Australian Government
Department of Health

National Strategic Action Plan for Lung Conditions

February 2019

We acknowledge Traditional Owners of Country throughout Australia and recognise the continuing connection to lands, waters and communities. We pay our respect to Aboriginal and Torres Strait Islander cultures, and to Elders both past and present.

Development of the National Strategic Action Plan for Lung Conditions was led by Lung Foundation Australia with funding from the Australian Government Department of Health.

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Foreword

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Chair, Lung Foundation Australia

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You only need to look at the facts.

Seven million Australians – that is almost one in three people – live with a lung condition. They may have received a devasting diagnosis of lung cancer or Idiopathic Pulmonary Fibrosis (IPF). Perhaps they have suffered through an ongoing condition such as Chronic Obstructive Pulmonary Disease (COPD), asthma or bronchiectasis. They may have contracted a lung disease simply because of their occupation.

Of the leading causes of death in this country, lung disease is the second biggest, following closely behind heart disease. And yet, we find that lung cancer in particular, is the least funded of all commonly diagnosed cancers. We find that the current survival rate of IPF is as low as some of the most devasting cancers. The prevalence of bronchiectasis continues to increase worldwide – disproportionately affecting Australian Indigenous children. And one in seven Australians over the age of 40 are diagnosed with COPD, with no known cure. Those who are already burdened by socio-economic disadvantage are also disproportionately affected by occupational and environmental determinants of respiratory ill health, and are less able to access appropriate care.

Beyond these startling facts, we also know that people with lung disease face something entirely different from other chronic and terminal illnesses: discrimination.

Australians living with a lung condition feel isolated and discriminated against. Discrimination and stigma prevent the achievement of good outcomes following a diagnosis - because people feel ashamed and delay seeking help. It is estimated that 50% of Australians living with lung cancer experience distress, anxiety or depression, which worsens their quality of life.

This fact alone should compel us to make lung disease a health priority for Australia – so as to address the long standing inequity that comes with it – and propel us forward to achieve better healthcare for people living with lung conditions and their families. As well, investment in lung disease research will improve our understanding and knowledge of lung disease in order to prevent it and treat it optimally.

This Action Plan addresses not only the causes, treatment and management of lung disease, but outlines tangible and practical actions that we can take to begin to make a difference to the lives of those millions of Australians.

These, and the other recommendations in this Action Plan, should be supported by all levels of government and acted on to begin to reduce inequality and the burden of lung disease on individuals and society. It is my hope that this Action Plan will be funded and implemented so that we redress these deficiencies in the care and management of people with lung disease. Only in this way will we embody the fairness and equity for which Australians are so well known.

Facts can change. Let this Action Plan be a catalyst for that change.

Executive Summary

The National Strategic Action Plan for Lung Conditions (the Action Plan) provides a detailed, person-centred roadmap for addressing one of the most urgent chronic conditions facing Australians.

In Australia, seven million (almost one in three) live with a lung condition, such as lung cancer, Chronic Obstructive Pulmonary Disease (COPD), asthma and bronchiectasis. Lung conditions are Australia's second leading cause of death and account for more than 10 per cent of the total health burden. Lung conditions have a marked effect on people's ability to enjoy life, be active and productive, and realise their full potential. People living with these conditions, their families, the healthcare system and the broader community experience significant health and economic burden.

This Action Plan outlines a comprehensive, collaborative and evidence-based approach to reducing the individual and societal burden of lung conditions and improving lung health. The plan addresses the broad spectrum of lung conditions, ranging from the common cold which impacts the health of many Australians and their participation in the workforce, education and social activities, to lung cancer which is Australia's biggest cancer killer with an estimated 9,020 deaths in 2017: more than breast, prostate and ovarian cancers combined.

The Action Plan aligns with the National Asthma Strategy 2018; and due to this existing policy response to improving asthma outcomes in Australia, asthma is not included as a priority condition in this Action Plan. Many of the interventions outlined, however, will benefit people with asthma.

The Action Plan has a strong focus on:

- Addressing health determinants and risk factors for lung conditions to enhance the lung health of the Australian community
- Optimising quality of life for people with lung conditions
- Redressing areas of poorer health outcomes and unmet need
- Action at the wider health-system level to ensure real and lasting improvement for all Australians
- Delivering tangible improvements in health outcomes, equity and economic benefits.

The plan articulates a goal supported by **six high-level priorities** that together aim ***to improve the lives of all Australians through better lung health***. Each priority has a number of **recommended actions** informed by evidence and these actions are detailed within this Action Plan. The table below outlines the goal, six high-level priorities and a key objective for each priority area.

Goal: To improve the lives of all Australians through better lung health

Priority Area	Objective
1. Prevention and Risk Reduction	Prevent lung conditions and reduce the risk of lung disease.
2. Awareness and Stigma	Raise awareness about lung conditions and reduce stigma, discrimination and social isolation.
3. Diagnosis, Management and Care	Translate science into quality diagnosis, management and care of lung conditions.
4. Partners in Health	Support people with lung conditions to participate in shared decision making and self-management.
5. Equitable Access	Ensure equitable and timely access to evidence-based diagnosis and management of lung conditions.
6. Research and Monitoring	Increase research capacity to redress under resourcing of research into highly prevalent lung conditions.

An evaluation framework is proposed to assess progress of the Action Plan over a five year period.

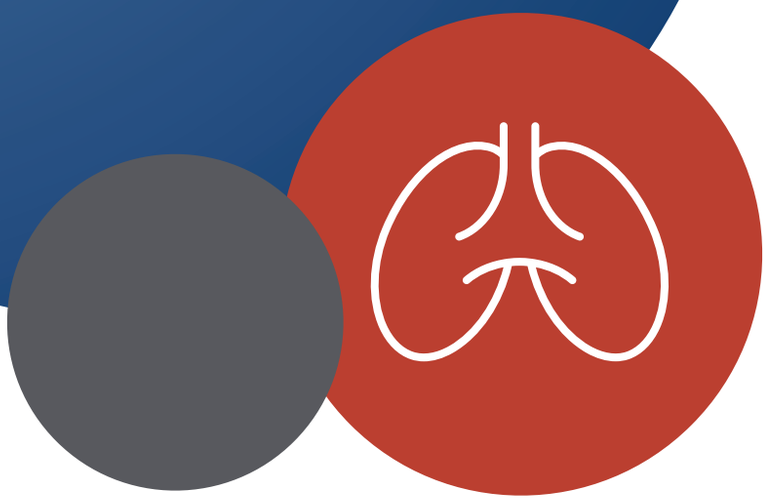
Acronyms

ACSQHC	Australian Commission on Safety and Quality in Health Care
AIHW	Australian Institute of Health and Welfare
CF	Cystic Fibrosis
COPD	Chronic Obstructive Pulmonary Disease
CT	Computerised Tomography
DALYs	Disability Adjusted Life Years
FCTC	Framework Convention on Tobacco Control
ILD	Interstitial lung diseases
MBS	Medical Benefits Schedule
MRFF	Medical Research Future Fund
MSAC	Medical Specialist Advisory Committee
MDT	Multidisciplinary team
NHMRC	National Health and Medical Research Council
PHN	Primary Health Networks
SLCNs	Specialist Lung Cancer Nurses
WHO	World Health Organization

For brevity in this Action Plan, Aboriginal and Torres Strait Islander people are at times referred to as Indigenous.

A glossary of terms is provided in Appendix 1.

Contents



The National Strategic Action Plan for Lung Conditions (the Action Plan) is the overarching plan to advance lung health in Australia.

This is the first National Strategic Action Plan for Lung Conditions.

This Action Plan was developed through extensive collaboration with people with lung conditions and their families, health consumer advocates and representatives, health professionals, researchers, and policy makers. The Lung Foundation received 880 submissions during the consultation and especially recognises the substantial contribution of the Advisory Group members including The Thoracic Society of Australia and New Zealand.

Definition of lung health

The World Health Organization (WHO) defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1948).

Good lung health aims to achieve this state of wellbeing by keeping people free from lung conditions and minimising the impact of existing conditions.

Lung condition(s) is a general term used to describe a large group of conditions that affect and impair the function of the airways and lungs. Lung conditions are sometimes referred to as lung disease, airways disease, respiratory disease or pulmonary disease. Lung conditions cause symptoms such as difficulty breathing, coughing and tiredness.

There are over **30 types of lung conditions**, including lung cancer, Chronic Obstructive Pulmonary Disease (COPD), bronchiectasis and respiratory infection (American Lung Association, 2018).

Working across lung conditions

The Action Plan is Australia's coordinated response to the complex challenges presented by lung conditions. It has a broad focus on addressing a range of lung conditions, rather than a single lung condition, by tackling the shared health determinants, risk factors and multi-morbidities across a broad range of lung conditions.

