Lung Foundation Australia

Making Lung Cancer A Fair Fight: A Blueprint for Reform

Foreword

Lung Foundation Australia is the only national charity and leading peak body dedicated to supporting anyone with a lung disease. Since 1990, we have been the national point-of-call for patients, their families, carers, health professionals and the general community. Our mission is to improve lung health and reduce the impact of lung disease for all Australians.

Making Lung Cancer a Fair Fight: A Blueprint for Reform is a first-of-its-kind report addressing the social, economic and mental health issues of Australians living with lung cancer. It was developed in collaboration with PricewaterhouseCoopers (PwC).

This report provides a clear indication to date of the true burden of lung cancer in Australia, now and over the next decade, and the confronting challenges facing those living with lung cancer. Importantly, it outlines solutions to improve outcomes. It is Lung Foundation Australia's hope that the launch of *Making Lung Cancer a Fair Fight: A Blueprint for Reform* can be used to inform decision makers to adopt key reforms to address the disjointed care, mental health and stigma that Australians with lung cancer face - and make lung cancer a fair fight.

Lung Foundation Australia aims to ensure lung health is a priority for all, from promoting lung health and early diagnosis, to supporting people with lung disease and championing equitable access to treatment and care. Our work is centred on the needs of those living with lung disease, and underpinned by the values of compassion, courage, respect and collaboration.

Lung Foundation Australia

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Lung Foundation Australia is a proud member of the Recognise Health initiative of the Lowitja Institute which promotes understanding of the important link between health and wellbeing and constitutional recognition of Aboriginal and Torres Strait Islander people. We call on all Australians to support recognition of Aboriginal and Torres Strait Islander people in the Australian Constitution. We look forward to a time when all Aboriginal and Torres Strait Islander people can fully participate in all that Australia has to offer, enjoying respect for our country's first cultures and leadership, and the dignity and benefits of long healthy lives. Australia's First Peoples continue to die far earlier and experience a higher burden of disease and disability than other Australians. This is the result of long-term economic disadvantage and social exclusion, among other factors. Constitutional recognition would provide a strong foundation for working together towards better health and social wellbeing in the hearts, minds and lives of all Australians. Lung Foundation Australia is amongst 125 leading non-government health organisations across the Australian health system that have signed this statement in support of constitutional change.

Lung Foundation Australia commissioned PricewaterhouseCoopers Consulting (Australia) Pty Limited ("PwC Consulting") to prepare this report to provide an accurate representation of the true burden of lung cancer in the Australian community, now and over the next decade, for the purpose of informing decision makers to adopt key reforms. Lung Foundation Australia accepts no responsibility for the accuracy or completeness of any material contained in the report. Additionally, Lung Foundation Australia disclaims all liability to any person in respect of anything, and of the consequences of anything, done or omitted to be done by any such person in reliance, whether wholly or partially, upon any information presented in this report.

All quotes and case studies presented in this report are accurately conveyed from real people living with lung cancer.

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Executive summary

1 Burden and challenges of lung cancer in Australia

Lung cancer is the leading cause of cancer death in the country. It has the lowest five-year relative survival rate (17 per cent) when compared to the other top five most commonly diagnosed cancers, which have survival rates between 69 and 95 per cent.[1] Further, it is the fifth most commonly diagnosed cancer in Australia and it is estimated that there will be approximately 12,740 people newly diagnosed in 2018.[2] This number is projected to reach almost 160,000 new diagnoses over the next 10 years to 2028.[3]

This report has been prepared to raise awareness about the burden of lung cancer in Australia and the particular challenges faced by people diagnosed with the condition. The report outlines feasible and pragmatic recommendations that will lead to better outcomes for people living with lung cancer.

There are considerable challenges specifically faced by people living with lung cancer that impact their overall health outcomes and quality of life. The following three themes were identified through stakeholder consultations as being the most important challenges faced by Australians with lung cancer, and are explored in more detail in this report:

1. **equity of access** to diagnostics and care
2. **stigma** experienced by patients
3. the need for **psychosocial support.**

Access to quality diagnostics and care

Better access to certain cancer services impact health outcomes for people. The following were identified as high priority and challenging areas for people living with lung cancer:

- sufficient access to lung cancer clinical nurse specialists (CNS) and/or lung cancer care coordinators, to help better navigate the health system and assist in access to care, treatment and support
- timely access to goals which impact people's prognosis
- increased referrals to multidisciplinary teams (MDTs) and specialist care, which remain clinical best practice and improve patient outcomes.

In addition, these challenges are amplified for people living with lung cancer who live in regional and remote areas. Research has found that a disproportionately high number (almost half) of Australians diagnosed with advanced lung cancer (Stage III-IV) live in regional and remote areas.[4] Delays in diagnosis and access to care are evident for people living with lung cancer and result in poorer outcomes.[5]

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[1] Australian Government. Cancer Australia, 2018. 'Lung cancer statistics' [online] Available from: https://lung-cancer.canceraustralia.gov.au.

[2] Australian Institute of Health and Welfare, 2017. 'Cancer in diagnostic testing and care to meet recommended diagnosis and treatment timeframe Australia 2017' Cancer series no.101. Cat. no. CAN 100. Canberra: AIHW [online] Available from: https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2017; Australian Government. Cancer Australia, 2018. 'Lung cancer statistics' [online] Available from: https://lung-cancer.canceraustralia.gov.au.

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People living with lung cancer experience high levels of stigma

There are a variety of risk factors (e.g. exposure to toxic substances, pollution, smoking, family history, etc.) that may contribute to the development of lung cancer. While smoking is prominent amongst these risk factors, approximately one fifth (21 per cent) of people living with lung cancer are life-long non-smokers.[6]

People living with lung cancer experience stigma in society, including from their communities, health providers, employers and even themselves. One study suggests that approximately **30 per cent** of people living with lung cancer blame themselves for their diagnosis.[7] Smoking is viewed as the main contributing factor for lung cancer and as a result, current and former smokers and non-smokers alike who have lung cancer often feel blamed for their illness. This judgment negatively impacts the perceived worthiness of people to access support, and reduces their sense of entitlement to care and empathy. A national consumer survey undertaken by Lung Foundation Australia in 2017[8] found over a third of Australians believe people living with lung cancer 'only have themselves to blame' and health professional attitudes are as negative as those of patients, caregivers and the general public.[9]

There is a high need for psychosocial support

People living with lung cancer experience high levels of anxiety and depression, with approximately half having distress, anxiety and/or depression. There appear to be insufficient appropriate services available to support this high need, with one study finding that there is insufficient support for the majority of people.

In 2018, it is estimated that about **6,200** newly diagnosed people living with lung cancer will develop anxiety and depression. This means that approximately **131,400** people living with lung cancer may experience anxiety and depression over 10 years to 2028. This further highlights the high need for psychosocial support for people living with lung cancer.

2 Economic costs of lung cancer in Australia

Lung cancer leads to costs to the health system, people living with lung cancer and their families. The economic burden of lung cancer for patients diagnosed in 2018 is estimated to reach:

- **$283.7 million** in direct costs, including treatment costs, out-of-hospital costs and out-of-pocket expenses.
- **$13.5 million** in indirect costs, including absenteeism resulting from the additional time off work taken by people living with lung cancer because of their illness.

These costs are broken down in Chapter 2.

People living with lung cancer die earlier (prematurely) by an average of 11 years compared to the general population.[12] It is estimated that this amounts to approximately **137,600 years of life lost** in 2018. These years of life lost incur an economic cost of approximately $6.9 billion to society in 2018.[13]

With population projections and new incidences of lung cancer growing at a similar rate, the costs over 10 years to 2028 are estimated to be **$6.2 billion** in direct costs and **$325.9 million** in indirect costs (absenteeism) and years of life lost from premature deaths will grow to approximately **2.9 million years** by 2028. Over 10 years, these years of life lost incur a cost of approximately $144.8 billion.[14]

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[6] Cancer Australia, 2014. 'Risk factors for lung cancer: An overview of the evidence'.

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[10] Chambers SK, Baade P, Youl P, Aitken J, Occhipinti S, Vinod S, Valery PC, Garvey G, Fong KM, Ball D, Zorbas H, Dunn J, O'Connell DL, 2015. 'Psychological distress and quality of life in lung cancer: the role of health related stigma, illness appraisals and social constraints', Psychooncology 24 (1569-1577).

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[13] The cost of one year of "quality life" is estimated to be $50,000. Taylor, C. and Jan, S. (2017). Economic evaluation of medicines. Australian Prescriber, 40 (76-78).

[14] Ibid.

The burden of lung cancer in Australia

Approximately

12,741

Australian men and women will be diagnosed with lung cancer in **2018**

Mortality

it is the leading cause of cancer death in Australia, with an estimated

9,198

Australians dying of lung cancer in 2018.

Psychosocial burden

It is estimated that approximately

6,200

newly diagnosed people with lung cancer will develop anxiety and depression.

In 2018, the economic cost of lung cancer is estimated to reach:

$283.7 MILLION

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

$13.5 MILLION

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

137.6 THOUSAND

years of life lost due to premature mortality

3 Recommendations and required action

Based on identified need and challenges, the Steering Committee (listed on page ix) has collaboratively developed a set of recommendations to improve health outcomes and quality of life for people living with lung cancer in Australia. Further details and potential actions under each recommendation are documented in Chapter 4.

1. Improve access to quality diagnostics and care for people living with lung cancer

Earlier diagnosis and treatment can improve health outcomes and survival rates for people living with lung cancer diagnosed in earlier stages.[15] Improving access to quality diagnostics and care can improve health outcomes of people living with lung cancer.

- **Recommendation 1** - Increase the availability of lung cancer clinical nurse specialists (CNS') and care coordinators at the time of diagnosis to assist people in navigating the complexities of the health system from the time of diagnosis and improve outcomes.
- **Recommendation 2** – Increase access to multidisciplinary team (MDT) care, which leads to better health outcomes for people living with lung cancer.

2. Promote awareness to shift perceptions away from stigma

Stigma has negative impacts on mental health outcomes and the quality of life for people living with lung cancer.[16] Reducing lung cancer stigma may also help to also reduce associated negative outcomes.

- **Recommendation 3** – The needs of people living with lung cancer and the complexity of the disease should be included in professional training and medical workforce curriculum to promote awareness and provide strategies to shift perceptions away from stigma
- **Recommendation 4** – Launch a campaign that encourages people to 'Give Everyone a Fair Go' by increasing public awareness of the complexities associated with lung cancer to reduce stigma.

3. Address the need for psychosocial support

People living with lung cancer experience relatively high levels of depression and anxiety, and improved access to psychosocial support will help reduce this burden[17] and improve people's quality of life overall.[18]

- **Recommendation 5** – All people living with lung cancer who experience psychosocial distress and require support should be referred to psychosocial support services as early as practicable in their cancer journey.
- **Recommendation 6** – Improve the availability of appropriate psychosocial support services for people living with lung cancer, such as counselling.

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[15] Goldstraw P, Chansky K, Crowley J, Rami-Porta R, Asamura H, Eberhardt WE, Nicholson AG, Groome P, Mitchell A, Bolejack V, 2015. 'The IASLC Lung Cancer Staging Project: Proposals for Revision of the TNM Stage Groupings in the Forthcoming (Eighth) Edition of the TNM Classification for Lung Cancer', Journal of Thoracic Oncology 11 (39-51); Janssen-Heijnen ML, Maas HA, Siesling S, Koning CC, Coebergh JW, Groen HJ, 2011.'Treatment and survival of patients with small-cell lung cancer: small steps forward, but not for patients', Annals of Oncology, 23 (954–960).

[16] Chambers SK, Baade P, Youl P, Aitken J, Occhipinti S, Vinod S, Valery PC, Garvey G, Fong KM, Ball D, Zorbas H, Dunn J, O'Connell DL, 2015. 'Psychological distress and quality of life in lung cancer: the role of health-related stigma, illness appraisals and social constraints', Psycho-Oncology, 24 (1569-1577).

[17] Raingruber B, 2011. 'The Effectiveness of Psychosocial Interventions with Cancer Patients: An Integrative Review of Literature (2006-2011)', ISRN Nursing (1-27).

[18] Uitterhoeve RJ, Vernooy M, Litjens M, Potting K, Bensing J, De Mulder P, van Achterberg T, 2004. 'Psychosocial interventions for patients with advanced cancer – a systematic review of the literature', British Journal of Cancer, 91:6 (1050-1062); Raingruber B, 2011. 'The Effectiveness of Psychosocial Interventions with Cancer Patients: An Integrative Review of Literature (2006-2011)', ISRN Nursing (1-29). Epub 2011 Nov 16; Rueda JR, Solà I, Pascual A, Subirana Casacuberta M, 2011. 'Non-invasive interventions for improving well-being and quality of life in patients with lung cancer', The Cochrane Database of Systematic Reviews 10.

Disjointed Care, Depression & Discrimination

The burden unfairly impacting aussies with lung cancer & associated costs

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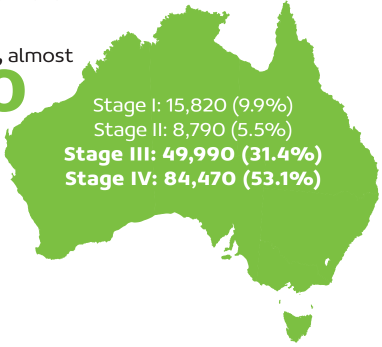
Lung cancer in Australia: **A growing burden**

Approximately **12,741** Australian men and women will be **diagnosed with lung cancer in 2018**

Over the next 10 years, almost **160,000** **will be diagnosed with lung cancer** (with advanced lung cancer (stage III-IV) affecting disproportionately more Australians)



Stage I: 15,820 (9.9%)
Stage II: 8,790 (5.5%)
Stage III: 49,990 (31.4%)
Stage IV: 84,470 (53.1%)

Lung cancer is the **number 1** cause of **cancer death**

9,021 **died of the disease in 2017**

5 YEAR survival rate

Lung cancer has the lowest 5-year survival rate of the 5 most commonly diagnosed cancers:

Breast cancer: 91%
Colorectal cancer: 69%
Prostate cancer: 95%
Melanoma: 91%
Lung cancer: 17%

2018

In 2018, 137,600 years of life were lost as those with lung cancer died prematurely. This will grow to a staggering **2.9 million years of life lost by 2028**

As burden of disease climbs, **costs skyrocket**

In 2018, the economic burden associated with the 12,740 people newly diagnosed is **$297.2 million**

By 2028, there will be almost 160,000 new diagnoses, and a total of 268,200 people living with lung cancer, at a cost of $6.6 billion

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If you have lungs, **you can get lung cancer**

Smoking is just one risk factor. Others include:

- Exposure to asbestos, radon and occupation materials
- Air pollution
- Family history
- Personal history of lung disease
- Genetics

1 in 5 people living with lung cancer are **life-long non-smokers**

Disjointed care delays diagnosis & impacts outcomes & costs

Delays in diagnosis and care result in poorer outcomes

28% of people are not staged when diagnosed; potentially missing out on life changing treatment and care

Compared to other common cancers, far fewer people with lung cancer are diagnosed early:

Stage I lung cancer: 11.7%
Stage I prostate cancer: 35.9%
Stage I breast cancer: 42.8%
Stage I colorectal cancer: 22.1%

> *"Navigating the health system as a lung cancer patient can be stressful, confusing and overwhelming when you are emotionally vulnerable. At times I felt like I was lost in a foreign country in the dark with no map to help me navigate."*

20% **do not receive any treatment following their diagnosis.** Others can wait up to 2 months until they are treated

Treatment delays increase the chances of disease progression

As cancer progression increases, so too does the cost of treatment. **For example,** it costs an average of $15,500 more to treat stage IV lung cancer than stage I

Access to lung cancer clinical nurse specialists (CNS) is inadequate despite the benefit they provide; people who have access to a CNS are **34% more likely to receive treatment than those who do not**

Only one in two have access to multidisciplinary teams (MDTs) and therefore best practice care and outcomes

Access to MDTs increases:

- Staging evaluation from **79% to 93%**
- Adherence to treatment guidelines from **81% to 91%**
- Time from diagnosis to treatment from an average of **29 to 11 days**

Aussies living with lung cancer in regional areas are worse off

29% **of people living with lung cancer live in regional areas** yet **49%** of them are diagnosed with advanced lung cancer (stage III-IV)

Fewer oncologists, fewer services, and travel for care hinders access

Over the next 10 years, out-of-pocket travel costs for regional/remote Australians living with lung cancer will reach **$36.3 million**

Every Australian is entitled to the same public access to diagnostics, treatment and care – regardless of the disease they have, the cause of their cancer or their place of residence.

