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 and the accompanying document, Lung Conditions in Australia 2018 was led by Lung Foundation Australia with funding from the Australian Government Department of Health.

Diagrams are used with permission.

# **INTRODUCTION**

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. This document has been developed to be read in conjunction with the Action Plan and provides evidence on the:

* Health, social and economic impact of lung conditions
* Eight priority lung conditions
* Priority populations affected by lung conditions
* Six priority areas identified for action

The Action Plan addresses eight lung conditions that together make up much of Australia’s lung burden. This includes lung conditions where there continues to be an unmet need and people currently experience poor outcomes. The eight priority lung conditions highlighted in this document are:

* 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).

Many of the interventions will benefit all people with lung conditions including those people with asthma. Asthma, however, has not been identified as a priority condition in the Action Plan due to the existing policy response to improving asthma outcomes in Australia through the National Asthma Strategy 2018.

The Action 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 several **recommended actions** informed by evidence. The following table outlines the goal, six high-level priorities and 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. |
| 1. Awareness and Stigma | Raise awareness about lung conditions and reduce stigma, discrimination and social isolation. |
| 1. Diagnosis, Management and Care | Translate science into quality diagnosis, management and care of lung conditions. |
| 1. Partners in Health | Support people with lung conditions to participate in shared decision making and self-management. |
| 1. Equitable Access | Ensure equitable and timely access to evidence-based diagnosis and management of lung conditions. |
| 1. 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**

ABPA Allergic bronchopulmonary aspergillosis

AAT Alpha-1 antitrypsin

ACSQHC Australian Commission on Safety and Quality in Health Care

AIHW Australian Institute of Health and Welfare

CT Computerised tomography

CF Cystic Fibrosis

COPD Chronic Obstructive Pulmonary Disease

DALYs Disability Adjusted Life Years

EBUS Endobronchial ultrasound

FCTC Framework Convention on Tobacco Control

GOLD Global Initiative for Chronic Obstructive Lung Disease

IPF Idiopathic Pulmonary Fibrosis

ILD Interstitial lung diseases

LAM Lymphangioleiomyomatosis

MDT Multidisciplinary team

MRFF Medical Research Future Fund

OECD Organisation for Economic Co-operation and Development

PET Positron emission tomography

PH Pulmonary hypertension

PHNs Primary Health Networks

PPHs Potentially Preventable Hospitalisations

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.

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# **THE HEALTH, SOCIAL AND ECONOMIC IMPACT OF LUNG CONDITIONS**

Internationally, the World Health Organization (WHO) recently identified chronic respiratory disease as one of the four leading chronic conditions worldwide, along with cardiovascular disease, cancer and diabetes ([WHO, 2018](#_ENREF_59)). In Australia, lung conditions place a significant burden on individuals affected by the disease, our health care system, workforce and broader economy.

***Health impact***

Lung conditions are a common chronic condition that require care across the life course.

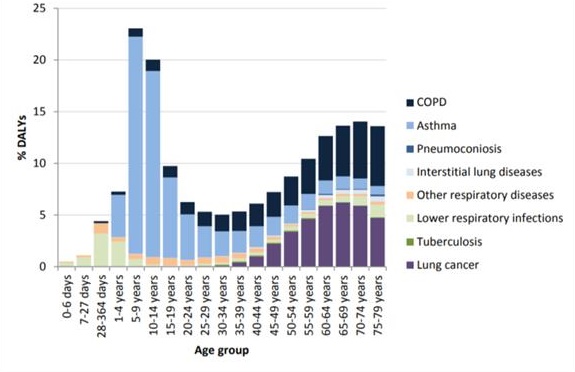
| In Australia, seven million people (one in three) live with a lung condition (AIHW, 2018a). |
| --- |

Lung conditions are a major contributor to ill-health, disability and premature mortality. Aboriginal and Torres Strait Islander people experience higher rates of lung conditions and worse outcomes compared with non-Indigenous Australians (Australian Health Ministers' Advisory Council, 2017a).

Lung conditions account for more than 10 per cent of the total health burden in Australia ([Poulos et al., 2014](#_ENREF_46)). The contribution of lung disease to overall burden is greatest in children and older adults as illustrated in Figure 1. Among infants most of the burden of lung disease is due to lower respiratory infections (pneumonia and bronchiolitis), in children, asthma and bronchiectasis are the major contributor, and in older Australians, lung cancer and chronic obstructive pulmonary disease (COPD) comprise the majority of the burden of lung conditions (Begg et al., 2008; Chang et al., 2010; [Poulos et al., 2014](#_ENREF_46)).

Among people with lung conditions in Australia, COPD contributes one-third of the burden ([Poulos et al., 2014](#_ENREF_46)).

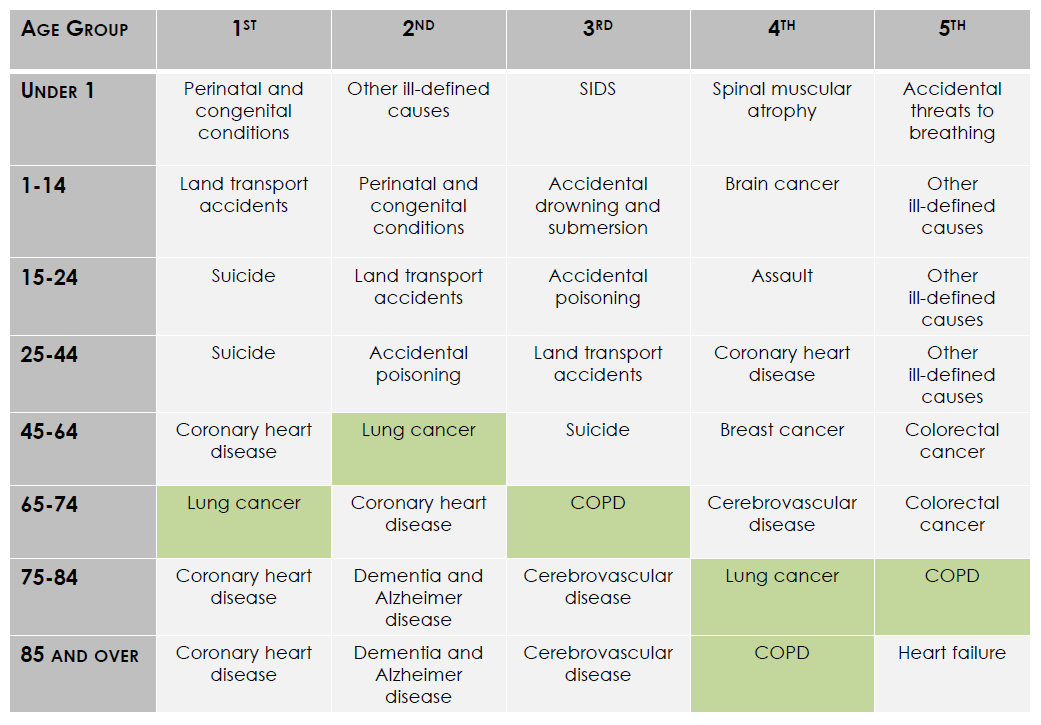
*Figure 1: Burden (Disability Adjusted Life Years, or DALYs) due to lung disease as a proportion of total DALYs, Australia, 2010, by age (*[*Global Burden of Disease 2010, 2014*](#_ENREF_28)*)[[1]](#footnote-1)*



| Lung conditions are Australia’s second leading cause of death ([AIHW, 2018](#_ENREF_6)b) |
| --- |

Lung conditions are our nation’s second leading cause of death, due largely to the high mortality rates of lung cancer and COPD in older Australians, as shown in Figure 2 ([AIHW, 2018](#_ENREF_6)a).

