

# **Research-Driven Cancer Care – New Zealand’s Challenge**

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*for*

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## Executive summary

An optimal environment of research-driven cancer care ensures that research is effectively integrated with cancer care. Patients with cancer are ideally diagnosed and treated in a setting of multi-disciplinary care and clinical research. This facilitates delivery of the latest, most advanced cancer care to patients in their communities, producing significant health benefits to individuals and economic benefits to the country.

The prospect of these benefits, along with the demands of the New Zealand Health Strategy 2000 <sup>1</sup> and the New Zealand Cancer Control Strategy 2003 <sup>2</sup>, create a strong challenge to New Zealand to establish and support research-driven cancer care.

There is compelling evidence of incremental benefits from cancer research through improved standards of cancer care and reduced cancer mortality and morbidity. These health and economic gains can be substantial and in Australia between 1980 and 2005 have been valued at between A\$151b and A\$331b.<sup>3</sup> Projected reductions in cancer deaths between 2006 and 2016 will deliver an estimated A\$510b in health benefits, representing approximately 5% of projected gross domestic product over that period.

Health gains resulting from cancer research take place both locally and internationally and the question arises as to why a small country like New Zealand needs to invest in cancer research and not simply incorporate international research findings. International research findings are critical to improve decision-making in cancer care. However, the full benefits of clinical cancer research can only be realised where there is associated **local** clinical trials activity. Active participation in local research in New Zealand will:

- Provide research findings relevant to our unique population mix
- Increase patient recruitment to clinical trials
- Facilitate timely implementation of study findings through ‘readiness’ to use the new treatment strategies
- Facilitate recruitment and retention of clinical personnel through the opportunities to participate in cancer research programmes
- Contribute to the development and maintenance of a “research culture” which is vital to sustainable research-driven cancer care.

In Australia recognition of the critical contribution of local research to effective clinical cancer care resulted in a state-wide, government-supported approach to cancer control in New South Wales (NSW), delivered through the Cancer Institute NSW (established in 2003). In the UK the National Cancer Research Network (NCRN) infrastructure was established to support high quality cancer clinical studies and to better integrate research with cancer care.<sup>4</sup>

By contrast, cancer research in New Zealand is uncoordinated and of variable quality. New Zealand lacks a national cancer research strategy, a funding formula and a clinical fellowship programme. Limited availability of skilled research staff, the absence of a functional national cancer trials infrastructure, minimal training opportunities and restricted investigator time and capability constrain clinical trial activity. Funding is limited and dominance of any one particular funding stream carries the risk that funder agendas affect balance in research portfolios, restricting the opportunity to develop New Zealand investigator ideas.

As a result, patient numbers in trials are low and there is inequitable access to trials. Researchers struggle to progress ethnicity questions when studies are designed overseas and not conducted, at least in part, in New Zealand.

As a result of these shortcomings New Zealand suffers from delays in the implementation of the latest treatment and preventive activities, with resulting delays in the health system cost-savings associated with these innovations. Similar health gains in terms of percentage GDP (as that seen in Australia) could deliver savings for New Zealand in the next decade of over NZ\$80b.

Despite the deficiencies a number of “readiness” factors exist in New Zealand that would facilitate the development of research-driven cancer care. We have a small population and cancer patients, when offered the opportunity, are very willing to participate in clinical trials. We have an advanced national health index (NHI) system, which assists patient follow up, and an established national cancer registry. Importantly, Government agencies can be engaged much more readily than is the case in larger countries.

Workforce and infrastructure advantages extend across the broader health sector and the oncology working environment including a skilled and motivated healthcare workforce, strong linkages between research scientists and clinicians and a high calibre of academic personnel.

There are high levels of co-operation and collaboration at the cancer specialist level through national working parties and specific cancer interest groups. Strong linkages between New Zealand and Australia enable co-operation on trials where there is a need for more patients or greater financial support.

These strengths can create opportunities to overcome the challenges we face in developing research-driven cancer care in New Zealand.

