Improving outcomes for Australians with lung disease

Submission for the 2018-19 Federal Budget from Lung Foundation Australia
Introduction

Lung disease has a major impact in Australia, both in terms of healthcare utilisation and lost quality of life for patients and carers. Lung disease contributes more than 10% to the overall health burden in Australia (1). When we consider the impact on Aboriginal and Torres Strait Islander populations and Australians living in regional, rural and remote areas across Australia, this burden is even greater (2) (3).

For people living with lung disease in Australia (1):

- Lung cancer represents the leading cause of death (40% of deaths from lung disease)
- Chronic Obstructive Pulmonary Disease (COPD) contributes to one-third (1/3) of the overall health burden and to almost 1/3 of all respiratory deaths
- Lower respiratory infections are the leading cause of hospital admission
- Asthma represents the leading cause of disability

Over the past 15 years, the Commonwealth has taken a national strategic approach to improving outcomes in one lung disease – asthma. This strategic approach, along with sustained investment in research, clinical and community education & support, has driven a dramatic reduction in hospitalisations and asthma deaths in Australia. Equally beneficial outcomes can be expected if a similar investment were implemented in other, higher impact lung diseases such as chronic obstructive pulmonary disease (COPD), lung cancer, Idiopathic Pulmonary Fibrosis (IPF) and respiratory infection.

It is important to acknowledge gains made by government in tobacco control, the establishment of the Medical Research Future Fund (MRFF) and recent access to life changing medications for those with IPF and lung cancer.

Despite these positive developments, lung disease still does not receive the funding and support warranted by its outcomes and relative to its burden.

This submission outlines a number of high priority, cost-effective actions that will lead to better outcomes for patients, including support for: timely and accurate diagnosis; a reduction in preventable hospitalisations; improvements in the capacity of patients and carers to take an active role in managing their condition; and life-changing research.

Lung Disease in Australia – The key facts that need to change

- COPD is the second leading cause of potentially preventable hospitalisations (PPHs) – responsible for 10% of all PPHs (3)
  - Compared with the OECD average of 198 COPD hospital admissions per 100,000 people, Australia experienced 305 COPD hospital admissions per 100,000 people in 2013, putting Australia fourth from the bottom of 34 OECD countries. (4)
  - The rate of potentially preventable hospitalisation for COPD was 5 times higher for Aboriginal and Torres Strait Islander Australians than other Australians (3)
- Lung cancer is the biggest cancer killer in Australia, killing more people than breast, ovarian and prostate cancers combined (5)
  - Indigenous Australians are 1.7 times more likely to develop lung cancer and twice as likely to die from lung cancer than non-indigenous Australians (6)
  - There is unacceptable variation in the care received by patients with lung disease between local areas (3)
• Acute respiratory infection caused 130,000 hospitalisations in 2011/12 (1.4% of all hospitalisations) and 3,000 deaths in 2012 (2.1% of all deaths in Australia in that year) (1). In 2017 there was an unexpected high rate of influenza related illness and hospital admissions. Many are preventable.
  o Respiratory tract infections are a major health burden leading to school, work and productivity loss (7).

Alignment with Government Strategy

The recommendations outlined in this submission align with current government policy and strategy, specifically:

The Australian Commission on Safety and Quality in Healthcare, in its Second Atlas of Healthcare Variation (2017), reported that the lack of adherence to best practice in primary care contributes to variation in hospitalisation and health care costs by leading to differences in patient education for effective self-management, rates of influenza and pneumonia vaccination, smoking cessation uptake, delayed diagnosis and late access to care. The Commission recommends: “Earlier diagnosis through greater use of spirometry in primary care, strong care coordination and improved access to pulmonary rehabilitation could substantially improve outcomes for people with COPD in Australia.” (3)

The Senate Select Committee into Funding for Research into Cancers with Low Survival Rates (LSR) (2017) recommends:

• Make low survival rate cancers (including lung cancer) a National Health Priority Area
• Implement awareness activities to reduce the amount of time to detect and diagnose LSR cancers
• Improve awareness of LSR cancers amongst general practitioners
• Improve access to specialist cancer care coordinators or nurses for LSR cancers

National Strategic Framework for Chronic Conditions (2017) Strategic Priority areas identified include:

• Promote health and reduce risk
• Timely and appropriate detection and intervention
• Continuity of care
• Partnerships for health.
**Cost Effective Interventions**

This submission identified opportunities to change the face of lung disease in Australia. The opportunities have been selected because of the effectiveness of each and where an evidence base supports national implementation.