The Action Plan takes a holistic, person-centred approach to address a range of different but common lung conditions to reduce their burden on the individual and the community, to reduce mortality and to optimise quality of life. As with most chronic conditions, lung disease may co-exist with other common chronic conditions such as heart disease, depression, osteoporosis and diabetes. This Action Plan addresses these comorbidities when clinically relevant to a patient living with lung condition(s) and to this end aligns with the National Strategic Framework for Chronic Conditions (the Framework) including principles and enablers within this framework. It also recognises that while Australians may live in a range of places, from very remote to large urban settings, all should be able to access person-centred care for lung conditions and achieve the best possible lung health.

Partnerships

The effective prevention and management of chronic conditions is strongly influenced by the contributions made by a wide range of Partners. These Partners include:

- Individuals, carers and families
- Communities
- All levels of government
- Non-government organisations
- Public and private health sectors, including all health care providers and private health insurers
- Industry
- Researchers and academics.

All Partners have shared responsibility for health outcomes according to their role and capacity within the health care system. Greater cooperation between Partners will lead to more successful individual and system outcomes. Actions included in this Action Plan are intended to guide Partner investment in the prevention and management of lung conditions and should be implemented collaboratively to achieve the best health outcomes.

Implementation partners are detailed in Appendix 2: Implementation Partners.

Priority lung conditions

This Action Plan seeks to address factors that are common across most lung conditions so that actions taken will make the most gains for the greatest number of people. It also highlights eight condition areas that together make up much of Australia's lung burden. In

addition, the Action Plan provides an opportunity to highlight some under-recognised and rare conditions where the impact is significant.

Eight priority lung condition areas of this Action Plan include:

- Lung cancer
- Chronic Obstructive Pulmonary Disease (COPD)
- Bronchiectasis
- Respiratory infection
- Interstitial Lung Diseases (ILD)
- Occupational lung diseases
- Respiratory lung disease overlap (multiple lung diseases in one person)
- Rare lung conditions, including Cystic Fibrosis (CF).

Each of these eight conditions are detailed further in the accompanying document titled, ***Lung Conditions in Australia 2018: A supporting document to the National Strategic Action Plan for Lung Conditions.*** There are a large number of other lung conditions in Australia, including asthma, allergies and allergic rhinitis/hay fever. The Action Plan aims to be relevant to the individuals, families and communities who experience these conditions by addressing a wide range of issues affecting lung health. The Action Plan also aligns with the National Asthma Strategy 2018; due to the existing policy response to improving asthma outcomes in Australia, asthma is not included as a priority condition in this Action Plan. Many of the interventions outline, however, will benefit people with asthma.

Health, social and economic impact of lung conditions

Internationally, the WHO recently identified chronic respiratory disease as one of the four leading chronic conditions worldwide, along with cardiovascular disease, cancer and diabetes (WHO, 2018). In Australia, lung conditions place a significant burden on individuals affected by the disease, our healthcare system, workforce and the broader economy.

An extensive review of the health, social and economic impact of lung conditions is provided in the accompanying document titled, *Lung Conditions in Australia 2018: A supporting document to the National Strategic Action Plan for Lung Conditions.*

This review is supported with evidence and includes the rationale for addressing the eight priority lung conditions identified in the Action Plan. The burden of disease is significant and the impact on the Australian community is highlighted below:

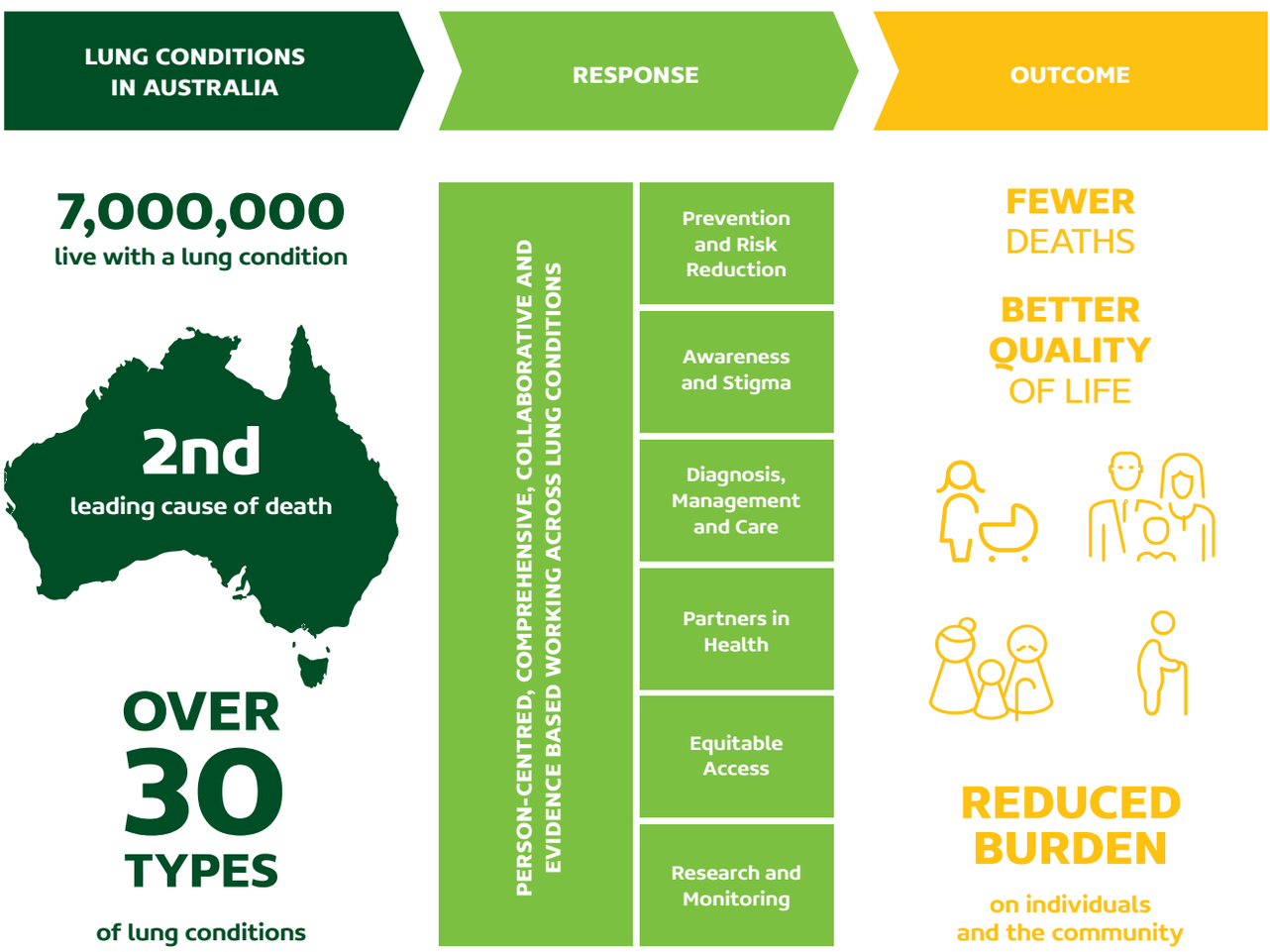
- In Australia, seven million people almost one in three live with a lung condition (AIHW, 2018a)
- Lung conditions are Australia's second leading cause of death (AIHW, 2018b)
- Many people with lung conditions experience loss of time from school or work, inability to stay in a job, difficulty participating in social activities, anxious and depressive symptoms and disorders, and impaired quality of life
- People with COPD have a prevalence of panic disorder approximately 10 times greater than the general population, and commonly experience panic attacks (Yang et al., 2018)
- Lung conditions pose a substantial economic burden on people with these conditions and their families, the health care system and the broader economy (Access Economics Pty Limited, 2008; PwC, 2018).

Lung conditions impact all Australians, but some populations are disproportionately affected.

A Strategic Approach to Improving Lung Health

This Action Plan outlines a strategic approach to reducing the burden of lung conditions and improving lung health, as illustrated in Figure 1.

Figure 1: National Strategic Action Plan for Lung Conditions



The plan articulates a goal supported by **six high-level priorities** that together aim ***to improve the lives of all Australians through better lung health.*** Each priority has a number of **recommended actions** informed by evidence and these actions are detailed within this Action Plan.

The six priority areas are interconnected and together, they represent a comprehensive approach to improving lung health for all Australians.

This Action Plan seeks to address factors that are common across most lung conditions so that actions taken will make the most gains. The plan will deliver tangible improvements in health **outcomes**, equity and economic benefits.

