/or changes submitted thus far have been incorporated.

## Objectives

- ❖ At a national level, provide a strategic approach to cancer screening, and the assessment and surveillance of those with familial risk, to ensure quality, acceptability and effectiveness.
- ❖ Establish a process to assess the value of early detection of cancer other than that obtained through organised screening.

## Group B1

### Issues

1. National body (collaborative and inclusive of all stakeholders) to promote and make recommendations on cancer screening and surveillance of those at high risk, and early detection based on evidence and quality standards relating to New Zealand setting using a continuum of decision-making. Implementation (including workforce/\$) timing/ planning/target setting, action on evaluation and feedback.
2. Be proactive rather than reactive (genetics (including anticipating genetic profiling of all cancers), culturally-appropriate information, assessment of new technologies/drugs, education services, research)
3. Maori-led process that ensures participation of Maori at every level and is responsible for operationalising the Treaty.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Objective 1: screening. Adequate resourcing for Cancer Registry.				
Mechanism for identifying appropriate areas for screening.	National body using expert work groups, performance indicators (this was not linked exclusively to the mechanism for identifying appropriate areas for screening and should be listed as another area under Objective 1).			
Address linkage with private services, including access and support for those diagnosed.				
Focus on outcomes, whole screening pathway, accessibility of all groups of people.				
National oversight to link all screening strands plus follow - on support and surveillance, and continuum of decision-making – whether to screen, implications/cost/funding, monitor what is going on.				Include mechanism to address problems identified. (This is part of the audit/monitoring cycle)
Recognise cultural issues and beliefs that reflect aspirations and values of Maori.	Reflected in way in which services are delivered.			
Objective 2: Early detection Access to surveillance follow -up for those identified at high risk.	Linkage to screening activities so not isolated/marginalised.			
Availability of services and workforce to respond to early detection activities and genetic screening.	Workforce development and training. Understanding of 'the system'.			
Information and education on risk and applicability.	Focus on getting right information to right people, and address funding	Cancer Society does this now.		

## Group B2

### Issues

1. National evidence-based approach for cancer screening and surveillance of familial risk groups, including national funding.
2. Monitoring and review by the Cancer Control Agency.
3. Recommendations as to what is and what should not be funded (with only approved tests being publicly funded).
4. Culturally appropriate accessible programmes to reduce differences in mortality/morbidity.
5. Effective strategies for implementing recommendations, incorporating feedback.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Objective 1: National Screening Committee – establish it.	Guidelines, evidence-based.	Report to high level.		
Public funding only for approved screening.	Clearly defined relationships with others (eg, treatment, flow-on effects). Include high risk familial screening.	Report to Cancer Control Agency.		Monitoring and review.
Objective 2: Process to assess value of early detection. More research.	National programme for high risk group surveillance and detection of familial cancers and screening. Public funding only for evidence-based screening.			Monitoring and review of objective by Cancer Control Agency.
Much more public and health professional education.				

# Workshop Summaries – Goal 3: Care and treatment of those with cancer

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The summaries below include the objectives for discussion listed in the programme for Workshop Groups C (morning) and H (afternoon). They include the key issues identified and the proposed actions. They record the raw data but do not include the initial ‘brainstorming’ material or any very broad statements of principle; the recurring themes throughout both of these will be integrated, however, into the final workshop report. Where there was more than one group, responses from each are listed separately.

Sometimes the relationship between objectives and actions was not explicit, and often the relationship between *What should be done* and the implementation process (in columns 2–5) was not at all clear in the scribing. Where links were not identified in the workshop report, some effort has been made to make the connections between these. The initial wording was taken verbatim from the recording sheets. To ensure the accuracy of workshop documentation, drafts were sent to all relevant workshop facilitators and scribes for review and correction. All suggested additions and/or changes submitted thus far have been incorporated.

## Workshop C

### Objectives

- ❖ Ensure patient-centred and integrated care for those with cancer, their family and whanau.
- ❖ Improve the quality of care delivered to adolescents, their family and whanau.
- ❖ Ensure that those with cancer and their family/whanau have access to high-quality information on treatment and care, including complementary and alternative medicine.

### Group C1

1. Goal 3/Objective 3:
  - ❖ Care co-ordinator eg breast care nurse – by appropriately training workforce.
  - ❖ Individualised care programmes especially for cultural needs.
2. Goal 3/Objectives 3–4:
  - ❖ National co-ordination of planning and care delivery including cultural needs and developmentally appropriate.
3. Goal 3/Objective 4:
  - ❖ Needs assessment of adolescents including Maori and Pacific peoples.
  - ❖ Health practitioners trained in adolescent health.
4. Goal 4/Objective 4:
  - ❖ Ensure patients can access validated information sources (consult with New Zealand Charter of Health Practitioners).

