

WHITE PAPER

Towards a national cancer research plan

Developed by the Cancer Research Leadership Forum (CRLF)

3 February 2012



Members of the Steering Committee

Chair: Carole Renouf, CEO, National Breast Cancer Foundation



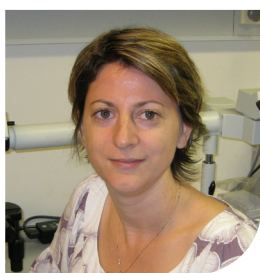
Prof Ian Olver AM
CEO, Cancer Council
Australia



Leanne Warner
CEO, Cure Cancer
Australia Foundation



Edith Hurt
Research Program
Manager, Cure Cancer
Australia Foundation



Dr Alison Butt
Director, Research
Investment, National
Breast Cancer Foundation



Dr Cleola Andriesz
General Manager
Knowledge Management,
Cancer Australia



Patricia Hancock
Consumer Representative
Cancer Voices Australia

Foreword



The members of the Cancer Research Leadership Forum (CRLF) are dedicated to reducing the burden of cancer in Australia. Cancer will directly affect one in two men and one in three women in our society, as well as indirectly affecting families, friends and colleagues. It is only through research that significant gains have been achieved to date in cancer detection, treatment, services and prevention. It is only through research that we can change the health future.

Quality research requires generous funding, and we believe that opportunities to attract funding will be significantly enhanced by the development of a coordinated and cohesive Australian cancer research plan. Our federated system and the multiplicity of cancer research funding bodies make this a challenge to achieve, but it is possible through collaboration.

Why should members of the community or third sector see it as fitting to facilitate the development of a national cancer research plan? Because we owe it to our constituents, supporters and donors, who are the people with cancer or at risk of cancer. Because our promise to them is that we will use their funds to make the greatest possible difference. Because although we are often constrained in terms of resources, we are not acting under the same constraints as the public or private sectors. Because advocacy and change agency is an integral part of our mission.

We are committed to driving development of a national plan that will, at the very least, inform our own funding strategies and ensure that singly and collectively – and wherever possible, also collaboratively - we make the most of every dollar with which the community entrusts us to arrive at better treatments, ever-increasing survival rates, and ultimately prevention and cure. It is our hope that funding agencies outside our sector will also see the benefits of a coordinated and cohesive approach, and we are most grateful to the Macquarie Group Foundation for its leadership in this regard.

A handwritten signature in dark ink, reading "Carol Kersh".

Chair, 'Towards a National Cancer Research Plan' Steering Committee

Acknowledgements

We gratefully acknowledge the input and assistance of all the organisations and individuals listed below.

- Bowel Cancer Australia
- Cancer Australia
- Cancer Council Australia
- Cancer Voices Australia
- Cure Cancer Australia Foundation
- Leukaemia Foundation
- Melanoma Institute Australia
- National Breast Cancer Foundation
- Prostate Cancer Foundation of Australia
- Lisa Herron: Copy
- Kate Patterson: Design

We also extend our sincere thanks to the Macquarie Group Foundation which provided crucial seed funding for this project.

Macquarie Group
Foundation



Contents

Page 3	Foreword
Page 4	Acknowledgements
Page 6	About the Cancer Research Leadership Forum
Page 7	The need for a national cancer research plan
Page 8	Steps towards a national cancer research plan
Page 9	The cancer burden
Page 10	What cancer research has achieved, and is yet to achieve
Page 12	Cancer research funding in Australia needs coordination
Page 15	Cancer plans are effective
Page 16	Anticipated outcomes
Page 22	How to provide input or comment

NOTE: Sections of this issues paper contain some questions designed to stimulate discussion and feedback.

About the Cancer Research Leadership Forum

The CRLF is also working to:

- ***Evaluate and implement strategies for co-funding of cancer research projects by CRLF members***
- ***Inform government and other funders about cancer research priorities and funding needs***
- ***Promote the value of cancer research to the Australian community***

The Cancer Research Leadership Forum (CRLF) was established in 2009 to foster collaboration between the national community-supported cancer organisations that fund cancer researchers and their work in Australia.

Current members are Bowel Cancer Australia, Cancer Council Australia, Cure Cancer Australia, Leukaemia Foundation, Melanoma Institute, National Breast Cancer Foundation and Prostate Cancer Foundation of Australia. Several members of the CRLF co-fund cancer research with the Australian Government agency, Cancer Australia.

The members of the CRLF share a common goal: to reduce the cancer burden in Australia.

CRLF members are working together to augment their efforts to achieve this through coordinated planning, sharing of learnings and co-funding of national cancer research projects.

One of the CRLF's major initiatives is to facilitate the development of a national cancer research plan to streamline and boost available cancer research funding to make the greatest impact for people affected by and/or at risk of cancer.