*Figure 2: Leading underlying causes of death, by age group, 2014–2016 (*[*AIHW, 2018*](#_ENREF_6)*a)*



Lung cancer is Australian’s biggest cancer killer with an estimated 9,020 deaths in 2017, more than breast (3,086), prostate (3,450) and ovarian (1,046) cancers combined (AIHW, 2017c). People living with lung cancer also have poor five-year survival (17%) when compared to the other four of the five most commonly diagnosed cancers (breast cancer 91%; bowel cancer 69%, prostate cancer 95%, melanoma 91%) (PwC, 2018).

***Social impact, including mental health and wellbeing***

In Australia many people struggle with chronic and serious lung conditions that have a major impact on their lives and the lives of their families.

| 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. |
| --- |

Lung conditions are often misunderstood and stigma is widespread, particularly in relation to lung cancer ([Ipsos MORI, 2011](#_ENREF_33), [Lung Foundation Australia, 2017b](#_ENREF_40), [Lung Foundation Australia, 2017a](#_ENREF_39), [Jarrett, 2015](#_ENREF_34)).

There are a variety of risk factors such as exposure to toxic substances, pollution, smoking, and family history that may contribute to the development of lung cancer. While smoking is prominent amongst these risk factors, approximately one fifth (21%) of people living with lung cancer are life-long non-smokers (Cancer Australia, 2014a). Despite this, 90% of Australians believe smoking is the only lung cancer risk factor (Lung Foundation Australia, 2017b).

Australians have the least sympathy for someone diagnosed with lung cancer, compared to other cancers, based on its association with tobacco smoking ([Ipsos MORI, 2011](#_ENREF_33)). Over a third (35%) of Australians consider those with lung cancer to be their “own worst enemy” ([Lung Foundation Australia, 2017b](#_ENREF_40)).

In Australia, over 40% of people with lung conditions feel stigma from the view that lung diseases are self-inflicted and smoking-related, and many feel isolated and shame, guilt or fear of being discriminated against ([Lung Foundation Australia, 2017a](#_ENREF_39)).

Lung conditions have a substantial impact on the mental health and wellbeing of those affected. Anxiety and depression are common, and are associated with worse quality of life, self-management and exercise performance, and with increased medical symptom reporting, exacerbations, hospitalisations, length of hospitalisations, medical costs, and mortality ([Yang](#_ENREF_42) et al., 2018).

Approximately half of all people living with lung cancer have anxiety and/or depression (Chambers et al., 2015). In 2018, it is estimated that about 6,200 newly diagnosed people living with lung cancer will develop anxiety and depression. This means that approximately 131,400 people living with lung cancer may experience anxiety and depression over 10 years to 2028 (PwC, 2018).

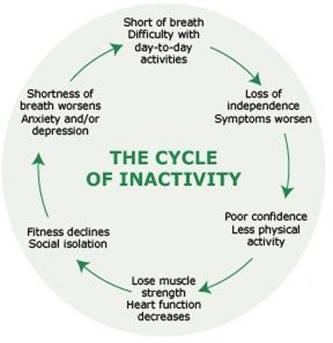
COPD is a disabling condition, which can lead to increased dependency and social isolation. Having COPD has been linked with depression ([Van Manen et al., 2002](#_ENREF_57)), panic attacks ([Mikkelsen et al., 2004](#_ENREF_43)), and a general fear of becoming breathless when undertaking activities ([Smoller et al., 1996](#_ENREF_51)).

| People with COPD have a prevalence of panic disorder approximately 10 times greater than the general population, and commonly experience panic attacks ([Yang](#_ENREF_42) et al., 2018). |
| --- |

The losses and changed life experienced by people living with COPD and other lung conditions may result in lowered self-esteem and a need to re-evaluate self-identity ([Scharloo et al., 1998](#_ENREF_50)). This has broader implications for family members and carers as well as patients ([Kanervisto et al., 2007](#_ENREF_35)). For example, an individual may be required to cease employment, which may have an effect on their sense of self-worth. More broadly other consequences may include the impact on family finances because of the loss of income. There is an increased need for carers to provide not only social support but, as disease progresses, increasing levels of physical support, and this may have implications for the carer’s earning capacity.

The cycle of inactivity (Figure 3) shows how people living with COPD may find it difficult to continue their normal exercise routine, and how this can result in other social impacts ([Cooper, 2009](#_ENREF_22)).

*Figure 3: The cycle of inactivity for people with COPD and other lung conditions (Cooper, 2009).*



***Economic impact***

| Lung conditions pose a substantial economic burden on people with these conditions and their families, the health care system and the broader economy. |
| --- |

In 2008 it was estimated that lung disease cost the country $9 billion in treatment and lost productivity. Additionally, the overall value of loss of wellbeing due to COPD was estimated at a further $89.4 billion ([Access Economics Pty Limited, 2008](#_ENREF_2)).

Lung conditions have a marked effect on the working population and their ability to be active and productive ([Fletcher et al., 2011a](#_ENREF_23), [Fletcher et al., 2011b](#_ENREF_24)). For example, COPD is a major economic burden for countries throughout the world, and a leading threat to productivity ([Fletcher et al., 2009](#_ENREF_25)). Many people with COPD struggle to remain in active employment and are forced to give up work or retire prematurely because of COPD (Fishwick et al., 2010; [Fletcher et al., 2011b](#_ENREF_24)). An international study which estimated the burden of COPD across 12 countries showed the proportion of people prevented from working due to their COPD ranged from 6% (Italy) to 52% (USA and UK) with 8 countries reporting this to be greater than 20% (Foo et al., 2016).

Lung conditions are a major contributor to health care utilisation in Australia. Respiratory conditions are the second most common health issue managed by General Practitioners (GPs) ([The Royal Australian College of General Practitioners, 2018](#_ENREF_53)). COPD is a common lung condition and the leading cause of potentially preventable hospitalisations (PPHs) (AIHW, 2018c).

Recent data on the cost of lung cancer in Australia shows that the economic burden of lung cancer for patients diagnosed in 2018 is estimated to reach:

* $253.3 million in direct costs, including treatment costs, out-of-hospital costs and out-of-pocket expenses
* $13.5 million in indirect costs, including absenteeism resulting from the additional time off work taken by people with lung cancer because of their illness ([PwC, 2018](#_ENREF_47)).

People with lung cancer die earlier (prematurely) by an average of 11 years compared to the general population ([OECD, 2018](#_ENREF_45); [AIHW, 2017](#_ENREF_5)a). It is estimated that this amounts to approximately 137,600 years of life lost in 2018 ([PwC, 2018](#_ENREF_47)).

