



The Next Breath

Accelerating Lung Cancer Reform in Australia 2022-2025



Lung Foundation Australia's
Second National Blueprint
for Action on Lung Cancer

Lung Foundation Australia is the nation's leading peak body for respiratory health and lung disease. Lung Foundation Australia funds life-changing research and delivers support services to enable Australians with lung disease and lung cancer to live their best life.

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*"My lung cancer diagnosis was shattering.
The confusion, anxiety and fear were debilitating.
My hope is for every Australian touched by lung cancer
to have access to the best treatment and care."*

- Georgia, mother of two living with lung cancer

Pictured: Georgia and
her daughter Bonnie.
Image credit: Izzy
Dalliston



Contents

Acknowledgements	4
Executive Summary	5
Foreword	6
Introduction	8
The Growing Burden of Lung Cancer in Australia	9
Lung Cancer Patient Journey	14
Recommendations for Lung Cancer Reform in Australia	18
1. Lung Cancer Prevention and Risk Reduction	19
2. Lung Cancer Screening	23
3. Specialist Lung Cancer Nurses	27
4. Comprehensive Genomic Profiling	33
5. Lung Cancer Survivorship	39
6. Clinical Quality Registry	45
Glossary	48
Technical appendices	49
References	50

Acknowledgement of Country

Lung Foundation Australia acknowledges Australia's First Nations People and pay our respect to Aboriginal and Torres Strait Islander Elders, past, present and emerging. We do so in a spirit of reconciliation recognising that Aboriginal and Torres Strait Islander people across Australia are significantly overrepresented in lung disease and lung cancer. We commit to partnering with communities to address this and Close the Gap.

Click here to watch the 'Turn the tide on lung cancer' video featuring our lung cancer patient advocates featured on the front cover (from left to right): Deb, Carolyn, Michael, Jenny, Lorraine, Michel, Andrea, Rebecca, Roy and Jodee.



Lung Foundation Australia sincerely thanks the individuals and organisations who contributed time, expertise and resources to the development of this Blueprint, including the Lung Cancer Blueprint Expert Advisory Group, contributors, project team, consultants, and corporate supporters.

Lung Cancer Blueprint Expert Advisory Group

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Lung cancer is a major area of unmet need in Australia

The Next Breath: Accelerating Lung Cancer Reform in Australia 2022-2025 (the Blueprint) identifies the critical issues in lung cancer that need investment and coordinated national action. It provides a framework to drive significant and positive change to transform lung cancer care and improve outcomes for Australians with lung cancer, their carers and families.

The lung cancer community is determined to change the story of lung cancer and improve outcomes for all, particularly those who are disproportionately affected by lung cancer, including Aboriginal and Torres Strait Islander people and those living in rural, regional and remote communities. We remain focused on making lung cancer a fair fight.

Six recommendations for lung cancer reform in Australia are outlined in this Blueprint. The recommendations build on Australia's strong foundations and past successes and will move us into a new era for lung cancer care and survival, where lung cancer is transformed from a fatal condition to one that is treatable.

	Key recommendations
Building on success and maintaining momentum	 Lung Cancer Prevention and Risk Reduction Invest in lung cancer prevention policy and programs including smoking cessation and tobacco control, healthy and safe workplaces, and clean air.
	 Lung Cancer Screening Implement a targeted national lung cancer screening program to diagnose Australians with lung cancer at an earlier stage of disease and save lives.
	 Specialist Lung Cancer Nurses Invest in 100 government-funded Specialist Lung Cancer Nurses by 2025.
Extending into new frontiers	 Comprehensive Genomic Profiling Implement government-funded Comprehensive Genomic Profiling as standard of care for Australians with lung cancer.
	 Lung Cancer Survivorship Greater research investment and focus on lung cancer survivorship through practical resources.
	 Clinical Quality Registry Develop a world-leading national clinical quality registry for lung cancer to improve the quality and value of lung cancer care.

This Blueprint was a collective effort by the Australian lung cancer community. Priority areas of reform were identified following extensive consultation with experts and the lung cancer community, and in response to evidence regarding unmet need and potential for impact. Lung Foundation Australia acknowledges the many individuals and organisations that helped make it possible. In particular we thank the Australian men and women with lung cancer, their families and carers for shaping this report with their lived experience and demonstrating great strength in paving the way for improved lung cancer outcomes.

The Australian lung cancer community envisages a future where lung cancer is diagnosed earlier, and people living with lung cancer can access the world-class treatment, care and support they need and deserve. We want all Australians living with lung cancer to breathe easier and live their best life. Our bold ambition is to eliminate lung cancer as a cause of death. This is possible with the right reform.

The confronting reality in 2022 is that lung cancer care in Australia, and indeed globally, remains fraught with intractable challenges. Lung cancer is one of the most commonly diagnosed cancers but is often diagnosed late, with many experiencing barriers to accessing care, inconsistent quality of care and stigma, all of which leads to unmet needs and poor outcomes. More Australians die of lung cancer than any other cancer, and shockingly, just 20% of people with lung cancer are alive five years after diagnosis. Despite efforts over time, lung cancer outcomes are undeniably poor and lag behind other cancers.

The persistent gaps in health outcomes and funding are both significant and unacceptable.

However, we have entered an era of new hope. Our understanding of what takes place in lung cancer cells, how the immune system controls lung cancers and how to act on this new knowledge has greatly increased. It's an incredibly exciting time for lung cancer research and treatment, as this new information empowers us to help Australians with lung cancer like never before.

The Next Breath: Accelerating Lung Cancer Reform in Australia is Lung Foundation Australia's National Blueprint for Action on Lung Cancer (the Blueprint). It provides a roadmap for the federal, state and territory governments, policy makers and the broader lung cancer community to improve lung cancer care and outcomes. It is informed by evidence and co-designed with Australians living with lung cancer.

The Blueprint identifies key priorities to guide lung cancer action, investment and reform in Australia. Priorities include:

- Lung cancer prevention and risk reduction
- A targeted, national lung cancer screening program
- Access to Specialist Lung Cancer Nurses
- Comprehensive genomic profiling as standard of care
- Strengthened survivorship and mental health support; and
- A world-leading national clinical quality registry for lung cancer.

Taking urgent action in these areas will improve outcomes for all Australians with lung cancer, while ensuring we reduce the unfair impact of lung cancer on high-risk groups and communities.

This is Australia's second lung cancer Blueprint. It builds on recent progress and commitments since Lung Foundation Australia launched Australia's first Blueprint in 2018, *Making Lung Cancer A Fair Fight: A Blueprint for Reform*, which united the sector around common goals. Notable progress includes Cancer Australia's enquiry into national targeted lung cancer screening, funding of a Specialist Lung Cancer Nurse pilot, and consumer-driven campaigns to reduce stigma. We're making strides, but so much more needs to be done.

Now more than ever, as we experience a global respiratory pandemic, our nation is acutely aware of the importance of healthy lungs. The COVID-19 pandemic has significantly impacted the Australian health system and reduced the delivery of cancer diagnostic and treatment services; many lung cancers remain undiagnosed and an influx of lung cancer referrals is expected in coming months and years. It is time for decisive and strong action to identify more Australians early, treat with urgency, and in doing so improve lung cancer outcomes.

The Blueprint provides us all with a framework to drive significant and positive change over 2022-2025 that transforms lung cancer from a fatal condition to one that is treatable. The Blueprint aligns with the *National Strategic Action Plan for Lung Conditions* and the *National Oncology Alliance Vision*, and will form the basis of the lung cancer communities' input into the new National Cancer Plan under development.

We urge you to work with us to accelerate lung cancer reform in Australia and improve outcomes for people with lung cancer, those that care for them, their families and community.

It is time for Australia to break the barriers limiting progress. We believe that a new era for lung cancer care is within reach.



Nicole Rankin

Associate Professor Nicole Rankin

Chair, Lung Foundation Australia's Lung Cancer Blueprint 2.0 Expert Advisory Committee

Head, Evaluation and Implementation Science Unit, University of Melbourne



“It is time for Australia to break the barriers limiting progress. We believe that a new era for lung cancer care is within reach.”

Lung cancer doesn't discriminate

Lung cancer occurs when abnormal cells in the lung grow in an uncontrolled way. It often spreads (metastasises) to other parts of the body before the cancer is detected in the lungs.

Lung cancer affects men, women, people who currently smoke, those who have quit and those who have never smoked. In fact, 1 in 5 people living with lung cancer have no smoking history.

Anyone can be diagnosed with lung cancer - if you have lungs, you can get lung cancer.

Policy context

The Next Breath: Accelerating Lung Cancer Reform in Australia 2022-2024 (the 'Blueprint') will drive reform to improve lung cancer care and outcomes.

The Blueprint is the only national policy statement in Australia with a specific focus on lung cancer. It sits within a broad health policy environment that includes cancer, respiratory and lung health, preventive health and chronic conditions, and policies focused on improving the health workforce and health outcomes for Aboriginal and Torres Strait Islander people and other priority populations.



The Blueprint aligns with key national policies and strategies, including:

- National Strategic Action Plan for Lung Conditions¹
- National Oncology Alliance Vision 20-30 report²
- National Cancer Plan (scheduled for completion in 2023)³
- National Preventive Health Strategy 2021-2030⁴
- National Strategic Framework for Chronic Conditions⁵
- National Aboriginal and Torres Strait Islander Health Plan 2021-2031⁶
- National Agreement on Closing the Gap⁷
- Australia's Long Term National Health Plan⁸
- Australia's Primary Health Care 10 Year Plan 2022-2032⁹
- National Tobacco Strategy 2022-2030 (scheduled for completion in 2022)¹⁰
- Stronger Rural Health Strategy¹¹
- National Nursing Strategy (scheduled for completion in 2023)¹².

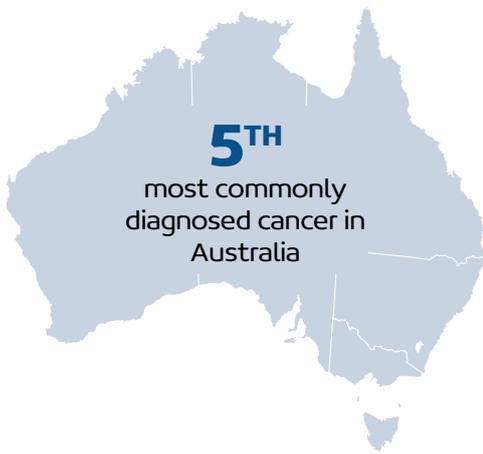
The Blueprint priorities and recommendations will form the basis of the lung cancer communities' input into the National Cancer Plan, which is currently being developed by Cancer Australia and is scheduled for completion in 2023³.



The Blueprint will play a key role in driving Australia's progress towards a number of international policy agendas, including:

- Lung Ambition Alliance's Lung Cancer 2030 goals
- World Health Organization (WHO) Resolution Cancer prevention and control in the context of an integrated approach¹³
- WHO Framework Convention on Tobacco Control (FCTC)¹⁴
- 2030 UN Sustainable Development Goals.

The growing burden of lung cancer in Australia



13,810 Australians were diagnosed in 2021 – that’s **37 people a day**

22,800
Australian men
and women
currently have
lung cancer



50%

decline in referrals for lung cancer during the peak of the COVID-19 pandemic resulting in up to **1,000 Australians** potentially living with undiagnosed lung cancer

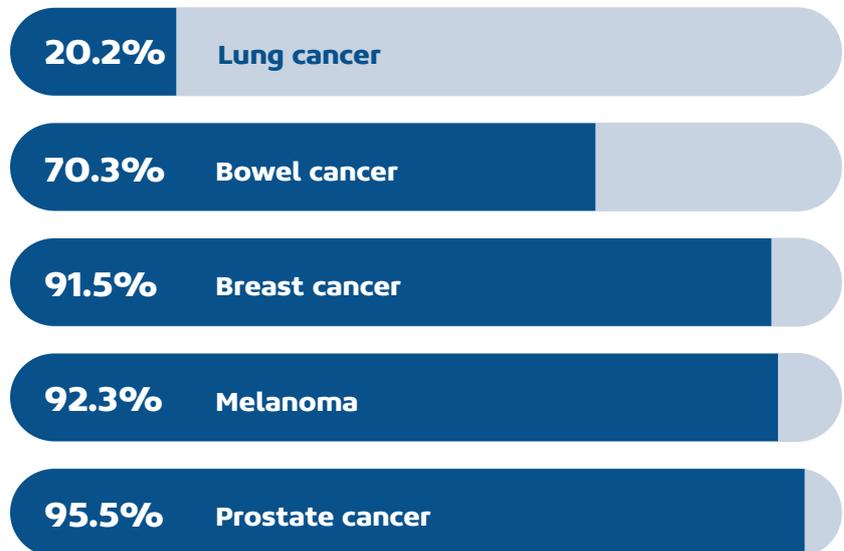
Almost **168,000**
people will be diagnosed with lung cancer over the **next 10 years**

Lung cancer is Australia’s leading cause of cancer death

8,693

Australians lost their lives to lung cancer in 2021 – that’s almost one person every hour

Lung cancer’s **5-year survival rate** is the lowest of the 5 most common cancers



149,000

years of life lost due to premature mortality

Anyone can get lung cancer

Risk factors include:



Exposure to asbestos, radon and occupation materials



Air pollution



Family history



Personal history of lung disease



Genetics



Smoking



1 in 5 people

living with lung cancer have no smoking history

Lung cancer is costly

By 2031 it's predicted that the economic burden of lung cancer will increase to

\$8.5 billion



Lung cancer is the **third most expensive** cancer

The current annual costs of lung cancer are:

\$448 million

in direct costs, including treatment, out-of-hospital costs and out-of-pocket expenses

\$14.9 million

in indirect costs, including absenteeism resulting from additional time off work taken

Delays in diagnosis and treatment

Nearly half (48%) of lung cancer patients wait more than

42 days before accessing treatment



42%

of lung cancer cases are diagnosed at stage IV and only **3.2%** survive 5 years

28.5%

of people are not staged when diagnosed, potentially missing life-changing treatment and care

An unfair fight

Aboriginal and Torres Strait Islander people are **twice as likely** to be diagnosed with and to die from lung cancer than non-Indigenous Australians



People experiencing socio-economic (SES) disadvantage are **twice as likely** to be diagnosed with and to die from lung cancer than people in higher SES areas

Compared to major cities, Australians living in regional, rural and remote areas experience

12%

lower survival rate

31%

more cases

Mental health impacts



50% of Australians living with lung cancer experience **distress, anxiety** and/or **depression**, which worsens quality of life

Compared to other cancers, the prevalence of poor mental health is **29.6% higher** for people with lung cancer



People living with lung cancer experience **stifling stigma**

Stigmatisation further exacerbates psychological distress, placing them at a high risk of suicide



Over a third of Australians believe people with lung cancer **“only have themselves to blame”**

Lung cancer is common and remains a critical issue

Lung cancer is the fifth most commonly diagnosed cancer in Australia¹⁵.