Stigma is stifling

People living with lung cancer experience stigma in society, from healthcare professionals, employers, and themselves

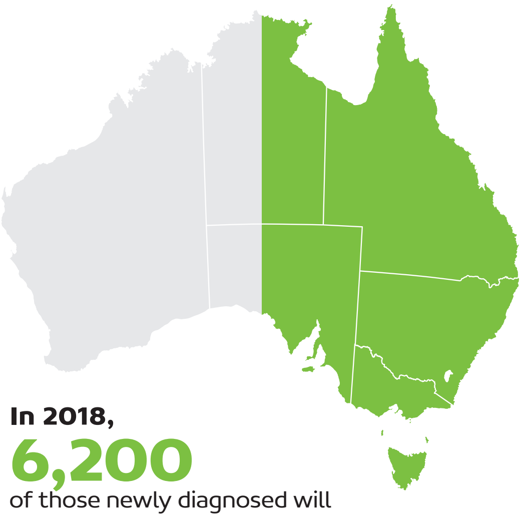
1/3 of Australians believe people with lung cancer **"only have themselves to blame"**

Judgement negatively impacts:

- ✓ The perceived worthiness of people to access support and care
- ✓ Their overall health outcomes
- ✓ Their quality of life

The sense of guilt may result in people delaying seeing a healthcare professional, which may mean they are diagnosed with later stage disease where their chance of survival decreases

Too many are grappling with mental health issues alone



In 2018, **6,200** of those newly diagnosed will develop anxiety and depression

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

Over the next 10 years, 131,400 people diagnosed may develop anxiety and depression

Compared to other cancers, the prevalence of poor mental health is 29.6% higher than average:

Lung cancer: 49%
Breast cancer: 24%
Renal cell carcinoma: 15%
Colon cancer: 20%
Head and neck cancer: 18.5%

Yet there are insufficient services across the country to offer support

Psychosocial support can:

- ⊕ Reduce depression and anxiety
- ⊕ Improve quality of life
- ⊕ Enhance hope which may reduce pain and psychosocial distress

Making lung cancer a fair fight: a blueprint for reform

✓ Improve quality diagnostics and care

1. Australian Government to fund more lung cancer clinical nurse specialists to assist people to navigate best practice care pathways to improve outcomes
2. Increase access to multidisciplinary team (MDT) care in local health districts, and facilitate earlier referrals and GP education in regional areas

✓ Shift perceptions away from stigma

3. Increase education on the needs of people living with lung cancer and disease complexities in medical workforce training and curriculum, with strategies to improve outcomes
4. Fund a public awareness campaign that encourages Australia to **"give everyone a fair go"**

✓ Address the need for psychosocial support:

5. Screen all people living with lung cancer to understand individual psychosocial support needs, complete mental health plans and refer patients for help as early as appropriate

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Cancer Nurse Coordinator, Orange Hospital

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Dr H. John Fardy
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Consumer Representative and Carer

Finally, thank you to **opr Life** for their help in launching the report.

Glossary

Acronym	Description
ACIM	Australian Cancer Incidence and Mortality
AIHW	Australian Institute of Health and Welfare
CALD	Culturally and Linguistically Diverse
CNS	Clinical Nurse Specialist
EBUS	Endobronchial Ultrasound
ECOG	Eastern Cooperative Oncology Group
FDA	Food and Drug Administration
IPTAAS	Isolated Patients Travel and Accommodation Assistance Scheme
MDT	Multidisciplinary Team
SCLC	Small Cell Lung Cancer
NSCLC	Non-Small Cell Lung Cancer
QALY	Quality-Adjusted Life Year
RACGP	Royal Australian College of General Practitioners
TGA	Therapeutic Goods Association
VPTAS	Victorian Patient Transport Assistance Scheme
YLL	Years of Life Lost

Contents

1 Burden and challenges of lung cancer in Australia

1.1 Lung cancer in Australia

Lung cancer is the leading cause of cancer death in the country. It is the fifth most commonly diagnosed cancer in Australia and it is estimated that there will be approximately 12,740 people newly diagnosed in 2018.[19] This number is projected to reach almost 160,000 new diagnoses over the next 10 years to 2028.[20]

1.1.1 Risk factors for lung cancer

There are a variety of risk factors that may contribute to the development of lung cancer. While smoking is amongst these risk factors, approximately one-fifth (21 per cent) of people living with lung cancer are life-long non-smokers.[21] A study by McCarthy and colleagues in 2012 notes that lung cancer ranked as the 7th cause of cancer death in life-long non-smokers.[22] It is important to consider the multitude of risk factors which cause lung cancer.

In 2014, Cancer Australia published a report on the other environmental and personal risk factors that may contribute to the development of lung cancer.[23] These include:

- exposure to substances including asbestos, radon, occupational materials (e.g. uranium, chromium, nickel, diesel fumes and soot)
- air pollution
- family history
- personal history of lung disease
- genetics.

1.1.2 Lung cancer survival and deaths

Lung cancer was the number one cause of cancer death in Australia in 2017 with 9,021 people dying of the disease, constituting almost one fifth (18.9 per cent) of all cancer deaths that year.[24]

People living with lung cancer also have poor five-year survival when compared to the other four of the five most commonly diagnosed cancers (see Table 1). From 2010 - 2014, people living with lung cancer had a 17 per cent chance of surviving for five years.[25] Further, the average life expectancy for Australians in 2018 is 82.5 years old, whereas lung cancer cuts this average life expectancy by almost 11 years to 71.7 years of age (median diagnosis age of 65 years old).[26] People who are diagnosed with lung cancer in an earlier stage have a better chance of survival than those diagnosed with later stage cancer.[27]

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[19] Cancer Australia, 2018. 'Lung cancer statistics' [online] Available from: https://lung-cancer.canceraustralia.gov.au/statisticshttps://lung-cancer.canceraustralia.gov.au/.

[20] Incidence from 2017 to 2018: Australian Institute of Health and Welfare, 2017. Cancer in Australia 2017. Cancer series no.101. Cat. no. CAN 100. Canberra: AIHW; Incidence from 2019 to 2020: Australian Institute of Health and Welfare, 2012. 'Cancer incidence projections: Australia, 2011 to 2020', Cancer Series no. 66. Cat. No. CAN 62; Incidence from 2021 to 2028 (assumption of 2.0% growth per year, based on rate median growth from 1982-2014): Australian Institute of Health and Welfare, 2017. 'Australian Cancer Incidence and Mortality (ACIM) books' [online] Available from: https://www.aihw.gov.au/reports/cancer/acim-books/contents/acim-books.

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[25] Cancer Australia, 2018. 'Lung cancer statistics' [online] Available from https://lung-cancer.canceraustralia.gov.au/statistics.

[26] OECD, 2018. 'OECD Health Statistics 2018' [online] Available from: http://www.oecd.org/els/health-systems/health-data.htm; Australian Institute of Health and Welfare, 2017. 'Australian Cancer Incidence and Mortality (ACIM) books' [online] Available from: https://www.aihw.gov.au/reports/cancer/acim-books/contents/acim-books.

[27] Lung cancer is staged from Stage I-IV on the Tumour, Node Metastases (TNM) system which is based on the size of the primary tumour, whether the disease has spread to nearby lymph nodes (local/regional metastasis), and whether it has spread further throughout the body (distant metastasis).

Table 1 Comparison of five-year survival rate between lung cancer and top four most commonly diagnosed cancers in Australia, 2010-2014

Diagnosis ranking	Most commonly diagnosed cancers	5-year survival rate, 2010 - 2014
1	Breast cancer	91%[28]
2	Colorectal (bowel) cancer	69%[29]
3	Prostate cancer	95%[30]
4	Melanoma	91%[31]
5	Lung	17%[32]

Source: PwC analysis, Cancer Australia (2018)

There are two main types of lung cancer: non-small cell lung cancer (NSCLC) making up 85 per cent of people diagnosed and small cell lung cancer (SCLC) accounting for 15 per cent of diagnoses.[33] People with SCLC generally have lower survival rates (see Table 17). Further, there are certain genetic traits that are linked to lung cancer diagnoses.[34]

1.2 Challenges associated with lung cancer

There are considerable challenges faced by people living with lung cancer that do not only impact their overall health outcomes but may adversely influence their quality of life. The following three themes were identified through stakeholder consultations as being the most important challenges faced by Australians with lung cancer, and will be explored in detail in this report:

1. **access** to quality diagnostics and care
2. **stigma** experienced by patients
3. the need **for psychosocial support.**

1.2.1 Access to quality diagnostics and care

There is a mismatch between clinical best practice treatment and care delivered for people living with lung cancer. Examples of this include:

- delays in diagnosis and access to care
- inadequate referrals to multidisciplinary teams (MDT) and specialist care
- insufficient access to lung cancer clinical nurse specialists (CNS) and/or lung cancer care coordinators.

These challenges are amplified for people living in regional and remote areas.

Insufficient access to coordination of care

The lung cancer CNS and care coordinators help facilitate timely access to care.[35] The health system is complex and difficult to navigate, particularly when dealing with the stress and uncertainty of a cancer diagnosis. These coordinator roles are important for people with cancer to have access to guidance on treatment pathways and best practice care, including options for psychosocial support and palliative care.[36] For example, data from UK National Lung Cancer Audit indicates that people living with lung cancer who had access to a CNS are more likely to receive anti-cancer treatment (e.g. chemotherapy, radiotherapy, chemoradiation) than those who did not (64.8 per cent versus 30.4 per cent respectively).[37]

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[28] Cancer Australia, 2018. 'Breast cancer statistics' [online] Available from: https://breast-cancer.canceraustralia.gov.au/statistics.

[29] Cancer Australia, 2018. 'Bowel cancer statistics' [online] Available from: https://bowel-cancer.canceraustralia.gov.au/statistics.

[30] Cancer Australia, 2018. Prostate cancer statistics [online] Available from: https://prostate-cancer.canceraustralia.gov.au/statistics.

[31] Cancer Australia, 2018. Melanoma of the skin statistics [online] Available from: https://melanoma.canceraustralia.gov.au/statistics.

[32] Cancer Australia, 2018. 'Lung cancer statistics' [online] Available from: https://lung-cancer.canceraustralia.gov.au/.

[33] Australian Institute of Health and Welfare & Cancer Australia 2011. 'Lung cancer in Australia: an overview', Cancer series no. 64. Cat. no. CAN 58.

[34] American Cancer Society, 2017. 'Targeted therapy drugs for non-small cell lung cancer' [online] Available from https://www.cancer.org/cancer/non-small-cell-lung-cancer/treating/targeted-therapies.html.

[35] McPhillips D, Evans R, Ryan D, Daneshvar C, Sarkar SA, Breen DMcPhillips, D. et al, 2015. 'The role of a nurse specialist in a modern lung-cancer service', *British Journal of Nursing* 24 (21-27).

[36] Cancer Australia, 2013. 'Best practice approaches to lung cancer care: A review of literature' [online] Available from https://canceraustralia.gov.au/sites/default/files/publications/lclr_best_practice_approaches_to_the_management_of_lung_cancer_in_australia_a_review_of_the_literature_52d607caba2fa.pdf.

[37] The NHS Information Centre, National Lung Cancer Audit, 2010. 2011. 'National Lung Cancer Audit' [online] Available from: https://www.hqip.org.uk/wp-content/uploads/2018/02/national-lung-cancer-audit-2010.pdf., The NHS. Information Centre: Leeds, UK.

The value of care coordination

The lung cancer CNS and care coordinator provides an ongoing point of contact for people living with lung cancer as they navigate the health system. These roles are important in supporting people living with lung cancer, their carers and their families by giving them informed advice and options on how to proceed on their cancer journey.

When surveyed, over 95 per cent of patients believed that these roles should be included as a part of the MDT managing their treatment,[1] and 100 per cent of patients who had this form of coordination for their care answered 'yes' when asked if they felt that the coordinator role improved the efficiency of patient pathways.[1]

From the perspective of a person with lung cancer:

> *"Navigating the health system as a lung cancer patient can be stressful, confusing and particularly overwhelming when you are emotionally vulnerable. At times, I felt like I was lost in a foreign country in the dark with no map to help me navigate. It was such a relief and comfort when I met my CNS who answered my questions, guided me through the complex processes, explained confusing paperwork, and helped me resolve logistical challenges. Access to CNS should be a norm, not a rare luxury."*

Lung cancer CNS and care coordinators are able to offer support and advice that is specific to lung cancer and are aware of the nuances and sensitivities of the illness to better support patients. In regional and remote areas, these roles may need to be substituted through upskilling and training local nurses to better understand the specific needs of lung cancer patients.

A description of this role from the perspective of a Lung Cancer Nurse Coordinator (CNC):

> *"The diagnosis and subsequent treatment of lung cancer can leave patients and their families overwhelmed, anxious and afraid. Unsure of what lies ahead, as the Lung Cancer Nurse Coordinator (CNC) I can provide a central point of contact, lead them through this uncertainty and assist them to navigate their way through the complexities of the disease, multiple specialists and the multiple treatment modalities available.*
>
> *By ensuring that their care is co-ordinated and delivered in a timely, effective and efficient manner, the CNCs can provide the education, information, support and reassurance through each step of their diagnosis and treatment. By building relationships with patients and their family, I am able to assess and identify their holistic needs and ensure access and referral to appropriate support mechanisms to meet these needs, such as palliative care and psychological support."*

Interviews conducted for this report suggest there is insufficient access to these coordinator roles in Australia. It is unclear how many lung cancer nurses there are in Australia, however in 2011 it appeared that there were only seven for 3,610 people diagnosed in that year alone in New South Wales (which equates to an annual case load of 515 patients per lung cancer CNS).[38] A study from the UK found that the CNS annual case load was 122 patients and this was considered 'overstretched' compared to breast cancer CNS where the annual case load was only 79. [39]

The lung cancer CNS can help to make sure that people living with lung cancer receive appropriate initial treatment as well as ensuring longer term follow-up. It was estimated that 20 per cent of people living with lung cancer received no active treatment after diagnosis.

There are some cases where treatment is not appropriate, however some of this gap also results from nihilism (i.e. the belief that treatment will not help). There may also be challenges with healthcare providers keeping up to date with new treatment options emerging. People without access to care coordination are at a greater risk of therapeutic nihilism, especially in people with advanced and terminal disease.[40] They are also at greater risk of developing more severe treatment and cancer related toxicities. Early intervention through regular contact with care coordinators is critical in reducing these risks.[41]

Inadequate referrals to specialist and MDT care

Access to MDT assessment and specialist care are recommended by Cancer Australia as clinical best practice for people living with lung cancer.[42] While considered best practice for treatment planning and care, it is estimated that only about half of people living with lung cancer are managed through MDTs. MDTs are important because they can help patients to access specialist care, which is linked to better quality care and survival outcomes.[44]

After diagnosis, further tests are conducted to determine the stage (severity) of the disease and whether the cancer has spread to other parts of the body.[45] In Australia, more than a quarter (28 per cent) of people living with lung cancer are not staged at diagnosis.[46]

This may be due to various reasons including patients being too ill to undertake staging investigations, therapeutic nihilism and distance from oncology services. These factors have been linked to higher rates of no treatment[47] and can also be the reason why the patient or physician do not seek additional tests after diagnosis. Knowing the disease stage helps care providers plan the most suitable and appropriate treatment[48] and it has been shown that access to MDT and specialist care is linked to a higher number of patients receiving a complete staging evaluation (from 79 to 93 per cent).[49]

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[38] Australian Institute of Health and Welfare, 2017. 'Australian Cancer Incidence and Mortality (ACIM) books' [online] Available from: https://www.aihw.gov.au/reports/cancer/acim-books/contents/acim-books.

[39] UK Lung Cancer Coalitions, 2012. 'The Dream MDT for lung cancer: Delivering high quality lung cancer care and outcomes', [online] Available from: https://www.nursingtimes.net/Journals/2012/11/20/w/h/f/The-Dream-MDT-for-Lung-Cancer.pdf.

[40] Vinod SK, Sidhom MA, Gabriel GS, Lee MT, Delaney GP, 2010. 'Why Do Some Lung Cancer Patients Receive No Anticancer Treatment?', *Journal of Thoracic Oncology* 5 (1025-1032).

[41] Consultation with a medical oncologist.

[42] Cancer Australia, 'Lung Cancer Framework, Principles for Best Practice Lung Cancer Care in Australia' [online] Available from: https://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/lung-cancer-framework.

[43] Cancer Australia, 2011. 'Report on Lung Cancer in Australia. Literature review and consultation on factors impacting on lung cancer outcomes' [online] Available from: https://canceraustralia.gov.au/system/tdf/publications/lung-cancer-in-australia_504af021db4f4.pdf?file=1&type=node&id=2806. – This report found that 53 per cent of people with lung cancer were seen by a MDT at staging and diagnosis, and 58 per cent of people during treatment.

[44] Ibid.

[45] Cancer Australia, 2016. 'Optimal care pathway for people with lung cancer' [online] Available from: https://www.cancer.org.au/content/ocp/health/optimal-care-pathway-for-people-with-lung-cancer-june-2016.pdf.

[46] Cancer Australia. National Cancer Control Indicators. 'Stage distribution by cancer type and sex, 2011' [online] Available from: https://ncci.canceraustralia.gov.au/diagnosis/distribution-cancer-stage/distribution-cancer-stage.