Four steps are critical for creating an environment of research-driven cancer care in New Zealand before reaping the benefits:

1. **Establish an appropriate infrastructure for cancer research:** A sustainable infrastructure is required to enable clinical investigators to initiate and conduct relevant clinical trials which have the greatest potential to improve the health of New Zealanders. Human resources need enhancing particularly in the area of trial

coordinators & statisticians. Physical resources such as clinic space, clinical & research databases and tumour tissue banks need to be developed in a nationally planned and sustainable fashion.

2. **Attract, retain and develop the cancer research workforce:** The above infrastructure will help attract, retain and develop high calibre clinical and translational researchers who will also contribute to the healthcare workforce. The OECD has recently highlighted the need for New Zealand to take action to avoid a significant health worker shortage.
3. **Achieve high level commitment to enhanced research funding:** Commitment to research investment at the highest levels is essential to overcome current low levels of funding and to ensure sustainability of funding, development and maintenance of an effective cancer research infrastructure with the ability to manage a balanced research portfolio. Research is a long-term investment that can be difficult to balance against the day-to-day needs of the health system. It is critical that key players recognise that investment in research returns dividends across many portfolios in addition to health.
4. **Improve perceptions of research and build a strong research culture:** There are three key strategies to build a positive research ‘culture’;
  - a. engage and educate the general community,
  - b. communicate the cost-benefits of research to politicians and government officials
  - c. inform healthcare and research providers and their organisations about the mutual benefits of research to their respective goals.

Concerted efforts in these four areas will contribute to improved research portfolio management, more adequate and sustainable research funding, and improved rates of patient recruitment into clinical trials (currently below 5%). This would, in turn, reduce the incidence and impact of cancer in the population and reduce health inequalities relating to cancer.

A *national cancer research strategy* is critical in facilitating these four areas. Key initial stages in such a strategy include determining research priorities through wide consultation with the sector and establishing adequate investment, possibly as a percentage of health care spending. The research strategy will be critical in constructing a balanced research portfolio that is highly relevant to the New Zealand environment.

Cancer clinical trials provide the essential link between advances in medical science and resulting improvements in the standard of cancer care medicine. In short, these advances in knowledge result in an improved standard of cancer care. New Zealand needs to systematically develop research-based cancer care in order to avert delays in the implementation of the latest treatment and preventive strategies and realising the health system cost-savings and broader economic benefits associated with these innovations.

## **The challenge to invest in cancer research**

*Cancer control research seeks to identify and evaluate the means of reducing cancer morbidity and mortality and of improving the quality of life of people living with, recovering from or dying of cancer. Research is needed across the spectrum of cancer control to provide the basis for continual improvement.*

*New Zealand Cancer Control Strategy, 2003. p18*

Reducing the incidence and impact of cancer is one of the New Zealand Government's 13 population health objectives, as identified in the New Zealand Health Strategy 2000. Like a number of OECD countries, New Zealand has accepted the conclusion of the World Health Organization (WHO) that development and implementation of a national cancer control strategy is the most effective way of achieving this goal.

The New Zealand Cancer Control Strategy 2003 is the first phase in the development and implementation of a comprehensive and coordinated programme to control cancer in New Zealand. A key arm of the Strategy is investment in cancer research (Goal 6 and its related objectives; refer Exhibit 1). There is significant evidence relating to the benefits of cancer research, as documented in the next section of this report.

These requirements and the significant cost, in financial and patient terms, of not progressing in cancer research create a strong challenge for New Zealand to not only invest in cancer research but to establish and support research-driven cancer care.

An environment of research-driven cancer care ensures that research is effectively integrated with cancer care. Patients are diagnosed and treated in a setting of multi-specialty care and clinical research. This facilitates delivery of the latest, most advanced cancer care to individuals in their communities, producing significant individual benefits and broad economic benefits.

