



Cancer Institute (NSW) Bill.

Second Reading

The Hon. TONY KELLY (Minister for Rural Affairs, Minister for Local Government, Minister for Emergency Services, and Minister Assisting the Minister for Natural Resources (Lands)) [10.09 p.m.]: I move:

That this bill be now read a second time.

I seek leave to have the second reading speech incorporated in *Hansard*.

Leave granted.

The bill introduces a key plank of the New South Wales Government's health policy for the March 2003 election, namely, the establishment of a cancer institute for the people of New South Wales. Cancer accounts for 28 per cent of all deaths, and almost 30,000 new cases of cancer are reported in New South Wales each year. Such a toll has a devastating impact on our community, and clearly warrants a focussed and co-ordinated response. Guiding our efforts in the drafting of the bill has been the principle that our efforts in the struggle against cancer should be not only caring but also clever. The bill equips us with a new weapon in this battle, the New South Wales Cancer Institute, which will become the tip of our spear in the fight against cancer.

The concept of a cancer institute for New South Wales was first considered almost 60 years ago when the then Premier, Sir William McKell, allocated £350,000 for that purpose. On his appointment as Governor-General the idea lapsed. Today the time has come for William McKell's proposal for a New South Wales Cancer Institute to become a reality. The concept of cancer control in the legislation encompasses a very broad range of activities, including research, prevention, diagnosis, care and treatment. The proposed institute will place itself at the heart of all aspects of cancer-related activities. It will become the State's driving force to tackle cancer head on, and that is clearly spelt out in the objectives for the institute.

Clause 5 sets out the objectives, which are to increase the survival rate for people with cancer, to reduce the incidence of cancer in the New South Wales community, to improve the quality of life for cancer patients and their carers, and to provide an expert resource on cancer control. We want to see less cancer, fewer deaths from cancer and better care for those with cancer. I stress that our goal is focused on outcomes. The success of the bill will not be measured by the amount of money invested in these efforts, but in the number of lives saved and the improvements we deliver to the lives of those suffering from the disease.

In fulfilment of the Government's commitment, the bill establishes the Cancer Institute as a separate statutory corporation with a governing board of up to 11 members, including the institute chief executive, who will be titled the Chief Cancer Officer. The board will be accountable, through the Minister, to the New South Wales community. Appointments to the board will provide not only a mix of skills, including clinical and research professionals, but also people with consumer and patient perspectives. The board's primary focus will be on how the cancer effort can deliver better outcomes for the people of New South Wales.

Clause 8 of part 2 of schedule 1 to the bill will ensure the transparency and probity of board decision making through appropriate management of any potential conflicts of interest. In addition, to enhance the objectivity and independence of the institute's activities the Minister may, under clause 21, establish an independent panel of experts, including people drawn from outside New South Wales, to review and report to the Minister on the institute's performance in achieving its objectives. It is the Government's intention that an international review panel will be convened to review periodically the institute's performance.

Consistent with the need for accountability to the people of New South Wales, the institute will be required to provide an annual report to the Minister within four months of the end of each financial year for tabling before Parliament. The reporting requirements demanded of the institute are explicit. Its annual report to Parliament must include details of the outcomes achieved from the institute's initiatives during the financial year; details about trends in the incidence, mortality and survival rates of cancer; and an overview of cancer-related research and philanthropy in New South Wales during the previous financial year.

This annual report will be in addition to the annual financial reporting requirements required of statutory bodies receiving funding through the Health appropriation. Clause 6 of the bill provides a set of guiding principles for the institute in undertaking its functions. These principles recognise that accountability, equity, the optimal use of resources and appropriate linkages both inside and outside New South Wales are essential to the success of the

overall cancer effort. Most importantly, they recognise that at the centre of the cancer effort, regardless of its form, is the cancer patient.

The role of the institute will involve the promotion of efficiency in clinical and research practices. The supply of funds is not limitless and, although some areas of activity will receive resource enhancement, the Government would expect value-for-money testing of programs and services to optimise the use of public funds. The provisions dealing with the functions of the institute are set out in clause 12. The institute will have broad functions in relation to all aspects of cancer research. The establishment of the institute offers an opportunity to identify current resources going to cancer-related research and advice on future priorities for research in this area.

Although the institute will be able to conduct its own research where appropriate, it will also commission and sponsor research by other organisations. The institute will play a key role in fostering collaboration and co-operation across the various bodies involved in cancer research. To achieve a more comprehensive understanding of the cancer research effort in New South Wales and maximise the benefits of available research funds, it is proposed that the institute establish a publicly available register of bodies and individuals contributing to the cancer research effort.