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Objective 1: Care co-ordinators – primary, secondary, tertiary.	Scope the remit and job size/description of the proposed role of a “global” cancer care co-ordinator.	Oncologist/GP/district nurse/social worker/specialist nurse/Maori representative	Now –soon	Task force?
Classification of cancer patients – categorisation of illness.				
One-stop shop – multi-disciplinary, central point – cf funding through 21 DHBs.	National Cancer Rx Co-ordination			
Enhanced information hubs – harness IT for patients needs.	Collaborative IT strategy nationally to enhance inter DHB patient movement and co-ordination of care	Ministry of Health IT group		
Bypass DHBs – need national structure.				
Objective 2: adolescents Define age: 12–24, 14–21, what? No uniformity!		National – not DHBs	ASAP	
Care co-ordinator.	In conjunction with Maori, Pacific, other Research – what we need, and what adolescents require (needs assessment)	Paediatric oncology, medical, radiation, surgery, social worker, NGOs		
Parent involvement.		Parents, adolescents/patients, whanau, Ministry of Education		
Peer networks.	Internet chat room (with oversight)			
School interaction.		Ministry of Education		
Mandatory national multidisciplinary discussions, appropriate to condition.	This relates to adolescent malignancy management: Could be introduced as policy that all adolescents with suspected malignancy admitted/seen anywhere must be discussed with a minimum quota of specialists before Rx (eg, paediatric surgeon, paediatric oncologist, haematologist, radiation oncologist).			
Rehabilitation programme.	For adolescents.			
Objective 3: Information on treatment and care. Individualised tailored take-home folder for patients.	Continuity of information from Internet, cancer society, clinicians, specialists, nurses, etc.	Needs recommended/authorised and peer reviewed sources of internet information		

The group also emphasised the need for robust information, including professional IT systems and communication and patient information resources as well as funding, funding, funding!

## Group C2

### Issues

Objective 1: Ensure patient-centred and integrated care for those with cancer, their family and whanau.

- ❖ Data: ensure data entry is recommended and funded, and that the minimum data set is linked to the cancer registry.
- ❖ Patients have access to key workers who are members of the multi-disciplinary team and will facilitate their needs during cancer care.
- ❖ All patients have access to quality information through their cancer centres.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Ensure that data entry is recognised and funded.	Prioritise as high priority to Ministry of Health/DHB. Establish funding.	IT subcommittee of NZC working party to inform process	High priority – initial scope 6–9 months	
Patients have access to key workers who are members of MD team and will facilitate their needs during cancer care.	Recommend that: <ul style="list-style-type: none"> <li>❖ they are created positions</li> <li>❖ that they focus on patients who are treated by a number of disciplines or who live some distance from treatment centre.</li> </ul>	Cancer managers to develop and recommend to DHBs	One year	
All patients have access to quality information through their treatment centre.	All centres to lodge patient information sheets on a website. Centres to work towards consistent treatment approaches. To facilitate this we suggest that the centres initially put their detailed protocols on a clinician-access website. Once national treatment approaches have been fully discussed and approved they will be available to all.	NZCTWP	Six months	
Care delivery to adolescents.	<ul style="list-style-type: none"> <li>❖ Six centres</li> <li>❖ Consistency</li> <li>❖ Rehabilitation, support follow-up</li> </ul>	Community/MD GP/practice nurse liaison Paediatric steering committee Subgroup with oncologist New Zealand Working Treatment Party must be involved		
Mechanism to introduce new drugs, procedures and new technologies	Cancer treatment WP to develop mechanism of early alert. Standards. Six centres to enter protocols on clinician-accessed website with the aim of establishing consistent treatment approaches.	DHBs/Pharmac develop a process for funding Cancer treatment WP		

## Workshop H

### Objective

- ❖ Provide optimal treatment for those with cancer; develop defined standards for diagnosis, treatment and care.

### Group H1

#### Key points – national umbrella

1. Data – patient-centred with built-in audit linked to outcomes.
  - ❖ Obligation to participate ?statutory to ensure including private.
2. NZ NICE [National Institute for Clinical Excellence?]
3. Patient-centred approach with multi-disciplinary team using national standards at local, regional and national levels and communication between the three.
4. Resource \$ and people.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Develop co-ordinated database (possibly more than one, interest-based), accessible to all providers for the patient on their journey.	Determine the outcome you want and then determine the data. Develop a minimum data set with subgroups adding on. Global view plus individual information. More pattern of care data critical.			
All cancers should be managed in a multidisciplinary approach.	BSA have very tight standards – used these as a model.			
Improve access to free surveillance for those with familial cancer (eg, young breast cancer).		Need consistency in practice between one DHB and another.		
Measure and plan for screening and early detection to flow on to treatment.				
Centralised resources, so long as evidence is there about better results and costs and people not disadvantaged, and staff not deskilled.	Explore the paediatric model of centralised by shared care.			
Explore concept of care facilitator, not involved in direct delivery, possibly not a health professional, appropriately trained and good communication skills.				
Quality framework to support both process and outcomes standards. Establish link, will determine approach.	Identify lead agency/group then collaborate. Include all groups they may impact on; don't do individually. Pick off 1–2 disease sites first and/or establish common pathway.		Start now and do this first.	
Adopt a similar process to UK – NICE.				

