

Federal Election Platform 2019 Australian Lung Cancer Program

Purpose

The 2019 election manifesto for lung cancer has been prepared for candidates standing in the Australian Government election.

Overview

Lung Foundation Australia (LFA) has worked with the lung health community to identify key areas for intervention to address the poor outcomes currently experienced by people with lung cancer.

To recap, 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 was **approximately 12,740 people newly diagnosed in 2018** ⁽²⁾.

In October 2018, the first of two key policy documents were launched. **Making Lung Cancer a Fair Fight: A Blueprint for Reform** (the Blueprint) outlines the significant challenges faced by people living with lung cancer that impact their overall health outcomes and quality of life. Through stakeholder consultations three themes were identified and explored in detail in this report. The themes are:

- Equity of access to diagnostics and care
- Stigma experience by patients
- The need for psychosocial support.

In February 2019, Lung Foundation's National Strategic Action Plan (the Action Plan) was launched and this reinforced the priorities identified for action in the Blueprint.

There are 5 specific priorities in this brief which are tangible and achievable and could be delivered in the short to medium term, these are:

- 1. Lung Cancer nurse positions to facilitate coordination of care and improve outcomes for patients (\$15 million)**
- 2. Access to medicines for lung cancer (listing through Pharmaceutical Benefits Schedule)**
- 3. Primary care lung cancer assessment and early diagnosis training program (\$2 million)**
- 4. Campaign focused on occupational hazards which cause lung cancer (\$1.2 million)**
- 5. Campaign focused on stigma, discrimination and social isolation, as well as symptoms to improve knowledge and change attitudes (\$1.2 million)**

The following provides an outline for each of these actions. Investment in these identified priority areas will improve the quality of life for people at risk and with existing lung cancer, and produce social and economic benefits for the individual, their families, the community and the broader health system.

Priority 1: Lung Cancer nurse positions to facilitate coordination of care and improve outcomes for patients

Aim

To increase the survival of people affected by lung cancer through improved coordination of care.

Target Audience

Consumers, carers, health professionals

Rationale

Lung cancer nurses help facilitate timely access to care⁽³⁾. 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⁽⁴⁾. 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)⁽⁵⁾.

Interviews conducted for the Blueprint suggest there is insufficient access to lung cancer nurses 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 nurse)⁽⁶⁾.

This demonstrates that there is a critical shortage of lung cancer nurses, which is inconsistent with evidence-based clinical practice guidelines and international best practice, and is compromising quality of care⁽⁷⁾⁽⁸⁾. **As per best practice guidelines, a lung cancer nurse should be associated with each of the Lung Cancer Multidisciplinary Teams** in Australia⁽⁷⁾.

Outcomes

Anticipated short to medium term outcomes include:

- Timely access to evidence-based treatments for people with lung cancer
- Reduce impact of co-morbidities such as anxiety and depression
- Improved quality of life for people with lung cancer

Longer term the impact will be increased survival of people with lung cancer and reduced social and economic costs to the individual, their families, employers and the community as a whole.

Budget – \$15 million for 20 positions over 5 years

Priority 2: Access to medicines for lung cancer

Aim:

Provide timely and equitable access to evidence-based medicines for people with lung cancer.

Target Audience:

Consumers

Rationale:

Patients with lung cancer are often diagnosed at a late stage with almost 50% at stage IV and over 30% at stage III⁽⁹⁾. This can have a flow on impact to the choice of treatment options available and their prognosis. It is therefore, crucial that effective treatments for patients are provided quickly and easily for this population to extend life and improve quality of life.