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<th>Intervention</th>
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<td>1. Widen access to pulmonary rehabilitation</td>
<td>Overall savings to the sector through prevented hospitalisations and reduced length of stay</td>
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| 2. Facilitate earlier detection and diagnosis of lung disease through awareness, primary care education and appropriate reimbursement for spirometry testing at primary care | **Awareness**: $5M over 3 years  
**GP education**: $200,000 one off development costs  
**Spirometry reimbursement**: MBS fee |
| 3. Increase capacity of primary care sector to manage chronic lung disease by scaling up existing national training initiatives | $5M over 3 years |
| 4. Provide funding for Specialist Lung Cancer Nurses (SLCNs)               | $8M to implement a two year pilot program and evaluation              |
| 5. Support chronic lung disease patients and their carers to self-manage through provision of national COACH program | $1.2M over 3 years |
| 6. Redress research funding gap for lung disease to reflect the burden of disease | $8.1M over 3 years |
What is pulmonary rehabilitation?

- Comprehensive 8 week EXERCISE and EDUCATION program provided by specially trained health professionals
- Teaches people with lung disease the skills that they need to know to stay well and out of hospital:
  - How to manage breathlessness so they are not over-using medicines
  - How to coordinate breathing with movement so they can resume activities of daily life
  - How to clear lung secretions to reduce infections
  - How to cope with anxiety, depression and panic attacks
- Other education: medications, social services, diet, intimacy
Given the potential for this intervention to reduce hospitalisations from chronic lung disease, we recommend immediate approval of this application.

**Recommendation:** Approve Application 1405 to MSAC which would provide an MBS item number for the delivery of pulmonary rehabilitation in the community.

**Cost:** Expected overall saving to the sector as cost of delivery would be offset by reduced healthcare costs and hospital admissions.
2. Facilitate earlier diagnosis of lung disease through awareness, GP education and national spirometry plan

Awareness and GP education: Lung disease is often diagnosed late through lack of awareness of symptoms and lack of urgency about symptoms.

- Symptoms of lung disease include shortness of breath, cough, chest pain, haemoptysis, all of which can be attributed to different causes and lifestyle choices.
- Cough is one of the most common presentations to general practice, yet there is currently no national training available focusing on cough and other symptoms of lung disease (15).
- Diagnosis of COPD is often not confirmed until symptoms are significant and well progressed. In fact, half of the people with symptoms don’t have a confirmed diagnosis (16) and are therefore not taking the important steps that can improve their health and prevent increasing disability.
- Lung cancer is often confirmed late, often following emergency presentation, as symptoms of cough and breathlessness are ignored. Persistent symptoms, especially in people with risk factors, must be urgently investigated. Australian guidelines state that a cough lasting for three weeks should prompt further investigation (17) (18).
- Lung disease is so closely associated with smoking that there is a lack of awareness of other risk factors (genetic, occupational), and symptoms in smokers are frequently dismissed (19)
- Rarer lung diseases, such as idiopathic pulmonary fibrosis and pulmonary arterial hypertension, are particularly challenging, but may present with identical symptoms, such as chest tightness and breathlessness.

Early and accurate diagnosis is required to institute early treatment and management, avoid inappropriate prescribing, and to prevent avoidable healthcare costs and resource utilisation (20).

A national awareness campaign, including primary care education, would:

- Increase understanding that lung disease can affect anyone, not just current smokers
- Improve knowledge of occupational risks of lung disease
- Enhance understanding of symptoms (cough of three weeks, shortness of breath, chest pain) of lung disease and urgency to act
- Ensure primary care practitioners know the appropriate referral pathways and urgency for referral
In the UK, a National Health Service campaign, “Be Clear on Cancer”, focusing on respiratory symptoms, showed that 700 more lung cancer cases were diagnosed during the campaign period compared to a similar period the previous year. It also showed diagnoses happened at an earlier stage - 400 more people had their cancers diagnosed at an earlier stage and 300 additional patients had surgery as a first treatment for diagnosed lung cancer which gives them the best chance of prolonged survival. The campaign also resulted in an increase in two week referrals for suspected lung cancer of 30%. Spontaneous recognition of breathlessness as a symptom of lung disease and heart disease increased 50% and 42% respectively (21). The campaign has been repeated three times, the third time combining breathlessness and cough to increase earlier diagnosis of both lung cancer and COPD.

A national awareness campaign in Australia focusing on cough and breathlessness would aim to increase recognition of important symptoms of lung disease and drive those with symptoms to speak to their doctor. The campaign would include supporting primary care education (on-line education module focusing on symptom recognition, a systems approach to identifying those at high risk of lung disease; and information on appropriate referral pathways).

