

## Senate inquiry into funding for research into cancers with low survival rates

Submission from Cancer Council Australia and the Clinical Oncology Society of Australia

March 2017

**Cancer Council Australia** represents the national interests of its members, the eight state and territory Cancer Councils. Collectively, after government Cancer Council is the largest funder of cancer research in Australia by a significant margin, investing \$65 million in 2016 in direct and partnership grants.

The **Clinical Oncology Society of Australia** (COSA) is the peak national body representing health professionals from all disciplines whose work involves the care of cancer patients.

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### Recommendations

- Develop through the NHMRC a national priority driven cancer research assessment framework to prioritise government funding towards high burden cancer, and investigation of clinical variation through investment in health services research;
- Set up a collaborative model between the Medical Research Future Fund and the NHMRC to provide dual funding streams for investments in priority-driven biomedical and health services cancer research;
- Implement the Australasian Tele-Trial Model and introduce an accredited clinical trial site registration scheme nationally. This will bring about change in reform relating to remote monitoring, national ethical processes and governance arrangements and other contractual processes at a health system level to improve clinical trial enrolment, and reduce financial and human resource cost to conducting research;
- Work across all jurisdictions to extend coverage of existing subsidy arrangements for patient travel and accommodation to patients who are successfully recruited into a clinical trial where a site or satellite site is not available locally; and
- Commonwealth to develop and promote the adoption and reporting of health service indicators and performance measures, including the reporting of clinical trials enrolment.

### Overview

Cancer Council Australia and the Clinical Oncology Society of Australia (COSA) commend the Senate for conducting this inquiry and welcome the opportunity to provide context and independent recommendations.

In Australia, 68% of people diagnosed with cancer are still alive five years after a cancer diagnosis (2009-2013)<sup>1</sup>. This has increased by over 20% since 1986<sup>1</sup>. However, the increase in survival following a diagnosis of cancer has not been consistent across all cancer types.

### Cancer in Australia

## **Cancer survival in Australia**

The Australian health system has been shown to deliver better cancer outcomes than health systems in comparable countries. A recent study that compared survival rates for 11 common cancers across 67 countries has shown that survival rates in Australia were amongst the best in the world<sup>2</sup>. Specifically, five-year net survival was high for all 11 cancers, in particular cancers of the colon, rectum, breast and prostate. Australia's world-leading cancer survival outcomes are likely due to the significant investments in screening, early detection and treatment that the Australian Government has made over many years along with a readily accessible public health system. There is also evidence that clinical trials help to improve cancer outcomes overall and Australia has a long standing commitment to international trials of new therapeutics.

The Australian population is geographically dispersed, which brings with it specific challenges with regard to healthcare delivery, particularly issues around equity of access to health care services. In addition, the population is culturally diverse which also brings with it unique health challenges. Both of these issues impact on cancer survival.

### **What is 'low survival cancer'?**

Relative survival is the accepted benchmark for cancer survival. It refers to the probability of being alive for a given amount of time after diagnosis compared with the general population. In 2009-2013, in Australia, five-year relative survival was lowest for those diagnosed with pancreatic cancer (8%) and mesothelioma (6%), and brain cancer (21%), compared to people diagnosed with testicular cancer (98%), and thyroid cancer (96%)<sup>1</sup>.

It is also important to consider factors such as the age of affected individuals when examining the impact of low survival cancers. For example, brain cancer and Central Nervous System tumours, which disproportionately affects younger people has a significant associated societal burden with regard to years of life lost and productivity lost<sup>3</sup>. Although many people who have undergone treatment for cancer do survive, they still experience the consequences of treatment and in some cases, these side effects are long lasting and have a significant impact on their quality of life.

Factors that impact on cancer survival are numerous and do include research funding, as well as health system design and delivery factors which will be discussed below.

### **Medical Research Future Fund**

The introduction in 2015 and subsequent legislation of Australia's Medical Research Future Fund (MRFF) provides a landmark opportunity to address inequities in research investment and outcomes relating to low-survival cancers. Opportunities to align the MRFF's strategy and innovation priorities apply to all the terms of reference for this inquiry. A number of the MRFF's strategic priorities for 2016-18 are directly relevant, including:

- Public good demonstration trials;
- Drug effectiveness and repurposing;
- Clinical researcher fellowships;
- Support for independent clinical trials networks;
- A focus on health services and building evidence in primary care;
- Priority driven national and international collaborations; and
- Targeted translation topics in areas of well-documented health inequity.

Below we discuss how the MRFF could support a world-leading, priority-driven cancer research program to provide specific opportunities for delivering maximum returns on investment, consistent with the fund's criteria.

## ***Addressing the terms of reference***

**The impact of health research funding models on the availability of funding for research into cancers with low survival rates, with particular reference to:**

- a) The current National Health and Medical Research Council funding model, which favours funding for types of cancer that attract more non-government funding, and the need to ensure the funding model enables the provision of funding research into brain cancers and other low survival rate cancers;**

In the period 2006 to 2011, a total of \$1.77 billion in funding was provided in Australia to 4,924 cancer research projects and research programs, people support scheme awards and building cancer research capacity initiatives and infrastructure<sup>4</sup>. Australia is fortunate to have multiple funding organisations, including Commonwealth and State and Territory governments, community-funded cancer charities, and private sector organisations; however, different drivers, regulations and funding strategies mean this investment is fragmented, creating unnecessary competition, duplication, inefficiencies and gaps<sup>5</sup>.

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. Cancer Council Australia and COSA recommend improved coordination of investment in cancer research and improved funding efficiency through a national priority driven cancer research assessment framework.

It is the role of the NHMRC as Australia's leading expert research body, to take the lead in addressing current gaps in research funding for low survival cancers. There is an opportunity for the NHMRC to review and modify its current funding assessment criteria to better reflect the *impact* of low survival cancers in Australia. In doing so, it must take into account factors such as the burden of disease, including numbers of life years lost, survival rates, and in particular an absence of improvement in survival rates over time, as well as historic underfunding. This modified assessment criteria would inform the development of a national priority driven cancer research assessment framework, which could be used by other public, as well as private and community-based funders of cancer research in Australia to inform their own assessments of applications for research funding. This has the potential to reduce the impost on individual researchers and research groups when developing applications for funding, and would help enhance the impact of Australia's collective investment in cancer research.