13,810 Australians were diagnosed with lung cancer in 2021 – that’s 37 people a day¹⁶.

Currently in Australia there are 22,800 Australian men and women living with lung cancer¹⁵. Lung cancer is a common cancer for both men and women, however rates for males have been decreasing steadily over time, while those for females have been increasing, largely due to changes in smoking rates over time¹⁶.

The number of new cases of lung cancer is increasing, mostly due to Australia’s ageing population – age is a big driver for all cancers, but particularly lung cancer¹⁷. **Over the next 10 years, almost 168,000 people will be diagnosed with lung cancer.**

Worldwide, lung cancer is one of the most frequently diagnosed cancers, with over 2 million new cases per year¹⁸.

Australia’s lung cancer crisis has been compounded by COVID-19

The COVID-19 pandemic has had a significant impact on the detection and management of lung cancer. Australian data shows devastating reductions in services, particularly in the early stages of the pandemic.

- **Decline in referrals for lung cancer.** At the peak of the COVID-19 pandemic in March to April 2020, Australian medical oncologists reported a shocking 50% decline in referrals for lung cancer from GPs. This meant that up to 1,000 Australians were potentially living with undiagnosed lung cancer^{19, 20}.
- **Substantial reductions in procedures relating to cancer-related investigations and treatment.** For example, lung cancer diagnostic procedures were 8% lower than expected²¹.
- **Decline in cancer pathology notifications.** For example, in Victoria there was a 10% reduction in cancer pathology notifications to the population-based cancer registry during the COVID-19 restrictions in 2020, corresponding to an estimated 2,530 undiagnosed cancers²².
- **Decrease in the rate of cancer-related hospitalisations, after increasing annually for over 20 years¹⁶.**

This data raises serious concerns about delays in diagnoses and treatment. We know that fewer people were diagnosed with cancer during COVID-19 restrictions than would otherwise have been the case¹⁶, and there is a real possibility of a future spike in numbers. Furthermore, the significant drop in people accessing healthcare including cancer-related services during the pandemic may lead to more lung cancers being diagnosed at a later stage, and poorer patient outcomes²¹.

Australians with lung cancer are highly vulnerable to SARS-CoV-2 infections and suffer from an increased risk of death compared with other cancers²³. In a recent survey by the Global Lung Cancer Coalition, all lung cancer patients in Australia had felt worried/anxious as their treatment has been delayed/cancelled as a result of COVID-19²⁴.

The COVID-19 pandemic continues to have knock-on impacts, such as redeployment of staff and resources to the front line²⁵, however the full impact of the pandemic on lung cancer diagnosis and treatment will not be known for several years¹⁶.

Lung cancer is the leading cause of cancer death

Lung cancer is a complex and often fatal disease.

In 2021, 8,693 Australians lost their lives to lung cancer – that’s approximately one every hour¹⁶.

More Australians die of lung cancer than any other cancer, and it has the highest cancer burden²⁶. While only 2.4% of the lung cancer burden is from living with the disease, the high numbers of cases diagnosed every year, and the number of people dying from lung cancer, mean that it also contributes substantially to the non-fatal burden in Australia²⁶.

Lung cancer is the leading cause of cancer death globally^{27, 28} with an estimated 1.76 million deaths per year²⁸. Across the world, lung cancer is responsible for one in every five cancer deaths.

Cancer is a barrier to increasing life expectancy in every country of the world²⁹.

Lung cancer survival rates remain low despite dramatic advances in treatment

Australia has among the best survival rates for cancer in the world, yet lung cancer is often diagnosed late, and lung cancer survival rates are low.

Lung cancer still has the lowest 5-year survival rate of the five most commonly diagnosed cancers, at just 20%. This means that about 20 out of 100 people (20%) with lung cancer will be alive five years after diagnosis. While this represents a 3% increase on the survival rate of 17% captured in Australia's first Blueprint³⁰, we should see survival increase at a much faster rate given the technology, testing and treatments available today with further hope on the horizon.

Lung cancer survival lags behind other cancers. This is 50% lower than bowel cancer that sits in 4th place, and over 70% lower than those in the top 3 of survival.

Cancer 5-year survival rates:

- Prostate cancer: 95.5%
- Melanoma: 92.3%
- Breast cancer: 91.5%
- Bowel cancer: 70.3%
- **Lung cancer: 20.2%**³¹

Survival varies by remoteness and socioeconomic status. Survival is higher among people living in major cities compared to regional areas; 43% compared to 31% for stage II lung cancer³². People experiencing low SES are twice as likely to be diagnosed with and to die from lung cancer than people in least disadvantaged communities³³.

Lung cancer is diagnosed late

Prognosis for lung cancer is poor compared with most other cancers, largely because many cases are detected at an advanced stage, when treatment options are limited.

We know that stage of diagnosis is the most important factor in the prognosis of people living with lung cancer: early detection of cancer improves survival. Yet lung cancer is still diagnosed late.

Cancer staging is a way to describe a cancer. The stage of a cancer describes the size of a tumour and how far it has spread from where it originated when first diagnosed. Cancers are assigned a number between I and IV – the higher the number, the further the cancer has spread and more advanced the cancer is.

Most common cancers are diagnosed as early stage, except for lung cancer.

Cancers diagnosed as early stage (stage I or stage II)³⁴:

- **Lung cancer: 19%**
- Bowel cancer: 46%
- Breast cancer: 78%
- Prostate cancer: 82%
- Melanoma: 92%³⁴

Table 1: Lung cancer incidence by stage of diagnosis and 5-year survival rate³¹

Cancer stage at diagnosis	Number of cases	Percentage (%) of total cases	5-year survival rate
Stage I	1,183	11.7	67.7%
Stage II	662	6.5	32.3%
Stage III	1,131	11.2	17.1%
Stage IV	4,273	42.2	3.2%
Unknown	2,885	28.5	-

Five-year survival for stage I lung cancer is 67.7%, but just 11.7% of people with lung cancer are diagnosed at this stage. Australians living in remote and very remote regions are less likely to be diagnosed with stage I disease¹⁷.

Around four times as many people present with incurable disease; 42% receive their diagnosis as stage IV (the most advanced), when their likelihood of surviving five years is less than 5%.

The average stage at diagnosis is III.

As cancer progresses, so too does the cost of treatment. For example, it costs an average of \$1,568.63 more to treat stage IV lung cancer than stage I³⁵.

Nearly a third of cases are not staged at all³¹, which is alarming, as accurate staging for lung cancer is a critical element in treatment planning³⁶.

Lung cancer has a much higher percentage of cases that are not staged compared to other cancers.

Cancers not staged at diagnosis³⁴:

- **Lung cancer: 28.5%**
- Bowel cancer: 12%
- Breast cancer: 6%
- Prostate cancer: 3%
- Melanoma: 3%

Lung cancer care is inconsistent and fragmented

Australian and international data show wide variation in lung cancer care, even in the provision of standard treatments^{37,38}.

Lung cancer care in Australia is informed by clinical practice guidelines^{39,40} and optimal care pathways^{36,41,42}. Although there are no national data assessing compliance with the guidelines⁴³, the lung cancer patient journey is often disjointed and characterised by variations in care and delays that are inconsistent with best practice and result in poorer outcomes.

Variation in care, and in particular diagnostic and treatment delays, worsen outcomes for Australians with lung cancer and reduce survival^{44,45}.

- **Diagnostic delays**⁴⁴. One study found the average diagnostic interval to be over 3 months from presentation and was particularly long for patients with early stage lung cancer (average 168 days)⁴⁶.
- **Lack of cancer staging**. 28.5% of people are not staged when diagnosed with lung cancer, potentially missing out on life-changing treatment and care³¹.
- **Delays in commencing treatment**. Nearly half (48%) of lung cancer patients wait more than the recommended 42 days³⁶ from diagnosis to commencing treatment⁴⁷.

A recent national survey exposed serious flaws in the services and infrastructure available in Australia for the treatment of lung cancer. It highlighted widespread deficiencies in staffing at specialist centres, including less than half of the centres having a Specialist Lung Cancer Nurse, and 23% have no access to thoracic surgery at multidisciplinary team (MDT) meetings⁴³. Access to diagnostic and treatment facilities was limited for some institutions. No Australian centres fully conformed with the recommended guidelines for staffing.

Lung cancer is costly

The cost of lung cancer has skyrocketed since Australia's first Lung Cancer Blueprint in 2018. The cost of lung cancer:

\$448 million in direct costs, including treatment costs, out-of-hospital costs, and out-of-pocket expenses⁴⁸, an increase from \$283.7 million in 2018.

\$14.9 million in indirect costs, including absenteeism resulting from additional time off

work taken, an increase from \$13.5 million in 2018.

149,000 years of life lost due to premature mortality, an increase from 137,600 in 2018³⁵.

Australians with lung cancer and their carers and families experience a substantial economic burden. The economic burden of lung cancer also impacts the healthcare system, workforce and broader economy.

Of all cancer types, healthcare for lung cancer is the third most costly in Australia, but there is little detailed information about these costs. One study on health system costs for lung cancer care showed excess costs from one-year pre-diagnosis to three years post-diagnosis averaged ~\$51,900 per case⁴⁹.

It's predicted, if left unaddressed, the economic burden of lung cancer in Australia could inflate to \$8.5 billion by 2031³⁵.

Lung cancer continues to be an unfair fight

Lung cancer outcomes vary across the country⁵⁰. Outcomes vary significantly between Indigenous and non-Indigenous Australians, different SES areas, and people treated in different areas of Australia, including between metropolitan and rural areas and even between different hospitals^{38,51}. Lung cancer continues to be an unfair fight.

Aboriginal and Torres Strait Islander people are twice as likely to be diagnosed with and to die from lung cancer than non-Indigenous Australians⁵², and more likely to be diagnosed with cancer that has progressed to an advanced stage⁵³.

People experiencing low SES are twice as likely to be diagnosed and to die from lung cancer than people in higher SES areas³³.

Australians living in regional, rural and remote areas^{54, 56} are more likely to be diagnosed with and die from lung cancer than people living in major cities. They experience 31% more cases³³; are less likely to be diagnosed with stage I disease¹⁷; have lower survival (31% survival compared to 43% for major cities³²); and 33% higher mortality³³. People living in regional, rural and remote areas also have lower access to healthcare⁵⁷ and longer wait times to access specialist care⁵⁸⁻⁶⁰.

People from culturally and linguistically diverse backgrounds also experience inequitable access and outcomes, and lung cancer incidence in some communities is expected to increase greatly based on smoking trends³³.

The Lung Cancer Patient Journey

The lung cancer patient journey can be debilitating - physically and mentally

PRE-TREATMENT PHASE

AWARENESS AND SCREENING WHERE AVAILABLE

May be symptomatic, but often no sign of disease
 Suspicious lesion picked up incidentally by primary care physician or lung specialist, or local screening programme
Shock, feeling overwhelmed
 I didn't expect it could be cancer



REFERRAL AND INVESTIGATIONS

Patient referred for specialist care
 Imaging and biopsy
 Lung function testing
 Disease staging
Distress, anxiety
 Why do I need all these tests?

TESTING FOR MUTATION

Depending on local availability and funding, patient may be offered testing for genetic mutations
Is a mutation a good or bad thing?
 What does it mean for me?
 How could it change my treatment?

DIAGNOSIS AND NEXT STEPS

Cancer is confirmed and staged
 Patient and physician begin exploring treatment options
 Further confirmation by pathologist via bloodwork and biopsy
A lot of complex information to understand at once - what's the right decision?
 Concern for self and loved ones
Stigma - did I bring this on myself?
 What happens now?

TREATMENT DECISIONS

Discussions over treatment and/or new testing
 Costs, funding, mutation status, and personal impact of treatment options considered in Molecular Tumour Board (MTB)
 Options include surgery, chemotherapy, radiotherapy, targeted therapy, cancer immunotherapy
Fear, uncertainty
 Will I get the right treatment?
 Can I expect to be cured?
 Can we start right away?

CLINICAL TRIAL PARTICIPATION

Depending upon availability and funding, discuss potential benefit of trial participation to patient and role of clinical trials broadly in advancing treatment landscape/patient outcomes
What are clinical trials?
 Practical considerations, concerns over side effects

SECOND OPINION

Patient seeks out advice on whether there is an alternative to the proposed treatment plan
Am I doing the right thing?
 What did other people do in my position?

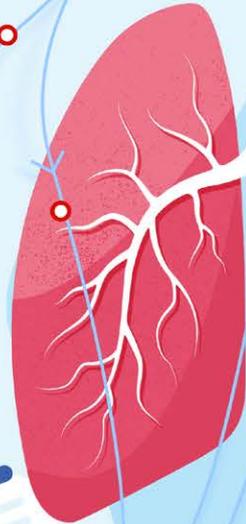
NO SECOND OPINION

Second opinion often not taken into consideration during the journey and patients are not educated on what to ask
Low confidence and health literacy
 I don't know what to ask

TREATMENT BEGINS

Patient begins treatment journey
Hope and determination
 What are the side effects of my treatment?
 What are the risks?
 What happens if this doesn't work?
I want to know more, but there's so much information out there - who can I trust?
Need clear communication from my HCPs (could I be part of a clinical trial?)

Patients often feel a sense of stigma associated with lung cancer, which can manifest as guilt, shame, anxiety, and depression. Stigma can negatively impact on every stage along a patient's lung cancer journey.