Knowing the improvements in targeted treatments - and survival rates - for cancer even since I was diagnosed ten years ago, I need no convincing of the benefits of a coordinated, national cancer research plan. In times of scarce resources it seems not only logical but imperative that the member organisations of the Cancer Research Leadership Forum work collaboratively and not in competition for the funding dollars and research capacity of the country.

A national plan can only help to focus the cancer research agenda towards better outcomes for those of us who face a diagnosis and ongoing treatment, hopefully ensuring that for more and more people, cancer is not necessarily a death sentence.

Patricia Hancock, Consumer Representative, TNCRP Steering Committee

The need for a national cancer research plan

The CRLF believes that there is a need for an overarching national cancer research plan for Australia to coordinate investment in research and accelerate our progress in cancer control

At current rates, 1 in 2 Australians will be diagnosed with cancer by the age of 85. Cancer research is key to increasing our understanding of cancer, enabling advances in prevention, detection and treatment, and thus reducing the incidence and improving outcomes for Australians affected by this disease. Significant gains in knowledge about cancer types, causes and targeted treatments in recent years have increased the potential for major advances in cancer prevention and care in the next decade.

In Australia in 2011, almost \$300 million was awarded to Australian cancer research projects, programs, infrastructure and support by a large group of government and non-government funders. Australia is fortunate to have multiple funding organisations. However, different drivers, regulations and funding strategies mean this investment is fragmented, creating unnecessary competition, duplication, inefficiencies and gaps.

While major funders such as the National Health and Medical Research Council (NHMRC) or Cancer Australia have a national charter, Australia presently does not have a mechanism or strategy to coordinate planning and funding of cancer research across all funders. There is an opportunity to enhance the impact of our collective investment in cancer research and maximise our efforts to make the advances needed to address Australia's growing cancer burden.

The CRLF believes that there is a need for an overarching national cancer research plan for Australia to coordinate investment in research and accelerate our progress in cancer control. The overall objective is to benefit people with, and at risk of, cancer by improving funding efficiency.

This issues paper has been developed to engage all key stakeholders in discussion about what such a plan should encompass; and determine the best strategies for coordinating and co-funding cancer research to more efficiently and quickly advance knowledge and translate that knowledge to care to benefit people with cancer.

A national cancer research plan will:

- Identify research priorities.
- Guide community-funded cancer organisations' individual and collective funding strategies to optimise use of existing resources, develop capacity in areas of need and ensure a balance of funding allocated to research into different types of cancers and research across the cancer spectrum.
- Enable Australian cancer research and funding organisations to 'collaborate, share data and define complementary research objectives to optimise the use of the limited funds available for cancer research and reduce duplication of effort'¹, as recommended by the Union for International Cancer Control's World Cancer Declaration (2011).

¹<http://www.uicc.org/declaration>

Q1. What should be the objectives of a national cancer research plan?

Q2. What would be the incentives and disincentives to adoption of a national cancer research plan?

The CRLF envisages three steps towards a national cancer research plan.

- 1** Broad consultation with consumers, researchers and funders about what a national cancer research plan should cover:
 - What are our national research priorities?
 - How can we nurture and develop Australia's research strengths?
 - Where are the gaps in capacity, infrastructure and funding that need to be addressed to enable us to accelerate progress in cancer control?

This issues paper invites stakeholders to consider these and other questions, identify other issues that should be considered, and submit recommendations and ideas. For details of how to provide feedback, see page 22.

- 2** Following the consultation phase, the CRLF will convene a national cancer research summit in September 2012, bringing together key stakeholders to agree on priorities and develop strategies for coordinating and funding research projects, infrastructure and workforce to accelerate our efforts to reduce the impact of cancer in Australia and globally.

The agenda for the summit will be informed by responses to this issues paper, but is likely to include discussion about priorities in all types of research including basic, prevention, treatment, supportive care, survivorship and palliative care. It will also include a focus on three challenging areas in cancer research funding: workforce; infrastructure support; and support for long-term research (beyond the usual three to five year grant period).

- 3** A report of the outcomes of the summit will be published in early 2013, and should form the basis of a national plan.

The cancer burden

In Australia, cancer is a leading cause of death and a significant cause of morbidity. In 2010 an estimated 43,600 people died from cancer and 113,700 new cases were diagnosed (excluding non melanoma skin cancer)². Cancer is Australia's biggest disease burden with substantial direct health costs of more than \$3.8 billion (2004-2005)³.

Cancer is predominantly a disease of older people; our growing and ageing population has contributed to a 27% increase in the incidence rate of all cancers combined since 1982⁴. However, significant improvements have been made in screening and early detection, more accurate diagnosis and more effective treatment. The cancer death rate (deaths per 100,000 people) has declined and now more than 60% of people with cancer survive more than five years after diagnosis (compared to 47% in 1982). We now know that more than 30%, perhaps as many as 40% of cancers are due to behavioural and/or dietary risks and are therefore targets for prevention strategies⁵.