[47] Vinod SK, Sidhom MA, Gabriel GS, Lee MT, Delaney GP, 2010. 'Why Do Some Lung Cancer Patients Receive No Anticancer Treatment?', *Journal of Thoracic Oncology* 5 (1025-1032).

[48] Cancer Australia. 2016. 'Optimal care pathway for people with lung cancer' [online] Available from: https://www.cancer.org.au/content/ocp/health/optimal-care-pathway-for-people-with-lung-cancer-june-2016.pdf.

[49] Freeman RK, Van Woerkom JM, Vyverberg A, Ascioti AJFreeman RK et al, 2010. 'The effect of a multidisciplinary thoracic malignancy conference on the treatment of patients with lung cancer', *European Journal of Cardio-Thoracic Surgery* 38 (1–5).

What is a multidisciplinary team (MDT)?

MDT care involves an integrated approach to treatment planning, where medical professionals collaborate to discuss and make joint decisions on the appropriate treatment for patients.[50] MDTs include, but are not limited to medical and radiation oncologists, respiratory physician, surgeon, radiologist, pathologist, psychologist, palliative care physicians, and a lung cancer CNS or care coordinator.[51]

Multidisciplinary team care is considered best practice for the diagnosis, treatment planning and care provided to people with any type of cancer.[52]

People living with lung cancer are able to access better quality care when they are managed by an MDT. For example, research has found that MDT involvement improved adherence to treatment guidelines by professionals.[53]

Allied health professionals such as psychologists, social workers, dieticians, exercise physiologists and/or counsellors may also be included where appropriate. A more holistic suite of treatment and supportive care options may be accessed through MDT care. Access to MDTs is linked to better access to best practice care, increasing the adherence to treatment guidelines from 81 to 91 per cent, and a shorter time period between diagnosis to treatment (from 29 to 11 days).[54]

There also appear to be gaps in specialist referrals, and anecdotal evidence from consultation and interviews suggests this gap is one that needs to be rectified for Australians with lung cancer.

Delays in diagnosis and access to care

Delays in access to diagnosis and care are evident for people living with lung cancer and result in poorer outcomes.[55] Generally, most people living with lung cancer are diagnosed in later stages across different countries.[56] However in countries like the UK and Denmark, a higher proportion of people are diagnosed in earlier stages compared to Australia.[57] Considerable efforts are being placed into diagnosing cancer at an earlier stage compared to Australia.[58] For example, in the UK, innovative approaches to cancer diagnosis are being tested including streamlining patient diagnostic pathways. These initiatives enable improved triaging for GPs through a new electronic referral system to radiologists.[59] In Canada, multidisciplinary diagnostic centres that include patient navigator roles have been introduced in some jurisdictions.

Additionally, compared to other cancers, people living with lung cancer, have a lower chance of being diagnosed in earlier stages in Australia. For example, the proportion of people diagnosed in Stage I for lung cancer is 11.7 per cent,

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[50] Cancer Australia, 2018. 'All about multidisciplinary care' [online] Available from: https://canceraustralia.gov.au/clinical-best-practice/multidisciplinary-care/all-about-multidisciplinary-care.

[51] Cancer Australia, 2011. 'Report on Lung Cancer in Australia. Literature review and consultation on factors impacting on lung cancer outcomes' [online] Available from: https://canceraustralia.gov.au/system/tdf/publications/lung-cancer-in-australia_504af021db4f4.pdf?file=1&type=node&id=2806.

[52] Cancer Australia, 2018. 'All about multidisciplinary care' [online] Available from: https://canceraustralia.gov.au/clinical-best-practice/multidisciplinary-care/all-about-multidisciplinary-care.

[53] Freeman RK, Van Woerkom JM, Vyverberg A, Ascioti AJ, 2010. 'The effect of a multidisciplinary thoracic malignancy conference on the treatment of patients with lung cancer', *European Journal of Cardio-Thoracic Surgery* 38 (1–5).

[54] Ibid.

[55] Wang T, Nelson RA, Bogardus A, Grannis FW Jr, 2010. 'Five-year lung cancer survival: which advanced stage nonsmall cell lung cancer patients attain long-term survival?', Cancer, 116:6 (1518–1525).

[56] Walters S, Maringe C, Coleman M, Peake M, Butler J, Young N, Bergstrom S, Hanna L, Jakobsen E, Kolbeck K et al, 2013. 'Lung cancer survival and stage at diagnosisin Australia, Canada, Denmark, Norway, Sweden and the UK: a population-based study, 2004–2007', *Thorax* 68 (551-564).

[57] PwC analysis; National Cancer Control Indicators, 2018. 'Distribution of Cancer Stage' [online] Available from https://ncci.canceraustralia.gov.au/diagnosis/distribution-cancer-stage/distribution-cancer-stage; Kang, S, Koh, E, Vinod, S and B Jalaludin, 2012. 'Cost analysis of lung cancer management in South Western Sydney', Journal of medical imaging and radiation oncology 56 (235-241); Walters S, Maringe C, Coleman M, Peake M, Butler J, Young N, Bergstrom S, Hanna L, Jakobsen E, Kolbeck K, 2013. 'Lung cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the UK: a population-based study, 2004–2007.' *Thorax* 68 (551-564).

[58] Fuller E, Fitzgerald K, Hiom S. 2016. 'Accelerate, Coordinate, Evaluate Programme: a new approach to cancer diagnosis.' The British journal of general practice: the journal of the Royal College of General Practitioners 66 (176-177); Cancer Care Ontario. 2014. 'Strategic Directions for the Diagnostic Phase' [online] Available from: https://archive.cancercare.on.ca/cms/One.aspx?portalId=1377&pageId=314809.

[59] Ibid.

compared to 35.9 per cent, 42.8 per cent and 22.1 per cent for prostate, breast and colorectal cancers respectively.[60]

Multiple complex diagnostic tests and consultations are required for lung cancer diagnosis and staging. For example, an endobronchial ultrasound (EBUS), a type of lung cancer diagnostic procedure, requires much more of coordination than other more basic diagnostic tools such as blood samples and CT scans. These complex diagnosis pathways can contribute to patients experiencing a potential delay of up to two months from diagnosis to first treatment.[61] This is a long time for cancer patients to be waiting considering guidelines which state initial treatment should start within six weeks of initial GP referral.[62] Delays are also particularly experienced by people whose treatment is managed in public hospitals, with these people having to wait up to twice as long as those in a private setting.[63]

This issue of delayed diagnosis and access to care is worse for Indigenous Australians. Indigenous Australians have almost twice the risk of being diagnosed with lung cancer and higher mortality rates compared to non-Indigenous Australians.[64] They also have more advanced disease at time of cancer diagnosis. It is suggested that Indigenous Australians have lower access to effective cancer care than other Australians and these contribute to survival disadvantage.[65]

Culturally and Linguistically Diverse (CALD) Australians with lung cancer also face poorer survival rates and are less likely to receive timely and appropriate care.[66] It is important to consider the specific needs of the Indigenous and CALD populations with lung cancer to support delivery of timely and appropriate care for all Australians.

Case study - Carolyn Riordan

I am a wife and a mother of four beautiful daughters. I didn't think it was possible for me to get lung cancer. I had never smoked and my exposure to passive smoke was minimal. As a Japanese language high school teacher there was no occupational exposure. Yet five months ago the impossible became possible.

We didn't fight for cancer research when my beautiful daughter at 20 was diagnosed with Stage 4 Hodgkin's lymphoma. It stopped her in her tracks but there were treatment options with good results and wonderful care from her oncologist, and remission and good statistics. She went through gruelling chemotherapy treatment but she survived and we were grateful and she recovered and got on with her life. No one thought she deserved it or that she brought it on herself. But lung cancer is different. There is no cure. There is no remission; at best there is progression free survival.

Waiting times for testing results, although crucial to treatment options, needs to be explained. I couldn't understand why after a diagnosis of metastatic lung cancer it took so long for treatment to start. Google should not be the main source of information after a lung cancer diagnosis.

More money needs to go into research to give people with lung cancer a fighting chance. And we can make that happen. It is just a matter of changing how we think. Stigma affects decision into where money for research goes both consciously and subconsciously.

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[60] PwC analysis; National Cancer Control Indicators, 2018. 'Distribution of Cancer Stage' [online] Available from https://ncci.canceraustralia.gov.au/diagnosis/distribution-cancer-stage/distribution-cancer-stage; Kang, S, Koh, E, Vinod, S and B Jalaludin, 2012. 'Cost analysis of lung cancer management in South Western Sydney', *Journal of medical imaging and radiation oncology* 56 (235-241).

[61] Cancer Australia, 2013. 'Best practice approaches to lung cancer care - Final report' [online] Available from: https://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/best-practice-approaches-management-lung-cancer-australia.

[62] Cancer Australia. 2016. 'Optimal care pathway for people with lung cancer' [online] Available from https://www.cancer.org.au/content/ocp/health/optimal-care-pathway-for-people-with-lung-cancer-june-2016.pdf

[63] Evans SM, Earnest A, Bower W, Senthuren M, McLaughlin P, Stirling R, 2016. 'Timeliness of lung cancer care in Victoria: a retrospective cohort study', *The Medical Journal of Australia*, 204 (1-9).

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[66] Mazza D, Xiaoping L, Walter FM, Young JM, Barnes DJ, Mitchell P, Brijnath B, Martin A and Emery JD, 2018. 'The LEAD study protocol: a mixed-method cohort study evaluating the lung cancer diagnostic and pre-treatment pathways of patients from Culturally and Linguistically Diverse (CALD) backgrounds compared to patients from Anglo-Australian backgrounds', *BMC Cancer* 18 (754-762).

Burden of late diagnosis of lung cancer

Delays to diagnosis can be due to a myriad of factors including difficulty in recognising lung cancer symptoms and the presence of comorbidities.[67] Delay in diagnosis results in consequent delays to treatment. Delays to treatment increase the chances of disease progression, and some may move into more advanced stages of disease while they wait.[68]

Relative to Canada (with a comparable health system), it is estimated that Australia has a higher proportion of Stage III diagnosis (32 per cent in Australia vs 19.0 per cent in Canada), and a lower proportion of diagnosis in Stage I (11.7 per cent in Australia vs 20.1 per cent in Canada).[69] Later diagnosis affects people's health outcomes, mortality and costs to treat. This is outlined in Table 2.

For example, it costs $12,400 more to treat a patient diagnosed in Stage III than Stage I, and 30 per cent of people diagnosed in Stage III die within the first year, compared to about six per cent for those diagnosed in Stage I.

Table 2 Comparison between stages at diagnosis

In 2018	Stage I	Stage II	Stage III	Stage IV
Average cost to treat, per patient	$19,000	21,600	$35,000	$34,500
One year mortality rate[70]	5.7%	15.9%	30.7%	55.1%

Source: PwC analysis, Goldstraw et al (2015)

In a hypothetical scenario, if Australia's diagnoses were closer to that of Canada, with more people being diagnosed early (Stage I) and fewer people being diagnosed later (Stage III), then it would change health costs and mortality rates for people. This could have an estimated lower total cost to treat of **$15 million** for new incidences in 2018 and **$342.1 million** over 10 years by 2028 for all patients.

In addition, survival would improve, resulting in avoiding approximately **4,050 premature lung cancer deaths** over 10 years, amounting to **43,708 years of life saved** from 2018-2028 (at a value of $2.2 billion).

These results are hypothetical and aim to show a scale of potential impact if people were diagnosed earlier in Australia.

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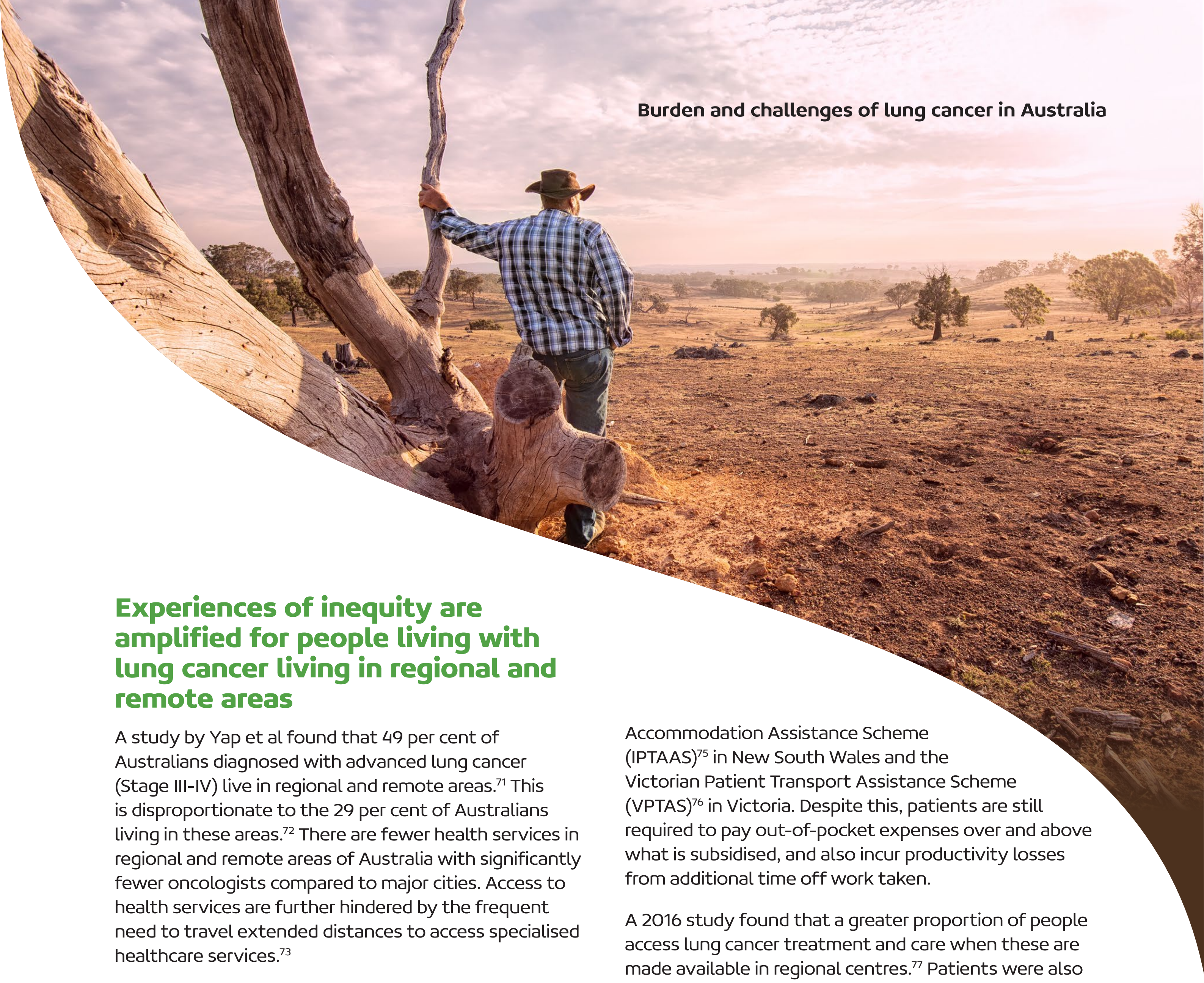
[67] Hill L, Collier G, Gemine R, 2017. 'A Patient Perspective: Identifying and Understanding the Barriers Associated with the Diagnostic Delay of Lung Cancer', European Medical Journal 5 (92-98).

[68] Mohammed N, Kestin LL, Grills IS, Battu M, Fitch DL, Wong CY, Margolis JH, Chmielewski GW, Welsh RJMohammed N, et al, 2011. 'Rapid Disease Progression with Delay in Treatment of Non-Small Cell Lung Cancer', International Journal of Radiation Oncology, Biology, Physics 79 (466-472).

[69] National Cancer Control Indicators, 2018. 'Distribution of Cancer Stage' [online] Available from: https://ncci.canceraustralia.gov.au/diagnosis/distribution-cancer-stage/distribution-cancer-stage.

[70] Ibid.



Experiences of inequity are amplified for people living with lung cancer living in regional and remote areas

A study by Yap et al found that 49 per cent of Australians diagnosed with advanced lung cancer (Stage III-IV) live in regional and remote areas.[71] This is disproportionate to the 29 per cent of Australians living in these areas.[72] There are fewer health services in regional and remote areas of Australia with significantly fewer oncologists compared to major cities. Access to health services are further hindered by the frequent need to travel extended distances to access specialised healthcare services.[73]

The time and distance required to access diagnostic and oncology services that are not available in regional and remote areas incurs a significant burden for patients and their carers.[74] State governments have provided travel and accommodation subsidies to assist with the cost of travel arrangements, like the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)[75] in New South Wales and the Victorian Patient Transport Assistance Scheme (VPTAS)[76] in Victoria. Despite this, patients are still required to pay out-of-pocket expenses over and above what is subsidised, and also incur productivity losses from additional time off work taken.

