



Transforming the agenda for COPD

A path towards prevention and lifelong lung health



**Lung
Foundation
Australia**

**Lung Foundation Australia's Blueprint
for Action on Chronic Obstructive
Pulmonary Disease (COPD) 2022-2025**

Lung Foundation Australia is Australia's leading peak body for respiratory health and lung disease. Lung Foundation Australia funds life-changing research and delivers support services to enable Australians with lung disease including lung cancer to live their best lives.

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“COPD can be lived with, but there are levels of living. You can live better with COPD if you know about it and you do something about it straight away.”

**- Brian (pictured),
lives with COPD**



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Acknowledgement of Country

Lung Foundation Australia acknowledges Australia's Aboriginal and Torres Strait Islander peoples and pays respect to their Elders, past, present and emerging. We do so in a spirit of reconciliation, recognising that Aboriginal and Torres Strait Islander peoples across Australia are significantly overrepresented in lung disease and lung cancer. We commit to partnering with communities to address this and Close the Gap.

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Corporate supporters

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Foreword

This Blueprint for COPD seeks to highlight a serious lung disease that has flown under the radar for far too long in Australia. This is despite its high prevalence, contribution to disability, cost to the community and impact on patients and their families.

Amongst lung diseases, COPD suffers from stigma that has relegated it to a much lower priority in attracting health care resources and research funding dollars than can be justified, given its burden and cost to the community. The view that COPD only results from tobacco smoking is also no longer tenable. New knowledge, comprehensive approaches to treatment and recent research has changed our understanding of COPD and this Blueprint attempts to show how this growing body of knowledge must be used to prevent the onset of lung disease, to change the lives of patients, to achieve better care, and to drive reform of service delivery to improve COPD outcomes.

Australia has one of the most advanced healthcare systems in the world, but we are lagging behind in achieving better outcomes for people with COPD. There is also a marked discrepancy between the outcomes for people with COPD in regional and rural Australia and those in less affluent areas compared to people in metropolitan areas and high-income areas. Aboriginal and Torres Strait Islander peoples are affected by both a high prevalence of COPD and poor access to care. Much can be done to address these inadequacies of care delivery, and this Blueprint describes the innovations and changes in service delivery that could accelerate this. It identifies some quick wins, but also some essential long-term strategies to address the burden of COPD. The origins of COPD from early life and through the lifespan develop in response to a range of environmental insults creates a golden opportunity for preventative interventions to ensure lung health for all Australians, rather than waiting until lung disease is taking a toll on an individual that is both costly and irreversible.

On behalf of the Expert Steering Committee, I invite you to open your mind to these possibilities, to seek to support and implement these recommendations in whatever context you work and live, and to embrace the possibility of lung health over the lifespan of all Australians.



A handwritten signature in black ink that reads "Christine Jenkins".

Professor Christine Jenkins AM

Professor of Respiratory Medicine, The George Institute for Global Health and UNSW Sydney
Chair, COPD Blueprint Expert Steering Committee

“

“Australia has one of the most advanced healthcare systems in the world, but we are lagging behind in achieving better outcomes for people with COPD.”

Executive summary

Transforming the agenda for COPD: A path towards prevention and lifelong lung health - Lung Foundation Australia's Blueprint for Action on Chronic Obstructive Pulmonary Disease (COPD) 2022-2025 identifies the critical issues in COPD that need investment and coordinated national action. It provides a framework to drive significant and positive change in order to improve outcomes for Australians living with COPD, their carers and families, and the lives of all Australians through better lung health.

This Blueprint is a vital adjunct to the National Strategic Action Plan for Lung Conditions, the Australian Government's overarching plan to advance lung health in Australia and the first national policy statement in Australia with a specific focus on COPD.

COPD is a progressive, long-term lung condition that leads to increasing breathing difficulties, disability and premature death. It is a common disease that affects both men and women, with approximately 1 in 13 Australians over the age of 40 estimated to have COPD, and people living with COPD often have other chronic diseases and long-term chronic conditions. The lung health community is determined to improve outcomes for all, particularly those who are disproportionately affected by COPD, including Aboriginal and Torres Strait Islander peoples, and those living in regional and remote communities and areas of socioeconomic disadvantage.

In Australia, as in most other developed countries, COPD is under recognised, underdiagnosed and under treated. COPD is a major public health problem due to its high prevalence, its rising number of cases, and its very significant personal, social, and economic costs. There is currently no cure for COPD, but early diagnosis and treatment are important to slow the progression of the disease and support people with COPD to breathe better, stay out of hospital and live longer. It is timely and critical for Australia to take action to establish pathways for the lifelong prevention of COPD, to diagnose COPD earlier, to create greater awareness of COPD and to provide compassion for people living with COPD. This action includes the elimination of stigma, optimising adherence to evidence-based best practice care for COPD, ensuring integrated and coordinated care, piloting and testing innovative new models of care and investing in COPD data infrastructure and research.

The Blueprint will improve the lives of all Australians through better lung health and contribute towards achieving the following high-level outcomes:

- Preventing lifelong exposure to COPD risk factors and COPD onset
- Preventing late diagnosis and delayed treatment
- Preventing COPD exacerbations and poorer health outcomes
- Preventing accelerated loss of lung function and disease progression
- Preventing COPD-related hospitalisations
- Preventing premature death.

Five priority areas for reform are outlined in this Blueprint. The recommendations will help to transform the agenda for COPD towards prevention and lifelong lung health.

- 1 Lifelong prevention of COPD.** Target risk factors such as prematurity, nutrition, and respiratory infections, accelerate efforts to reduce smoking prevalence, and improve indoor and outdoor air quality.
- 2 Early and accurate COPD risk identification and diagnosis.** Identify those at risk, explore opportunistic and systematic case-finding, enhance spirometry use and access in primary care, enable earlier spirometry in the life course, and embed COPD within Medicare services.
- 3 Community management.** Implement workforce education and training, enhance multidisciplinary care in the community, increase access and uptake of pulmonary rehabilitation, and increase availability and uptake of immunisation for those living with COPD.
- 4 Acute care management.** Ensure optimal access and delivery of acute care, increase adherence to guidelines-based management, and utilise virtual and digital innovations.
- 5 COPD research and translation.** Boost investment in COPD research, optimise COPD guidelines implementation, and invest in national data infrastructure.

This Blueprint is the result of a collective effort by the Australian lung health community. Priority areas of reform were identified following extensive consultation with experts and the COPD patient and carer community, and in response to evidence regarding unmet need and potential for impact. Lung Foundation Australia acknowledges the many individuals and organisations that helped make it possible. In particular we thank the Australians living with COPD, their families and their carers for shaping this report with their lived experience and for demonstrating great strength in paving the way for improved COPD outcomes. This Blueprint has been directly informed by your lived experience.

“

“People living with COPD, like myself, continue to be forgotten. We experience stigma, barriers in accessing health professionals and services, and it seems to all depend on where you live. It is time for us to be treated better. We want to live well and I really hope that this Blueprint is the start of things changing for the better.”

- Cathy, 61, living with COPD

Introduction

About COPD

Chronic Obstructive Pulmonary Disease (COPD) is a progressive, long-term lung condition that leads to increasing breathing difficulty, disability and premature death. COPD is the collective term for a number of lung diseases.

COPD causes narrowing of the bronchial tubes in the lungs (sometimes called bronchi or airways) making it difficult to breathe. Several different processes can cause the airways to become narrow and limit airflow in and out of the lungs. These include destruction of parts of the lung, mucus blocking the airways, and inflammation of the lining of the air passages¹⁻⁴.

About the Blueprint

This Blueprint for action on COPD, *Transforming the agenda for COPD: A path towards prevention and lifelong lung health*, aims to drive reform to improve the lives of all Australians through better lung health and improved COPD care and outcomes.

This Blueprint is a vital adjunct to the National Strategic Action Plan for Lung Conditions⁵, the Australian Government's overarching plan to advance lung health in Australia.

This is the first national policy statement in Australia with a specific focus on COPD.

It is underpinned by Lung Foundation Australia's values, namely:

- **Bold** | be proactive and take risks that achieve our Mission.
- **Entrepreneurial** | be focused on outcomes.
- **Fair** | be equitable and work in the interests of all our stakeholders, particularly patients and their carers.
- **Agile** | create positive change.
- **Innovative** | be inventive to achieve our Mission.
- **Respectful** | be honest and work hard every day in every way – we are funded by the community, they should expect nothing less⁶.

Policy context

The Blueprint is the only national policy statement in Australia with a specific focus on COPD. It sits within a broad health policy environment that includes respiratory and lung health, preventive health and chronic conditions, and policies focused on improving the health workforce, health care system, and outcomes for Aboriginal and Torres Strait Islander peoples and other populations with unmet needs.

The Blueprint aligns with key national policies and strategies, including:

- National Strategic Action Plan for Lung Conditions⁵
- National Preventive Health Strategy 2021-2030⁷
- Australia's Long Term National Health Plan⁸
- National Strategic Framework for Chronic Conditions⁹
- National Aboriginal and Torres Strait Islander Health Plan 2021-2031¹⁰
- National Agreement on Closing the Gap¹¹
- Australia's Primary Health Care 10 Year Plan 2022-2032¹²
- National Tobacco Strategy 2022-2030 (scheduled for completion in 2022)¹³
- Stronger Rural Health Strategy¹⁴
- National Nursing Strategy (scheduled for completion in 2023)¹⁵
- State and territory policies and strategies.