## **b) The obstacles to running clinical trials for brain cancers and other cancers with relatively lower rates of incidence.**

National and international collaboration are key strategies to facilitate meaningful conduct of research targeted to patient groups with low incidence and low survival cancers, and less common and rare cancers. Recent Commonwealth department consultations and agency inquiries indicate that the Government is interested in reducing regulatory barriers, duplication, administrative burden, and increasing capacity to collaborate and share information across Australia and internationally.

### ***What is a clinical trial, and why is research important?***

Clinical trials are a fundamental component of health and medical discovery, and establish the effectiveness and cost effectiveness of an intervention. Collaborative clinical trials bring together diverse skills and capabilities of researchers to answer a scientific question however, currently, there is minimal support for the critical infrastructure that enables these networks. Although outcomes of a clinical trial will primarily ensure the patient receives high quality treatment, the delivery of effective healthcare has a broader societal impact.

### ***Implications for cancer research***

The greatest challenge to conducting modern clinical trials is how cancer is classified and treated. Advances in the understanding of the molecular pathology of cancer are creating opportunities for the development of therapies with sustainable and impactful clinical benefit while challenging the traditional model of therapeutic development and clinical care<sup>6</sup>.

Increasingly, the molecular pathology of the disease rather than the location of the tumour informs the classification of cancer. Patients categorised in these sub-types share a predictive factor which identifies whether the tumour is likely to respond to a particular treatment. The classification of cancer has a critical impact on how the disease is treated and accessibility to appropriate therapeutic options. It also impacts on recruitment numbers for a clinical trial. Small study numbers impact the ability to apply a traditional trial design to produce results with a high level of certainty. This challenges how national regulatory bodies assess the efficacy of the therapeutic product, and the relevance of the comparator product to determine cost effectiveness.

Although the cause of many less common and rare cancers is poorly understood, there is generally high acceptance of a genomic association<sup>7</sup>. As the research community continues to understand the cause of, and subsequently how to identify rare subsets of common cancers, there will be a dramatic improvement to the design of therapy and increased ability to predict a positive outcome for a patient.

### ***Defining low incidence cancer***

Incidence is the number of new cases within a timeframe, generally a year. Therefore, 'low incidence cancers' are cancers with relatively small patient numbers. For example, brain cancer with 1,636 new cases reported in 2013, has lower incidence compared to the 19,233 new cases of prostate cancer in that same year<sup>8,9</sup>. The Australian Institute of Health and Welfare (AIHW) reports incidence in traditional tumour stream categories however, cancers are increasingly being identified as sub-types of common cancers based on a shared characteristic, such as the presence of a genetic marker, which is not captured through national reporting.

For the purpose of this submission, the definition of low incidence is the number of new cases per year for a defined patient population whether this is based on tumour stream or other characteristic such as an identified genetic mutation.

### **Approaches to support clinical trials**

In Australia, structural barriers, rather than a lack of funding, are the greatest obstacles to conducting clinical trials in low incidence and low survival cancers. Implementing systematic changes to improve collaboration will support the sustainability of the cancer research sector and translation of outcomes into practice. Currently, Commonwealth and state and territory levels of the Australian government are responsible for enforcing various legislation related to the conduct of ethical research in Australia.

A number of clinical trials close without recruiting a patient. In 2014, 30% of registered clinical trials in New South Wales reported nil patient enrolment within the reporting period<sup>10</sup>.

**Table 1: Ratio of newly-enrolled participants to cancer incidence (per 100 cases), by clinical group (ranked), NSW, 2014.<sup>11</sup>**

Clinical group	NSW recruiting trials			
	No. of trials	No. of trials with nil enrolments	No. of trials with enrolments	% of trials with enrolments
Bowel	16	7	9	56.3
Breast	34	14	20	58.8
Cancer unknown primary	0	0	0	0.0
Gynaecological	16	3	13	81.3
Head and neck	1	0	1	100.0
Lymphohaematopoietic	63	17	46	73.0
Neurological	3	0	3	100.0
Respiratory	32	9	23	71.9
Skin	21	4	17	81.0
Upper gastrointestinal	18	5	13	72.2
Urogenital	26	5	21	80.8
<b>All cancers</b>	<b>294</b>	<b>89</b>	<b>205</b>	<b>69.7</b>

N= Number of cancer cases (Incidence).

\* The reporting period for clinical trial data is 2014, and 2010 for cancer incidence (latest available data).

Recently, a medical oncologist working in a regional cancer centre reported that 12% of his patients were recruited into a trial. With small investment and greater collaboration, this can be achieved and extended in most major towns.

Different approaches are required to address low incidence cancers with poor survival. Cancers of low survival that occur frequently would benefit from large scale Australian collaboration, whereas cancers that are rare or less common require an international focus. Cancers with a relatively small research workforce would benefit from an international collaborative research approach to ensure that improvements in outcomes can be realised for these tumour types<sup>12</sup>. Therefore, funding schemes need to encourage and facilitate multidisciplinary and cross-sector collaboration and international partnerships, in order to expedite advances in cancer control that will benefit Australians affected by cancer. Funding allocated to small projects should be redirected into high impact projects with sufficient resources to increase capacity for research into cancers with relatively low incidence. Therefore, investment in brokering for Australia as a trial destination for less common or rare cancers is only one part of a complex trials system that requires new strategies.

### ***i. Research governance and ethics arrangements***

Australia requires a nationally consistent approach to reform and research governance arrangements related to clinical trials. Currently, there are systematic barriers at both Commonwealth and state and territory levels to conducting multi-centre research. These barriers negatively impact on the cost and time taken to commence research. The aim is to develop reform options that drive interest in Australia as a destination to conduct clinical trials without compromising on patient safety. Current governance and ethics requirements are administratively burdensome and resource intensive, and take considerable time to satisfy<sup>13</sup>.

#### *National Mutual Acceptance scheme*

An analysis of clinical trials recently conducted in Australia identified critical success factors, and also reasons why a trial was unsuccessful. The main issue reported by sponsors was the relatively slow time to trial commencement. The report noted multiple factors which impact on the time to commencement, including the inability to meet recruitment targets; cost disadvantage; lack of consistency of Human Research Ethics Committee requirements, and timeliness of governance approval<sup>13</sup>.