TREATMENT PHASE

POST-TREATMENT PHASE

SURGERY

If tumour can be removed, patient is scheduled for surgery
Stress of preparing for admission and recovery
Support for activities of daily living post-surgery
What are the risks of the operation?
Hope that this will 'cure' me



ONGOING ASSESSMENT

Regular imaging studies to track the progress of treatment and restage disease
Management of side effects
Anxiety over results
Ready to plan for the future

SUPPORTIVE CARE

Holistic patient care supporting overall health and wellbeing during survivorship journey – depends on availability at country/regional level
 Mental and psychosocial care
 Practical supportive care, such as financial assistance, travel, returning to employment
 Pulmonary rehab, management of other conditions
Value of holistic help based on individual need and circumstances, including practical and psychological support
Seeing the patient as a person



RELAPSE

Decision on whether to continue treatment or choose end of life care
Bombshell of being told you have cancer all over again.
Can I go through another round of treatment?
Should I try?
I will look for further treatment options and will keep my hope up
Need for emotional support for patient and family

LIVING WITH LUNG CANCER

Patient is informed no further treatment required at this time
Relief and happiness
What do I do with my life now?
Patient hits personal and treatment-related milestones
Ability to take a longer term view

CHEMOTHERAPY/RADIOOTHERAPY

Patient is scheduled for several cycles of chemotherapy and/or radiotherapy
Side effects can affect quality of life – weighing up potential benefits vs changes to life now
Worries over physical consequences
Will it affect my family, my work, my everyday life?



TARGETED THERAPY/ IMMUNOTHERAPY

Patient started on monoclonal antibodies, immunotherapy or other novel therapy
Need for long-term data
How long will it last?
Relief that options are available

END OF LIFE CARE

Patient is moved from medical to end of life management
 May include palliative radiotherapy, chemotherapy or monoclonal antibodies
Mixture of emotions – fear, anger, disappointment, guilt and acceptance
How long have I got?
Getting affairs in order and aiming for best quality of life
Conversations with loved ones



Information

Black – practical steps
 Blue – emotional journey

This visual was co-created with the Roche Global Lung Cancer Patient Council

Diagram adapted from the Lung Cancer Patient Journey, created by Roche and their global lung cancer patient council (December 2020)

Having lung cancer is as emotionally challenging as it is physically debilitating. The unpredictability of how the condition manifests, and over what timeframe, can be frightening and all consuming. What is clear is that all aspects of people's lives can be affected, taking a toll physically, mentally and financially.

“Unnerving not knowing what the future may hold. This causes me to have frequent periods of anxiety which in turn affects other elements of my health and wellbeing.”

- ACT resident with lung cancer⁶¹

Physical health deteriorates and symptom management takes a toll

People living with lung cancer often experience debilitating symptoms. Symptoms result from both the disease itself, and the treatment, which results in a higher symptom load than other cancer types⁶²⁻⁶⁴. This takes a toll on physical health, and quality of life often deteriorates over time.

Physical symptoms include:

- Pain
- Shortness of breath and difficulty breathing
- Cough
- Long-term physical, emotional, and cognitive fatigue⁶⁵⁻⁶⁷
- Reduced ability to exercise and move around freely.

“I was very young, extremely independent, worked full time, and I found things like having a shower started to become very difficult. Like brushing your teeth, preparing food, all the freedoms that you took for granted...even just talking.”

- QLD resident with lung cancer⁶¹

The mental health burden is immense and heartbreaking

Having lung cancer is as emotionally challenging as it is physically debilitating. Mental health and wellbeing remains a major issue for people living with lung cancer, their carers and families.

Psychological distress often exists at high levels throughout the patient journey^{63,64}. 50% of Australians living with lung cancer experience distress, anxiety and/or depression, which worsens their quality of life^{30,68}. People with lung cancer have 29.6% higher than average prevalence of poor mental health compared to other cancers⁶⁸.

Australians with lung cancer report a high level of unmet physical and psychological need, including gaps with meeting their daily living needs^{62,69}.

People living with lung cancer experience stifling stigma. Stigmatisation further exacerbates psychological distress, placing them at a high risk of suicide^{70,71}.

“Hard mentally because the survival stats are dire and almost as bad as the disease is friends' and family's reactions. Many people are terrified due to Googling stats, so they have run off and I haven't heard from them.”

- WA resident with lung cancer⁶¹

“These are the things that are missing from helping people get through this. I see it every day on a Facebook group I am in. The amount of stress that people have from trying to organise the little things, and if that could happen, it would lessen the stress.”

- SA resident, carer of parent with lung cancer (since passed)⁶¹

The bill shock burden needs to be addressed

Australians diagnosed with cancer frequently experience financial burden, despite universal health coverage and government-funded social welfare programs⁷². Individuals are currently the largest non-government contributors to health spending in Australia, providing \$30.6 billion during the period 2017-2018⁷³.

Out-of-pocket costs can range from a few hundred to tens of thousands of dollars, with a landmark patient survey by Consumers Health Forum of Australia reporting that half of cancer patients have out-of-pocket costs of more than \$5,000⁷⁴.

In one Australian study, one in ten cancer patients experienced catastrophic spending on healthcare, with 7% reporting on out-of-pocket costs that equated to 10%-20% of their total household income, 4% reporting 20%-40% and 1% reporting more than 40%⁷⁵. Furthermore, 19% reported a change in employment circumstances post-diagnosis⁷⁵.

These costs, expected or not, can financially cripple lung cancer patients and their families, especially when one or more people are unable to work within the household. While Australia's health system enables patients to make a personal contribution to their healthcare, 'bill shock' is prevalent in Australia, and a cause of stress that is difficult to manage^{74,76}.

High costs can result in Australians in need of healthcare delaying their treatment or forgoing it completely⁷². Increased financial burden due to costs of cancer care and treatment can lead to poor quality of life among cancer survivors⁷⁷.

Younger people (under 65 years), Aboriginal and Torres Strait Islander people, people in rural and/or remote areas, households with low income, those who were unemployed and people without private health insurance are at increased risk of experiencing financial burden⁷⁷.



"I have lost track of the number of times that somebody says, 'oh well you deserve to have lung cancer'. I said 'why?', and they said, 'well you must have smoked' and I said, 'well why does somebody who has smoked deserve any disease?' I didn't smoke but there is a stigma."

- Person with lung cancer⁶¹

Recommendations for Lung Cancer Reform in Australia

- 1 Lung Cancer Prevention and Risk Reduction
- 2 Lung Cancer Screening
- 3 Specialist Lung Cancer Nurses
- 4 Comprehensive Genomic Profiling
- 5 Lung Cancer Survivorship
- 6 Clinical Quality Registry

1

Lung Cancer Prevention and Risk Reduction

A number of factors can increase the risk of lung cancer:



Smoking



Air pollution



Family history



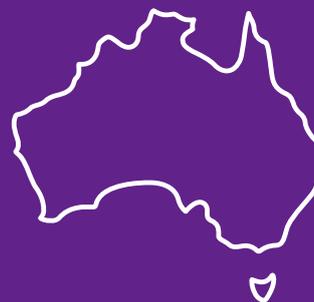
Exposure to cancer-causing agents (carcinogens) at work



Genetics



Personal history of lung disease



Australians have a

1 in 20

risk of being diagnosed with lung cancer by the age of 85

The direct health system costs of lung cancer in 2016 can be attributed to:

Tobacco use

\$270 million

Occupational exposures and hazards

\$28 million

Air pollution

\$4 million

Recommendation



Invest in lung cancer prevention and risk reduction policy and programs including smoking cessation and tobacco control, healthy and safe workplaces, and clean air.

A number of factors can increase the risk of lung cancer, including smoking tobacco, air pollution, family history, genetics, a personal history of lung disease, and exposure to cancer-causing agents (carcinogens) at work.

Australians have a 1 in 20 (or 4.9%) risk of being diagnosed with lung cancer by the age of 85¹⁵. Almost 80% of lung cancer expenditure is attributed to risk factors⁴⁸.

We can reduce the risk of lung cancer by avoiding known and modifiable risk factors. Other risk factors, such as age and a family history of lung cancer, cannot be changed.

Lung cancer prevention focuses on reducing the risk factors for the disease, including behavioural risk factors such as smoking, as well as ensuring the places where Australians live, work, learn and play both promote and protect good health and wellbeing.

A long-term investment in lung cancer prevention and risk reduction will:

- Decrease the number of Australians diagnosed with lung cancer each year
- Reduce lung cancer burden
- Reduce lung cancer deaths
- Reduce the growing costs of lung cancer treatment.



Smoking cessation and tobacco control

Tobacco is the leading cause of lung cancer, and the leading cause of death and disease in Australia. Stopping current smoking could prevent 53.7% of lung cancers over 40 years and 18.3% in 10 years⁷⁸.

Lung cancer attributed to tobacco use costs the health system over \$270 million annually⁴⁸. The social costs of smoking are estimated as \$19 billion in tangible costs and \$118 billion of intangible costs to Australian society⁷⁹.

The most comprehensive study of cancer causation in Australia estimated that 81% of lung cancers in 2010 were caused by tobacco smoking⁸⁰. Smoking is a highly stigmatised behavioural risk factor for lung cancer that is often linked with socioeconomic status, ethnicity, education level and geographic remoteness. Differences in smoking rates are seen between urban and rural populations as well as Indigenous and non-Indigenous communities⁸¹.

It is critical that smoking cessation and tobacco control efforts do not stigmatise individuals including people with lung cancer who have a history of smoking. People living with lung cancer experience

high levels of stigma in society, including from their communities, health providers, employers and even themselves. Over a third (35%) of Australians surveyed believe people living with lung cancer are their “own worst enemy,” who “have only themselves to blame.” One in ten Australians also believe that those with lung cancer “got what they deserved”. This judgement negatively impacts the perceived worthiness of people to access support, and reduces their sense of entitlement to care and empathy. Everyone deserves care, support and understanding.

It is important to recognise that nicotine is a harmful and highly addictive drug for which patterns of use and the development of dependence are strongly influenced by structural factors (e.g. availability, price, social pressures, regulations). For many years the tobacco industry has profited off a known harmful and addictive substance. The tobacco industry is extremely well resourced and continues to launch new cigarette brands, new products, market to youth, and challenge effective tobacco control legislation with a focus on maximising sales and profits⁸².

E-cigarettes are presenting an emerging challenge in Australia, with use among young people increasing. Despite nicotine-containing e-cigarettes being illegal without a prescription we know Australians, including children, are accessing these harmful devices and damaging their lungs. In 2019, 26.1% of people aged 18-24 reported ever-use of e-cigarettes⁸³. The proliferation of e-cigarette use, particularly the flavoured e-liquids (nicotine and non-nicotine), is presenting a significant public health challenge and undermining Australia’s tobacco control successes of the past decades, with evidence that e-cigarettes are harmful and increase the likelihood of tobacco use⁸⁴.

While Australia has been successful in reducing smoking rates through implementation of a range of world-leading policy levers, public awareness campaigns and program supports, tobacco control policy in Australia has slowed in recent years. There is evidence of progressive reforms in other countries, including new and innovative approaches in New Zealand such as phasing out sales of cigarettes^{85,86}. Meanwhile, Australia has not had a national mass-media anti-smoking campaign since 2018⁸⁷.

Australia’s *National Preventive Health Strategy 2021-2030* includes the goal of reducing smoking rates to below 10% by 2025 and 5% or less for adults by 2030⁴, however it lacks clear actions on how this will be achieved. Furthermore, Australia is a signatory to the World Health Organisation Organization (WHO) Framework Convention on Tobacco Control (FCTC) and has set the goal of reducing smoking rates to under 5% by 2030⁸⁸,

however we currently fall short of adopting the full suite of measures at the highest implementation level. Since 2018, Australia has fallen out of the best-practice group in relation to the provision of cessation services, tobacco taxation, and mass media campaigns⁸⁹, indicating a waning commitment to the FCTC.

A renewed focus and targeted investment in tobacco control is required to realise our national goals and international commitments.

Ending the tobacco epidemic is a priority for all Australian governments and has a high level of continued public support for policy measures to reduce tobacco-related harm⁴. Significantly reducing and eventually eliminating tobacco use in Australia would dramatically reduce illness, increase quality of life, and reduce health, social and economic inequalities for people who smoke, their families and the wider Australian community. It would prevent hundreds of thousands of premature deaths and reduce the burden of costly tobacco-attributable disease including lung cancer⁴.

“We need to embed proactive smoking cessation care across our health system. Making it clear that tobacco-dependence is a recognised clinical condition – and treating it as such – would increase the use of evidence-based cessation treatment and thus increase quit rates. Importantly, it would also shift community attitudes around smoking being “a choice”, rather than a challenging addiction. People who smoke should be provided the same compassionate, non-judgmental care that anyone else with a clinical condition receives in a high-quality health system. With a renewed investment and showing compassion, together we can make a real difference in reducing the burden of smoking in Australia.”

- Dr Sarah White, Head of Quit

National priorities for action

- Launch the National Tobacco Strategy in 2022, with clear actions and appropriate investment to ensure implementation of recommendations
- Accelerate efforts to reduce smoking prevalence and work towards a tobacco-free society, including an amplified focus on e-cigarettes and flavoured e-liquids
- Implement the National Preventive Health Strategy 2021-2030 and the related policy achievements.

Outcomes

- Fewer people, particularly children and young people, using smoking products including e-cigarettes and flavoured e-liquids
- Increased provision and access to evidence-based smoking cessation services
- Integration of smoking cessation across the lung cancer care continuum⁹⁰
- Lower rates of smoking among population groups at higher risk, including Aboriginal and Torres Strait Islander people
- Increased protections from the harm of second-hand smoke (e.g. expand smoke-free places).



Healthy and safe workplaces to prevent occupational lung disease and lung cancer

All Australians should be able to work in an environment free from harm. With over 13 million workers in Australia, and occupational lung disease typically under-recognised, we need to ensure that those at risk are protected and supported.

Occupational lung diseases are an important and under-recognised cause of respiratory ill health in Australia⁹¹. Lung cancer attributed to occupational exposures and hazards costs the health system over \$28 million each year⁴⁸.

Occupational lung diseases can be prevented by identifying and removing workplace carcinogens (asbestos, radon and other occupational substances) and occupational hazards, and creating healthy and safe workplaces. Lung conditions and lung cancer have an enormous employment and productivity impact through time away from work and lower effectiveness; hence the urgent need for greater workplace awareness, education and controls aligned with the hierarchy of control⁹².

The resurgence of silicosis, an entirely preventable and life-limiting lung condition that can lead to lung cancer, has shone a light on occupational lung disease and the importance of effective prevention, early detection, monitoring and reporting. In addition,

it is important to provide support to workers, and their families, through their occupational lung disease or lung cancer journey.