A 2016 study found that a greater proportion of people access lung cancer treatment and care when these are made available in regional centres.[77] Patients were also travelling an average of 128.6km less after the opening of a regional centre.[78]

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[71] Yap S, Goldsbury D, Yap ML, Yuill S, Rankin N, Weber M, Canfell K, O'Connell DL, 2018. 'Patterns of care and emergency presentations for people with non-small cell lung cancer in New South Wales, Australia: A population-based study', *Lung Cancer* 122 (171-179).

[72] AIHW, 2016. 'Australia's Health 2016 - Australians: Who we are' [online] Available from: https://www.aihw.gov.au/getmedia/ff410cf7-bd90-47dc-bf6b-22007c9a0904/ah16-1-2-australians-who-we-are.pdf.aspx.

[73] Garvan Research Institute, 2016. 'A Rural Perspective: Cancer and Medical Research 2016', [online] Available from: https://www.garvan.org.au/news-events/files/a-rural-perspective-cancer-and-medical-research.pdf

[74] Butler SM, 2016. 'Changes to radiotherapy utilisation in Western NSW after the opening of a local service', *Journal of Medical Radiation Sciences* (1-8).

[75] EnableNSW, Travel Assistance (IPTAAS) HealthShare [online] Available from: http://www.enable.health.nsw.gov.au/services/iptaas.

[76] Victorian Department of Health, 2018. Victorian Patient Transport Assistance Scheme (VPTAS) [online] Available from: https://www2.health.vic.gov.au/hospitals-and-health-services/rural-health/vptas-how-to-apply.

[77] Butler SM, 2016. 'Changes to radiotherapy utilisation in Western NSW after the opening of a local service', *Journal of Medical Radiation Sciences* (1-8).

[78] Ibid.

1.2.2 Stigma

People living with lung cancer experience stigma in society, including from health providers, employers and even themselves. One study suggests that approximately **30 per cent** of people living with lung cancer blame themselves for their diagnosis.[79] Smoking is viewed as a contributing factor for lung cancer and as a result, smokers and life-long non-smokers alike often feel blamed for their illness. This judgement negatively impacts the perceived worthiness of people to access support, care, and even sympathy.

People living with lung cancer bear a considerable personal burden resulting from feeling blamed for their illness, adversely impacting their overall health outcomes and quality of life. For example, stigma has negative impacts on mental health outcomes, which may lead to fatalism (view that we are powerless to do anything) and nihilism.[80] This sense of guilt may also result in people delaying presentation for diagnosis and treatment, which may then mean they are diagnosed at a later stage of their disease, and their chance of survival decreases.[81] Consultations also revealed that some people hide their disease from family and friends, with this lack of support leading to emotional distress, and even anxiety and depression.[82]

A national consumer survey undertaken by the Lung Foundation Australia in 2017[83] found that over a third of Australians believe people living with lung cancer "only have themselves to blame", and one in ten believe that those with lung cancer "got what they deserved." The survey also revealed that 35 per cent of Australians would not speak out if they were diagnosed with lung cancer because of fear of judgement, or at least were uncertain about whether they would disclose their diagnosis. These findings mirror results from a 2017 study which found almost one third of all people (28 per cent) in Australia have less sympathy for people living with lung cancer than other forms of cancer.[84] The issue of stigma is not limited to the public. Health professional attitudes are as negative as those of patients, caregivers and the general public.[85]

Give all Australians a 'fair go'

Australian culture is world-renowned for its egalitarianism, as a country that gives everybody a 'fair go'. As outlined in this report, people living with lung cancer experience higher levels of stigma for their diagnosis, which unfairly impacts their mental health, emotional wellbeing and health outcomes. People are blamed and feel guilty for their illness. Australians are entitled to the same public access to diagnostics, treatment and care – regardless of the disease they have, the cause of their cancer or their place of residence. Anyone can get lung cancer, regardless of whether they smoke, stopped smoking or never smoked in their lives. Nobody deserves lung cancer.

> *"My compulsion to tell people I have never smoked and was born into a family of never-smokers comes from an entrenched community stigma around lung cancer being brought on by people themselves. Since being diagnosed with lung cancer, I've found myself sitting in the same room with people who smoke, who used to smoke and who have never smoked. At the end of the day, we all have lung cancer and we need to be treated the same way."*
> ***Prof Nghi Phung, wife, mother and specialist in gastroenterology and addiction medicine, diagnosed with lung cancer in February 2017 at the age of 49.***

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[79] Jarrett L, 2015. 'Health-related stigma in advanced lung cancer' Vanderbilt University. Nashville, Tennessee.

[80] Crane M, Scott N, O'Hara BJ, Aranda S, Lafontaine M, Stacey I, Varlow M, Currow DCrane M et al, 2016. 'Knowledge of the signs and symptoms and risk factors of lung cancer in Australia: mixed methods study', *BMC Public Health* 16 (508).

[81] Carter-Harris L, Hermann CP, Schreiber J, Weaver MT, Rawl SMCarter-Harris L et al, 2014. 'Lung cancer stigma predicts timing of medical help-seeking behaviour', *Oncology Nursing Forum* 41 (E203-210).

[82] Chambers SK, Baade P, Youl P, Aitken J, Occhipinti S, Vinod S, Valery PC, Garvey G, Fong KM, Ball D, Zorbas H, Dunn J, O'Connell DL, 2015.Chambers SK, Baade P, et al. 'Psychological distress and quality of life in lung cancer: the role of health-related stigma, illness appraisals and social constraints', *Psycho-Oncology* 24 (1569-1577).

[83] Lung Foundation Australia, 2017. 'Lung Foundation Australia Annual Report', [online] Available from: https://lungfoundation.com.au/wp-content/uploads/2018/03/XANZOO180209_LFA_Annual-Report_web.pdf

[84] Sriram N, Mills J, Lang E, Dickson HK, Hamann HA, Nosek BA, et al.2015. 'Attitudes and Stereotypes in Lung Cancer versus Breast Cancer', *PLOS one* 10 (12-13).

[85] Brown NM, Lui CW, Robinson PC, Boyle FM. 'Supportive care needs and preferences of lung cancer patients: a semi-structured qualitative interview study', *Support Care Cancer* 23 (1533-1539).

1.2.3 Psychosocial support

People living with lung cancer experience considerable mental health issues, with approximately half experiencing distress, anxiety and/or depression.[86] There appears to be insufficient appropriate services available to support this high need based on evidence from recent studies.[87]

Understanding psychosocial support

Psychosocial support refers to any psychological care and/or social services provided to people diagnosed with cancer. There are many methods and forms of delivery that psychosocial support services may take, including mental health counselling, education and group support amongst many other similar services that help patients to manage distress and to deal with the emotional and practical concerns of having cancer. Universal and supportive care can be delivered through peer support and a range of professionals including social workers and counsellors; with extended, specialist and acute care being provided by psychologists and psychiatrists.[1]

Psychosocial support could be delivered in a stepped-care model, with different types of support provided for varying levels of psychological distress. Best practice models include all people with cancer being screened for distress using a validated tool.[1] People with high levels of distress could be assessed by a member of the treatment team and offered referral for an appropriate intervention. A stepped care model is a framework that helps to match psychological support with individual needs and preferences.[1] Table 3 provides an example of the stepped care framework. This highlights varying levels of need and that a 'one size fits all' approach will not be appropriate.

There is more than one framework for psychological support and the table below is an example of how the varying levels of psychological need and care can be considered and organised in one model.

Case Study – Marilyn Nelson

In 2013 at the age of 61, I was diagnosed with lung cancer out of the blue after having a CT scan on my neck and upper back for ongoing nerve pain. The CT scan showed the cause of my nerve pain, but it also unexpectedly showed a 3cm mass at the top of my right lung. I had not experienced any symptoms at all. I'm a never-smoker. It was a complete surprise. That seems to be a very common story. I quickly felt the stigma of lung cancer.

Every single person I told I had lung cancer immediately asked me, "were you a smoker?" Not one person just said "oh no, I'm so sorry to hear that". It was always "did you smoke?" I know how bad that made me feel, it must be so much worse for someone who has a smoking history. This lack of compassion adds greatly to the sense of isolation we feel.

It's just cruel to not respond with kindness to someone who tells you they have cancer – very cruel. I eventually learned to always say, "I have lung cancer, but I never smoked". Even then, I've found most people still do not respond with kindness; mostly they give me a look of doubt. They don't seem to believe me that never-smokers also get lung cancer, and in large numbers too. I now use it as an opportunity to educate people.

For the first 18 months I was treated in the private system. During that whole period, there was no-one I could call if I had queries, apart from the medical oncologist's secretary who was very nice and would pass messages on and I would await an answer. Answers were usually short – yes/no/make an appointment. Very little information really. I must say that most of the information I had, I obtained myself from the web. I have now become a lung cancer advocate working towards better treatment for lung cancer patients; more support; more compassion; and more funding for clinical trials. It's my way of finding some meaning and purpose in having this awful disease.

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[86] Ibid.

[87] Brown NM, Lui CW, Robinson PC, Boyle FM. 'Supportive care needs and preferences of lung cancer patients: a semi-structured qualitative interview study', Support Care Cancer 23 (1533-1539). ; Giuliani ME et al, 2016. 'The prevalence and nature of supportive care needs in lung cancer patients', *Curr Oncol* 4 (258-65).

Table 3 Stepped-care model for psychological support[88]

Level of distress	Methods and relevant services	Professionals involved in support	Example of psychosocial issue
Minimal - mild	**Universal care:** general information and advice Telephone helplines, printed and audio-visual materials, face-to-face or online patient education, brief emotional support	Treating clinician, GP, other appropriately trained professionals such as cancer nurse, social worker	Side effects of medications and/or treatments, practical concerns
Mild - moderate	**Supportive care:** psycho-education, emotional support, peer support Hospital or community-based programs, telephone helplines, peer support group and group therapy	Treating clinician, GP, other appropriately trained professionals such as cancer nurse, social worker	Treatment decision making, problem solving and coping strategies
Moderate	**Extended care:** focused counselling (individual, couple, family or group) with psycho-education and coping skills training Face to face or online coping skills training (e.g. problem solving, communication, relaxation skills), psychological therapy (e.g. cognitive behavioural therapy), pharmacotherapy	GP, social worker, psychologist, psychiatrist, cancer nurse	Adjustment to cancer, stress management
Moderate – severe	**Specialist care:** skilled therapist(s) Hospital and community based psychotherapy, relationship and family therapy, psychological therapy, pharmacotherapy	Psychologist, psychiatrist with GP	Mood and anxiety disorders, trauma, relationship problems
Severe	**Acute care:** specialist care Specialist community and hospital based mental health services or psychotherapy, psychiatric inpatient services, pharmacotherapy	Psychologist, psychiatrist with GP	Multiple complex psychiatric difficulties, risk issues, severe personality and relationship issues

Different forms of support will be appropriate for patients at different times during diagnosis, treatment and after active treatment has finished. There is a significant evidence base that shows that interventions for anxiety and depression in people with cancer are effective in both the short and long term.[89] Access to psychosocial support can reduce levels of depression and anxiety, improve quality of life and enhance functional status for people with cancer.[90] Further, psychosocial support can also enhance hope in people living with lung cancer which may reduce levels of pain and psychological distress.[91]

In addition, there is sometimes low use of supportive care services that are available. One study found that drivers of underutilisation are not as simple as a lack of awareness or availability of services, but rather that the form and method of delivering these supports to people living with lung cancer required better alignment with needs.[92]

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[88] Psycho-oncology Co-operative Research Group, 2017. 'Clinical Pathway for screening, assessment and management of anxiety and depression in adult cancer patients' [online] Available from: https://www.pocog.org.au/doc/ClinicalPathways_Sept%202017.pdf; Hutchinson SD, Steginga, SK, Dunn J, 2006. 'The tiered model of psychosocial intervention in cancer: a community based approach', *PsychoOncology* 15 (541-546); Department of Health, Western Australia, 2008. 'Psycho-Oncology Model of Care' Perth: WA Cancer and Palliative Care Network, Department of Health, Western Australia.

[89] Butow P, Price MA, Shaw JM, Turner J, Clayton JM, Grimison P, Rankin N, 2015. 'Clinical pathway for the screening, assessment and management of anxiety and depression in adult cancer patients: Australian guidelines', *Psycho-oncology* 24 (987-1001).

[90] Raingruber B, 2011. 'The Effectiveness of Psychosocial Interventions with Cancer Patients: An Integrative Review of Literature (2006-2011)', California State University, Sacramento California, USA.; Rehse B and Pukrop R, 2003. 'Effects of psychosocial interventions on quality of life in adult cancer patients: meta analysis of 37 published controlled outcome studies', *Patient Education and Counselling* 50 (179-186).

[91] Berendes D, Keefe FJ, Somers TJ, Kothadia SM, Porter LS, Cheavens JS,Berendes, D. 2010. 'Hope in the Context of Lung Cancer: Relationships of Hope to Symptoms and Psychological Distress', *Journal Pain Symptom Management* 40 (174-182).

[92] Brown NM, Lui CW, Robinson PC, Boyle FM, 2015. 'Supportive care needs and preferences of lung cancer patients: a semi-structured qualitative interview study', *Support Care Cancer* 23 (1533-1539).

It is important that psychosocial support meets the unique needs of different cohorts. There are four key groups to consider when developing appropriate psychosocial support services and programs:

- **people undergoing curative treatments** require support from the point of diagnosis through to treatment, especially to manage feelings of anxiety and/or panic attacks which may be associated with the physical problems, like breathlessness or psychological concerns, such as a "fear of the cancer spreading."[93] Psychosocial support is also key to discussing distress related to new symptoms (e.g. breathlessness), side-effects associated with curative treatments (e.g. hair loss, fatigue), and dealing with psychological stress post-surgery and after recovery[94]
- **people on long-term targeted therapies and immunotherapies** require support through the experience of being in the advanced stages of lung cancer (Stage IIIB and IV) and when treated with often high-cost drugs. There are many points along this journey when stressors increase greatly, such as the time of cancer progression. Counselling, education and psychosocial support are important in managing expectations, especially around what it's like to live with cancer, anticipated success of the treatment and associated prognosis
- **people undergoing palliative care** require support in understanding palliative care as a form of supportive care for symptom management, as well as an end of life option.[95] When appropriate, patients could be supported with information about palliative care at the end of life and how it can improve quality of life and minimise feelings of distress[96]
- **carers and family of people living with lung cancer** require support in coming to terms with the shock of diagnosis, accessing information on the disease, possible carer duties, and preparing for changes in their own lives (e.g. changes to routine, working arrangements, their financial situation etc.).[97]

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[93] Giuliani ME, Milne RA, Puts M, Sampson LR, Kwan JY, Le LW, Alibhai SM, Howell D, Abdelmutti N, Liu G, Papadakos J, Catton P, Jones J, 2016. 'The prevalence and nature of supportive care needs in lung cancer patients', *Current Oncology* 23 (258-265).

[94] Collins LG, Haines C, Perkel R, Enck RE,2007. 'Lung cancer: diagnosis and management', *Am Fam Physician* 75 (56–63).

[95] Fadul N, Elsayem A, Palmer JL, Del Fabbro E, Swint K, Li Z, Poulter V, Bruera E, 2009. 'Supportive versus palliative care: what's in a name?: a survey of medical oncologists and midlevel providers at a comprehensive cancer center', *Cancer* 115 (2013-2021).

[96] Ambroggi M, Biasini C, Toscani I, Orlandi E, Berte R, Mazzari M, Cavanna L, 2018. 'Can early palliative care with anticancer treatment improve overall survival and patient-related outcomes in advanced lung cancer patients? A review of the literature', *Supportive Care in Cancer* 26 (2945-2953).

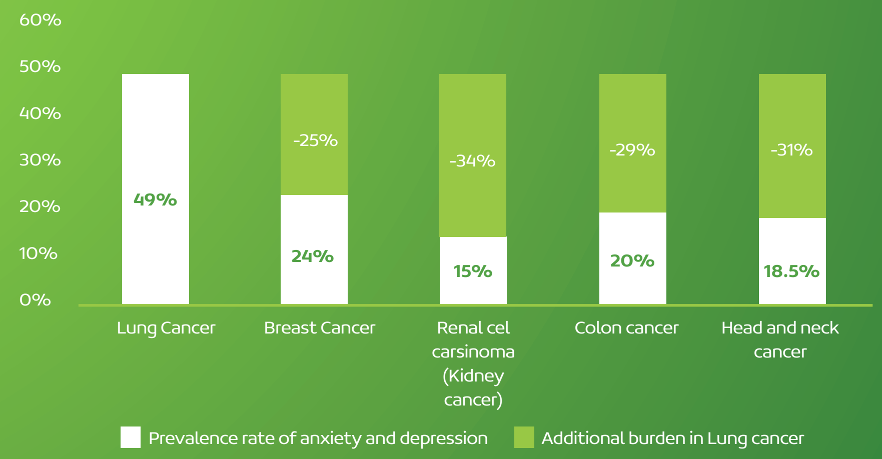
[97] Friðriksdóttir N, Saevarsdóttir T, Halfdánardóttir SÍ, Jónsdóttir A, Magnúsdóttir H, Olafsdóttir KL, Guðmundsdóttir G, Gunnarsdóttir S, 2011. 'Family members of cancer patients: Needs, quality of life and symptoms of anxiety and depression', *Acta Oncologica* 50 (252-258).