The overarching priority population of this Action Plan is people affected by lung conditions. Within this group, several **priority populations** have been identified based on extensive consultation with experts and the lung health community, and in response to evidence around poorer health outcomes and unmet need.

The **priority populations** identified in the Action Plan include:

- Aboriginal and Torres Strait Islander people
- People living in regional, rural and remote areas
- People who smoke
- Workers currently and previously exposed to occupational dusts, gases, fumes and vapours
- People from culturally and linguistically diverse backgrounds
- People experiencing socio-economic disadvantage.

The actions outlined in all priority areas of this Action Plan apply equally for priority populations as they do for the wider population. However, given the disproportionate burden of lung conditions and disparities in health outcomes experienced between populations, targeted action is essential to ensure that priority populations receive equitable access to evidence-based diagnosis, management and care. Action to improve health outcomes of priority populations will align with Australia's renewed commitment to Closing the Gap. More information on priority populations is provided in the accompanying document titled, *Lung Conditions in Australia 2018: A supporting document to the National Strategic Action Plan for Lung Conditions.*

Determinants of health

This Action Plan recognises that health is not created in a vacuum but is influenced by many different factors across the life course. The determinants of health, although many and varied; fall into four main categories:

- **Physical environment** – for example, workplaces and housing, sanitation and the natural and built environments
- **Social environment** – for example, education, employment, political structures, relationships and culture
- **Economic factors** – for example, income, expenditure and affordability
- **Individual characteristics** – for example, gender, genetics, physical and/or mental determinants (Australian Health Ministers' Advisory Council, 2017a).

Action to address the determinants of health is critical to improving the lives of all Australians living with lung conditions, particularly priority populations. People with socio-economic disadvantage are disproportionately affected by occupational and environmental determinants of respiratory ill health and are less able to access appropriate care.

Principles

This Action Plan is underpinned by eight guiding principles in line with the Framework (Australian Health Ministers' Advisory Council, 2017b):

- Equity
- Collaboration and partnerships
- Access
- Evidence-based
- Person-centred approaches
- Sustainability
- Accountability and transparency
- Shared responsibility.

Enablers

In line with the Framework (Australian Health Ministers' Advisory Council, 2017b), this Action Plan draws on seven enablers that will assist in achieving the goal of this plan:

- Governance and leadership
- Health workforce
- Health literacy
- Research
- Data and information
- Technology
- Resources.

Priority Area 1:

Prevention and Risk Reduction *(Breathing well)*

Objective: Prevent lung conditions and reduce the risk of lung disease

This Action Plan has a focus on prevention for a healthier and more productive Australia. Preventing lung conditions and reducing the risk of their development means reducing or avoiding exposure to common risk factors. This Action Plan focuses on addressing health determinants and reducing and avoiding exposure to key risk factors including occupational risk factors, acute respiratory infections in early childhood, and poor air quality.

To prevent lung conditions and reduce the risk of lung disease, this plan focuses on reducing or avoiding exposure to common risk factors:

- Tobacco smoke
- Occupational hazards
- Chronic cough
- Respiratory infections
- Poor air quality.

Comprehensive and effective approaches to **tobacco control** are critical to the success of this Action Plan. Tobacco use causes lung conditions and is the predominant cause of Chronic Obstructive Pulmonary Disease (COPD) and lung cancer (Surgeon General, 2014). Exposure to tobacco smoke makes chronic lung conditions more severe and increases the risk of respiratory infections (United States Centers for Disease Control and Prevention, 2014). There is also evidence to suggest that youth who smoke may be more likely to develop asthma (Surgeon General, 2014). Additionally, exposure to second-hand smoke can trigger an asthma attack in both children and adults (United States Centers for Disease Control and Prevention, 2014).

Avoidance of direct and indirect exposure to **tobacco smoke** is therefore of primary importance not only for healthier lungs, but as a preventative measure for all the main categories of non-communicable diseases. Of all behavioural risk factors, tobacco use is the leading cause of preventable death and disability in Australia (AIHW, 2016). There is no safe level of tobacco consumption (Surgeon General, 2014).

Accordingly, this Action Plan supports accelerated efforts in reducing smoking prevalence and working towards a tobacco-free society. Consistent with this approach, this Action Plan also recognises Australia's obligations as a party to the World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC), which aims to protect present and future generations from the devastating health, social, environmental and economic consequences of tobacco consumption and exposure to tobacco smoke. Under the FCTC, Australia must adopt and implement effective measures for preventing and reducing tobacco consumption, nicotine addiction and exposure to tobacco smoke. The FCTC also obliges Australia to take steps to protect its tobacco control setting and implementation from interference from the tobacco industry and its interests.

Further information regarding Australia's approach to tobacco control refer to the 'National Tobacco Strategy' ***www.nationaldrugstrategy.gov.au***

This Action Plan recognises concerns regarding the marketing and use of **e-cigarettes** and the risks that these products pose to population health. Numerous Australian health organisations have expressed concerns regarding the direct harms that e-cigarettes pose to health, and acknowledge that there is insufficient evidence to support claims that e-cigarettes are safe (Rubinstein, et al., 2018). In view of this situation, Australian governments have

recently affirmed their support for a informed and considered approach to these products.

Occupational lung diseases are an important and under-recognised cause of respiratory ill health in Australia (Hoy & Brims, 2017).

Occupational lung diseases can be prevented by identifying and removing occupational hazards and creating healthy and safe workplaces. Lung conditions 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.

Cough is a common symptom of lung disease and one of the most common presentations to general practice, yet there is currently no national education available focusing on chronic cough and other symptoms of lung disease (Britt et al., 2014). Australian Cough Guidelines have been developed (Gibson et al., 2010), however awareness and implementation is low.

Immunisation is important for people with a lung condition and for the health of the Australian population in general. For people living with a lung condition, immunisation is recognised as an evidence-based approach to preventing **respiratory infections**. This Action Plan focuses on increasing vaccination rates among priority populations and supports the ongoing investment in promoting and delivering immunisation services in the Australian community including the provision of education and incentives for families and vaccination providers.

Air quality greatly influences lung function for all Australians. Exposure to indoor and outdoor pollutants currently occurs in a variety of environments including workplaces, public and commercial buildings as well as rental accommodation. These pollutants consist of a variety of combinations of volatile organics such as dusts, gases, fumes, vapours and moulds. The extent of exposure to indoor and outdoor air pollutants in the community and workplaces is largely unknown and there is a need to investigate further to reduce the impact on the population. Efforts to monitor and improve indoor and outdoor air quality will promote good lung health, including tobacco control strategies (e.g. no smoking in public places) which have been proven successful over the last 30 years. Prevention of exposure to new pollutants is also important, including the recently recognised silica dust and the combination of volatile compounds in e-cigarettes.

Outcomes

Action to prevent lung conditions and reduce the risk of lung disease will contribute to the overarching outcomes of this Action Plan by delivering:

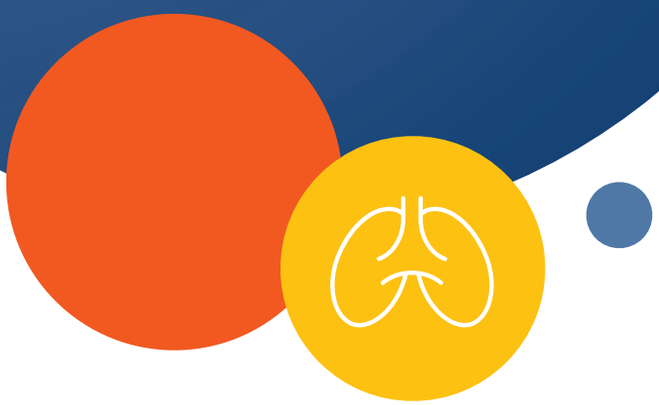
- Reduction in smoking prevalence, particularly in priority populations
- Safer workplaces and more productive Australians
- Increased uptake of vaccines, particularly in priority populations
- Education on the importance of investigating chronic cough
- Cleaner indoor and outdoor air quality so Australians can breathe well.