National priorities for action

- Fund and deliver multi-faceted education and awareness campaigns for occupational lung disease and lung cancer targeting a range of stakeholders, including tailored communications for culturally and linguistically diverse workers
- Develop workplace-specific occupational lung disease and lung cancer materials and information to educate stakeholders, including at-risk workers and industries, on the known risk factors and symptoms. Support employers to act to reduce occupational carcinogens and hazards and provide healthy and safe workplaces
- Ensure timely review of Workplace Exposure Standards, to ensure health-based standards are implemented
- Implement nationally consistent, evidence-based and best-practice occupational health monitoring and surveillance
- Invest in and implement greater regulation and enforcement of Workplace Health and Safety Laws across Australia, so workers are protected and occupational lung disease and lung cancer is prevented
- Implement the National Dust Disease Taskforce⁹³ recommendations, including the development and implementation of a National Silicosis Prevention Strategy and accompanying National Action Plan, including a full ban on the importation of some or all engineered stone products.

Outcomes

- Improved workplace health and safety literacy, knowledge and awareness of the risk related to occupational carcinogens and harmful hazards among stakeholders including workers
- Reduced occupational exposure to carcinogens and harmful hazards
- Safer workplaces and more productive Australians
- Reduced rates of occupational lung diseases and lung cancer.



Air quality

Lungs are made to breathe clean air, and the environments where we work, live, and play have a significant short- and long-term impact on health.

Air pollution is the presence of one or more contaminants in the atmosphere - such as dust, fumes, gas, mist, odour, smoke or vapour - in quantities and duration that can damage human health. The main pathway for exposure to air pollution is inhalation. Breathing in these pollutants can cause lung cancer, as well as a range of other conditions including pneumonia, Chronic Obstructive Pulmonary Disease, heart disease, stroke, worsen asthma and other respiratory conditions, and has even been linked to diabetes, adverse pregnancy outcomes and neurological diseases. Air quality can be impacted by natural or seasonal events like bushfires, wood fires, road traffic, construction, mining, transportation, agriculture and other occupational and manufacturing processes. Air pollutants are often invisible, so it is important Australia does not become complacent and instead should take a more proactive approach to protecting health and ensuring good air quality.

Air pollution is responsible for \$16 billion in costs annually, as well as more than 3,000 premature deaths⁹⁴. Lung cancer attributed to air pollution costs over \$4 million annually⁴⁸.

Lung conditions have a marked effect on people's ability to enjoy life, be productive and realise their full potential.

National priorities for action

- Develop a National Strategic Action Plan for Air Quality, which will complement the Australian Government's National Strategic Action Plan for Lung Conditions¹
- Adopt the World Health Organisation Air Quality Guidelines (AQG)⁹⁵.

Outcomes

- Healthy and safe environments where Australian's work, live, and play
- Cleaner indoor and outdoor air quality so Australians can breathe well
- Reduced lung cancer rates and respiratory health burden associated with poor air quality.

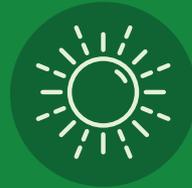
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Lung Cancer Screening

In the first 10 years, a targeted screening program would:



Save over 12,000 lives

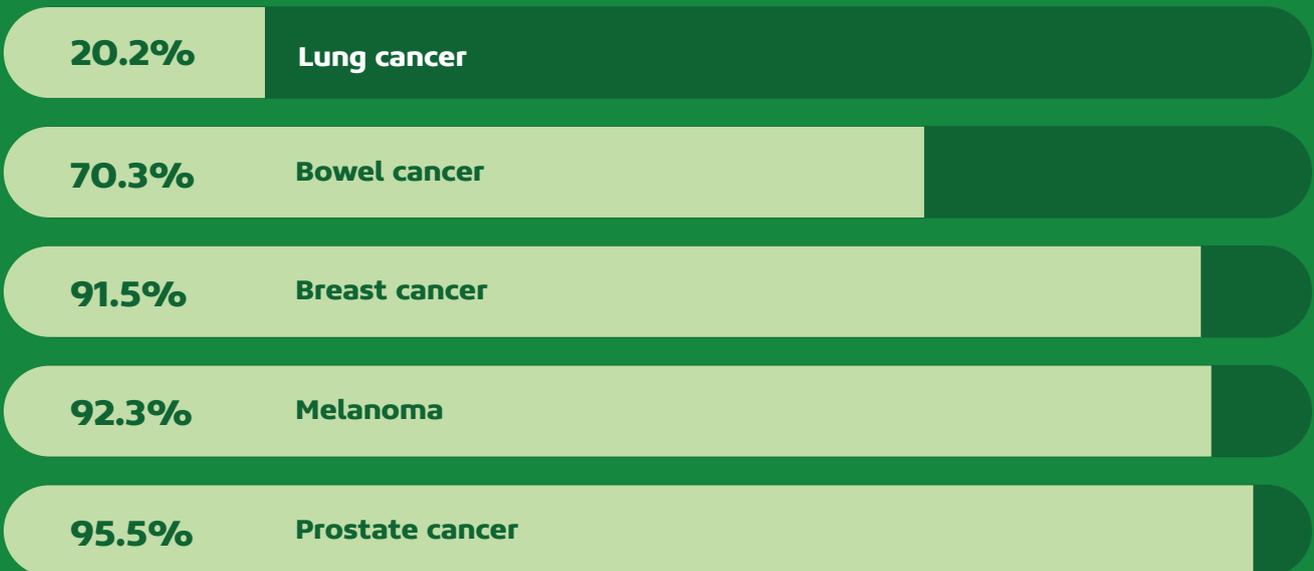


Improve quality of life



Be cost-effective

Lung cancer's 5-year survival rate is the lowest of the 5 most common cancers



Recommendation



Implement a targeted, national lung cancer screening program to diagnose Australians with lung cancer at an earlier stage of disease and save lives.



“A targeted lung cancer screening program in Australia would enable unprecedented changes in clinical management and enable us to tackle the persistently poor outcomes for lung cancer that we’ve observed over many decades. Trials in the US and Europe involving nearly 70,000 people have proven that lung cancer screening is clinically effective. Pilot programs are being implemented across the world and are detecting lung cancers early when curative treatments can be offered. If implemented, a national screening program has the potential to transform outcomes for Australians.”

- Associate Professor Nicole Rankin, University of Melbourne

A national lung cancer screening program would shift diagnosis of lung cancer to an earlier stage and save lives which would, in turn, dramatically reduce the economic toll of cancer on society.

The screening program will use low-dose computed tomography (LDCT) scans in asymptomatic high-risk individuals and will transform the persistently poor outcomes experienced by Australians with lung cancer^{96,97}.

A national lung cancer screening program will enable diagnosis of lung cancers at an early stage, when curative treatment options are available. This is vital to improving health outcomes, survival rates and quality of life. Australians with screen detected lung cancers will need access to funded treatment options including Pharmaceutical Benefits Scheme (PBS)-listed drugs and clinical trials.

Cancer Australia’s Lung Cancer Screening Enquiry report from 2020 recommended a targeted lung cancer screening program be pursued as a priority, based on international and national evidence of clinical effectiveness and safety. What it proposed was a feasible model utilising existing infrastructure in the Australian healthcare system and included a cost-effective economic evaluation. It found that in the first 10 years, a targeted program would:

- Diagnose lung cancers earlier, with over 70% of all screen detected lung cancers diagnosed at an early stage
- Save lives by preventing over 12,000 deaths
- Improve quality of life, with up to 50,000 quality adjusted life years (QALYs) gained
- Be cost-effective, with an incremental cost-effectiveness ratio of \$83,545 per QALY gained⁹⁸.

Through research, analysis and consultation with key stakeholders, Cancer Australia has commenced

work to define the elements for delivery of a cost-effective and equitable lung cancer screening program in Australia.

Following the 2021-2022 budget commitment of \$6 million for early scoping which was highly commended by the community, there was no funding allocated to lung cancer screening in the 2022-2023 budget. We urge the Australian Government to scale up the previous funding to initiate a pilot program and develop national standards, with the aim of reaching full implementation by 2025.

A targeted lung cancer screening population cohort will include the eligibility criteria of people who currently smoke or have previously quit smoking and are aged 55 to 74 years in the general population and aged 50 to 74 years for Aboriginal and Torres Strait Islander people. Lung cancer has a greater impact on Aboriginal and Torres Strait Islander people, people in regional and rural areas, and people living in lower socioeconomic communities. The earlier entry age for Aboriginal and Torres Strait Islander people reflects the fact that they are younger with regards to both lung cancer diagnosis and mortality and therefore have poorer outcomes.

To optimise entry, people would be able to access different pathways into the program, including via a primary care health professional (e.g. general practitioner or Aboriginal health worker), specialist provider or through self-referral to complete a risk assessment. A validated risk assessment tool, also known as a personal risk calculator, will be completed for people entering the program to assess their suitability for a LDCT scan. The risk assessment tool, the PLCO_m2012, gathers data about an individual’s age, ethnicity, education, personal history of cancer, family

history of cancer, smoking status and smoking intensity. If an individual's risk assessment meets a threshold level, they are offered a scan following shared decision-making and informed consent processes.

“In 2017 I was diagnosed with two primary cancers; breast cancer and lung cancer. I was not experiencing symptoms of either cancer. The breast cancer was picked up early, through screening, and was cured through two surgeries. A devastating diagnosis but an excellent outcome. Unfortunately the lung cancer was only found by accident, it had already spread, and it will most likely kill me. I wish there had been a lung cancer screening program in place to find my cancer early, just like the breast cancer.”

- Lorraine, living with lung cancer

The Cancer Australia proposed program is underpinned by a Screening and Assessment Pathway, which determines an individual's journey through screening according to their risk profile. Once enrolled in the program, the participant is offered screening at regular intervals. If a 'positive' result of a lung nodule that requires further investigation is made, appropriate management will be offered, including further tests and investigations. For people diagnosed with a lung cancer, referral systems to ensure timely management through specialist multidisciplinary services are vital to ensure that curative treatments are offered.

In order to attract high-risk people into a targeted lung cancer screening program, investment in promotion and awareness raising is fundamental to ensuring program success and sustainability. Education of the community and healthcare providers about the benefits and harms of screening is essential in establishing an equitable program. People who are not eligible will need information about the rationale for not being offered a LDCT scan.

The healthcare workforce needs to be prepared for changes from the introduction of a national screening program at the key time points including

promotion and recruitment; during LDCT scan assessment and reporting; in the management of lung nodules and incidental findings; in the diagnostic treatment phases for those people diagnosed with lung cancer; and in the coordination and follow up when people return for subsequent scans. A prepared workforce will be able to meet the demand of new lung cancer cases and have capacity across professional disciplines to deliver an equitable and accessible program.

Education and training of the workforce includes a focus on primary care practitioners, nurses and Aboriginal and Torres Strait Islander health workers, who will facilitate shared decision-making and informed consent processes; radiologists in the acquisition, interpretation and reporting of LDCT scans; and multidisciplinary teams inclusive of cardio-thoracic surgeons, oncologists and specialist lung cancer nurses who will coordinate treatment.

The communication of screening results to participants will need tailored resources that take into consideration people's health literacy. A broader set of education and training resources for other workforce disciplines will support the program and assist in educating people at high-risk. A national quality framework and program standards will need to be developed through engagement with key stakeholders. Best-practice approaches to the co-design of participant resources and information is necessary, particularly with Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities, and to appeal to those people who currently smoke tobacco. A significant component includes radiological and data reporting standards, which will be informed by international examples from countries or jurisdictions that currently offer (e.g. United States, Canada) or are pilot testing (United Kingdom) lung cancer screening programs.

A targeted lung cancer screening program should include smoking cessation interventions to maximise program efficiency and the opportunity to encourage people who currently smoke to quit. The program infrastructure must include national standards for the reporting and interpretation of lung cancer nodules. A lung cancer screening register, which is integrated in the National Cancer Screening Register, will be required to track people throughout their screening journey, and to facilitate quality assurance measures and reporting of program outcomes. The delivery and policy aspects of

the program are currently being considered by Cancer Australia, including infrastructure such as mobile screening units to support regional and remote communities, in which late-stage cancer diagnosis is higher. Primary care and specialist lung cancer nurses will be integral to the success of the targeted program, to facilitate rapid referral into treatment centres, or to primary care for managing incidental findings.

5-year survival rate compared to cancers with national screening programs

Lung cancer	20%
Bowel cancer	70%
Cervical cancer	74%
Breast cancer	92%

National priorities for action

In addition to implementing a sustainable national lung cancer screening program, we call on Australian governments to:

- Continue investing in work to enhance the cost-effectiveness and success of a targeted lung cancer screening program through pilot projects, research and policy development
- Develop a national evaluation framework to establish and determine the standards across all program elements
- Invest in promotion and awareness raising of the Australian community through education, recognising the need to co-design resources for Aboriginal and Torres Strait Islander people and other priority groups to ensure an equitable program
- Invest in the education and training of the workforce, acknowledging the central role of primary care healthcare providers (including general practitioners, nurses, Aboriginal and Torres Strait Islander health workers and health promotion workers), and multidisciplinary teams inclusive of radiologists, respiratory

physicians, specialist lung cancer nurses, cardiothoracic surgeons and oncologists across secondary and tertiary sectors

- Dedicate resources for the development of a quality assurance framework and funding of innovative research that will facilitate the principles outlined by Cancer Australia: agile, accessible, values-based, person-centred, informed by best-practice, evidence-based, and research and data-driven.