# **PRIORITY LUNG CONDITIONS**

This Action Plan identifies priority lung condition areas that together make up much of Australia’s lung burden, based on the large numbers of people affected, and inequities in health status and outcomes for Aboriginal and Torres Strait Islander people and other priority population groups. In addition, the Action Plan provides an opportunity to pay attention to some under-recognised and rare conditions where the impact is significant.

The eight priority lung condition areas are:

* Lung cancer
* Chronic Obstructive Pulmonary Disease (COPD)
* Bronchiectasis
* Respiratory infection
* Interstitial lung diseases (ILD)
* Occupational lung disease
* 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 below.

## Lung cancer

Lung cancer is a collection of abnormal cells or a malignant tumour which grows in an uncontrolled way in one or both of the lungs, often blocking an airway and spreading in the lung tissue.

Active and passive smoking are the causes of most lung cancers, but it can also be caused by exposure to asbestos, radiation and air pollution. One in three women and one in 10 men diagnosed with lung cancer have no history of smoking ([Barton et al., 2009](#_ENREF_14)). The risk of developing lung cancer increases with age, and many who develop it have given up smoking much earlier. Lung cancer rates and trends largely reflect smoking patterns and prevalence from 30-40 years ago.

Lung cancer is often diagnosed late because symptoms can be nonspecific. There is also no routine screening in Australia for early detection. Most likely, there will be a range of medical tests which need to be performed to confirm the type of lung cancer, the size of the tumour and whether it has spread outside of the lungs.

Some patients can have curative surgery if the tumour is diagnosed early. Otherwise, there is currently no cure for lung cancer, but there are treatments available that can help extend a patient’s life and improve their quality of life, including targeted therapies, immunotherapy, radiotherapy and chemotherapy.

Lung cancer survival has improved a little, but still remains low ([Australian Centre for Asthma Monitoring, 2011](#_ENREF_8)). Lung cancer causes more deaths than any other cancer in Australia - more than breast, prostate and ovarian cancers combined ([AIHW,](#_ENREF_38) 2017c).

The stigma surrounding lung cancer due to its association with tobacco smoking is a major barrier to accessing research, funding, treatment and support.

The latest global cancer data shows lung cancer is the most commonly diagnosed cancer worldwide, and is also responsible for the largest number of deaths due to the poor prognosis for this cancer ([AIHW, 2011](#_ENREF_11)).

In Australia:

* 12,740 people were diagnosed with lung cancer in 2018. That’s 34 people a day (AIHW, 2018d). Reliable national data on the incidence of cancer for Aboriginal and Torres Strait Islander people are not available ([International Agency for Research on Cancer, 2018](#_ENREF_32)).
* One Australian dies every hour from lung cancer ([AIHW,](#_ENREF_37) 2018d). The mortality rate is significantly higher for Aboriginal and Torres Strait Islander people than for non-Indigenous Australians ([AIHW, 2011](#_ENREF_11)).
* Lung cancer is the most commonly diagnosed cancer among Aboriginal and Torres Strait Islander people ([Lung Foundation Australia, 2017b](#_ENREF_40)).
* Lung cancer has one of the lowest survival rates of any cancer in Australia: 11% of males and 15% of females are alive 5 years after their diagnosis ([AIHW, 2011](#_ENREF_11)).
* The incidence rate of lung cancer over the past 25 years has fallen in males (decreased by 32%) but risen in females (increased by 72%), which reflects historical differences in smoking behaviour ([Haigh et al., 2018](#_ENREF_31)).
* The number of hospitalisations for lung cancer is increasing. Lung cancer was responsible for one in 19 cancer-related hospitalisations and one in 187 hospitalisations for all causes in Australia in 2008-09 ([AIHW, 2011](#_ENREF_11))
* Stigma is rife. In a global survey conducted in 15 countries, Australians had the least sympathy for someone diagnosed with lung cancer, compared to other cancers, based on its association with tobacco smoking ([AIHW, 2011](#_ENREF_11)). Over one third (35%) consider those with lung cancer to be their “own worst enemy” and one in ten will say they ‘got what they deserved’ ([AIHW](#_ENREF_11), 2011).

## **Chronic Obstructive Pulmonary Disease (COPD)**

Chronic Obstructive Pulmonary Disease (COPD) is a common, preventable and treatable disease that is characterized by persistent respiratory symptoms and airflow limitation that is due to airway and/or alveolar abnormalities usually caused by significant exposure to noxious particles or gases ([Ipsos MORI, 2011](#_ENREF_33)). It includes emphysema and chronic bronchitis. Most cases of COPD are caused by smoking, and most people diagnosed are over the age of 40. A small number of COPD patients have a rare genetic condition, Alpha-1 antitrypsin (AAT) deficiency, which causes emphysema. Spirometry (measuring the lung capacity) is the most important test to diagnose and monitor COPD.

In a person with COPD the airways are permanently partly blocked, making it hard to breathe. Symptoms include shortness of breath, cough and phlegm or mucus. COPD progresses over time and is often undiagnosed until late in the disease. Symptoms tend to come on gradually over many years and people who unknowingly have COPD may mistake their symptoms as signs of ageing, lack of fitness or asthma.

COPD is not curable, but it can be managed and treated to reduce symptoms and exacerbations. There are things that people can do to be more active, breathe more easily, keep out of hospital and improve their quality of life. This includes stopping smoking, correct use of medicines and pulmonary rehabilitation ([GOLD, 2018](#_ENREF_29)). Pulmonary rehabilitation is an exercise and education program that takes place over several weeks. It helps people to learn about their condition and be more confident about managing it, and to participate in more social and physical activities.

In Australia:

* Approximately 1.45 million Australians have COPD ([Toelle et al., 2013](#_ENREF_54))
* one in seven people over the age of 40 has COPD and many don’t know it ([Yang](#_ENREF_42) et al., 2018)
* COPD is the most common potentially preventable hospitalisation (AIHW, 2018c)
* Despite falling death rates, COPD is still a leading cause of death and disease burden after heart disease, stroke and cancer ([Toelle et al., 2013](#_ENREF_54))
* Aboriginal and Torres Strait Islander Australians have approximately 2.5 times the rate of COPD as other Australians ([National Health Performance Authority, 2015](#_ENREF_44))
* In 2008, COPD cost the economy an estimated $98 billion ([Access Economics Pty Limited, 2008](#_ENREF_41)).

## **Bronchiectasis**

Bronchiectasis is a common lung condition caused by chronic infection in small airways that results in some parts of the lung becoming damaged, scarred and dilated, allowing infected mucus to build up in dilated, damaged airways. Bronchiectasis often results in a chronic cough, producing mucus, and shortness of breath.

The most common cause of bronchiectasis is severe pneumonia, particularly in childhood. It is a condition that often presents with other common lung conditions such as asthma and COPD. Although the causal relationship between these conditions is complex, it is known that the prevalence of bronchiectasis appears to be increased in people with severe forms of COPD (Du et al., 2016; Lonni et al., 2015; Ni et al., 2015; Olveira et al., 2017). Other common causes include immune deficiencies and cystic fibrosis (CF).

Correct diagnosis of bronchiectasis can be delayed by years or even decades in both children and adults, and it is likely that many remain undiagnosed and untreated, putting these people at risk of recurrent infections, lung damage and accelerated lung decline ([AIHW, 2015](#_ENREF_12)).

