

March 29, 2017



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Submission to the Select Committee into Funding for Research into Cancers with Low Survival Rates

Lung Foundation Australia

To the members of the Select Committee

Lung Foundation Australia is a national not-for-profit organisation working to make lung health a priority for all in Australia. To achieve this, we work with patients, carers and clinicians to:

- Promote lung health
- Raise awareness of lung disease and symptoms of lung disease to facilitate early diagnosis
- Promote evidence-based management of lung disease through the development and translation of guidelines across a variety of clinical and patient settings
- Provide clinical and patient education to promote evidence-based management of chronic lung disease
- Advocate on behalf of those with lung disease
- Raise money to support research

With regard to the Terms of Reference of this committee, it is the Lung Foundation's view that, for people diagnosed with lung cancer, the issue is *even more fundamental* than specific deficiencies in the current funding model for research. The intersection of the **stigmatisation** of lung cancer, **lack of a national programme** for early detection, **inconsistent access** to best practice models of care and a **chronically low level of research funding** have created a situation where, today, more Australians are dying from lung cancer than breast, prostate and ovarian cancer combined.

Lung cancer is a significant cause of ill health and early death in Australia. Lung cancer is not rare and in 2016 it was estimated that more than 12,000 new cases were diagnosed. Compounding this, lung cancer is Australia's biggest cancer killer – lung cancer kills more Australians than any other cancer. The outlook for a person diagnosed with lung cancer is extremely poor, with only 15% of all those diagnosed with lung cancer still alive after 5 years – this figure drops to 1 in 100 for those diagnosed with lung cancer that is at an advanced stage. For Aboriginal and Torres Strait Islanders, 5 year survival is only 7%.



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The Lung Foundation has been working with stakeholders to improve outcomes for Australians with lung cancer and, in 2016, published the report "Improving outcomes for Australians with lung cancer. A Call to Action." A copy is included in this submission for the Committee's consideration.

The report discusses four key areas for action:

- Raise the profile and reduce the stigma of lung cancer
- Prioritise early detection efforts where cure is most likely to be achieved
- Improve access to best practice care for all patients with lung cancer
- Increase research funding for lung cancer

With respect to the question of research, it is clearly understood that sustained investment and focused research have contributed to significantly improved survival rates in other cancers – to 90% for breast, 94% for prostate and 43% for ovarian cancer. By comparison, investment in lung cancer research and, consequently, improvements in lung cancer survival rates have, to date, been woeful. Between 2009 and 2011, while lung cancer accounted for three times as many deaths as breast cancer lung cancer, research funding was one-fifth that of breast cancer research. The result is that, while in 1968 lung cancer caused 32 deaths per 100,000 of our population, in 2013 it caused 31 deaths per 100,000.

Lung Foundation Australia has made a significant contribution towards increased research for lung cancer through a number of ongoing initiatives:

- Annual awards for lung cancer research since 2006
- Establishing the Australasian Lung Cancer Trials Group (ALTG) in 2004 to support investigator-led clinical trials; and in 2015 supporting the ALTG to establish a worldwide network for clinical trials in lung cancer, the Thoracic Alliance for Cancer Trials (TACT)
- The annual Shine A Light on Lung Cancer campaign to raise awareness and funds for lung cancer research
- Lungs for Life – a broad research collaboration with the Thoracic Society of Australia and New Zealand (TSANZ) with lung cancer as one of its three priorities

We are proud of our efforts to date but it is not enough. Lung cancer continues to cause a disproportionate amount of suffering and cost in Australia and this must change. It is our view that only by addressing the four areas identified in the attached report, systematically and through a concerted effort, will we see a meaningful lessening of the burden of health posed by lung cancer.

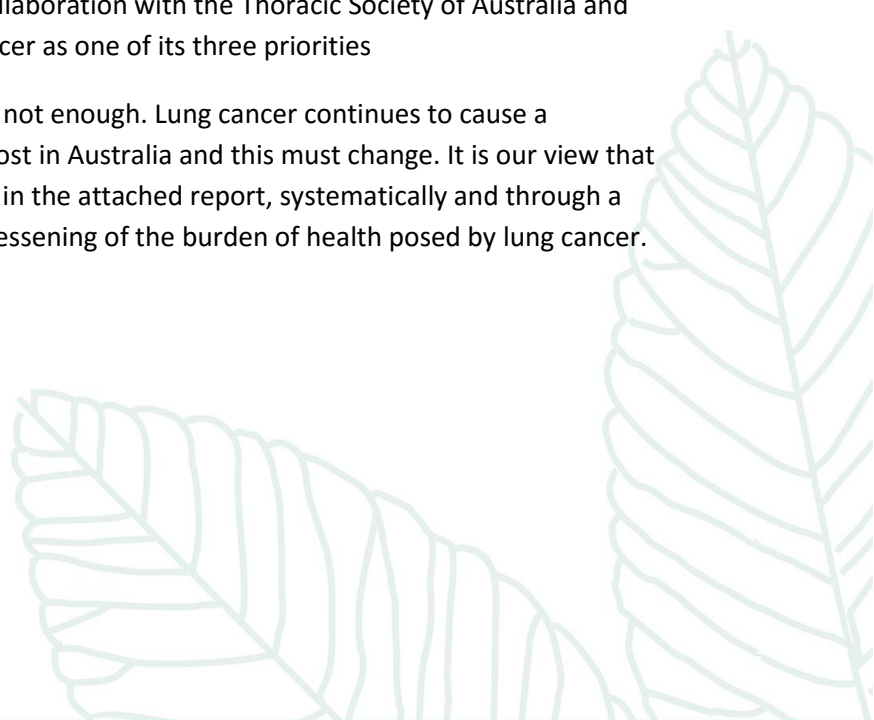
Kind regards

Heather Allan
Chief Executive Officer



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Improving outcomes for Australians with lung cancer

A Call to Action



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Disclosures

- David Ball has participated in Advisory Boards for Boehringer Ingelheim (with payment to his institution) since 2014 and has received travel support from IBA Proton Therapy.
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- Kwun Fong has participated at conferences and educational meetings where travel reimbursement has been partly or wholly provided by Industry; organised and attended professional meetings including those run by the Thoracic Society of Australia and New Zealand, Asia-Pacific Society of Respiriology, the Australian Lung Cancer Conference; and is Chair of the Lung Foundation Australia Lung Cancer Consultative Group.

Foreword

Lung Foundation Australia is the only national charity dedicated to supporting anyone with a lung disease and our vision is to ensure lung health is a priority for all in Australia. Lung cancer places a heavy burden on our community and this report reflects our emphasis on promoting lung health, early diagnosis, equitable access to care, funding of quality research and, above all, support for those with lung disease, their families and carers.

Lung cancer is a major global health problem. The World Health Organisation's GLOBOCAN database estimated there were 1.83 million new cases and 1.59 million deaths from lung cancer in 2012, making it the biggest cause of cancer deaths worldwide¹. Australians are not spared from this awful disease – lung cancer kills more Australians each year than any other cancer. While effective tobacco control remains the keystone of lung cancer elimination, for the first time there is a growing range of interventions that are likely to benefit people who are either at risk of, or diagnosed with, lung cancer.

This report highlights opportunities to change the face of lung cancer in Australia; we can each play our part from practice to policy, from research to implementation, from individuals to organisations. Together we can make change happen and help the many at risk and affected by this disease, so that it can become the rare disease that it was a century ago.