The psychosocial burden of lung cancer

People living with lung cancer suffer a high personal psychosocial burden relative to other cancers, with research suggesting that approximately half of such people may have anxiety and/or depression.[98] In 2018, it is estimated that about **6,200** newly diagnosed people living with lung cancer will develop anxiety and depression. This means that a total of approximately **131,400** of all people diagnosed to 2028 with lung cancer may have anxiety and depression.

The prevalence of anxiety and depression in people living with lung cancer is relatively high when compared with other major cancers, with a prevalence of poor mental health outcomes that is **29.6 per cent higher** than the average of other major cancers (see Figure 1).[99] This further highlights the high need for psychosocial support for people living with lung cancer.

Figure 1 Comparison of prevalence of anxiety and depression in other cancers compared to lung cancer[100]



Source: PwC analysis, Kissane et al (2014), Thekdi et al (2015), Mayr and Schmid (2010), Rieke (2017)

Anxiety and depression worsens the quality of life of people living with lung cancer. A metric generally used to measure length and quality of life for people is the Quality Adjusted Life Year or QALY.[101] One study found a measurable impact from anxiety and depression on people living with lung cancer. [102] This combined with the estimated total number of people living with lung cancer and anxiety and depression would equal an estimated **4,700 QALYs** in 2018 and **99,200 QALYs** over 10 years by 2028.

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[98] Chambers SK, Baade P, Youl P, Aitken J, Occhipinti S, Vinod S, Valery PC, Garvey G, Fong KM, Ball D, Zorbas H, Dunn J, O'Connell DL, 2015. 'Psychological distress and quality of life in lung cancer: the role of health-related stigma, illness appraisals and social constraints', *Psycho-Oncology*, 24 (1569-1577).

[99] Kissane DW, Grabsch B, Love A, Clarke DM, Bloch S, Smith GC, 2004. 'Psychiatric disorder in women with early stage and advanced breast cancer: a comparative analysis', The Australian New Zealand Journal of Psychiatry, 38 (320-326); Thekdi SM, Milbury K, Spelman A, Wei Q, Wood C, Matin SF, Tannir N, Jonasch E, Pisters L, Cohen L, 2015. 'Posttraumatic Stress and Depressive Symptoms in Renal Cell Carcinoma: Association with Quality of Life and Utility of Single Item Distress Screening', Psychooncology 24 (1477-1484); Mayr M, Schmid RM, 2010. 'Pancreatic Cancer and depression: myth and truth', BMC Cancer, 10 (569); Rieke K, Schmid KK, Lydiatt W, Houfek J, Boilesen E, Watanabe-Galloway S, 2017. 'Depression and survival in head and neck cancer patients', *Oral Oncology* 65 (76-82).

[100] Ibid.

[101] Department of Health, 2002. 'Quality-adjusted-life-years (QALYs)' [online] Available from: http://www.health.gov.au/internet/publications/publishing.nsf/Content/illicit-pubs-needle-return-1-rep-toc~illicit-pubs-needle-return-1-rep-5~illicit-pubs-needle-return-1-rep-5-2.

[102] A utility value of 0.11 is estimated in people with lung cancer who also have anxiety and/or depression, compared to the Australian average of 0.87 - World Health Organisation, 'Chapter 3 The global burden of disease concept' [online] Available from: http://www.who.int/quantifying_ehimpacts/publications/en/9241546204chap3.pdf; Clemens S, Begum N, Harper C, Whitty JA, Scuffham PA, 2014. 'A comparison of EQ-5D-3L population norms in Queensland, Australia, estimated using utility value sets from Australia, the UK and USA', *Quality Life Research* 23 (2375-2381).

2 Economic costs of lung cancer in Australia

2.1 Cost of lung cancer

There are many costs associated with lung cancer affecting multiple stakeholders including the Commonwealth, state and territory governments, people living with lung cancer, private health insurers, carers and family members and employers. Table 4 provides some examples of costs to different stakeholders from lung cancer in Australia. The economic analysis results in this report focus on costs that are quantifiable and where there is sufficient publicly available information.

Table 4 Key stakeholders and relevant burden to each

Government	Patients	Private health insurers	Families and carers	Employers
• **Healthcare spending** • **Investment in smoking interventions** • **Welfare subsidies (unemployment, sickness, disability, carers payments)** • **Lower tax revenue (from reduced productivity)** • **Hospital infrastructure** • **Transport subsidies** • **Research**	• Premature mortality • Quality of life • Out-of-pocket expenses • Psychosocial burden • Stigma and social isolation • Travel costs • Absenteeism • Presenteeism • Transport	• Medical care claims • Investments in lung cancer interventions • Research	• Quality of life • Home service care • Absenteeism for carers	• Absenteeism[103] • Presenteeism[10]

Source: PwC analysis and stakeholder interviews

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[103] Defined as decreased worker productivity through absences from work

[104] Defined as lost productivity that occurs when employees come to work, but as a consequence of illness or other medical conditions, are not fully functioning

The economic burden of lung cancer for new patients diagnosed in 2018 is estimated to be $297.2 million in direct and indirect costs.

With the population projections and new incidences of lung cancer growing at a similar rate, the costs over ten years to 2028 are estimated to be **$6.2 billion** in direct costs and **$325.9 million** in indirect costs (absenteeism) and years of life lost from premature deaths will grow to approximately **2.9 million years** by 2028. These costs are summarised in Table 5.

Table 5 Summary of the burden of lung cancer in Australia, 2018-2028

Cost category	2018 (New incidences - 12,741 people)	10 year projection
Direct costs		
Treatment costs	$242.0 million	$4.8 billion
Out-of-pocket expenses	$1.5 million	$36.3 million
Out of hospital costs	$40.2 million	$1.5 billion
Total	**$283.7 million**	**$6.2 billion**
Indirect costs		
Absenteeism	$13.5 million	$325.9 million
Total	**$297.2 million**	**$6.6 billion**

Source: PwC analysis

2.2 Direct costs

It is estimated that the direct cost of lung cancer in Australia (inclusive of treatment costs, patient out-of-pocket expenses, and out of hospital costs) amounts to **$283.7 million** for new incidences of lung cancer diagnosed in 2018. These estimated costs, and projections over 10 years, are summarised in Table 6.

Cost item	2018 (New incidences - 12,741)	10 year projection (All patients - 159,000)
Treatment costs		
Surgery	$7.9 million	$111.8 million
Chemotherapy	$42.7 million	$876.1 million
Radiation therapy	$14.5 million	$442.4 million
Concurrent chemotherapy and radiation	$43.0 million	$1.1 billion
Targeted therapy	$20.1 million	$284.2 million
Immunotherapy	$81.8 million	$1.2 billion
Follow-up	$32.0 million	$748.9 million
Subtotal treatment costs	**$241.9 million**	**$4.8 billion**
Patient out-of-pocket expenses		
Travel costs, regional/remote patients	$1.5 million	$36.3 million
Out of hospital costs		
Staging investigations	$40.2 million	$569.5 million
Palliative care services	–	$916.4 million
Subtotal out of hospital costs	**$40.2 million**	**$1.4 billion**
Total	**$283.7 million**	**$6.2 billion**

Source: PwC analysis. Note totals may not sum due to rounding.

If costs outlined in Table 6 are separated according to stage of disease, the costs are highest in the later stages, with 88 per cent of total direct costs incurred in Stages III and IV for NSCLC and 65 per cent of costs incurred in the extensive stage for SCLC over the ten years.

Additionally, it is more costly to treat patients as the cancer progresses into later stages in general. For example, on average it costs $15,500 more to treat Stage IV lung cancer than Stage I. A breakdown of costs by stage is outlined in Appendix A.

It is also important to note that the estimated costs are based on treatment costs available in 2018 and do not account for the introduction of future targeted therapies and immunotherapies that may lead to higher costs for treatment. For example, there are several immuno-oncology medications in the pipeline including atezolizumab, durvalumab, and pembrolizumab (TGA registered and/or FDA approved) for lung cancer patients. These new medicines, if approved and subsidised through the PBS will provide additional treatment options and hope for some late stage lung cancer patients. They may also increase the overall future treatment costs per year, however at this stage it is not possible to estimate by how much. In summary, the estimated treatment costs, including the costs with immuno-oncology medicine and targeted therapies, increase according to inflation rate (2.4% - see Table 14) and lung cancer incidence growth (see Table 10) and should be considered conservative.

2.3 Indirect cost

It is difficult for people with cancer to continue normally with their daily activities because of side effects (e.g. breathlessness), medical appointments, and potential treatment regimens (e.g. chemotherapy, radiation therapy cycles). Many people need to take time off work to attend appointments and manage treatment.

Based on average employment rates, time off needed and average salaries, it is estimated that the time in productivity loss will be **$13.5 million** in 2018, and reach **$325.9 million** by 2028.

In addition, based on consultations, it was noted that many people living with lung cancer leave work and don't return. There are no Australian studies or data to quantify the large cost of premature retirement to people and their families, however one international review found that only 20 per cent of people whose lung cancer is progression-free will return to work.[105] Considering this point, it should be noted that the estimated productivity costs are very conservative compared to the potential total scale of burden to people, their families and employers.

Table 7 Indirect cost summary, 2018 and 10-year projection

Cost item	2018 (New incidences - 12,741)	10 year projection (All patients - 159,000)
Indirect costs		
Absenteeism	$13.5 million	$325.9 million

Source: PwC analysis

2.4 Premature mortality

People living with lung cancer die earlier (prematurely) by 11 years on average compared to the general population.[106] It is estimated that this amounts to approximately **137,600 years of life lost** in 2018. These years of life lost incur a cost of approximately $6.9 billion in 2018.[107]

With population projections and new incidences of lung cancer growing at a similar rate, the years of life lost from premature deaths will grow to approximately **2.9 million years** by 2028. Over 10 years, these years of life lost incur a cost of approximately $144.8 billion.

Table 8 Premature mortality summary, 2018 and 10-year projection

Cost item	2018 (New incidences - 12,741)	10 year projection (All patients - 159,000)
Premature mortality		
Years of life lost (YLL)	137,600 years of life lost	2.9 million years of life lost

Source: PwC analysis

All details on assumptions for economic impact results are provided in Appendix B.

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[105] Kamal KM, Covvey JR, Dashputre A, Ghosh S, Shah S, Bhosle M, Zacker C, 2017. 'A Systematic Review of the Effect of Cancer Treatment on Work Productivity of Patients and Caregivers', *Journal of Managed Care & Specialty Pharmacy*, 23:2 (136-162).

[106] OECD, 2018. 'OECD Health Statistics 2018' [online] Available from: http://www.oecd.org/els/health-systems/health-data.htm; Australian Institute of Health and Welfare, 2017. 'Australian Cancer Incidence and Mortality (ACIM) books' [online] Available from: https://www.aihw.gov.au/reports/cancer/acim-books/contents/acim-books.

[107] The cost of one year of "quality life" is estimated to be $50,000. Taylor, C and Jan, S, 2017. 'Economic evaluation of medicines', *Australian Prescriber* 40 (76-78).

[108] Ibid.

3 Recommendations and required action

Based on identified needs and challenges, the Steering Committee (listed on page ix) developed the following set of recommendations to improve health outcomes and quality of life for people living with lung cancer in Australia. These recommendations aim to:

- improve access to quality diagnostics and care for all
- shift perceptions away from stigma
- address the need for psychosocial support.

Required actions for each recommendation have been developed. These are not intended to be exhaustive, however should help make potential next steps clearer and more concrete.

3.1 Improve quality diagnostics and care for people living with lung cancer

Earlier diagnosis and treatment can improve health outcomes for lung cancer patients as earlier diagnosis is associated with higher survival rates.[109] The following recommendations and actions aim to help improve access to quality diagnostics and care which can improve health outcomes of people living with lung cancer.

Recommendation 1
Increase the availability of lung cancer clinical nurse specialists and care coordinators to assist people in navigating the complexities of the health system from the time of diagnosis and improve outcomes.

Actions include:

- Australian Government to subsidise an increase in availability of lung cancer clinical nurse specialists and lung cancer care coordinator capacity in Australia. For regional and remote areas, it may be more practical to provide training to nurses who may need to cover multiple cancer/disease areas. The training curriculum for these roles may be supplemented by a mentoring program pairing up experienced lung cancer CNS'/nurse coordinators with people in training.
- Lung Foundation Australia in partnership with the Institute for Health and Biomedical Innovation has begun research to scope out the role and outcomes achieved by lung cancer support nurses.[110] Patient groups and/or organisations could commission additional research into the benefits and impact (including economic) of lung cancer clinical nurse specialists and care coordinators specifically.
- Cancer Australia to promote the role of the lung cancer care coordinator as best practice care for people living with lung cancer.

Recommendation 2
Increase access to multidisciplinary team (MDT) care which leads to better health outcomes for people living with lung cancer.

Actions include:

- Establish MDT teams in local health districts currently without them to support local patient needs and promote best practice care.
- Pathology and imaging centres/clinics to include local lung cancer MDT contacts within diagnostic reports to assist GPs and respiratory specialists in referring patients.
- GPs in regional and remote areas to be provided with services to enhance regional lung cancer care. These may include visiting specialist physicians, telehealth, access to lung MDTs and clinical resources for best practice in lung cancer care.
- Primary care providers assisted by RACGP and Primary Health Networks to maintain a clear, up-to-date understanding of the symptoms and best practice treatment of lung cancer, to provide referrals onto appropriate diagnostic testing to better identify lung cancer, and refer onto specialist care earlier.
- Cancer Australia to develop best practice pathways for patient referral and engagement with MDTs, including considerations of access for people living in regional and remote areas. These should be reviewed regularly for relevance.

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[109] Goldstraw P, Chansky K, Crowley J, Rami-Porta R, Asamura H, Eberhardt WE, Nicholson AG, Groome P, Mitchell A, Bolejack V, 2015. 'The IASLC Lung Cancer Staging Project: Proposals for Revision of the TNM Stage Groupings in the Forthcoming (Eighth) Edition of the TNM Classification for Lung Cancer', Journal of Thoracic Oncology 11 (39-51); Janssen-Heijnen ML, Maas HA, Siesling S, Koning CC, Coebergh JW, Groen HJ, 2011.'Treatment and survival of patients with small-cell lung cancer: small steps forward, but not for patients', *Annals of Oncology* 23 (954–960).

[110] Brunelli, V, Mulvihill C, Kerr, J and H Allan, 2018. 'Expectations, Standards and Performance Framework to support the novel role of the Lung Cancer Support Nurse, Lung Foundation Australia', Lung Foundation Australia and Institute for Health and Biomedical Innovation.

3.2 Shift perceptions away from stigma

Stigma has negative impacts on mental health outcomes and the quality of life for people living with lung cancer.[111] The following recommendations and actions aim to help reduce lung cancer stigma and also reduce associated negative outcomes.

Recommendation 3
The needs of people living with lung cancer and the complexity of the disease should be included in professional training and medical workforce curriculum to promote awareness and provide strategies to shift perceptions away from stigma.

Actions include:

- Specialist medical colleges and professional networks in Australia to provide training opportunities with a focus on the complexities and optimal therapy on lung cancer.
- Australian Safety and Quality Commission in Health Care to measure and follow up on therapeutic nihilism in lung cancer treatment.
- Medical education at university and post-graduate training levels should markedly improve training in tobacco cessation treatment with a focus on assisting people to overcome a severe addiction.

Recommendation 4
Launch a campaign that encourages people to 'Give everyone a Fair Go' by increasing public awareness of the complexities associated with lung cancer to reduce stigma.

Actions include:

- Lung Foundation Australia to learn from other community advocacy groups such as the Breast Cancer Network Australia and the Prostate Cancer Foundation of Australia (who have led successful awareness campaigns) and collaborate with them to initiate an awareness campaign such as 'Lend a Hand to Lung Cancer' campaign. Funding for such a campaign will need to be secured.

3.3 Address the need for psychosocial support

Improving access to psychosocial support could lead to more people living with lung cancer having decreased levels of depression and anxiety[112], and improved quality of life overall.[113] The following recommendations and actions will help address this need.

Recommendation 5
All people living with lung cancer should be screened for psychosocial support needs and if appropriate, should be **referred** to psychosocial support services as early as practicable in their cancer journey guided by the stepped-care model. Those with more severe needs should be referred to psychosocial support from professionals with experience in an oncology setting.