In relation to access to medicines, Australia is not performing well in comparison to other similar Organisation for Economic Co-operation and Development (OECD) countries⁽¹⁰⁾. A report from Medicines Australia, compared access to medicines against 19 other countries in the OECD and the data revealed⁽¹⁰⁾:

- Overall, Australia ranks 17th out of 20 OECD countries for access to new medicines
- Australia lists around 40% of all possible first-class medicines on the Pharmaceutical Benefits Schedule (PBS) – 4th last in the OECD
- On average, it takes almost four times longer for medicines to achieve reimbursement in Australia (426 days) compared to Japan (89 days), Germany (117 days) and Great Britain (128 days). The top 10 countries will reimburse on average within 181 days.
- The time to reimbursement has increased by 56 days (previously 370 days) compared to the previous report from Medicines Australia⁽¹¹⁾. This shows that the wait for people to access lifesaving medicines in Australia is increasing in time rather than declining.
- Cancer medicines become available at least three months later than the average new medicine in Australia

There is a need to reduce the time for listing of lung cancer medicines through the PBS. Whilst there are differences in systems to access to medicines, many OECD countries reimburse a new medicine at the same time it is registered⁽¹⁰⁾. The process undertaken to list medicines needs to be expedited so that patients are not left waiting for treatment which leads to a decline in health and increased social and economic burden.

Outcomes:

Anticipated outcomes for people with lung cancer include:

- Enhanced quality of life
- Reduced impact of co-morbidities such as anxiety and depression
- Increased survival

Budget – allocation through Pharmaceutical Benefits Schedule

Priority 3: Primary care lung cancer assessment and early diagnosis training program

Aim:

To increase awareness and uptake of risk assessment for lung cancer and application of best-practice management approaches for diagnosed patients in the primary care setting.

Target Audience:

General practitioners (GPs)

Rationale:

Whilst the final diagnosis of cancer is typically made in the hospital setting, GPs play a crucial role in the timely detection of lung cancer symptoms and initiating appropriate investigations to facilitate early diagnosis.

Despite availability of best-practice guidelines and frameworks in Australia, diagnosis of lung cancer often occurs in advanced disease, at stages III or IV. A large UK study has revealed that patients with lung cancer are among those who are likely to have three or more consultations with their GP before receiving referral for investigation of symptoms⁽¹²⁾. Diagnostic delays significantly limit treatment options and contribute to poorer patient outcomes and quality of life and distress^{(13) (14) (15)}.

The reasons for diagnostic delay are multi-faceted and can include^{(12) (13) (14) (15) (16) (17)}

- Poor symptom awareness by patients
- Poor patient access to GP care
- Poor predictive values (PPV) of single symptoms
- Presence of non-specific symptoms which may overlap with other benign conditions or 'non-classic' cancer signs (approx. 50% of patients)
- Lack of awareness or use of risk assessment tools and clinical guidelines in routine practice

Reducing diagnostic delays and increasing the proportion of early stage cancers has the potential to improve cancer survival in the longer term and reduce patient distress^{(12) (14) (17) (15)}.

This program will explore the concept of diagnostic delay in the Australian context and provide GPs with best practice information, strategies, tools and resources as per the Clinical Practice Guidelines for Treatment of Lung Cancer and Cancer Australia's Lung Cancer Framework. It will inform, support and empower GPs to undertake timely and appropriate investigation of patients with suspected lung cancer, and will highlight their role in managing the diagnosed patient across the continuum of care, and as part of the multi-disciplinary team.

Outcomes:

Anticipated short term outcomes include:

- improved patient care, quality of life and, reduced patient distress.
- Improved health professional knowledge and application of lung cancer risk assessment tools and models
- improved knowledge and application of best-practice information, strategies, tools and resources in the management of lung cancer

Longer term outcomes will include increased longer-term survivability of people with lung cancer (quality-adjusted life-years) through timely detection of lung cancer symptoms and earlier diagnosis.

Budget – \$2 million over 2 years

Priority 4: Deliver a 3-year campaign focused on occupational hazards

Aim

To reduce the risk of workers developing lung cancer as a result of participation in the workplace.

Target Audience

Employers, employees (current and retired), representative bodies (unions and industry), work health and safety stakeholders (e.g. Safe Work Australia)

Rationale

Occupational lung diseases are an important and under-recognised cause of respiratory ill health in Australia. There are limited data available on disease prevalence in Australia⁽¹⁸⁾. However, international studies have shown that approximately 15% of adult-onset cases of asthma and COPD are related to occupational exposures, and, importantly, 10-25% of cases of lung cancer⁽¹⁸⁾.