## Group H2

### Key recommendations

1. Task force should develop a mechanism for developing and setting national standards\* for the developing of cancer services and ongoing monitoring of delivery.
2. Standards will include planning of services from a macro to an individual level and will include \*access guidelines
  - ❖ Clinical pathways
  - ❖ Care plans and protocols
    - involvement of multi-disciplinary teams and
    - enhanced role of GP.

### Objective: Provide optimal treatment for those with cancer and develop defined standards for diagnosis, treatment and care

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Promote the good bits; gaps exist.	Forward planning, monitoring of plan, co-ordinating patient pathway, integrate patient care.			
Structure to monitor, collate information, ensure co-ordination – cancer unit, surgical, palliative care. Framework and resources. Not strip core activities from Cancer treatment centre.	Information and information network about types of cancer and treatment sites – some treatable everywhere, others regional centres, some national (rare – eg, paediatric, bone). Support for travelling patients and families.			
Set standards for treatment; currently varies by clinician, clinic, geography. Standards cover pathways, guidelines and protocols (eg, (1), (2), (3), (4)).	Multidisciplinary teams.	Clinicians should be involved in standard setting. GP awareness could have role in setting referral guidelines.		
(1) Access standard is the most important, defining how/when referrals should be made. Include standards for rare cancers, where treated, team involvement.	Has happened with screening. Establish a mechanism for developing/setting national standards to deliver integrated service.	Multidisciplinary team involvement including GPs	Priority given to common cancers.	
(2) Timely and equitable access to R/T services	Planning especially with problems extending to chemotherapy, etc. Capital, equipment – regional approach between cancer unit, surgical unit and palliative care. Extend model into surgical areas.	National approach. Explicit involvement of DHB running cancer unit..	Different time frames for different cancers – not equitable.	
(3) Care standards should include commitment to provision of information – rights, informed consent etc.	Standards cover pathways, guidelines and protocols. Standards defined by individual patient care plan.	Individual patient.		
(4) Should be nursing and social work standards in all areas – professional team approach. Need to be integrated and centred on the patient.				

## Group H3

### Key issues, Goal 3

1. Adequate resourcing (including workforce requirements and retention) to ensure patient-centred provision of evidence-based services that meet guidelines and standards as well as timely and equitable access to diagnostic and treatment services with future needs planning at a national level.
2. Focus on quality that includes credentialing, audit, sub-specialisation treatment standards, collaborative approach, consumer rights, appropriate facilities, training and retention of appropriately skilled workforce.
3. Ensuring those at highest risk of getting cancer and dying of cancer have priority and timely access to diagnosis and treatment.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Getting the information to services and research findings into practice.	A process for decision-making about new treatments and genetic information. Good IT system and data collection.			Review and keep up-to-date with evidence on guidelines, criteria.
Tackling problems of under-resourcing, workforce, quality, delays.	National guidelines needed for quality and timeliness of diagnosis.	Include DHBs at an early stage.		
Identify causes of problem areas (eg, oncology services) so they can be addressed.	Collaborative/multidisciplinary approach. Workforce and training.	Include DHBs at an early stage.		
Deal with the gap between standards and guidelines and what is really happening – under-accessing of services.	\$ need to match demand/need. Relieve pressure on radiation services.	Include DHBs at an early stage.		
Problem of expectations vs evidence. Deal with misinformation about allegations of over-use of services.	Issues of outcomes in relation to specialist surgery and general surgery. This is not related to the problem of expectations etc – it is a separate issue about sub-specialisation and quality outcomes so should be listed separately. Include DHBs at an early stage is relevant for this one.			

# Workshop Summaries – Goal 4: Improve quality of life through support, rehabilitation and palliative care

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The summaries below include the objectives for discussion listed in the programme for Workshop Groups D (morning) and I (afternoon). They include the key issues identified and the proposed actions. They record the raw data but do not include the initial ‘brainstorming’ material or any very broad statements of principle; the recurring themes throughout both of these will be integrated, however, into the final workshop report. Where there was more than one group, responses from each are listed separately.

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## Workshop D

### Objectives

- ❖ Establish integrated programmes of supportive care and rehabilitation with defined leadership.
- ❖ Continue to improve access to essential palliative care services that provide appropriate symptom relief and emotional, spiritual, cultural and social support for those with cancer, their family and whanau.
- ❖ Ensure an integrated and comprehensive service is provided to all those with cancer who require palliative care, and their family and whanau.

