Opportunities to reduce the social and economic burden of cancer in New Zealand

Submission to the Minister of Health from the New Zealand Cancer Control Trust on the Report of the Ministerial Review Group of 31 July 2009.

The New Zealand Cancer Control Trust

The New Zealand Cancer Control Trust (the Trust) is committed to a planned and integrated approach to reducing the burden of cancer in New Zealand. The Trust was the non-Government partner that worked alongside the Ministry of Health to develop *The New Zealand Cancer Control Strategy*.

Purpose of paper

The proposed changes to the health system in New Zealand provide an important opportunity to enhance efforts to reduce the economic and social burden of cancer in New Zealand. This paper briefly outlines the Trust's views on some of the key issues in cancer control that on the one hand have the potential for significant gains and savings if addressed, but conversely have risks and costs if not addressed. As an independent advocate for cancer control with links to international expertise, the Trust would be pleased to offer further advice and assistance in relation to these and other issues.

Key points

- The Trust supports the establishment of a National Health Board (NHB) and the opportunities it provides. These include opportunities for:
 - efficiencies and improvements in those cancer-related programmes and services which need to be managed nationally
 - addressing cancer prevention within the context of an integrated approach to the prevention of chronic diseases
 - o strengthening the National Screening Unit as an essential national entity.
- The Trust supports the proposed strengthening of the National Health Committee's
 role and recommends that this role should include the evidence-based assessment
 of new and existing cancer screening programmes.
- The proposed reconfiguration of the health system provides an opportunity to ensure a uniform and equitable approach to cancer diagnosis and treatment.
- Consideration will need to be given to assigning responsibility for routine monitoring of New Zealand cancer-related data to inform the development of services and policies.
- Consideration will need to be given to the best location for the Cancer Registry.
- A National Quality Agency will provide enhanced opportunities for advancing quality improvement in cancer control at a national level.

Background

While improvements have been made in New Zealand over the past 20 years, our death rates from some types of cancer are high by international standards. For example, New Zealand's bowel cancer death rates are among the highest in the world. These are likely to remain so as screening, at most, only reduces the risk of death from bowel cancer by up to 15%. A range of well coordinated approaches is needed if we are to minimise the costs and the human suffering from cancer, including prevention, earlier diagnosis and uniform availability of the most appropriate treatment. There are disparities in survival after a diagnosis of cancer between different ethnic groups and between different regions in New Zealand, and these could be improved.

The World Health Organization continues to advocate for countries to establish a national cancer control programme to "reduce cancer incidence and mortality and improve quality of life of cancer patients, through the systematic and equitable implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment and palliation, making the best use of available resources" (World Health Organization 2002). To make the greatest gains, initiatives must be planned and coordinated and must span all of these activities included within what is known as the "cancer control continuum". To focus on only some aspects of the continuum without attention to others will not achieve the greatest reduction in our burden of cancer.

Achievements to date

Over the past twenty years New Zealand has taken some significant steps to reduce our burden of cancer through planned and coordinated approaches, most of which have been initiated or developed on a national basis. Among these are:

- Two national population cancer screening programmes, overseen at a national level by the National Screening Unit (NSU)
- The New Zealand Cancer Control Strategy (2003) and its initial Action Plan 2005-10 (2005), with goals that extend across the cancer control continuum
- Establishment of the Cancer Control Council to monitor effectiveness of the Strategy
- Evidence-based guidelines with audit possibilities, including:
 - Suspected Cancer (to assist with timely and appropriate referral)
 - Management of Early Breast Cancer
 - Management of Melanoma in Australia and New Zealand (addressing prevention, diagnosis, treatment and care)
- Planned and coordinated achievements in tobacco control through a coalition of NGOs
- The establishment of four Regional Cancer Networks
- The development of regional tumour streams by Regional Cancer Networks, with some national coordination, to harmonise management and treatment availability in different DHBs and different networks
- Establishment of targets for treatment waiting times.