While the incidence of some cancers such as prostate and breast cancer has increased due to advances in screening and detection, this has been coupled with significant advances in treatments, leading to improved outcomes. For example, in 1995 there were over 12,000 cases diagnosed and 2564 deaths attributed to prostate cancer (80% five-year survival rate); in 2007 this had increased to over 19,000 cases diagnosed and 2938 deaths (85% five-year survival rate). Nevertheless some cancers still have very low survival rates with little improvement over the past three decades. For example, pancreatic cancer has a five-year relative survival rate of only 5%⁶.

One of the major challenges in cancer research is that cancer is not one disease, it is many. Knowledge from the Cancer Genome Project has highlighted that cancers from the same tissue can be very different at the molecular level⁶. Cancer is the result of the accumulation of multiple genetic changes, often over a significant period of time, from a variety of factors. These include preexisting genetic factors, modifiable risk-factors (such as smoking, diet, physical activity, alcohol consumption and UV radiation) and viral infection (e.g. human papillomaviruses and hepatitis C). This understanding of the complexity of cancer and its multiple causes increases the case for prioritising and boosting research, as there is now recognition of the need to target individual cancers and further prevention efforts.

²Australian Institute of Health and Welfare and Australasian Association of Cancer Registries. Cancer in Australia: an overview, 2010. Cancer series no. 60 Cat. No. CAN56. Canberra AIHW.

³Australian Institute of Health and Welfare. Health System expenditure on disease and injury in Australia, 2004-2005. AIHW 2010

⁴www.aihw.gov.au/cancer/

⁵www.who.int/cancer/about/facts/en/index.html

⁶www.sanger.ac.uk/genetics/CGP/

What cancer research has achieved, and is yet to achieve

Cancer research is key to understanding the types, causes and most effective ways of detecting and treating cancer.

Research at the basic biology level has produced significant improvements in the health and wellbeing of the Australian community. Advances in our fundamental understanding of cancer biology have enabled advances in prevention, better screening and diagnostic techniques and better therapeutic strategies and, as a result, major improvements in cancer survival rates for many common cancers.

Basic research has produced knowledge that has had substantial impact on cancer prevention and treatment, including:

- Identification of the link between tobacco smoking and lung cancer. Tobacco smoking is the largest single cause of lung cancer, responsible for about 90% of lung cancers in men and 65% in women⁷. An understanding of the role of smoking in the aetiology of lung cancer has led to strong tobacco control measures and public health campaigns that have reduced male smoking rates in Australia from 72% in 1945 to 15% in 2011, and consequently lung cancer incidence rates.
- Development of more effective, targeted therapies. One example is the discovery that a particularly aggressive subset of breast cancers have increased levels of a protein called human epidermal growth factor receptor type 2 (HER2) on their cell surface. This discovery led to the development of a drug, Trastuzumab (Herceptin), that specifically targets and kills breast cancer cells that express this protein.
- Development of a vaccine to prevent cervical cancer. Following the discovery that most cervical cancers are caused by human papillomaviruses (HPV), research by an Australian team headed by Professor Ian Frazer and colleagues in the 1990s led to development of a vaccine that is now used in many countries to protect young people against infection by the virus types most commonly causing cervical cancer.

Traditionally, basic biological research has been the most generously funded and this has led to major advances in cancer prevention and treatment. Cancer Australia's analysis of research funding in 2003 to 2005 found the majority of funding was directed to research in biology and treatment, and direct funding to research in aetiology, prevention, early detection diagnosis and prevention, and cancer control, survivorship and outcomes was comparatively low⁸.

⁷Australian Institute of Health and Welfare and Cancer Australia. Lung cancer in Australia: an overview: Cat. no. CAN 58. Canberra: AIHW (2011).

⁸Cancer Australia. Cancer research in Australia: An overview of cancer research projects and research programs in Australia 2003 to 2005.

A national cancer research plan will ensure we prioritise and support research across the spectrum to reduce the cancer burden and improve quality of life for the community

Given the predicted increase in cancer incidence and prevalence in coming years, and increasing knowledge about the potential to prevent many cancers, we need greater investment in population health and health services research. We now know that about one-third of cancers are potentially preventable, increasing the impetus to help individuals reduce their cancer risk through improved diet and physical activity, maintaining a healthy weight, not smoking, limiting alcohol and using sun protection.