Christine Jenkins
Board Chair, Lung Foundation Australia

Kwun Fong
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- Members of the Occupational and Environmental Lung Disease Special Interest Group of the Thoracic Society of Australia and New Zealand (TSANZ)
- Consumers whose stories and experiences are featured throughout

Executive Summary

Lung cancer is a common and deadly disease in Australia today. In 2016 it is estimated that more than 12,000 Australians will be diagnosed with lung cancer and almost 9,000 will lose their lives to the disease². Lung cancer is Australia's biggest cancer killer, causing almost 20% of all cancer deaths², and more than breast³, prostate⁴ and ovarian⁵ cancer combined. The outlook for patients with lung cancer is poor, with only a 15% chance of surviving for five years after diagnosis² and, for patients diagnosed with advanced disease, this drops to 1 in 100⁶. People in rural, remote and Indigenous communities are at even greater risk of being diagnosed with, and dying from, lung cancer^{7,8}.

Fortunately, the landscape for the management of lung cancer is changing rapidly as advances in research and technological developments bring new hope through novel screening, diagnostic and treatment approaches. However, the experience of patients with lung cancer is one of a forgotten disease characterised by low public awareness and negative stereotypes contributing to delays in diagnosis, lack of support systems and inequitable access to best practice and new treatment approaches.

We must act now.

Lung Foundation Australia has identified four areas where some of the most significant obstacles facing patients with lung cancer must be addressed:

- **Raise the profile and reduce the stigma** of lung cancer.
- **Prioritise early detection efforts** where cure is most likely to be achieved, including identifying and implementing an effective national screening strategy.
- **Improve access to best practice care** for people with lung cancer whoever they are and wherever they live.
- **Increase research funding** targeted to lung cancer to improve health outcomes.

Stigma and awareness

Parallels have been drawn between lung cancer and other highly stigmatised conditions such as mental illness, HIV/AIDS and obesity^{9,10}. Stigma in lung cancer is evident among healthcare professionals and the general public¹¹, as well as patients with lung cancer, and has significant individual and societal consequences¹². Patients with lung cancer delay seeking help or stop treatment early¹²; or may not be referred for specialist management^{13,14}; and there is little public sympathy or support through volunteering, donations or advocacy for greater awareness and research funding of lung cancer^{9,10}. In a survey of attitudes towards people with lung cancer, Australians had the least sympathy of all of the 15 nationalities surveyed¹⁵.

The earlier lung cancer is detected, the greater the chance of successful treatment and possible cure¹⁶. The symptoms of lung cancer are difficult to distinguish from other respiratory conditions¹⁷ and may be overlooked. Public awareness campaigns and primary care are crucial in diagnosing lung cancer earlier and referring

patients for further investigation as quickly as possible. Persistent symptoms, especially in people with risk factors, must be urgently investigated – a cough that lasts for three weeks should prompt further investigation^{17,18}.

National screening strategy

Screening is the best opportunity to reduce deaths from lung cancer. The 20% reduction in lung cancer deaths reported in screening trials¹⁹ is larger than any new treatment for lung cancer to date²⁰. However, while screening is recommended by professional groups worldwide^{21,22} and has been implemented, with Medicare funding, in the US^{23,24}, it is not currently recommended in Australia²⁵. There is an urgent need and an important opportunity for government to rapidly implement an appropriate screening programme for lung cancer in Australia.

Access to care

Lung cancer diagnosis and management is becoming increasingly sophisticated and patients with lung cancer need timely access to the appropriate expertise for each stage of their journey²⁶. Australian guidelines highlight the need for rapid referral of patients with suspected or proven lung cancer to a hospital and specialist linked with a lung cancer multi-disciplinary team (MDT), as the standard of care for all lung cancer patients^{17,27,28}. MDTs need clear and readily accessible referral pathways – including outreach services – and the right capabilities, resources and processes to provide best practice care from diagnosis, through initial treatment and beyond²⁶. The Australian network of dedicated lung MDT services offers an important opportunity to systematically address variations in care¹⁷.





Access to effective medicines

Regulatory and reimbursement processes also need to keep pace with the rapid advances in scientific research in lung cancer. Lung cancer is emerging as a model of precision, or personalised, medicine, in which treatment decisions are individually tailored to the patient¹⁶. Precision medicine is particularly relevant to choices about use of innovative new medicines for lung cancer; however, most patients cannot afford to wait and the quality of their care is negatively impacted when the appropriate course of treatment for their situation is either not yet available or is not subsidised by the Pharmaceutical Benefits Scheme in Australia²⁹. Unlike the US and

Europe, Australia has no process to expedite review of critical or breakthrough medicines for either regulatory or reimbursement approval²⁹. Submissions to the Australian Therapeutic Goods Administration for approval of cancer medicines lag almost six months behind the US and Europe and reimbursement decisions, requiring repeated submissions, take on average approximately 3 years²⁹. Pathways for patients with lung cancer to access non-approved or non-reimbursed treatments are available, including clinical trials; however there are clear limitations to each³⁰.

Research funding

Research offers hope and the benefits of research for improving outcomes in cancer are undisputed. Funding for research needs to keep pace with gains in scientific knowledge so that patients with lung cancer are not left behind. In the past 25 years, sustained investment in research in Australia has resulted in remarkable improvements for some cancers, but thus far not lung cancer. Despite causing the largest number of cancer deaths, lung cancer receives less than five cents of every cancer research dollar³⁰. Achieving improvements in lung cancer outcomes requires a similar commitment to research as has been made for other commonly diagnosed cancers.

With the publication of this report, Lung Foundation Australia calls on funders, policy makers, clinicians, other stakeholders and the wider community to help us improve outcomes for those who are currently battling lung cancer and for those who will be diagnosed with lung cancer in years to come.



Calls to Action

Raise the profile and reduce the stigma of lung cancer

Lung cancer doesn't discriminate and neither should we. We need to challenge the stereotypes that surround lung cancer and raise awareness of its human impact, to ensure equitable and compassionate care for all patients with lung cancer.

- Government to fund public health campaigns that: raise awareness about the seriousness of lung cancer and its impact on our community; discourage smoking without demonising the person; and encourage smokers to seek medical help early without fear of discrimination.
- Community leaders, the media and celebrities to lend their voice and support to challenge the stereotypes surrounding lung cancer.

Prioritise early detection efforts where cure is most likely to be achieved

The health burden of lung cancer in Australia will only be reduced through early diagnosis and action on screening. Primary care is critical in helping identify patients with the earliest symptoms or signs of lung cancer; and screening is the best opportunity we have to reduce deaths from lung cancer.

- Government to fund a national public and healthcare professional symptom awareness campaign based on Lung Foundation Australia's Lung Health Checklist and focused on the importance of cough as a symptom.
- Healthcare professionals to place a higher priority on considering lung cancer when assessing patients with symptoms – particularly cough.
- Government to rapidly implement a national screening strategy.

Improve access to best practice care for all patients with lung cancer

Improving outcomes for patients with lung cancer requires ensuring all patients have early access to specialised care services, whoever they are and wherever they live. Modernisation of the regulatory and reimbursement system must be a priority today; otherwise we will never be able to provide the best treatments for the patients of tomorrow.