¹ The cancer control continuum has been used at least since the mid-1970s to describe the various points from cancer prevention, screening and early detection, diagnosis and treatment, survivorship (rehabilitation) and palliative care. It is useful to view plans, progress and priorities and to help identify research gaps, where collaboration with others is needed to have an impact and where more resources may be needed. http://cancercontrol.cancer.gov/OD/continuum.html

The proposed changes to the New Zealand health system provide an important opportunity to build upon developments to date in order to further reduce the economic and social burden of cancer in New Zealand. It is important that any restructuring of our health services maintains or improves coordination of prevention, screening, treatment, rehabilitation and palliative care. Unless this happens the effectiveness of current programmes will be reduced.

Areas for potential gain across the cancer control continuum

1. The Trust supports the establishment of a National Health Board (NHB).

The establishment of National Health Board provides an opportunity for efficiencies and improvements in those cancer-related programmes and services which need to be managed nationally. In our view these include:

- Planning and funding of all cancer services
- Responsibility for the development and improved management of national screening programmes
- Development of best practice guidelines
- Coordination of Regional Cancer Networks
- Coordination of Clinical Networks
- Monitoring to ensure compliance with agreed programmes to reduce the burden of cancer and reduce inequalities
- Greater standardisation of cancer services, and access to them, throughout the country
- Greater standardisation and timely implementation of new cancer control initiatives.

2. Establishment of a NHB provides the opportunity to include cancer prevention within the context of an integrated approach to the prevention of chronic diseases.

The establishment of a NHB provides an opportunity to develop a more integrated cost-effective approach to primary prevention of cancer through its alignment with other chronic diseases, in particular cardiovascular disease, chronic respiratory diseases and diabetes. As highlighted at the 2nd International Cancer Control Congress in Rio de Janeiro in 2007, such an approach has been adopted in number of countries, including Canada, China and Australia. These governments acknowledge that diseases that share key risk factors and related interventions should be addressed together in a systematic and coordinated way.

According to Australia: The Healthiest Country by 2020 – National Preventative Health Strategy released in June 2009 by the Australian Government, an integrated chronic disease approach is needed to:

"minimise the impending overload of the health and hospital systems, and to increase the productivity, and therefore the competitiveness, of Australia's workforce. It will assist in avoiding the health and social costs that would otherwise be incurred if we do little or nothing" (Australian Government Preventive Taskforce 2009).

Citing inequalities comparable to those in New Zealand, the Australian strategy also highlights the country's "national commitment to fairness", noting that:

"good and bad health is unevenly distributed – there is a social gradient, which means that those... with less money, less education and insecure working conditions are much more likely to get sick and die earlier. This inequity is extremely acute for Indigenous Australians" (Australian Government Preventive Taskforce 2009).

Another potential model for an integrated approach to chronic disease prevention is the 2008-2013 Action Plan for the Global Strategy for the Prevention and Control of Noncommunicable Diseases developed by the Secretariat of the World Health Organization. The plan was developed in response to the Resolution on Cancer Prevention and Control by the World Health Assembly (World Health Organization 2008).

3. Establishment of an NHB provides the opportunity to strengthen the National Screening Unit as an essential national entity.

The National Screening Unit was established in response to the Gisborne Inquiry in 2000 to address an identified need for centralisation of all national aspects of cancer screening programmes to minimise the likelihood of another major systemic screening programme failure. The Ministerial Inquiry was charged with investigating the high under-reporting of abnormal smears in the Tairawhiti region and whether there was evidence of wider systemic issues (Duffy, Barrett et al 2001).

The Gisborne Inquiry not only found unacceptable practices at the laboratory concerned (resulting in women developing invasive cervical cancer when, had the programme been operating effectively, these cases could have been diagnosed and treated in the early stages to prevent cancer), but also identified a range of factors affecting the performance of the National Cervical Screening Programme (NCSP). The latter highlighted the need for centralisation of the NSCP and the national breast screening programme (BreastScreen Aotearoa). This reflected internationally recognised key organisational requirements for successful population screening programmes (Miller 1992).