Early diagnosis and treatment are important to lessen the lung damage. The diagnosis of bronchiectasis is nearly always made using a computerised tomography (CT) scan, as a chest x-ray may not always show changes suggestive of bronchiectasis. Once a person has bronchiectasis they usually have it for life, though there is some evidence that it is possible to stop the disease getting worse − or even reverse it − in children ([Access Economics Pty Limited, 2008](#_ENREF_2)).

Good care helps people with bronchiectasis to stay as well as possible. Treatment aims to decrease airway blockage and reduce the load of infected mucus in the airways, making it easier to breathe. This includes sputum clearance once or twice a day to clear the lungs, using antibiotics and medicines, chest physiotherapy, and exercise such as pulmonary rehabilitation.

In Australia:

* Bronchiectasis is a common condition, however there is little information available on the overall Australian prevalence or incidence ([Chang et al., 2010](#_ENREF_17)).
* Bronchiectasis is a major contributor to chronic respiratory morbidity in less-affluent populations, both indigenous ([The Asthma and Respiratory Foundation of New Zealand, 2015](#_ENREF_52)) and non-indigenous ([Poulos et al., 2014](#_ENREF_46), [Chang et al., 2008](#_ENREF_18), [Bilton, 2008](#_ENREF_15)).
* In Aboriginal and Torres Strait Islander communities in Australia bronchiectasis is a significant problem. The prevalence of childhood bronchiectasis in the central-Australian Indigenous population is estimated to be 14 per 1,000 Indigenous children ([Twiss et al., 2005](#_ENREF_55)).
* Over recent years, bronchiectasis has increased as a cause of death in Australia. There were 381 deaths due to bronchiectasis in 2016 ([King et al., 2005](#_ENREF_36))
* The hospitalisation rate for bronchiectasis was 23.2 per 100,000 in 2011-12 ([Chang et al., 2002](#_ENREF_19)).

## **Respiratory infection**

Respiratory infection covers a range of acute episodic events which affect the respiratory system, with the most common being pneumonia, influenza and the common cold.

**Pneumonia**

Pneumonia is a common and potentially fatal lung infection. One of the most life threatening types is Pneumococcal Pneumonia.

Pneumococcal pneumonia can affect anyone, but those at a higher risk include older Australians aged 12 months and over, tobacco smokers, Aboriginal and Torres Strait Islander people, infants aged 12 months and under, and people with medical conditions such as diabetes, cancer or a chronic condition affecting the lungs, heart, kidney or liver.

Symptoms of pneumonia include difficulty breathing, cough, fever, fatigue and chest pain.

Pneumonia is easily spread through sneezing and coughing. The infection can develop in just one to three days. Treatment can include hospital admission, plenty of fluids, antibiotics, and rest. In Australia, there are over 77,500 pneumonia hospitalisations each year (Poulos et al., 2014), and the average stay rises with age – from six days for those under 65 years to 13 days for those 65 years and over (ANZSGM, 2016).

One of the most common types of bacterial pneumonia is pneumococcal pneumonia, caused by infection with *Streptococcus pneumoniae*. There are vaccines against this strain that reduce the risk of infection.

**Influenza**

Influenza is a viral disease that infect the nose, throat, and lungs. It spreads through droplets in the air when people with influenza cough, sneeze or talk, and by hand to hand contact. While often called the “flu”, the common cold is rarely due to the influenza virus. True influenza causes a much more severe illness than the usual cold.

Influenza causes widespread illness every year. Flu symptoms such as sore throat, fever, headache, muscle and joint pain, cough, nasal congestion, fatigue, vomiting and diarrhoea often appear suddenly. Influenza can be severe or even fatal. People with chronic lung conditions are at higher risk of complications.

Immunising people who are at risk of complications from the flu is the most important way to reduce the number of flu infections and deaths. Influenza immunisation is recommended for people in known high-risk groups. People in high-risk groups should be vaccinated with a new vaccine each year since yearly vaccination has been found to be effective in preventing severe symptoms. Uptake of these vaccinations, while better in people with COPD or asthma than in those without these conditions, is not at 100%, as recommended in the guidelines (AIHW, 2012).

It is estimated that each year influenza causes an average of 13,500 hospitalisations and more than 3,000 deaths among Australians aged over 50 years, which suggests more than double the number of deaths from motor vehicle accidents can be attributed to complications from influenza. The highest rates of hospitalisation are seen in children under 5 and the elderly (Healthdirect, 2018).

**The common cold**

The common cold is a viral infection and the most common contagious disease in Australia. It is the most cited reason for absence from school or work, and the commonest reason for a visit to a family doctor. The virus that causes the common cold and several related viruses also cause many exacerbations of asthma and COPD.

Cold viruses usually infect the nose, throat and lungs with little or no fever. Over 100 different viruses can cause a common cold. There is often more than one strain circulating in the community at any one time.

Cold viruses are spread from person to person in the small drops produced during coughing and sneezing. They can also be passed by hand to hand contact and by contact with many objects in everyday life on which the virus can survive for a few hours after hands touch infected noses and eyes.

Over half of Australians catch a cold in winter and over a quarter catch one in the spring. School children and people working in hospitals may experience from six to twelve colds a year. Parents or families with young children in day care, pre-school and primary school get about six colds a year. Older adults who are not in contact with children may have two or three colds a year.

Individuals differ in the number of symptoms they have. Cold symptoms usually appear from one to four days after the virus enters the body. The cold can be spread to others even before any symptoms appear. Symptoms usually begin with an itchy or sore throat. This is followed by a stuffy blocked nose, sneezing and watery eyes. Within two days, other symptoms may develop including a runny nose, husky voice, muscle aches and pains and headache. Fever occurs in children but is rare in adults. Symptoms then gradually improve.

Colds can lead to other illnesses, such as bacterial infections in the ears, sinuses, airways and lungs. People with other lung problems such as asthma, COPD, bronchiectasis and CF are at considerable risk of exacerbations when they develop a cold.

## **Interstitial lung diseases (ILD)**

A large group of different diseases can damage the interstitium and together these diseases are termed “interstitial lung disease”. The “interstitium” is the tissue through which oxygen from the lung’s tiny air sacs (the alveoli) passes to enter the lung’s small blood vessels (capillaries). It also provides a framework to maintain the lung’s shape. When the interstitium is damaged, the major effect is to reduce the lung’s normal ability to deliver oxygen to the bloodstream. ILD can distort the lungs’ shape, generally making them smaller and stiffer, and change the shape of the airways that pass through damaged areas of lung.

ILD can occur at any age, in both men and women. They are not contagious and are only rarely handed down from one generation to the next. There are several well-recognised types that have known triggers, but other types have no known cause, and are the subject of intense research to understand more about them.

A common symptom is breathlessness, initially only during exertion, but with more advanced disease, it occurs even during rest. People with ILD often also suffer cough, particularly when the ILD pattern is based around the lungs’ airways. Although these symptoms vary amongst individuals, they can be severe and disabling, particularly when people also suffer from anxiety or depression, each of which are common in ILD.