### Group D1

#### Key issues

1. Identification of key components of effective models, and development/implementation of a formal accreditation/monitoring process for all providers.
2. Co-ordinated, needs-focused regional network re supportive and palliative care, which includes all stakeholders and an IT component (national database, updated regularly).
3. Education for both public and providers (co-ordinated) which recognises needs of diverse population.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored
<p>Identify service models that are already in existence, and working smoothly.</p> <p>Using information gathered from item 1, develop 'best practice' guidelines for providing a seamless continuum of services to people living with cancer.</p> <p>Develop overriding principles which are followed in every region.</p> <p>Develop a functioning network which includes all key providers (DHBs, GPs, treatment providers, support providers, hospice, etc), and integrates a national database.</p>	<p>Input from patients and providers re their experiences, and what they identify as successful/helpful</p> <p>Input from key stakeholders, with an eye towards meeting the needs of cancer patients.</p> <p>To agree on minimum standards.</p> <p>Appoint a Cancer Co-ordinator for administrative management, develop a workable, user-friendly database.</p>	<p>DHBs, providers, clients/whanau</p> <p>Ministry of Health, DHBs, GPs, NGOs, patients/whanau</p> <p>DHB NZ, Ministry of Health</p> <p>All service providers</p>		<p>CC task force</p> <p>CC task force in conjunction with key stakeholders</p> <p>A separate body should be set up to monitor DHBs</p>
<p>Base services on need, regardless of category.</p>	<p>Shift from a prognosis –based service provision (which is unreliable and inequitable), to service provision based on need, and focusing on quality of life. This would include changes in the way in which services are funded</p>	<p>Ministry of Health, DHBs, academic community (in terms of how we train new medical staff to look at cancer patients and their needs)</p>		
<p>Recognise diversity of New Zealand's population, acknowledge importance of role of family/whanau, and develop guidelines re cultural diversity needs.</p> <p>Establish what 'supportive care' means, spirituality</p>	<p>Empower clients and whanau by informing them about continuum of support services; be inclusive of different ethnic/religious/cultural groups when developing service provision models/standards.</p> <p>Treat the whole patient/person not just the diseased cell.</p> <p>Acknowledge palliative care is not necessarily hospice. (Note: this strikes me as not so much a task for anyone to ??)</p>	<p>Key stakeholders, clients, whanau, members of immigrant and minority communities</p>		

## Group D1

### Key issues

4. Co-ordinated, needs focused regional network re supportive and palliative care, which includes all stakeholders and an IT component.
5. Education for both public and providers (co-ordinated) which recognises needs of diverse population.
6. National CC body which identifies key components of effective models, and develops/ implements a formal accreditation/monitoring process for all providers.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Build on and support work currently being done. Strengthen existing systems of integration of service/ co-operation.	Network. Look at models that work.	DHBs, providers		
Base services on need, regardless of category.				
Throw out focus on prognosis – it is not reliable.				
Develop overriding principles which are followed in every region.	Set minimum standards	DHB NZ		Set up a separate body to keep an eye on DHBs
Treat the whole patient/person not just the diseased cell.	Acknowledge palliative care is not necessarily hospice.			
Establish what 'supportive care' means.	Acknowledge importance of role of family/whanau.			
Coordination between service providers – cancer co-ordinator.	Develop patient management system (IT) to ease transitions. Follow patient through spectrum of services.			
Inform clients about continuum of support services, family/whanau should have control and responsibility.	Empower patients via information about available services. Need full information.			
Recognise diversity of New Zealand's population – cultural beliefs, spirituality.	Develop guidelines re cultural diversity needs.			

## Group D2

Three key issues required to implement the strategy.

1. Multidisciplinary education in cancer and palliative care survivors – develop tools.
2. Holistic, family-centred care modelled on Maori cultural belief from diagnosis.
3. Integrated care, collaborative approach. Recognise who does what well and avoid duplication.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored
Teaching – undergraduates need to be more exposed to palliative care.			As soon as possible	
Psychosocial support in oncology from diagnosis, make consistent over country.	Standardised tool for use in this area. Literature search. DHB commitment (eg, breast screening).	Some being used well.		
Paediatric model – primary, secondary, tertiary, involves paediatric nurse, GP and family.	Designated cancer check with GP (funded). GPs need training. Ringfence funding.			
National lead with regional focus – integration not recognised well.	Some palliative care units within DHBs work well with hospice – most effective.	Otago and MidCentral have worked on interdisciplinary cancer group		
Build on traction developed by paediatric services; children are more likely to survive.	Assess rehab needs and what help is required. Collaboration between Ministries of Education and Health.	Ministry of Education and Ministry of Health		
Advise task force to prioritise children – major cost efficiency to care for future.	Reference group to look at requirements. Must have leverage and outlive Government change. Demand DHBs have cancer as priority.	DHBs through district plans		DHBs have money and power Ministry of Health has overview of services
Look at rural groups especially for travel and access.				