Priority Area 1: **Recommended Actions**

Action	Implementation
1.1 Support accelerated efforts in reducing smoking prevalence and working towards a tobacco-free society.	Align with and support implementation of Australia's National Tobacco Strategy (a new National Tobacco Strategy is currently under development) and help to ensure that Australia meets its international commitments under the WHO FCTC. Support evidence-based tobacco control efforts and an informed and considered approach to e-cigarettes.
1.2 Deliver awareness and education campaigns to improve knowledge of occupational hazards that affect the lungs and to promote safe workplaces.	Deliver multi-faceted awareness and education campaigns for occupational lung conditions that targets employers, employees, representative bodies (e.g. unions and industry groups where appropriate) and key work health and safety stakeholders (e.g. Safe Work Australia). Due to the latency period of occupational diseases, these campaigns should also target workers previously exposed to occupational hazards, including retired workers. Develop workplace-specific lung health materials to educate employers and employees on the preventable causes and symptoms of occupational lung disease, and support employers to act to reduce occupational hazards and provide healthy and safe workplaces. Develop workplace strategies which enable people with lung conditions to remain in active employment for longer. The campaign will target high risk industries (e.g. mining, manufacturing, engineered stone working and building) and align with existing legislative requirements.
1.3 Deliver education to parents, carers and health professionals to address chronic cough, particularly in high risk populations including Aboriginal and Torres Strait Islander children.	Deliver a national education program to address chronic cough in Aboriginal and Torres Strait Islander children and potential for bronchiectasis. Education to increase the alignment of current practice with evidence-based cough guidelines, CICADA: Cough in Children and Adults: Diagnosis and Assessment. Develop and deliver appropriately targeted and complementary information for parents, carers and health professionals (e.g. development of local health pathways).
1.4 Deliver awareness and education campaigns on the benefits of immunisation to increase uptake in high risk populations.	Deliver multi-faceted awareness and education campaigns to reduce the risk of respiratory infection. This includes the development of materials on the benefits of immunisation to increase uptake, and education for families and carers to reduce respiratory infection transmission. The campaign will target high risk populations including people with chronic lung conditions, Aboriginal and Torres Strait Islander people and older people. The approach to the development of messages and resources will involve engagement with consumers and be delivered in a manner that is culturally safe, respectful and appropriate to the needs of priority population groups.
1.5 Develop a national personalised air quality monitoring system to help individual Australians and policy makers understand current environmental conditions and breathe easier.	Scale up existing best-practice models. Promote action towards a nationally consistent air quality standard.

Priority Area 2:

Awareness and Stigma
(Supportive communities)



Objective: Raise awareness about lung conditions and reduce stigma, discrimination and social isolation

A key priority of this Action Plan is to raise awareness of the challenges of lung conditions and reduce stigma, discrimination and social isolation associated with lung conditions. This Action Plan also focuses on raising awareness of the symptoms of lung conditions within the consumer and health provider setting to enhance early diagnosis and treatment.

Lung conditions are often misunderstood, and stigma is widespread (PwC, 2018). 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 (Australian Health Ministers' Advisory Council, 2017a).

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.

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

Lillian, lives with lung cancer

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 professionals because they underestimate the severity of their disease (Sabit et al., 2007, Reddel et al., 2015) or misattribute symptoms to other causes such as ageing (Sabit et al., 2007). Almost 50% of all Australians rarely or never think about the health of their lungs (Galaxy Research Omnibus, 2014). It is also important to raise awareness of the importance of lung function testing to confirm a diagnosis, as it is currently under-used which contributes to lung conditions being under-diagnosed and delays in diagnosis (Agusti et al., 2003, Guerra, 2009, Barton et al., 2009, Australian Centre for Asthma Monitoring, 2011).

'Community awareness is low, community understanding is even lower and community attitude is terrible. For some reason the community will not talk about lung disease even though the causes are similar to conditions like heart disease where interest, care and empathy is shown.'

Bill, lives with Idiopathic Pulmonary Fibrosis (IPF)

Outcomes

Action to raise awareness and reduce the stigma of lung conditions will contribute to the overarching outcomes of this Action Plan by delivering:

- Increased public awareness of the importance of lung conditions and their symptoms
- Reduced stigma, discrimination and social isolation of people with lung conditions and addressing the common misconceptions regarding lung conditions
- Increased knowledge of the symptoms of lung conditions and urgency to act
- Improved mental health and wellbeing, quality of life and social participation of people with lung conditions and their families
- Improved access to care and earlier diagnosis for people with suspected lung conditions.

Priority Area 2: **Recommended Actions**

Action	Implementation
2.1 Deliver a comprehensive public health program to reduce stigma, discrimination and social isolation associated with lung conditions.	Develop and deliver a national lung health community awareness campaign to increase public awareness of the challenges of lung conditions. Disseminate information through multiple platforms including targeted social media, websites, webinars and face-to-face opportunities. Utilise public figures to raise awareness of lung conditions and reduce stigma. Where appropriate, partner with industry and sports organisations to promote awareness and increase understanding that lung conditions can affect anyone, not just current smokers. Deliver training opportunities for health professionals with a focus on the special needs of people with lung cancer and the challenges of the disease. Investigate, measure and develop interventions to reduce the effects of therapeutic nihilism (i.e. attitudes that nothing can be done for this patient group) in treatment of lung conditions.
2.2 Deliver an awareness and education campaign to increase knowledge of the symptoms of lung conditions and enhance early and accurate diagnosis.	Develop and deliver an awareness and education campaign to consumers and health professionals using multiple platforms to highlight symptoms and risk factors for lung conditions. These campaigns will engage the public to be cognisant of misconceptions relating to lung conditions and to encourage early presentation to appropriately skilled health professionals to confirm or refute a diagnosis. Design, launch and evaluate a campaign to raise health professional awareness of lung condition symptoms, urgency of symptoms and evidence-based diagnosis, including the importance of appropriate lung function testing to confirm a diagnosis and assess severity.

Priority Area 3:

Diagnosis, Management and Care
(Knowledge translation)

Objective: Translate science into quality diagnosis, management and care of lung conditions

Australia has an outstanding reputation internationally for applying scientific rigor and evidence to achieve improved patient outcomes. However, many health systems are failing patients and leading to poorer outcomes. This Action Plan will prioritise the generation of evidence to strengthen the basis and delivery of appropriate, sustainable, efficient and best quality care.

In Australia, early and correct diagnosis is an issue for some lung conditions including lung cancer (Walters et al., 2013; Wang et al., 2010) and Chronic Obstructive Pulmonary Disease (COPD) (Agusti et al., 2003, Guerra, 2009; Liang et al., 2018; Walters et al., 2005; Walters et al., 2011; Xuan et al., 2011; Zwar et al., 2011). It is estimated that more than 50% of COPD cases where the patient has symptoms are undiagnosed (Xuan et al., 2011), and the majority of diagnoses occur in hospital after the person with a lung condition presents with an exacerbation (Walters et al., 2005). Late diagnosis, under-diagnosis and misdiagnosis can have a large impact on health outcomes including quality and length of life and health care efficiency. Early presentation and correct diagnosis of lung conditions is a priority.

Several different health professionals are involved in the care of people with lung conditions and often a range of health professionals work together in Multidisciplinary Teams (MDTs) to deliver comprehensive patient care. To diagnose lung conditions correctly and provide the best care possible, **health professionals** need ongoing education on lung conditions. This is particularly important for primary care professionals, including those in **regional, rural and remote** areas where the greatest variation in care exists and poorer health outcomes are evident (ACSQHC, 2017).

Health professionals need access to relevant clinical guidance in a form that is easy for them to use. **Evidence-based clinical practice** guidelines and optimal care pathways for lung conditions support health professionals to provide best-practice care. Training for all health professionals in the content and use of evidence-based guidelines and tools will also help them to provide nationally consistent advice and care.

'The education provided through the Active Learning Module on COPD filled gaps in my knowledge. I was able to ask questions that I thought were stupid, but it appeared that others in the room were at a similar level to me. Questions such as, how exactly do I perform and interpret spirometry? And how do I know when it's been done adequately to interpret results confidently?'

Dr. Srishti Dutta, General Practitioner

Outcomes

Action to translate science into quality diagnosis, management and care of lung conditions will contribute to the overarching **outcomes** of this Action Plan by delivering:

- Suitably trained health professionals in primary care
- Evidence-based diagnosis, management and care for people with lung conditions, including early and correct diagnosis
- Reduced disparity in lung health outcomes between people living in regional, rural and remote areas and metropolitan areas
- Improved quality improvement systems in primary care.