The Blueprint will play a key role in driving Australia's progress towards a number of international policy agendas, including:

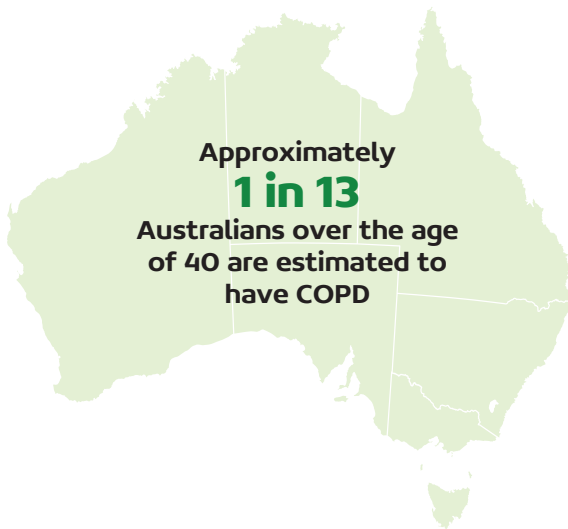
- Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease 2022 Report¹⁶
- The 2030 Agenda for Sustainable Development and the Sustainable Development Goals (SDGs)¹⁷
- WHO Framework Convention on Tobacco Control (FCTC)¹⁸.

Audience

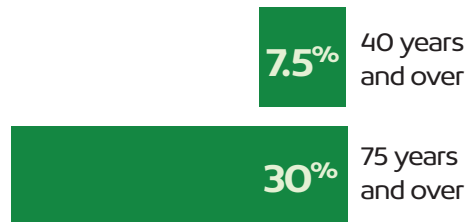
This strategy has been developed for policy makers at all levels of government as well as a range of non-government stakeholders, including industry, unions, workers, employers, regulators, medical and health professionals, and researchers.

The substantial and growing burden of COPD in Australia

COPD is common and cases are rising



The prevalence of COPD is estimated to be



Around **50%** of people with COPD do not know they have it

COPD-related hospitalisations are high and largely preventable

#1 cause of potentially preventable hospital admissions in Australia

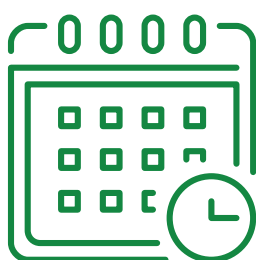
In 2017-18 there were **77,754** hospitalisations of people **45 and over** where COPD was the principal diagnosis

COPD admissions accounted for **392,434** bed days in 2017-18



Potentially preventable hospitalisations for chronic conditions in 2017-18

Chronic condition	Per 100,000 people (age-standardised)
COPD	267
Heart failure	206
Asthma	134
Type 1 diabetes	64
Rheumatic heart disease	17



The **average length of stay for COPD** without complications in 2017-2018 was **5.0 days**. COPD admissions peak in winter, causing bed block and delaying surgery for other conditions

In recent years, the rate of COPD hospitalisations has increased by **8%** nationally



Australia's COPD hospital admission rate is **1.7x higher** than the OECD average

COPD is a leading cause of death

Across 2018 to 2020, **20,930** Australians lost their lives to COPD, and an additional **26,389** people had COPD listed as an associated cause of death

COPD was the **3rd** leading cause of death in 2020 for people 65-74 years

COPD is costly

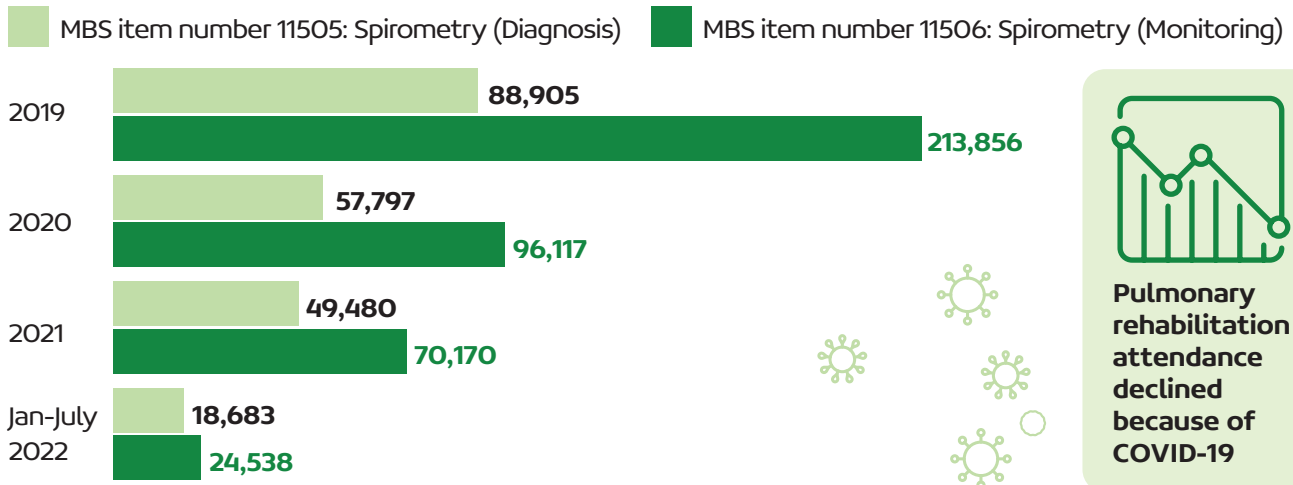
In 2018-2019, COPD cost the Australian health system an estimated

\$935 million

Many people with COPD are still in the prime of their working lives



COPD diagnosis and management has been severely impacted by COVID-19



COPD burden is high and unfairly distributed

Potentially preventable hospitalisations for COPD are:

5.4x

higher for Aboriginal and Torres Strait Islander peoples

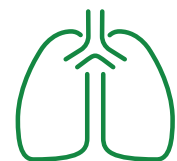
3.2x

higher for people living in regional and remote areas

2.8x

higher for people in low socioeconomic areas

Respiratory diseases were the **4th** leading cause of death of Aboriginal and Torres Strait Islander peoples in 2015-2019, responsible for 10% of total deaths of Aboriginal and Torres Strait Islander peoples (**1,498 deaths**)



Aboriginal and Torres Strait Islander peoples

2.3x prevalence of COPD

2.8x rate of deaths

4.8x rate of hospitalisations

compared to non-Aboriginal and Torres Strait Islander peoples

COPD is common and cases are rising

COPD is a common lung disease affecting both men and women. Approximately 1 in 13 Australians over the age of 40 are estimated to have COPD¹⁹.

The prevalence of COPD is estimated to be 7.5% for Australians aged 40 years and over, and 30% for people aged 75 and over¹⁹, however, it is now almost 15 years since this national survey was undertaken and updated epidemiologic studies in Australia are urgently needed.

The number of COPD cases in Australia is expected to increase as our population ages²⁰. The prevalence of COPD increases with age, and COPD is mostly diagnosed in people aged 45 and over². However, it is often present, although unrecognised or under recognised, long before diagnosis in an early, silent form of the disease.

This substantial underdiagnosis of COPD^{16, 19, 21} means that the number of Australians living with COPD is much higher than the data indicates. Around 50% of people with COPD symptoms do not know they have the condition. This denies them the opportunity to take the crucial early steps needed to stem the progression of the disease that will improve their quality of lives and keep them out of hospital²².

COPD diagnosis and management has been severely impacted by the COVID-19 pandemic

The COVID-19 pandemic has had a significant impact on the diagnosis and management of COPD.

During the pandemic, recommendations were made that spirometry should not be performed except in specific circumstances. This advice, aimed at reducing the potential spread of COVID-19 infection, was widely adopted. Not surprisingly, during the pandemic Medicare Benefits Schedule (MBS) data shows substantial reductions in the use of spirometry in primary care during this period, with the trend persisting into 2022. Given that spirometry is an essential diagnostic test for COPD, this is likely to have a major impact on the diagnosis and monitoring of COPD and other respiratory disorders. See Table 1.

Table 1: Medicare item reports – number of services for spirometry in primary care 2019-2022²³

	2019	2020	2021	Jan-July 2022
MBS item number 11505 Spirometry (Diagnosis)	88,905	57,797	49,480	18,683
MBS item number 11506 Spirometry (Monitoring)	213,856	96,117	70,170	24,538

Another impact of the pandemic was that face-to-face services deemed non-essential were generally suspended, including pulmonary rehabilitation (PR), a highly effective evidenced-based intervention used to treat and manage COPD. The urgent re-establishment of PR services to their full service levels is critical.

Although the pandemic has made the diagnosis and routine management of COPD more difficult, there have been some positive and unexpected outcomes. These include reductions in the number of COPD exacerbations, hospital admissions and emergency department presentations²⁴⁻²⁶, emphasising the importance of vaccination and avoidance of respiratory viral infections.

COPD-related hospitalisations are frequent

COPD admissions account for a substantial number of hospital bed days in Australia each year. For example, in 2017-18, 392,434 bed days were the result of admissions related to COPD²⁷. The average length of stay for COPD in 2017-18 was 5.0 days²⁷. COPD admissions tend to peak in winter, causing bed block and delaying surgery for other conditions.

Re-admission rates for patients hospitalised with an acute exacerbation of COPD are high. One Australian study shows readmission rates at 28 days were 25.4%, with one death during admission (0.6%) and eight deaths (6.1%) post-discharge within 28 days²⁸.

In recent years, the rate of COPD hospitalisations has increased nationally by 8%²⁹.

The rate of hospitalisation for COPD was 18 times higher in the area of the country with the highest rate compared with the area with the lowest rate²⁹, a divide which reinforces the data that when it comes to your health, where you live matters.

Australia's COPD hospital admission rate is 1.7 higher than the OECD average³⁰.

Potentially preventable hospitalisations for chronic conditions, 2017-18²⁷

COPD is the leading cause of potentially preventable hospitalisations

COPD-related hospitalisations are frequent and largely preventable.

Hospitalisations due to COPD are classified as 'potentially preventable'. COPD is the leading cause of potentially preventable hospitalisations (PPHs) for chronic conditions²⁹.

Chronic condition	Per 100,000 people (age-standardised)
COPD	267
Heart failure	206
Asthma	134
Type 1 diabetes	64
Rheumatic heart disease	17

What are potentially preventable hospitalisations (PPHs)?

Potentially preventable hospitalisations (PPHs) are defined as admissions to hospital where the hospitalisation could have potentially been prevented through the provision of appropriate, individualised preventive health interventions and early disease management usually delivered in primary-care and community-based care settings³¹.

PPHs are used as a measure of access to timely, effective and appropriate primary and community health care.