**Appropriate payment for spirometry testing at primary care:** Earlier diagnosis is not only a result of lack of awareness. A further barrier to timely diagnosis of lung disease is the lack of routine assessments and testing of those at risk of lung disease in the primary care setting. This means that people are missing out on the opportunity for earlier diagnosis and, therefore, earlier treatment and management. Amongst primary care practitioners, studies show that spirometry testing (essential to making a diagnosis of airways disease (9)) is not consistently done to confirm a diagnosis (22).

This lack of confirmation of airways disease through spirometry, results in delayed management and inappropriate prescribing.

An Australian study of COPD patients seen by a general practitioner found that 50% of them were diagnosed without spirometry testing and 65% of patients with COPD were diagnosed on presentation to hospital with an exacerbation (23). A further study identified that **82% of study participants were initiated on medicine without a lung function test** performed within 12 months, either before or after their initial prescription (24). This is confirmed by MBS data.

There are practical barriers to the performance of spirometry in primary care. These predominantly relate to the inadequate reimbursement for spirometry, given the cost of equipment and time taken to perform the tests.

The recent national Thoracic Medicine and Sleep Clinical Committee for the MBS review included consideration of remuneration for spirometry testing at primary care. A recommendation to increase payment to better reflect the time and skill required to conduct quality spirometry was made by the review committee. The federal government should accept this recommendation and rapidly implement it.

**Recommendation:** Implement a national program to promote early diagnosis of lung disease including: development of online primary care education on symptoms and referral pathways for lung disease; community awareness campaign highlighting symptoms and risk factors for lung disease; and increased reimbursement for spirometry conducted at primary care (as recommended by the recent MBS review on spirometric testing).

**Cost:** $5.2M over three years + MBS item cost. Savings are difficult to predict but we could expect to see a savings in PBS and MBS payments from avoidance of unnecessary treatment, lower adverse effects of treatment, accurate diagnosis leading to more appropriate referral for treatment and lifestyle changes.
3. Increase capacity of primary care to manage chronic lung disease by scaling up existing national training initiatives

Most chronic lung disease, particularly COPD, can and should be managed by primary care.

In Australia, COPD is a leading cause of mortality and morbidity. Compared to OECD countries, COPD is poorly managed in Australia, leading to higher rates of potentially preventable hospital admissions (4). In fact, compared to the OECD, Australia has one of the highest rates of potentially avoidable hospitalisations for COPD (4).

There is poor uptake and delivery of COPD Guidelines aligned management, including (25):

1. Promotion of physical activity and referral to pulmonary rehabilitation
2. Development of an agreed action plan, in partnership with patients
3. Medication and device technique training for patients with regular review
4. Adult vaccination, including influenza and pneumococcal and promotion of interventions that reduce infection transmission to vulnerable people
5. Recognition of factors predisposing people to pneumonia and when to use and not to use antibiotics
6. Promotion of the important role of patient self-management.

Wide variation of care for COPD contributes to morbidity and mortality: The Australian Commission on Safety and Quality in Healthcare, in its Second Atlas of Healthcare Variation, reported that the lack of adherence to best practice in primary care contributes to variation in hospitalisation and health care costs, leading to differences in patient education for effective self-management, rates of influenza and pneumonia vaccination, smoking cessation uptake, delayed diagnosis and late access to care. Variation of care for COPD was found to be the worst amongst the five chronic diseases driving the bulk of hospitalisations in Australia. When measuring Guideline-recommended care delivery for COPD, a massive 16-fold difference was observed between local areas. The Commission recommends: “Earlier diagnosis through greater use of spirometry in primary care, strong care coordination and improved access to pulmonary rehabilitation could substantially improve outcomes for people with COPD in Australia.” (3)

More training opportunities need to be offered to build the capacity of primary healthcare professionals in the identification diagnosis and management of patients with COPD and asthma-COPD overlap.

Lung Foundation Australia has a proven program and track record in delivering education to primary care professionals through a network of trained and expert clinicians. In building workforce capacity we focus on collaboration and already work with several key partners in this space, including Australian College of Rural and Remote Medicine, Pharmaceutical Society Australia and Australian Practice Nurses Association, on COPD training initiatives. An investment into this already established infrastructure and training resources would widen the reach of this program, particularly into regional, rural and remote settings.

Recommendation: Invest in growing the existing and proven primary healthcare professional training program that supports general practitioners and other primary healthcare professionals to implement evidence-based COPD Guidelines management to ensure patients are empowered to self-manage (with a particular focus on rural and remote health care professionals).