Priority Area 3: **Recommended Actions**

Action	Implementation
3.1 Develop and deliver a national lung health training and education framework for health professionals.	Similar to the National Asthma Council of Australia's Asthma best-practice education and training program, deliver a national education and training framework on lung health for health professionals. The national training framework will: • Be available in a variety of formats (e.g. face-to-face, online and blended learning) to optimise accessibility • Scale up existing education, training and support programs to increase reach and accessibility • Involve a review of current and future education and training needs of the multidisciplinary lung disease workforce • Focus on upskilling primary health care professionals (e.g. doctors, nurses, allied health care providers, pharmacists, Indigenous health workers, cultural liaison officers) in regional, rural and remote areas. Education to focus on: • Identifying people at risk of lung conditions (symptoms and case finding) • Diagnosis of lung conditions (spirometry use and referral pathways for complex lung function testing and radiological imaging, e.g. Computed Tomography (CT) scans) • Management using evidence-based strategies (including shared decision making and self-management strategies, care plans, palliative care principles and practices and advanced care planning) • Referral pathways (MDT, psychosocial support, community organisations, evidence-based programs such as pulmonary rehabilitation).
3.2 Ongoing revision, dissemination and implementation of evidence-based clinical practice guidelines and tools for lung conditions.	Investigate and map the existence of standards of care across all lung conditions in Australia and develop a report with recommendations for addressing gaps. Develop a central database of current evidence-based clinical practice guidelines and tools, clinical trials and research projects in the field of lung conditions. Extend the reach and implement evidence-based guidelines for lung conditions, including regular updates in response to emerging issues and new evidence, to ensure clinical care reflects best-practice. Review standard health assessments to include symptoms of lung conditions such as breathlessness and cough, drawing on existing best practice examples, including the Lung Foundation Australia's Lung Health Checklist and Indigenous Lung Health Checklist.

Action	Implementation
	Extend the reach of evidence-based tools currently available to support activity in: • Identifying people at risk of lung conditions (e.g. Lung Health Checklist in standard health assessments) • Confirmation of diagnosis • Optimising function • Preventing deterioration • Developing support networks • Managing acute episodes. Fund several academic scholarships to develop and pilot innovative practice-based applications such as electronic software and apps to increase the uptake of evidence-based clinical guidelines.
3.3 Investigate, design and pilot clinical practice audits.	Partner with organisations involved in developing and conducting clinical audits such as peak professional bodies, government organisations and non-government organisations to promote and actively facilitate uptake of clinical practice audits in primary care as a continuous quality improvement strategy. Investigate and pilot promising clinical practice audits to test effectiveness and confirm relevance of international models to the Australian context. Test clinical practice audits to focus on lung conditions, in particular severe asthma, COPD, occupational lung diseases, bronchiectasis and interstitial lung diseases. Audits to align with the Royal Australian College of General Practitioners' Continuing Professional Development program requirements.
3.4 Investigate and promote equitable access to evidence-based diagnostic tests, medicines and novel treatments.	Work with the Pharmaceutical Benefits Advisory Committee and Medical Services Advisory Committee to better understand the barriers to access to effective medicines and medical services, and optimal mechanisms for delivering new medicines and novel treatments for people with lung conditions. Develop a report with recommendations for the Minister for Health within 12 months. Ensure rapid and equitable access to evidence-based clinical assessment and diagnostic testing for new therapies as they become available for optimal treatment of lung conditions. This may also require changes to the Medical Benefits Schedule (MBS). Promote the optimal use of new evidence-based medicines and novel treatment through education and information resources.

Priority Area 4:

Partners in Health
(Self-management)

Objective: Support people with lung conditions to participate in shared decision making and self-management

'Bronchiectasis is definitely manageable. I chose to be an equal partner in staying informed and understanding the nature of my illness. I continue to find ways to support myself and the care that is needed to stay healthy.'

Joanne, lives with bronchiectasis

The important role of self-management for those with chronic conditions is well established, however in practice, people with lung conditions are not consistently receiving appropriate education, information or referrals to support their self-management (Lung Foundation Australia, 2016).

Supporting people with lung conditions to increase knowledge, confidence and skills for effective self-management practices will empower them to play an active role in their own health care, better manage their condition, and lead more active and productive lives. Access to community-based support for effective self-management practices is important for people with lung conditions and will complement and work in partnership with support provided through their medical management and care. Evidence-based **tools, information and support services** that support shared decision making between people with lung conditions and health professionals are critical. **Innovative technologies and strategies** to support patients to be actively involved in their lung health are required.

Outcomes

Action to support effective self-management practices will contribute to the overarching **outcomes** of this Action Plan by delivering:

- Improved knowledge of lung conditions and self-management amongst those affected and their health professional advisors
- People with lung conditions actively involved in their lung health
- Shared decision making between people with lung conditions and their health professionals
- New approaches, tools and knowledge for supporting effective self-management.

'My practice nurse has been amazing, and the support and knowledge she has given me has been invaluable. I could ask her anything, and if she didn't know the answer she would find out for me.'

Meredith, lives with Chronic Obstructive Pulmonary Disease (COPD)

Priority Area 4: **Recommended Actions**

Action	Implementation
4.1 Provide tools, information and support services for people with lung conditions to support effective self-management practices.	Extend the reach of evidence-based web and phone-based tools, information and support services to support effective self-management practices. Extend the reach of existing resources by making them available nationally in multiple formats to maximise uptake and accessibility. Develop new tools, information and support services to address gaps and unmet need. Scale up existing helpline services to ensure national access and maximise impact. Build on the existing model to enable patient/caller follow up, create pathways to health services, and opportunities to monitor and evaluate telehealth, video-conferencing and other information technology interventions to increase reach for health professionals and patients in regional, rural and remote areas. Consult with Aboriginal and Torres Strait Islander people and culturally and linguistically diverse communities, peak bodies and health professionals to ensure the development of culturally appropriate and safe tools, information and support services. Explore approaches to increase uptake of care plans and COPD Action Plans and investigate use including electronic-health adaptations. Develop a literacy lexicon for lung health (what you need to know to understand) to improve lung health literacy.
4.2 Develop and pilot innovative technologies and strategies that support patients to be actively involved in their lung health.	Fund a three year pilot of telephone coaching to support patient/carer self-management for lung disease including COPD, occupational lung disease, Interstitial Lung Disease (ILD) and bronchiectasis. Where appropriate, fund several industry-academic scholarships to develop novel technologies to support effective self-management strategies and monitoring of lung health.

Priority Area 5:

Equitable Access
(Best care for all)

Objective: Ensure equitable and timely access to evidence-based diagnosis and management of lung conditions

This Action Plan is focused on providing best care for all, with a particular focus on supporting priority populations that experience barriers to accessing care and poorer health outcomes, including Aboriginal and Torres Strait Islander people, regional, rural and remote communities, culturally and linguistically diverse communities, and socioeconomically disadvantaged people.

'Access is really important in remote and rural areas, where there are often limited or no services or support for patients and families. People often have to leave their community and support network to access services or care, this is of concern particularly for Aboriginal and Torres Islanders who have to leave family, country and cultural support.'

Dr. Kerry Hall, Research Fellow, Menzies Health Institute

Pulmonary rehabilitation is the most effective evidence-based intervention to manage breathlessness in chronic lung conditions. It improves exercise capacity, quality of life, and teaches people the skills to manage their condition and stay well. Pulmonary rehabilitation is cost-effective, although access in Australia is extremely limited; less than 10 per cent of people with Chronic Obstructive Pulmonary Disease (COPD) have access to pulmonary rehabilitation (AIHW et al., 2013).

'I don't know what I would be like if I hadn't done pulmonary rehabilitation. Pulmonary rehabilitation gives you the tools that you need to be as fit as you can be. Fit to fight – maintaining fitness is critical and the effects of exercise make you feel so much better overall.'

Ian, lives with COPD

Specialist Lung Cancer Nurses (SLCNs) have a critical role in coordinating and optimising care for people with lung cancer. In addition, they provide patients with clinical, social and emotional support. SLCNs are a core member of the Multidisciplinary Team (MDT) for the treatment of lung cancer (Cancer Council Australia, 2017). There is a critical shortage of SLCNs in Australia, which is inconsistent with evidence-based clinical practice guidelines and international best-practice and is compromising quality of care (Cancer Council Australia 2017; Senate Select Committee 2017).

In some settings, lung care is provided by a MDT within the healthcare system, however, this is not universal and is usually focused on initial diagnosis and major treatment decisions only. A comprehensive **workforce plan** for lung conditions is required to guide workforce design and development in Australia.

A palliative approach is central to best-practice end of life care and in fact often begins at the time a life-limiting disease is diagnosed, beginning with minimal palliative care and increasing input as required. The pattern of disease progression in several lung conditions, particularly COPD, is unpredictable and there is no clear transition to a period that can be identified as end stage. It should be recognised that active disease management and a palliative approach are complementary, not mutually exclusive. **Supportive and palliative care** are important for the management of lung conditions and end-of-life care, yet access to specialist services is problematic due to low awareness and a lack of referral processes. Increasing access is important, alongside training and education of all health professionals involved in lung conditions in palliative care principles and practice including advance care planning.