### ***Exhibit 1: New Zealand Cancer Control Strategy 2003, Goal 6 and its related objectives***

*[I]mprove the effectiveness of cancer control in New Zealand through research and surveillance. p21*

- *Objective 1: Extend and enhance research across the continuum of cancer control. p52*
- *Objective 2: Improve the use, efficiency and scope of national data collection and reporting. p54*

## The benefits from cancer research

There is compelling evidence of a return from cancer research with its resulting improved standards of cancer care and reduced cancer mortality and morbidity.

Cancer mortality rates have fallen substantially in the past 10 to 15 years in New Zealand and internationally. There are numerous contributing factors but, for most cancers, reduced mortality can be directly related to the insights, clinical trials and new treatments that culminate from cancer research.<sup>3</sup>

*There is good evidence that research in cancer will relieve human suffering by further improving cancer treatment, screening and prevention.*

Chief Cancer Officer, CEO, Cancer Institute, New South Wales, Australia 2008.<sup>3</sup>

The health gains associated with reduced cancer mortality and morbidity in cancer patients in Australia between 1980 and 2005 have been valued at between A\$151b and \$A331b. Ongoing reductions in cancer deaths between 2006 and 2016 will deliver an estimated A\$510b in health benefits, representing roughly 5% of projected gross domestic product over that period.<sup>5</sup>

Of course, health gains result from cancer research that takes place both locally and internationally and the question arises as to why a small country like Australia or New Zealand might invest in cancer research and not simply follow the lead based on international research findings.

Critically, significant benefits remain after correcting for the health gains attributable to cancer research from overseas and other factors such as other health research, the impact of environmental factors and public policies affecting health. That is, local research adds further benefit from a patient perspective and, as a result, from an economic perspective.

For example, evaluation of the health gain to individuals that can be **directly** attributed to local cancer research in Australia shows that for every dollar spent on cancer research, the return in health benefits is around \$3.39 (or \$3.43 for NSW calculations). The ways in which effective local clinical research specifically contributes to improved clinical care are discussed in a later section of this report.

A number of countries have recognised the critical role of local research as the foundation to effective clinical cancer care and are reaping the benefits of a structured approach to cancer research. The resulting improved quality, speed and integration of research ultimately translates into improved patient care.

A state-wide, government-supported approach to cancer control in NSW is delivered through the Cancer Institute NSW which was established in 2003. The number of patients on clinical trials has increased by 50%<sup>\*</sup> since initiation of the Cancer Institute NSW's

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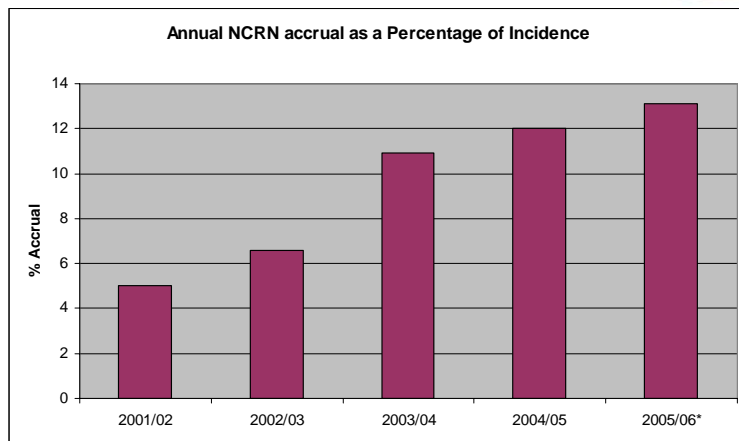
<sup>\*</sup> The percentage of patients recruited is a key performance indicator for research based cancer care. It is also one of the research related outcomes set out in the New Zealand Cancer Control Strategy Action Plan 2005-2010: increased participation in clinical trials (outcome 49)

research programme. A four-year target was to get 10% of all cancer patients into clinical trials.