Prevention is a powerful driver for the community as a whole: preventing a cancer is better for the individual – avoiding the physical, psychological and financial burden of cancer – and the community, through reduced health costs, than treating an established cancer. Supporting research to further our understanding of how to prevent cancers and the most effective prevention strategies will ultimately reduce Australia's cancer incidence and mortality rates. It will also have flow-on effects on general population health and wellbeing.

More focus on clinical, health services and translational research is needed to improve the services people with cancer receive, and ensure innovation and efficiency in delivery of cancer care.

Research by Australian clinical trials groups has achieved:

- An estimated \$50 million in reduced annual health costs from trials of high-dose versus standard-dose chemotherapy for advanced breast cancer.
- \$10 million in annual savings from unnecessarily invasive melanoma surgery⁹.

Increasing recognition of the unmet needs of people with cancer and their carers and family members, and the growing number of cancer survivors are driving demand for more psychosocial and survivorship research.

A national cancer research plan will ensure we prioritise and support research across the spectrum to reduce the cancer burden and improve quality of life for the community (Figure 1).

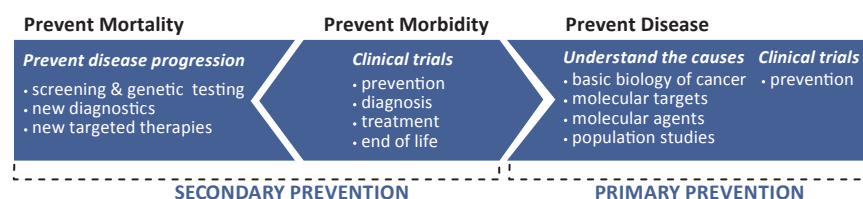


Figure 1. The prevention continuum outlining the research necessary to prevent cancer mortality, morbidity and to ultimately prevent the disease itself.

⁹Cancer Council Australia. Election priorities 2010. www.cancer.org.au/policy/electionpriorities2010/cancerresearch.htm

Cancer research funding in Australia needs coordination

Historically the scope and nature of cancer research in Australia has been shaped by fragmented forces

Funding for cancer research in Australia is provided by the Commonwealth and State Governments, community-funded organisations and the private sector. There are a large number of government agencies, cancer organisations and other bodies providing funding, including:

- National Health and Medical Research Council (NHMRC)
- Other Australian Government bodies – Cancer Australia, Australian Research Council
- State Government bodies
- Community-funded cancer charitable organisations
- Public hospitals
- Pharmaceutical companies
- Overseas organisations

A survey by Cancer Institute NSW identified 158 organisations funding cancer research in NSW alone (2004-2006)¹⁰. Historically, the scope and nature of cancer research in Australia has been shaped by fragmented forces: Federal government funding agendas; differences in State/Territory research priorities and structures; the development of a hardworking but diverse and uncoordinated not-for-profit sector; and the growing influence of consumer advocacy and expectations.

Australian governments have an extensive range of policies, programs and regulations that respond to these forces and affect funding supply and demand. Similarly, non-government organisations and businesses that fund research are responding to these forces in many ways — for example, some charities have adapted their research priorities and plans in response to changing consumer priorities and demands for greater accountability from funding bodies and researchers.

The existence of multiple funders from the public, private and third sectors has resulted in myriad funding approaches and programs

The existence of multiple funders from the public, private and third sectors has resulted in myriad funding approaches and programs. Historically, each agency or organisation has funded research that supported their own charter (e.g. focused on a particular cancer type), and there has been little collaboration or communication between them. This has resulted in inefficiencies, duplication and gaps in research funding.

In Australia in 2011 nearly \$300 million was allocated to cancer research. The Federal government is the main funding body of cancer research in Australia, largely through competitive funding via the NHMRC. In the 2009-10 financial year the NHMRC contributed \$163 million towards cancer research. Cancer Australia, the Australian Government's cancer agency, is also a significant funder awarding over \$20 million in 2011. There are also state government funding bodies, such as Cancer Institute NSW, which contributed \$38 million to cancer research funding in 2010 and the Victorian Cancer Agency, which contributed over \$7 million in 2010. The Australian Cancer Research Foundation awarded \$9 million in 2011 and the national community-funded non-government organisations that are members of the CRLF collectively granted over \$74 million to cancer research projects in 2011.

¹⁰Welberry H, Edwards C, Weston A et al. Cancer research in NSW 2001-2006. Sydney: Cancer Institute NSW, 2008.

There are three main approaches to the allocation of cancer research funding in Australia

Community funded cancer organisations are significant contributors to cancer research funding across Australia

1 The NHMRC awards a range of competitive grants that support projects, infrastructure or people (fellowships, scholarships and awards). The NHMRC allocates funding to Australian Government-defined health priority areas, one of which is cancer and cancer prevention. It funds 'investigator initiated' research: an individual or small group of researchers apply for funding to do the research that they believe is important and reflects their own areas of expertise.