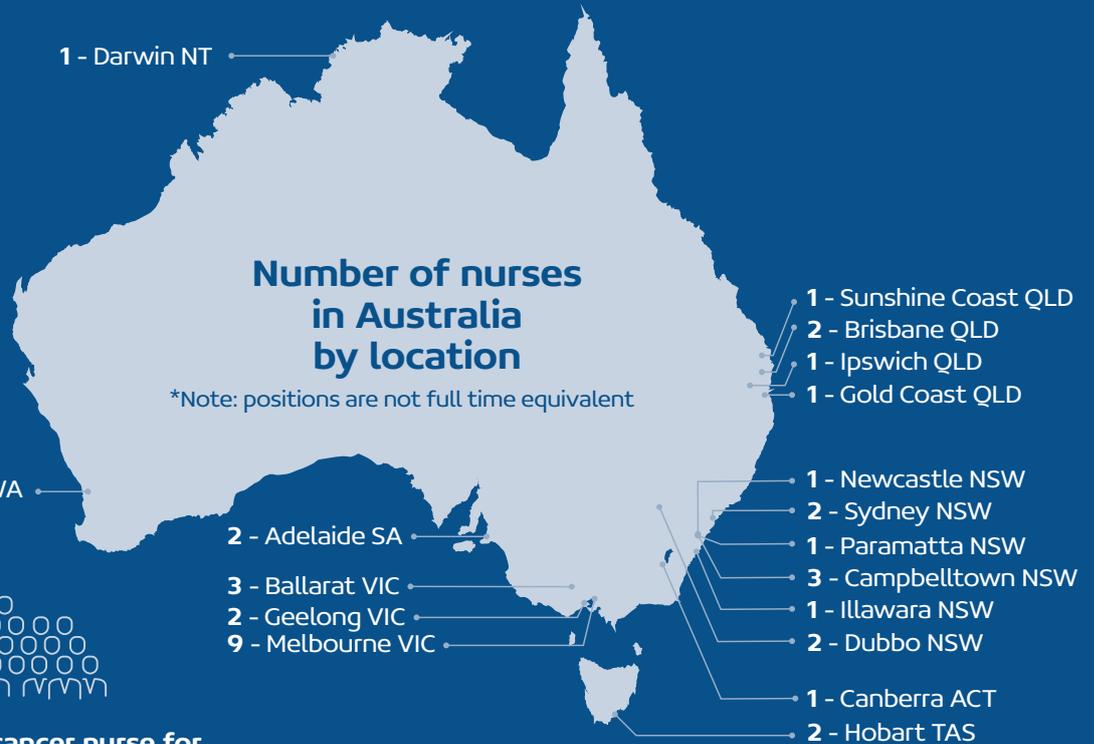
Outcomes

- More than 12,000 deaths will be prevented in the decade following the introduction of a national screening program
- Lung cancers diagnosed at earlier stage, resulting in curative treatments being offered and up to 50,000 QALYs gained
- Significantly improved health outcomes including survival and quality of life for Australians with lung cancer
- A national lung cancer screening program that is evidence-based, acceptable to participants and supported by a capable and skilled workforce.

The key to improving survival and quality of life of Australians affected by lung cancer is to diagnose it early. We urge the Australian Government to implement lung cancer screening in full by 2025.

3

Specialist Lung Cancer Nurses



There is only 1 lung cancer nurse for every 616 patients compared to breast cancer with 1 nurse for every 168 patients.

Major inequity in Commonwealth funding for lung cancer nurses since 2019

\$0.9 million lung

\$30 million breast

\$23 million prostate

When a Specialist Lung Cancer Nurse (SLCN) is involved:

44%
are more likely to have access to treatment

75%
fewer presentations to emergency department (ED)

There are **37 SLCNs** to support the **22,800** Australians living with lung cancer

Recommendation



Invest in 100 government-funded Specialist Lung Cancer Nurses by 2025.

“I hope that one day there will be less ignorance about the causes of lung cancer, and that others living with the disease will be able to access the support they need, including the specialist care only a SLCN can deliver. Australia can - and should - invest in significantly more nurse specialists.

In April 2017, I was diagnosed with breast cancer. I immediately and consistently received overwhelming warmth and support from everyone, and people understood that something devastating was happening to me. Although the cancer was only in my right breast, in June 2017 I opted to have a double mastectomy because the initial lumpectomy failed to remove all the cancer. I received informed and kind advice from my surgeon and breast cancer nurses as I decided whether to have one or two breasts removed. I was soon told I was cancer free, and I felt enormously relieved. I felt like my cancer journey was over.

However, within weeks, doctors found a lesion in my right lung which I wasn't told about for months. Eventually, in October 2017, I was told I had inoperable stage IIIA lung cancer that had recently spread to a lymph node in the centre of my chest.

The reaction to a lung cancer diagnosis is very different to a breast cancer diagnosis. Even people I had known for years quizzed me on my smoking status, medical professionals assumed I was or had been a smoker. I was a lifelong distance runner and a never-smoker but was left wondering, had I been a smoker, whether people would think lung cancer was my own fault.

Following 'go hard' chemotherapy and radiotherapy, and later, the removal of the middle lobe of my right lung, I am left with about 30% lung function and a permanently damaged trachea. The cancer still spread, and in August 2019 I was told I had stage IV lung cancer with a lesion in my liver. Since then, I've been taking a targeted therapy that has shrunk the cancer, but I continue to only have 30% lung capacity as a result of earlier treatments.

Having been through two different cancer diagnosis, I have experienced many contrasts in my journey. For example, when I had breast cancer, I had ready access to breast cancer nurses, while as a lung cancer patient, I'm yet to meet one in the course of the four years of my treatment.”

- Lorraine, living with lung cancer

Why SLCNs are critical

SLCNs are important at every step in the lung cancer patient pathway:

- Prevention and screening
- Diagnosis and staging
- Multidisciplinary team (MDT) treatment and management
- Progression
- Mental health and wellbeing
- Survivorship
- End of life care.

We know that patient outcomes and overall wellbeing are drastically improved when a SLCN is involved⁹⁹.

- 44% more likely to have access to treatment¹⁰⁰
- 75% fewer avoidable ED presentations due to SLCN symptom assessment and management¹⁰¹
- Increased receipt of anticancer therapy due to patients' improved health status and therefore eligibility for treatment^{100, 102}
- Reduced wait times from referral to treatment, improving the potential for better overall health outcomes¹⁰³.

SLCNs also play a critical role in reducing mental and psychological distress in people living with lung cancer^{99, 104}.

Role of the SLCN

A SLCN is an advanced practice registered nurse working in the specialist field of lung cancer. They are an expert practitioner responsible for advanced and complex cancer healthcare delivery, including coordination, leadership, consultancy and advocacy, and deliver quality and safe, individualised care to people living with lung cancer and their families and carers.

The role is multifaceted and SLCNs operate across the five domains of advanced nursing practice – clinical care, optimising health systems, leadership, research and education¹⁰⁵⁻¹⁰⁸. SLCNs are responsible for providing an evidence-based approach to screening, assessment and intervention as critical supportive care components of a patient's cancer experience, and are core members of the lung cancer MDT¹⁰⁹.

Importantly, SLCNs provide a consistent, timely point of contact for patients and their families and MDT members, ensuring a seamless continuum of care between the patient's primary place of treatment, home and community. This consistency is pivotal to improving access to treatment, and the SLCN role is essential to ensuring that people with lung cancer have early access to supportive care, from pre-diagnosis through to treatment, and end-of-life.



“Like the positive outcomes reported by people living with other cancers in Australia and around the world who have access to a specialist cancer nurse, an investment of 100 SLCNs will significantly improve the trajectory for Australians with lung cancer. With access to a SLCN, people will not fall through the gaps in our excellent but complex healthcare system. They will be supported in their most vulnerable and distressed moments with timely, evidence-based, expert care and interventions, to promote wellbeing and live their best lives.”

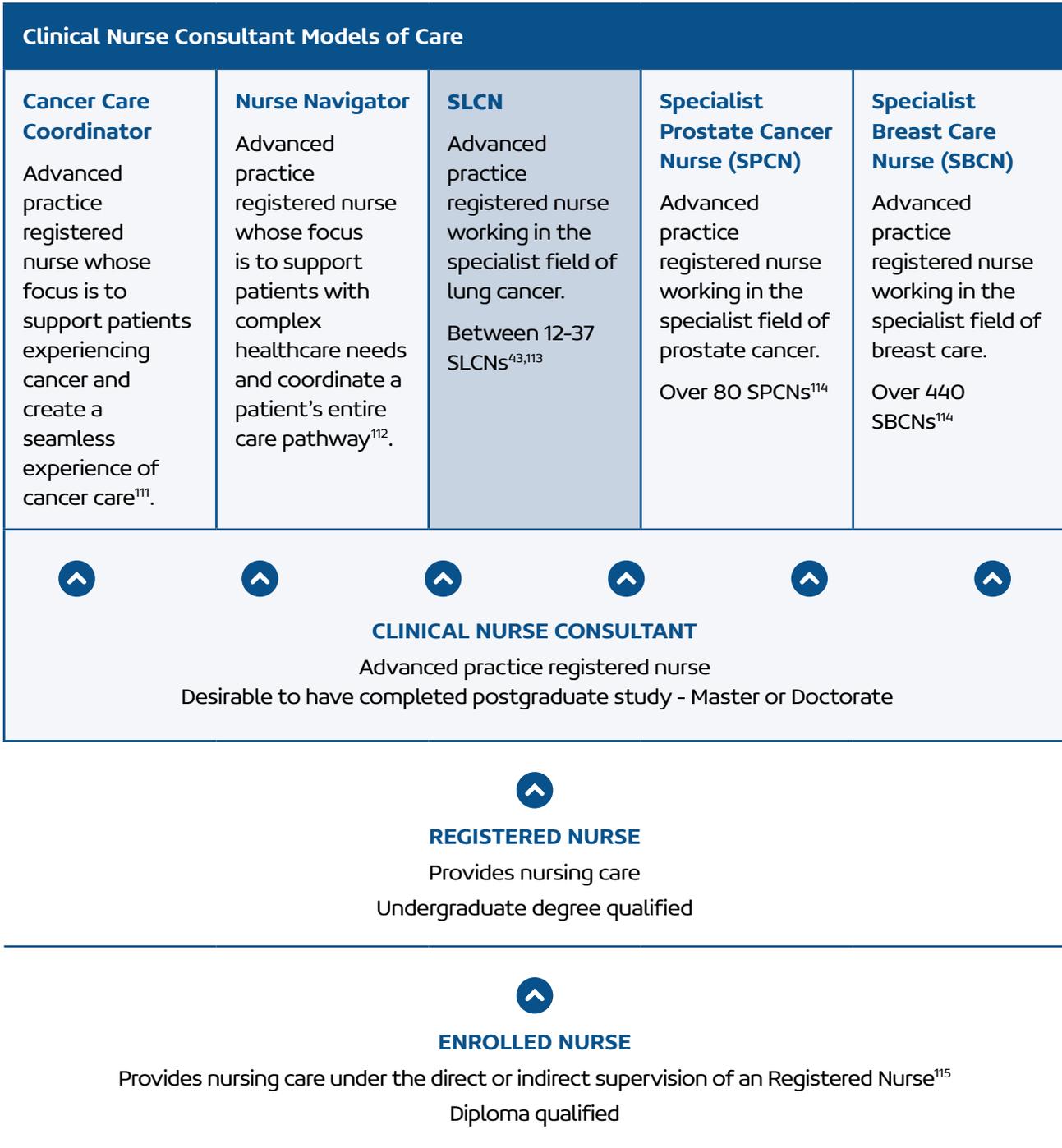
**- Dr Vanessa Brunelli,
Queensland University of Technology**

SLCNs within the Australian nursing workforce

Nurses make up the largest clinical workforce in Australia¹¹⁰. The nursing workforce is made up of different roles that vary in grade, scope of practice, and seniority. Legislated roles are nationally organised, despite variation in how they may be implemented in different healthcare contexts.

SLCNs are advanced practice registered nurses working in the specialist field of lung cancer. The SLCN operates as one of many different Clinical Nurse Consultant models of care (see figure on next page).

The Australian nursing workforce - pathway to SLCN



A critical shortage of SLCNs is compromising lung cancer care

There is a critical shortage of specialist lung cancer nurses in Australia.

A survey of the SLCN workforce conducted by Lung Foundation Australia in 2018 identified twelve¹² full time equivalent (FTE) SLCNs positioned around Australia¹¹³. In recent years the workforce has increased marginally; a 2021 survey identified 37 Clinical Nurse Consultants nationally, including SLCNs (these positions are not all full time)⁴³. The Australian Government's commitment in the 2020-21 Budget (\$900,000) to fund an additional five FTE nurses is welcome, but the commitment is disproportionate to the burden of lung cancer on families across Australia, and the need for a significant uplift in the number of SLCNs nurses remains⁴³.

SLCNs are a core member of the MDT for lung cancer care³⁶.

The delivery of timely, equitable and quality care to people living with lung cancer and their families remains inconsistent and access to SLCNs is inadequate, with 37 SLCNs to support the 22,800 Australians currently living with lung cancer. This critical workforce shortage places the delivery of lung cancer care in Australia well short of clinical practice guidelines and international best-practice^{39,40,116} which recognise SLCNs as a core member of the MDT for lung cancer care. From the patient perspective, it risks sustaining the current state of high unmet supportive care needs^{62,69}, poorer health outcomes^{63,64,70,71,117} and lower overall quality of life^{118,119} when compared to those living with other cancers and who experience the involvement of a specialist cancer nurse in their care^{120,121}. Australians living with this complex and burdensome disease deserve to experience the fundamental care and benefits similar to others with different cancer types.

The demand for timely, equitable and quality care exceeds the current SLCN workforce capacity. The need for reform is real, immediate and increasing.

Investing in the SLCN workforce will deliver strong benefits

Investing in the SLCN workforce will:

- Improve health-related quality of life outcomes of people living with lung cancer and their families
- Align and improve the quality of lung cancer care consistent with evidence-based clinical practice guidelines and international best-practice
- Reduce variation in lung cancer and improve timeliness of care
- Alleviate the critical SLCN workforce shortage^{109,122}, reduce the high caseload burden on the existing limited workforce and resolve critical access issues to SLCNs⁴³
- Ensure the SLCN workforce is appropriately positioned to support the increasing number of people who will be diagnosed with lung cancer through the national lung cancer screening program, to truly realise the potential of this investment
- Address the current inequity of access to SLCNs compared to other cancer types.

How does lung cancer compare to other cancers?

Cancer-related disease burden	Lung	#1	Lung cancer: Highest burden of disease
	Breast	#3	
	Prostate	#5	
Number of deaths	Lung	8,739	Lung cancer: Highest number of deaths
	Breast	3,243	
	Prostate	3,582	
5-year survivorship	Lung	20%	Lung cancer: Lowest 5-year survival rate
	Breast	92%	
	Prostate	95%	
Commonwealth funding for nurses since 2019	Lung	\$900,000	Lung cancer: Lowest level of investment
	Breast	\$30 million	
	Prostate	\$23 million	

Inequities of access to specialist nurses

	Specialist nurses	People living with cancer	Specialist nurse patient load
Lung	37	22,800	616
Breast	440	74,000	168

New PwC analysis proves government investment in SLCNs makes sense³⁵

- New analysis reveals 230 SLCNs nationally would provide the level of care needed for the 22,800 Australians living with lung cancer right now. This is based on best available evidence, which provides that the optimal caseload is 100 patients per FTE SLCN nurse.
- The analysis finds that two key economic benefits of SLCNs is in reducing avoidable ED presentations through SLCN-delivered symptom management and increasing the timeliness of access to treatment.