When the National Screening Unit was first established under the Health Funding Authority and subsequently moved to the Ministry of Health, it had strong clinical leadership and soon met other requirements identified by the Gisborne Inquiry. The Trust notes with concern that over the ten years since the NSU was established some of the key national functions have been diluted or discontinued, and the Trust believes these changes have increased the risk of another major systemic failure in one of our national cancer screening programmes.

The Trust notes the recommendation of the Ministerial Review Group that "the Ministry of Health be asked to consider if the NSU should remain a national service and be moved to the NHB, or if it is better to devolve its functions to DHBs to manage either regionally or locally". Failure to retain and strengthen the NSU would be counter to accepted international best practice for population screening programmes and to the recommendation made by the Gisborne Committee of Inquiry in 2001 that:

" a programme of this nature is best run as a national programme from a centralised office. It is particularly important that with the current restructuring of the health sector and the use of 22 district health boards the Programme should not be subject to the threat of any further fragmentation" (Duffy, Barrett et al 2001).

The Report of the Ministerial Review Group and its emphasis on strengthening of national services would suggest that the Group would agree with our stance on strengthening the National Screening Unit as an essential national entity. Nevertheless, careful consideration will need to be given to ensuring that the Unit provides all the essential national functions required for screening programme safety and cost-effectiveness.

In the Trust's view, a national population register also is needed to increase the effectiveness of screening programmes for cancer and other diseases. The use of population registers to identify and invite participants is recommended by the World Health Organization (World Health Organization 2002). Without such a register, screening programmes in New Zealand are unable to achieve the coverage required to be cost-effective.

As several Trustees have specialised expertise and experience in cancer screening, the Trust would be pleased to offer additional advice in this area.

4. Strengthening of the National Health Committee's role should include the evidence-based assessment of new and existing cancer screening programmes.

As highlighted in *The New Zealand Cancer Control Strategy*, high-level cancer screening recommendations have been made by different working parties at different times. This work frequently has been carried out "as the result of external requests from special interest groups rather than as part of an organised, ongoing approach" (Minister of Health 2003). The strategy recommends the establishment of an effective national mechanism to provide high-level strategic advice to cancer screening at a national level.

A strengthened National Health Committee with its proposed capability to conduct evidence-based assessment of the likely costs and benefits of new and existing procedures and interventions would be an appropriate body to provide advice on cancer screening. We note that the NHC when first established provided such advice to Government, having developed screening assessment criteria for this purpose (National Health Committee 2003).

5. Proposed reconfiguration of the health system provides an opportunity to ensure a uniform and equitable approach to cancer diagnosis and treatment.

The New Zealand Cancer Control Strategy Action Plan 2005-2010 identifies the need for planning of cancer treatment services on a national basis. It states that "national planning is needed because:

- demand for cancer treatment is predicted to continue to increase
- many services are provided on a regional or supra-regional basis
- the significant cost of provision of some services and capital investment requires national co-ordination to ensure effective utilisation of resources
- present waiting lists for oncology services are due in part to a failure to plan for increasing demand" (Ministry of Health 2005).

The proposed health system changes provide an important opportunity to address the need for national service planning, thereby ensuring a more uniform and equitable approach to cancer diagnosis and treatment.

We note, for example, that the Ministerial Review Committee recommends a strengthened and expanded role for PHARMAC in assessing the relative cost-effectiveness of medical devices as well as new and existing pharmaceuticals. While current PHARMAC assessment processes for pharmaceuticals may be sound, the Trust believes that additional judgement is required to assess the appropriateness of introducing cancer drugs and medical devices into the context of the New Zealand health system.

With an expanding range and combination of therapies and devices available, the need also exists for the establishment of a prioritisation process. The Trust therefore supports the full development, with sector involvement, of a prioritisation tool that currently is in an infant stage.