The National Cancer Research Network (NCRN) infrastructure was established in the UK to support high quality cancer clinical studies and to better integrate research with cancer care. The NCRN contributes to the maintenance of an extensive portfolio of high quality studies and has surpassed its goal of doubling the number of cancer cases accrued into cancer clinical studies; as at 2007, 14% of UK cancer patients are involved in clinical trials compared with 3.5% pre NCRN (refer Exhibit 2).

**Exhibit 2: Patient accrual, as a percentage of cancer incidence, since formation of NCRN**

### NCRN Accrual 2001-2006



UK Clinical Research Network (UKCRN)

### New Zealand's current research situation

By contrast, cancer research in New Zealand is uncoordinated and of variable quality as highlighted in the New Zealand Cancer Control Strategy, 2003.

*Some research is currently being conducted in New Zealand in most fields of cancer control, but the effort is somewhat unco-ordinated and unevenly distributed, and varies greatly in quality and quantity.*

New Zealand Cancer Control Strategy, 2003

The lack of a national cancer research strategy, funding formula and clinical fellowship programme contributes to uncoordinated local research and impacts negatively on the quantity and quality of research able to be conducted in New Zealand.

Limited availability of skilled research staff, minimal training opportunities and restricted investigator time and capability constrain clinical trial activity.

Funding for clinical research units in New Zealand is limited to charitable sources and income from studies sponsored by the biotechnology and pharmaceutical industry. Funder agendas can affect balance in the research portfolio and can limit the opportunity to advance investigator ideas that fall outside funder preferred areas of research interest.

These issues have resulted in:

- Low numbers in clinical trials. Participation can be high in some studies at some centres, but participation remains low overall because of a lack of relevant studies.
- Inequitable access to trials.
- Inability to progress ethnicity questions where studies are designed overseas and are not conducted, at least in part, in New Zealand.
- Restricted opportunity to develop New Zealand investigator ideas.
- Delays in the implementation of latest treatment and preventive activities, with resultant delays in the health system cost-savings associated with these innovations.

On the positive side, a number of factors are in place in New Zealand that will greatly assist in the development of research-driven cancer care including:

- A small population.
- The advanced national health index (NHI) system, which assists patient follow-up.
- An established national cancer registry.
- A tendency for cancer patients to be willing to consider participation in clinical trials, when provided with this opportunity, despite a largely negative view of research in the general population.
- The ease with which Government can be engaged relative to larger countries.
- Significant workforce and infrastructure advantages.

The workforce and infrastructure advantages extend across the broader health sector and include:

- Strengths in the oncology working environment. Cancer research is centred in a limited number of locations,<sup>†</sup> facilitating patient entry into research programmes and making it easier to coordinate nationwide activities. The location of most cancer centres near university facilities enables mutually beneficial relationships and networks to develop to support clinical trials research.
- A skilled and motivated health care work force. Typically, oncologists have an interest in clinical research and cooperate readily in clinical trials activity and setting standards of care. Many have been trained in research methods and have gained significant research experience outside New Zealand. Research coordinators are experienced, skilled and highly motivated. They are organised into a national group providing a high level of cooperation between cancer centres. Other health professionals are typically willing collaborators, for example, by adapting their procedures to the requirements of a specific trial.
- An established clinical trials coordinating centre, Cancer Trials New Zealand (CTNZ), which has links to the cancer centre clinical research units and university researchers.
- Strong existing linkages between research scientists and clinicians.
- A high calibre of academic personnel.
- A high level of cooperation and collaboration at the oncologist level through national working parties and specific cancer interest groups.
- Good linkages between New Zealand and Australia which allow co-operation on trials where there was a need for more patients or greater financial support.

These strengths can be drawn on to counter the significant challenges to the development of research-driven cancer care in New Zealand.

Importantly some of the factors listed are already contributing to an environment of high quality research which sees examples of New Zealand “punching above its weight” in patient recruitment. This reputation will add value to any investment in clinical trials research infrastructure in this country and will help to attract and retain a high calibre of clinical researchers and research managers.