Actions include:

- Lung Foundation Australia to identify and collate an overview of lung cancer specific psychosocial support programs and resources for people in a central location. People living with lung cancer, their carers/families, GPs, lung cancer CNS and other lung cancer specialists can use this centralised source for information and referrals. The overview can also highlight where additional programs are needed.
- Lung cancer CNS' and/or care coordinators to connect people with the appropriate psychosocial support services for their needs.
- Specialist medical colleges and professional networks (e.g. RACGP) to encourage all GPs and cancer specialists to provide a mental health plan and referrals to psychologists/clinical psychologists for people living with lung cancer, where it is appropriate.
- MDTs to refer to and engage with local psychosocial support professionals in a meaningful way, when it is appropriate and available.
- Lung Foundation Australia and Cancer Council to highlight the value of available guidelines (e.g. Cancer Council Australia's wiki guidelines on psychosocial support and other available international sources) to

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[112] Raingruber B, 2011. 'The Effectiveness of Psychosocial Interventions with Cancer Patients: An Integrative Review of Literature (2006-2011)', ISRN Nursing (1-27).

[113] Uitterhoeve RJ, Vernooy M, Litjens M, Potting K, Bensing J, De Mulder P, van Achterberg T, 2004. 'Psychosocial interventions for patients with advanced cancer – a systematic review of the literature', British Journal of Cancer 91 (1050-1062); Raingruber B, 2011. 'The Effectiveness of Psychosocial Interventions with Cancer Patients: An Integrative Review of Literature (2006-2011)', ISRN Nursing (1-27); Thompson E, Sola I, Subirana M, 2005. 'Non-invasive interventions for improving well-being and quality of life in patients with lung cancer – A systematic review of the evidence', *Lung Cancer* 50 (163-176).

[111] Chambers SK, Baade P, Youl P, Aitken J, Occhipinti S, Vinod S, Valery PC, Garvey G, Fong KM, Ball D, Zorbas H, Dunn J, O'Connell DL, 2015. 'Psychological distress and quality of life in lung cancer: the role of health-related stigma, illness appraisals and social constraints', *Psychooncology* 24 (1569-1577).

health care professionals and encourage consistent use of these guidelines. The Cancer Council Australia guidelines are particularly valuable as they are based on the highest level of evidence (level I as the highest level[114],[115]), tailored to the Australian context and are updated on a regular basis.

Recommendation 6
Improve availability (capacity) of appropriate psychosocial support services for people living with lung cancer.

Actions include:

- State and territory governments to conduct assessments of local workforce capacity for relevant roles including CNS, care coordinators, social workers and psychologists and identify and help address gaps in workforce capacity.
- Research funding bodies to prioritise research/pilot programs for improving access to psychosocial support services for people living with lung cancer, specifically to address the potential gaps in current capacity and identify what is required (i.e. funding and level of capacity) to deliver optimal care now and to meet future demand.
- State and territory governments to develop psychosocial support telehealth options for people living with lung cancer, especially those living in regional and remote areas.

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[114] Cancer Council, 2017. 'Clinical guidelines' [online] Available from https://www.cancer.org.au/health-professionals/clinical-guidelines/.

[115] Australian Government National Health and Medical Research Council, 'NHMRC additional levels of evidence and grades for recommendations for developers of guidelines Stage 2 Consultation Early 2008 – end June 2009' [online] Available from: https://www.mja.com.au/sites/default/files/NHMRC.levels.of.evidence.2008-09.pdf.

A Appendix A
Estimated cost breakdown

Table 19 Direct cost summary in $ million by clinical stage (2018 and 10-year projection) – non-small cell lung cancer

Stage	**Stage 1**		**Stage 2**		**Stage 3A**		**Stage 3B**		**Stage 4**	
Period	**2018**	**10 y**	**2018**	**10 y**	**2018**	**10 y**	**2018**	**10 y**	**2018**	**10 y**
Patient population	1,267	15,819	704	8,788	1,564	19,530	1,912	23,870	5,382	67,197
Treatment costs										
Surgery	3.5	49.6	1.3	19.0	3.0	43.2	-	-	-	-
Chemotherapy	0.5	18.4	0.3	8.1	2.3	60.3	-	-	28.4	591.7
Radiation therapy	3.5	127.3	4.5	143.2	6.4	171.8	-	-	-	-
Concurrent chemotherapy and radiation	0.4	12.7	0.1	4.3	15.4	410.9	24.7	349.5	-	-
Targeted therapy	-	-	-	-	-	-	5.6	79.6	14.4	204.6
Immunotherapy	-	-	-	-	-	-	17.3	245.9	64.4	913.0
Follow-up	1.8	63.6	1.0	31.1	2.9	77.4	6.2	165.6	17.5	364.2
Subtotal costs	**9.7**	**271.6**	**7.2**	**205.7**	**30.1**	**763.7**	**60.1**	**851.5**	**124.8**	**2,073.5**
Patient out-of-pocket expenses										
Follow-up	1.8	63.6	1.0	31.1	2.9	77.4	6.2	165.6	17.5	364.2
Out of hospital costs										
Staging investigations	4.0	56.6	2.2	31.5	4.9	69.9	6.0	85.5	17.0	240.6
Palliative care services	-	8.3	-	14.9	-	74.9	-	91.5	-	538.9
Subtotal costs	**4.0**	**64.9**	**2.2**	**46.4**	**4.9**	**144.8**	**6.0**	**177.0**	**17.0**	**779.5**
Total	**13.8**	**341.8**	**9.5**	**254.7**	**35.2**	**913.4**	**66.3**	**1,034.5**	**142.4**	**2,866.4**

Source: PwC analysis. Note totals may not sum due to rounding.

Table 20 Direct cost summary in $ million by clinical stage (2018 and 10-year projection) – small cell lung cancer

Stage	**Stage I-III, Limited**		**Stage IV, Extensive**	
Period	**2018**	**10 years**	**2018**	**10 years**
Patients	527	6,585	1,384	17,274
Treatment Costs				
Surgery	-	-	-	-
Chemotherapy	2.6	54.2	8.8	143.4
Radiation therapy	-	-	-	-
Concurrent chemotherapy and radiation	2.4	51.1	-	-
Targeted therapy	-	-	-	-
Immunotherapy	-	-	-	-
Follow-up	0.7	15.5	1.9	31.6
Subtotal treatment costs	**5.7**	**120.8**	**10.7**	**175.0**
Patient out-of-pocket expenses				
Travel costs	0.1	1.3	0.2	2.7
Out of hospital costs				
Staging investigations	1.7	23.6	4.4	61.8
Palliative care services	-	51.8	-	136.1
Subtotal out of hospital costs	**1.7**	**75.4**	**4.4**	**197.9**
Total	**7.5**	**197.5**	**15.2**	**375.6**

Source: PwC analysis. Note totals may not sum due to rounding.

Table 21 Treatment costs by stage, average per patient and total treatment cost in 2018

Stage	Average treatment cost per patient, 2018	Total treatment cost, 2018
NSCLC (% of patients in stage)		
Stage I (11.7%)	$19,000	$13.8 million
Stage II (6.5%)	$21,600	$9.5 million
Stage III (32.1%)	$35,000	$95.3 million
Stage IV (49.7%)	$34,500	$142.4 million
SCLC (% of patients in stage)		
Stage I-III, Limited (27.6%)	$22,200	$7.5 million
Stage IV, Extensive (72.4%)	$19,400	$15.2 million

Source: PwC analysis, National Cancer Control Indicators (2018), Kang et al (2012). Note totals may not sum due to rounding.

B

Appendix B
Methodology and sources

Overview

PricewaterhouseCoopers Consulting Australia (PwC) developed an economic model to estimate the annual direct and indirect costs of lung cancer in Australia from 2018 to 2028. The impact of premature mortality related to the disease was also modelled in terms of years of life lost (YLL) and the associated economic cost to society for YLL. Additionally, the impact on cost to treat, number of deaths and years of life lost due to delay in lung cancer diagnosis in Australia was also calculated. The wellbeing impact was modelled based on the prevalence of anxiety and depression in people living with lung cancer and the impact of poor mental health outcomes on quality of life was measured using quality-adjusted life years (QALY) living with lung cancer, especially those living in regional and remote areas.

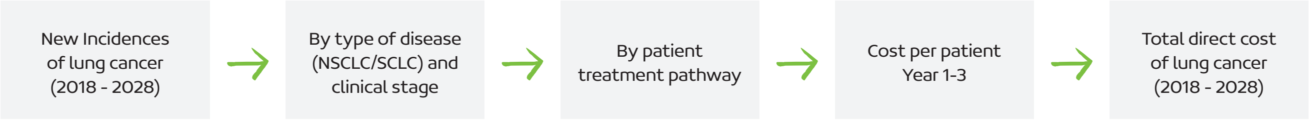
Direct costs

The direct health and non-health costs included in the model are summarised in Table 9 and the modelling illustrated in Figure 2.

Table 9 Direct health and non-health costs included in economic model

Direct health costs	Direct non-health costs
• Staging • Surgery (major and minor) • Chemotherapy • Radiation therapy • Concurrent chemotherapy and radiation • Targeted therapy • Immunotherapy • Patient follow-up • No active treatment/Palliative care	• Travel costs for patients living in regional and remote areas

Figure 2 Direct cost modelling approach



The direct costs were estimated using a bottom up approach, estimating costs per patient by disease type, stage and treatment pathways.

Indirect costs

Due to the severity of disease and intensity of the treatment, patients with lung cancer may be required to take time off work. To account for this, absenteeism was included in the model as an indirect cost.

Premature mortality

Patients with lung cancer have a shorter life expectancy when compared with the general population. YLL and the associated economic cost to society was used to measure the impact of lung cancer in Australia over 10 years.

Psychosocial burden: quality-adjusted life years (QALYs)

Almost half of all lung cancer patients experience anxiety and depression.[116] In order to calculate the impact of depression and anxiety on a lung cancer patient's wellbeing, quality-adjusted life years (QALY) per year from 2018 to 2028 was estimated.

Costs from delayed diagnosis: hypothetical cost to treat and years of life lost (YLL)

Mortality rates and costs vary according to the disease stage, with people diagnosed in earlier stages having lower mortality rates and lower costs to treat when compared with those diagnosed in later stages. Canada has a higher percentage of patients diagnosed in Stage I and a lower percentage of patients diagnosed in Stage III when compared to Australia. In a hypothetical scenario, if Australia's diagnoses were closer to that of Canada, with more people being diagnosed early (Stage I) and fewer people being diagnosed later (Stage III), then it would impact health costs and mortality rates for people. The difference in distribution of patients in Stage I and Stage III in Canada was used to calculate YLL and additional cost to treat patients due to later diagnosis in Australia.

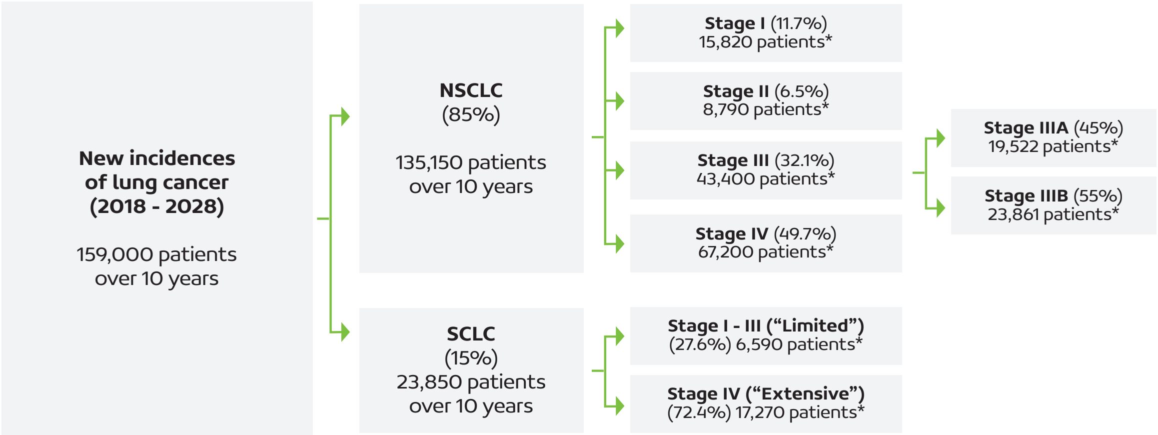
Direct cost methodology and sources

Patient treatment pathways

The distribution of people between non-small cell (NSCLC) and small cell lung cancer (SCLC), and staging used in the model were sourced from the Australian Institute of Health and Welfare (AIHW) (see Figure 3 and Table 10).

The number of new incidences per year was sourced from AIHW projections to 2020, and historic incidence growth rates used where AIHW projections were not available (see Table 10 for epidemiology data and sources).

Figure 3 Breakdown by lung cancer type and stage



**Number of lung cancer patients over 10 year (from 2018 to 2028)*

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[116] Chambers SK, Baade P, Youl P, Aitken J, Occhipinti S, Vinod S, Valery PC, Garvey G, Fong KM, Ball D, Zorbas H, Dunn J, O'Connell DL, 2015. 'Psychological distress and quality of life in lung cancer: the role of health-related stigma, illness appraisals and social constraints', *Psycho-Oncology* 24 (1569-1577).

Table 10 Epidemiology data, disease and clinical stage breakdown

Data	Source/Assumption
Year of incidence (cases) • 2017 (12,434) • 2018 (12,741) • 2019 (13,270) • 2020 (13,640) • 2021 (13,913) • 2022 (14,191) • 2023 (14,475) • 2024 (14,764) • 2025 (15,060) • 2026 (15,361) • 2027 (15,668) • 2028 (15,981)	**Incidence in 2017-18** Australian Institute of Health and Welfare, 2017. Cancer in Australia 2017. Cancer series no.101. Cat. no. CAN 100. Canberra: AIHW. **Incidence in 2019-20** Australian Institute of Health and Welfare, 2012. 'Cancer incidence projections: Australia, 2011 to 2020', Cancer Series no. 66. Cat. No. CAN 62. **Incidence in 2021-28** Assumption of growth of 2.0% a year (based on rate median growth from 1982-2014): AIHW, 2017. 'Australian Cancer Incidence and Mortality (ACIM) books' [online] Available from: https://www.aihw.gov.au/reports/cancer/acim-books/contents/acim-books.
Split between two different types of lung cancer: • NSCLC: 85% • SCLC: 15%	Australian Institute of Health and Welfare & Cancer Australia, 2011. 'Lung cancer in Australia: an overview', Cancer series no. 64. Cat. no. CAN 58. Canberra: AIHW.
Patient stage at diagnosis: • Stage I: 11.7% • Stage II: 6.5% • Stage III: 11.2% • Stage IV: 42.2% • Unknown: 28.5%	Cancer Australia. National Cancer Control Indicators. 'Stage distribution by cancer type and sex, 2011' [online] Available from https://ncci.canceraustralia.gov.au/diagnosis/distribution-cancer-stage/distribution-cancer-stage.
Patient staged at diagnosis in Australia (adjusted) - NSCLC: • Stage I: 11.7% • Stage II: 6.5% • Stage III: 32.1% • Stage IV: 49.7%	Based on expert opinion and literature, it was assumed that patients in unknown stages had NSCLC in advanced stage (Stages III or IV). Aligning with this, patients classified with unknown stage in Australia (28.5% - see above source) were distributed between Stages III and IV (NSCLC), following the same proportion of patients staged in the Australian study published by Kang and colleagues, where all patients were staged.[117]
Clinical stage III split: • NSCLC IIIA: 45% • NSCLC IIIB: 55%	Duggan K, Vinod SK, Yeo AET, 2003 'Treatment patterns for lung cancer in Western Sydney, Australia: do patients get treated according to guidelines?' [online] Available from: https://www.swslhd.health.nsw.gov.au/cancer/pdf/Lung_Guidelines.pdf.
Split between two different types of SCLC lung cancer: • Stage I-III ("limited"): 27.6% • Stage IV ("extensive"): 72.4%	Kang S, Koh ES, Vinod SK, Jalaludin B, 2012. 'Cost analysis of lung cancer management in South Western Sydney', Journal of medical imaging and radiation oncology 56 (235-241).

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[117] Kang, S, Koh, E, Vinod, S and B Jalaludin, 2012. 'Cost analysis of lung cancer management in South Western Sydney', *Journal of medical imaging and radiation oncology* 56 (235-241).

Using the Australian Clinical Practice Guidelines for Treatment of Lung Cancer[118] and BMJ Best Practice and Clinical practice guidelines for the treatment of lung cancer,[119] patients were allocated to standard treatments (Figure 4, Figure 5 and Figure 6). In order to capture the main costs related to patient's treatment, broad categories of treatments were included, namely chemotherapy, radiation (alone or in combination with chemotherapy), targeted therapy and immunotherapy. Additionally, follow-ups were allocated according to clinical stage, and palliative care allocated for a proportion of patients receiving no active treatment and as treatment at the end of life. The frequency of each treatment was derived from Australian studies and international literature (see Table 11 and Table 12). The treatment pathways were also tested with the steering committee experts. Note that totals may not sum due to rounding.