Government health agencies in New South Wales, Queensland, South Australia, and Victoria agreed to implement the National Mutual Acceptance scheme which supports single ethical review of multi-centre clinical trials and human research conducted within public health organisations<sup>14</sup>. It enables the project to be submitted to one reviewing Human Research Ethics Committee which is certified by the NHMRC. Once approved, participating organisations in the participating states recognise that the study has gained scientific and ethical approval. Interestingly, despite the establishment of the National Mutual Acceptance Scheme, reluctance of sites to take a lead role in the ethics review process due to administrative burden remains a barrier to the timely commencement of clinical trials<sup>13</sup>.

Although progress is being made, ongoing improvements to national streamlining of ethics and governance approvals to facilitate multi-centre, multi-jurisdictional trials are required to further reduce administrative burden.

#### *Site Specific Assessment*

Local indemnity arrangements have the biggest impact on the time from ethics approval to commencement of a clinical trial. Currently the governance officer at every hospital or institution participating in the trial must approve a site specific application from the lead site and Principal Investigator. Some pharmaceutical companies have indicated that opening a trial within 30 days of obtaining ethical approval would be an incentive for them to invest in Australia. The introduction of accredited clinical trial sites would reduce the need and delay attributed to achieving individual site specific approval<sup>15</sup>. This simplified and streamlined approach, as described below, to achieving multi-centre site approval would reduce the cost, and expedite the approval processes to support faster commencement of the study.

#### *Accredited Trials Sites and Clusters*

For public institutions, site specific governance for accredited trials sites should be coordinated at a state and territory or national level. An independent assessment would be applied to sites seeking to become an accredited trial site which would provide them with pre-approval and recognition that it is a well-equipped trials location dedicated to advancing the understanding of cancer. In the United Kingdom a registered network of clinical trial units has been established which brings together academic clinical trials units who have been assessed by an international panel of experts in clinical trials research<sup>16</sup>. Clinical researchers and funders can then easily identify and engage



with units that have expertise in centrally coordinating multi-centre clinical trials, trial design, data management, and analysis.

To expand on this, an 'accredited trial site cluster' could be a network of institutions identified as having clinical trials capacity as an established multi-centre collaborative. The level of support provided to the smaller sites would be determined by the complexity of the trial and the clinical capabilities at the site. Increased capacity could be provided from the primary site to potential rural and remote locations through tele-trial models and use of e-technology, such as the Australasian Tele-trial Model<sup>17</sup>.

An accredited trials site program would require the development of an assessment process to determine the capability of the site and the investigator/s at the site. Under the program, accredited sites would be able to recruit for any trial which it has approved capability provided the trial has been approved by the primary site governance and ethical approval process. An accredited trials site program would build capacity, reduce inequity to participating in clinical trials based on geography, broaden potential recruitment channels, and reduce administrative burden associated with individual site specific approvals.

A national register of accredited sites for clinical trials would include details of the site and evidence of their accreditation, which would assist in the initial selection of candidate sites to participate in recruitment for the study<sup>5</sup>. Without accredited trials sites, the system will continue to experience wastage and Australia will be unable to present improved time to trial commencement. As part of the program, benchmarks and performance indicators must be established to demonstrate Government's support for appropriate recruitment into clinical trials for eligible patients.

The production of data through multi-centre primary research would be better supported by a national, streamlined ethics application and approval process.

#### ***ii. Use of technology for innovative clinical trials models***

The implementation of an e-health platform will allow national access to patient records for the purposes of clinical trials and enable secure remote access to assist monitoring the patient for the duration of the trial.

The Australasian Teletrial Model developed by COSA outlines the key considerations for increasing access to clinical trials for people with cancer living in rural and remote communities, and facilitate study activity across rural and remote locations<sup>17</sup>. It has the potential to connect research centres, and improve the rate of recruitment to highly specialised clinical trials, including low incidence cancers.

The model documents a feasible and effective tele-health strategy to increase access to clinical trials closer to home using traditional video-conferencing technology and web based systems. In addition, the model will aid collaboration and networking between centres. This will have a flow on effect for delivering greater engagement in research activity, improving adherence to evidence based practice, improving the rate of recruitment of patients into clinical trials, reducing the disparity in cancer outcomes for geographically dispersed populations, building clinical trial capacity, and providing trial-related training<sup>17</sup>.

Since 2011, utilisation of tele-health in the delivery of services has increased. In the first quarter of the 2011/2012 financial year 1,809 claims relating to telehealth services were processed through Medicare compared to 40,570 in the quarter ending 30 June 2016<sup>18</sup>.

The integration of tele-health and tele-trials is a critical strategy to address the huge and unprecedented growth in health care need.

### **iii. Supportive care barriers to access to clinical trials participation**

#### *Financial assistance:*

People living in rural and remote areas experience barriers to accessing clinical trials, such as limited availability of trial sites locally, and increased cost and inconvenience of travel to major centres where the trials are taking place<sup>19,20</sup>.

Financial assistance to support travel for specialist medical services that are not available locally are offered by state and territory governments and administered through public hospitals. Currently, patients who choose to participate in a clinical trial do not qualify for these schemes<sup>17,21</sup>. For the patient, this can reduce their available treatment options and for the researcher, it can limit representation of the rural and remote population in their study.

The various patient travel subsidy schemes lack flexibility to respond to complex circumstances of individual patients, constrain decision making and segregate eligible patients from participating in clinical trials. Additionally, these programs are under-funded and do not meet the real life costs of travel and accommodation. The schemes do not ensure a patient has equitable access to all treatment options regardless of geographic location, and in the interests of the individual and the public, the Government must encourage participation in clinical trials for all cancer patients regardless of geographic location.

#### *Support for participation from Non-English speaking and low literacy communities:*

In Australia, around 28% of the population was born overseas<sup>22</sup>. In 2011, 81% of Australians aged 5 years and over, spoke only English at home while 2% do not speak English at all. The most common languages spoken at home (other than English) were Mandarin (1.7%), Italian (1.5%), Arabic (1.4%), Cantonese (1.3%) and Greek (1.3%). These rates more than doubled in the long standing migrant populations<sup>22</sup>. Australia has a unique challenge of ensuring its population has access to cancer information and opportunities to participate in clinical trials without the barrier of language.