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<sup>†</sup> Cancer research activities are concentrated within six District Health Boards (DHBs), each with cancer treatment centres hosting clinical research units (Auckland, Palmerston North, Hamilton, Wellington, Christchurch and Dunedin).

## The critical role of *local* clinical research activity

Clinical cancer research aims to advance knowledge and improve decision-making in cancer care.<sup>6</sup>

International research findings are a critical source of this advanced knowledge. However, the full benefits of clinical cancer research are only realised where there are **local** clinical trials active alongside international clinical trials.

Effective local clinical research contributes to improved clinical care because it:

1. **Provides research findings relevant to New Zealand’s unique population mix:** Certain information essential for effective clinical care can only become available through New Zealand-based research.

*Although overseas research findings are an important source of new knowledge, there is much vital information that can only be obtained by New Zealand-based research; for example, the reasons for significant disparities in the incidence of, and survival from, some forms of cancer between New Zealand and similar countries, and between population groups within New Zealand.*

New Zealand Cancer Control Strategy 2003

2. **Increases numbers in clinical trials:** Active local clinical research increases the percentage of cancer patients included in clinical trials. Numbers of patients participating in cancer clinical trials in England increased four-fold as a result of active local research resulting from formal establishment of local cancer research networks.<sup>3</sup>
3. **Facilitates implementation of study findings:** Active research involvement promotes timely implementation of study findings because of clinician knowledge regarding therapeutic strategies and other factors that contribute to “readiness” to use the new treatment strategies, such as funding planning. This can mean more rapid introduction of newer and better treatments and treatment strategies. By contrast, without local engagement in a research study, no such infrastructure is developed and there is typically a delay in implementation of the finding(s) of that study.
4. **Facilitates professional staff recruitment and retention:** An active research programme provides the professional development opportunities and improved treatment options that make it easier to recruit and retain personnel active in cancer research and treatment.

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<sup>3</sup> A specific goal from inception of the NCRN in 2001 was to double the number of patients in England who were participating in cancer clinical trials; this goal was achieved by 2004 with approximately 10–11% of patients recruited.

Critically, a robust *local* clinical research activity contributes to the development and maintenance of a “research culture”. It is accepted in countries such as the Australia, the United Kingdom, Canada and the United States that a vibrant clinical research culture contributes to the health care system as a whole, delivering benefits to patients and the wider community through the improved health outcomes and through other ways such as commercialisation of scientific, technical or educational innovations.

## **Potential benefits of research-driven cancer care for New Zealand**

The positive impact of a structured approach to cancer clinical trials activity in other countries points to the benefits that would be gained by more structured clinical trials research in cancer care in New Zealand:

- **Patient benefits:** There is excellent evidence that a clinical research structure improves the pattern of care and the quality of services provided to patients. Better health outcomes result from early access to new therapies, more rapid introduction of more effective treatments and the prospect of improved therapies in future. Patient benefit has been a key driver for the clinical research network in the UK.
- **Community benefits:** Research will be a critical part of dealing with the challenge of the projected increase in cancer patients over the next decade. Cancer is a leading cause of death in New Zealand (29% of deaths from all causes) and the number of people developing and dying from cancer is predicted to increase steadily.<sup>2</sup> The community will benefit from the improved health outcomes and better value from health spending that derive from research-driven cancer care.
- **Fiscal benefits:** The Australian experience offers some insight into the financial benefits of local cancer research.

A similar health gain in terms of percentage GDP as that estimated for Australia (refer above) 6), would deliver savings for New Zealand in the next decade of approximately NZ\$81b.<sup>5</sup>

The economic value of health research is well recognised by the UK’s National Health Service (NHS). Health research is seen to support the NHS reform through provision of new ideas, new evidence, new products and improved efficiency and to underpin economic growth through a healthier work force and by providing an attractive environment for investment by pharmaceutical and biotechnology companies.<sup>7</sup>

- **Clinicians’ benefits:** For clinicians, research-driven cancer care means faster introduction of better treatments for patients and a more rewarding professional life.
- **Institutional status and recruitment benefits:** An active research programme in cancer clinical trials assists institutions to attract and retain more high quality staff. Additionally, trials improve clinical practice in the institutions that conduct them, enhancing an institution’s reputation and further assisting recruitment and retention.