Classifying a hospitalisation as 'potentially preventable' does not mean that the hospitalisation itself was unnecessary, it means that optimal management at an earlier stage might have prevented a patient's condition worsening to the point where they needed hospitalisation²⁷.

In 2017-18 there were 77,754 potentially preventable hospitalisations for people of all ages, with the unadjusted (crude) rate of hospitalisation being 316 per 100,000 population²⁷.

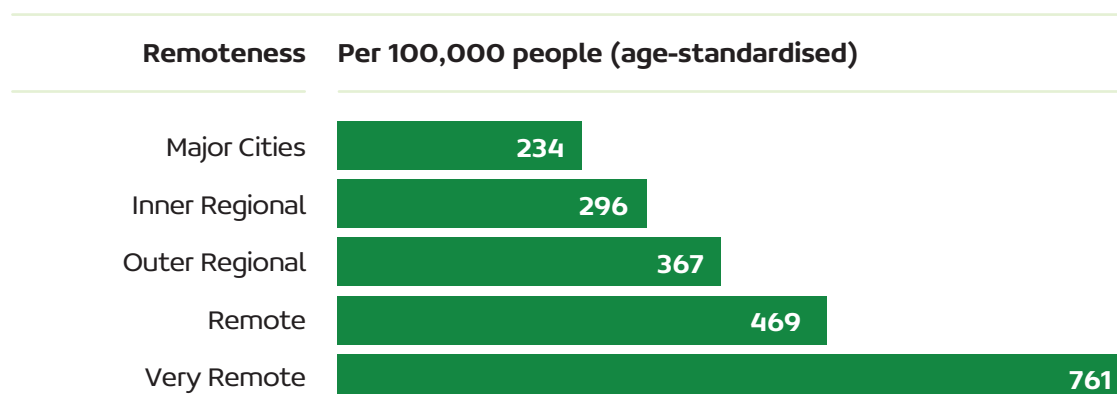
Gross disparities in PPHs across Australia exist, and the health gap is widening for people living in regional and remote areas, areas of socioeconomic disadvantage²⁷, and for Aboriginal and Torres Strait Islander peoples²⁹.

Potentially preventable hospitalisations (PPHs) for COPD are higher for:

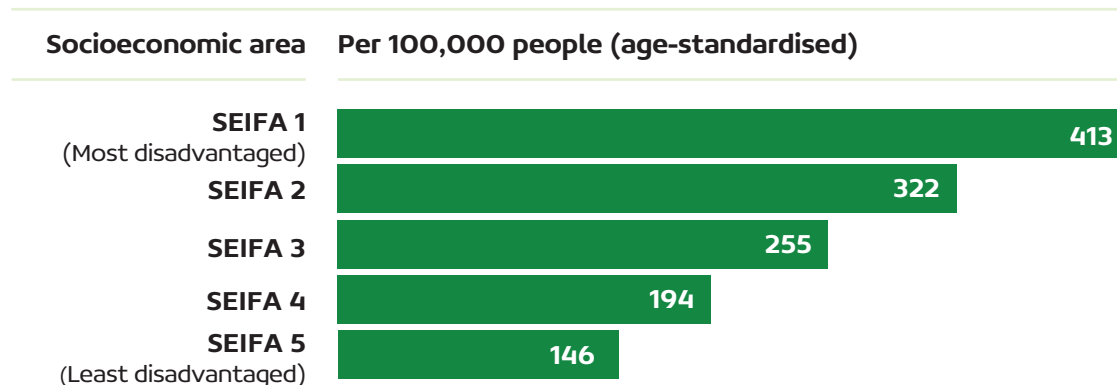
- Aboriginal and Torres Strait Islander peoples. The rate for Aboriginal and Torres Strait Islander peoples is 5.4 times that of non-Indigenous Australians.
- People living in regional and remote areas. The rate for people in very remote areas is 3.2 times that of those in major cities.
- People living in areas of socioeconomic disadvantage. The rate in the most disadvantaged areas is 2.8 times that in the least disadvantaged areas²⁷.

See page 14 for more.

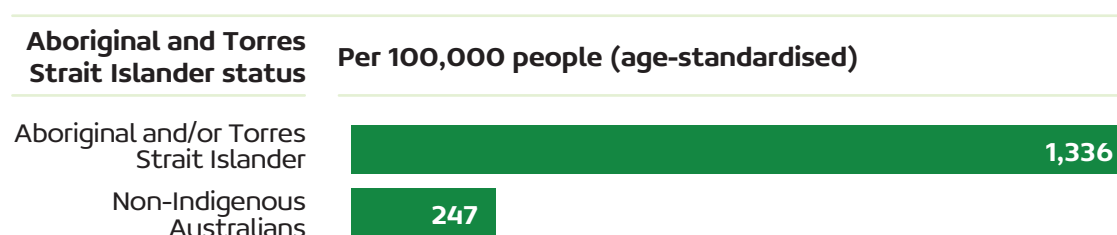
Disparities in potentially preventable hospitalisations for COPD by remoteness, 2017-18



Disparities in potentially preventable hospitalisations for COPD by socioeconomic area, 2017-18



Disparities in potentially preventable hospitalisations for COPD by Aboriginal and Torres Strait Islander status, 2017-18



COPD is a leading cause of death

COPD was the third leading cause of death for people aged 65-74 in 2020, after lung cancer and coronary heart disease³².

In 2020, 6,311 Australians lost their lives to COPD. This is a rate of 25 per 100,000 people³³. However, this is likely a significant under-estimation of the true rate, as cardiac disease accounts for 40-50% of deaths in people with COPD³⁴.

Across 2018 to 2020 combined, 20,930 Australians lost their lives to COPD. An additional 26,389 people had COPD listed as an associated cause of death³².

People who smoke tobacco are 12 times more likely to die from COPD than people who do not smoke³⁵.

COPD mortality rates are higher for Aboriginal and Torres Strait Islander peoples³⁶, people living in remote areas, and those in areas of socioeconomic disadvantage³⁷.

COPD has a high cost

In 2018-19, COPD cost the Australian health system an estimated \$935 million, representing 21% of disease expenditure on respiratory conditions and 3% of total disease expenditure. This expenditure consisted of:

- \$578 million for hospital care (62% of total expenditure on COPD);
- \$259 million for pharmaceuticals (28%); and
- \$98 million for non-hospital medical services (10%)³⁸.

Many people living with COPD are still in the prime of their working lives, however older workers with a chronic health condition are more likely to prematurely withdraw from the workforce³⁹, negatively impacting individual earnings and societal productivity.

There is a substantial financial burden for Australians living with COPD. In 2008, it was estimated that the individual cost of living with

COPD in Australia, including the value of loss of wellness, equalled \$82,925 per person, per year⁴⁰. More recent data is urgently needed to better understand the current impact of COPD on Australian workers.

COPD burden is high and unfairly distributed

Burden of disease measures the impact of living with illness and injury and dying prematurely.

In Australia in 2018, COPD accounted for almost half of the total burden of disease due to respiratory conditions (48%) and 3.5% of the total disease burden⁴¹.

In 2018, COPD was the fourth leading specific cause of total disease burden⁴¹.

The impact of COPD varies between population groups. The burden of disease is higher for Aboriginal and Torres Strait Islander peoples³⁶, people living in remote areas and areas of socioeconomic disadvantage².

Aboriginal and Torres Strait Islander peoples are disproportionately impacted

Aboriginal and Torres Strait Islander peoples are disproportionately impacted by COPD.

The prevalence of COPD among Aboriginal and Torres Strait Islander peoples is 2.3 times as high as non-Aboriginal and Torres Strait Islander peoples^{2, 42, 43}.

Respiratory diseases were the fourth leading cause of death of Aboriginal and Torres Strait Islander peoples in 2015-2019, responsible for 10% of total deaths of Aboriginal and Torres Strait Islander peoples (1,498 deaths)³⁶. The rate of deaths due to COPD for Aboriginal and Torres Strait Islander peoples was 2.8 times that of non-Aboriginal and Torres Strait Islander peoples³⁶.

The rate of hospitalisations for Aboriginal and Torres Strait Islander peoples was 4.8 times higher than the rate for non-Indigenous Australians²⁹.



“I find it harder to enjoy life because of the restriction of COPD.”

- John, 76 years, living with COPD

Preventing COPD across the lifespan

Opportunities to prevent COPD, to reduce the risk of the disease and to prevent its progression exist at every stage of human life, starting with preconception. It is never too late or too early to take action.

Many factors can influence a person's risk of developing COPD. The presence of one or more of these risk factors can help to explain why a particular individual or population group is more likely to develop the disease. COPD risk factors can be viewed as being present across different 'levels', including individual, family, workplace, environmental, and society. The combined and cumulative effects of different risk factors over a person's life can impact on their chances of developing COPD. Risk factors are influential over time and can make a difference throughout a person's life. For example, risk factors such as air pollution can contribute to the increased risk of developing COPD later in life.

Due to this 'lifelong impact' and the fact that some factors can be changed and modified, there are many ways that COPD can be prevented. Action can start from preconception and continue throughout an individual's life. When risk factors are reduced, an individual is less likely to be at risk of developing COPD or of having their condition progress and worsen. Avoiding and reducing COPD risk factors helps to protect the lungs and promote lifelong lung health.

Health professionals play an important role across an individual's lifespan, from preconception right through to older adulthood.

As Australians go through their lives, they are likely to come into contact with a range of health professionals. COPD is a chronic condition, meaning that people often live with the disease for many years. Many people with COPD also have other chronic diseases and long-term chronic conditions. People living with COPD require access to comprehensive multidisciplinary COPD care across the health spectrum, including primary to tertiary care. This brings them into contact with a range of health care services and professionals.