Figure 4 Treatment pathway for Stage I, II and IIIA NSCLC – modelled data

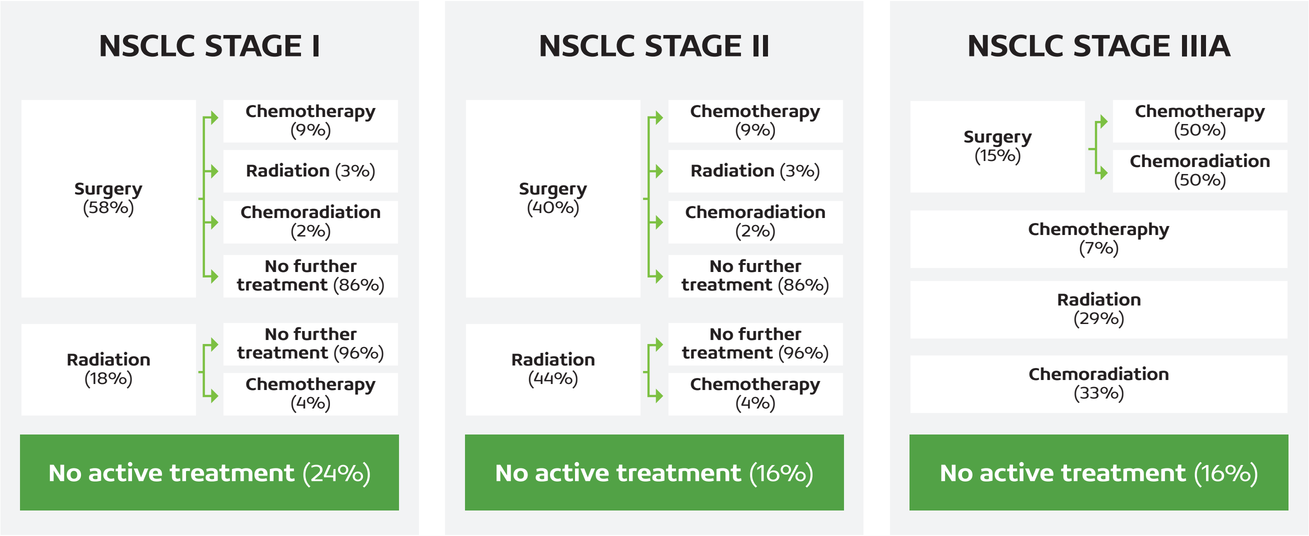


Figure 5 Treatment pathway for Stage IIIB and IV NSCLC

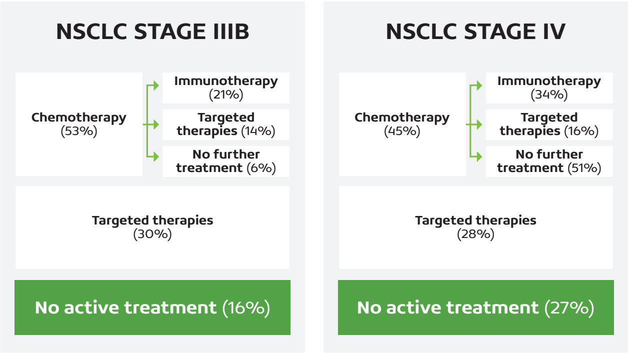
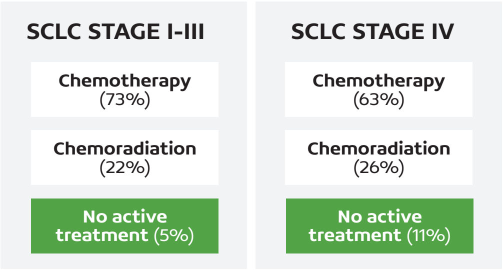


Figure 6 Treatment pathway for Stage I-III and IV SCLC



Note: Totals may not sum due to rounding.

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[118] Cancer Council Australia Lung Cancer Guidelines Working Party. Clinical practice guidelines for the treatment of lung cancer. Sydney: Cancer Council Australia [online]. Available from: https://wiki.cancer.org.au/australia/Guidelines:Lung_cancer.

[119] BMJ Best Practice: Non-small cell lung cancer. Treatment. [online] Available from https://bestpractice.bmj.com/, BMJ Best Practice: small cell lung cancer. Treatment. [online] Available from https://bestpractice.bmj.com/.

Table 11 NSCLC patient treatment pathway and frequency

Data input for NSCLC	Source/Assumption
The treatment pathways were built based on: • Cancer Council Australia's, Clinical Practice Guidelines for Treatment of Lung Cancer • BMJ Best Practice and Clinical practice guidelines for the treatment of lung cancer (UK)	Cancer Council Australia Lung Cancer Guidelines Working Party. 'Clinical practice guidelines for the treatment of lung cancer. Sydney: Cancer Council Australia' [online] Available from: https://wiki.cancer.org.au/australia/Guidelines:Lung_cancer. BMJ Best Practice: Non-small cell lung cancer. Treatment. [online] Available from https://bestpractice.bmj.com/
No active treatment	
Proportion of patients receiving no active treatment as initial treatment, by stage: • Stage I: 24% • Stage II: 16% • Stage III: 16% • Stage IV: 27%	Vinod SK, Sidhom MA, Gabriel GS, Lee MT, Delaney GP, 2010. 'Why Do Some Lung Cancer Patients Receive No Anticancer Treatment?', Journal of Thoracic Oncology 5 (1025-1032).
Surgery	
Proportion of patients receiving surgery as initial treatment, by stage: • Stage I: 58% • Stage II: 40% • Stage IIIA: 15%	Rose J et al, 2016. 'The Natural History of Operable Non-Small Cell Lung Cancer in the National Cancer Database', Thorac Surg 101 (1850–5).
Treatment after surgery	
Treatment received after surgery, for patients in Stage I-II: • Chemo and radiation: 2% • Radiation alone: 3% • Chemotherapy: 9%	Puri V, Crabtree TD, Bell JM, Broderick SR, Mogensztern D, Colditz GA, Kreisel D, Krupnick AS, Patterson GA, Meyers BF, Patel A, Robinson CG, 2015. 'Treatment Outcomes in Stage I Lung Cancer: A Comparison of Surgery and Stereotactic Body Radiation Therapy (SBRT)', J Thorac Oncol 10 (1776–1784)
Treatment received after surgery, for patients in Stage IIIA: • Chemotherapy: 50% • Chemoradiation: 50%	Cancer Council Australia Lung Cancer Guidelines Working Party. 'Clinical practice guidelines for the treatment of lung cancer. Sydney: Cancer Council Australia' [online] Available from: https://wiki.cancer.org.au/australia/Guidelines:Lung_cancer. BMJ Best Practice: 'Non-small cell lung cancer. Treatment' [online] Available from https://bestpractice.bmj.com/

Data input for NSCLC	Source/Assumption
Chemotherapy	
Proportion of patients receiving chemotherapy as initial treatment, by stage: • Stage IIIA: 7% • Stage IIIB: 53% • Stage IV: 45%	Noh JM, Ahn YC, Lee H, Pyo H, Kim B, Oh D, Park H, Lee E, Park K, Ahn J, Ahn M, Sun JM, 2015. 'Definitive Bimodality Concurrent chemo radiotherapy in Patients with Inoperable N2-positive Stage IIIA Non-small Cell Lung Cancer', *Cancer Res Treat* 47 (645-652). According to BMJ Best Practice and Clinical practice guidelines for the treatment of lung cancer (UK), the management of NSCLC patients in stage IIIB is essentially the same as for those with Stage IV, which is chemotherapy as first-line treatment in patients not eligible for target therapy and in Eastern Cooperative Oncology Group (ECOG) performance status of 0 to 2.[120] Assumption: Chemotherapy was allocated to patients receiving active treatment, who were not receiving targeted therapies as the first line of treatment.
Treatment after chemotherapy	
Treatment received after chemotherapy, for patients in Stage IIIB: • Immunotherapy: 21% • Targeted therapy: 14% • No further treatment: 64%	Brahmer J, Reckamp KL, Baas P, Crinò L, Eberhardt WE, Poddubskaya E, Antonia S, Pluzanski A, Vokes EE, Holgado E, Waterhouse D, Ready N, Gainor J, Arén Frontera O, Havel L, Steins M, Garassino MC, Aerts JG, Domine M, Paz-Ares L, Reck M, Baudelet C, Harbison CT, Lestini B, Spigel DR, 2015. Nivolumab versus Docetaxel in Advanced Squamous-Cell Non-Small-Cell Lung Cancer. *N Engl J Med* 373 (123-135). Assumption based on Gefitinib clinical trial: Zhao H, Fan Y, Ma S, Song X, Han B, Cheng Y, Huang C, Yang S, Liu X, Liu Y, Lu S, Wang J, Zhang S, Zhou C, Wang M, Zhang L, INFORM investigators, 2015. 'Final overall survival results from a phase III, randomized, placebo-controlled, parallel-group study of Gefitinib versus placebo as maintenance therapy in patients with locally advanced or metastatic non-small-cell lung cancer', J *Thorac Oncol,* 10 (655-64).
Treatment received after chemotherapy, for patients in Stage IV: • Immunotherapy: 34% • Targeted therapy: 16% • No further treatment: 51%	Ibid.

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[120] BMJ Best Practice, 'Small cell lung cancer treatment' [online] Available from https://bestpractice.bmj.com/.

Data input for NSCLC	Source/Assumption
Radiation therapy	
Patients who are inoperable receive radiation therapy as initial treatment, by stage: • Stage I: 18% • Stage II: 44% • Stage IIIA: 29%	Cancer Council Australia Lung Cancer Guidelines Working Party. 'Clinical practice guidelines for the treatment of lung cancer. Sydney: Cancer Council Australia' [online] Available from: https://wiki.cancer.org.au/australia/Guidelines:Lung_cancer. BMJ Best Practice: Non-small cell lung cancer. Treatment. [online] Available from https://bestpractice.bmj.com/ Noh JM, Ahn YC, Lee H, Pyo H, Kim B, Oh D, Park H, Lee E, Park K, Ahn J, Ahn M, Sun JM, 2015. 'Definitive Bimodality Concurrent chemo radiotherapy in Patients with Inoperable N2-positive Stage IIIA Non-small Cell Lung Cancer', Cancer Res Treat 47 (645-652).
Chemoradiation	
Patients who are inoperable receive chemoradiation therapy as initial treatment, by stage: • Stage IIIA: 33%	Noh JM, Ahn YC, Lee H, Pyo H, Kim B, Oh D, Park H, Lee E, Park K, Ahn J, Ahn M, Sun JM, 2015. 'Definitive Bimodality Concurrent chemo radiotherapy in Patients with Inoperable N2-positive Stage IIIA Non-small Cell Lung Cancer', Cancer Res Treat 47 (645-652).
Treatment after radiation therapy	
Treatment received after radiation, for patients in Stage I-II: • No further treatment: 96% • Chemotherapy: 4%	Puri V, Crabtree TD, Bell JM, Broderick SR, Mogensztern D, Colditz GA, Kreisel D, Krupnick AS, Patterson GA, Meyers BF, Patel A, Robinson CG, 2015. 'Treatment Outcomes in Stage I Lung Cancer: A Comparison of Surgery and Stereotactic Body Radiation Therapy (SBRT)', J Thorac Oncol 10 (1776–1784).
Targeted therapy and immunotherapy	
Number of new patients starting treatment with targeted therapy and immunotherapy in the period of July 2017 to June 2018: Based on total number of services (from July 2017 to June 2018) listed on PBS item reports for initial treatment codes only, and the maximum number of services per PBS code, the number of new patients were estimated (between July 2017 and June 2018). If the number of services were unavailable for the full period, the data was extrapolated to an annual figure.	Medicare Statistics, 2018. 'Pharmaceutical Benefits Schedule Item Reports' [online] Available from: http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp. Initial treatment codes used to identify new patients on targeted therapy (specific to lung cancer): • Erlotinib, codes: 10014C, 10020J and 10022L • Afatinib, codes: 11341X, 11329G, 11347F and 11335N • Gefitinib, code: 11264W

Data input for NSCLC	Source/Assumption
• Target therapy: **2,565 patients** • Immunotherapy: **1,014 patients** Targeted and immunotherapies have indications for NSCLC patients in stage IIIB and IV. The total number of patients receiving targeted therapy were allocated along the patient treatment pathway, and the number of patients on targeted therapy and immunotherapy was projected to grow over 10 years aligning with new incidences of lung cancer diagnosed.	• Gefitinib, code: 11264W • Ceritinib, code: 11056X • Alectinib, code: 11226W • Crizotinib, codes: 10322G and 10323H Initial treatment codes used to identify new patients on immunotherapy (specific to lung cancer): • Nivolumab, code: 11143L
Of those patients who receive targeted therapy: • 80% received it as the first line of treatment • 20% received it as the second line of treatment	Australian Government, Department of Health, 2017. 'The pharmaceutical Benefits Scheme. Drug utilisation sub-committee: Erlotinib and Gefitinib: 24 month predicted versus actual analysis' [online] Available from: http://www.pbs.gov.au/industry/listing/participants/public-release-docs/2017-02/tkis-nsclc-24-month-review-dusc-prd-2017-02.pdf.
Follow-up investigations	
Number of follow-up investigations, by stage: • Stages I-II: 3 per year • Stage IIIA: 4 per year • Stages IIIB and IV: 7 per year	Assumption based on expert opinion
Palliative care	
Access to palliative care based on location: • Metropolitan patients: 85% of lung cancer patients who die will have access to palliative care • Regional/remote patients: 40% of lung cancer patients who die	Assumption based on expert opinion Duggan KJ, Wiltshire J, Strutt R, Boxer MM, Berthelsen A, Descallar J, Vinod SK, 2018. 'Palliative care and psychosocial care in metastatic non-small cell lung cancer: factors affecting utilisation of services and impact on patient survival', *Supportive Care in Cancer* (1-9). Data extracted from SESI Clinical Cancer Registry May 2010. National Cancer Control Indicators, 2018. 'Stage distribution by cancer type and sex, 2011' [online] Available from: https://ncci.canceraustralia.gov.au/diagnosis/distribution-cancer-stage/distribution-cancer-stage. Australia Institute of Health and Welfare, 2018. 'Palliative care services in Australia' [online] Available from: https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/summary.

Data input for NSCLC	Source/Assumption
Access to palliative care based on location: • Metropolitan patients: 85% of lung cancer patients who die will have access to palliative care • Regional/remote patients: 40% of lung cancer patients who die	Assumption based on expert opinion Duggan KJ, Wiltshire J, Strutt R, Boxer MM, Berthelsen A, Descallar J, Vinod SK, 2018. 'Palliative care and psychosocial care in metastatic non-small cell lung cancer: factors affecting utilisation of services and impact on patient survival', *Supportive Care in Cancer* (1-9). Data extracted from SESI Clinical Cancer Registry May 2010. National Cancer Control Indicators, 2018. 'Stage distribution by cancer type and sex, 2011' [online] Available from: https://ncci.canceraustralia.gov.au/diagnosis/distribution-cancer-stage/distribution-cancer-stage. Australia Institute of Health and Welfare, 2018. 'Palliative care services in Australia' [online] Available from: https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/summary.
Treatment pathways were based on: • Cancer Council Australia's, Clinical Practice Guidelines for Treatment of Lung Cancer • BMJ Best Practice and Clinical practice guidelines for the treatment of lung cancer (UK)	Cancer Council Australia Lung Cancer Guidelines Working Party. 'Clinical practice guidelines for the treatment of lung cancer' [online]. Available from: https://wiki.cancer.org.au/australia/Guidelines:Lung_cancer. BMJ Best Practice, 'Small cell lung cancer treatment' [online] Available from https://bestpractice.bmj.com/.
Proportion of patients receiving no active treatment, by stage: • Stage I-III: 5% • Stage IV: 11%	Vinod SK, Sidhom MA, Gabriel GS, Lee MT, Delaney GP, 2010. 'Why Do Some Lung Cancer Patients Receive No Anticancer Treatment?', *Journal of Thoracic Oncology* 5 (1025-1032).
Proportion of patients receiving chemotherapy, by stage: • Stage I-III: 73% • Stage IV: 63%	Caprario, l, 2013. 'Effects of Chemotherapy on Survival of Elderly Patients with Small-Cell Lung Cancer,' *Journal of Thoracic Oncology* 8. Chemotherapy allocated to patients receiving active treatment who are not receiving targeted therapies as the first line of treatment.
Proportion of patients receiving chemoradiation, by stage: • Stage I-III: 22% • Stage IV: 26%	Ibid.
Palliative care: See approach used for NSCLC patients	See Table 11
Number of follow-up investigations: • All stages: 3 per year	Assumption based on expert opinion

The overall survival rates for people with NSCLC and SCLC were derived from international studies (see Table 13). Direct costs were modelled over three years from diagnosis based on available data and consultation with experts.