Cost: $5 Million over three years.
4. Provide funding for specialist lung cancer nurses (SLCNs)

Lung cancer is the biggest cancer killer in Australia. It accounts for more cancer deaths than breast, ovarian and prostate cancers combined (5). In 2016, more than 12,000 Australians were diagnosed with lung cancer and almost 9,000 lost their lives to the disease (26). This is equivalent to approximately 25 deaths per day from lung cancer. The incidence of lung cancer in Australia continues to increase in males and females and the prognosis for those diagnosed remains poor (26). The 5-year relative survival from lung cancer remains low at 15% (6). For those diagnosed with lung cancer at an advanced stage, the 5-year relative survival is only 1% (6), or a 1 in 100 chance of surviving 5 years from diagnosis. These figures for 5-year relative survival are significantly lower than for other frequently diagnosed cancers, for example, prostate cancer (6).

Evidence indicates that lung cancer patients experience higher symptom distress and experience more psychological distress and report a higher number of unmet supportive care needs than patients with other types of cancer (27) (28) (29). Stigmatisation experienced by lung cancer patients (27) (28) further exacerbates psychological distress placing them at a higher risk of suicide compared to people with other cancer types (30). It is perhaps unsurprising that people living with lung cancer report a lower quality of life than people living with other cancer types (32) (33).

One of the key challenges for lung cancer patients is that in presenting to a primary care setting, they may be delayed in their referral to a specialised lung cancer multidisciplinary team (MDT) (29). Several factors can explain this, including: lack of awareness of relevant symptoms and lack of sense of urgency about symptoms; varying levels of awareness about the appropriate referral pathway; a belief that lung cancer only occurs in smokers; gaps in the coordination of a complex diagnostic pathway; perceived nihilism of some referring doctors and other clinicians; and limited sharing of information from multiple providers across different information platforms (30).

Despite the demonstrated personal, social and economic impacts of lung cancer in Australia and the systemic challenges that exist around the lung cancer pathway, there is minimal supportive care for those diagnosed with lung cancer.

Evidence suggests that Specialised Lung Cancer Nurses (SLCNs) are well placed to address the gaps and barriers and challenges faced by people at all stages in the lung cancer trajectory (ref). In the UK, for example, the SLCN role has been shown to be a catalyst in patient access to treatment, including assessment, managing symptoms, psychosocial support, and information provision. (31)

The Clinical Practice Guidelines for the Treatment of Lung Cancer, commissioned by Cancer Australia, state that best practice lung cancer treatment and care is delivered by an MDT, of which the SLCN is cited as a core member. Moreover, the Guidelines state that the SLCN is the health professional recognised as being the one constant health professional for lung cancer patients across their disease journey. SLCNs ensure patients’ needs and preferences are addressed from pre-diagnosis through to end of life.
In the UK, the National Health Service (NHS) is aiming to provide lung cancer nurses to meet the needs of 90% patients at diagnosis. They already reach over 70% patients. The role of the SLCN is critical to coordinate and optimise care for patients, as well as to provide them with clinical, social and emotional support (30).

**Cancer Australia’s Clinical Practice Guidelines for the Treatment of Lung Cancer:** Including a LCN in the care of patients from early in the diagnosis-decision making stage may be highly valuable.

By extension of the universal acceptance of the role of breast care nurses, it seems more than probable that patients with lung cancer would benefit in a similar fashion (30).

The recently released **Senate Report into Low Survival Rate Cancers** recommends: The committee recommends that the Australian government, in conjunction with its state and territory counterparts, works to improve access to specialist cancer care coordinators or nurses for low survival rate cancer patients in every state and territory (32).

There is a critical shortage of SLCNs in Australia. Currently, the funding model for the role is driven at the hospital or clinic level resulting in diversity in the way the role is implemented that does not necessarily associate with optimal patient care. Clinical Practice Guidelines (30) recommend there should be at least one SLCN per MDT. There are currently 66 MDTs in Australia and there are 29 SLCNs positioned in teams across Australia. This situates the delivery of lung cancer care well short of best practice.

Most of these 29 nurses are employed in a part-time or half-time capacity, equating to approximately 8 full time equivalent (FTE) positions. Data by Cancer Australia report 12,434 new lung cancer cases were identified in 2017 (26). This means there was an estimated one SLCN for every 1,500 new patients each year. This compares poorly to the UK ratio of one SLCN to every 100-200 patients (33).

**Recommendation:** Provide funding to ensure a SLCN or oncology nurse is associated with each of the 66 Lung Cancer MDTs in Australia.