Preventing COPD across the lifespan

Preconception

Individual and environmental risk factors

- Maternal and paternal smoking
- Air pollution



Key professionals involved and intervention opportunities

- Aboriginal and Torres Strait Islander Health Worker/Practitioner
- GP
- Obstetrician-gynecologist
- ✓ Opportunistic screening and counselling

Childhood

Individual and environmental risk factors

- Inadequate management of a chronic wet cough including post-acute respiratory infection (>4 weeks in children)
- Recurrent lower respiratory tract infections
- Second-hand smoke exposure
- Air pollution
- Asthma mismanagement
- Poor nutrition
- Obesity



Key professionals involved and intervention opportunities

- GP
- Aboriginal and Torres Strait Islander Health Worker/Practitioner
- Child health clinic / community nursing
- Paediatrician / Paediatric respiratory specialist
- Pharmacist
- Child care services, educators and teachers
- Child/school nurse
- ✓ Various health professionals for smoking cessation advice
- ✓ GP for vaccinations and nutrition advice

Adulthood (20-65)

Individual and environmental risk factors

- Smoking and vaping
- Adverse occupational exposures
- Second-hand smoke exposure
- Obesity
- Infections (TB and HIV)
- Air pollution



Key professionals involved and intervention opportunities

- GP
- Pharmacist
- Aboriginal and Torres Strait Islander Health Worker/Practitioner
- Employers
- ✓ Lung health check
- ✓ Opportunistic screening through age-based health assessments e.g. if someone is an ex-smoker or has experienced risk factors
- ✓ Screening associated with comorbidities e.g. cardiac events
- ✓ Active case finding within primary care leveraging guidelines-based QI tools and processes
- ✓ Various health professionals for smoking cessation advice
- ✓ Vaccinations

Fetal life/Infancy

Individual and environmental risk factors

- Pre-term birth
- Low birthweight
- Ventilatory support
- Oxygen therapy
- Poor nutrition
- Gestational smoking
- Second-hand smoke exposure
- Air pollution
- Frequent respiratory infections



Key professionals involved and intervention opportunities

- Paediatrician
- Hospital, community nurse or GP
- Aboriginal and Torres Strait Islander Health Worker/Practitioner
- ✓ GP for identifying and addressing frequent respiratory infections
- ✓ Various health professionals for smoking cessation advice

Adolescence

Individual and environmental risk factors

- Commencement of smoking and/or vaping
- Commencement of high-risk occupational exposures e.g. trades, apprenticeships
- Air pollution
- Asthma mismanagement
- Second-hand smoke exposure
- Obesity
- Infections (TB and HIV)



Key professionals involved and intervention opportunities

- GP
- Education services
- Employers
- School-based health nurse
- Aboriginal and Torres Strait Islander Health Worker/Practitioner
- ✓ Can access appointments on their own from 16yrs

Older adulthood (65+)

Individual and environmental risk factors

- Smoking and vaping
- Second-hand smoke exposure
- Obesity
- Asthma mismanagement
- Infections (TB and HIV)
- Air pollution



Key professionals involved and intervention opportunities

- Aged care facilities
- Pharmacist
- Hospital, community nurse or GP
- Aboriginal and Torres Strait Islander Health Worker/Practitioner
- ✓ GP awareness and active case finding for COPD
- ✓ Pharmacologic and non-pharmacologic therapies, regular review and appropriate referral
- ✓ Various health professionals for smoking cessation advice
- ✓ Mental health support
- ✓ GP and hospital referral to palliative care

COPD patient journey

Symptom onset

Early symptoms e.g. chronic cough, chronic breathlessness. Lack of understanding of risk factors and case finding leads to symptoms being normalised by HCPs and patients.

Emotion: Frustration, nervousness, uncertainty.

Diagnosis delayed

Lack of referral and access to recommended diagnostics can lead to missed or incorrect diagnosis. This delays treatment, contributing to avoidable disease progression.

Emotion: Frustration, uncertainty followed by anger and concern.

Diagnostics undertaken

Spirometry performed.

Emotion: Relief about access to appropriate testing. Confusion, anxiety and uncertainty about results of testing and what this might mean.

Care in the community / supportive care

Evidence-based programs, health service interactions and tools to support symptom management and improve quality of life when living with COPD.

Pulmonary rehabilitation

Refer early to pulmonary rehabilitation for exercise and education on non-pharmacological strategies for managing breathlessness.

Exercise maintenance

Ensure participation in supervised exercise to maintain benefits of pulmonary rehabilitation.

Specialist care

Surveillance and monitoring to support optimal disease management.

Career / finances

Provide support to maintain workforce participation, as well as access to financial support and advice.

Primary care

COPD Action Plan

Complete the shared care tool to manage flare-ups and regularly review treatment.

Immunisations

Influenza, pneumococcal and COVID-19 vaccinations are up to date.

Inhaler technique

Review inhaler technique: identify and correct errors.

Mental health

Complete mental health treatment plan and referral.

Identification and management of comorbidities

Consider comorbidities associated with COPD and manage accordingly.

Supportive care for activities of daily living

- Palliative care
- Subsidised equipment dependent on eligibility criteria e.g. oxygen therapy
- MyAgedCare
- Hospital in the Home

To see the key health professionals involved in the COPD journey, view the digital version of this report via lungfoundation.com.au/COPDbaselineprint

Arrow key

- ← Common journey and experiences of COPD patients
- ←..... Possible pathway
- ← Next step in disease pathway

Heading key

- Purple: Major stage in COPD journey
- Light green: Potential pain points
- Dark green: Important professionals/interventions for living well with COPD

Misdiagnosis

Testing not performed according to guidelines or not completed. Can lead to incorrect diagnosis such as asthma.

Emotion: Despondent, exhausted, frustrated, anxious.

Respiratory specialist

Specialist engaged in diagnostics, treating and long-term management of COPD in day-to-day life.

Emotion: Relief and confidence from having specialist input, and affirmation from a confirmed diagnosis.

Correct diagnosis

COPD is confirmed. Spirometry test results are not discussed in detail including what this means for severity and ongoing treatment and management.

Emotion: Anger, shame / embarrassment, anxiety, fear, mood swings, stigma, shock.

Living with COPD

COPD is a progressive and lifelong condition. Many people with COPD live with other health conditions (comorbidities) that also require treatment and self-management. Fragmented care coordination for COPD, and comorbidities, causes additional stress from navigating the health system. Patients must be educated and empowered with the support of a range of HCPs in their team to live well.

Emotion: Confronted, disheartened, frustrated. Social isolation from stigma and/or symptom burden. Feelings of confidence and hope created with access to evidence-based support.

COPD exacerbation

Exacerbations (flare-up of normal symptoms) contribute to disease progression and worsening severity. Often results in ED visit due to anxiety and terror of breathlessness. Hard to communicate needs in high stress environment in ED e.g. speaking while breathless, confusion or exhaustion from low oxygen saturation.

Emotion: Terror, fear, anxiety, frustration, helplessness, feeling of impending doom.

Hospital discharge

Transition from hospital to home planning is critical. Involves referral and education on available supportive care. Poor communication in a patient's discharge can affect likelihood of readmission. Patients need clear instructions on next steps for self-management to be pro-active and empowered. Perceived judgement and stigma results in resistance or hesitation to seek future medical care.

Emotion: Fear, anxiety, uncertainty, confusion.

Disease progression

Increasing breathlessness, patients have little access to or knowledge about symptom control options. Increased need for supportive care with activities of daily living. Difficult to access available care services and equipment due to eligibility criteria commonly excluding progressive conditions e.g. COPD.

Emotion: Exhausted, anxious and overwhelmed. Feel helpless and ignored when deterioration perceived as end of life.

End of life

Patients often unaware that end of life care (form of palliative care) is available to people with chronic conditions such as COPD. Many HCPs don't bring it up with patients, families, and carers as they lack confidence and formal training on how to discuss dying.

Emotion: Frightened, distressed, anxious, sad, alone and isolated.

Living with COPD

COPD impacts every aspect of a person's life, including physical and mental health, relationships, work, finances and interests.

People living with COPD often experience breathlessness, coughing and wheezing. Ultimately, these symptoms can occur daily and get progressively worse over time.

“Not being able to breathe is the most frightening experience you can have.”

- Kaye, living with COPD

COPD can interrupt daily activities, sleep patterns and the ability to work and exercise.

People with COPD rate their health as worse than people without the condition. In the 2017-18 National Health Survey, of those aged 45 years and over with COPD:

- One in five (20%) rated their health as poor, compared with 5.4% of those without COPD
- People with COPD were more likely to report high (19%) and very high (17%) levels of psychological distress compared to people without COPD (8.3% and 4.0%, respectively)
- People with COPD were more likely to report moderate (36%) and severe (22%) bodily pain compared to people without COPD (23% and 7.8%, respectively)⁴⁴.

People with COPD often have other chronic diseases and long-term chronic conditions.

In the 2017-18 National Health Survey (NHS), for people aged 45 and over with COPD, 90% had at least one other chronic condition; among them, 55% had arthritis and 43% had asthma. Nearly one in five (18%) had one other selected chronic condition, and over two in three (72%) had two or more other selected chronic conditions²⁶.

Chronic conditions that are commonly found in people with COPD, and that can impact on COPD, include:

- Arthritis
- Asthma
- Back problems
- Cancer
- Diabetes
- Heart, stroke and vascular disease

- Kidney disease
- Mental and behavioural conditions
- Osteoporosis
- Bronchiectasis
- Obstructive sleep apnoea^{45, 46}.

Comorbidities can complicate management options and multiply the effects of chronic conditions. Cardiovascular disease in COPD is often unrecognised and untreated, further biasing people living with COPD from receiving best-practice management^{47, 48}. Living with COPD and managing different conditions often means balancing multiple, and at times competing, priorities⁴⁶.

“When you are diagnosed with COPD, other organs or parts of your body also become affected. Because your lungs don't work normally, it puts strain on your heart and other organs and parts of your body and they also become a medical problem. I like to view this as looking at a motor vehicle. If you keep it serviced, it will perform well and last forever. Whereas, once people are diagnosed with COPD, it then affects other organs or parts and ruins your life plans and affects family and friends.”