## Workshop I

### Objectives

- ❖ Ensure all people with cancer and their families/whanau are able to access the appropriate resources for support and rehabilitation that they need.
- ❖ Ensure all survivors of childhood and adolescent cancer receive timely and on-going support and rehabilitation, including early identification of, and intervention in, late effects.
- ❖ Ensure optimal independence and function for those with cancer through systematic assessment and appropriate multi-disciplinary intervention for their social and vocational needs.

### Group I1

#### Key statements

1. Establishment of an independent vehicle to oversee the implementation and monitoring of the strategy and to ensure it is adequately funded.
2. Development of minimum standards for best practice which are nationally promulgated, regionally delivered, locally response, community and family-centred, individualised and accountable.
3. Intersectoral collaboration to address issues of inequality, rehabilitation, support and support the work of Paediatric Oncology Steering Group.
4. Appropriate educational outcomes for health professionals, children, adolescent health and quality of life, all survivors across age continuum.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Appropriate assessment/rehabilitation/care from paediatric through adolescence – right across continuum including psychosocial.	Information hub or centre, website – stage/age and development appropriate. Requires regional networking process to address inequalities, streamlined system.	Some national, some regional, ensure consistency. DHB compliance.		
Early identification, protocols.	Checklist/workshops for GPs, knowledge of referral on ??	GP full participation. Case manager to educate all who are involved.		
National strategy.	Teeth, funding including financial support.	WINZ/MSD. NB 1964 Act, implications.		
Siblings' rights and care.	Provide support (emotional and educational) to adolescent aged siblings of people with cancer.	CanTeen, Child Cancer Foundation.		
Human rights considerations: Human Rights Act, Disability Strategy, Education Act 1989 and United Nations Convention on the Rights of Children. Patient's right to educational support, jobs, insurance and a future after surviving their illness.	Back payments; informed of their rights. Social Security Act is in breach of human rights. Amend Society Security Act 1964. Alleviate employer concern at employing cancer survivors.			
Performance indicators.	Taskforce to address all area – health, education, funding at highest level. Minimal standards for best practice.	MSD, Health, Special Education, disability services, insurance.		
Chronic illness strategy to cover all aspects across the spectrum. The Child Health Strategy, "Our Children's Health" (Ministry of Health 1999) and the revised Disability Strategy need to be invoked. Strive for similar benefits for cancer patients as those defined as disabled.	Needs-based provision of service across the board. Prognosis – free funding, needs-based. National ongoing funding, data-based system.			
Nationally promulgated, regionally delivered, locally responsive, community and family-centred, individually audited, accreditation accountable.		Broader than health – support and rehabilitation issues.		Taskforce mandated to look at national body which will make sure that there is an appropriate body to ensure the strategy is implemented, monitored, audited.

## Group I2

### Recommendations

1. It is important that consideration be given to family/whanau ora, beginning at diagnosis; community-based co-ordinated care should be a requirement not just a good idea. If there were national service specifications, support and rehabilitation would be offered at a similar level throughout the country.
2. Recognition of existing models that are successful is important. These models could be used as a basis for developing effective local services.
3. The use of the concept of a 'key worker' would work well for integrating patient care. This key worker does not have to be of any particular professional group but would be nominated by the patient.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Address issues of access/care relating to equity/inequality issues. Recognise people may not travel along 'normal' cancer pathway.	Ensure workforce has adequate cultural understanding. Community oncology service. Travel/accommodation/access to finance.			Taskforce responsible to Ministry or Minister?
Oncology recruitment/training an issue especially in nursing.	Post-graduate training in oncology. Nursing speciality required, works well in some areas. Training for GPs.			
Social-psychological health.	Need to know what is available. Multi-disciplinary team.	Nurse provides links with service providers. Multi-disciplinary teams.		
Idea of a key worker, selected from team. Staff/patients both benefit from integrated approach.	Patient chooses key worker.	Should/should not be a nurse.		
Patients should be empowered to make choices.	Whanau ora should start at diagnosis. Patient and family-led service.			
Survivors of cancer in childhood may have 'late effects' 20 years on.				
Adolescents have different issues from children.	Family support. Models from areas that are working recognised and used.	Children of parents with cancer.		

## **Group I3**

### **Recommendations**

1. A Pacific group should be established to support Audrey Aumua in her role as a member of the Cancer Control Taskforce.
2. Providers in the sector should be well equipped to meet the needs of people from cultural background different to their own.

### **Key issues relating to each objective**

#### Objective 1

- ❖ National policy on assessment of and access to support and information resources in order to support the patient and family to achieve maximum independence and best outcome.
- ❖ Intersectoral collaboration to improve service delivery – minimise duplication and ensure best use of existing services NGO/statutory and minimise impact of cancer on families.
- ❖ Prioritise development of psychosocial services for patient and family.

#### Objective 2

- ❖ Include family in all aspects of care.