Australia has a rate of malignant mesothelioma among the highest in the world, and the legacy of past occupational asbestos exposure remains a heavy burden⁽¹⁹⁾. Recently, there has been a re-emergence of silicosis and coal workers' pneumoconiosis (black lung) from exposure to dusts from cutting engineered stone and also from coal mine dust exposure; these diseases have a very long latency period and result in significant disablement across the life course; silica exposure is also a cause of lung cancer, COPD and autoimmune disease^{(20) (21) (22)}.

Occupational lung diseases can be prevented by identifying and removing occupational hazards and creating healthy and safe workplaces. Lung cancer have an enormous employment and productivity impact through time away from work and lower effectiveness; hence the urgent need for greater workplace awareness and education.

Outcomes

In the short term, the anticipated outcomes from an awareness and education campaign will be:

- Increased knowledge of workplace hazards and how to mitigate risk
- Increased behaviour change to protect workers of identified hazards
- Workplace modification to reduce risk of hazards
- Increased knowledge of and access to support services for those diagnosed

Longer term the impact will be reductions in social and economic costs to the individual, their families, employers and the community as a whole.

Budget – \$1.2 million over 3 years

Priority 5: Deliver a 3-year campaign focused on stigma, discrimination and social isolation, as well as symptoms

Aim

To reduce the psychosocial impact of lung conditions on people diagnosed and to motivate those with symptoms to take action, resulting in early diagnosis and management.

Target Audience

Health professionals, consumers, sports and industry organisations

Rationale

Lung conditions are often misunderstood and stigma is widespread. The loss of independence, social isolation, discrimination, stigma, and potential disability experienced by people with lung conditions can have lasting impacts through reduction in quality of life and lost opportunities that extend beyond individuals to their carers and families, and to future generations⁽²³⁾.

Reducing **stigma**, discrimination and social isolation is critical to improving the mental health and wellbeing, quality of life and social participation for people with lung conditions. Stigma contributes to lack of support for people with lung disease, delayed presentation and poorer outcomes.

Awareness of the symptoms of lung conditions is the first step in addressing the under-diagnosis and diagnostic delays associated with lung conditions. Currently, people with lung conditions are not presenting to health care professionals because they underestimate the severity of their disease⁽²⁴⁾ ⁽²⁵⁾ or misattribute symptoms to other causes such as ageing⁽²⁴⁾. Almost 50% of all Australians rarely or never think about the health of their lungs⁽²⁶⁾.

Outcomes

In the short term, the anticipated outcomes from an awareness and education campaign will be increased:

- knowledge of stigma in our community towards people with lung conditions
- empathy for people with lung conditions
- knowledge of the symptoms associated with lung conditions
- action to investigate symptoms of lung disease.

Longer term the impact will be reductions in social and economic costs to the individual, their families, employers and the community as a whole.

Budget – \$1.2 million over 3 years (\$500,000 has been promised to Lung Foundation over a 4-year period and is a portion of what is required)