	Funding	
	+100 SLCNs	+230 SLCNs
Would support:	10,000 Australians (44% of patients)	All Australians with lung cancer
At an annual cost of:	\$15,381,250	\$34,321,030
While delivering health savings of:	\$18,101,850	\$41,140,560
Equating to:	428 life-years saved	973 life-years saved
At cost-benefit ratio of:	1.18	1.20

National priorities for action

- Invest in 100 government-funded SLCNs by 2025
- Fully implement the SLCN pilot project
- Develop a workforce plan for lung conditions, as recommended in the National Strategic Action Plan for Lung Conditions (Action 5.3)¹, to address the current shortage of SLCNs, guide workforce design and development, and future proof Australia’s multidisciplinary lung and respiratory health workforce
- Continue funding Lung Foundation Australia’s Lung Cancer Support Nurse Service, a national telephone helpline to support people living with lung cancer and their families with education, information, intervention, and referral. This is a particularly vital lifeline for people living with lung cancer who live in rural or remote locations where access to healthcare, particularly specialised cancer treatment, is limited or non-existent.

Outcomes

- Improved value and quality of patient-centred lung cancer care
- Improved access to lung cancer treatment and timeliness of treatment
- Increased receipt of anticancer therapy
- Strengthened patient capacity to self-manage
- Improved outcomes for patients and carers affected by lung cancer (cancer outcomes, quality of life and wellbeing)
- Improved cancer service alignment with optimal lung cancer care
- Reduced avoidable ED presentations.



100 SLCNs will deliver over \$18 million in health savings.

4

Comprehensive Genomic Profiling

There is **no public funding** for broader comprehensive genomic testing in the clinical care of cancer



Comprehensive Genomic Profiling (CGP) at diagnosis is estimated to lower treatment cost by

21% per person

Investing in CGP will deliver strong benefits for Australians with lung cancer



Greater diagnostic accuracy



Targeted treatment options



Improved patient outcomes:

- Survival, including progression-free survival (PFS)
- Quality of life and mental health



Cost savings

Recommendation



Implement Government-funded Comprehensive Genomic Profiling as standard of care for Australians with lung cancer.

“ I was diagnosed with lung cancer when I was 47 years old.

At this time in my life, I was living the dream on the Northern Beaches of Sydney. I was an extremely active mother of a 10 and a 12-year-old. I was flying, literally, around the world as a flight attendant and was very active at the gym doing high energy classes. Above all, I was an extremely busy, hands-on mum and volunteered at my children's schools regularly. As you can imagine, my stage IV lung cancer diagnosis was a complete shock – especially as there were no obvious warning signs or symptoms.

I have now been living with lung cancer for three-and-a-half years. During this time, my condition has worsened, and I'm told it is not curable. However, I remain hopeful that research will keep me alive for many more years to come. I am currently being treated with a targeted therapy which is specific to the genetic mutation that caused my lung cancer. Knowing if your lung cancer may be suitable to targeted therapies such as the one I am currently receiving is only possible using biomarker testing or genetic profiling. All people with lung cancer should receive genetic profiling as soon as possible.

I hope the clinical trial I am part of will enable improved treatments for this disease in the future.

I have learnt that life is very precious, and short. I am determined to be a survivor of this disease, and am trying to get back to my job as a flight attendant, as well as helping in my son's school canteen. As well as my medical treatment, being open about my diagnosis and connecting with nature and yoga has enabled me to heal emotionally and physically, as well as surrounding myself with loving and supportive family and friends.

- Georgia, living with lung cancer

Genomics are changing the cancer landscape

Despite advances in diagnostics and treatment, the 5-year survival for all lung cancer in Australia remains terribly low at only 20%, with minimal improvement in the last 40 years. CGP presents an opportunity to position lung cancer at the forefront of personalised medicine and redress the persistent poor outcomes for Australians with lung cancer.

Genomics has transformed the diagnosis and treatment of cancer over the last two decades.

Lung cancer is a heterogeneous disease that is increasingly being classified and treated based on its molecular profile, not simply by tissue of origin.

We now know that each patient, even those sharing the same diagnosis of lung cancer, has a unique set of genomic changes that can influence how they will respond to therapy. In order to select the best cancer treatment, a comprehensive profile of the tumour at the DNA level is needed. Targeted therapies attack specific modifications on, or in, the tumour cells and often cause fewer side effects

because they focus on targeting what is wrong with the cancer cell, instead of killing normal, healthy cells too.

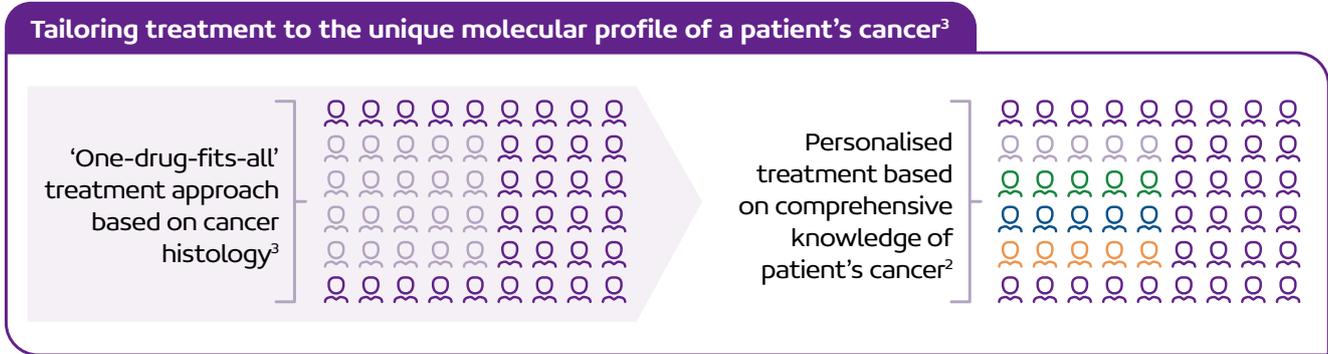
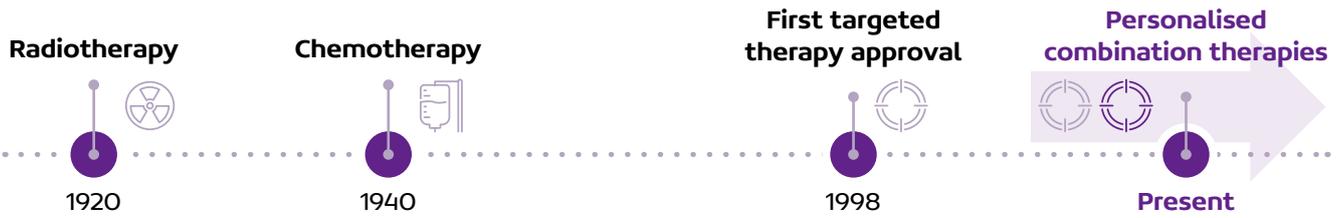
Genomic testing has revolutionised the way cancer treatments are being developed and applied through enabling targeted and personalised therapies aimed at particular mutations, and immunotherapies directed at a patient's own immune system¹²³.

Using a tumour's unique genomic fingerprint to match patients to their most effective treatment is the cornerstone of personalised (or precision) medicine.

CGP will deliver strong benefits for Australians with lung cancer, including:

- Greater diagnostic accuracy¹²⁸
- Targeted treatment options¹²⁹
- Improved patient outcomes¹³⁰:
 - Survival, including progression-free survival¹³¹
 - Quality of life and mental health¹²⁸
- Cost savings^{128, 132}.

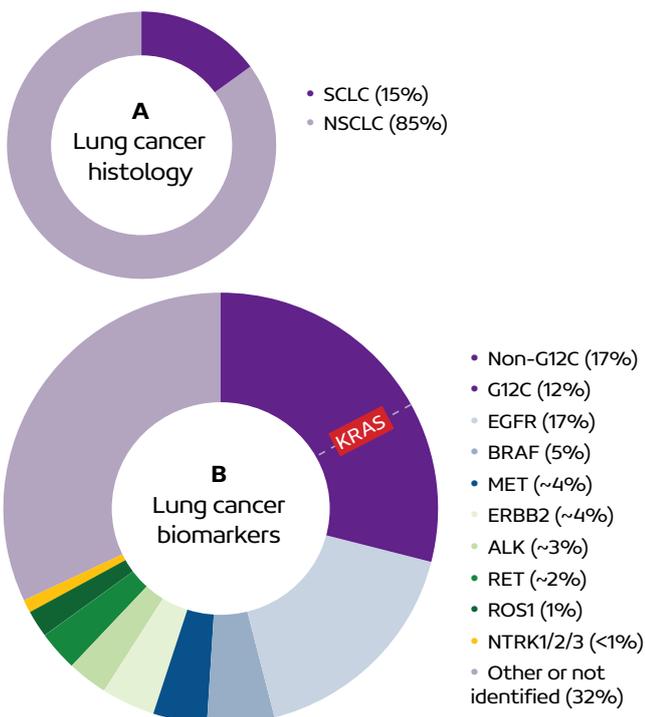
The evolution of cancer care¹²⁴⁻¹²⁷



Lung cancer is at the forefront of personalised medicine

Historically, lung cancer has been classified broadly according to the size of the cancer cells seen under a microscope: non-small cell lung cancer (NSCLC) (85% of total diagnoses) or small cell lung cancer (SCLC) (15% of total diagnoses)²⁸. However, during the past decade, the discovery of predictive biomarkers has created new treatment opportunities with targeted therapy and immunotherapy. We now understand that there are over 30 mutations associated with lung cancers¹²⁸.

Lung cancer histology and biomarkers²⁸



“Being able to access a targeted therapy has been literally life-saving for me and dozens of patients like me that I connect with online. We are now living for many more years on these new treatments and we are living relatively well. We also have the luxury of hope now, because developments in this area have not only improved our situations but will do even more for lung cancer patients to follow. I am so passionate about the possibilities for research and treatment that comprehensive genomic testing will unlock. We can now realistically imagine a future where a lung cancer diagnosis is not an automatic death sentence. This helps me find peace in this dreadful situation.”

- Person living with lung cancer

CGP for Australians with lung cancer would, in many cases, lead to funded targeted treatments

There are many known biomarkers and available treatments for lung cancer. NSCLC has around ten drug targets and over 30 drugs¹²⁸. For most Australians with lung cancer, CGP will identify biomarkers that lead to funded, treatment options (Pharmaceutical Benefits Scheme (PBS) drugs or clinical trials) – the results create a clear, actionable treatment pathway.

Given that access to treatments is critical to realising the value of genomic testing, CGP for Australians with lung cancer is warranted. Australians with lung cancer who undergo genomic testing have a higher chance of experiencing improved health outcomes than in cancers that are less well-understood¹²⁸.

Limited funding means Australians have inequitable access

Currently, there is no public funding for broader comprehensive genomic testing in the clinical care of cancer¹²⁸.

Medicare Benefits Schedule (MBS)-funded tests are mostly single gene tests or small panels. Tests funded through the MBS provide a way of identifying eligible patients for the PBS-funded targeted treatments.

CGP is usually only offered in the clinical research setting or when patients are willing to pay out-of-pocket (OOP). Some people willing to pay OOP send samples overseas for CGP at private companies. The cost of CGP (250-500 genes) is \$1,200-\$6,000¹²⁸. Most patients cannot afford the OOP costs, presenting an equity issue.

Inequitable clinical access to CGP is an issue in the absence of MBS funding, as only patients who can afford to pay thousands of dollars OOP are able to receive the tests.

Furthermore, a large number of genomic tests are funded outside of the MBS. There are over 80 genomic tests (46 of which are cancer-related) listed on the MBS, while there are approximately 1,700 types of tests being performed by laboratories across Australia^{128,133}.

Internationally, organisations such as the American Society of Clinical Oncology and National Comprehensive Cancer Network have issued guidelines recommending broad molecular profiling tests such as CGP for specific cancer types, including advanced NSCLC. Countries such as the United States and Japan are seeing high adoption rates of genomic-based diagnostics, particularly for NSCLC¹³⁴. A recent Canadian paper recommends tumours with five or more genomic biomarkers linked to approved therapies should be prioritised for CGP funding to replace current limited testing modalities¹³⁵. Large panels are increasingly being incorporated into standard of care in other countries¹³⁶, with a shift away from single-gene testing or smaller targeted panels¹³⁷.

Australians with lung cancer have high unmet clinical need for the latest personalised medicine technologies. Increasing access to CGP is a critical component to improving the quality of care that

Australians with lung cancer receive. Public funding for CGP in the clinical care of lung cancer would enable equitable access to the tests needed to prescribe targeted therapies, including innovative treatment through clinical trials¹²⁸, and further integrate genomics into clinical practice.

A broader approach to genomic testing is needed

There are different types of genomic tests, which can be categorised by the scale of gene analysis. A CGP panel looks for a large number of genetic alterations and proteins in all the genes known to be involved in cancers. There is a wide range of panel sizes; recent Medical Services Advisory Committee guidelines define a large gene panel as >200 genes¹³⁸. CGP typically tests 300-500 genes¹²⁸.

A broader approach to genomic testing that moves beyond the narrow scope of single gene tests or small panels will help Australia to harness the potential of personalised medicine.

The advantages of a broader approach to genomic testing using CGP:

- Improve the chance of finding actionable biomarkers and connecting people to funded treatments
- Avoid 'testing odysseys' where multiple successive tests are conducted before a useful biomarker is identified
- Reduce cases of insufficient biopsy tissue needed for multiple successive tests
- Identify emerging biomarkers to future proof the panel
- Access to information not only on mutations, but also structural variants and patterns associated with cancer¹²⁸
- Increase the likelihood of creating new treatment pathways in the future
- Gain a deeper understanding of cancer
- Improve management of cancer for future patients as well as current patients
- Economically favourable, as upfront CGP is less costly than sequential single gene tests^{135,139}, including reduced treatment costs^{140,141}
- Shorter wait time for results and reduced time to diagnosis; in one study, time to diagnosis was reduced by 2.8 weeks compared to sequential single-biomarker testing¹⁴¹.