- Cancer Australia to disseminate learnings from the Lung Cancer Demonstration Project, including clear minimum standards, to national lung multi-disciplinary teams (MDTs) in order to address variations in care.
- Government to improve access to new treatments for high mortality cancers, including lung cancer, through more flexible and efficient regulatory and reimbursement processes.
- Government, manufacturers and healthcare professionals to improve access to clinical trials:
 - Government to advocate for and fund more clinical research in Australia.
 - Manufacturers to open more study sites in Australia.
 - Healthcare professionals to ensure all options are identified and considered, for all patients with lung cancer, to participate in a clinical trial.

Increase research funding for lung cancer

Research offers hope, whether for a cure or improvement in quality of life. The benefits of research on improving outcomes in cancer are undisputed and improved survival rates for other commonly diagnosed cancers have been achieved through a consistent commitment to research. Investing in research dedicated to lung cancer will level the playing field.

- Government to establish a dedicated fund for lung cancer to increase research funding to \$20 million, per year, by 2020.
- Philanthropic community to establish specific targets for donations to lung cancer research.

Lung Foundation Australia Commitments

- Continue programmes to educate and raise awareness about lung cancer; and support patients, families and carers.
- Work with primary health networks and lung multi-disciplinary teams (MDTs) to develop and deliver training for primary care on recognition of lung cancer risk, investigations and referral pathways to MDTs with effective outreach networks.
- Continue to raise funds and invest in lung cancer research.

Facts about lung cancer

- Lung cancer kills more Australians every year than any other cancer – in 2016 it's estimated that the equivalent of 25 people each day will die from lung cancer².
- YET there is no screening programme in Australia to detect lung cancer.
- AND less than five cents of every cancer research dollar in Australia goes to lung cancer³⁰.
- Lung cancer is more common in men than women – in 2016 there will be an estimated 7,130 new cases in men and 5,073 in women².
- The risk of developing lung cancer increases with age².
- Indigenous Australians are 1.7 times more likely to develop and die from lung cancer than non-indigenous Australians^{8,34}.
- The biggest risk factor for lung cancer is exposure to tobacco smoke, however one in three women and one in ten men diagnosed with lung cancer will have never smoked and this proportion has increased over time³¹.
- Other risk factors for lung cancer include exposure to dust, gas, fumes and asbestos³² – occupational exposure is estimated to contribute to 29% of lung cancer in men and 5.3% in women³³.
- The outlook for a person diagnosed with lung cancer is extremely poor. 15% will live for 5 years while only 1 in 100 of those diagnosed with advanced lung cancer will live this long^{2,6}.
- The likelihood of an Aboriginal and Torres Strait Islander diagnosed with lung cancer living for 5 years is only 7%³⁴.

Introduction

Lung cancer is common and deadly

In 2016 it is estimated that more than 12,000 Australians will be diagnosed with lung cancer and almost 9,000 will lose their lives to the disease². One of every ten new cancer cases in Australia is lung cancer, making it the fifth most commonly diagnosed cancer in the country². Especially high rates of new lung cancer diagnosis are seen in very remote and inner regional areas of Australia⁷, while Aboriginal and Torres Strait Islander Australians are 1.7 times more likely to develop lung cancer than non-Indigenous Australians^{7,8}.

Lung cancer is Australia's biggest cancer killer. It causes almost 20% of all cancer deaths, which is more than breast, prostate and ovarian cancer combined^{2,3,4,5}. The highest death rates from lung cancer are seen in very remote communities⁷ while Aboriginal and Torres Strait Islander Australians are 1.7 times more likely to die from lung cancer than non-Indigenous Australians³⁴.

The biggest risk factor for lung cancer is exposure to tobacco smoke, however one in three women and one in ten men diagnosed with lung cancer will have never smoked and this proportion has increased over time³¹. Other risk factors for lung cancer include exposure to dust, gas, fumes and asbestos³² – occupational exposure is estimated to contribute to 29% of lung cancer in men and 5.3% in women³³.

Lung cancer survival lags behind other cancers

The overall chance of living at least 5 years following a lung cancer diagnosis is 15% while for those diagnosed at an advanced stage it is just 1 in 100^{2,6}; and for Aboriginal and Torres Strait Islanders 5 year survival is only 7%³⁴. With sustained investment and focused research, survival rates for other cancers have improved dramatically in the past 25 years – to 90% for breast³, 94% for prostate⁴ and 43% for ovarian cancer⁵. By comparison, investment in lung cancer research and, consequently, improvements in lung cancer survival rates have, to date, been woeful: in 1968 lung cancer caused 32 deaths per 100,000 of our population and in 2013 it caused 31 deaths per 100,000².

Lung cancer can be prevented, diagnosed and treated

Fortunately, the landscape for the management of lung cancer is changing rapidly. Advances in research and technological developments are bringing new hope, with the emergence of techniques for screening, new diagnostic testing, minimally invasive surgery, refinements in radiation treatment and innovative new medicines¹⁶. Cancer Australia, the national cancer control agency, specifically identified "Best practice care for Australians with lung cancer" as a goal in its 2014-2019 strategic plan³⁵.

Stigma persists

Yet the experience of patients with lung cancer in Australia is one of a forgotten disease, with low public awareness and negative stereotypes contributing to delays in diagnosis, lack of support systems, and inequitable access to best practice and new treatment approaches based on geography.

1 Raise the profile and reduce the stigma of lung cancer

Lung cancer patients experience stigma

The link between lung cancer and tobacco smoking – including public health campaigns to discourage smoking – has led to negative associations and attitudes about lung cancer and towards people with the disease. Patients with lung cancer report feelings of guilt and shame, contributing to a sense they are somehow less worthy¹². Discrimination or the fear of discrimination leads to feeling alienated, fearful or undeserving¹²; and the fear that symptoms might not be taken seriously leads to delays in seeking diagnosis and treatment¹².

The stigma associated with lung cancer and the effect it has on patients' experience and treatment has been likened to other highly stigmatised conditions such as mental illness, HIV/AIDS and obesity^{9,10}. However, while there have been effective campaigns to reduce social stigma and thereby improve diagnosis and treatment of HIV/AIDS and mental illness, this has not been the case for lung cancer³⁶.

These negative associations are found among culturally and linguistically diverse groups within the Australian population³⁷, including the Indigenous community where it is seen as a death sentence, punishment, curse or payback³⁸.

While tobacco smoking is the largest single cause of lung cancer, one in three women and one in ten men diagnosed with lung cancer will have never smoked; this proportion has increased over time². Occupational exposure is estimated to contribute to 29% of lung cancer in men and 5.3% in women³³.

The issue of stigma is not limited to patients. Healthcare professionals' (HCPs) attitudes are as negative as those of patients, caregivers and members of the general public¹¹; and HCPs also underestimate survival rates for different stages of lung cancer and the likely benefit of chemotherapy^{12,39}. Up to 11% of patients diagnosed with lung cancer were not referred for specialist management and as many as 33% did not receive cancer-specific treatment^{13,14}.

"I cough 20 hours a day. It's frustrating, it's exhausting, it's debilitating. What the cough isn't – is contagious. Upon hearing me cough uncontrollably, many around me assume that it is (contagious), leading to uncomfortable stares, nasty looks and judgemental comments. I was waiting in a line and I was coughing and a woman commented "Hurry up, hope you don't die in here!" I couldn't believe it. I left in tears. I wanted to say to her "I'm not contagious, I've got cancer", but I hate having to justify myself all the time. I shouldn't have to."