Cultural value, languages and ethnicity can influence therapeutic decisions and their experience of the illness and relationship with their healthcare practitioner. Communication barriers, including the lack of culturally relevant cancer information and language barriers mean that trial participation from culturally and linguistically diverse (CALD) communities remains at sub-optimal levels and skews bias towards results the non-CALD population<sup>23</sup>. The need for an interpreter for the duration of the trial also adds a level of complexity and increased cost to the trial.

Improving participation in clinical trials in these groups requires targeted, wider education and availability of resources such as participant information sheets and related study documentation in-language culturally specific, and written at an appropriate level for English speaking participants with low literacy. It also involves ensuring the participant has access to an interpreter, and involvement of the patient's carers and community in decision making is appropriate.

### **iv. Publicly funded research**

Funds allocated and prioritised for education, training and research within public hospital budgets must be utilised for these purposes and not re-allocated to other services. The aim of retaining the funds for these activities is to attract quality clinical staff to public institutions, and continue to support the research and clinical workforce interface. Clinicians who have a focus on continued professional development and advancing understanding of best practice cancer care, are a critical enabler to patient participation in clinical trials. The funding channels for these components are established however, ensuring the allocated funds remain assigned to those functions is the critical



factor. The use of these funds supports clinical staff to build track records, continue to develop their skills, remain informed of best practice, and engage with multidisciplinary staff.

The Productivity Commission released its draft report from the Data Availability and Use consultation citing multiple recommendations related to making public and private datasets more available. Draft recommendation 5.3: *'The Australian Government should abolish its requirement to destroy linked datasets and statistical linkage keys at the completion of researchers' data integration projects. Data custodians should use a risk-based approach to determine how to enable ongoing use of linked datasets. The value added to original datasets by researchers should be retained and available to other dataset users.'*<sup>24</sup> If the Government accepts this recommendation, duplication of access, cost and administrative burden associated with considering requests for previously linked data sets would be reduced. It would enable researchers to build on these linked datasets, and increase the capacity of many researchers to coordinate and deliver more accurate outcomes in under-investigated areas.

**v. Increasing awareness of active clinical trials**

Clinical staff are an important recruitment tool in referring eligible patients into clinical trials. Ensuring oncology health professionals are aware of active trials and have access to information about these studies, will enable clinicians to more accurately refer patients to eligible studies. This will also increase the ability for studies to reach optimal recruitment targets to support the production of accurate outcomes. Increased investment in education initiatives targeted at both clinicians and patients would contribute to ensuring all eligible patients have an opportunity to be referred into a clinical trial.

The Government has demonstrated support for clinical trials by promoting portals for easy access to information about active trials and their eligibility criteria. The [NHMRC](#) lists all sites that have information related to clinical trials being conducted in Australia or internationally that include Australia. Within this list is the [Australian New Zealand Clinical Trials Registry \(ANZCTR\)](#) which is a registry hosted by a not-for-profit organisation that provides a platform for researchers to list their trial, and for potential participants to search and register their interest. Additional novel approaches to increasing health professional awareness of relevant clinical trials could be the integration of notifying the treating clinician on the histopathology report, and with the advent of electronic health records, the ANZCTR could link into these pathology details stored on the patient's electronic file.

In addition, the NHMRC has created short web-site pages to raise awareness of the [Laws and Regulations that apply to ethics review and research governance](#) and the [Indemnity and insurance arrangements for clinical trials in Australia](#). The purpose of these sites is to support the NHMRC's initiatives to develop a nationally consistent approach to clinical trials, improve efficiency and streamline administration and costs to position Australia as a world leader in clinical research<sup>25</sup>.

**c) The low survival rate for brain cancers, lack of significant improvement in survival rates, and strategies that could be implemented to improve survival rates and;**

In the past 25 years, continued investment in research in Australia has resulted in significant improvements for some cancers, with survival rates increasing to 90% for breast, 94% for prostate and 44% for ovarian cancer<sup>1</sup>. In order to achieve improvements in outcomes for low survival cancers such as lung, pancreatic and brain cancer, the same commitment to research is required; however, careful consideration needs to be given to how Australia's limited cancer research funding dollars are prioritised.

The former CEO of the NHMRC recently suggested that while prioritising a health condition is tempting for governments, and no-one would argue against the strongest possible worldwide research effort on any area of ill health, this approach will not achieve the greatest benefit for Australia<sup>26</sup>. He explained that even devoting all of the Australian Medical Research Future Fund (MRFF) to a single disease would represent only a small increase in the worldwide research effort (approximately 1-2%), and that this was unlikely to make much difference, no matter how large the burden of the disease on individuals and societies<sup>26</sup>.

Prioritising quality and impact over specific health problems and enabling research into uniquely or predominantly Australian issues such as the health of Indigenous Australians, or research focused on making the Australian health system work better for the patient and the taxpayer, should be a priority<sup>26</sup>. Finally, he explained that Australian medical research is too fragmented, and that there is much duplication of research resources and services, and little coordination, highlighting the need for improved collaboration<sup>26</sup>.

Outlined below is a brief discussion of potential strategies that could be implemented to improve survival rates for low survival cancers in Australia.

***Development of an Australian priority-driven cancer research program***

Progress in cancer control in Australia could be accelerated by targeting a greater proportion of the available funding to priority-driven research, addressing identified gaps and reflecting the burden of different cancers. A recent audit of cancer research funding in Australia from 2006 to 2011 highlighted gaps in the awarding of funding relative to disease burden and mortality<sup>1</sup>. Specifically, this analysis showed that cancers that cause an increasing relative death and disease burden are among the most poorly researched, including cancers of the lung, pancreas, brain, kidney and bladder. This is reflective of an outdated culture of investigator-driven, rather than priority-driven, biomedical research, and may also be attributed in part to charities and other community-based organisations dedicated to raising money for research into cancers such as breast, prostate and leukaemia.