#### Objective 3

- ❖ Access to psychological support and rehabilitation.
- ❖ Work with employer groups around education, employer support, intersectoral co-operation and retraining.
- ❖ Research existing models.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
For objective 1: national policy for travel and accommodation (including support person).		All groups (eg, young families and elderly)		
National strategy of support for family members.	Use family as unit of assessment rather than individual.			
Access to sickness benefit – caregiver may need to stop work as well as patient.				
Psychosocial support at oncology outpatient department.	Education/upskilling for those who hold these positions.	Liaison with WINZ		
National rationalisation of support needs and services that takes account of regional differences.	Promote.	Through DHBs		
Ability of DHBs to put support funds into treatment.	Clarify DHB funding streams.			
Remove barriers to whanau support.	Assist in access to community resources and NGOs.	NGOs		
Implement palliative care strategy.	Clarify service boundaries.			
Give psychological rehab through attention to physical rehabilitation.				
Establish a Pacific working group.	Identify Pacific components and priorities for implementation.			
Objective 2: Early assessment of possible cancer treatment sequelae.	Surveillance through integrated programme. Individual plan and review. National database.	Caseworker similar to ACC system		
Continue service on after 17 years, to progress to adult services after this age.	Needs-based rather than diagnosis-based intervention.			
Create a plan that incorporates adolescents' family.		Include families/communities		
Objective 3: Work with employer groups, intersectoral (eg, Workbridge).	Education, employer support. Retraining for those who cannot return to previous job, Research disability, Australian service models.	Identify groups currently not being reached.		
NGO commitment to find out how they can best help.		NGOs		

# Workshop Summaries – Goal 5: Improving the delivery of services

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## Workshop E

### Objectives

- ❖ Develop a co-ordinated national cancer workforce strategy.
- ❖ Ensure appropriate programmes and services are accessible to Maori across the cancer control continuum.
- ❖ Ensure active involvement of consumers across the spectrum of cancer control.

### Group E1

#### Recommendations

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

1. Need to focus on the development of broader workforce training relating to health determinants of health and health inequalities.
2. The distribution of overall expenditure in terms of the cancer control continuum needs to consider prevention as well as cure. This may mean that funding needs to be shifted to increase the investment in prevention activities.
3. Need to better understand the workforce capacity with an emphasis on increasing Maori and Pacific capacity.
  - ❖ A structure or process required to address identified gaps. This will require a stocktake on what tasks are currently being undertaken by the workforce involved with cancer continuum.

Objective 2: Ensure appropriate programmes/services accessible to Maori across cancer control continuum.

1. This will also require a stocktake of activities already being undertaken across the continuum and the contribution being made to gains in Maori health outcomes. Particular focus is needed on:
  - ❖ disparities and make addressing these a priority
  - ❖ using positive existing work to model future ways to make gains
  - ❖ community-driven approaches.

Objective 3: Ensure the active involvement of consumer representatives across the spectrum of cancer control.

1. Establish a network to work alongside current health structures to clarify needs and priorities for cancer control.
2. Transparency of information needed about where cancer control sits on DHBs list of priorities in DHB annual plans, agendas, strategic plans. Need public behind you to make a difference.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored
Stocktake of workforce. Look at skills needed across the continuum.	Stocktake needs to take account of input from 'unpaid' workforce.	HWAC is doing this at a DHB level.		
Improve integration of the workforce to ensure that it is relevant to people being treated.	Structure to monitor issues over service delivery in CC continuum. Structure not on place to achieve this.			
Long-term planning for a cancer control workforce, including career planning, to ensure it is based on service delivery needs.	Consider and address 'environmental' issues for the cancer control workforce and its impact on the retention of oncologists/nurses, etc.			
Training needed to increase staff understanding of Treaty of Waitangi and Pacific cultural issues especially at secondary and tertiary levels of care.	Equity of access to workforce – roles and responsibilities need to be clearly defined.			
Considered 'tied' tobacco taxes to increase services, specifically for smoking cessation and prevention.				
Implementation of recommendations from research.	Draw on research into effects of health reforms in evaluation report.			
Actions needed within each objective in the strategy to specifically to relate to improved Maori access to activities services and to remove barriers.	Intersectoral collaboration for pathway in Maori Health Strategy.			
Ministry should be auditing contracts at local/iwi level to ensure accountability to communities (ie, that communities have the ability to comment on the effectiveness etc, of services for them).	Accountability could be actioned nationally.	DHBs and other service providers		
Consumer issues: <ul style="list-style-type: none"> <li>❖ Ensure groups developing strategies require input from consumer representatives.</li> <li>❖ Develop criteria for who would fit definition of consumer representative.</li> </ul>	Consumers are already heavily involved – need training for consumer reps – advocacy/representation/ media/science.	National body like Cancer Society, Cancer Trusts.		