2 Cancer Australia is the Australian Government's national cancer control agency. In recognition of the need to coordinate and harmonise the funding of cancer research at the national level, Cancer Australia has developed a Priority-driven Collaborative Cancer Research Scheme (PdCCRS) in collaboration with the NHMRC. The PdCCRS model enables government and other funders of cancer research to collaboratively fund cancer research project grants that address evidence-based research priority areas set by Cancer Australia and/or its funding partners. Several members of the CRLF are partners in the PdCCRS.

3 Community funded cancer organisations are significant contributors to cancer research funding across Australia. Each has a different research funding strategy (some more formal than others) and most have expert advisory groups to inform decisions about research priorities and awarding of available funding. Priority-setting may be done in consultation with consumers and the community, or at times reflect the preferences of donors (e.g. through specific bequests, corporate support or fundraising campaigns). Some of the national cancer organisations have developed priority-driven strategies (and/or are a partner in Cancer Australia's PdCCRS) and are able to fund both novel and longer-term research, which most government schemes are unable to support.

Some community funded organisations support research into a number of cancers (such as the Cancer Councils and Cure Cancer Australia Foundation). Others have a specific commitment to supporting research across the cancer spectrum from prevention right through to palliative care and survivorship in their cancer area (such as the National Breast Cancer Foundation). Others raise money to improve outcomes for people with a specific type of cancer or to meet particular needs of people affected by cancer.

**Q3 What is the right balance
between investigator initiated
and priority driven research?**

**Q4 How should the proportional
allocation of funding to
different types of research
be determined? (e.g. basic,
clinical, psychosocial,
prevention, etc)**

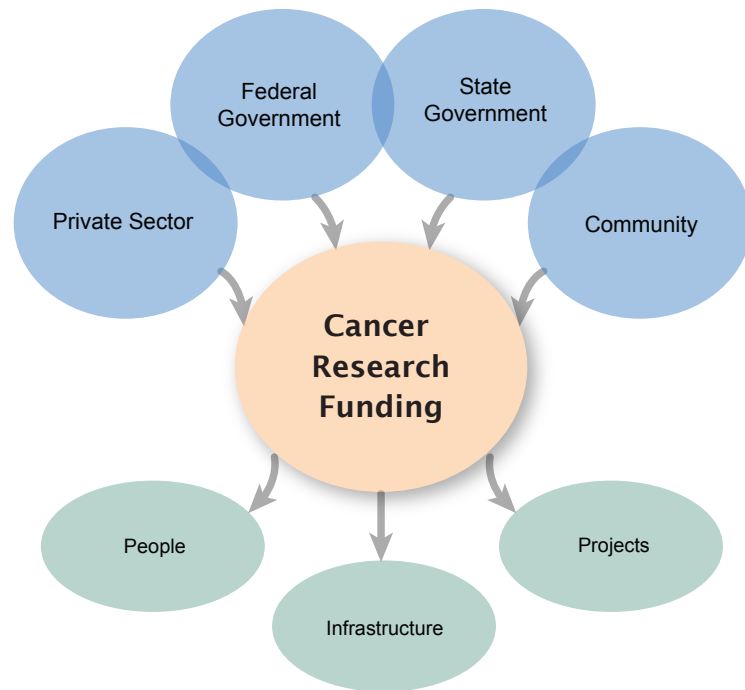


Figure 2. Schematic of funding inputs and outputs in Australia

Types of funding

Each of the funding bodies has a different focus or foci for awarding research grants and support. Some support project grants, some support people (through fellowships or training opportunities, for example) and others support facilities or infrastructure (Figure 2). The NHMRC funds all three. Approximately 70% of the NHMRC total annual budget is directed to research projects, 24% to people support and 6% to infrastructure.

Some organisations prioritise funding for one aspect of research, for example the Australian Cancer Research Foundation (ACRF) only grants funding for capital investment (buildings and equipment), and Cure Cancer Australia Foundation funds Fellowships for early career researchers.

To ensure a dynamic, successful cancer research sector all types of research projects, and people and infrastructure support need to be coordinated and funded in a sustainable manner. A combination of investigator driven and priority driven research, informed by consumer and community involvement, and funding across the research spectrum, is most likely to produce the greatest improvement in cancer outcomes.

Cancer plans are effective

National cancer plans have been successfully implemented in several other developed countries. Examples include the annual plan submitted by the National Cancer Institute (NCI) in the United States of America and the Canadian Breast Cancer Research Alliance. Of particular note is the National Cancer Research Institute (NCRI) and the National Cancer Research Network (NCRN) partnership established in the United Kingdom (UK) in 2001¹¹.