***Funding allocation***

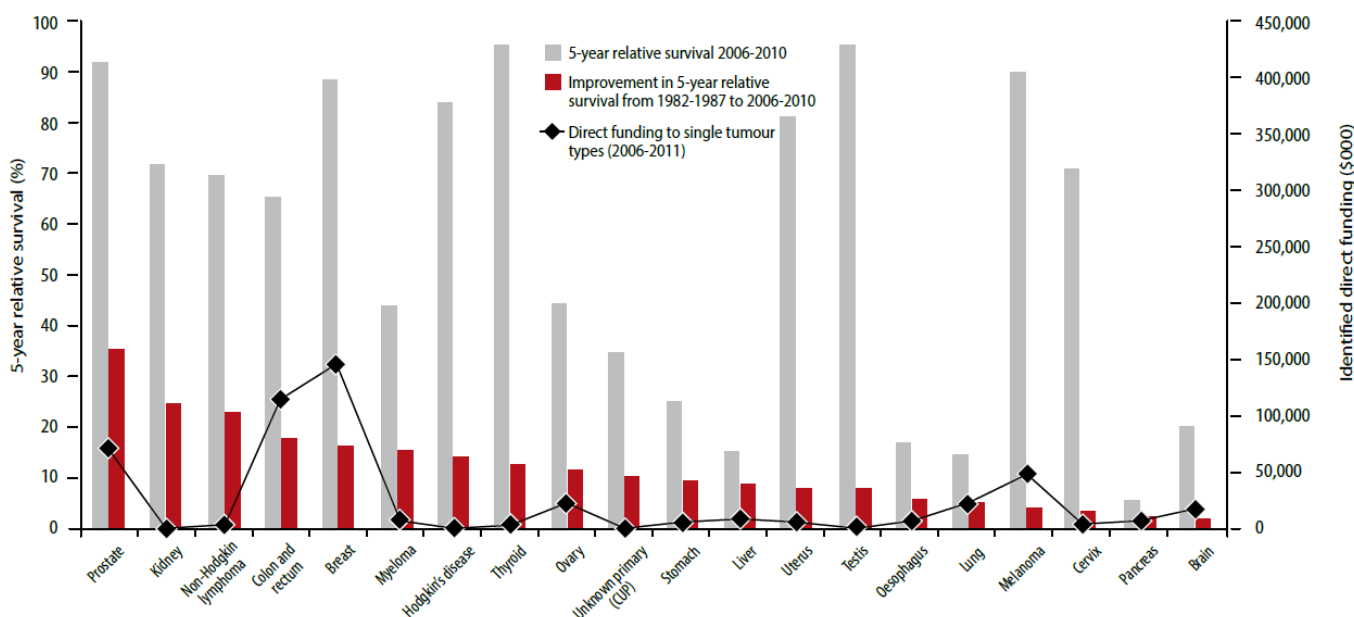
In Australia, lung cancer causes the largest number of cancer deaths; however, it receives a disproportionately low level of research funding, with less than five cents of every cancer research dollar going to lung cancer (Table 2)<sup>1</sup>. In the period from 2009-2011 lung cancer was responsible for three times as many deaths as breast cancer but only received one-fifth the amount of research funding.

**Table 2 Deaths from cancer, proportion and amount of funding (2009-2011) for the top 5 cancers in Australia, based on mortality<sup>1</sup>**

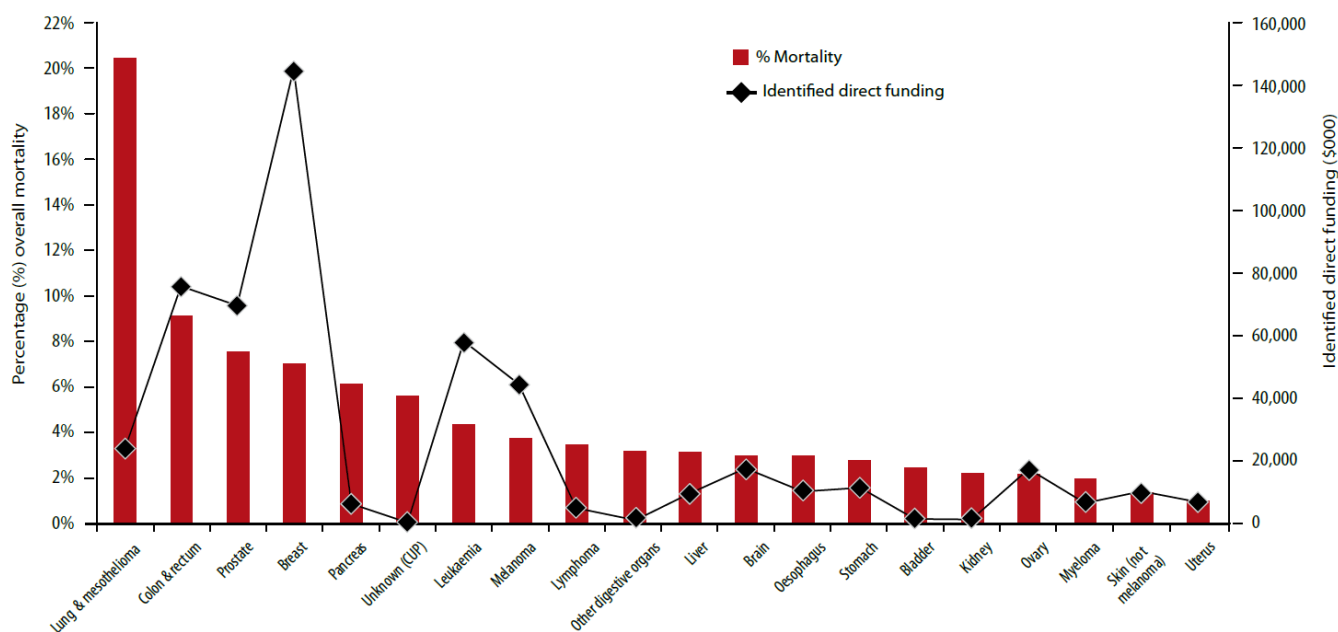
Cancer type	% of cancer deaths	% of funding	Amount of funding (\$M)
Lung	18.5	5	16.3
Colorectal	8.7	14	47.2
Prostate	7.5	13	41.6
Breast	6.5	26	85.9
Pancreas	5.6	2	5.3

There appears to be a relationship between improvements in 5-year relative survival rates and levels of direct research funding (Figure 1)<sup>1</sup>. In addition, for some cancers, the level of research funding compared with the burden of disease is low (Figure 2)<sup>1</sup>. These results highlight the importance of prioritising research funding investment towards those cancers with a high burden of disease.