Jodie

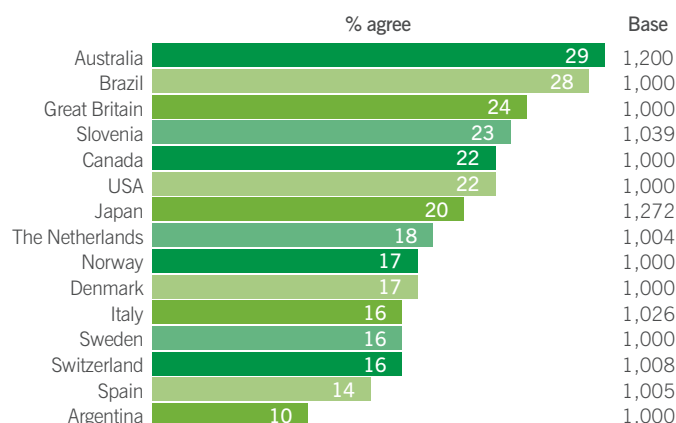
"Whenever I tell someone that I've been diagnosed with lung cancer, the usual response is rarely "I'm so sorry to hear". Most people's first reaction is to ask about my smoking history."

Lillian

The experience of patients is mirrored by public attitudes. In a global survey conducted in 15 countries Australians had the least sympathy for someone diagnosed with lung cancer, compared with other cancers, based on its association with tobacco smoking¹⁵ (Figure 1).

Figure 1: Lung cancer is mainly caused by smoking cigarettes and other tobacco products. Bearing this in mind, to what extent do you agree or disagree with the following statement...

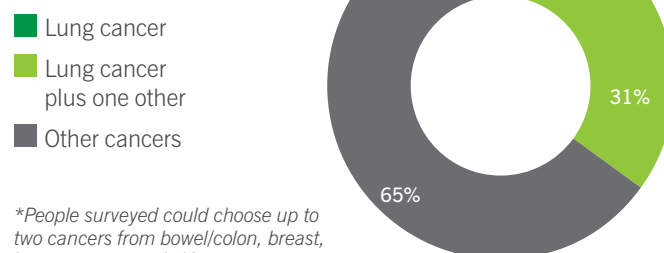
I have less sympathy for people with lung cancer than people with other types of cancer.



Source: Ipsos MORI

Low awareness of the problem compounds the situation: only 35% of those surveyed nominated lung cancer as the cause of most cancer deaths in Australia while 65% did not select lung cancer at all¹⁵ (Figure 2).

Figure 2: Which cancer do you think kills the most people in your country?*



*People surveyed could choose up to two cancers from bowel/colon, breast, lung, prostate and skin cancer.

“Stigma in lung cancer is huge. It doesn't only affect patients and hinder the efforts of clinicians. It translates into a lack of action in public policy, research and advocacy. It's hard to believe that Australia's biggest cancer killer receives less research and clinical trial funding than other cancers. Unfortunately, celebrities and community leaders also seem reluctant to step up as champions for the people affected by this stigmatised disease. Lung Foundation Australia is working hard to bridge these gaps and advocate for patients with lung cancer but our efforts are also hampered by these negative attitudes.”

Heather Allan, CEO, Lung Foundation Australia

Stigma has a broad impact

The individual impact of these prevailing negative attitudes is well documented. Patients with lung cancer delay seeking help, stop treatment early and experience significant psychological and social consequences¹². These include depression, lower self-esteem, lower social support, poorer social integration and higher social conflict¹², compounding the physical, social and psychological pressures associated with a diagnosis of lung cancer and treatment⁴⁰.

In addition to the individual impact there is a broader social one that manifests as relatively poor public support for lung cancer and research funding. In a 2008 US survey, only 9% of respondents supported a lung cancer organisation through volunteering or donating money; and only 12% identified lung cancer as their first preference to receive additional research funding^{9,10}. In contrast, 19% supported breast cancer organisations and 25% selected breast cancer to receive stronger research funding^{9,10}.

“It's not only the negative stereotypes associated with lung cancer that make it hard for patients to have a voice. Compared with other commonly diagnosed cancers – and breast cancer is the one most people think of – there are so few people who are living well enough, for long enough, with lung cancer to develop a strong and united voice. It takes time for messages to get through.”

Glenda Colburn, Director - Lung Cancer National Program, Lung Foundation Australia

Changing the Face of Lung Cancer

On World Cancer Day 2016 (February 4) Lung Foundation Australia launched a campaign through social media and a public event in Sydney to raise awareness of lung cancer, challenge the prevailing stereotypes and encourage people to undertake the Lung Foundation's "lung health checklist".

Stories from lung cancer patients and survivors across Australia were featured in the campaign, sharing experiences and advocating for all Australians to recognise that lung cancer is a disease that can affect anyone, anytime.

An estimated 350,000 people across Australia were reached through this campaign.



Call to action: Raise the profile and reduce the stigma of lung cancer

Lung cancer doesn't discriminate and neither should we. We need to challenge the stereotypes that surround lung cancer and raise awareness of its human impact, to ensure equitable and compassionate care for all patients with lung cancer.

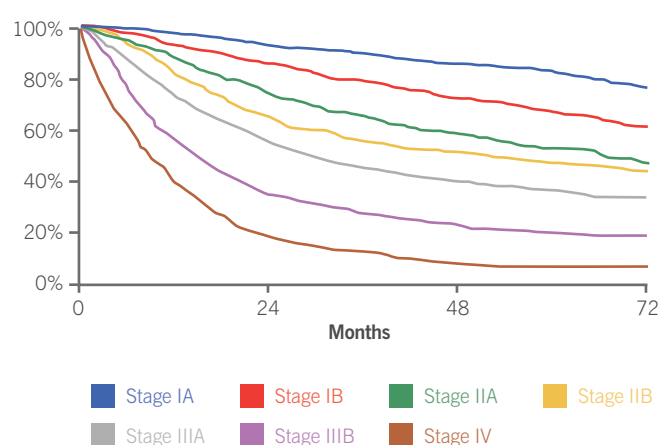
- Government to fund public health campaigns that: raise awareness about the seriousness of lung cancer and its impact on our community; discourage smoking without demonising the person; and encourage smokers to seek medical help early without fear of discrimination.
- Community leaders, the media and celebrities to lend their voice and support to challenge the stereotypes surrounding lung cancer.

2 Prioritise early detection efforts where cure is most likely to be achieved, including identifying and implementing an effective national screening strategy

Early detection saves lives

The earlier lung cancer is detected, the greater the chance of successful treatment and possible cure. Survival rates are best for people diagnosed with lung cancer at an early stage and worst for those diagnosed at a late stage¹⁶ (Figure 3).

Figure 3: Overall survival by clinical stage



Among the Indigenous community, diagnosis at a later stage and poorer access to healthcare services are believed to be responsible for a higher mortality rate compared with the non-Indigenous community⁴¹.

The role of primary care is crucial in identifying lung cancer earlier and an evidence-based guide for GPs to support investigating symptoms of lung cancer, with recommendations for referral and patient support, has been in place since 2012¹⁸.