New PwC analysis proves government investment in CGP makes sense³⁵

CGP at diagnosis is estimated to lower the cost of treatment by 21% per patient, due to personalised treatment increasing PFS, overall survival and response to treatment^{49,132}.

The case for CGP at the point of initial treatment planning

Cost	Cost of CGP per patient	\$3,000
	CGP for over 60% of lung cancer patients at the point of initial treatment planning	Total investment required in additional testing: \$26 million per annum
Benefits / Outcomes	Life years gained	110 per annum
	Estimated value	\$24 million per annum
	Estimated savings through personalised treatment	Total federal and state health savings: \$48 million per annum
	Increase in PFS	3 months per lung cancer patient. Every \$1,800 of funding leads to a month of PFS gained for a lung cancer patient in Australia
	Increase in overall survival	6 months per lung cancer patient, every \$900 of funding leads to a month of overall survival gained for a lung cancer patient in Australia

CGP Benefit Cost Ratio: 1.8

For every dollar invested, \$1.8 is saved by government.

“Genetic testing means appropriate treatment given to individual patients. Side effects from less effective treatments are avoided. Many lung cancer patients are financially impacted by their disease. By covering the cost of genetic testing some of this impact will be reduced. Genetic testing will also hopefully give data to researchers, improving our knowledge of lung cancer and possible treatments. Genetic testing should improve survival time and quality of life for lung cancer patients.”

- Person with lung cancer

Investment in national genomics infrastructure is required

Australia is in a good position to create a world-leading cancer genomics architecture to support genomics delivery and ultimately improve outcomes for Australians. Genomic technology is relatively early in its adoption and there is yet to be a coordinated national approach to its use.

National genomic infrastructure is critically important to the integration of genomics into clinical practice¹²⁸. Success in implementation is dependent on the infrastructure and capacity throughout the testing pathway from referral, through to carrying out the tests, interpreting the results¹³⁶ and accessing targeted therapies.

Genomics infrastructure includes:

- Workforce
- Financing
- Services (e.g. testing and sequencing)
- Data
- Research¹⁴².

Australia is well positioned to build on its ongoing genomics research initiatives which includes ASPIRATION, an observational cohort study to assess the clinical impact of comprehensive genomic profiling in metastatic lung cancer patients. An opportunity exists for Australia to create a hub for research and drug development and attract industry sponsors of clinical trials.

Analysis and interpretation of the test results are key elements of the CGP testing process. Processes and methods for managing such large amounts of information to derive clinically meaningful insights are required to maximise the utility of the technology¹²⁸, as are pathways to targeted therapies.

Given Australia’s relatively small population and lung cancer incidence, there are advantages to establishing a nationally coordinated approach. Australia has a unique opportunity to build a national genomics infrastructure that harnesses the existing expertise and infrastructure already in place and builds on overseas experience. It is important that infrastructure is future-proofed by reinforcing it ahead of future challenges.

Workforce is key

The number of genetics healthcare professionals in Australia is insufficient to meet the growing demand for genomics, with just 150 clinical geneticists and 220 genetic counsellors in clinical roles¹⁴³. More clinical genetic healthcare professionals are required

to ensure the Australian healthcare system has capacity to provide genomic medicine.

The outcomes of genomic medicine – greater diagnostic accuracy, targeted treatment options, and ultimately, improved patient outcomes – depend on skilled health professionals. Non-genetic healthcare professionals and the lung cancer workforce will increasingly have roles in the delivery of genomic medicine, and will need significant education and training that is fit-for-purpose depending on local service delivery models¹⁴³. Building a skilled, genomics-literate healthcare workforce is critical to enable mainstreaming of genomic medicine¹⁴². This is particularly important as the growing use of genomic investigations is rapidly exceeding the capacity of the expert genetic workforces^{144,145}, requiring non-genetic medical specialists to incorporate genomic medicine and take on tasks previously in the remit of genetic health professionals^{146,147}.

The workforce – oncologists, laboratory scientists, clinical pathologists, bioinformaticians, clinical geneticists, genetic counsellors, and non-genetics

healthcare professionals¹³³ – must know how to:

- Determine when to order genomics tests
- Interpret test results to inform clinical decision-making
- Counsel patients on genetic conditions and genomic tests
- Obtain informed consent
- Ensure understanding and appropriate action following test result or procedure¹⁴⁸.

We know that the Australian workforce is motivated to deliver genomic medicine, but education and training is required¹⁴³. Quality, evidence-based genomics education is essential to ensure that genomics is used appropriately and, ultimately, is translated to improved patient outcomes¹⁴⁹⁻¹⁵⁴. Genomics education needs across a range of health professions are known^{143,155,156}.

Ensuring the capacity of the Australian healthcare system to provide genomic medicine – in terms of workforce numbers and ability to adopt new genomic technologies – is a priority.

National priorities for action

- Implement government-funded CGP as standard of care for Australians with lung cancer
- Integrate genomics into clinical practice in Australia and develop clear genomic testing pathways from diagnostic test result to funded treatment options (PBS-listed drugs or enrolment in clinical trials)
- Fund, conduct and expedite lung cancer genomics research including clinical trials and research into liquid biopsies, including the potential to use liquid biopsies more broadly as an alternative to solid tissue biopsies for tumour sampling
- Develop a workforce plan for lung conditions, as recommended in the National Strategic Action Plan for Lung Conditions (Action 5.3)¹, to increase the number of clinical genetic healthcare professionals in Australia, guide workforce design and development, and future proof Australia's lung and respiratory health workforce¹⁴³
- Develop a national lung health training and education framework for health professionals,

as recommended in the National Strategic Action Plan for Lung Conditions (Action 5.2)¹, to improve the genomics literacy and capability of the genetics and cancer healthcare workforce

- Develop, deliver and evaluate education and awareness campaigns to build the genomics literacy of consumers and ensure they are equipped with the information needed to make informed choices regarding their lung cancer care.

Outcomes

- Improved lung cancer survival, including progression-free survival
- Improved quality of life and mental health for Australians with lung cancer
- Cost savings
- Access to health professionals appropriately trained in genetics and genomics when needed, and when it is appropriate to do so
- Equitable access to genomic testing and targeted therapies
- Adequate and competent workforce to meet current and future demand for genomics medicine.

5

Lung Cancer Survivorship

Almost
168,000

people will be diagnosed with lung cancer over the **next 10 years**

Lung cancer survivors have significant:



Unmet care needs



Poor health outcomes



Low overall quality of life

Lung cancer survivors face physical, emotional, financial and social issues that differ from those during active treatment.

This includes:



Ongoing side effects of treatment



Fear of a cancer relapse



Cancer-related fatigue



Cognitive changes



Pain



Distress, anxiety and depression



Sleep issues

Recommendation



Greater research investment and focus on lung cancer survivorship through practical resources.

“ I was 60 years old and had recently completed a 50km charity run when I was diagnosed with stage IV lung cancer in November 2019. I was feeling perhaps the fittest I had been in a number of years before that race. In the weeks after the race, my back became very sore and I felt unwell with what we thought was pneumonia. On the 12th November, I could not get out of bed due to excruciating nerve pain in my spine. When the ambulance team moved me into an upright position, I took four steps then my T7 vertebrae collapsed, crushing my spinal cord. Unbeknown to me, the cancer in my lung had spread to my spine. Since that day I have been living in a wheelchair and I was also given eight weeks to live.

It was an incredibly difficult time, not just for myself, but for my family and friends. Not only was I dealing with lung cancer and newly acquired paraplegia, but initially I still had to run my incredibly demanding business from a hospital bed, which in hindsight was a good distraction. I also had to wait three weeks for my spinal surgery to heal before the lung cancer could be treated.

It's been an interesting battle, however so far, I've beaten the odds due to a fantastic oncology team who are more scientists than doctors, as well as an extremely positive attitude. I now find myself cancer free, which is no small feat given the devastation of lung cancer – just 20% of those diagnosed are alive five years after diagnosis.

Even in the darkest of times and in the fight of my life there was always time to laugh with family, with nurses and clinicians – obviously a coping mechanism to downplay the seriousness of the situation.

For anyone else that finds themselves in the same position, I would say, be positive, trust in your oncology team, there are so many targeted treatments now and there are more coming every year. The more research into targeted treatments the better. I am still here because of a great team who never gave up on finding the gene that was causing the issue, then finding a mix of solutions to target that gene.

I am now continuing with regular physiotherapy to heal from the destructive impacts of the disease. I am proud to say that I'm slowly walking again, I have my eyes set on completing the 50km run again in the next few years.

- Craig, living with lung cancer



Defining 'cancer survivor' and 'survivorship'

The term 'cancer survivor' describes a person living with cancer from the point of diagnosis, through the balance of life^{36,157,158}. There are many types of survivors, including those living with cancer and those free of cancer¹⁵⁷. The term captures a population of people living with a history of cancer, rather than providing a label that resonates with everyone¹⁵⁷. Alternative terms include

'thrivers', 'someone who has had cancer'¹⁵⁹ and 'people living with and beyond cancer'¹⁶⁰, although currently, there is no consensus beyond the term 'cancer survivor'¹⁶¹.

Survivorship provides a focus on the health and wellbeing of a person living with a history of cancer. Survivorship includes a focus on the ongoing management, recovery, health and wellbeing during and after cancer treatment. Family members and caregivers are also part of the survivorship experience¹⁶⁰.

The number of lung cancer survivors is growing

Currently in Australia over 22,800 Australians are living with lung cancer, and this number is growing. Over the next 10 years, almost 168,000 will be diagnosed with lung cancer³⁵.

The number of people surviving lung cancer in Australia has increased, although compared to other cancers, lung cancer survival rates remain low. In fact, lung cancer remains Australia's most common cause of cancer-related death in people of all ages³¹. Advances in treatments (such as targeted therapy and immunotherapy) and early detection and screening for lung cancer will continue to drive improved survival rates. As lung cancer survival increases, an increasing number of Australians will require ongoing treatments, support and long-term follow-up care.

People with lung cancer have significant and high unmet needs

Lung cancer is at a critical point of transforming from a fatal condition to one that is treatable. It is time to broaden our focus to include the growing number of lung cancer survivors who have significant and largely unmet needs, and improve their health and wellbeing.

Lung cancer survivors experience significant physical, psychological, social and economic concerns, and may continue to experience burdensome symptoms for years. Lung cancer survivors have significant and high unmet care needs^{62,69,162}, poorer health outcomes^{63,64,70,71,117} and lower overall quality of life^{118,119}.

“I was very young, extremely independent, worked full time, and I found things like having a shower started to become very difficult. Like brushing your teeth, preparing food, all the freedoms that you took for granted...even just talking.”
- QLD resident with lung cancer⁶¹

Survivorship care programs and support services are often designed for cancer survivors in general, and not tailored to meet the specific needs of people living with lung cancer. People with lung cancer have significant and high unmet

needs, and their experiences are unique and dynamic; it is critical that lung cancer survivors receive the right information and support at the right time.

“Physically, emotionally and spiritually draining. I have pain associated with bone mets in the L2 vertebrae. I have also become quite isolated due to COVID and I have some low level depression.”
- NSW resident with lung cancer⁶¹

Delivery is fragmented and people are missing out

Survivorship programs and support services are available from a range of different providers, however, delivery is fragmented, meaning that some cancer survivors miss out.

Survivorship care providers in Australia include: community health, primary healthcare, state and territory governments, non-government and consumer organisations, private providers, tertiary cancer centres and dedicated survivorship centres.

Enhancing access to existing survivorship tools, information and support services that are proven to work is critical. For example, pulmonary rehabilitation is the most effective evidence-based intervention to manage breathlessness, a common symptom experienced by people with lung cancer. It improves exercise capacity, quality of life, and teaches people the skills to manage their condition and stay well. Pulmonary rehabilitation is cost-effective, although access in Australia is extremely limited. Furthermore, investment in new models of survivorship care and evidence-based tools, information and support services is urgently needed.

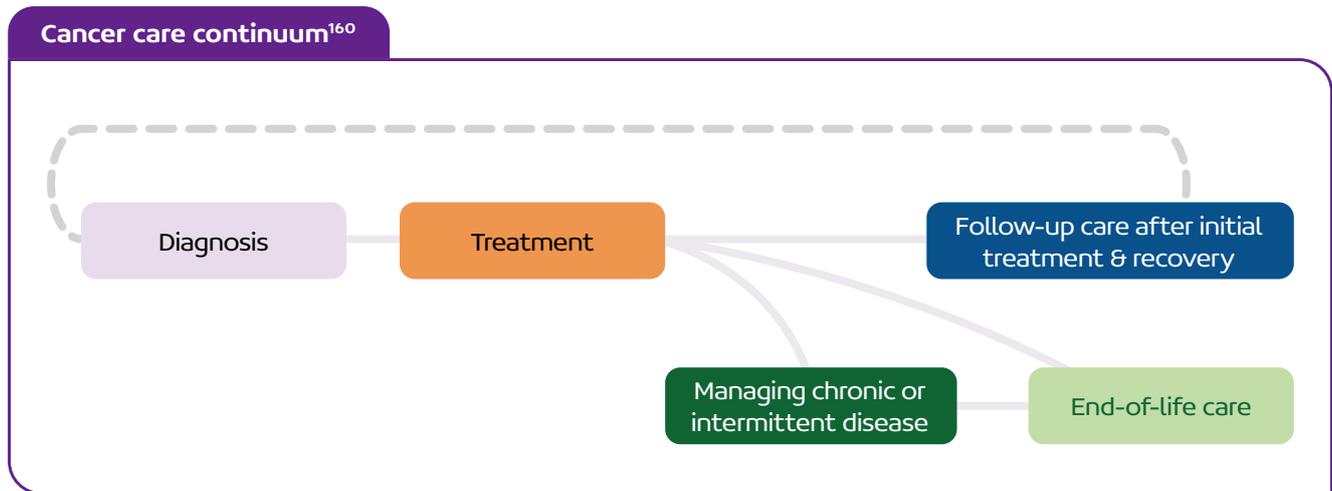
Cancer care is evolving

In the past, cancer care has focused on diagnosis and treatment. However, international research shows it is just as important to help cancer survivors cope with life beyond their acute treatment.

Survivorship care in Australia has also traditionally been provided to patients who have completed active treatment and are in the post-treatment phase, focusing only on the immediate side-effects of treatment and on the detection of metastases or recurrence of the cancer. However, this is not

considered best-practice and there is now a shift to provide holistic survivorship care and services from

the point of diagnosis and beyond treatment to improve cancer-related outcomes³⁶.