The NCRI comprises 22 members including the government funded Medical Research Council, the Association of the British Pharmaceutical Industry and the charity, Cancer Research UK. It formed a partnership with the NCRN to develop common plans for cancer research and avoid unnecessary duplication of effort to the benefit of the public.

- In the 10 years since the implementation of the plan, the annual cancer research spend has increased to over £500 million, the NCRN has achieved a four-fold increase in the recruitment of cancer patients into clinical trials research studies, and patient and public involvement in cancer research has grown¹².
- The NCRI has targeted areas that were previously underfunded, for example, prevention was targeted for special attention in 2002 and since then prevention research funding has increased 1% of the portfolio to 3.4%.
- The NCRI also has focused on improving funding for research into specific cancers that were historically not well funded, including cancers of the lung and the pancreas.

Within Australia there is a scarcity of coordinated cancer research planning. As noted, Cancer Australia's PdCCRS is the first successful attempt to coordinate and maximise investment in priority cancer research by government and non-government funders. The only other example of a national cancer research plan is the National Action Plan for breast cancer research released in 2004 and 2010 by the National Breast Cancer Foundation (NBCF)¹³.

There is international and national evidence that a strategic approach to coordinating and collaboratively funding cancer research can be achieved, and ultimately will produce greater improvements in cancer prevention and outcomes for people affected by cancer.

¹¹www.ncri.org.uk/

¹²NCRI and NCRN (2011) Celebrating a decade of progress through partnership in cancer research: www.ncri.org.uk/includes/Publications/reports/NCRI_NCRN_Decade_Web.pdf

¹³NBCF National Action Plan 2010: www.nbcf.org.au/page.asp?category_id=5&page_id=5

Anticipated outcomes

Outcome 1:

Strategic and coordinated investment that will improve outcomes across the cancer spectrum

A national cancer research plan defining strategies for research investment will improve outcomes across all cancers, particularly those that traditionally have received little research attention and support.

A recent audit by Cancer Australia of cancer research projects and programs in Australia from 2003 to 2005 found the majority of funding (70%) was directed to research focused on the five cancers of highest incidence. Cancer Australia attributes this in part to the charities and fundraising groups dedicated to raising money for research into 'high profile' cancers such as breast, prostate and leukaemia¹⁴.

The audit highlighted discrepancies in national cancer research funding relative to disease burden and mortality (Figure 3)¹⁴. Some cancers with high burden received proportionally very low levels of funding. Lung cancer was the leading cause of cancer death in 2003 (and is still the fourth most commonly diagnosed cancer and leading cause of cancer death in Australia), yet funding into lung cancer research was low in comparison to its burden. Lung cancer diagnosis continues to have a very poor prognosis with a 5 year relative survival rate of just 13%⁷.

Less than 1% of the funding in 2003 to 2005 was directed to pancreatic cancer and cancers of unknown primary site, which together are responsible for almost 1 in 20 cancers and 12% of cancer deaths.

¹⁴Cancer Australia. Cancer research in Australia: An overview of cancer research projects and research programs in Australia 2003 to 2005.

Q5. Should funding for certain cancers be prioritised, and should such priorities be determined?

Q6. How should funding for under-funded cancers be allocated?

Q7. What strategies will ensure that basic research findings are effectively implemented to provide the greatest impact on cancer clinical care?

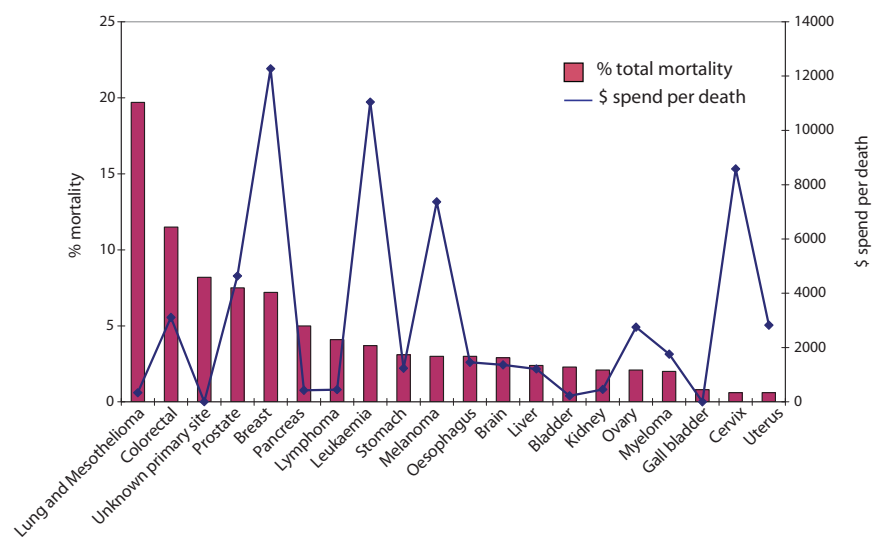


Figure 3. Direct funding per cancer death to tumour site-specific cancer research projects, compared with the top 20 tumours by mortality in 2003¹⁴.