Awareness of symptoms is key to early diagnosis

Most lung cancers are diagnosed at an advanced stage^{31,42}. Lung cancer is difficult to diagnose early because symptoms are difficult to distinguish from other illnesses. These include cough (sometimes with blood), breathlessness, chest pain, fatigue or unexplained weight loss¹⁷. For patients with few or no risk factors for lung cancer, the challenge is even greater for a GP to link a symptom like persistent cough to the possibility of lung cancer.

Persistent symptoms, especially in people with risk factors, must be urgently investigated. Australian guidelines state that a cough lasting for three weeks should prompt further investigation^{17,18}.

“Through our confidential telephone service I have supported nearly 150 patients with lung cancer and family members in the past 12 months. Some of these callers have had the experience of being treated for a symptom such as cough for longer than three weeks before eventually being diagnosed with lung cancer. For some people, there was a significant delay – one patient was treated for pneumonia for two months before being referred. This was a young woman who had never smoked so she certainly didn’t fit the “stereotype” for lung cancer – unfortunately the only real possibility for her cancer to have been detected earlier was if her doctor’s suspicions had been raised when the first – or even second – course of antibiotics didn’t resolve her symptoms.”

Claire Mulvihill, Lung Cancer Support Nurse,
Lung Foundation Australia

“After a very bad case of the ‘flu, a hospital specialist suggested I get a CT scan, to check I had not damaged my lungs. My GP ordered the scan and there was a lump. I had lost quite a bit of weight but the specialist said I need not worry, as I had never smoked and was quite healthy. After two more scans to check over 6 months, I got a second opinion and they found it was lung cancer! I was lucky it was still Stage 1 – I had an operation and after 13 years am still cancer-free. A lucky find and a second opinion: you can cure lung cancer if it’s found early.”

Sue

Screening saves lives

Screening detects disease in people who have not yet been diagnosed – either because they do not have any symptoms or have symptoms that have not been recognised. Organised cancer screening programs reduce illness from cancer and save lives. On this basis national screening programs to detect breast, bowel and cervical cancer have been implemented in Australia with confirmed reductions in mortality and diagnosis at earlier stages of disease^{43,44,45}.

Five years ago the US National Lung Screening Trial showed that screening for lung cancer can save lives¹⁹. Screening of people considered at particular risk of lung cancer is recommended by professional groups including the International Association for the Study of Lung Cancer (IASLC)²¹ and the United States Preventive Services Task Force (USPSTF)²²; and has been implemented in the US, with funding by Medicare^{23,24}. The use of low-dose computed tomography (LDCT) minimises exposure to radiation and a recent UK study has demonstrated that it is possible to design a cost-effective lung cancer screening programme, with the majority of the lung cancers detected at a stage where treatment would be potentially curative⁴⁶.

The US National Lung Cancer Screening Trial reported a 20% reduction in mortality from lung cancer as a result of screening with low-dose computed tomography (LDCT) scans¹⁹. There is no new treatment that can reduce lung cancer mortality by this amount²⁰.

Developing a national screening program must be a priority

Lung cancer screening is not currently recommended in Australia; the Standing Committee on Screening has stated that current evidence does not support screening, either for the general population or high risk groups; and that the evidence for lung cancer screening will be evaluated as it emerges²⁵.

There is both an urgent need and an important opportunity for government to play an active part in defining the appropriate approach to screening for lung cancer in Australia.

Call to action: Prioritise early detection efforts where cure is most likely to be achieved.

The health burden of lung cancer in Australia will only be reduced through early diagnosis and action on screening. Primary care is critical in helping identify patients with the earliest symptoms or signs of lung cancer; and screening is the best opportunity we have to reduce deaths from lung cancer.

- Government to fund a national public and healthcare professional symptom awareness campaign based on Lung Foundation Australia's Lung Health Checklist and focused on the importance of cough as a symptom.
- Healthcare professionals to place a higher priority on considering lung cancer when assessing patients with symptoms – particularly cough.
- Government to rapidly implement a national screening strategy.

3 Improve access to best practice care for people with lung cancer whoever they are and wherever they live

Best practice is evolving rapidly

Lung cancer treatment is becoming increasingly sophisticated and complex with: new diagnostic approaches and genetic testing of tumour samples; minimally invasive surgical techniques; precisely targeted radiation treatment; and innovative medicines¹⁶.

Patients with lung cancer need access at the right time to people with the right expertise, at each stage of their journey, ensuring all of the different diagnostic and treatment approaches are available when needed. These may be well-established as the “standard of care” or relatively unproven or experimental – the burden of illness posed by lung cancer on the individual and on our community demands that all avenues are investigated.

Cancer Australia’s principles for best practice management of lung cancer in Australia (2014)²⁶.

Principle 1: Patient-centred care

The patient with lung cancer and their carer(s) are the focus of best practice lung cancer care.

Principle 2: Timely access to evidence-based pathways of care

Best practice pathways are in place to support timely diagnosis and staging of lung cancer; and appropriate treatment, supportive, follow-up and palliative care are in place.

Principle 3: Multidisciplinary care

Multidisciplinary care is the standard of care for all lung cancer patients.

Principle 4: Coordination, communication and continuity of care

All relevant health professionals, including GPs, provide coordinated delivery of care across the lung cancer continuum of care.

Principle 5: Data-driven improvements in lung cancer care

Lung cancer data are collected, monitored and reviewed regularly to support continuous improvement in the delivery of best practice lung cancer care.

Importance of multi-disciplinary care

Australian guidelines highlight the need for rapid referral of patients with suspected or proven lung cancer to a hospital and specialist linked with a lung cancer multi-disciplinary team (MDT) service^{17,28}.

A range of health professionals, often across different delivery settings, are involved in caring for people with lung cancer. As well as expert opinions to determine and carry out best practice treatment plans, the accompanying effects of treatment need to be managed. These may include pulmonary rehabilitation to improve residual lung function after surgery; support to address the psychosocial impact of diagnosis and treatment; practical services to support daily functioning; and referral to palliative care services.

The MDT approach is the standard of care in cancer management and has been shown to improve survival, quality of life, delivery of best practice care in line with evidence-based guidelines, coordination of care, provision of information, support for patients and patient satisfaction^{17,27}.

Access to best practice

While the value of the MDT model of care is recognised, there are challenges for ensuring patients are managed optimally within this system. First, referral pathways need to be clear and readily accessible so that all patients with proven or suspected lung cancer are directed to a dedicated lung cancer MDT. Second, MDTs must be “fit for purpose” i.e. hospitals and MDT members have the right capabilities, resources and processes in place.

In June 2016, Lung Foundation Australia launched the first Australian directory of dedicated lung cancer MDTs. This online resource enables a referring clinician to locate lung cancer MDTs, summarises information about the available diagnostic and treatment services and, where available, links to the MDT’s referral pathway. The launch version of the MDT Directory listed 60 services and while the driving force behind referral to an MDT is common – improving outcomes through the provision of best practice care – no two MDTs are alike.