Common types of interstitial lung disease:

* ILD limited to the lung
  + Idiopathic pulmonary fibrosis
  + Other idiopathic interstitial pneumonias
* ILD caused by diseases that can affect other parts of the body
  + ILD associated with systemic diseases /connective tissue diseases – e.g., rheumatoid arthritis, scleroderma, sarcoidosis
* ILD associated with known triggers
  + Hypersensitivity pneumonitis – e.g. bird fancier’s lung, farmer’s lung
  + Asbestosis
  + Silicosis
  + Medication-induced lung disease.

**Idiopathic Pulmonary Fibrosis**

In Idiopathic Pulmonary Fibrosis (IPF) the tissue around the air sacs (alveoli) within the lungs become thickened and scarred – this is called fibrosis. This scarring makes the lungs stiff which makes it increasingly difficult to breathe. This slows the efficient delivery of oxygen into the bloodstream where it is needed to be transported to the rest of the body. The reason for the scarring in IPF is not known. This is why the disease is called idiopathic, which means “no known cause.”

Although IPF can affect people of any age, it typically affects middle aged to older people and is more common in men than women.

Early in the disease, symptoms can be very mild, which can make it difficult to detect. This can often lead to a delayed diagnosis. Common symptoms are shortness of breath, a cough that doesn’t get better and some people may produce clear phlegm. Other symptoms are reduced exercise capacity, feeling tired and gradual unintended weight loss.

Each person experiences IPF differently. Some people can remain stable for many years; others may decline rapidly; and others have a series of distinct ‘steps’ of suddenly feeling worse, followed by a period where their symptoms become stable. As the scarring is progressive and irreversible, all people with IPF decline over time.

In Australia, there is a conservative estimate of approximately 1,250 people being diagnosed with IPF each year, however currently it is not known exactly how many people are affected.

**Pulmonary hypertension**

Pumonary hypertension (PH) is a progressive condition that affects the vascular system of the lungs. In this condition the tiny arteries, arterioles and capillaries become narrowed, blocked or destroyed. This makes it harder for blood to flow through the lungs and raises pressure with the arteries of the lungs making the heart work harder, eventually causing the heart muscle to weaken and fail.

PH is associated with over 40 other chronic conditions including COPD, pulmonary fibrosis and sleep disorders. The condition is classified into five clinical groups and due to an evolving definition, the incidence and prevalence of the disease, it is difficult to define. Estimates of PH from one observational study in Armadale and surrounds in Western Australia showed a prevalence of 326 per 100,000 people (Strange 2012).

Symptoms of PH tend to worsen gradually over time, reducing exercise capacity and increasing breathlessness. Other symptoms include fatigue, dizziness or fainting spells, chest pain, swelling, bluish colour to lips or skin and racing pulse or heart palpitations. Due to the nature of the development of the condition, it is frequently under-diagnosed, however, data from international registries suggest that there is an increased awareness of the condition.

## **Occupational lung disease**

Occupational lung diseases are an important and under-recognised cause of respiratory ill health in Australia (Hoy & Brims, 2017). These disorders are preventable and are an increasingly treatable cause of much sickness, disability and death. In addition to the traditional “dust diseases”, occupational lung disease encompasses a wide spectrum of disorders, including:

* Asbestosis
* Malignant mesothelioma
* Coal workers’ pneumoconiosis (Black Lung)
* Occupational asthma
* Work-exacerbated asthma
* Occupational COPD
* Diffuse dust fibrosis
* Occupational lung cancers (e.g. from asbestos, arsenic, diesel exhaust)
* Hypersensitivity pneumonitis (e.g. Farmer’s lung)
* Bronchiolitis obliterans
* Occupationally acquired infections (e.g. Brucellosis, Q-fever, tuberculosis)
* Other pneumoconiosis e.g. hard metal lung disease, chronic beryllium disease
* Acute inhalational injuries.

Occupational lung disease is under-recognised in Australia, and there are limited data available on disease prevalence in Australia (Hoy & Brims, 2017). Because these diseases often have a long latency period, the link between past occupational exposures and current disease may not be made. However, international studies have shown that approximately 15% of adult-onset cases of asthma and COPD are related to occupational exposures, and, importantly, 10-25% of cases of lung cancer (Hoy & Brims, 2017). One quarter of working people with asthma either have their asthma caused by their work or made worse by their working conditions (Hoy & Brims, 2017). It is probable that many cases currently diagnosed as IPF have an occupational cause and represent dust-related pulmonary fibrosis (Khalil et al., 2007). Australia still has a rate of malignant mesothelioma among the highest in the world, and the legacy of past occupational asbestos exposure remains a heavy burden (Soeberg et al., 2018).

Recently, there has been a re-emergence of silicosis and coal workers’ pneumoconiosis from exposure to dusts from cutting engineered stone and also from coal mine dust exposure. These diseases have a very long latency period and result in significant disablement across the life course. Silica exposure is also a cause of lung cancer, COPD and autoimmune disease (Hoy et al., 2018; Matar et al., 2017; Zosky et al., 2016).

Cases of historical occupational diseases have been occurring with previously unrecognised exposures, and new types of occupational lung disorders are being described.

All causes of occupational lung disease are preventable and should not be occurring in Australia in the 21st century. New causes such as silicosis from cutting engineered stone or exposure to volatile components of e-cigarettes are examples of new risks that require ongoing monitoring and education.

## **Respiratory lung disease overlap**

Many adults have features of asthma, COPD and bronchiectasis. The existence of more than one lung disease in an individual has implications to consider in relation to diagnosis and management.

In milder COPD patients, bronchiectasis may be an incidental, subclinical finding on CT scan, as observed in the ECLIPSE study where the prevalence of bronchiectasis was 4% (Agusti et al., 2010). In contrast, patients with moderate to severe COPD have a higher prevalence of bronchiectasis of 30 to 60% (O’Brien et al., 2000; Patel et al., 2004; Whitters & Stockley, 2013; Yang et al., 2018).

A meta-analysis of observational studies totalling 5,329 patients with COPD showed that 30% had coexisting bronchiectasis, which increased the risk of exacerbations, bacteria in sputum, severe airway obstruction and mortality ([Du et al., 2016](https://copdx.org.au/copd-x-plan/references/references-a-g/#103); Yang et al., 2018).

Currently, COPD-bronchiectasis overlap is a neglected area of research which has implications for clinical practice (Hurst et al., 2015; Martinez-Garcia & Miravitlles, 2017).

Asthma–COPD overlap is not a single disease but is likely to have many underlying causes. It can develop in smokers, ex-smokers or non-smokers, particularly at older ages.

People with asthma–COPD overlap are at higher risk than people with either condition alone, with more symptoms, more flare-ups, greater need for health care utilisation, and higher mortality (Lung Foundation Australia & National Asthma Council Australia, 2017).

Approximately 15–20% of people with a diagnosis of COPD or asthma have both conditions (de Marco et al., 2013). People with both COPD and asthma experience significantly worse health outcomes than those with COPD or asthma alone (Anderson et al., 2013).

The co-existence of multiple airways diseases has been reported to be associated with increased lung inflammation, frequent exacerbations, worse lung function and higher mortality. In addition, many patients also have chronic rhinosinusitis and upper airway disease. The management of asthma, bronchiectasis, COPD and upper airway diseases is outlined in separate guidelines for each individual disorder. There is a growing recognition that the majority of patients have one or more conditions, and this requires a re-evaluation of how patients are managed (Polverino et al., 2018).