## **Moving forward in New Zealand**

Creating and reaping the benefits of an environment of research-driven cancer care in New Zealand requires development of an appropriate infrastructure, development of the cancer research workforce, and access to adequate and sustainable funding. Equally critical is the need to improve perceptions of research and build a strong research culture.

These four requirements are detailed below as the critical steps needed in New Zealand to move towards research-driven cancer care.

### *1. Develop an appropriate infrastructure for cancer research*

A robust and supportive infrastructure is required to bring together clinical investigators and support them. Ideally, the environment fosters collaboration and leadership.

An excellent environment is cited as a key component in the UK NCRN and leadership in local networks is cited as success factor.

Within that environment, the processes for undertaking research need to be kept as simple as possible.

The research infrastructure will provide the framework to ensure that New Zealand is able to operate a balanced cancer research portfolio and to attract and retain the personnel required for high quality research.

### *2. Attract, retain and develop the cancer research workforce*

New Zealand has a skilled and motivated health care work force. There is a need for overt support for and investment in this resource, for example through a clinical fellowship programme, in order to ensure this workforce remains available to assist in meeting research goals. Excellent people underpin the approach of the NCRN and the structures in place serve to attract and motivate these people.

The OECD has recently highlighted the critical need for New Zealand to take action to attract and retain staff to avoid a potential significant health worker shortage.<sup>8</sup> Research-driven cancer care provides an environment that will significantly assist in this.

In turn, workforce recruitment and retention will be among the benefits of research-driven cancer care. They will be markedly assisted by provision of an effective cancer research infrastructure and a balanced cancer research portfolio.

### *3. Achieve high level commitment to enhanced research funding*

New Zealand research suffers from a low level of funding across the research continuum and unequal distribution of funding streams.

Commitment to research investment at the highest levels is essential to ensure sustainability of funding, development and maintenance of an effective cancer research infrastructure, and the ability to manage a balanced research portfolio. Understanding the benefits that arise from investment in cancer research enables policy makers to make well-informed decisions about funding.<sup>9</sup>

Research is a long-term investment that can be difficult to balance against the day-to-day needs of the health system. It is critical that key players recognise that investment in research pays dividends but it may be in portfolios other than health.

#### *4. Improve perceptions of research and build a strong research culture*

Broad recognition of the value of an environment of research-driven cancer care is essential to the development of such an environment.

There are three key strategies to build a research ‘culture’ and thus improve the image of research. The first is to engage and educate the general community, the second to communicate the cost-benefits of research to politicians and government officials and the third to have healthcare and research providers and their organisations recognise the mutual benefits of research to their respective goals.

Concerted efforts in these four areas will contribute to improved research portfolio management, more adequate and sustainable research funding, and improved patient recruitment into clinical trials (currently below 5%). This would, in turn, bring patient benefits including reduced incidence and impact of cancer in the population and reduced health inequalities relating to cancer.

A national cancer research strategy is a critical first step in achieving the above. Key requirements of plan development will be to determine research priorities through wide consultation with sector and to establish adequate investment, possibly as a percentage of health care spending.

The research strategy will be critical in establishing a balanced research portfolio that is highly relevant to the New Zealand environment.

### **Conclusion**

The challenge to New Zealand to establish and support research-driven cancer care is underpinned by the urgent requirement to benefit from the patient and economic benefits that active local research will contribute and by the demands of the New Zealand Health Strategy 2000 and the New Zealand Cancer Control Strategy 2003.

Cancer clinical trials provide the essential link between advances in medical science and resulting improvements in the standard of cancer care.

New Zealand needs to move forward definitively to avert delays in the implementation of the latest cancer treatment and prevention activities and to benefit from the health system cost-savings and broader economic benefits associated with these innovations.

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