As noted in the research audit¹⁴, there are several factors other than burden of disease that influence levels of research funding for specific tumour sites including:

- Scientific opportunity
- Ability to be generalised to other cancers and other research
- Quality of research being undertaken
- Size of research workforce
- Fundraising

These factors need to be explored and considered in the development of a national cancer research plan that seeks to ensure 'underfunded' areas of cancer research are given greater attention.

Anticipated outcomes

Outcome 2:

An integrated, balanced approach to funding research that includes consumers, researchers, funding bodies and industry

People affected by cancer and advocacy groups are important contributors to and advocates for cancer research

Improving cancer outcomes requires cancer research across each stage of the cancer continuum. An integrated, balanced approach to cancer research planning is essential, incorporating stakeholders from all aspects of cancer research and care and particularly the people who are affected by cancer. People affected by cancer and advocacy groups are important contributors to and advocates for cancer research.

Consumer involvement in research planning and funding policies ensures the research agenda reflects the needs and issues of greatest priority to people affected by cancer, and ensures ‘higher quality, consumer respectful research’¹⁵. Cancer Australia and the consumer agency, Cancer Voices Australia have recently released the National Framework for Consumer Involvement in Cancer Control. This document provides a strategy for the inclusion of consumers in all aspects of cancer control and notes the benefit of consumer contributions to cancer research priority setting, design, evaluation, implementation and translation of research¹⁶.

Several Australian cancer funding organisations, including the state Cancer Councils, provide training for consumers to support their involvement in cancer advocacy, policy development and research.

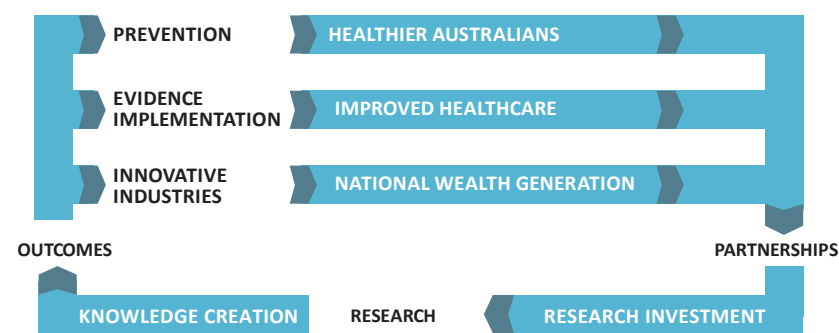


Figure 4. The virtuous cycle¹⁷ - investment in research leads to knowledge creation, which in turn enhances healthcare and partnerships between researchers, government and the private sector.

¹⁵Consumer involvement in research: The benefits (Position statement), Cancer Voices NSW, March 2011
¹⁶Cancer Australia and Cancer Voices Australia, 2011. National Framework for Consumer Involvement in Cancer Control. Cancer Australia, Canberra, ACT.
¹⁷National Health and Medical Research Council, 2010-2012 Strategic Plan, Australian Government, 2010.

Q8. How can consumers be more effectively engaged in research planning and funding decisions?

A successful approach to funding cancer research must be collaborative. Those involved in cancer research include research scientists, clinicians, funding bodies, patients, collaborative clinical trials groups, pharmaceutical companies and consumers (Figure 4).

Q9. How can collaborative links between the basic, clinical and policy aspects of cancer research be improved?

It is now being increasingly recognised that the traditional approach of research as a linear ‘bench to bedside’ endeavour is not enough. Consumers, researchers, clinicians, industry and funders need to be engaged at each stage from research planning to the dissemination of findings and translation to practice (Figure 5).

Greater multidisciplinary and research-practice collaboration ensures there is a conduit not only from bench to bedside, but bedside to bench: clinical and consumer priorities inform and direct research to improve the translation of findings to clinical practice and public health policy. There is still a long way to go to reach the ultimate goal: prevention.

