Cancer Care at a Crossroads: time to make a choice

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“...where our choices, or refusal to make choices, have clear implications for our ability to provide care in the future. How can we provide care, improve options and outcomes for patients with cancer, and do so within a socially responsible, cost-effective and sustainable framework?”

Sullivan et al, Lancet Oncology (2011)

Cancer is the leading cause of death in Aotearoa/New Zealand. The number of those affected by cancer is forecast to increase by 50% in the next 15 years, primarily driven by a growing and ageing population. Our survival rates from cancer lag behind those of Australia, Canada and Scandinavian countries, and are not improving at the same rate as elsewhere. Even more telling is that our outcomes for cancer vary within New Zealand. Our Indigenous and most marginalised fare worse, with Māori and Pacific people having higher rates of preventable cancers, worse survival and higher death rates than other New Zealanders. Increasingly, regional variations in care and outcome are being reported.

At the same time, the costs of cancer care are escalating beyond our capacity to afford them. Drivers include the rising number of people with cancer, increasing age and comorbidity of patients, technology and new drugs, increasing specialisation, and increasing awareness of and demand for supportive care. The pace of change in cancer management, particularly new drugs and technology, presents major challenges for our systems and services.

The management of cancer is uniquely complex, impacting on every aspect of our healthcare services, and so any solution must have a whole-of-system focus. Of course, many of the challenges we must face in relation to cancer care and control are not unique to us in New Zealand, and there is much to be learned by looking abroad.

These issues are not new. During the late 1990s, the sector worked together, led by the NZ Cancer Control Trust (funded by the Cancer Society of New Zealand and the Child Cancer Foundation), to develop a comprehensive Cancer Control Strategy. The Strategy was launched in 2003, more than a decade and a half ago. That strategy had a strong equity focus, its scope was broad, encompassing cancer prevention through to palliative care and research. It was followed by a series of cancer action plans that were more operational in their intent. By 2015, the focus of cancer control had largely narrowed to emphasise cancer treatment occurring in hospitals, with the advent of “better, sooner, more convenient cancer care”. This initiative was supported with treatment-related targets, which while popular, were not clearly related to improved outcomes. Achieving equity was largely absent from ongoing policy, and resource allocation was hamstrung by the reduced investment in Māori providers and the 2006 Ministry directive that the Treaty of Waitangi clause be removed from official documents. In the last three years the Cancer Control Council, and Te Kete Hauora, the Māori Health Business Unit at the Ministry of Health have been disestablished, key prevention opportunities such as Sunsmart initiatives, alcohol and tobacco supply reduction, and action against obesity have all seemed to falter. Many in the cancer sector came to view progress on cancer control as stalled, and lacking in key government leadership.

In response, the Cancer Care at a Crossroads conference was held in Wellington in early 2019. This was a landmark event jointly hosted by the University of Otago,
Wellington and the Cancer Society of New Zealand, in partnership with the Ministry of Health and the New Zealand Society for Oncology. It was attended by around 400 people from across the cancer control spectrum; people affected by cancer, NGOs, primary and secondary care service providers, academics and policy makers. The conference was opened by a powerful call to action from Blair Vining, who has terminal bowel cancer and his wife, Melissa, with the words [from Melissa] to the Minister of Health “You have failed Blair, you have failed me and my children, and you have failed many other New Zealanders by not having a cancer plan”.

Invited speakers covered wide-ranging topics, identifying strengths, weaknesses and high priority cancer control activities for governance, surveillance, prevention, early detection, treatment, palliative care and research. There was a strong focus on Māori leadership and rights, addressing health needs of Māori and other underserved populations, with a view to eliminating inequities in outcomes from cancer. Speakers from the UK, Canada, Australia and Europe described effective global responses, which included the development and redevelopment of dedicated cancer agencies, comprehensive cancer control plans, central planning and monitoring of both processes and outcomes within cancer systems. Local speakers and attendees highlighted a growing frustration at the sense of lack of progress in cancer control, and the mood was that we are indeed at a crossroads.

Several key themes emerged.