**Figure 1 Direct funding to single tumour type-specific cancer research projects and research programs in Australia (2006–2011), compared with the improvement in 5-year relative survival since 1982–1987 and the overall 5-year relative survival (2006–2010) for selected cancers<sup>1</sup>**



**Figure 2 Direct funding to tumour type-specific cancer research projects and research programs in Australia 2006 to 2011, compared with the top 20 cancers by mortality in Australia, 2010<sup>1</sup>**



### Workforce

Factors that impact on the level of research funding include the quality and size of the research workforce, and the fact that some tumour types have received lower levels of direct funding historically may reflect a small research workforce for these tumour types<sup>1</sup>.

In the UK, an inquiry into funding for research into brain tumours acknowledged that historical funding problems and a lack of leadership from successive governments in this area have left a gap in the research workforce<sup>27</sup>. The inquiry suggested that a quality workforce could significantly improve progress for brain tumour research, and recommended that the British Government ensure that there is adequate support for young scientists who wish to pursue a career in this area<sup>27</sup>.

The sustainability of the Australian cancer research workforce is compromised by job insecurity and a lack of sustainable career pathways<sup>5</sup>. This is due largely to short-term research grants, which discourage long-term retention of research staff, as well as annual funding cycles which leave some researchers vulnerable to funding gaps that can impact on completion of research<sup>5</sup>. Cancer Council Australia and COSA recommend the development of funding mechanisms that provide more support for early to mid-career researchers, and longer-term (five-year) funding for individual researchers or groups to improve job security. The provision of bridging or short term funding outside of existing funding timetables would also assist in retaining research staff.

### Prevention

Given the predicted increase in cancer incidence and prevalence in coming years, and increasing knowledge about the potential to prevent many cancers, greater investment in population health research is needed. We know that one-third of cancers are potentially preventable<sup>28</sup>, 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.

Traditionally, basic biological research has been the most generously funded and this has led to major advances in cancer treatment. An analysis of research funding during 2006 to 2011 found the majority of funding was directed to research in biology and treatment, and direct funding to research other in areas, including prevention and early detection, was comparatively low<sup>1</sup>.

### *Medical Research Future Fund*

Cancer Council Australia and COSA propose a world-leading, priority-driven cancer research program supported by the MRFF. The program will provide specific opportunities for delivering maximum returns on investment, consistent with the fund's legislated criteria. With a focus on disease burden, practical benefits, maximum value and complementarity, the program would help address a number of key challenges in cancer by:

- Addressing the underinvestment in researching poor-survival cancers such as lung, pancreatic and brain cancer.
- Studying variations in clinical outcomes within and between populations.
- Working with independent medical researchers on ways to expedite the evaluation and subsidy of new medicines with potential to extend and save lives.
- Collecting evidence on improved prevention, noting that a third of Australia's approximately 135,000 new annual cancer cases can be prevented.
- Developing innovative technologies for the early detection and diagnosis of cancers.

This program would provide an opportunity for Australia to lead the world in cancer research prioritisation and translation, converting the MRFF's legislated criteria into extraordinary outcomes in reduced disease burden.

In addition to disparities by cancer type, there are significant variations in clinical outcomes for the same cancers, for reasons that are not fully understood. Health services research that seeks to improve our health system, save resources and help ensure equitable outcomes for all Australians must be at the forefront of research investment, and is another critical component of an Australian priority-driven cancer research program (please see below for a more detailed rationale).

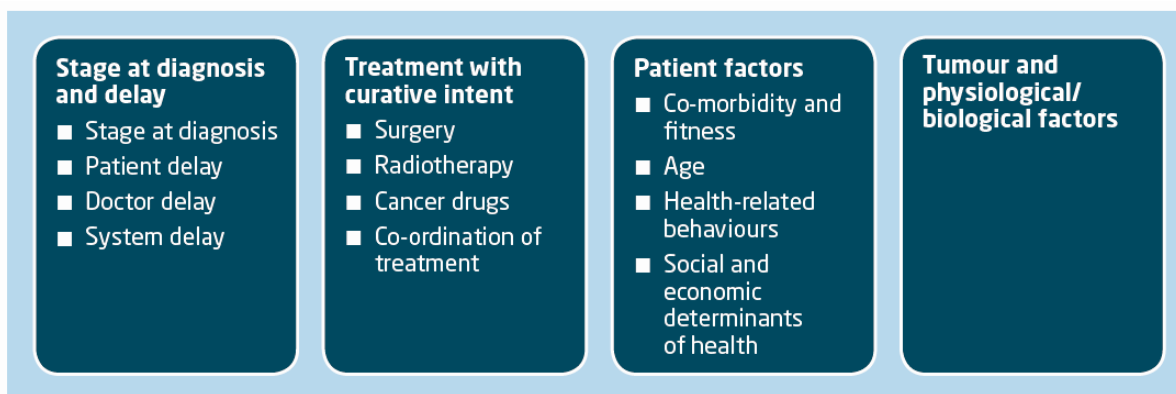
## **Increased investment in health services research**

In order to ensure that health service demands are being met and appropriate care is being delivered, it is critical to understand how people use the health system. Increased funding of health services research will facilitate a better understanding of how patients with cancer use the health system, from the time of diagnosis, through to the treatment, follow-up and survivorship phases, and will help identify initiatives that will be most effective at improving survival outcomes.

Clinical trials are generally conducted and funded as an activity that is separate to healthcare delivery. However, the ability to conduct trials within health services is critical to the continuous improvement of the quality of care delivered to patients. As a provider of treatment and care services, the healthcare system has a responsibility to measure and report its impact, and identify strategies to address service gaps and variations of care. The systematic application of clinical trials alongside the collection of clinical service delivery data to monitor the application of therapies would improve the quality of care delivered to the patient.

Variations in trends between cancers are due to a variety of factors, including differences in screening, diagnostic tests, and improvements in the quality and organisation of treatment. Studies attempting to explain cancer survival differences have focused on four main areas: stage at diagnosis and delay; treatment with curative intent; patient factors and; tumour and physiological/biological factors, as outlined in Figure 3 below<sup>29</sup>. Evidence suggests that combinations of some or all of these factors explain survival differences, and each of these factors relate to and influence each other<sup>29</sup>.