## Group E2

### Recommendations

1. National, independent leadership is required, but with all key stakeholders involved:
  - ❖ strategic leadership and monitoring plan
  - ❖ co-ordination (involving and activating other groups).
2. National, comprehensive and co-ordinated workforce plan is required. This should be high-level and overarching, but requires participation by a number of agencies.
3. Map competencies of the workforce across the continuum.
4. Invest in recruitment, training and retention of Maori throughout the workforce. Value change needed across all of society and the CC workforce (including access barrier relating to frontline staff.)
5. Urge the task force to model consumer representation at all levels of implementation of the CCS:
  - ❖ support initiatives to build national consumer voice, training and networking
  - ❖ potentially identify the need for a national database of consumer community groups.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
National, comprehensive, co-ordinated framework and leadership. DHB role goes across continuum – linkages with education etc.	Resources, data analysis Agreed standard across New Zealand in terms of skills and services. Overall policy and micro-plans can be complementary.	Educational, professional bodies, colleges, all stakeholders, Ministry of Health, DHBs. Need DHB buy-in.		Independent Cancer Control Agency working at high level, with workforce identification as one issue
National overview re competencies, decide who holds them, what are the workforce competencies required, what are the skills and who has them.	Consultative approach. Link with education and development of competencies at multiple levels.	Consortium approach with partnership rather than Ministry of Health led.		High-level Cancer Control Agency responsible for both leading and monitoring strategy, accountable to Government and Minister
Map/audit competencies.	Broader issues than just mapping competencies. Need competence across continuum of care.			
Alternative model? (grand plan at risk of failure) eg, microplan within radiation effectively implemented. (The merits of both approaches to workforce issues were debated, with no resolution; however most supported a national level plan/approach to workforce issues.)				
Maori access. Get more Maori into workforce across spectrum, beyond cancer control alone, will have beneficial impact.	Need culture shift in industry, pluralistic approach etc.			
Opportunities for educational/competency expansion.	Focus on people already working in the sector (long training time).			

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored?
Competencies need to include values (eg, whanau involvement in palliative care is culture change not necessarily recruitment issue).	Need to be explicit about values we are looking for. Effort going into cultural sensitivity lost when workforce goes overseas. Issues of skill and values retention need addressing.			
Tackle some forms of cancer that are amenable to prevention among Maori. Issues of trust and communication important – some programmes by/for Maori often very important as to who gives the information. In some cases more focus may be needed on supportive policy addressing prevention issues among Maori	Strengthen networks and health promotion efforts that already exist (eg, smokefree bars will have big influence on Maori). Keep in mind public health and health promotion programmes.			
Consumer representation. Ensure agencies like Cancer Society and other NGOs have increasingly important role in terms of consumers.	Need more than token commitment. Auckland developing Australian approach to breast cancer where all consumer groups involved.			
National consumer voice for New Zealanders.	A number of groups already exist that could be involved in creating a national entity. Needs distinct sources of funding, not drawing on NGOs sources.			
Develop registry of consumer groups.	Government support for registration of consumer groups. Training and guidelines required for identifying different consumer groups.			

# Workshop Summaries – Goal 6: Research and surveillance

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The summaries below include the objectives for discussion listed in the programme for Workshop Group J (afternoon). They include the key issues identified and the proposed actions. They record the raw data but do not include the initial ‘brainstorming’ material nor any very broad statements of principle; the recurring themes throughout both of these will be integrated, however, into the final workshop report. Where there was more than one group, responses from each are listed separately.

Sometimes the relationship between objectives and actions was not explicit, and often the relationship between *What should be done* and the implementation process (in columns 2–5) was not at all clear in the scribing. Where links were not identified in the workshop report, some effort has been made to make the connections between these. The initial wording was taken verbatim from the recording sheets. To ensure the accuracy of workshop documentation, drafts were sent to all relevant workshop facilitators and scribes for review and correction. All suggested additions and/or changes submitted thus far have been incorporated.

## Workshop J

### Objectives

- ❖ Extend and enhance research across the continuum of cancer control.
- ❖ Improve the use, efficiency and scope of national data collection and reporting.

### Group J1

#### Key issues

1. Need a cancer intervention and outcome-based national common data set (Cancer Registry).
2. Need a national stocktake of cancer research to develop national database of cancer research and researchers. This to be used to develop a national framework to facilitate research funding and research, and recruitment and training of more Maori and Pacific researchers.
3. Promotion to the public of the value of research-driven health care (open days, media releases, etc).

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored
Research into effect of patient management on outcomes as prescription changes.	Linking of diagnosis, prescription and outcomes over time – minimum dataset, prospective. Mandatory cancer registry. National database accessed by all centres.	NZHIS expertise		
Not all patients reach an oncology centre	These too need to be captured on database.			
Stocktake of research – national database (HRC).	Where money coming from? Collaboration, planning.			
National framework of cancer research.		Maori researchers		Who monitors?
Relationship between researcher and cancer control strategy.	DHBs to embrace research as a core activity.	HRC partnership with DHBs		
Raise image of science.	Open days etc.			