Outcomes

Action to ensure equitable and timely access to care will contribute to the overarching outcomes of this Action Plan by delivering:

- Increased access to pulmonary rehabilitation and supportive and palliative care, particularly for priority populations including Aboriginal and Torres Strait Islander people and people living in regional, rural and remote areas
- SLCNs in place throughout Australia to ensure people with lung cancer have their needs and preferences addressed from pre-diagnosis through to end-of-life
- A health workforce plan to ensure the workforce is suitably trained, resourced and distributed to meet identified need.

Priority Area 5: **Recommended Actions**

Action	Implementation
5.1 Expand service delivery of pulmonary rehabilitation beyond the hospital setting into the community and home setting to greatly increase access.	Fund an increase in pulmonary rehabilitation programs in the community and home settings to maximise patient access and choice, and ensure all Australians with lung conditions can benefit from pulmonary rehabilitation programs. Fund, upskill and accredit appropriate numbers of pulmonary rehabilitation programs, with a focus on regional, rural and remote communities. Build on existing models of best-practice, including the Pulmonary Rehabilitation Training Online which is already in place and can be used to upskill practitioners. Work with the Medical Services Advisory Committee (MSAC) to expedite implementation of MBS item numbers for the delivery of evidence-based interventions for people with lung conditions including an item number for the delivery of pulmonary rehabilitation in the community. Fund the existing Aboriginal Community Controlled Health Services model for culturally safe and accessible pulmonary rehabilitation for Aboriginal and Torres Strait Islander Australians with COPD to optimise reach and accessibility.
5.2 Fund SLCNs to provide care coordination and supportive care to people with lung cancer (similar to breast care nurses).	Consistent with the McGrath Foundation Breast Care Nurses, fund a network of Specialist Lung Cancer Nurses to act as care coordinators and case managers. Fund an initiative to place SLCNs in outer metropolitan, regional, rural and remote Australia, where access to support and care is particularly problematic. Funding lung cancer nurses is required to ensure a nurse is associated with each of the Lung cancer MDTs in Australia.
5.3 Develop a workforce plan for lung conditions.	Fund the development of a respiratory workforce plan to investigate areas of need, including adult and paediatric specialists, respiratory nurses, Indigenous health workers and patient navigators. Fund workforce positions where identified through the workforce plan. Broaden the scope of asthma educators in primary care to extend beyond asthma to include the provision of respiratory services for people with other lung conditions such as COPD, bronchiectasis, occupational lung diseases, rare lung diseases and Interstitial Lung Disesae (ILD).
5.4 Improve access to supportive and palliative care services, particularly for priority populations.	Establish processes for earlier referral to supportive care for people with lung conditions. Deliver a campaign to increase workforce awareness of the criteria for referral to palliative care. Deliver training and education on palliative care principles and practices and advance care planning to all health professionals involved in lung conditions, particularly those in primary care and ambulance services. Improve access particularly for priority populations including Aboriginal and Torres Strait Islander people and people living in regional, rural and remote areas. Implement a National Framework to standardise and ensure equitable, evidence-based access to oxygen therapy.
5.5 Develop and deliver Aboriginal and Torres Strait Islander people-led approaches to improving lung health.	Aboriginal and Torres Strait Islander people partner in, and lead, the planning, design, implementation and evaluation of locally responsive and culturally appropriate services, in order to reduce the disparity in health outcomes due to lung conditions between Aboriginal and Torres Strait Islander people and non-Indigenous Australians.

Priority Area 6:

Research and Monitoring
(Improved knowledge, investment and capability)

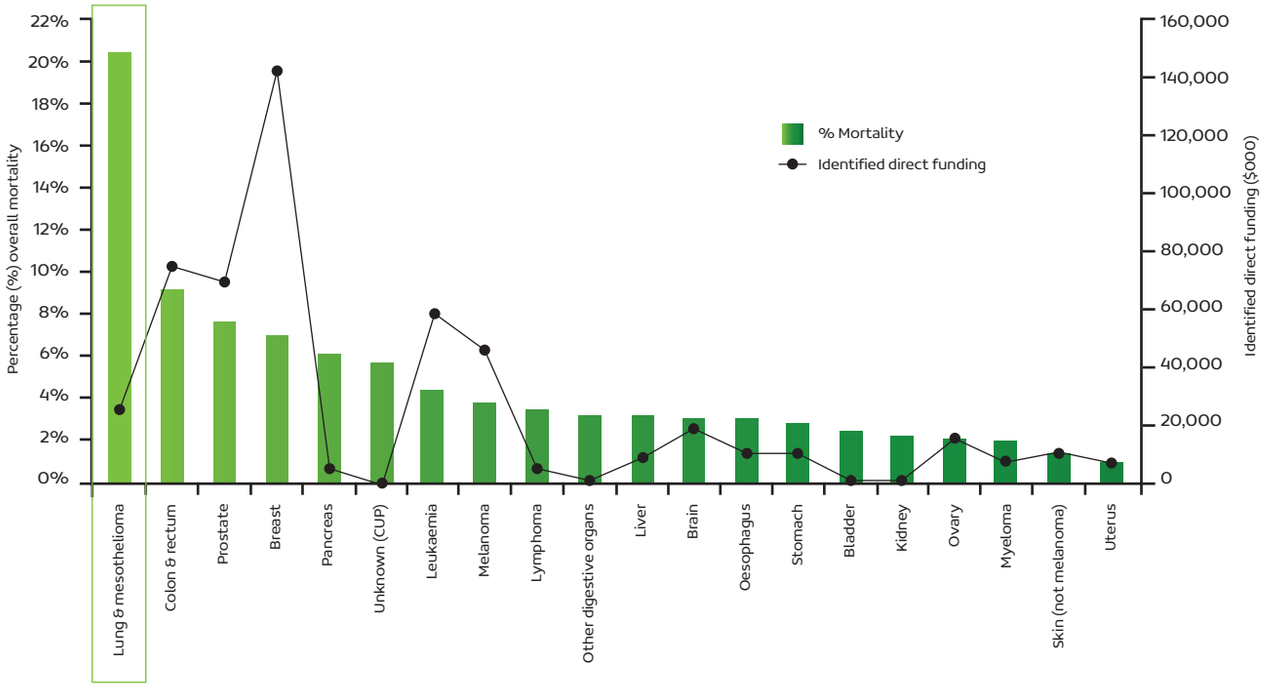
Objective: Increase research capacity to redress under resourcing of research into highly prevalent lung conditions

A key focus of this Action Plan is to increase knowledge about the prevention, diagnosis and management of lung conditions. This has a clear focus on translational and health services research and brings it in close alignment with the priorities of the Medical Research Future Fund (MRFF).

Building research capacity to redress under-resourcing of lung conditions research will offer significant opportunities to make immediate and longer-term improvements in health outcomes for people living with lung conditions. Research is underfunded in Australia, as demonstrated by Figure 2 which shows that lung cancer receives a disproportionately low level of research funding in Australia, despite causing the largest number of cancer deaths (Cancer Australia, 2014).

Research is essential to strengthening the knowledge base to effectively prevent, diagnose and manage lung conditions. Lung conditions have a major impact in Australia, both in terms of healthcare utilisation and lost quality of life for people with lung conditions and their carers, yet does not receive the investment and support warranted by its outcomes and relative to its burden.

Figure 2: Direct funding to tumour type-specific cancer research projects and research programs in Australia 2006 to 2011, compared with the top 20 cancers by mortality in Australia, 2010 (Cancer Australia, 2014).



Investing in the surveillance and monitoring of lung conditions is critical to systematically monitor the quality of health care, and to understand and monitor the epidemiology and burden of disease. This knowledge will inform clinical practice and guide health policy and strategies to improve the prevention, diagnosis and management of lung conditions.

'Olive's diagnosis brought more questions than answers, we have a name but little in the way of long term outcomes. There is not a lot of information about Surfactant Protein C (SP-C) Deficiency, which is associated with Interstitial Lung Disease, and due to the rareness of the condition; there are no clear guidelines, no protocols, and limited treatments. It would be great if we could get some more research.'

Rachel, Mother of Olive who lives with a rare lung condition

Lung conditions are complex, can span many life stages, and need to involve a range of different health professions to be managed well. Developing and testing integrated models of care with Multidisciplinary Teams (MDTs) will build on existing knowledge and learning about organisations and health professionals working together, sharing information and service delivery, and coordinating care to meet the needs of people with lung conditions and improve health outcomes.