Participation in the register will be voluntary, and participants will be able to provide a broad outline of their area of research, be it epidemiological, clinical or molecular. Strong evidence suggests that best practice principles applied consistently in cancer control will significantly reduce death rates from cancer. For example, the application of screening programs and better treatment for breast cancer in the past two decades has led to a 15 per cent increase in survival rates for breast cancer sufferers. A major role for the institute will be keeping abreast of the very latest developments and improvements in cancer control both in Australia and overseas, and disseminating these improvements and developments to organisations and practitioners in the field in a manner that ensures their comprehensive uptake.

Ensuring that the best health care is provided involves a systematic approach to the dissemination of relevant information. The bill allows the institute to develop clinical guidelines and protocols for use by health professionals and other health service providers or, where appropriate, to endorse a guideline or protocol developed by another body whether in Australia or overseas. The institute will be able to accredit cancer control programs that meet specified standards. This form of benchmarking will encourage excellence in cancer control.

The Institute will also be able to sponsor innovative programs within the public health system as well as work with the Department of Health and the public health system for the further promotion of a patient-focused, seamless multidisciplinary approach to cancer care. Another priority for the institute will be to foster improvements in the prevention and early detection of cancer. Prevention can include both promotion measures, such as programs to reduce the incidence of smoking, as well as campaigns for sun protection.

The institute will play a role in identifying and disseminating the latest developments in cancer screening, such as recent developments in screening for bowel cancer, and cancer genetics screening. It will be given a wide-ranging brief to review and evaluate existing programs and services, as well as new initiatives and pilots within the public health system. Recommendations of the institute for improvements to existing programs or new initiatives can be implemented by way of incorporation into the performance agreements between public health organisations and the director-general under the Health Services Act 1997.

It is also proposed to confer on the institute a policy, planning and review role in respect of cancer control. The bill sets out a specific and ambitious deadline by which the institute, in conjunction with the Department of Health, must develop a State cancer plan. It is envisaged that the plan will encompass the full spectrum of cancer control activities to be undertaken across New South Wales. This will include clinical initiatives and research projects, as well as prevention and information strategies. A State cancer plan is necessary to ensure an integrated statewide approach to cancer control. The 30 June 2004 time frame for the initial plan will give the necessary impetus for the institute to get on with the task of enhancing the State's cancer control effort.

The public funds which the institute will administer in each financial year will include not only its own operating budget. The institute will also have available funds for allocation to a range of cancer control activities such as research, innovative clinical programs and screening trials. One of the functions of the institute under clause 12 will be to submit recommendations to the Minister on how the funds it will administer in a particular financial year should be allocated. The establishment of the institute will enhance the expertise on cancer available to Government and the people of New South Wales. The institute will become a focal point for advice on all cancer-related matters. It will be able to receive specific references from the responsible Minister or the Director-General of Health, to provide advice and to undertake assessments of particular programs and services within the public health system.

The institute will also have a role in co-ordinating and managing statewide cancer data collection and analysis. It will be able to manage and utilise data collections based on identified patient data established under the notification provisions of the Public Health Act 1991. In addition, it is expected to review existing data collections with a view to identifying any gaps or other inadequacies. Where appropriate, it will be able to establish and

maintain its own data collections, subject to relevant privacy considerations, and to utilise information from other sources in undertaking its own epidemiology, research and policy work. In recognition of the increasing use of complementary therapies by cancer patients, the institute will be specifically empowered to investigate and evaluate these therapies.

Complementary therapies, when properly applied, may enhance the quality of life for cancer patients. The institute will assess both their effectiveness and safety and provide patients and doctors with better advice on their use. Other functions proposed for the institute in relation to cancer control include the dissemination of advice and information to the public, and the training and education of health personnel. The success of the institute in achieving its objects will depend, in large part, on a consultative and collaborative approach across all sectors which recognises the institute's diverse range of stakeholders and the need to forge strategic partnerships and undertake joint ventures as part of its overall approach. Given its importance, a specific function related to consultation and collaboration has been included.

Honourable members will be well aware that community participation and fundraising provides an important component of the overall resources devoted to the fight against cancer. While the institute will itself be able to engage in such activities, more importantly it will foster such activities across the community by other organisations. In turn, the institute may be the recipient of funds raised by community organisations or funds otherwise donated or bequeathed to it for cancer-related purposes. There are a plethora of bodies engaged in philanthropic activities associated with cancer relief. In order to maximise the benefits to cancer patients and their carers of the funds derived from charitable fundraising for cancer relief, it is desirable to harness the energies of these various bodies to achieve co-operative outcomes and a transparent and comprehensive picture of how cancer charity dollars are applied. To that end—and similar to the proposal for a publicly available research register—the institute will be able to establish a voluntary register of such bodies and will be required to provide an overview of cancer-related philanthropic activities in its annual report.

As the institute will be undertaking its own research and conducting and managing important databases, it will be required to establish its own institutional ethics committee as part of its administrative arrangements. It is also recognised that delays can occur in obtaining ethical approval for multi-centre research, including cancer-related research. The institute will have the opportunity to take a leadership role in developing more streamlined systems of ethical review for multi-centre and other cancer research. The institute will be involved in the allocation of funds for cancer-related research, prevention and detection, and health service enhancements across New South Wales.