- John, 76 years, living with COPD

The community, health professionals, and even patients themselves often blame the person with COPD for their condition, on the grounds that COPD is seen as a self-inflicted condition due to smoking tobacco being the leading cause of COPD. People with COPD are more likely to report experiencing stigma, irrespective of their smoking history, compared to those with other chronic illnesses or no chronic illnesses and this stigma is strongly related to delays or avoidance in seeking help from GPs when needed⁴⁹. Stigma can negatively impact every stage of a patient's COPD journey⁵⁰.

“So many people have no idea what COPD actually is, but most people do know what emphysema is and associate that with being a “smoker’s disease” – thus the judgement and stigma. I have actually had someone say to me that I deserve to be sick. Because of this stigma, I tell people I have a lung disease. I don’t go into any more detail. It avoids judgement. I tell people I get breathless really easily and I’m limited with what I can do physically. What I tell people very much depends on who they are and how close they are to me. Obviously, my family and friends know almost everything. But, outside that, I avoid going into detail unless it’s necessary.”

- Cathy, 61 years, living with COPD

Many people with COPD are still in the prime of their working lives, however, older workers with a chronic health condition are more likely to prematurely withdraw from the workforce³⁹, negatively impacting individual earnings and societal productivity.

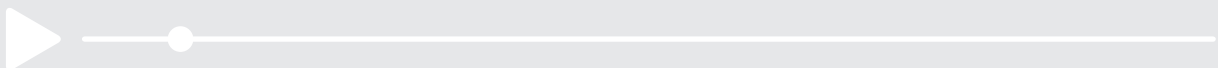
There is a substantial financial burden for Australians living with COPD. In 2008, it was estimated that the financial cost of COPD is \$7,446 per person with COPD per year. When burden-of-disease costs are included (loss of wellbeing due to disability and premature death), the total cost of COPD is \$82,925 per person with COPD per year, of which 95% of these costs are borne by individual people living with COPD⁴⁰.

“Having COPD is just too expensive for people on pensions. You have to spend a fortune just to keep yourself breathing.”

- Kaye, living with COPD



Scan the code to watch
Meredith’s story with COPD.



Recommendations for COPD reform in Australia

- 1 Lifelong prevention of COPD
- 2 Early and accurate COPD risk identification and diagnosis
- 3 Community management
- 4 Acute care management
- 5 COPD research and translation

Priority area 1

Lifelong prevention of COPD

Priorities

A

Target modifiable COPD risk factors across all stages of life to promote lifelong lung health.

B

Accelerate efforts to reduce smoking prevalence and work towards a tobacco-free society by targeting the commercial and social drivers of smoking and supporting people to quit.

C

Improve indoor and outdoor air quality.

“

“Prevention of COPD is a lifelong process which includes prevention of the development of COPD, identifying those at risk of developing COPD, and diagnosing those who have COPD early so that action can be taken before COPD enters a slippery slope that results in premature death.

COPD can arise when lung function is impacted by multiple adverse exposures at any time during the full life-course. Although smoking is still the major risk factor, genetics, early life adverse events, infections and environmental hazards are also now recognised as risk factors.

A high proportion of COPD arises from sub-normal lung function trajectories that track from childhood, and these lung function deficits can precede the clinical diagnosis of COPD for many years. Intervention at this early stage may have the most impact. However, COPD is currently diagnosed when it is full blown and when most people have entered the deadly slippery slope.

This new knowledge provides a huge opportunity to prevent COPD, but many health professionals and the community are not aware of this. It is, therefore, timely to raise awareness, develop strategies for lifelong prevention of this deadly disease, and identify those at risk – along with those who have early COPD – before they reach the deadly slippery slope.”

- Professor Shyamali Dharmage, The University of Melbourne

Outcomes

- Awareness raised that preventing COPD is a lifelong process.
- Poor lung function prevented by addressing all risk factors from early life. Lung health optimised by addressing risks and reducing exposures throughout life.
- COPD and future risk of developing the disease prevented through early identification of those at risk and intervention with health education and lung-health promotion.

Overview

A substantial proportion of the COPD burden is related to non-genetic causes that are modifiable and, therefore, preventable. Prevention of such avoidable risk factors, through strategies addressing COPD risk factors at all stages of life, including smoking cessation programs and clean air initiatives, is critical to address the expected increase in COPD disease burden. Preventing COPD by reducing smoking and air pollution has the additional benefit of also significantly preventing cardiovascular disease and lung cancer^{51, 52}.

Australia currently allocates less than 2% of all health spending to prevention⁵³. This situation is now poised to change following a commitment in Australia's National Preventive Health Strategy to increase the investment in prevention to 5% of total health expenditure across Commonwealth, state and territory governments by 2030⁷.

Australia is currently ranked 20th in the world for per capita expenditure on preventive health⁷.

There is clear evidence that many preventive health interventions are cost effective and offer good value for money^{7, 54-57}. Public health interventions are highly cost saving, returning an average of \$14.30 in benefits for every \$1 invested⁵⁸.

A COPD risk factors and lifelong lung health

While tobacco smoking is still considered as the major risk factor for COPD in many high-income countries, it is now clear that there are multiple COPD risk factors unrelated to smoking. This is demonstrated by the fact that up to 40% of people with COPD have never smoked tobacco⁵⁹.

These non-tobacco factors that result in COPD can affect anyone. No individual or group is exempt. Multiple risk factors can coexist, overlap and interact with each other throughout an individual's life, meaning their combined impact is multiplicative and not simply additive. Smoking rates are declining both nationally and globally, and the contribution that non-smoking-related factors make to the burden of COPD is likely to surpass the risk attributable to smoking within the next two decades⁶⁰. These risk factors can impact throughout an individual's life, affecting lung development and lung growth and/or decline. This, in turn, can create multiple pathways to reduced lung function and the development of COPD⁶¹. These pathways include COPD arising from lung function trajectories that do not reach peak growth by early adult life and/or that have an accelerated decline after this point⁶².

While knowledge has increased about the role risk factors other than smoking can play in developing COPD, there have been significant challenges involved in raising community awareness of such factors. Important and overlooked risk factors for COPD that can span the course of an individual's life include familial and genetic predisposition; prenatal and early-life events; frequent respiratory infections; and detrimental environmental exposures, such as occupational exposures and both indoor and outdoor air pollutants^{60, 63-68}.

Early-life-events include adverse events occurring in utero, such as smoke exposure and prematurity⁶⁴. Interestingly, recent evidence suggests that the exposure of parents to smoking when they themselves were in utero or during childhood and adolescence increases the risk of poor lung function consistent with COPD⁶⁹. This suggests that there could be transgenerational effects linked to COPD. While such past exposures cannot be modified during an individual's life span, information on transgenerational effects has the potential to bring an additional impetus to reduce risk behaviours. Impaired lung growth during childhood caused by a range of early-life adverse exposures, including early-life respiratory infections and uncontrolled childhood asthma, is associated with an increased risk of COPD^{60, 70}. Detrimental environmental exposures not related to smoking can include life-time air pollution exposures and occupational exposures⁷¹⁻⁷³. Apart from having a direct major impact of its own, smoking can also accentuate the adverse impact of most of these lifetime risk factors, which can then lead to COPD.

It is time to embrace a new view of COPD that moves beyond the connection to smoking, without diminishing the importance of smoking as a risk factor. A broadened understanding of the multiple and interacting risk factors for the disease provides an opportunity for COPD to be recognised more broadly – and not just as a disease of smokers. Such a view can form the basis of coordinated, evidence-based action to prevent and reduce future risk of COPD and promote lifelong lung health. This demands a lifetime approach to preventing COPD due to the very strong evidence identifying modifiable risk factors from early life through to adulthood.

Recommendations

- 1.1. Deliver a national education and awareness campaign targeting health professionals and the wider community that highlights non-tobacco COPD risk factors and the early origins of lung disease.
- 1.2. Ensure that health-professional training (vocational, undergraduate and post-graduate), including medical curricula, reflects the evidence regarding multiple COPD risk factors and the early origins of lung disease.
- 1.3. Invest in COPD prevention policy and programs at all stages of life (prenatal, infancy, adolescence, young adults, older adults), including:
 - Smoking cessation programs, including a focus on pregnant women and young people
 - Preconception and antenatal education and care (e.g., specialised clinics) to reduce the rate of preterm delivery
 - Education about transgenerational effects of smoking
 - Clean air, e.g., wood heater replacement, air purifier subsidy
 - Public health measures such as vaccination and hand hygiene to prevent respiratory tract infections in early life
 - Optimising asthma management in childhood and throughout young adulthood
 - Improving healthy eating and increasing physical activity, which are linked to better lung function
 - Workplace health and safety initiatives, including worker education, to minimise occupational exposures.

B Smoking cessation and tobacco control



“Far from being a ‘lifestyle choice’ or a ‘bad habit’, tobacco smoking is an addiction that is typically started in adolescence and leads to devastating health consequences such as COPD. People with COPD and other smoking-related diseases deserve compassion and support. It’s also critical that the Australian Government develops and implements a national plan for phasing out tobacco cigarettes from general retail stores. Cigarettes fall far short of the level of safety that Australians reasonably expect for consumer products. It’s time to regulate their supply in line with their harmfulness and addictiveness.”

- Professor Coral Gartner, The University of Queensland

Smoking tobacco is still the leading cause of COPD⁴⁶, and the leading cause of death and disease in Australia.

At all stages of prevention, smoking cessation is the single most effective way to prevent COPD and slow its progression. Stopping smoking can prevent and delay the development of COPD, reduce its progression, and can have a substantial effect on subsequent mortality⁷⁴.

Smoking is a highly stigmatised risk factor for COPD^{49, 50, 75}. The wider community, health professionals, and even patients themselves often blame an individual with COPD for their condition, on the grounds that COPD is seen as a self-inflicted condition due to smoking tobacco being the leading cause of COPD.

People with COPD are more likely to anticipate being stigmatised, irrespective of their current smoking status, compared to those with other chronic illnesses or no chronic illnesses. This perception is strongly related to a delay or avoidance in seeking help from a GP when needed⁴⁹. Stigma can negatively impact every stage of a patient’s COPD journey⁵⁰.