Lung cancer screening is recommended by professional groups worldwide (Field et al., 2014; Moyer et al., 2013; Oudkerk et al., 2017) and has been implemented, with Medicare funding, in the US (Centers for Medicare & Medicaid Services, 2015). The 20% reduction in lung cancer deaths reported in screening trials (Aberle et al., 2011) is larger than any new treatment for lung cancer to date (Brims et al., 2016). Recent national and international data have demonstrated that it is possible to design a cost-effective lung cancer screening program, with most of the lung cancers detected at a stage where treatment would be potentially curative (Black et al., 2014; Field et al., 2016; PwC, 2018). Screening is not currently recommended in Australia (Community Care and Population Health Principal Committee, 2015), but a highly regarded large European study suggests marked reductions in mortality are achieved by Computerised Tomography (CT) screening of an at-risk population of 50 – 74 year olds (Kauczor et al., 2015; American College of Radiology, 2018). The results of an Australian study, funded by National Health and Medical Research Council (NHMRC) are awaited and should influence policy.

Outcomes

Lung health research and monitoring will contribute to the overarching outcomes of this Action Plan by delivering:

- Enhanced lung health research capacity in Australia
- Evidence to inform best-practice and strengthen the knowledge base
- Insights on integrated models of care.

Priority Area 6: **Recommended Actions**

Action	Implementation
6.1 Invest in ongoing surveillance to monitor the quality of healthcare and to understand and monitor the epidemiology and burden of lung conditions.	Provide five year sustainability funding for existing respiratory registries (bronchiectasis, severe asthma, and Idiopathic Pulmonary Fibrosis (IPF)) to monitor outcomes to enable benchmarking and improvement in quality of care, ensure burden of disease is understood and Australian data are integrated with high quality data internationally. Facilitate establishment of a national register for occupational lung disease with an expert steering committee to develop processes that ensure quality data entry, collation and analysis. Investigate the establishment of a process for mandatory notification of occupational lung diseases. Undertake a feasibility study for a national register for rare lung diseases. Ensure that respiratory conditions are included in the development of clinical quality registry frameworks and guidelines.
6.2 Build knowledge about the prevention, diagnosis and management of lung conditions.	Conduct and support research to generate new evidence and address gaps in current knowledge. Establish 10 x five year national lung research fellowships, with a focus on lung diseases with poorer outcomes and unmet need. Fund implementation research to drive the uptake of best evidence into routine patient care (e.g. acute oxygen use, pulmonary rehabilitation, prompt and accessible spirometry testing at time of first treatment decision). Ensure lung conditions are included within the mission of the MRFF funded genomics program. Ensure that respiratory conditions are included within the MRFF funding programs for clinical treatment trials.
6.3 Invest in research that develops and pilots best-practice models of care to achieve optimal outcomes for people with lung conditions across priority populations and geographic regions.	Invest in research that develops and pilots best-practice models of care to achieve optimal outcomes for people with lung conditions across priority populations and geographic regions, and share learnings across the health sector. Develop and fund innovative and accessible models of care for people living with lung conditions including telehealth, remote diagnostic support, virtual MDT meetings, and models of expanded scope of practice for existing health professionals (e.g. allied health clinical support roles) providing care to populations with unmet needs for access to lung condition care. Establish a national taskforce to investigate and plan for the successful implementation of low-dose CT lung cancer screening in the Australian context. Develop shared care between health professionals (e.g. pharmacists, physiotherapists, allied health, nurses and doctors), and implement evidence-based tools to support shared care amongst providers, integrated service models and transition between services.

Achieving Progress

Willing cooperation and effective collaboration across the lung health sector has been key to developing this Action Plan. It is proposed that this approach be continued for the life of the Action Plan and beyond through the establishment of a Steering Group and secretariat that will have oversight of implementation and facilitate relationships, drive action and monitor progress.

The design, development and implementation of a comprehensive monitoring and evaluation plan will be an integral aspect of this governance role. The evaluation and monitoring plan will be linked to the overarching goal and will report on progress towards:

- Addressing health determinants and risk factors for lung conditions to enhance the lung health of the Australian community
- Optimising quality of life for people with lung conditions
- Redressing areas of poorer health outcomes and unmet need
- Action at the wider health-system level to ensure real and lasting improvement for all Australians
- Delivering tangible improvements in health outcomes, equity and economic benefits.

Annual progress checks together with a mid-term and final review will provide essential data on:

- Elements of the Action Plan that had been initiated, funded and the implementation commenced
- Any **outputs** or changes directly or indirectly attributable to the Action Plan such as evidence based resources and programs, guidelines and standards of care, workforce planning, policies, regulations and legislation and partnerships
- **Changes** in consumer and health professional knowledge, attitudes and behaviours
- Measurable **outcomes** of the Action Plan including increased access to services, improved quality of life, improved physical and mental health and wellbeing and reductions in the social and economic burden of lung conditions.

The overarching **outcomes** of this Action Plan include:

- Improved quality of life among people with lung conditions and their families
- Reduced prevalence of lung conditions
- Reduced lung condition-related deaths and premature deaths (Indigenous and non-Indigenous)
- Earlier diagnosis and improved self-management strategies
- Reduced variation in care and clinical outcomes
- Reduction in hospitalisations, including presentations to emergency
- Reduced disparity in health outcomes due to lung conditions between Aboriginal and Torres Strait Islander people and non-Indigenous Australians
- Reduced disparity in health outcomes due to lung conditions between people living in regional, rural and remote areas and metropolitan areas
- Reduced social and economic burden of lung conditions to individuals, families, the healthcare system and government, including impact on workforce productivity.

Additional measures will be developed to monitor progress against key initiatives and areas of work.

This plan will also address the more focused objectives set out under each priority area enabling regular review and the modification of actions based on evaluation. These include:

- Prevent lung conditions and reduce the risk of lung disease
- Raise awareness about lung conditions and reduce stigma, discrimination and social isolation
- Translate science into quality diagnosis, management and care of lung conditions
- Support people with lung conditions to participate in shared decision making and self-management
- Ensure equitable and timely access to evidence-based diagnosis and management of lung conditions
- Increase research capacity to redress under resourcing of highly prevalent lung conditions.

Development of the National Strategic Action Plan for Lung Conditions was led by Lung Foundation Australia with funding from the Australian Government Department of Health.

Development of the Action Plan took place during 2018. Many individuals and organisations contributed time and expertise to the development of the Plan, including people with lung conditions and their families, health professionals, key medical and respiratory organisations, the research community and health departments within the Australian Government and State and Territory Governments.

The Lung Foundation sincerely thank the members of the Advisory Group, and all of those who participated in the extensive consultation and development phase.

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Ms. Judy Powell	Advocacy and Policy Manager, Lung Foundation Australia
Ms. Maree Davidson	Director, Davidson Consulting (Strategy)
Ms. Rebecca Zosel	Director, Zosel Consulting (Principal Writer)

Appendix 1: Glossary

A list of key terms used in this Action Plan are provided below in alphabetical order. A number of definitions were sourced from the American COPD National Action Plan (National Heart Lung and Blood Institute, 2017).

Access to care means having the timely use of health care services to achieve the best health outcomes.

Care continuum is a concept involving an integrated system of care that guides and tracks a patient over time through a comprehensive array of health services.

Chronic conditions is often used interchangeably with 'chronic diseases', 'noncommunicable diseases', and 'long-term health conditions'. Chronic conditions (Australian Health Ministers' Advisory Council, 2017a):

- Have complex and multiple causes
- May affect individuals either alone or as comorbidities
- Usually have a gradual onset, although they can have sudden onset and acute stages
- Occur across the life cycle, although they become more prevalent with older age
- Can compromise quality of life and create limitations and disability
- Are long-term and persistent, and often lead to a gradual deterioration of health and loss of independence and while not usually life threatening, are the most common and leading cause of premature mortality.

Comorbidity describes two or more disorders, conditions or illnesses occurring in the same person. They can occur at the same time or one after the other. Comorbidity also implies interactions between the illnesses that can worsen the course of both.

CT scan is a Computerised Tomography scan that uses X-rays to create a picture of the body.

Culturally appropriate services are broadly defined as care and services that are respectful of and responsive to the cultural and linguistic needs of all individuals.

Determinants of health are factors which interact and influence knowledge, attitudes and beliefs, social norms and expectations, and means and opportunities – which can ultimately impact health. The determinants of health are many and varied, they operate at every life stage and interact to raise or lower the health status of individuals and populations.

A **disability** is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities and interact with the world around them.

Disability-adjusted life years, or DALYs, is a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability or early death.

Discrimination happens when a person, or a group of people, is treated less favorably than another person or group because of their background or certain personal characteristics, such as disease or disability including lung condition, age, race and sexual orientation.

Disparities refer to great differences in health outcomes between populations. Race or ethnicity, gender, sexual identity, age, disability, socioeconomic status, and geographic location all contribute to an individual's ability to achieve good health.