Best-practice survivorship care

The Clinical Oncology Society of Australia (COSA) Model of Survivorship Care includes five critical components:

1. Multidisciplinary, systematic approach to enhance coordinated care
2. Personalised, stratified pathways of care are provided
3. In addition to surveillance and treatment-related symptom management, survivorship care should support wellness and primary and secondary prevention
4. At transition to survivorship care, a treatment summary and survivorship care plan should be created
5. Survivors require equitable and timely access to care while minimising unnecessary use of resources¹⁶¹.

Best-practice survivorship care is underpinned by Cancer Australia's Principles of Cancer Survivorship:

1. Consumer involvement in person-centred care
2. Support for living well
3. Evidence-based care pathways
4. Coordinated and integrated care
5. Data-driven improvements and investment in research¹⁶⁰.

It is time to broaden our focus and look beyond diagnosis and treatment

The transition from active treatment to post-treatment care is critical to long-term health.

Lung cancer survivors face a number of physical, emotional, financial and social issues that are different from those experienced during active treatment for cancer, as well as unmet needs that affect their quality of life^{62-64,69-71,117-119,162}.

This can include ongoing side effects of treatment, fear of a cancer relapse, cancer-related fatigue, pain, distress, anxiety, depression, cognitive changes and sleep issues¹⁶³. Lung cancer survivors may also experience poor cardiorespiratory fitness and malnutrition following treatment due to ongoing treatment side effects (e.g. weight loss, or reduced oral intake)³⁶.

Survivors and their carers may experience impacted relationships and practical issues including difficulties with return to work or study and financial hardship. They may also experience changes to sex and intimacy. Fertility, contraception and pregnancy care after treatment may require specialist input³⁶. Access to a range of health professions may be required including physiotherapy, occupational therapy, social work, dietetics, clinical psychology, fertility and palliative care³⁶.

The experiences and goals of care for each cancer survivor are unique and dynamic.

SLCNs are important at every step in the lung cancer patient pathway and have a critical role in supporting lung cancer survivors to manage symptoms, access treatment and other support services in the community, and reduce mental and psychosocial distress. Key resources that can be used to improve communication and care coordination include: needs assessments, treatment summaries, and survivorship care plans developed by healthcare providers in conjunction with their patient after completing initial treatment³⁶.

The evidence base for lung cancer survivorship is limited

The evidence base for cancer survivorship overall is limited^{24,61}, and there is a paucity of lung cancer survivorship research¹⁶⁴. Key knowledge gaps include:

- Lung cancer specific survivor and caregiver experiences, issues and needs
- Survivorship topic areas: side/late symptoms and effects, psychological impact and issues, financial impact and toxicity, health behaviours, and workforce participation and return-to-work
- Map of existing lung cancer survivorship care and support services in Australia, including gaps
- New survivorship approaches and evidence-based support and care strategies from the point of diagnosis and beyond treatment
- Implementation of lung cancer survivorship care.

Lung cancer survivorship research will improve understanding of the sequelae of cancer and its treatment, and identify methods to prevent and mitigate adverse outcomes, including functional, physical, psychosocial, and economic effects. Research will also include and inform the design, delivery, and implementation of evidence-based strategies and the coordination of healthcare services to optimise survivors' health and quality of life from the time of diagnosis, through the balance of life¹⁵⁷.

New approaches and investment in lung cancer survivorship are urgently needed to optimise the health and wellbeing of the growing number of lung cancer survivors, family members and caregivers, and to address their significant and high unmet needs.

National priorities for action

1. Invest \$25 million minimum in lung cancer survivorship research through the Medical Research Future Fund to generate new evidence and address gaps in current knowledge, with a focus on developing and testing new approaches and evidence-based support and care strategies from the point of diagnosis and beyond treatment.
2. Invest in new models of survivorship care and evidence-based tools, information and support services.
 - Conduct a world-first trial for nurse-led lung cancer survivorship care to test the clinical and cost effectiveness of nurse-led survivorship care for improving the health and wellbeing of people with lung cancer. The trial should include systematic screening for burdensome symptoms and coordinating care between all providers to ensure a patient's needs are met³⁶.
 - In collaboration with COSA, update and adapt the COSA Model of Survivorship Care to tailor it for people living with lung cancer, and to ensure a culturally appropriate and safe model of survivorship care for Aboriginal and Torres Strait Islander people (a priority population for lung conditions due to poorer health outcomes and unmet need)¹.
3. Enhance access to existing survivorship tools, information and support services that are proven to work, including:
 - Extend the reach and uptake of existing information and support services by scaling up the implementation of evidence-based, local initiatives to ensure national reach, and making them available in multiple formats and languages to maximise accessibility.
 - Identify existing international resources and effective interventions: review to determine applicability to Australian context, and adapt as relevant and with permission for the Australian context¹⁶¹.
 - Invest in peer and consumer support programs, including supportive infrastructure and capacity building of lung cancer community champions, to enable lung cancer survivors to connect and access peer support, share lived experiences, and undertake advocacy to represent their needs and eradicate stigma.

- Fund an increase in the delivery of lung cancer survivorship care programs and support services to ensure lung cancer survivors achieve optimal health, wellbeing and quality of life outcomes, including:
 - > Pulmonary rehabilitation and physical activity programs in the community and home settings to maximise patient access and choice, and ensure all Australians living with lung cancer can benefit from pulmonary rehabilitation and physical activity programs¹
 - > Smoking cessation supports, where relevant
 - > Nutrition
 - > Psychological, cultural and spiritual, and social support needs (including educational, financial, and occupational issues).
 - Fund the scale-up of Lung Foundation Australia's existing helpline services to maximise impact and ensure national access including regional, rural and remote communities. Build on the existing model to enable patient/caller follow up, create pathways to health services, and opportunities to monitor and evaluate telehealth, video-conferencing and other information technology interventions¹.
 - Provide additional funding to the Australian Cancer Survivorship Centre (ACSC) to support a greater national role. Although many resources developed by the ACSC have national focus and reach, others have more of a Victorian focus and reach.
 - Strengthen referral pathways from hospital to community support organisations¹⁶⁵, such as Lung Foundation Australia.
 - Enhance the uptake and use of Survivorship Care Plans through education and awareness campaigns targeting people with lung cancer and the health and medical workforce.
 - Invest in one-to-one telehealth peer support workers and social workers.
4. Invest in education, training and resources for healthcare professionals to upskill in cancer survivorship with a focus on lung cancer survivorship, implement guidelines in practice^{36,39-41}, and provide best-practice survivorship care^{160,161}.

Outcomes

- Improved access to lung cancer survivorship care programs and support services
- Improved value and quality of patient-centred lung cancer care
- Improved health, wellbeing and quality of life for lung cancer survivors.

6

Clinical Quality Registry

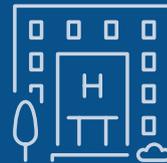
A clinical quality registry will:



Reduce variations in lung cancer care



Improve patient outcomes



Improve healthcare system outcomes



Provide a voice for consumers and families



Enhance lung cancer data and research

Recommendation



Develop a world-leading national clinical quality registry for lung cancer to improve the quality and value of lung cancer care.

“A clinical quality data platform for lung cancer is much needed in Australia to identify gaps and variations in approaches, and to systematically drive patient-centred improvements in the quality and value of lung cancer care.”

- Professor Fraser Brims, Respiratory physician and lung cancer researcher, Curtin University

A national clinical quality registry for lung cancer will provide Australia with the necessary infrastructure to drive continuous improvements in the value and quality of patient-centred lung cancer care and reduce unwarranted variation in care. The platform will enable the collection, monitoring, reporting and actioning of national clinical quality outcomes data in line with best-practice principles¹⁶⁶. Cancer treatment and linked outcome data will be collected, analysed and benchmarked against nationally agreed standards of care, with meaningful feedback given to providers. The role of audit and feedback in reducing unwarranted variation in healthcare and driving improved care and patient outcomes is well documented¹⁶⁷⁻¹⁷⁰. There is no Australian data-assessing compliance with the national, evidence-based guidelines, nor national data on the quality of care or lung cancer patient reported outcomes⁴³.

Australia is well positioned to build on existing good-practice, including the Australian Lung Cancer clinical quality dAta Platform and the Victorian Lung Cancer Registry to establish a national process for identifying variations in care at regional and institutional level – and to support institutions to deliver quality care and better patient outcomes. No such data platform or quality improvement tool for lung cancer exists in Australia or internationally.

A national clinical quality registry for lung cancer will:

- Systematically and reliably identify unwarranted variance in lung cancer standards of care and outcomes from around Australia
- Drive improvements in lung cancer care by staged, open reporting and comparison of results, together with innovation in implementation and change processes
- Develop a culture of responsibility and accountability from institutions
- Provide a voice for consumers and families
- Provide scope for future personalised medicine initiatives through linkage to biobanks
- Provide a unique platform for multiple research projects, cohort studies and long-

term linkage to real life lung cancer outcomes across the nation

- Maximise efficiency and return on healthcare investment.

A world-leading national clinical quality registry for lung cancer will include public and private healthcare and hospital data, and routinely collect patient-reported measures, including patient-reported outcomes, patient-reported experiences and health-related quality of life in order to understand the perceived value of different management and treatments for lung cancer. Quality indicators with a strong focus on timeliness of care and patient-reported measures is consistent with the International Consortium for Health Outcomes Measurement principles^{171, 172}.

A national clinical quality registry for lung cancer will provide a mechanism for implementing and evaluating the optimal care pathway for people with lung cancer³⁶, and vital, real-life evidence of effectiveness of new interventions (such as screening) or treatments (such as personalised therapies).

A national clinical quality registry for lung cancer aligns with the National Clinical Quality Registry and Virtual Registry Strategy 2020-2030¹⁷³ and the best-practice principles outlined in the Australian Commission on Safety and Quality in Health Care Framework for Australian clinical quality registries¹⁶⁶.

“There’s an inversely proportional relationship between research funding and the burden of the disease. Lung cancer is the highest burden of any cancer in Australia, and it has some of the lowest tier one research funding. It’s unacceptable in this day and age.”

- Professor Fraser Brims

The funding and research investment in lung cancer is disproportionate to the burden of disease and is contributing to the unacceptable and persistent poor outcomes for people living with lung cancer¹⁷⁴. Investment in a national clinical quality registry for

lung cancer that underpins innovation in lung cancer care and research, and links with other national and international registries and research, is a critical priority for Australia.

National priorities for action

- Define clinical quality standards of lung cancer care which, in turn, will help address variations in lung cancer care and outcomes¹⁷⁵
- Fund (\$15 million) and operationalise a national clinical quality registry for lung cancer.

Outcomes

- Reduction in unwarranted variation in lung cancer care
- Enhanced lung cancer data and research
- Improved value and quality of patient-centred lung cancer care
- Improved outcomes across the national healthcare system and for all Australians with lung cancer.

Glossary

AQG	Air Quality Guidelines
Biomarker	A biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease or condition. Also called molecular marker and signature molecule ¹⁷⁶ .
Burden of disease	Burden of disease analysis is a technique used to assess and compare the impact of different diseases, conditions or injuries and risk factors on a population. It uses information from a range of sources to quantify the fatal and non-fatal effects of these diseases in a consistent manner so that they can then be combined into a summary measure of health called disability-adjusted life years, or DALY ¹⁶ .
CGP	Comprehensive Genomic Profiling
COSA	Clinical Oncology Society of Australia
DALY	Disability-adjusted life years. A DALY combines the estimates of years of life lost due to premature death and years lived in ill health or with disability to count the total years of healthy life lost from disease and injury ¹⁶ .
ED	Emergency Department
EN	Enrolled Nurse
FCTC	Framework Convention on Tobacco Control
FTE	Full Time Equivalent
Hierarchy of control	The hierarchy of control is a system for controlling risks in the workplace. The hierarchy of control is a step-by-step approach to eliminating or reducing risks and it ranks risk controls from the highest level of protection and reliability through to the lowest and least reliable protection ⁹² .
LDCT	Low-dose computed tomography
MBS	Medicare Benefits Schedule
MDT	Multidisciplinary team
MRFF	Medical Research Future Fund
NSCLC	Non-small cell lung cancer
OOP	Out-of-pocket

Technical appendix

Click [here](#) to access details of the PWC inputs and calculations that were used to understand costs and benefits of components within this report.



PBS	Pharmaceutical Benefits Scheme
PFS	Progression-free survival. The length of time during and after the treatment of a disease, such as cancer, that a patient lives with the disease but it does not get worse. In a clinical trial, measuring the progression-free survival is one way to see how well a new treatment works ¹⁷⁶ .
Prognosis	The likely outcome or course of a disease; the chance of recovery or recurrence ¹⁷⁶ .
QALY	Quality-adjusted life year. A measure of the state of health of a person or group in which the benefits, in terms of length of life, are adjusted to reflect the quality of life. One QALY is equal to one year of life in perfect health. QALYs are calculated by estimating the years of life remaining for a patient following a particular treatment or intervention and weighting each year with a quality-of-life score (on a 0 to 1 scale). It is often measured in terms of the person's ability to carry out the activities of daily life, and freedom from pain and mental disturbance ¹⁷⁷ .
RN	Registered Nurse
SARS-CoV-2	SARS-CoV-2 causes a respiratory disease called coronavirus disease 19 (COVID-19). It is a member of a large family of viruses called coronaviruses.
SBCN	Specialist Breast Care Nurse
SPCN	Specialist Prostate Cancer Nurse
SCLC	Small cell lung cancer
SES	Socioeconomic status
SLCN	Specialist Lung Cancer Nurse
Survival rate	The percentage of people in a study or treatment group who are still alive for a certain period of time after they were diagnosed with or started treatment for a disease, such as cancer. The survival rate is often stated as a five-year survival rate, which is the percentage of people in a study or treatment group who are alive five years after their diagnosis or the start of treatment. Also called overall survival rate ¹⁷⁶ .
Stage	The extent of a cancer in the body. Staging is usually based on the size of the tumour, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body ¹⁶ .
WHO	World Health Organization
YLD	Years lived in ill health or with disability ¹⁶
YLL	Years of life lost due to premature death ¹⁶

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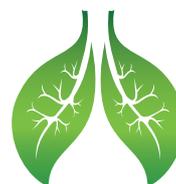
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