The Australian Lung Cancer Multi-Disciplinary Teams Directory⁴⁷

Features of the 60 MDTs identified:

Formal referral pathway for patients with lung cancer

40

Dedicated lung cancer clinic

18

Dedicated cancer care coordinator or lung cancer nurse*

29

EBUS*

42

10

PET* scanning

33

25

Thoracic surgery

38

10

SABR*

24

8

All of the above

11

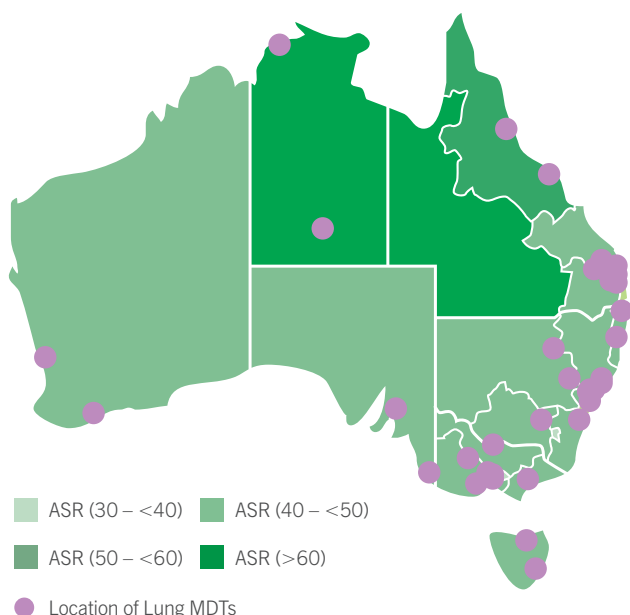
■ Directly ■ Indirectly

* PET – positron emission tomography; EBUS – endobronchial ultrasound; SABR – stereotactic ablative radiotherapy – are technologies for diagnosing, assessing the extent and treating lung cancer; “dedicated” is defined as at least 50% of staff time focused on lung cancer.

MDTs are primarily located in the south-eastern states and urban centres of the country, while the incidence of lung cancer is particularly high in the Northern Territory and Western Queensland Primary Health Networks (Figure 4). Linking patients to MDTs with significant experience gained from treating large numbers of patients, rather than increasing the number or geographic distribution of MDTs, will ensure best practice care.

Importantly, the existence of this national network of dedicated lung cancer MDTs presents an important opportunity to systematically address variations in care¹⁷.

Figure 4: Lung Cancer Incidence (Age-Standardised Rate, ASR) by Primary Health Network⁴⁸ and Location of Lung MDTs (at June 2016)⁴⁷



“Don’t be afraid to ask for a second medical opinion. If nothing else it may give you extra confidence with the doctor you are already dealing with. Most importantly, get yourself under the care of a multi-disciplinary team (MDT) specialising in lung cancer. Now that I’m under the care of a dedicated lung cancer MDT, my new medical oncologist recommended a clinical trial to me. One year on, I am still here and feeling very well, with only minor side effects. My scans continue to show a huge reduction in tumour sizes. I have had wonderful support from my family from day one. I know I can always rely on them, no matter what. But honestly, I’ve found it a very lonely journey. I now know I can get counselling help through my MDT.”

Marilyn

“Our hospital offers a dedicated lung cancer MDT which aims to improve patient care and outcomes through the development of an agreed treatment plan. As a specialised Lung Cancer Nurse Coordinator I am involved in the nursing care of our patients with lung cancer in all treatment areas and am an integral part of the MDT. I am an expert point of contact for our patients, providing both psychosocial and clinical support. My experience after 14 years in this field is that supporting patients with lung cancer to receive coordinated care is not only the best way to care for them but is also greatly appreciated by our patients, their families and carers.”

Mary Duffy, Lung Cancer Nurse Coordinator

Cancer Australia’s Lung Cancer Demonstration Project initiative was launched in 2014 within four health service collaborations in New South Wales, Queensland, Tasmania and Western Australia. The objectives of this project are to demonstrate lung cancer care delivery according to the “Principles of best practice management for lung cancer” and to identify key factors that contribute to ongoing delivery of best practice lung cancer care for national application⁴⁹.

Support for the whole journey

Patients with lung cancer and their families need support throughout their whole journey from diagnosis, through initial treatment and beyond²⁶. As well as treating the underlying lung cancer, supportive and palliative care services play an important role²⁶. Patients with lung cancer experience the highest level of psychosocial distress among cancer patients and are frequently affected by other health conditions that create not only physical symptoms but also have social, psychological and quality of life impacts⁵⁰.

As outcomes improve survivorship care – support for patients to “live with lung cancer” as a chronic disease – is becoming increasingly important. For some patients, depression and anxiety are a reality that stays with them long beyond treatment. Many disease-free cancer survivors experience some degree of anxiety over the possibility of a cancer recurrence, feeling their future may be cut short, while others experience “survivor guilt”⁵¹ as well as physical, interpersonal and financial repercussions⁵².

“Some days, I treat advanced lung cancer as a chronic disease. Other days, I recall the feeling I felt when I found out that the average life expectancy for my stage of disease is less than a year. While I feel blessed to be alive almost two years on, it can be a lonely journey.”

Lillian

Access to new medicines

Significant advances in lung cancer management have been achieved through the development of innovative drugs and the use of precision medicine, for which lung cancer is emerging as a “role model”¹⁶.

Precision medicine uses information from a patient's particular situation, such as diagnostic testing on a sample of tumour or previous response to other treatments, to make decisions that are individually tailored to the patient¹⁶.

Targeted therapies are medicines that block the growth and spread of cancer by interfering with specific “molecular targets” that are involved in the growth, progression, and spread of cancer. Examples of targeted therapies used to treat lung cancer include drugs that block the epidermal growth factor receptor (EGFR) or act on tumours with a mutation in the Anaplastic Lymphoma Receptor Tyrosine Kinase (ALK) gene⁵³.

Immunotherapies trigger the immune system to destroy cancer cells. In lung cancer, these are represented by new medicines known as “checkpoint inhibitors”⁵³.

Regulatory and reimbursement processes need to keep pace with the rapid advances in scientific research in lung cancer²⁹.

During 2009-2014, submissions to the Australian Therapeutic Goods Administration (TGA) for approval of cancer medicines were significantly later – by an average of 38 weeks – than in the US and Europe, leading to the later availability of new medicines for patients in Australia compared with overseas.

Unlike the US and Europe, Australia has no process to expedite review of critical or breakthrough medicines for either regulatory or reimbursement approval.

Based on standard TGA and PBS process timelines, review of a single submission for approval and reimbursement takes between 7 and 18 months.

For reimbursement applications, the time for review and listing on the PBS is 17 weeks – however, few applications receive approval first time and cancer medicines require an average of 2.3 submissions to obtain a positive reimbursement decision – this equates to approximately 3 years.

For some this potentially means cure, for others improved quality of life (by selecting treatments with fewer side effects), and for others still the prospect of living with cancer long-term, as a chronic disease. However, for people with an immediately life-threatening condition like lung cancer, precision medicine is only helpful when the selected treatments are available and affordable within a short timeframe.

A recent inquiry by the Australian Senate Community Affairs References Committee into the availability of new, innovative and specialist cancer drugs in Australia²⁹ heard that, for cancer patients, timely, affordable access to treatments is linked to quality of care. Most patients cannot afford to wait and the quality of cancer care is negatively impacted when the appropriate course of treatment for a patient's cancer profile is either not available in Australia or is not subsidised by the Pharmaceutical Benefits Scheme (PBS). Relatively inflexible processes, particularly the need for repeated submissions and the inability to evaluate submissions for the same drug in more than one disease indication at a time, contribute to delays in both approval and reimbursement.

There appears to be a vicious cycle in which, on the one hand, manufacturers cite a poor business case (due in part to long approval and reimbursement timelines) as the reason for placing a lower priority on filing new medicines in Australia; while on the other, regulatory and reimbursement authorities view decisions by manufacturers on the timing of submissions as commercial and beyond their control.