**Figure 3** Possible drivers of variation in cancer survival<sup>29</sup>



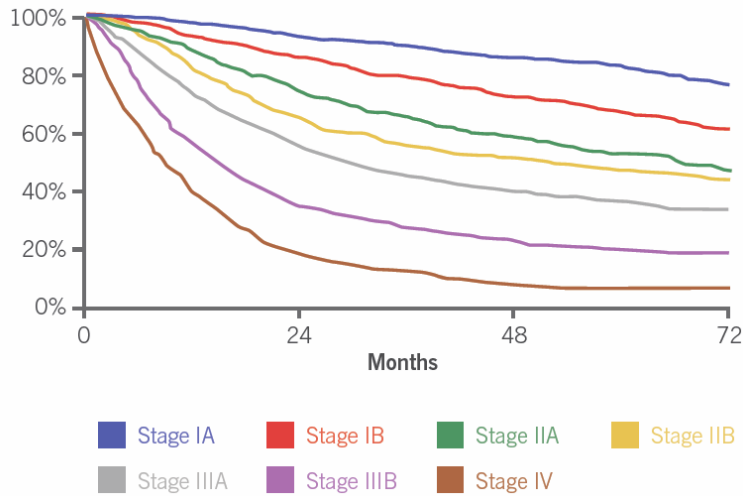
Cancer Council Australia and COSA recommend greater investment in research examining the drivers of variation in cancer survival, as this would deliver significant improvements in cancer outcomes for Australians. Some of these drivers are outlined below.

### **Stage at diagnosis and diagnostic delay**

When a cancer is diagnosed it is given a particular 'stage' to represent how far it has spread. As cancer is a progressive disease, the stage at diagnosis is related to survival. In the case of lung cancer for example, the earlier the cancer is detected, the greater the chance of successful treatment and potential cure (Figure 4)<sup>30</sup>.

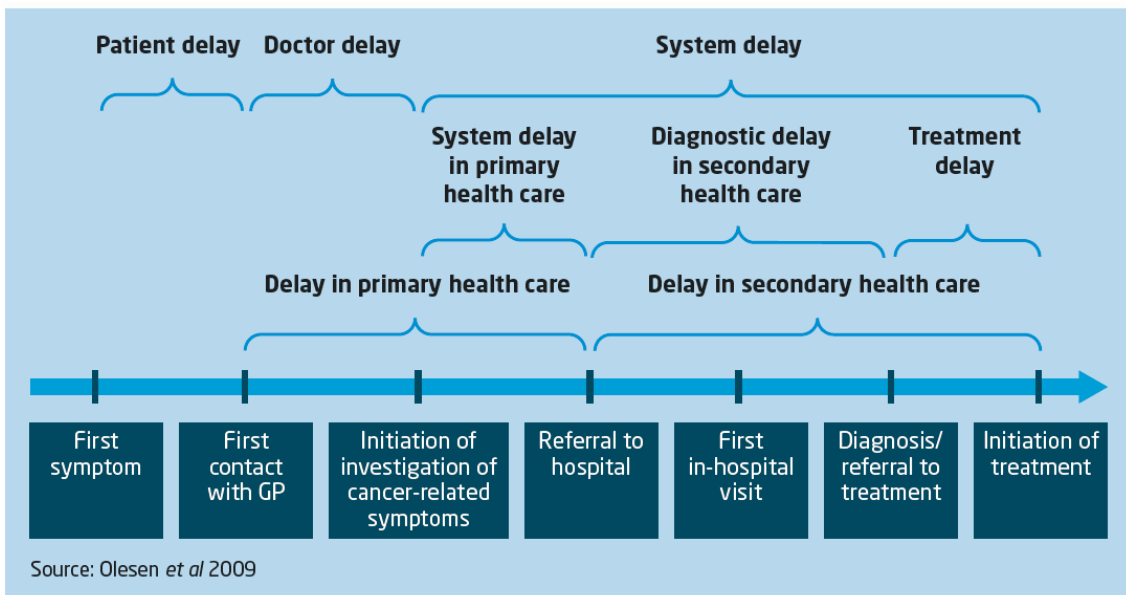


**Figure 4 Overall lung cancer survival by clinical stage<sup>30</sup>**



Researchers examining delay in the diagnosis and treatment of cancers producing symptoms have developed categories of delay – patient, doctor and system (Figure 5)<sup>31</sup>.

**Figure 5 Categorisation of delay<sup>(31)</sup>**



*Patient delays* occur if patients are unable to recognise signs and symptoms of cancer as suspicious, or if they do recognise the symptoms but delay seeing a health professional<sup>29</sup>. The Cancer Research UK ‘Be Clear on Cancer’ campaign aims to improve early diagnosis of cancer by raising public awareness of signs and/or symptoms of cancer, and encouraging people to see their GP without delay<sup>32</sup>. An evaluation of the program has shown a 62% increase in attendances for a persistent cough, which can be a symptom of lung cancer, in people aged over 50 during the campaign period.

*Doctor delays* occur if there are delays in recognising potential cancer-related symptoms, investigating them and referring the patient on for specialist assessment<sup>29</sup>. Delays in the primary care system can result in longer times to diagnosis for some patients with cancer, particularly for those with vague or low-risk symptoms.

A significant proportion of lung cancer cases are diagnosed at an advanced stage, as initial early symptoms are difficult to differentiate from other illnesses. Symptoms can include a persistent cough (sometimes with blood), breathlessness, chest pain, fatigue or unexplained weight loss<sup>33</sup>. For GPs, the challenge of diagnosing lung cancer is even greater in patients with few or no known risk factors for lung cancer<sup>33</sup>. Similarly, the early diagnosis of brain tumours is difficult, and people with this disease are often initially misdiagnosed. A recent study has shown that 61% of brain tumour patients were diagnosed in Accident and Emergency departments, one of the highest emergency presentation rates of all cancers<sup>27</sup>. Symptoms included headaches, fits, dizziness and back pain, hiccups, numb fingers, flu-like symptoms, a 'funny smell' and *déjà vu*, while the range of initial misdiagnoses was equally varied—from stress, depression and hormone problems to epilepsy, poor eyesight and vertigo<sup>27</sup>.

A GP may only see a small number of new cancers in any given year, and may go many years without seeing certain rare cancers. In the majority of cases, cancers are identified because of patient symptoms; however, for many patients who present with homogenous symptoms, these are often interpreted as something other than cancer. In the UK, the 'Head Smart' campaign, which aims to increase GP awareness of brain tumour symptoms in children and young people, has shown signs of success, reducing the time taken for diagnosis from more than 12 weeks to less than seven since it was introduced in 2011<sup>27</sup>.