“I hope we reach a place where we aren’t treated like it’s your fault for having COPD if you smoked. I smoked, but I also had respiratory problems from birth. Who is to know how I got it? I deserve to be treated with kindness and respect, not condemnation.”

- Naomi, 48 years, living with COPD

Smoking is often linked with socioeconomic status, ethnicity, education level and geographic remoteness. Differences in smoking rates are seen between urban and rural populations, as well as between Aboriginal and Torres Strait Islander peoples and non-Indigenous communities. It is critical that smoking-cessation and tobacco-control efforts actively support a paradigm shift from viewing smoking as a lifestyle choice to seeing it as an addiction, typically developed in adolescence. It should be noted that tobacco use disorder is classified as a medical condition in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) publication⁵⁰.

Tobacco products are extremely harmful and expose people to many chemicals that cause debilitating and deadly diseases. The nicotine in tobacco products is a highly addictive drug for which patterns of use and the development of dependence are strongly influenced by structural factors such as availability, price, social pressures, and regulations. For many years the tobacco industry has profited from a substance that is known to be harmful and addictive, all the while promoting smoking as a “free choice”. The tobacco industry is extremely well resourced and continues to launch new cigarette brands and new products, to market to youth, and to challenge effective tobacco control legislation with a focus on maximising sales and profits⁷⁶. Furthermore, the continued widespread availability of tobacco products in general retail stores contributes to the addictiveness of smoking by making tobacco highly accessible. People who want to quit smoking encounter triggers to purchase tobacco products every time they visit supermarkets, convenience stores, and petrol service stations. The relatively lax restrictions on tobacco retailing compared to other highly harmful and addictive substances also reduce perceptions of tobacco’s harmfulness. This regulatory anomaly should be urgently addressed⁷⁷.

Additionally, urgent action on e-cigarettes is needed, with current use by young Australians already high and increasing. Despite nicotine-containing e-cigarettes being illegal without a prescription, we know that Australians, including children, are accessing these harmful devices, which may lead to long-term lung damage. In 2019, 26.1% of people aged 18-24 reported having ever used e-cigarettes⁷⁸. A high proportion of e-liquids that claim to be nicotine-free, actually contain nicotine, thus facilitating nicotine addiction in young people⁷⁹. The growth in e-cigarette use, particularly the flavoured e-liquids (both with and without nicotine), presents a significant public health challenge and is undermining Australia’s tobacco control successes of the past decades. There is evidence that e-cigarettes are both harmful and associated with future tobacco use⁸⁰. The e-cigarette industry continues to grow rapidly, and current controls are failing to protect young people.

Australia has been successful in reducing smoking rates through the implementation of a range of world-leading policy levers, public awareness campaigns and program supports. However, tobacco-control policy implementation in Australia has slowed in recent years. At the same time, a number of other countries are implementing ongoing, progressive approaches. In New Zealand for example, measures include reducing the nicotine content of cigarettes to non-addictive levels, rapidly reducing the number of tobacco retail outlets by 95%, and completely phasing out sales of cigarettes by banning sales to anyone born after 31 December 2008^{81, 82}. Meanwhile, Australia is lagging on both new tobacco-control policies and traditional policy approaches. There has been no national mass media anti-smoking campaign since 2018⁸³. A consumer-led, refreshed national mass media campaign is required in Australia that links smoking to COPD and other common conditions, such as heart disease and stroke, emphasises the role the tobacco industry plays in putting profits before health and creating addicted customers, and supports people to quit in a supportive and non-judgemental way.

Australia’s National Preventive Health Strategy 2021-2030 includes the goal of reducing smoking rates to below 10% by 2025 and 5% or less for adults by 2030⁷, however it lacks clear actions on how this will be achieved. Furthermore, while Australia is a signatory to the World Health Organization’s (WHO) Framework Convention on Tobacco Control (FCTC)¹⁸, we currently fall

far short of adopting the full suite of measures needed to ensure our goal of reducing smoking rates is achieved. Since 2018, Australia has fallen out of the best-practice group in relation to the provision of cessation services, tobacco taxation and mass media campaigns⁸⁴, indicating a waning commitment to the basic measures outlined in the FCTC. New approaches, such as those being progressed in New Zealand, are also supported by the FCTC, which requires parties to regulate the contents and emissions of tobacco products (such as nicotine level).

A renewed focus and targeted investment in tobacco control is required to realise our national goals and international commitments.

Ending the tobacco epidemic is a priority for all Australian governments and has a high level of public support for policy measures aimed at reducing tobacco-related harm⁷. Significantly reducing and eventually eliminating the use of tobacco in Australia would dramatically reduce illness and improve quality of life. It would also reduce health, social and economic inequalities for people who smoke, their families and the wider Australian community – particularly for Aboriginal and Torres Strait Islander peoples who suffer disproportionately from the impacts of tobacco use. It would prevent hundreds of thousands of premature deaths and reduce the burden of costly diseases attributable to tobacco, including heart disease, lung cancer and COPD⁷.

Recommendations

- 1.4. Launch and implement the National Tobacco Strategy in 2022, with clear actions and appropriate investment. This should include a refreshed, national mass media campaign that portrays the tobacco industry as the root cause of smoking-related diseases, including COPD and other chronic conditions.
- 1.5. Implement the National Preventive Health Strategy 2021-2030, especially the policy goals of reducing tobacco supply, availability and accessibility; introducing stronger regulation of the contents of tobacco products (particularly nicotine content); and ensuring smoking rates fall to below 10% by 2025 and below 5% by 2030.
- 1.6. Embed smoking cessation support at every point of the COPD patient journey.
- 1.7. Increase access to affordable and effective smoking cessation support.
- 1.8. Deliver a national education and awareness campaign to address the stigma associated with COPD among people with COPD, health professionals and the general community.
- 1.9. Ensure health professional training (vocational, undergraduate and post-graduate), including medical curricula, emphasises that tobacco dependence is a recognised medical condition that is driven by a commercial industry.
- 1.10. Continue investment in the National Tackling Indigenous Smoking Program⁸⁵ and other initiatives to tackle smoking in Aboriginal and Torres Strait Islander communities.
- 1.11. Take urgent action in response to the rapidly escalating rate of e-cigarette uptake among young Australians by strengthening enforcement of existing laws. This includes eliminating all sales of e-cigarette products, components and liquids that fall outside of the existing TGA prescription pathways. This includes both domestic retail sales (brick-and-mortar and online) and overseas imports.

C Air quality

“Ensuring healthy lung growth throughout childhood is essential to having healthy lungs as an adult. At all stages of life, healthy lungs must breathe clean air to minimise the risk of COPD. It is essential to avoid unnecessary exposure to smoke, dusts and fumes and to reduce the risk of lung infections throughout life.”

- Professor Christine Jenkins AM, The George Institute for Global Health and UNSW Sydney

Lungs are designed to breathe clean air. The environments in which an individual works, lives, and plays will have significant short- and long-term impacts on their health. Air pollution is defined as the presence in the atmosphere of one or more contaminants – such as dust, fumes, gas, mist, odour, smoke or vapour – in quantities and for a duration that can damage human health. Multiple pollutants can potentially interact with each other to produce a greater combined effect than they would have individually. Such complex interactions may become more complex and prevalent in the future in line with climate change^{52, 86}. Air pollution is responsible for \$16 billion in costs annually, as well as more than 3,000 premature deaths in Australia alone⁸⁷.

The main pathway for exposure to air pollution is inhalation. Short-term effects can manifest in the form of an exacerbation of existing symptoms, impaired lung function, and increased hospitalisation and mortality rates. Long-term exposure to air with a high concentration of pollutants may also increase the incidence of COPD. In 2018, air pollution in Australia was causally linked to six diseases, including both COPD and lower respiratory infections (which can lead to COPD).

Prohibiting all kinds of smoking and eliminating exposure to any form of air pollution, both indoor and outdoor, would greatly reduce the burden of COPD⁵⁹. The impact of air pollution on COPD can be mitigated by maintaining a healthy lifestyle, including avoiding smoking and occupational exposures, maintaining physical activity, and having a healthy diet.

Outdoor air quality can be impacted by man-made, natural and seasonal events, such as bushfires, wood fires, road traffic, construction, mining, transportation, agriculture and other occupational and manufacturing processes. Motor vehicles are the major emitters of ambient air pollutants in urban Australia. However, rural and regional Australia faces issues of managing windblown dust from mining and agriculture, smoke and agricultural sprays. More action is needed.

It is well known that indoor air quality can influence lung function decline⁸⁸, which can lead to the development of COPD and also COPD exacerbations. Wood-burning heaters are often admired for the ambience they produce. However, smoke from wood heaters is a major source of air pollution in many parts of Australia and remains a real and significant health hazard. Using gas for cooking and heating can release a variety of air pollutants and worsen indoor air quality, which again can cause and exacerbate lung conditions, including COPD.

More than 40% of the world’s population is still exposed to high levels of air pollution from either indoor or outdoor sources or a combination of both. While air pollution levels are low in Australia, there is now recognition of the fact that there are no safe levels of air pollution. Even low air pollution levels can have major health impacts⁸⁹, particularly when experienced in combination with other risk factors. It is important Australia does not become complacent and instead takes a more proactive approach to protecting health and ensuring good air quality.

Recommendations

- 1.12. Develop a National Air Quality Strategy to complement the Australian Government’s National Strategic Action Plan for Lung Conditions.
- 1.13. Adopt the World Health Organisation Global Air Quality Guidelines (AQG).
- 1.14. Ensure air-quality guidelines and air-quality strategies take health impacts into consideration, not only the environment.