In undertaking its functions the board will need to draw upon a wide range of appropriate clinical and other health-related expertise, including from the New South Wales health system. To that end, under clause 9 of the bill it is proposed that the institute establish a number of expert advisory committees with members drawn from across various cancer-related fields and areas of practice. For example, the Clinical Services Advisory Committee offers the opportunity, through its membership, to draw on the skills and experience of health and related professionals practising in a variety of areas, including primary care, rural practice and paediatrics.

It is clear from the foregoing outline of the role and functions of the proposed institute that, in the absence of appropriate adjustment of the Cancer Council's role and functions, there is potential for overlap and duplication between the two bodies. The New South Wales Cancer Council, established under the New South Wales Cancer Council Act 1995, currently has a very broad range of cancer-related functions, some of which the council has not in practice been in a position to discharge. In practice a large part of the very valuable role it plays is in the areas of advocacy and patient support, fundraising, education and research. Another significant activity of the Cancer Council currently is the management of two NSW Health registers, the Pap test register and the Cancer Register, under a contract with the Department of Health.

Both registers are established under the Public Health Act 1991. Recognising the need for an adjustment of its role to complement that of the proposed institute, as well as the opportunity for restructuring and repositioning which the establishment of the institute represents, the board of the Cancer Council has indicated that it wishes to alter its legal status to that of a not-for-profit company limited by guarantee. This will enable it to better focus on its existing well-established role as a community charity capable of operating in a competitive commercial environment.

The New South Wales Cancer Council, along with seven other State voluntary cancer bodies, is now a member of the Cancer Council of Australia. A fundamental strategic direction for the council is greater integration with its national partners to lower costs, improve effectiveness and leverage international funding sources. It envisages that its future role—being focused on fundraising, community education and advocacy, and philanthropic activities for cancer patients and their families—would appropriately and usefully complement the role of the proposed institute. A future structure under the Corporations Law would provide the Cancer Council with the flexibility necessary to build on its current position as the premier cancer charity in New South Wales.

Given the Cancer Council's unique history as a statutory body with a strong existing partnership with government, and the cancer-related purposes of both the council and the institute, it is envisaged that these two bodies will

develop a close strategic partnership and working relationship in the future. The Commonwealth Corporations Act 2001 provides a mechanism for statutory corporations such as the Cancer Council to become registered as companies and operate in future within the corporate framework. These provisions enable a seamless transition from statutory corporation to registered company. It is proposed that the date of deemed registration of the council would be fixed by ministerial order, thereby enabling the timing of the transition to be set by the Minister, taking into account the readiness of the Cancer Council and the institute for the transition.

Repeal of the Cancer Council Act will take effect simultaneously with, or at a date subsequent to, the deemed registration of the Cancer Council under the Corporations Law. Before transition to registration under the Corporations Law there is a need for a due diligence process to be undertaken to identify the current assets and liabilities of the Cancer Council in its current form as a public body. This will form the basis for working with the Cancer Council to develop appropriate transitional arrangements in respect of the transfer of assets, liabilities and staff of the Cancer Council. Under clause 25 of the bill comprehensive transitional regulations to provide for such transfer can be made.

Honourable members should note that there has been significant public consultation on the proposals for the institute since they were announced before the March election. A copy of the proposed cancer strategy, which includes the establishment of the institute, has been available on the Department of Health's web site for public comment. Submissions from interested organisations and individuals were considered by the department in developing the bill's provisions. Over the past two months I have visited all the major hospitals treating cancer and the key research institutions to discuss this proposal and hear the views of staff.

Forums attended by researchers, clinicians, consumers and other key stakeholders have also been convened to discuss the proposed role and functions of the institute. Furthermore, the proposed arrangements for the future of the Cancer Council are consistent with the Cancer Council's own desired future direction.

This bill represents a great leap forward in the fight against cancer. In the years to come the New South Wales Cancer Institute will play a major role in cancer control in this State. Indeed, I believe that the New South Wales Cancer Institute is a first for Australia. I want to specifically thank all those who have provided input into this initiative and who played a role in its development, in particular my ministerial colleague Craig Knowles, who had the foresight to push this onto Labor's election platform and, of course, the Premier for his vision in giving it his full support. I also thank the many people who were involved in the consultations on the bill. The Cancer Institute's aims are bold and its functions broad. But it cannot achieve those aims in isolation. To fully realise its potential requires the continued co-operation and goodwill of the many organisations and individuals across the State that are involved in the cancer effort. I urge them to support this historic initiative. I urge honourable members to lend their support. I commend the bill to the House.

[Your feedback](#) [Legal notice](#)

Refer updates to Hansard Office on 02 9230 2233 or use the feedback link above.