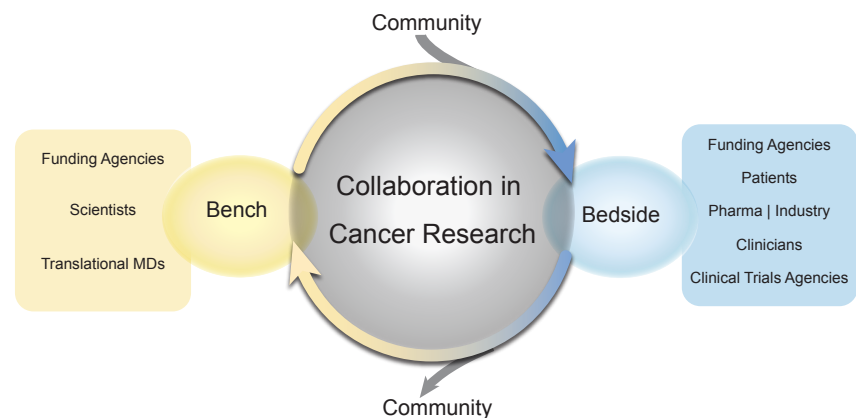


Figure 5. Collaborative strategy for cancer research

Anticipated outcomes

Outcome 3:

Sustainable, highly trained, multi-disciplinary research capacity

Australian cancer researchers are generally regarded as ‘punching above their weight’ in their contributions to knowledge and advances in cancer care.

Maintaining and enhancing Australia’s reputation for excellence in cancer research requires greater investment in our current and next generation of researchers and the resources they need.

Making the most of Australia’s research investment

The sustainability of our cancer research workforce is threatened by an ageing workforce, lack of career pathways and job insecurity. To ensure Australian cancer researchers are recruited and retained in Australia, a supportive, sustainable career pathway is essential. This includes more support for:

- Early to mid-career researchers
- Clinician and health service researchers
- Mechanisms to provide longer-term funding for researchers to enhance job security
- Career breaks / disruption and return to work
- Bridging / short term funding outside of existing funding timetables
- Novel, speculative research

Funding schemes need to encourage and facilitate multidisciplinary and cross-sector collaboration and international partnerships, to expedite advances in cancer control to benefit Australians affected by cancer.

Training a cancer researcher with a PhD costs the Australian Government nearly \$150,000¹⁸. A report commissioned by the Australian Society of Medical Research predicts it will cost \$570 million (2009 dollars) to replace all PhD researchers in medical research who will retire from the workforce by 2019¹⁹. Retaining our best researchers requires funding systems, infrastructure and resources that encourage and enable them to conduct quality and often long-term research.

¹⁸Deborah Schofield et al. 2011, A crisis in the making? Education, ageing populations and the future of the medical research workforce. Med. Educ. 45(2):200-7

¹⁹Deborah Schofield for the Australian Society of Medical Research (2009). Planning the Health and Medical Research Workforce 2010-2019

Q10. How can funding be sourced for long term population health studies?

Q11. Is cancer research funding in Australia sustainable?

Q12. Is there adequate funding for high risk research?

Q13. Are careers in cancer research being sustained through the current funding schemes?

Outcome 4:

Provision of enduring research infrastructure

Research infrastructure has been underfunded (compared to the real costs) and fragmented by the multiplicity of funding providers. The term 'infrastructure' refers to the full range of sustainable resources required to sustain the research effort.

Increased funding for the development of shared research assets, such as coordinated national bio-specimen banks and data registries, is essential if we are to protect and build on current research strengths. In particular, continuing long-term and coordinated support is needed in some cases, for example for Australia's cooperative trials groups to support clinical trials to advance cancer treatment.

A national cancer research plan should include recommendations for increasing and better coordinating funding for the strategic infrastructure – equipment, buildings, technical support staff – necessary to meet future cancer research needs. Sustaining independent trials groups will also help maintain and retain world-standard scientific and medical researchers in Australia.

Many questions about cancer causes and risk factors can be answered only through large-scale, longitudinal epidemiological studies, sometimes over decades. Such studies cannot be initiated with, or sustained by, multiple small scale and short term grants.

Current government funding schemes do not support studies of the size and duration that is necessary and while community funded organisations have provided some support their resources are limited. A mechanism to collaboratively fund and sustain these vital long term population studies is required.

How to provide input or comment

We invite all interested stakeholders to provide feedback on the issues and questions presented in this paper and make recommendations about the actions required to improve cancer research planning and coordination of funding in Australia.

Feedback can be provided by:

- Email: crlf@nbcf.org.au
- Mail: Cancer Research Leadership Forum
c/o National Breast Cancer Foundation
GPO Box 4126
Sydney, NSW, 2001

Submissions close 1 May 2012

Steps towards a national cancer research plan

1. Broad consultation with consumers, researchers and funders about what a national cancer research plan should cover. This issues paper invites stakeholders to consider these and other questions, identify other issues that should be considered, and submit recommendations and ideas.
2. Following the consultation phase, the CRLF will convene a national cancer research summit in September 2012, bringing together key stakeholders to agree on priorities and develop strategies for coordinating and funding research projects, infrastructure and workforce to accelerate our efforts to reduce the impact of cancer in Australia and globally.
3. A report of the outcomes of the summit will be published in early 2013, and should form the basis of a national plan.

For further information, contact:

National Breast Cancer Foundation
Phone: (02) 8098 4800