1. There was a strong consensus that New Zealand urgently needs strong central leadership in cancer control. Eighty-one percent of participants at the conference supported the idea of a national cancer agency to provide evidence-based, collaborative high-quality cancer control leadership to the sector. Internationally, there are many very successful models based on this concept (Table 1). Irrespective of the model, leadership needs to be goal-orientated, equity-focused, information-rich, have systematic decision-making processes that involve all stakeholders including cancer survivors, and driven to continual improvement. This is consistent with World Health Organization recommendations, which state that good cancer control requires a comprehensive, integrated programme of activities, clear identifiable leadership, involvement of the sector, evidence-based decision-making, a focus on continuous quality improvement and a stepwise approach to planning and implementation. New Zealand has four regional cancer networks, with some questioning whether an obvious solution is to combine these into one single national cancer network charged with leading the next steps in cancer control.

2. Achieving equity must be a central element of any cancer control activity. A critical element of this is committing to actively supporting the Māori right to self-determination and to freely pursue cancer control development in accordance with Māori aspirations. Māori and Pacific people in New Zealand have higher rates of most preventable cancers; 3–3.5 times the rate of lung cancer, 3–6 times the rate of stomach cancer, and 3–4 times the rate of liver cancer, and worse survival for almost all cancer sites. Evidence-based policy needs to be urgently implemented to prevent these cancers, particularly among those most affected. Reducing inequities in health extends to elements outside of the health system, factors often linked to disempowerment and poverty (such as income distribution and housing quality) that create inequalities in health generally and cancer specifically. The reasons for existing inequities are multifactorial, including Māori patients having later stage disease at diagnosis for some cancers, generally higher rates of comorbidity, poorer access to cancer care and sometimes poorer quality of care. An equity focus is required through the entire system; identifying root causes of inequity, valuing and integrating Māori knowledge and expertise within our health services, using tools such as equity-focused reporting to
identify ‘hotspots’ of inequity, and using continuous quality improvement approaches. In short, we must be prepared to invest disproportionately in our least privileged populations, so they can expect the same cancer outcomes as our most privileged. One goal that was articulated was that we should aim to achieve survival equity between Māori and non-Māori cancer patients by 2030.

3. Monitoring quality and equity across our cancer control continuum is fundamental to identify our priorities, evaluate what is working and what is not, and to shine light on the gaps in our knowledge. To be effective, we need to measure both processes and outcomes and we need to focus on high-priority areas first. Measurement needs to be undertaken with a clear purpose, requires high-quality data (including ethnicity), needs to have patient perspectives embedded and needs to be clearly attached to action for improvement where necessary. One of the highest-priority areas is ensuring that accurate and high-quality staging information is provided to the cancer registry in order that stage-specific survival can be ascertained so that we can focus on the areas of greatest need first, we can measure the value and impact of investment, and enable international benchmarking.

4. Good policy, planning and monitoring is only effective if there are organised, well-resourced implementation strategies in place. This needs to be coordinated and integrated across the entire health system, from national to regional and community-level implementation. Too frequently, policy has been developed and implemented without national consistency, or a clear evaluation plan. One such example was the “Tumour Standards”, which were not clearly defined, were not resourced for implementation, and there was no baseline or follow-up measurement.

5. A need for broadening of technology assessment. Cancer care is becoming increasingly technology dependent. While New Zealand has a long history of controlled and constrained investment in cancer drugs through PHARMAC, the same rigour and review does not currently apply to the use of novel high-cost surgical techniques such as robotic or laparoscopic surgery, stereotactic radiosurgery or investment in high-cost and complex imaging such as PET/CT (including access criteria). As the role for clinical genomics expands, this will also challenge our ability to implement this important component of cancer care equitably and evenly. In the UK, the National Institute of Health Care and Excellence (NICE) performs this function; there is no equivalent in New Zealand and a review of this function is timely. The need for better access to cancer drugs was voiced by patient advocates, and tensions with other priorities for investment in cancer control were noted. PHARMAC Chairman Steve Maharey promised an improvement of PHARMAC’s timeliness of assessment and hinted at other changes he would be proposing to his board during the course of his tenure.

6. High quality, accessible, timely, equitable and coordinated treatment and care processes. There were calls for improvements in care, with clear streamlined processes for diagnosis, treatment and referral. Well-coordinated and patient-centred care ensures the right patient has access to the care they need at the right place and in a timely fashion. This requires coordination across the entire system, which in turn requires a clear governance and organisational structure led nationally, and operationalised at national, regional and local levels. It involves adherence to current best practice and sometimes referral of people to wherever best outcomes are being achieved. It means that some treatments will not be available everywhere, but that common conditions should be treated expertly in a relatively consistent manner close to home with uniform outcomes. It also means focusing on all elements of the treatment pathway
so that they are designed in such a way that they eliminate inequities. It means focusing on the care of the whole person and their whānau, not just their disease.