While precision medicine is helping to identify more subgroups of patients whose lung cancer is likely to respond well to specific, innovative treatments, within each subgroup there are fewer patients and therefore a weaker business case.

Patients with lung cancer and their families experience financial, physical, emotional and psychological burdens as they wait for new medicines to be available⁵⁴. Often they have to take their care into their own hands, paying significant amounts of money to ensure the best possible care⁵⁴. Delays in reimbursement also limit a doctor's ability to deliver the best possible care to Australian cancer patients⁵⁴.

“You have to be rich to have cancer! The financial burden on my whole family has been significant. Our cost of living has markedly increased. Not only am I unable to work, but my husband (who is now also my carer) has needed time off work to assist. Then there are the additional day-to-day home and medical expenses added to our overall cost of living. It would be an understatement to say life is tough.”

Lisa

“Timely access to new drugs that can improve quality of life and survival is critical for patients with lung cancer. Unfortunately the delays inherent in our system mean that Australian patients are often waiting much longer than patients in other countries for access once drugs have been shown to be effective. Clinical trial participation and compassionate access schemes can be helpful but have their own limitations and are not a substitute for a robust system that ensures timely and appropriate availability of new agents.”

Michael Boyer, medical oncologist

Access to non-approved treatments

For some patients, access to drugs that are not yet approved in Australia may need to be considered. The report of the Senate Inquiry into availability of new, innovative and specialist cancer drugs in Australia summarised a number of alternative pathways for access²⁹:

- Manufacturer-supported compassionate or early access schemes
- Hospital formularies paying for an individual patient's treatment
- Privately funded by the patient, including obtaining the treatment from, or travelling to, a country where the treatment is approved

Each of these pathways has clear limitations²⁹. Compassionate or early access schemes are usually capped, either in terms of time or financial commitment and hence are of benefit for only a limited number of patients. Coverage by a public hospital formulary is determined by individual hospitals, or states and territories, leading to inequities in access across sites. The costs of privately purchasing a new treatment or, in some cases, accessing it by relocating overseas, are prohibitive for most patients.

Clinical trials are an important avenue for patients to access non-approved or experimental treatments and Cancer Australia's principles of best practice management state that all lung cancer patients should be considered for clinical trials²⁶.

“I opted for non-standard chemo[therapy] based on evidence of improved results. This came at a huge financial cost and our medical expenses are well into six figures. The choice of treatment was rewarded, with scan results showing no evidence of disease after about 25 cycles of chemo. I've now had over 60 cycles and the cancer has shown no progression.”

David

However, there are multiple access limitations to clinical trials for new cancer drugs: not all new cancer drugs are tested in Australia; patients need to be under the care of a clinician who is involved in the trial; the centre involved in the trial may be located far from where the patient lives; strict criteria determine whether a patient is eligible to be enrolled; patients may be hesitant to participate in a trial due to concerns about the “experimental” nature of a trial or

lack of understanding of the potential benefits of research; patients may not be aware of ongoing trials for which they may be eligible; and information available publicly for patients to explore clinical trial options is inconsistent.

“I've spoken with other patients about trials and in so many cases they were given only one option for a trial because that's what was being done at their hospital. Some have said they would have chosen to travel further for a different trial that offered another treatment, but this wasn't presented to them as an option. It seems to be very dependent on what patients are told or find out for themselves. If I didn't find my trial online, my treatment pathway would've been very different.”

Lillian

Call to action: Improve access to best practice care for people with lung cancer.

Improving outcomes for patients with lung cancer requires ensuring all patients have early access to specialised care services, whoever they are and wherever they live. Modernisation of the regulatory and reimbursement system must be a priority today; otherwise we will never be able to provide the best treatments for the patients of tomorrow.

- Cancer Australia to disseminate learnings from the Lung Cancer Demonstration Project, including clear minimum standards, to national lung multi-disciplinary teams (MDTs) in order to address variations in care.
- Government to improve access to new treatments for high mortality cancers, including lung cancer, through more flexible and efficient regulatory and reimbursement processes.
- Government, manufacturers and healthcare professionals to improve access to clinical trials:
 - Government to advocate for and fund more clinical research in Australia.
 - Manufacturers to open more study sites in Australia.
 - Healthcare professionals to ensure all options are identified and considered, for all patients with lung cancer, to participate in a clinical trial.

4 Increase research funding targeted to lung cancer to improve health outcomes

Research is underfunded

Research offers hope, whether for a cure or for an improvement in quality of life. The benefits of research on improving outcomes in cancer are undisputed. In the past 25 years, sustained investment in research in Australia has resulted in remarkable improvements for some cancers, with survival rates rising to 90% for breast³, 94% for prostate⁴ and 43% for ovarian cancer⁵. Achieving similar improvements in lung cancer outcomes requires the same commitment to research.

“I am a great believer that where there is hope, there is life in trying. I don't believe “hope” is false. Hope is what keeps me going every day. I believe in scientific breakthroughs. I am a testament to scientific advances already. Over half of the treatments provided to me in my near five years survival have been in clinical trials. My experience of clinical trials has been excellent and I personally owe my life to them.”

Jay

Despite causing the largest number of cancer deaths, lung cancer receives a disproportionately low level of research funding in Australia, with less than five cents of every cancer research dollar going to lung cancer³⁰ (Table 1).

Table 1. Deaths from cancer, proportion and amount of funding (2009-2011) for the top 5 cancers in Australia, based on mortality