Evidence-based practice(s) are the conscientious, explicit, and judicious use of current best evidence when making decisions about the care of patients with lung conditions. This involves integrating individual clinical expertise with the best available external clinical evidence from systematic research.

Healthcare cost: direct vs. indirect Direct costs are those costs borne by the healthcare system, community, and patients' families in addressing an illness. Indirect costs are mainly productivity losses to society caused by the health problem or disease.

Health determinants are factors which influence health. Many factors combine together to affect the health of individuals and communities. The determinants of health include the social and economic environment, the physical environment, and the person's individual characteristics and behaviours.

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

Latency period refers to the time that passes between being exposed to something that can cause disease (such as radiation or a virus) and having symptoms (National Cancer Institute, 2018).

Lungs are the two spongy organs in the chest cavity, made up of large numbers of tiny air sacs. The lungs are used for respiration (breathing).

Lung condition(s) is a general term used to describe a large group of conditions that affect and impair the function of the airways and lungs. Lung conditions are sometimes referred to as lung disease, airways disease, respiratory disease or pulmonary disease. There

are over 30 types of lung conditions, including lung cancer, Chronic Obstructive Pulmonary Disease (COPD), bronchiectasis and respiratory infection. Lung conditions cause symptoms such as difficulty breathing, coughing and tiredness.

Lung health aims to achieve a state of wellbeing by keeping people free from lung conditions and minimising the impact of existing conditions.

Lung function tests, or Pulmonary Function Tests, measure how well the lungs work. They include tests that measure lung size and air flow, such as spirometry and lung volume tests. Other tests measure how well gases, such as oxygen, get in and out of the blood. These tests include pulse oximetry and arterial blood gas tests. Another pulmonary function test, called Fractional exhaled Nitric Oxide, measures nitric oxide, which is a marker for inflammation in the lungs. One or more of these tests may be used to diagnose lung and airway diseases, compare lung function to expected levels of function, monitor if a patient's disease is stable or worsening, and see if a treatment is working.

Mortality rate is a measure of the frequency of occurrence of death in a defined population during a specified interval.

A **multidisciplinary team**, often abbreviated as MDT, involves a range of health professionals working together to deliver comprehensive patient care. Collaborative teams vary according to patients' needs, patient load, organisational constraints, resources, clinical setting, geographic location, and professional skills.

Palliative care an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. "Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications." (World Health Organization, 2017)

Patient navigators are proposed as a core part of the MDT that care for people with lung conditions. Patient navigators will coordinate and case manage patients and families affected by lung conditions, with a focus on priority populations.

Patient registries are organised systems that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure and that serves predetermined scientific, clinical, or policy purpose(s).

Patient-centred care is defined as health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences, and that patients have the education and support they need to make decisions and participate in their own care. 'Patient-centred care' is often used interchangeably with 'person-centred care'.

People living with conditions is used to encompass people with lung conditions and their carers, families and people who care about them. This reflects a socially and culturally inclusive approach to lung health, and recognises that healthcare and wellbeing is a family and community matter, not an individualistic, clinical issue.

Person-centred care focuses on developing relationships and plans of care collaboratively between staff and patients. Person-centred care values the needs of patients, carers and staff, with emphasis on the reciprocal nature of all relationships. 'Person-centred care' is often used interchangeably with 'patient-centred care' (ACSQHC, 2011).

Prevalence is the proportion of a population which has (or had) a specific characteristic in a given time period – in medicine, typically an illness, a condition, or a risk factor, such as depression or smoking.

Appendix 1

Prevention involves action at the primary, secondary and tertiary levels to prevent disease. In the case of lung conditions, primary prevention strategies that aim to limit the incidence of disease and disability in the population are focused on reducing or avoiding exposure to common risk factors (e.g. tobacco smoke and occupational hazards) and fostering protective factors (e.g. physical activity). Additionally, there is a strong focus on secondary prevention (early detection/ intervention) and tertiary prevention (reducing the progression of the disease and improving the individual's quality of life) strategies.

Priority populations are defined as populations that are disproportionately affected by lung conditions. Some populations are disproportionately affected due to a complex interaction between the physical environment, social and cultural determinants and biomedical and behavioural risk factors. This is demonstrated by a higher prevalence of lung conditions and a greater burden of disease, resulting in inequitable health outcomes (Australian Health Ministers' Advisory Council, 2017a).

Pulmonary rehabilitation is a broad program that helps improve the well-being of people who have chronic (ongoing) breathing problems. The program includes exercise and education and benefits people who have lung cancer, COPD, sarcoidosis, Idiopathic Pulmonary Fibrosis, or cystic fibrosis.

Respiratory system is the system of the body responsible for breathing.

Risk reduction is a key component of disease prevention. In the case of lung conditions, reducing or avoiding exposure to common risk factors (e.g. tobacco smoke and occupational hazards) is a core disease prevention strategy.

Self-management can be defined as the decisions and behaviours that patients with lung conditions engage in that affect their health. Self-management support is the care and encouragement provided to people with lung conditions and their families to help them understand their central role in managing their illness, make informed decisions about care, and engage in healthy behaviours. Self-management support can assist and empower people to learn more about their conditions and to take an active role in their health care.

Social isolation is a state of complete or near-complete lack of contact between an individual and society. It differs from loneliness, which reflects a temporary lack of contact with other humans. Social isolation can have significant adverse impacts on individuals' mental health and wellbeing, community cohesion and civic engagement.

Socio-economic disadvantage is often defined in terms of people's access to material and social resources as well as their ability to participate in society. Socio-economic disadvantage is often measured using socio-economic Indexes for Areas (SEIFA), a product developed by the Australian Bureau of Statistics (ABS) that ranks areas in Australia according to relative socio-economic advantage and disadvantage.

Spirometry is a lung function test that measures the rate of air flow and estimates lung size. For this test, a person breathes multiple times, with regular and maximal effort, through a tube that is connected to a computer. Some people feel lightheaded or tired from the required breathing effort.

Supportive care is care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment. 'Supportive care' is often used interchangeably with 'palliative care' (National Cancer Institute, 2018).

Surveillance is defined as an ongoing, systematic collection, analysis and interpretation of health-related data essential to the planning, implementation, and evaluation of public health practice.

Stigma is a perceived negative attribute that causes someone to devalue or think less of the whole person. In the case of lung conditions, stigma is a mark of disgrace from the predominate view that lung diseases are self-inflicted and smoking-related. When a person is labelled by their illness they are no longer seen as an individual but as part of a stereotyped group. Negative attitudes and beliefs toward this group create prejudice which leads to negative actions and discrimination.

Telehealth allows health professionals to examine, diagnose, and treat patients using technology like a phone, computer, or other device.

Appendix 2: Implementation Partners

Implementation partners will include organisations from across various sectors, operating at local, state, territory and national levels. Dependent on the priority and action, partners may be required to work in direct collaboration or in parallel. Partners need to include education providers and peak bodies, primary, secondary and tertiary healthcare providers, general practice, pharmacy, allied health and specialist colleges and representative bodies, researchers, advocates, industry groups, industry partners (where appropriate), the media, and policymakers and governments.

Below is a summary of identified partners who will be critical to collaboration and implementation of the Action Plan. These lists are indicative and not exhaustive as potential partners will continue to be identified. Lead partners for each action will need to be determined through the implementation planning process.

Patients, their families, partners, carers and community leaders Primary, secondary and tertiary healthcare providers Commonwealth and State and Territory Governments		
Health organisations, advocacy and support groups	• Lung Foundation Australia • Thoracic Society of Australia and New Zealand • Asthma Australia • National Asthma Council Australia • Cystic Fibrosis Australia • Patient/consumer peak body associations • Cancer Council Australia • Australian Centre for Airways disease Monitoring	• Primary Health Networks (PHNs) • Local Hospital Networks (LHNs) • Local/regional health prevention and promotion networks • NPS MedicineWise • Cancer Australia • Healthdirect Australia • Australian Dust Diseases Coalition • Advance Care Planning Australia
Professional colleges and peak bodies	• National Aboriginal Community Controlled Health Organisations • Federation of Ethnic Communities Councils of Australia • Palliative Care Australia • Australian College of Rural and Remote Medicine • Royal Australian College of General Practitioners • Clinical Oncology Society of Australia • Royal Australian College of Physicians • Pharmaceutical Society of Australia	• Pharmacy Guild of Australia • Australian Association of Consultant Pharmacists • Australian Physiotherapy Association • Exercise and Sport Science Australia • Fitness Australia • Occupational Therapy Australia • Dietitians Association of Australia • Australian Primary Health Care Nurses Association • Australian College of Nursing • Australian Medical Association
Research Organisations	• Universities • Research institutes • NHMRC Centres of Research Excellence related to lung disease.	

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