7. **Prevention is critical.** Up to half of all cancers are theoretically preventable, yet little research or resource is dedicated to addressing optimal approaches to prevention in New Zealand. Even when there is clear evidence for action, we frequently allow vested interests to limit our progress. These interventions can be broad-based and determinants-focused such as ensuring adequate housing to reduce the rates of chronic infections among underserved populations (including H pylori and hepatitis viruses which cause stomach and liver cancers respectively), those which focus on differential exposures to risk factors including tobacco control, policies to address the growing obesity problem in New Zealand, and policies which address alcohol consumption as a cause of cancer, and policies that are situated within the health sector such as policies for immunisation against HPV and hepatitis B, and cervical screening.

8. **Engagement of primary care.** With increasing numbers of people surviving cancer, there is an increasing role for primary care and general practice. Additionally, there is an important role for primary care in the surveillance and follow-up of people who have completed secondary care treatment. This would enable unburdening of secondary services to facilitate more rapid access to diagnosis. There is likely to be a need for streamlining the evaluation of high-risk symptoms clinics to facilitate referral pathways along patient-centred pathways rather than the more traditional specialty-based referral paths. Primary care is also uniquely well placed to monitor, manage and evaluate comorbid conditions, which can impact substantially on the outcomes for those with cancer.

9. **Research matters.** Research activities must continue to occur across the cancer control continuum and be integrated where possible, and leveraged to provide maximum benefit for our relatively modest means. Research priorities for New Zealand include those that will advantage those with greatest need, and must be in line with obligations under te Tiriti o Waitangi. Any cancer control priorities must also blend with the priorities of the Health Research Strategy, which are currently under review.

**Outcomes**

The meeting garnered three days of continuous media attention, and saw the Minister of Health answering questions across a variety of media outlets about his Government’s response to cancer control. The Minister noted he had heard the call and was deeply moved by Blair and Melissa Vining, and promised to commence work on a national cancer plan, with a draft to be delivered by June. The voice of the sector and the demand for change was clearly conveyed.

The remaining question is what the quality and scale of the response will be. Will a new cancer control plan address the entrenched structural issues in New Zealand, that have seen the delivery of inequitable and uneven care? Will we have a programme that delivers bold and evidence-based prevention goals that challenge our political comfort? Will there be a leadership framework and technology evaluation process that sets us on a path that can engage with the realities of managing growth in demand and cost, as well as ensuring high-quality and equitable care? A repacking of current efforts and labelling this as a cancer control plan would risk selling New Zealand short for a generation. We are at a crossroads and face a choice; that choice (or failure to make a choice) will have profound implications for many years to come.
Table 1: Examples of centrally funded comprehensive cancer institutes.

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<th>Institute</th>
<th>Goal</th>
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<tr>
<td>Cancer Australia, Australia</td>
<td>Government funded agency. Set up in 2006. Aim to “reduce the impact of cancer, address disparities and improve outcomes for people affected by cancer by leading and coordinating national, evidence-based interventions across the continuum of care.”</td>
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<tr>
<td>NSW Cancer Institute, NSW Australia</td>
<td>Established in 2003 under statute to lessen the impact of cancer across the state (NSW) “reduce the incidence of cancer in the community; increase the survival rate for people diagnosed with cancer; improve the quality of life for people with cancer and their carers; provide a source of expertise on cancer control for the government, health service providers, medical researchers and the general community.”</td>
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<tr>
<td>Canadian Partnership Against Cancer, Canada</td>
<td>Founded in 2007. Federal Government funded to “accelerate action on cancer control for all Canadians” and “collectively focused on the long-term objectives of reducing the incidence of cancer, reducing the likelihood of dying from cancer and improving the quality of life of those affected by cancer.”</td>
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<tr>
<td>Danish Comprehensive Cancer Centre, Denmark</td>
<td>Set up in response in 2017 in response to a 2016 Cancer plan to “[gather] management and professional capacities within cancer and healthcare in Denmark.”</td>
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<tr>
<td>Netherland Comprehensive Cancer Organisation (IKNL)</td>
<td>A national organisation that is the “quality institute for oncological and palliative research and practice. IKNL collaborates with healthcare professionals and managers and patients on the continuous improvement of oncological and palliative care.”</td>
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Competing interests: Nil.

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