Also, while PHARMAC identifies the pharmaceutical cancer treatments which all DHBs must fund, DHBs currently hold the funding for these medicines. Changes to the health system provide an important opportunity to transfer this funding to one national agency.

Strengthened national initiatives relating to treatment also should include:

- redefined service specifications for regional cancer treatment centres to ensure greater uniformity of services
- use of current data to greatly improve the independent monitoring of the quality of cancer care (an area that has been neglected in New Zealand over several decades)
- expansion of data collected to allow comparisons of the performance of regional cancer treatment centres
- addressing a fragile workforce across cancer services and related services, e.g. pathology, an essential service for cancer diagnosis.

6. Consideration will need to be given to assigning responsibility for routine monitoring of New Zealand data to inform the development of services and policies.

The experience of the national screening programmes strongly indicates that monitoring of cancer control activities and their relationship to outcomes would considerably improve their focus and effectiveness. The monitoring of the screening programmes involves monitoring the primary care interaction, referral, assessment, diagnosis and treatment, which are a considerable part of the cancer control continuum for cancer of the breast and cervix. Monitoring along disease management rather than service lines has greatly improved the management for patients with these diseases. Monitoring must also include assessment of disparities in cancer survival between different ethnic groups and between different regions in New Zealand.

7. Consideration will need to be given to the best location for the Cancer Registry.

The Cancer Registry within the Ministry of Health operates on a shoestring and has limited opportunities to attract additional funding for the work they do. This can also result in major underutilisation of this national resource. The registry is the essential instrument for monitoring cancer control success at the population level. The registry needs to be closely aligned with organisations with expertise in the monitoring of cancer control activities across the cancer control continuum. The registry might be suitably placed under the responsibility of the National Quality Agency.

8. A National Quality Agency will provide enhanced opportunities for advancing quality improvement in cancer control at a national level.

The Trust supports the establishment of a National Quality Agency and sees many potential benefits for cancer control. Quality management is important right across the cancer control continuum. However, it is of critical importance in cancer screening because there is often a fine balance between the expected benefits and potential harms of screening. As identified by the National Health Committee, "poor screening programme quality, or a decline in screening programme quality, can tip the balance between benefits and harms the wrong way" (National Health Committee 2003).

A new national focus on quality will enable a broader approach to implementing quality initiatives in cancer management where there is evidence to show benefit. We appreciate that the initial focus for the National Quality Agency will be focused on secondary and tertiary services, including cancer services.

We support the existing quality projects being undertaken by the Quality Improvement Committee that impact favourably on cancer control, including:

- the saving 1,000 lives campaign based on the successful NHI campaign in the US which has some benefits for cancer patients having surgery and those at risk of DVTs
- the work on infection control, incident management and medicine safety that will benefit cancer in-patients as well as those using community based services
- the Optimising the Patient Journey (OPJ) initiatives that currently focus on what happens in hospitals and is about to include primary health care both at the start and completion of hospital care.

The Trust would urge Government to consider taking a much broader approach to quality to enable the scope of the new National Quality Agency to go beyond hospital inpatients. We believe there is a compelling case for formalising the consumer centred screening pathway (that forms the backbone of the cancer screening programmes) as an OPJ approach and in doing so make the cancer screening programmes part of the national quality agenda. This would also serve to improve the interface between screening programmes and cancer treatment for those identified with the disease via the screening programmes.

There will need to be clarification around the interface between the work of the National Quality Agency and the work of the Cancer Control Council with respect to cancer control.

Conclusion

While significant achievements in cancer control have been made over the past ten years, New Zealand continues to be faced with increasing numbers of people being diagnosed with cancer. The death rates for some types of cancer in New Zealand remain high by international standards. The proposed changes to the New Zealand health system provide an opportunity for the Government to enhance cancer control in New Zealand and for it to regain lost ground against other countries with which we like to be compared.

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