**Cost:** $8 Million to support a two year pilot program to position SLCNs in lung cancer MDTs. This funding would enable rigorous independent evaluation and the opportunity to fine-tune the program. Key drivers include sustainability of the program and assurance that cost savings can be reinvested in services.
5. Support patients and their carers to self-manage through the provision of a national COACH program

The important role of self-management for those with chronic disease is well documented. Self-management interventions in patients with COPD are associated with improved health-related quality of life, a reduction in respiratory-related and all cause hospital admissions, and improvement in breathlessness (34).

Literature reports, however, that patients are not consistently receiving education and information on and motivation about actions they can take to help self-manage their condition. Nor are they being referred regularly to Lung Foundation Australia for support (see Box).

The patient experience – study by For Benefit Insights

The ‘Living with COPD Report’ was developed to gain a better understanding of patient experiences. Information was drawn from seven focus groups comprising a total of 39 patients (mixture of mild, moderate and severe COPD) in four locations. The findings of the study highlighted the need for earlier identification of people at risk of COPD and improved self-management support from primary healthcare professionals. These included:

- Almost 80% of diagnoses were made by specialists or due to the patient presenting to hospital. These people could have been identified and diagnosed in a primary care setting.
- A poor explanation of COPD at diagnosis and an absence of resources such as printed information. There was also a low knowledge of Lung Foundation resources. Patients could be referred to the Lung Foundation to access evidence-based self-management material.
- GPs were noted as the cornerstone of care but there was higher engagement from specialists in review of patients including their medicines.
- Low levels of inhaler device checks were conducted. Some patients had to learn proper technique by reading the instructions provided with the medicine.

A national program designed to systematically refer to and provide coaching support will support patients to take more control of their disease and manage their symptoms, thus keeping them well, enhancing quality of life, and staying out of hospital. Targeting efforts to ensure those living in rural and remote locations will go some way to reducing the variation of care that those living outside the main centres are able to access.

The Coach Program (www.thecoachprogram.com) is an evidence-based program that has been shown to help patients achieve better health outcomes. Lung Foundation Australia recommends funding to support the employment of a COPD nurse to pilot, implement and evaluate the COACH Program embedded into the support the Lung Foundation already provides.
**Recommendation:** Fund the provision of a national Coaching and self-management support program embedded in Lung Foundation Australia. Pilot this program for patients with chronic lung disease, particularly those with chronic obstructive pulmonary disease or pulmonary fibrosis.

**Cost:** $1.2Million to establish the Coaching program and pilot over three years.
6. Redress research funding gap for lung disease to reflect the burden of disease

Despite the significant burden of lung disease (see Page 1) in Australia, research in lung disease is significantly underfunded. The National Health and Medical Research Council (NHMRC) has allocated 5.3% of its funding from 2012-2016 for respiratory research (35). Lung disease accounts for 10.3% of the total burden of disease in Australia (1).

Despite being the biggest cancer killer in Australia, accounting for 20% of all cancer deaths, in 2006-2011 lung cancer received only 5% of tumour specific research funding nationally (5).

This relative under-funding of research in lung cancer and other lung diseases is a significant barrier to attracting the brightest researchers to work in lung cancer or other lung diseases in Australia. This will have a serious negative impact on the quality of research applications into lung disease in the future, putting Australia at risk of falling behind internationally.

The Select Committee into Funding for Research into Cancers with Low Survival Rates (LSR) recommended increasing research funding for LSR cancers (including lung cancer) by:

- Having NHMRC identify LSR cancers a National Health Priority
- Having NHMRC introduce options to extend existing funding to recipients of current grants (32)

Investment in lung disease research undoubtedly drives improvement in quality experiences and outcomes for patients and which, in turn, contributes enormous social and economic benefits. Importantly, research funding will support promising researchers to include lung disease research in their career plans.

Australian government funding for 20 mid-career research fellowships and 10 linked PhD fellowships will help to future proof Australian research in lung disease and improve outcomes for patients.

Recommendation: Fund 20 mid-career research fellowships across the various lung diseases, with a priority placed on those with highest burden, including lung cancer, COPD, Idiopathic Pulmonary Fibrosis, Respiratory Infection and Bronchiectasis. It is also recommended that 10 PhD fellowships be linked to some of the mid-career fellowships. Each three year mid-career fellowship would offer $80,000 per annum in salary plus $40,000 annually for project support ($7.2M over three years). Each three year PhD fellowship would offer $30,000 per annum in salary ($900,000). Total $8,100,000 over three years.
Lung Foundation Australia

Lung Foundation is the only national charity that represents anyone with a lung disease. The mission of the Lung Foundation is to reduce the impact of lung disease in Australia through:

- Promoting lung health
- Promoting timely diagnosis of lung disease
- Supporting those with lung disease and their carers
- Promoting equitable access to evidence-based care
- Driving quality research.

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References