In all of the above, the ‘who’, ‘when’ and ‘who monitors’ is dependent upon, and potentially inter-related to, the particular cancer control ‘vehicle’ yet to be created. There was also general agreement that the current system is not working.

## Group J2

### Issues

1. Cancer research priorities must be determined. *Who?* Who not critical but may be Ministry of Health/HRC/autonomous group representing NGOs etc/ministerial appointed committee. *What?* Must align with cancer control strategies, be representative of needs of people and priorities, and be cognisant of two purposes of Cancer Control Strategy: to reduce incidence overall, *and* to reduce inequalities. *When?* Urgently – process completed within one year.
2. Support for NCTWP for development of enhanced data set:
  - a) Rapid development of core (or backbone) data-set with defined national minimum data set (ie, refinement of Cancer Registry).
  - b) Development of module that can be bolted on to backbone, to meet requirements of:
    - ❖ regional interests (eg, additional data on treatment modalities given research interest of researchers in region)
    - ❖ national interests (eg, occasional or ongoing need to collect supplementary social, ethnic, psychosocial or other data for in depth research or enhanced monitoring).
3. Recognising importance of need for partnership with Maori. Recognising need for DHB co-operation in implementation of cancer control activities. Need consideration of socioeconomic inequalities in cancer in addition to ethnic inequalities.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored
Research across the continuum. Social, people-centred studies are underfunded, also palliative care research and impact of burden on families and societies.	New Zealand-specific research. Need to include primary prevention, screening, research on access to services. Need representation on review boards of all types of researchers.			Need for evaluation of services – DHB mandate.
Improve data collection and reporting – use, efficiency, scope.	Make recent cancer registry data available (two-year delay at present). Develop minimum national data set including stage, treatment.	Multidisciplinary		
Use database for individual/clinical needs and national aggregate data.	Accurate information to individuals re privacy issues – must be considered upfront.			
Additional consideration given to ethnicity/inequality data, research and workforce.	Consistency of ethnicity data collection made explicit – implicit is not enough.	MSD link into existing work		
Must be co-ordinated approach to reflect all working parties. Decide on priorities.	Consistent definitions of research across DHBs.	Independent body to co-ordinate funding. Use existing HRC structure (? too biomedical?) Cancer Institute could accept investors/funding		
Identify where inequalities arise.	Enhanced data set.	Maori/Pacific, Asian, other ethnicities participation on cancer 'body'		

### Group J3

#### Issues to highlight

1. Gaps in research continuum, for example:
  - ❖ psychosocial
  - ❖ outcomes
  - ❖ prevention..

Co-ordinating role of Cancer Control Agency in addressing this and liaising /working with other stakeholders.
2. Further research \$\$\$.

  - ❖ Role for Cancer Control Agency to identify areas for research to justify requests for funding (as well as addressing cost-effectiveness of existing research capabilities).

3. Importance of linkage of various data holdings; expanding databases (eg, psychosocial factors) and improving quality.
  - ❖ Deal to privacy issues.
  - ❖ Address issue of Maori data.

What should be done?	What do we need to do it?	Who involved and how?	When?	Who and how monitored
Oversight of cancer research, identifying gaps and setting research agenda, including who funds it.	Develop research strategy Identification/evaluation of current research. Need commissioned plus investigator-led research.	Cancer Control Agency to set agenda; develop strategy in collaboration with stakeholders.		Body responsible for implementing strategy.
Research across the continuum. Insufficient social, people-centred studies, also palliative care research and impact of burden on families and societies.	New Zealand-specific research. Need to include primary prevention, screening, research on access to services; evaluation of services. Need wider representation (all types of researchers) on funding/ review bodies.	Cancer Control Agency to oversee strategy. Multiple stakeholders (evaluation of services – DHB mandate).		Body responsible for implementing strategy.
Address level of research funding. Research funding overall is low. Get best value for money in research	Need forum for cancer research. Identify multiple funders: public (eg, HRC, Ministry of Health), private and voluntary agencies (eg, Cancer Society); assess cost-effectiveness of current research activity.	HRC is compiling database of funded research. SPARC involvement.		
Security of jobs for researchers.	Effect of PBRF unknown. Recruitment, training and retention of scientists remains problematic.	Who sets cancer research agenda?		
Improve use, efficiency, scope of national data collection and monitoring. CC strategy has substantial data needs.	Coordination; standardised national data set. Private sector data (treatment). More data (eg, psychosocial, more variables). Data needs to be accessible – epidemiological data exists in universities.	DHB hospitals also compile information. Cancer Control Agency.		
Access to data on patients and health professionals involved in their care. Privacy is an issue.	Data record needs comprehensive history of patient and procedures, with times. Cancer Registry could compile list of data stakeholders. Data exist for different purposes – cancer registry, familial cancer database etc.	Periodic surveys available (eg, household health survey).	In part under way by existing initiatives.	