Table 13 Overall survival rates for people with NSCLC and SCLC

Survival input	Source/Assumption
Overall survival for NSCLC patients by clinical stage (in the first/second year): • Stage I (average between IA and IB): 94% / 89% • Stage II (average between IIA and IIB): 84% / 69% • Stage IIIA: 76% / 55% • Stage IIIB: 62% / 34% • Stage IV: 45% / 17%	Goldstraw P, Chansky K, Crowley J, Rami-Porta R, Asamura H, Eberhardt WE, Nicholson AG, Groome P, Mitchell A, Bolejack V, 2015. 'The IASLC Lung Cancer Staging Project: Proposals for Revision of the TNM Stage Groupings in the Forthcoming (Eighth) Edition of the TNM Classification for Lung Cancer', Journal of Thoracic Oncology 11 (39-51).
Overall survival for SCLC patients by clinical stage (in the first/second year): • Stage I-III: 43% / 27% • Stage IV: 13% / 7%	Janssen-Heijnen ML, Maas HA, Siesling S, Koning CC, Coebergh JW, Groen HJ, 2011.'Treatment and survival of patients with small-cell lung cancer: small steps forward, but not for patients', Annals of Oncology, 23 (954–960).

Major cost inputs

Patient pathway costs were modelled over the first three years following diagnosis. Cost inputs were sourced from Australian studies and reports and inflated to values in 2018 (see Table 14).

Table 14 Cost inputs and sources

Cost item	Inputs/Assumption	Source
Average annual inflation rate	2.4% annually **Note:** The costs reported below are inflated to their value in 2018.	ABS, 2018. 'Cat 6401.0 - 'Consumer Price Index, Australia', Mar 2018.
Staging investigations	One staging investigation per new incidence of lung cancer at **$3,155** It Includes: • Chest x-ray • Bronchoscopy • CT guided fine needle aspiration biopsy • Whole body bone scan • Positron emission tomography scan • Pulmonary function test • Clinician consultation fee	Kang, S, Koh, E, Vinod, S and B Jalaludin, 2012. 'Cost analysis of lung cancer management in South Western Sydney', Journal of medical imaging and radiation oncology, 56 (235-241).
Follow-up investigations	**$464** per follow up investigation It includes: • Clinician consultation fee • Chest x-ray • Blood test	Medicare Benefits Schedule Book Operating from 01 July 2018, 2018. Department of Health.
Surgery	• **$12,985** for surgery with major complexity • **$4,767** for surgeries with minor complexity Assumption: Surgeries in early stage lung cancer (Stage I and II) were allocated a cost for minor complexity surgery and Stage III was allocated the cost for major complexity lung cancer.	IPHA, 2018. 'National Hospital Cost Data Collection Cost Report: Round 20 Financial Year 2015-16'.

Cost item	Inputs/Assumption	Source
Chemotherapy	• **$558** per service **Assumption:** Patients had an average of three chemotherapy services per cycle. Patients diagnosed with NSCLC (stages I and II) and SCLC (stage I-III) had on average, four cycles per year and those with NSCLC (stages III and IV) and SCLC (Stage IV) had six cycles per year	IPHA, 2018. 'National Hospital Cost Data Collection Cost Report: Round 20 Financial Year 2015-16'.
Radiotherapy	• **$474** per service **Assumption:** Patients had on average 30 services per year	IPHA, 2018. 'National Hospital Cost Data Collection Cost Report: Round 20 Financial Year 2015-16'.
Palliative care	• **$11,217** per separation	IPHA, 2018. 'National Hospital Cost Data Collection Cost Report: Round 20 Financial Year 2015-16'.
Targeted therapies	**Total cost (July 2017 to June 2018):** The total cost was sourced from the Medicare Statistics website, using the codes in the next column (initial and continuing treatments). For some of the medicines, data was not available for the whole period between July 2017 and June 2018). In these cases, the available data was extrapolated across the one-year period. • Total cost: 18.0 million (including erlotinib, afatinib, ceritinib, alectinib, gefitinib and crizotinib: **Assumption:** The cost above accounts 50% of public PBS cost for targeted therapies as a conservative assumption to acknowledge commercial-in-confidence rebate schemes. The cost of targeted therapies over 10 years increases in line inflation (as above) and growth in new incidences of lung cancer diagnosed. This is a conservative estimate as it does not consider the introduction of new targeted therapies in the future.	Medicare Statistics, 2018. 'Pharmaceutical Benefits Schedule Item Reports' [online] Available from: http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp. • Erlotinib, codes: 11259N, 11260P, 11263T, 10025P, 10019H and 10028T • Afatinib, codes: 11348G, 11342Y, 11359W and11336P • Gefitinib, code: 8769M See Table 11 for initial treatment codes

Cost item	Inputs/Assumption	Source
Immunotherapy	The same methodology was used to calculate immunotherapy costs. • Nivolumab: 81.6 million **Assumption:** The cost above accounts for 50% of public PBS cost for immunotherapy as a conservative assumption to acknowledge commercial-in-confidence rebate schemes. **Assumption:** The cost of immunotherapy over 10 years increases in line inflation (as above) and growth in new incidences of lung cancer diagnosed. This is a conservative estimate as it does not consider the introduction of new targeted therapies in the future.	Medicare Statistics, 2018. 'Pharmaceutical Benefits Schedule Item Reports' [online] Available from: http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp. • Nivolumab, code: 11158G, 11152Y and 11153B. See Table 11 for initial treatment codes
EGFR Biomarker	A test of tumour tissue (epidermal growth factor receptor (EGFR) - gene status) is needed for access to erlotinib, gefitinib or afatinib under the PBS. MBS item 73337 was used to estimate the number of services and cost of this test (from July 2017 to June 2018): • 3,912 services • Total cost: $1,273,917	Medicare Statistics, 2018. 'Pharmaceutical Benefits Schedule Item Reports' [online] Available from http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp.
FISH test	Fluorescence in situ hybridisation (FISH) test requested by a specialist or consultant physician to determine if requirements relating to ALK gene rearrangement status for access to crizotinib, ceritinib or alectinib under the PBS are fulfilled. MBS item number 73341 was used to calculate the number of services and cost of this test (from July 2017 to June 2018): • 353 services • Total cost $114,714	Medicare Statistics, 2018. 'Pharmaceutical Benefits Schedule Item Reports' [online] Available from http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp.
Travel costs (regional/ remote patients)	Includes: • Two days car rental: $80 • One night accommodation: $161	Assumption based car rental costs in 2018. Hotels.com Hotels Price Index – Australia, 2017 [online] Available from: https://hpi.hotels.com/au-2017/australia-is-buzzing/.

Indirect cost methodology and sources

Indirect costs associated with absenteeism were measured by calculating the difference in days of sick leave taken by people living with lung cancer, when compared with sick leave days taken by the general population (see calculation in Figure 7 and sources in Table 15).

Figure 7 Approach to calculate absenteeism costs

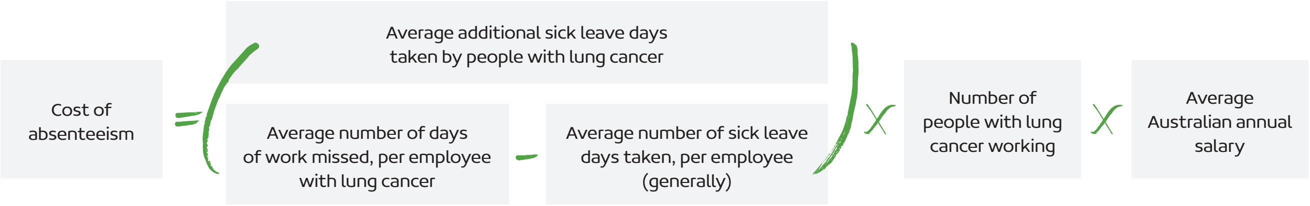

Table 15 Absenteeism cost inputs and sources

Input	Data	Source
Number of days of work missed for people with cancer, 1 year (temporary)	20.5 days NHS (UK) estimate of cancers generally applies to the Australian context.	Access Economics. ‘Estimating the Costs of Cancer’ [online] Available from: https://www.cancercouncil.com.au/wp-content/uploads/2010/11/costofcancer_costs.pdf.
Average number of sick leave days taken, per employee (generally)	7.9 public sector 5.5 private sector	CIPD, 2016. ‘Absence management survey’.
All employees average weekly total earnings	$1,713	ABS, 2018. ‘Cat 6302.0 - Average Weekly Earnings, Australia’, Nov 2017.
Proportion of people living with lung cancer working	28%	PwC analysis; AIHW, 2017. ‘Australian Cancer Incidence and Mortality (ACIM) books’ [online] Available from https://www.aihw.gov.au/reports/cancer/acim-books/contents/acim-books.

Premature mortality methodology and sources

Premature mortality was measured by calculating the difference in average life expectancy of the general population with the average life expectancy of somebody with lung cancer (see calculation in Figure 8 and sources in Table 16).

In order to measure the cost of years of life lost, the number of years of life lost estimated was multiplied by the cost of one year of “quality life” lost, at a cost of $50,000 per year.[121]

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[121] Taylor C and Jan S, 2017. ‘Economic evaluation of medicines.’ *Australian Prescriber* 40 (76-78).

Figure 8 Approach to calculate premature mortality

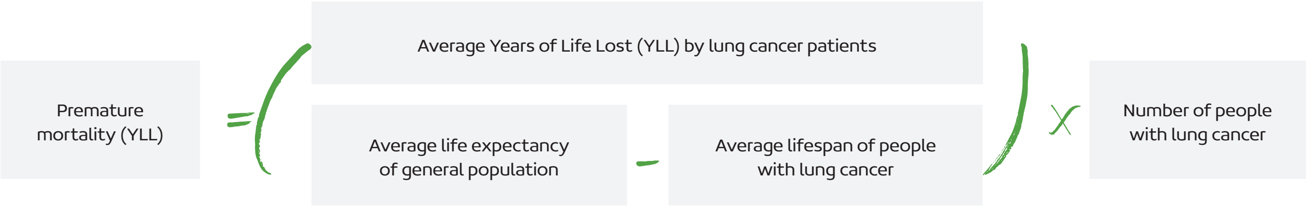


Table 16 Premature mortality inputs and sources

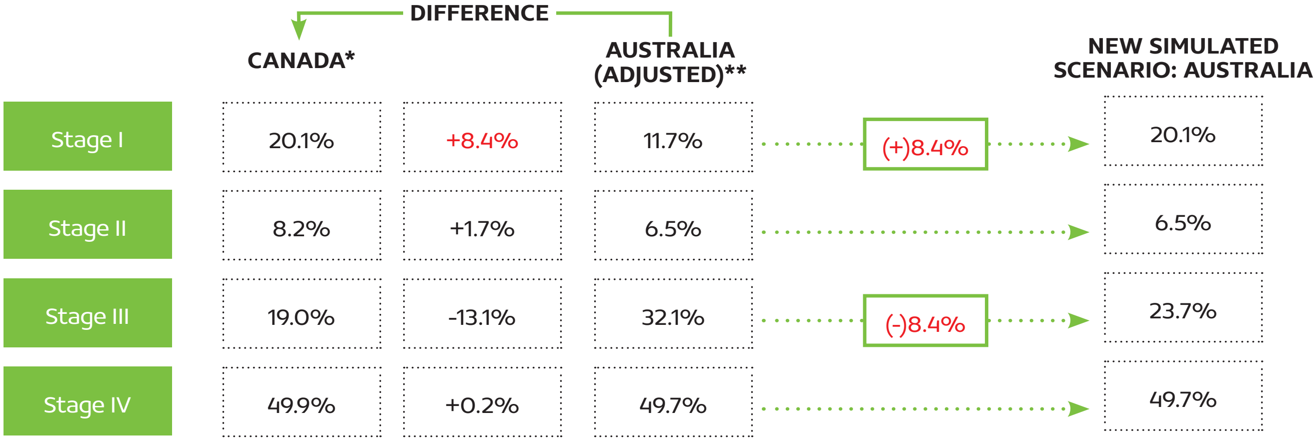
Input	Data	Source
Average life expectancy for general population	82.5 years old	OECD, 2018. 'OECD Health Statistics 2018'.
Average life expectancy of lung cancer patients	71.7 years old	AIHW, 2017. 'Australian Cancer Incidence and Mortality (ACIM) books' [online] Available from https://www.aihw.gov.au/reports/cancer/acim-books/contents/acim-books.
Number of people living with lung cancer who die	Modelled by applying the mortality rate of the lung cancer population	Goldstraw P, Chansky K, Crowley J, Rami-Porta R, Asamura H, Eberhardt WE, Nicholson AG, Groome P, Mitchell A, Bolejack V, 2015. 'The IASLC Lung Cancer Staging Project: Proposals for Revision of the TNM Stage Groupings in the Forthcoming (Eighth) Edition of the TNM Classification for Lung Cancer', Journal of Thoracic Oncology 11 (39-51) Janssen-Heijnen ML, Maas HA, Siesling S, Koning CC, Coebergh JW, Groen HJ, 2011.'Treatment and survival of patients with small-cell lung cancer: small steps forward, but not for patients', Annals of Oncology, 23 (954–960).
Proportion of people living with lung cancer working	28%	PwC analysis; AIHW, 2017. 'Australian Cancer Incidence and Mortality (ACIM) books' [online] Available from https://www.aihw.gov.au/reports/cancer/acim-books/contents/acim-books.

Costs from delayed diagnosis: hypothetical cost to treat and years of life lost (YLL)

Compared to Canada, Australia has a lower rate of lung cancer patients diagnosed on clinical stage I and a higher rate of patients diagnosed on stage III. These patients on stage III have higher mortality rates and higher costs to treat, when comparing with patients diagnosed on stage I.

In Canada, there is a difference of 8.4 per cent more people diagnosed in Stage I compared to Australia and 12.3 per cent less in Stage III. In a hypothetical scenario, if more people in Australia were diagnosed at Stage I and less in Stage III to match Stage I levels in Canada, then it would impact health costs and mortality rates for people. The logic is outlined in Figure 9.

Figure 9 Approach to calculate hypothetical costs from delayed diagnosis



** 2.8% of patients in Canada were staged as unknown, ** patients in unknown stage were distributed between stages III and IV (see Table 10)*

Table 17 Delayed diagnosis calculation inputs and sources

Data	Source/Assumption
Patient staged at diagnosis adjusted (Australia): • **Stage I: 11.7%** • **Stage II: 6.5%** • **Stage III: 32.1%** • **Stage IV: 49.7%**	National Cancer Control Indicators, 2018. 'Distribution of Cancer Stage' [online] Available from https://ncci.canceraustralia.gov.au/diagnosis/distribution-cancer-stage/distribution-cancer-stage. Kang, S, Koh, E, Vinod, S and B Jalaludin, 2012. 'Cost analysis of lung cancer management in South Western Sydney', *Journal of medical imaging and radiation oncology* 56 (235-241). See Table 10 for allocation of 28.5% of patients with an unknown stage of lung cancer.
Patient staged at diagnosis (Canada): • **Stage I: 20.1%** • **Stage II: 8.2%** • **Stage III: 19.0%** • **Stage IV: 49.9** • **Unknown: 2.8%**	National Cancer Control Indicators, 2018. 'Distribution of Cancer Stage' [online] Available from https://ncci.canceraustralia.gov.au/diagnosis/distribution-cancer-stage/distribution-cancer-stage.

Psychosocial burden: quality-adjusted life years (QALYs)

Quality-adjusted life years were measured by comparing the average utility value of the Australian population with the utility value of people living with lung cancer who have anxiety and depression (see calculation in Figure 10 and sources summarised in Table 18).

Figure 10 Approach to calculate QALYs lost due to depression in lung cancer patients

(Mean utility score, Australia − Utility score, people with lung cancer who have anxiety and/or depression) X Number of people with lung cancer who have anxiety/or depression, per year = QALYs lost (2018 - 2028)

Table 18 QALY inputs and sources

Input	Data	Source
Prevalence of depression and anxiety in lung cancer patients	Approximately 49% of lung cancer patients experience anxiety and/or depression	Carter-Harris L et al, 2014. 'Lung cancer stigma predicts timing of medical help-seeking behavior', *Oncol Nurs Forum* 3 (203-210).
Mean utility score, Australia	0.87	Clemens et al, 2014. 'A comparison of EQ-5D-3L population norms in Queensland, Australia, estimated using utility value sets from Australia, the UK and USA', *Qual Life Res 23* (2375-2381).
Impact of depression on quality of life for lung cancer patients, utility value	-0.76 Noting utility score for people living with lung cancer and anxiety and/or depression is 0.11.	World Health Organization. 'Introduction and methods: Assessing the environmental burden of disease at national and local level. Chapter 3 .The Global Burden of Disease concept' [online]. Available from http://www.who.int/quantifying_ehimpacts/publications/en/9241546204chap3.pdf?ua=1.

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