Research priorities for priority area 1: Lifelong prevention of COPD

- Explore novel and pragmatic approaches to identify those at risk of developing COPD (pre-COPD/early COPD).
- Identify interventions to prevent progression of pre-COPD/early COPD.
- Undertake behavioural insights research with a range of stakeholders, including people living with COPD and health professionals. This should be aimed at ensuring that community-awareness activities and upskilling of health professionals in COPD prevention is tailored to the audience and effective at influencing behaviour. This should include a focus on barriers to adoption of COPD management guidelines (known as COPD-X) and how to overcome them, the uptake of effective self-management practices, and overcoming clinical and political complacency.
- Explore changing COPD epidemiology including emerging novel risk factors, and the burden and costs of COPD.
- Investigate the short- and long-term impact of e-cigarettes on lung health, including COPD.
- Investigate the impact of vaping on young lungs, including direct and passive exposure among teenagers.
- Explore effective interventions to reduce stigma associated with COPD and other lung conditions.
- Investigate options for reducing tobacco supply, availability and accessibility, and regulating an unregulated industry. Focus on the supply of vaping liquids through internet sales, social media promotion, and illegal trade practices through shopfront sales.
- Examine the combined effects of different pollutants, which are likely to become more complex with climate change.
- Conduct additional research on populations at risk and formulate corresponding protective strategies, especially around targeted smoking-cessation education and support.
- Investigate interventions to reduce harm on the lungs from air pollution, such as air purifiers and mask wearing.



“I think the Government needs to look at what is going to happen in the next few years due to the climate changing, with smoke from bushfires affecting so many people of all ages, and then also the significant rain we are experiencing is also affecting people. In summary, a lot of people are going to have lung infections in the near future and will be putting their hand out for help unless something is put in place now to help them and be able to put their hand up and say they are doing something about it.”

- John, 76 years, living with COPD



Naomi's story

In 1974, I was born nearly three months early due to my mother having placenta praevia. I was 1.1 kilograms and was born not breathing. The doctors managed to save my life, but I developed foetal respiratory distress syndrome. Over the next few years, I was plagued by chronic bronchitis, pneumonia and felt like I lived in an oxygen tent. Eventually, my parents realised it was due to my having a hole in my heart from birth (patent ductus arteriosus, or PDA) and I was operated on at six years of age.

Growing up, I no longer had many respiratory issues and it wasn't until after I had my first child at 21 that a lung X-ray showed the extent of the scarring on my lungs. Doctors at the time said that there was nothing to worry about, so I didn't.

Due to childhood trauma, I started smoking at 16. It was my best friend and crutch. I always came back to cigarettes after having my children. It wasn't until my 30s that I started coughing and getting breathless. I was told by doctors it was because I smoked. 'Give up' they said, which without help or addressing the underlying cause was next to impossible. Eventually after continual infections, I was diagnosed with asthma and put on a preventer which did help at the time.

In 2010, I fell pregnant for the third time and during the third trimester I could not control my coughing. I sometimes thought I was going to black out. Yet again, the doctor I saw made me feel like it was all in my head. But I knew it wasn't normal. It wasn't until December 2020 that I had enough. I had already had six lung infections that year and I wanted my asthma assessed. I couldn't live like this anymore.

Seven months prior, I had successfully quit smoking and wanted a solution so I could close this chapter of my life. I requested an appointment with a respiratory specialist.

While I was having my lung function test, I wasn't worried, except about the technician, who was getting frustrated with me because, apparently, I wasn't doing it right. Upon completion she casually told me I showed signs of COPD. My world stopped. The only thing I knew about COPD was the clients I saw in my professional years before who were terminal.

With my mind reeling, I saw the specialist who told me I was stage 2 COPD with 72% lung capacity. I kept thinking, I have a nine-year-old and I have to work for over 20 more years. What am I going to do? He was quite abrupt, said that it's not so bad and could be worse. I asked if many people in their 40s get diagnosed, and he said it's one of the largest groups he sees. The first medication I tried I ended up with mouth ulcers to which three different doctors told me never happens with that medication. Finally, I summoned the courage to insist I change medication and haven't looked back. My yearly lung function test in February this year showed 80% capacity, which I didn't know could happen. I thought you only went downhill not up. But I'm not complaining.

At nearly two years since diagnosis, I have learnt a lot and I live my life with plans in place for if something happens but I'm trying not to let it define me.

Pictured: Naomi, 48 years, living with COPD and her daughter Cate.

Priority area 2

Early and accurate COPD risk identification and diagnosis

Priorities

A

Embed COPD risk assessment and the earlier identification of those at risk and those with COPD within Medicare services.

B

Urgently explore opportunistic and systematic case-finding for COPD.

C

Identify strategies to enhance spirometry use and access in primary care.

D

Pilot innovative strategies to enable the earlier performance of spirometry in the life course, including respiratory diagnostic hubs and referral pathways.

“

“It can be years before people with COPD arrive at a formal diagnosis, or they never receive one at all. Everyone who presents with breathlessness should receive a timely diagnosis and the treatment they need. Early and accurate diagnosis of COPD is critical, along with the earlier identification of those at risk of developing COPD as they will benefit from targeted prevention strategies and ultimately, improved outcomes.”

- Dr Kerry Hancock, GP

Outcomes

- People at risk of developing COPD and those with early-stage disease proactively identified in community healthcare settings.
- More timely and appropriate medical and risk-modification interventions provided to support improved outcomes for those at risk of developing, and those with, COPD.
- Late and misdiagnosis of COPD minimised.

Overview

The rates of underdiagnosis and misdiagnosis of COPD in Australia are substantial^{19, 90}.

Inaccurate diagnosis is more common in younger patients and those with comorbidities⁹⁰.

The substantial underdiagnosis of COPD^{16, 19, 21} means that the number of Australians living with COPD is much higher than the data indicates. Around 50% of people with COPD symptoms do not know they have it. What's more, few advances have been made in the way COPD is detected.

A delayed or inaccurate diagnosis can mean that people don't receive the care they need when it matters most. Without this timely intervention, it can be difficult to control exacerbations and to stop the progress of the disease. Early and accurate diagnosis supports more timely and more appropriate medical and risk-modification interventions and, consequently, improved outcomes.

The early identification of those at risk of developing COPD is critical as they will benefit from targeted prevention strategies, including risk modification and close monitoring.

A

Embed COPD risk assessment and the earlier identification of those at risk and those with COPD within Medicare services

A proactive approach to identifying people at risk of developing COPD, and early and accurate diagnosis and intervention is critical.

1 in 13 Australians over the age of 40 are estimated to have COPD, however a large number of people are undiagnosed. Additionally, some have early COPD and are marching towards development of what is defined as COPD under the current definitions. Many of these interact with the health system on a regular basis but remain undiagnosed because:

- people do not recognise the symptoms as they develop gradually over a long period of time;
- many people think it is normal to have a cough and to be short of breath;
- people often put the symptoms down to smoking and think nothing can be done; and
- doctors often treat the symptoms but fail to diagnose the underlying lung disease⁹¹.

This lack of early diagnosis leads to poor outcomes for people when they are diagnosed, with a reduced chance of survival and a significantly impaired quality of life. COPD is a progressive disease, which means it gets worse over time. However, with timely and appropriate care and treatment, there is the potential to slow down or modify the progressive nature of the disease.

Embedding risk assessment and the earlier identification of those at risk of COPD and those with COPD within Medicare services would recognise the time and skill required by GPs in delivering such preventive health care, and is recommended against

the backdrop of persistently inadequate investment in COPD and respiratory health.

Two new Heart Health Check items introduced to the MBS in 2019 provide a clear example for how Medicare can support the earlier identification of chronic conditions, enabling more timely and appropriate medical intervention with a view to supporting improved outcomes (See Box 1). Taking a similar approach to the Heart Health Check items, an interim Lung Health Check item could be added to the MBS and then monitored over time to measure impacts and outcomes. It could then be adjusted accordingly.

Recommendations

- 2.1. Introduce a new interim MBS item to allow GPs and medical practitioners to conduct a Lung Health Check specifically for young adults with chronic respiratory symptoms and/or risk factors and linked to the performance of spirometry, to support the earlier identification of COPD and active intervention to support improved outcomes.
- 2.2. Incorporate lung health assessment using a validated pragmatic risk calculator into existing chronic-disease related MBS item: Health assessment for people aged 45 to 49 years who are at risk of developing chronic disease, MBS item 701 (brief), 703 (standard), 705 (long) and 707 (prolonged)⁹².

Box 1: MBS items for Heart Health Check

Two new items were introduced to the Medicare Benefits Schedule (MBS) in April 2019 to allow GPs (item 699) and medical practitioners (item 177) to conduct a heart health check that lasts at least 20 minutes.

These MBS items are specifically for assessing the cardiovascular risk of patients. They support the earlier identification of cardiovascular disease and more timely and appropriate medical intervention to support improved outcomes.

MBS item 699

Professional attendance on a patient who is 30 years of age or over for a heart health assessment by a general practitioner at consulting rooms lasting at least 20 minutes and including:

- collection of relevant information, including taking a patient history
- a basic physical examination, which must include recording blood pressure and cholesterol
- initiating interventions and referrals as indicated
- implementing a management plan
- providing the patient with preventative health care advice and information.

Fee: \$76.95 Benefit: 100% = \$76.95⁹³

There have been over 360,000 Heart Health Checks claimed between April 2019 and September 2022. There has been notably strong primary health care professional engagement with over 87,000 health professionals accessing the Heart Foundation's Heart Health Check Toolkit to support implementation of Heart Health Checks in primary care.

B

Opportunistic and systematic case-finding for COPD

The aim of targeted COPD case-finding is to identify those at risk of developing COPD (refer to Box 2) and those with undiagnosed COPD, as they will benefit from early intervention, including risk modification strategies and disease management⁹⁴.

Given the substantial number of people with COPD who are not yet diagnosed, there is a clear case for targeted case-finding strategies for COPD

within community health care settings, such as general practice and pharmacies. Opportunistic and systematic case-finding for COPD in such settings can support the early and timely diagnosis of COPD and deliver improved outcomes for individuals. The identification of people at risk of developing COPD is important to enable targeted prevention strategies including risk modification and close monitoring, which are important to slow and perhaps arrest the development of COPD⁵⁹.