## **Rare lung conditions**

Rare diseases are diseases which affect a small number of people compared to the general population and specific issues are raised in relation to their rarity. In Europe, a disease is considered to be rare when it affects one person per 2000 population (Orphanet, 2012).

There are many rare lung conditions.  The Australasian Registry Network for Orphan Lung Disease (ARNOLD) looked at 30 rare lung conditions, however clinicians estimate there are many more than this, perhaps hundreds. Included in this category is Cystic Fibrosis, the most common lethal genetic disease affecting Australians.

Examples of rare lung diseases include sarcoidosis, an inflammatory disorder often affecting the lungs and other organs; alpha-1 antitrypsin (AAT) deficiency, a genetic disorder that leads to emphysema; lymphangioleiomyomatosis (LAM), a cystic lung disease, and many congenital lung disorders. There are also rare clinical phenotypes of common diseases, such as Allergic Bronchopulmonary Aspergillosis (ABPA), a complication due to fungal sensitisation and colonisation in a minority of people with asthma.

The causes and pathophysiology of these diseases are varied and complex, and include genetics, the environment and micro-organisms. To date, the cause remains unknown for many rare diseases (Orphanet, 2012).

The prevalence of rare lung disorders varies widely by disease type. Rare lung diseases generally affect individuals from birth through about age 60 and are uncommon in the elderly. Some diseases are more prevalent in certain racial and ethnic populations, such as sarcoidosis in African Americans, for unknown reasons.

Rare diseases are in many cases serious, chronic, and debilitating, and, once properly diagnosed, often require expensive, long-term treatments. Treatment of rare lung diseases often involves the use of unconventional therapies and orphan drugs, such as antitrypsin replacement for hereditary emphysema. An orphan drug is one that treats rare, or “orphan” diseases and would not ordinarily be profitable for pharmaceutical companies to develop (American Thoracic Society, 2012).

Estimating the economic burden of rare lung disease is difficult, however the rarer the disorder, the more tests and healthcare visits are likely required to arrive at the correct diagnosis. These delays result in greater expenses, unnecessary tests, and missed opportunities for early intervention. For example, the average interval from onset of symptoms to the diagnosis of LAM, which affects smooth muscle tissue in the lungs and airways, is three to five years (McCormack, 2008). Most patients suffer two episodes of pneumothorax (collapsed lung) before the diagnosis is made.

Those affected by these diseases all face similar difficulties in their quest for a diagnosis, relevant information and proper direction towards qualified professionals. Specific issues are equally raised regarding access to quality health care, overall social and medical support, effective liaison between hospitals and general practices, as well as professional and social integration and independence. Those affected by rare diseases are also more psychologically, socially, economically and culturally vulnerable (Orphanet, 2012).

The field of rare diseases suffers from a deficit of medical and scientific knowledge. There is no cure for most rare diseases, but the appropriate treatment and medical care can improve the quality of life of those affected and extend their life expectancy (Orphanet, 2012).

# **PRIORITY POPULATIONS**

Lung conditions can impact all Australians, but some populations are disproportionately affected. These groups have a higher prevalence of lung conditions and a greater burden of disease, resulting in inequitable health outcomes. Greater investment and sustained efforts are required to positively advantage priority populations and overcome current inequities in health outcomes.

The Action Plan is committed to delivering culturally safe and appropriate care and services that are respectful of and responsive to the cultural and linguistic needs of all individuals.

**Aboriginal and Torres Strait Islander people**

Aboriginal and Torres Strait Islander people experience higher rates of lung conditions and worse outcomes compared with non-Indigenous Australians ([Australian Health Ministers’ Advisory Council, 2017a](#_ENREF_9)).

Aboriginal and Torres Strait Islander peoples experience higher mortality and morbidity from lung conditions such as asthma, bronchiectasis, chronic obstructive pulmonary disease (COPD) (including bronchitis and emphysema), pneumonia and invasive pneumococcal disease than other Australians ([Australian Health Ministers’ Advisory Council, 2017a](#_ENREF_9)). While Indigenous lung disease mortality rates have fallen since 1998; self-reported lung disease, hospitalisation and mortality rates are still twice as high for Indigenous people ([Australian Health Ministers’ Advisory Council, 2017a](#_ENREF_9)). In the case of lung cancer, Aboriginal and Torres Strait Islander people have almost twice the risk of being diagnosed and experience barriers to accessing care which results in delayed diagnosis and more advanced disease at the time of diagnosis compared to non-Indigenous Australians (Cheng et al., 2016; Condon et al., 2005).

**People living in regional, rural and remote areas**

Australians living in rural and remote areas face unique challenges due to their geographic location, and they often have poorer health outcomes than people living in major cities. Disease burden, mortality rates and the number of hospitalisations all increase as remoteness increases (AIHW, 2018a). Recent data indicated that the top nine Primary Health Network (PHN) areas for PPHs for COPD were all located in regional, rural and remote areas (ACSQHC, 2017). High rates of PPHs can indicate decreased access to timely and appropriate provision of primary or community-based healthcare (AIHW, 2017b; Australian Health Ministers’ Advisory Council, 2017a).

The challenges of geographic spread, low population density, limited infrastructure, as well as the higher costs of delivering rural and remote health care, can affect access to healthcare (AIHW, 2018a). One recent study found 49 per cent of Australians diagnosed with advanced lung cancer live in regional and remote areas (Yap et al., 2018). This is disproportionate to the 29 per cent of Australians living in these areas (ABS, 2017a).

**People who smoke**

Given the overwhelming harms to lung health posed by tobacco products, the Action Plan also prioritises people who smoke. Further information regarding Australia’s approach to tobacco control is outlined in Australia’s National Tobacco Strategy.

**Workers currently and previously exposed to occupational dusts, gases, fumes and vapours**

As noted in the previous section, Priority Lung Conditions, occupational lung diseases are an important and under-recognised cause of respiratory ill health in Australia. It affects people in the workforce, can have an impact on the ability of people to continue to work and because of the latency of many occupational lung conditions it also affects those that have retired from work. Occupational lung conditions, therefore have an impact from a health, wellbeing and social perspective as well as an economic perspective through loss of productivity.

All causes of occupational lung disease are preventable and can be addressed through multi-dimensional interventions involving employers, employees, representative bodies and key work health and safety stakeholders.

**People from culturally and linguistically diverse backgrounds**

Australia’s population includes many people who were born overseas, have a parent born overseas or speak a variety of languages. According to the 216 Census of Population and Housing, almost half of Australians (45% or 10.6 million) were either born overseas (26% or 6.2 million) or had one or both parents who were born overseas (19% or 4.5 million) (ABS, 2017b). Culturally and linguistically diverse Australians with lung cancer face poorer survival rates and are less likely to receive timely and appropriate care (Mazza et al., 2018). Australians who were born overseas are also at much higher risk of chronic lung disease due to scarring from childhood infections and tuberculosis (Denholm, 2013).