A number of other initiatives have been suggested to facilitate earlier diagnosis of cancers within general practice<sup>29</sup>:

- Further improvements of referral guidelines for suspected cancer in primary care, using the best evidence to determine alarming symptoms.
- Significant event audits of cancer diagnoses in general practice, so that practices can reflect and learn from their experiences.
- Ensuring practices have good systems for getting test results quickly and recalling patients for follow-up appointments.
- Improving GPs' direct access to diagnostic tests for cancer, such as blood tests, x-rays, ultrasound and CT and MRI scans.
- Improving communication between primary and secondary care, so that GPs can access advice from specialist colleagues when needed.

In Australia, there is an opportunity for Government to provide greater leadership and support in order to:

- Raise awareness of low survival cancers amongst GPs and other healthcare professionals to facilitate earlier diagnosis.
- Raise public awareness of cancer symptoms and encourage people to see their GP if they experience certain symptoms.
- Fund more research aimed at improving our understanding of the patient, doctor and system factors that result in diagnostic delay of low survival cancers, and cancer more broadly.

## **Coordination of cancer care**

Cancer care is complex and requires a range of disciplines to work together, across different settings, over extended periods<sup>34</sup>. The delivery of services is fragmented and patients can become 'lost' in the system, resulting in system delays where there are unnecessary waits for investigations or assessments, and between the decision to treat and the time that treatment starts<sup>34</sup>.

In Australia, a variety of approaches have been used to address the coordination of cancer care and improve continuity of care<sup>34</sup>. Studies have demonstrated the link between the use of multidisciplinary teams and improved survival in lung cancer<sup>35</sup>. While it has been a focus of cancer policy for a number of years to expand the use of multidisciplinary teams, there is a paucity of evidence showing the effectiveness of multidisciplinary team work<sup>35</sup>.

More research is needed to confirm the association between multidisciplinary care and improvements in key cancer outcomes, which to date have been established by limited observational studies.

## **Vulnerable and high risk groups**

Both internationally, and in Australia, cancer patients from more *socioeconomically disadvantaged* backgrounds have been shown to have poorer outcomes for a number of major cancers<sup>36</sup>. The underlying causes of these socioeconomic disparities in survival are still poorly understood; however, a number of factors are thought to contribute, including health system factors, and variations in treatment<sup>36</sup>.

Significant disparities exist between *Indigenous Australians* and non-Indigenous Australians with regard to cancer incidence, diagnosis, treatment and outcomes<sup>37</sup>. In addition, survival is lower for Indigenous compared with non-Indigenous Australians for most cancer types, and Indigenous Australians with cancer are more likely to be diagnosed with advanced disease, and are less likely to receive optimal treatment<sup>37</sup>. Improving cancer outcomes for Indigenous Australians will require a strong focus on earlier diagnosis and subsequent intervention<sup>37</sup>.

In Australia, there is a well documented disparity in cancer outcomes between rural patients and urban patients<sup>38</sup>. These differences are due to a number of factors, including diagnostic delays as a result of fewer medical practitioners in rural and remote areas, and fewer diagnostic facilities such as computed tomography scanning and tissue biopsy services which limit early detection<sup>31</sup>. A number of initiatives have been trialled to try and address these disparities, including telehealth, specifically the Australasian Tele-trials Model<sup>17</sup>, and the use of care coordinators; however, more research is needed to determine the effectiveness of these interventions<sup>38</sup>.

In Australia, ongoing funding is needed for research aimed at improving our understanding of health inequalities in the wider social and economic determinants of health, and in earlier stage diagnosis and access to treatment.

## ***Changes to research funding and policy to facilitate improved collaboration***

Changes to Australian cancer research and policy would enable researchers to better collaborate, share data and define complementary research objectives, in order to optimise the use of limited funds and reduce duplication of effort.

## **Research infrastructure**

In Australia, increased funding for the development of shared research assets and infrastructure is critical in order to address existing shortfalls and ensure Australia's cancer research sector remains internationally competitive<sup>5</sup>.

Specifically, new, longer-term and more flexible funding grants are needed to enable the development and maintenance of equipment, technologies and other large-scale research infrastructure such as *biobanks* and genomics services.

Government also needs to facilitate, and advocate for, increased access to existing national research infrastructure including data, equipment, and technology. In the US, Congress passed the 21st Century Cures Act in December 2016 authorising \$1.8 billion in funding for the National Cancer Moonshot Initiative over seven years, which is seeking to make 10 years of progress on cancer research in half that time, with a goal to end cancer in our lifetime<sup>39</sup>. This initiative highlights the importance of scientific collaboration and information sharing, and its success will depend in large part on the ability of the US Government to facilitate *open access to cancer research data*.

### *Biobanks*

Biobanking is a key infrastructure capability that is essential for health and medical research, and for improving the prevention, diagnosis, treatment and ongoing management of diseases, including cancer. A recent public inquiry into funding for research into brain tumours in the UK reported that an absence of co-ordination and awareness had impeded collection of tissue samples, making fundamental research into different tumour types extremely difficult<sup>28</sup>.

In Australia, a number of mostly disease specific biobanking facilities have been implemented since the 2000s, with a focus on cancer; however, currently, Australia's biobanking sector remains fragmented, poorly regulated and lags well behind many other countries<sup>40</sup>. Specifically, a current lack of biobank oversight means that the numbers of biobanks that currently exist in Australia, how most of these biobanks operate, and whether they are effectively supporting Australian research by performing at internationally-accepted standards, is not known.

In countries such as Canada, Spain and France, national support has allowed biobanks to be identified, networked, evaluated, and supported<sup>41-43</sup>. In Australia, there is a need for investment in a *national biobanking network*, which would enhance research effectiveness, by facilitating the collection of samples of greatest use to researchers, as well as increased international collaboration opportunities for Australian researchers.

### *Open access to data*

While there is significant government investment in cancer research in Australia, the scientific publishing environment necessitates that research articles remain hidden behind paywalls, and delayed from release by long embargo periods. In order to hasten advances in cancer research in Australia, a new approach is required, which rewards collaboration and the sharing of research data.

There is an opportunity for the Australian Government to show international leadership on the issue of open access to research data, by ensuring that all federal government departments and agencies, as well as cancer research centers, and universities, that fund cancer research are required to adopt and implement open access policies that require knowledge to be openly licensed and freely-available without restrictions or embargoes.

### **d) Other relevant matters.**

No other items for discussion.

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