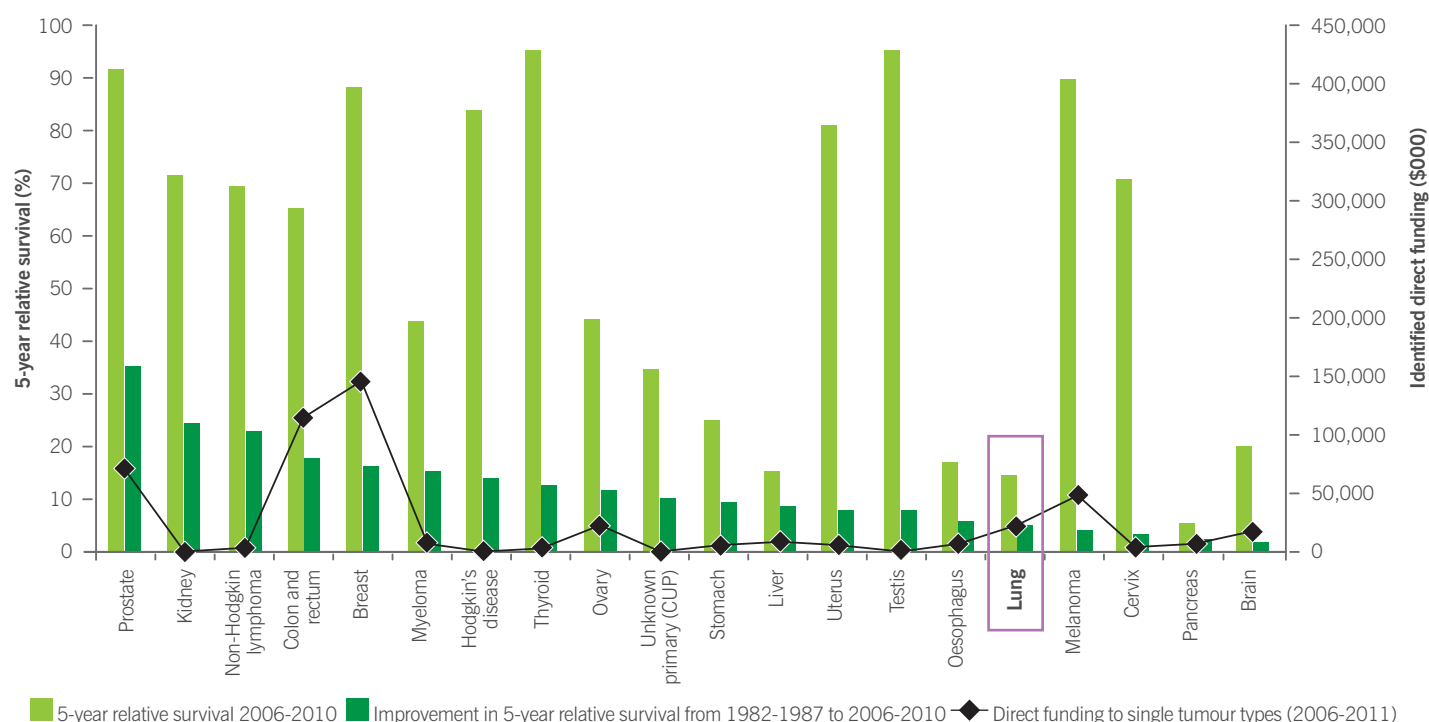
Cancer type	% of cancer deaths	% of funding	Amount of funding (\$M)
Lung	18.5	5	16.3
Colorectal	8.7	14	47.2
Prostate	7.5	13	41.6
Breast	6.5	26	85.9
Pancreas	5.6	2	5.3

Based on Australian Institute of Health and Welfare material.

In the period 2009-2011 lung cancer was responsible for three times as many deaths as breast cancer and received one-fifth the amount of research funding³⁰.

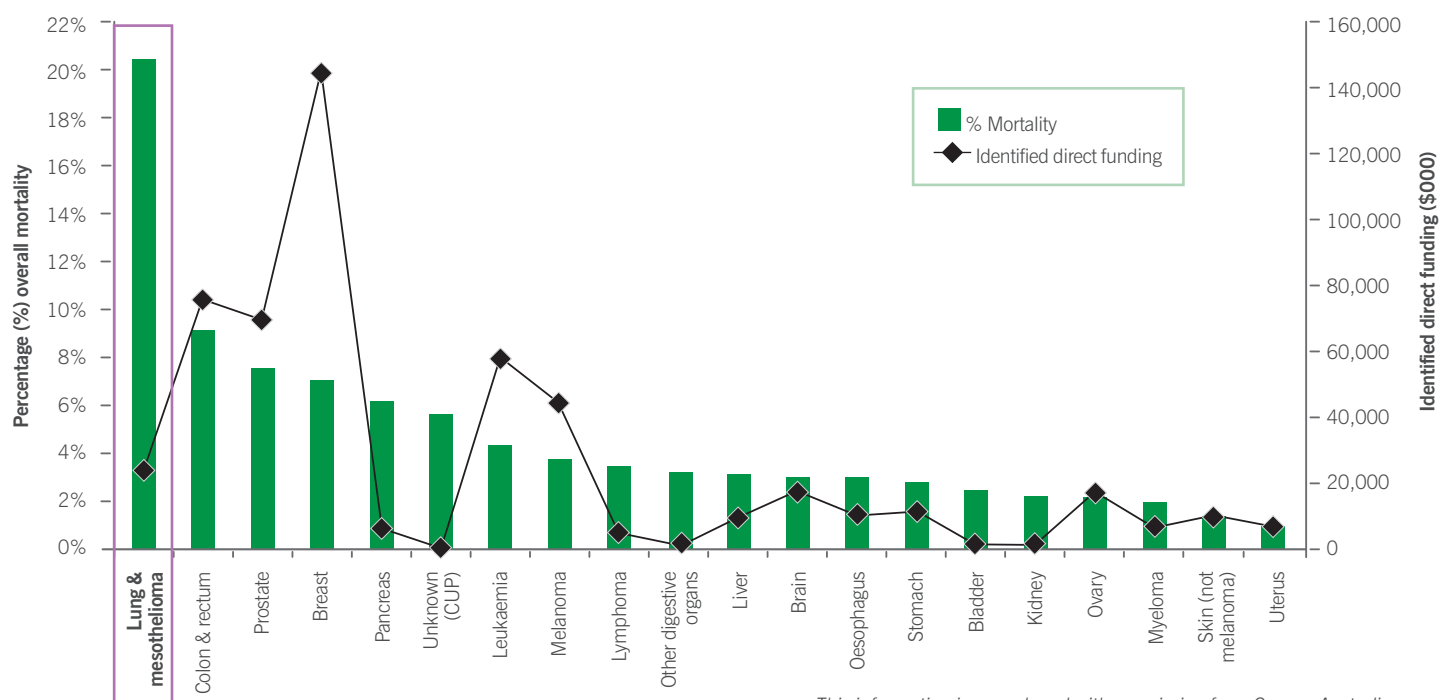
In its 2014 report into cancer research in Australia, Cancer Australia noted that improvements in 5 year survival rates appeared to have a relationship with levels of direct research investment (Figure 5)³⁰. Furthermore, the proportion of research in some cancers (including lung cancer) compared with the burden of disease was low (Figure 6); and research funding investment could be prioritised toward cancers with a high impact and burden of disease, among them lung cancer³⁰.

Figure 5. 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



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Figure 6: 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



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Lung cancer treatment is complex and lung cancer research is consequently also complex and costly. Looking to the future, as understanding of the mechanisms that drive lung cancer and the potential benefits of newer therapies develop, funding for research needs to keep pace so that people with lung cancer are not left behind and benefit from these gains in knowledge.

Call to action: Increase research funding for lung cancer

Research offers hope, whether for a cure or improvement in quality of life. The benefits of research on improving outcomes in cancer are undisputed and improved survival rates for other commonly diagnosed cancers have been achieved through a consistent commitment to research. Investing in research dedicated to lung cancer will level the playing field.

- Government to establish a dedicated fund for lung cancer to increase research funding to \$20 million, per year, by 2020.
- Philanthropic community to establish specific targets for donations to lung cancer research.

Lung Foundation Australia contributions to lung cancer research⁵⁶

- Establishment of the Australasian Lung Cancer Trials Group (ALTG) in 2004 to support investigator-led clinical trials in thoracic cancer.
- Clinical trials led by the ALTG represent \$7.5 million in research funding.
- Establishment and hosting of the bi-annual Australian Lung Cancer Conference, being held for the sixth time in 2016.
- Establishment of the ALTG Preceptorship in Lung Cancer to educate advanced trainees and junior consultants in the translation of research evidence into best clinical practice for lung cancer.
- The annual Shine A Light on Lung Cancer campaign to raise awareness about lung cancer and funds for lung cancer research – over \$40,000 was raised for lung cancer research in 2015.
- Since 2006, Lung Foundation Australia has awarded over \$1.4 million to talented researchers across the country. Lung Foundation Australia is committed to improving lives today, while searching for tomorrow's cures.

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