**People experiencing socio-economic disadvantage**

Socioeconomic factors are important determinants of health. Generally, people in lower socioeconomic groups are at greater risk of poor health, have higher rates of illness, disability and death, and live shorter lives than people from higher socioeconomic groups (AIHW 2018a; Mackenbach, 2015, Sahni et al., 2017). Compared with people in the highest socioeconomic group, people in the lowest socioeconomic group were:

* 2.7 times as likely to have COPD in 2014-15
* 2.2 times as likely to die from COPD in 2011-15, and
* Experienced burden of disease that was 2.0 times as high for lung cancer in 2011 (AIHW, 2018d).

# **PRIORITY AREAS FOR ACTION: NATIONAL STRATEGIC ACTION PLAN FOR LUNG CONDITIONS**

## **Priority Area 1: Prevention and Risk Reduction**

To prevent lung conditions and reduce the risk of lung disease, evidence-based interventions have been incorporated into the Action Plan. These actions reduce or avoid exposure to common risk factors or address symptoms of lung disease such as:

* Tobacco smoke
* Occupational hazards
* Chronic cough
* Respiratory infections
* Poor air quality

Below is the evidence to support the inclusion of these areas for intervention in the Action Plan.

**Tobacco smoke**

* Tobacco use causes lung diseases and is the predominant cause of COPD and lung cancer (Surgeon General, 2014).
* Exposure to tobacco smoke makes chronic lung diseases more severe and increases the risk of respiratory infections (United States Centers for Disease Control and Prevention, 2014).
* Youth who smoke may be more likely to develop asthma (Surgeon General, 2014). Exposure to second-hand smoke can trigger an asthma attack in both children and adults (United States Centers for Disease Control and Prevention, 2014).
* 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).
* The marketing and use of e-cigarettes and the risks that these products pose to population health are a concern. There is insufficient evidence to support claims that e-cigarettes are safe (Rubinstein, et al., 2018).
* There is also concerns regarding the impact of e-cigarettes on smoking initiation and cessation, dual use with conventional tobacco products and take-up by children and youth (Chapman, et al., 2018).

Australia’s obligations as a Party to the WHO Framework Convention on Tobacco Control (FCTC) - 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 (WHO, 2005).

**Occupational hazards**

* Occupational lung diseases are an important and under-recognised cause of respiratory ill health in Australia (Hoy & Brims, 2017)
* The prevalence is increasing, particularly in emerging industries such as the production of engineered stone products and the exposure to silica dust (Matar et al., 2017)
* Recently, there has been a re-emergence of coal workers’ pneumoconiosis from exposure to coal mine dust (Zosky et al., 2016).

Occupational lung diseases can be prevented by identifying and removing occupational hazards and creating healthy and safe workplaces. Education and awareness raising are also effective interventions.

**Chronic Cough**

* Cough is a common symptom of lung disease and one of the most common presentations to general practice ([Britt et al., 2014](#_ENREF_16)).
* Australian Cough Guidelines have been developed ([Gibson et al., 2010](#_ENREF_27)), however awareness and implementation is low.
* Left untreated chronic cough may lead to the development of bronchiectasis.

Awareness and education focusing on chronic cough and other symptoms of lung disease can increase proactive action to treat.

**Respiratory Infections**

Immunisation for annual influenza and pneumococcal helps keep Australians healthy, productive and out of hospital (Nichol et al., 1994; Kopsaftis et al., 2018; Bonten, et al., 2015).

The 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.

**Poor Air quality**

* Air quality greatly influences lung function for all Australians (Paulin & Hansel, 2016).
* Exposure to indoor and outdoor pollutants currently occurs in a variety of environments including workplaces, public and commercial buildings as well as rental accommodation.
* 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.

Efforts to monitor and improve indoor and outdoor air quality will promote good lung health. Prevention of exposure to new pollutants is also important, including the recently recognised silica dust and the combination of volatile compounds in e-cigarettes.

## **Priority Area 2: Awareness and Stigma**

Interventions have been incorporated into the Action Plan to:

* reduce stigma, discrimination and social isolation associated with lung conditions.
* raise awareness of the symptoms of lung conditions to enhance early diagnosis and treatment.

Below is the evidence to support the inclusion of these areas for intervention in the Action Plan.

**Stigma**

As discussed in the health, social and economic impact section of this document, stigma has a significant impact on health outcomes for people with lung conditions. This stigma arises from a general misunderstanding of lung conditions and a negative association with smoking ([Ipsos MORI, 2011](#_ENREF_33); [Lung Foundation Australia, 2017b](#_ENREF_40); [Lung Foundation Australia, 2017a](#_ENREF_39); [Jarrett, 2015](#_ENREF_34)).

Stigma acts a barrier to accessing health services and the impact on people with lung conditions is loss of independence, social isolation, discrimination, and reduced 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](#_ENREF_10)).

Raising awareness and providing education can increase understanding and sympathy for people with lung conditions.

**Symptoms Awareness**

* people with lung conditions are not presenting to health professionals because they underestimate the severity of their disease ([Sabit et al., 2007](#_ENREF_49), [Reddel et al., 2015](#_ENREF_48)) 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](#_ENREF_26)).
* lung function testing is currently under-used which contributes lung conditions being under-diagnosed and delays in diagnosis ([Agusti et al., 2003](#_ENREF_4), [Guerra, 2009](#_ENREF_30), [Barton et al., 2009](#_ENREF_14), [Australian Centre for Asthma Monitoring, 2011](#_ENREF_8)).

Raising awareness of the symptoms of lung conditions is the first step in addressing under-diagnosis and diagnostic delays.

## **Priority Area 3: Diagnosis, Management and Care**

The Action Plan identified that interventions were required to strengthen the delivery of appropriate, sustainable, efficient and best quality diagnosis, management and care for people with lung conditions.

**Diagnosis**

* Early and correct diagnosis is an issue for some lung conditions including lung cancer (Walters et al., 2013; Wang et al., 2010) and COPD ([Agusti et al., 2003](#_ENREF_4), [Guerra, 2009](#_ENREF_30); 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).
* Spirometry testing is not consistently performed in primary care to confirm or assess the severity of a diagnosis of lung condition(s) (Toelle et al., 2013). One study has shown that 82% of patients were initiated on medication for a presumed lung condition without a lung function test (Poulos et al., 2016).
* Spirometry test results are often misclassified which leads to late, under and mis- diagnosis (Liang et al., 2018; Walters et al., 2011; Zwar et al., 2011).
* In a retrospective study in the United Kingdom of almost 39,000 patients, opportunities for diagnosis were missed in 85% of patients in the 5 years preceding diagnosis of COPD (Jones et al., 2014).

**Management and care**

* Awareness of clinical guidelines in primary care remains low and there is a 16-fold variation in care for COPD patients, based mainly on location and sociodemographic features (ACSQHC, 2017).

The implementation of systems and processes to utilise evidence-based tools and guidelines will assist in improvements to identification and diagnosis of patients with lung conditions. To diagnose lung conditions correctly and provide the best care possible, health professionals need ongoing education on lung conditions.

## **Priority Area 4: Partners in Health**

Interventions in this priority area focus on shared decision making and self-management.