References

1. **Australian Government. Cancer Australia.** Lung cancer statistics. *Lung Cancer*. [Online] Cancer Australia, 4 September 2018. [Cited: 4 March 2019.] <https://lung-cancer.canceraustralia.gov.au/statistics>.
2. **Australian Institute of Health and Welfare.** *Cancer in Australia 2017. Cancer series no. 101. Cat. no. CAN 100.* Canberra : AIHW, 2017. 2205-4855.
3. **McPhillips, D, et al.** The role of a nurse specialist in a modern lung-cancer service. *British Journal of Nursing*. 2015, Vol. 24, pp. 21-27.
4. **Cancer Australia.** *Best practice approaches to lung cancer care - A review of the literature.* Surry Hills : Cancer Australia, 2013. 978-1-74127-243-7.
5. **The NHS Information Centre for Health and Social Care (The NHS IC).** *National Lung Cancer Audit.* s.l. : Healthcare Quality Improvement Partnership, 2010.
6. **Australian Institute of Health and Welfare.** Cancer Incidence and Mortality Across Regions (CIMAR) books. *AIHW*. [Online] Australian Government, 14 December 2016. [Cited: 4 March 2019.] <https://www.aihw.gov.au/reports/cancer/cimar-books/contents/cimar-books>.
7. **Cancer Council Australia Lung Cancer Guidelines Working Group.** *Clinical practice guidelines for the treatment of lung cancer.* Sydney : Cancer Council Australia, 2017.
8. **Senate Select Committee.** *Select Committee into Funding for Research into Cancers with Low Survival Rates.* Canberra : Commonwealth of Australia, 2017. 978-1-76010-677-5.
9. **PWC.** *Making Lung Cancer a Fair Fight: A Blueprint for Reform.* 2018.
10. **Medicines Australia.** *Compare Edition 4: Comparison of access and reimbursement environments, A report benchmarking Australia's access to new medicines.* s.l. : Medicines Australia, 2018.
11. **Medicines Australia.** *Compare Edition 3: Comparison of Access and Reimbursement Environments, A report benchmarking Australia's access to new medicines.* s.l. : Medicines Australia, 2017.
12. **Allgar, V L and Neal, R D.** Delays in the diagnosis of six cancers: analysis of data from the National Survey of NHS patients: Cancer. *Br J Cancer*. June 6, 2005, Vol. 92, 11, pp. 1959-70.
13. **Abel, G A, et al.** Measures of promptness of cancer diagnosis in primary care: secondary analysis of national audit data on patients with 18 common and rarer cancers. *Br J Cancer*. 2013, Vol. 108, pp. 686-90.
14. **Emery, J.** Assessment of cancer risk in men and women. *Br J Cancer*. 2013, Vol. 63, pp. 4-5.
15. **Zabora, J, et al.** The prevalence of psychological distress by cancer site. *Psychooncology*. Jan-Feb, 2001, Vol. 10, 1, pp. 19-28.
16. **Nielsen, T N, Hansen, R P and Vedsted, P.** [Symptom presentation in cancer patients in general practice]. *Ugeskr Laeger*. Oct 11, 2010, Vol. 172, 41, pp. 2827-31.
17. **Vinod, S K, et al.** Gaps in Optimal Care for Lung Cancer. *Journal of Thoracic Oncology*. August, 2008, Vol. 3, 8, pp. 871-879.
18. **Hoy, R and Brims, F.** Occupational lung diseases in Australia. *Medical Journal of Australia*. 2017, Vol. 207, pp. 443-448.
19. **Soeberg, M, et al.** Australia's ongoing legacy of asbestos: significant challenges remain even after the complete banning of asbestos almost fifteen years ago. *International Journal of Environmental Research and Public Health*. 2018, Vol. 15, p. 384.
20. **Hoy, R, et al.** Artificial stone-associated silicosis: a rapidly emerging occupational lung disease. *Occupational and Environmental Medicine*. 2018, Vol. 75, pp. 3-5.
21. **Matar, E, et al.** Complicated silicosis resulting from occupational exposure to engineered stone products. *Medical Journal of Australia*. 201, Vol. 206, pp. 385-386.

22. **Zosky, G R, et al.** Coal workers' pneumoconiosis: an Australian perspective. *Medical Journal of Australia*. 2016, Vol. 204, pp. 414-418.
23. **Australian Health Ministers' Advisory Council.** *National Strategic Framework for Chronic Conditions*. Canberra : Australian Government, 2017.
24. **Sabit, R, et al.** Arterial stiffness and osteoporosis in chronic obstructive pulmonary disease. *American Journal of Respiratory and Critical Care Medicine*. 2007, Vol. 175, pp. 1259-65.
25. **Reddel, H K, et al.** Asthma control in Australia: a cross-sectional web-based survey in a nationally representative population. *Medical Journal of Australia*. 2015, Vol. 202, pp. 492-497.
26. **Galaxy Research Omnibus.** 2014.