* The important role of self-management for those with chronic conditions is well established (Massimi et al., 2017; Zwerink et al., 2014)
* People with lung conditions are not consistently receiving appropriate education, information or referrals to support their self-management (Lung Foundation Australia, 2016).

The implementation of interventions with patients to increase knowledge, confidence and skills for effective self-management practices are needed to assist them to better manage their lung condition, including increased access to:

* Community-based information and support services focused on self-management
* Tools to assist in monitoring and management
* Health professionals trained in providing a shared-decision making approach and supportive self-management practices.

## **Priority Area 5: Equitable Access**

The Action Plan identified that interventions were required to address barriers to accessing care particularly for priority populations. Specific areas where access could provide significantly improved outcomes for patients with lung conditions include:

* Pulmonary rehabilitation
* Specialist Lung Cancer Nurses (SLCNs)
* Infrastructure
* Supportive and palliative care

**Pulmonary rehabilitation:**

* Is the most effective evidence-based intervention to manage breathlessness in chronic lung conditions (Alison, et al., 2017).
* improves exercise capacity, quality of life, and teaches people with lung conditions the skills to manage their condition and stay well (Alison, et al., 2017).
* Is cost effective, although access in Australia in extremely limited with less than 10 per cent of people with COPD accessing pulmonary rehabilitation (AIHW, et al., 2013).

**Specialist Lung Cancer Nurses (SLCNs):**

* Coordinate and optimise care for people with lung cancer. In addition, they provide patients with clinical, social and emotional support.
* Are a core member of the multidisciplinary team for the treatment of lung cancer (Cancer Council Australia, 2017).
* Are in short supply 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).
* SLCNs should be associated with each of the Lung Cancer MDTs in Australia (Cancer Council Australia, 2017).

**Infrastructure:**

* Access to diagnostic services are challenging for people who are required to travel for detailed lung function testing, lung imaging and bronchoscopy and other specialised procedures. As a result, diagnosis is late and health outcomes are worse for people living in regional, rural and remote areas of Australia (AIHW, 2018a).
* Bronchoscopic procedures such as endobronchial ultrasound (EBUS) and positron emission tomography (PET) staging is recommended to ensure patients are provided with the most appropriate treatment for lung cancer (Lilo, et al. 2017; Mac Manus & Hicks 2012; Gregory et al., 2012).
* Of the 74 medicare eligible PET units located in Australia (Australian Government, 2018), 62 are based in major cities or outer metropolitan areas, 9 in inner regional areas and 2 in outer regional areas, using ARIA+ Score (Australian Government, 2011).

**Supportive and palliative care:**

* Research has consistently shown that individuals with COPD who access palliative care services have a lower death rate in Intensive Care Units, reduced frequency of invasive ventilation and longer overall survival rate the earlier palliative care referral is made (Palliative Care Australia, 2018; Palliative Care Australia & National Centre for Social and Economic Modelling, 2017)
* Early integration of palliative care with respiratory, primary care, and rehabilitation services, can improve patient and caregiver outcomes (Maddocks, et al., 2017; Higginsone, et al., 2014; Matthews & Johnston 2017)
* Access to palliative care for patients with lung conditions is poor and barriers need to be addressed to deliver optimal care (Boland, et al., 2013; Gershon, et al., 2018).
* The pattern of disease progression in a number of lung conditions, particularly COPD, is unpredictable and there is no clear transition to a period that can be identified as requiring palliative care services and this acts as a barrier (Maddocks, et al., 2017). It should be recognised that active disease management, i.e. supportive care and a palliative approach are complementary, not mutually exclusive.

Increasing access to specialist supportive and palliative care services is important, alongside training and education of all health professionals involved in lung conditions in palliative care principles and practice including advanced care planning.

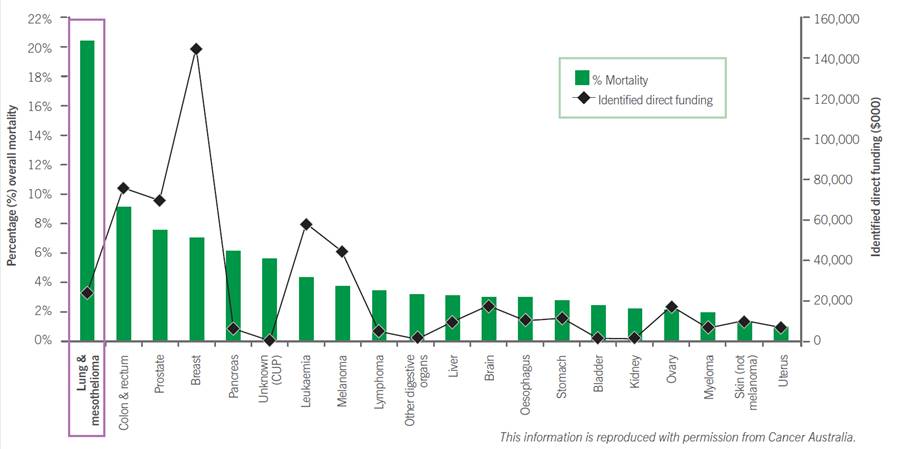
## **Priority Area 6: Research and Monitoring**

A key focus of the 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).

**Research** is essential to strengthening the knowledge base to effectively prevent, diagnose and manage lung conditions.

Research is underfunded in Australia, as demonstrated by Figure 4 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, 2014b).

*Figure 4: 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, 2014b).

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**Survellance and monitoring**Investing in surveillance and monitoring will inform clinical practice and guide health policy and strategies to improve the prevention, diagnosis and management of lung conditions.

**Integrated models of care**Developing and testing integrated models of care with 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:**

* 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).
* 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).
* The European Union has recommended that planning for implementation of low-dose CT screening should start throughout Europe as soon as possible and European countries need to set a timeline for implementing lung cancer screening to ensure that patients receive the most appropriate treatment (Oudkerk, et al., 2017).

Screening is not currently recommended in Australia (Community Care and Population Health Principal Committee, 2015), but a recently reported, highly regarded large European study suggests marked reductions in mortality are achieved by CT screening of an at-risk population of 50 – 74 year olds (Kauczor, et al., 2015; American College of Radiology, 2018).

# **APPENDICES**

## **Appendix 1: Glossary**

A list of key terms used in this Action Plan are provided below in alphabetical order. Several 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** are often used interchangeably with ‘chronic diseases’, ‘noncommunicable diseases’, and ‘long-term health conditions’. Chronic conditions have (Australian Health Ministers’ Advisory Council, 2017b):

* 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, sex, sexual identity, age, disability, socioeconomic status, and geographic location all contribute to an individual’s ability to achieve good health.

**E-cigarettes** are known by many different names such as electronic cigarettes, e-cigs, electronic nicotine delivery systems, alternative nicotine delivery systems, personal vaporisers and vapes. The action of using an e-cigarette is sometimes referred to as vaping.

**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.

**Health care cost: direct vs. indirect** Direct costs are those costs borne by the health care 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 (PFTs), 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 (FeNO), 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 care 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** is 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 new and core part of the multidisciplinary team 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** isused 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 health care 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.

**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 benefit 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 disadvantageis 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 care professionals to examine, diagnose, and treat patients using technology like a phone, computer, or other device.

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1. Data for bronchiectasis not included [↑](#footnote-ref-1)