COPD prediction models are being developed to identify individuals at risk of COPD⁹⁵, however the tools currently available to predict COPD are limited. This is in stark contrast to the tools and protocols available for type 2 diabetes and heart disease. For these conditions, risk calculators created using algorithms derived from prediction models can be used to educate the public about their risks and to flag the need for further clinical steps. In the case of type 2 diabetes, this may include confirmatory tests, while for cardiovascular disease it can be checks for elevated blood pressure and lipids. There is a pressing need for new and innovative approaches, such as risk calculators to improve the risk assessment and prediction of COPD, and research and funding to develop and test these approaches.

The proactive identification and diagnosis of patients at risk of or with early COPD can be supported in primary care settings through a number of measures. These include heightened professional development, suitably adapted medical software packages, and clinical-decision support systems. Additionally, incentives and funding could be provided for audits and quality-improvement programs, such as the Practice Incentives Program Quality Improvement (PIP QI) initiative.

Recommendations

- 2.3. Urgently explore opportunities for the evidence-based early identification of those at risk of developing COPD.
- 2.4. Urgently explore opportunities and innovative strategies for early identification of those with COPD.



Scan here to read the Opportunistic and systematic case-finding for COPD - A GP experience with risk prediction and prevention advice.

Box 2: People at risk of having COPD or developing COPD

Individuals aged 35 years or older who meet at least one of the following criteria may be at risk of COPD and should be the focus of targeted COPD case-finding:

- Smoker or ex-smoker
- Works or worked in a job where they were exposed to dust, gas, or fumes
- Coughs several times most days
- Coughs up phlegm or mucus most days
- Out of breath more easily than others of a similar age
- Experiences chest tightness or wheeze
- Has frequent chest infections⁹⁴.

C

Identify strategies to enhance spirometry use and access in primary care

Spirometry forms the foundation for the diagnosis of COPD.

Despite the years-long emphasis on the crucial role of spirometry in the diagnosis of COPD, this simple technology is still not universally available, much less routinely used⁵⁹.

Even though spirometer ownership in general practice throughout Australia is high, the frequency of use is low⁹⁶, and has further declined during the COVID-19 pandemic. The decline in spirometry performance is likely to result in a corresponding decline in technical ability. The low rates of spirometry performance and test accuracy in general practice suggest the need for the delivery of comprehensive and regular training in spirometry performance and its interpretation (see priority area 3A: Workforce education and training), as well as for specialist confirmation of 'probable COPD' diagnoses in primary care.

A survey of Australian general practitioners suggests that some of the barriers to providing spirometry in primary care include equipment costs and insufficient remuneration⁹⁶. Meanwhile, the COVID-19 pandemic has created additional costs of providing infection control and these are likely to present an additional barrier.

See Table 2 for spirometry fees and benefits.

Table 2: Spirometry fees and benefits under the Medicare Benefits Schedule (MBS)^{97, 98}

	Item	Schedule Fee	Patient rebate 85%
Spirometry – Diagnosis	11505	\$45.30	\$38.55
Spirometry – Monitoring	11506	\$22.65	\$19.30

Recommendations

- 2.5. Increase the MBS rebate (Item 11505) for diagnostic spirometry in primary care, commensurate with the time and skill required.
- 2.6. Ensure that 'probable COPD' diagnoses in primary care are confirmed by spirometry and specialist review, with interpretation by telemedicine available to optimise access, particularly in rural and remote areas.

D Pilot innovative strategies to enable the earlier performance of spirometry in the life course, including respiratory diagnostic hubs and referral pathways

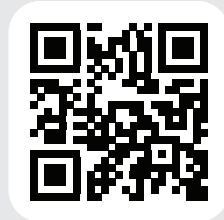
COPD is a prevalent respiratory disease, yet erroneous or delayed diagnosis in primary care is common.

It is critical that strategies are explored to enable the performance of spirometry earlier in the life course. A recent UK study suggests that respiratory diagnostic hubs (RDHs) within primary care are effective in establishing diagnosis in patients with suspected COPD and asthma⁹⁹. Further investigation is required into the potential role of RDHs and referral pathways in enabling the earlier performance of spirometry, improving patient access and supporting an accurate diagnosis of COPD.

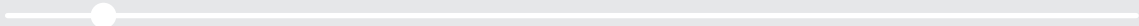
It is important that strategies are developed that target areas and population groups experiencing high COPD burden. This includes people living in remote areas, people in areas of socioeconomic disadvantage and Aboriginal and Torres Strait Islander peoples.

Recommendations

- 2.7. Pilot respiratory diagnostic hubs for people with chronic lung symptoms and/or risk factors for chronic respiratory disease and facilitate referral pathways to facilities with respiratory laboratories.



Scan to watch our webinar on spirometry to get a better understanding of its role in managing lung health.



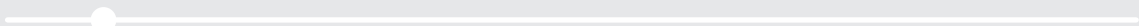


Research priorities for priority area 2: Early detection and accurate diagnosis

- Develop and trial pragmatic and feasible COPD risk-prediction tools to identify people at risk of developing COPD or with early COPD. Include digital tools.
- Explore new approaches for accurate, accessible and affordable diagnosis of COPD via tests with increased sensitivity to detect the pathological processes associated with COPD at an early stage.
- Explore evidence-based opportunities to increase spirometry use and access, including respiratory diagnostic hubs and mobile spirometry services.
- Evaluate the health and economic benefits of case-finding, screening and early diagnosis.
- Explore the earlier onset of COPD in individuals who have never smoked.
- Support the uptake and implementation of the Practice Incentives Program Quality Improvement (PIP QI) initiative for COPD.
- Tailor culturally appropriate strategies for COPD risk assessment and the early detection of COPD in Aboriginal and Torres Strait Islander peoples.
- Reach and effectively engage with Aboriginal and Torres Strait Islander peoples and non-English speaking communities regarding COPD.



Scan to hear about Meredith's
journey to a COPD diagnosis.



Priority area 3

Community management

Priorities

A

Workforce education and training.

B

Multidisciplinary care in the community.

C

Widespread access and uptake of pulmonary rehabilitation.

D

Immunisation availability and uptake for all people with COPD.



“Living well and staying out of hospital requires people with COPD to actively self-manage their condition, every single day. This includes managing multiple drug and non-drug treatments for COPD, as well as managing treatments for other chronic health conditions. The challenges of self-management are even greater for people with COPD living in rural and regional areas, those from culturally diverse backgrounds, and those who are socioeconomically disadvantaged, as these individuals may have even more limited support for their healthcare. Effective support for community management of COPD is critical, including access to multidisciplinary team-based care.”

- Professor Anne Holland, President Elect, The Thoracic Society of Australia and New Zealand (TSANZ)

Outcomes

- Skilled and competent workforce.
- Improved access to multidisciplinary care in the community.
- Appropriate funding mechanisms put in place to enable access to pulmonary rehabilitation and immunisation, driving better care and outcomes.
- Risk of respiratory infections is reduced through appropriate uptake of vaccinations.

Overview

COPD is a chronic condition which means that people often live with the disease for many years. Access to a range of health care services in the community is critical for the ongoing care and management of COPD and multimorbidities, including self-management support.

Community management of COPD occurs within primary care and across a range of community services. Timely and adequate health care in the community is critical and help to prevent hospital admissions.



“The most important thing I learned is knowing your limits. I have found that you can do all the things you once did but the dreaded breathlessness can catch you by surprise. You have to have an action plan in place and be prepared.”

- Naomi, 48 years, living with COPD

A Workforce education and training

A skilled and competent health workforce is critical to improving the care and outcomes of people living with COPD.

A range of health professionals have a role in the prevention, diagnosis, treatment and management of COPD in the community health care setting. These include general practitioners, practice nurses, pharmacists, physiotherapists, exercise physiologists and other allied health care providers, maternal and child health professionals, and Aboriginal and Torres Strait Islander health workers and cultural liaison officers.

Workforce education and training that focuses on promoting uptake of Australia’s guidelines for the

management of COPD, *COPD-X Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease*⁴⁶, is critical to drive the uptake of best evidence into routine patient care. See priority area 5B: Implement COPD guidelines. Key content areas for COPD workforce education and training are outlined in Box 3.

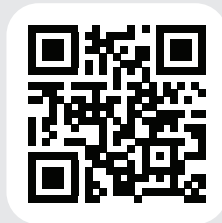
Education and training delivered by traditional and innovative techniques is required. To optimise accessibility, this should be available in a variety of formats, including face-to-face, online and blended learning. All education and training initiatives provided should meet the requirements of relevant professional bodies.

Box 3: Key content areas for COPD workforce education and training

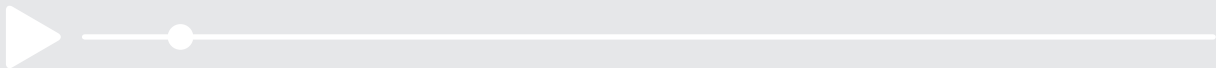
- COPD prevention, including multiple, overlapping, lifelong and interacting risk factors.
- Identification of people at risk of COPD, including symptoms and case-finding.
- Diagnosis of COPD, including spirometry use and referral pathways.
- Management using evidence-based strategies (including COPD Action Plans, self-management strategies, and guideline-based exacerbation management.
- Choosing an appropriate inhaler device and regular inhaler-technique checks – for example, see the UK algorithm on choosing an appropriate inhaler device for the treatment of COPD¹⁰⁰.
- Pulmonary rehabilitation
- Advanced care planning
- Referral pathways, including Pulmonary Rehabilitation, supportive and palliative care, multi-disciplinary teams, psychosocial support, community organisations, and peer support.

Recommendations

- 3.1. Develop and deliver a national COPD training and education program for health professionals involved in the prevention, diagnosis, treatment and management of COPD.
This should include:
 - Strategies focused on upskilling Aboriginal and Torres Strait Islander Health Workers.
 - Training and education on palliative care principles and practices, including referrals and advance care planning. This is particularly important for those working in primary care and ambulance services.
 - Promotion and scaling-up of existing education and training programs to increase reach and accessibility. See the Lung Learning Hub case study on page 40.
 - General-practice-based professional development activities that include reviewing outcomes and measuring performance, such as clinical practice audits.



**Scan to hear more from Adjunct Associate Professor
Debbie Rigby on the important role of pharmacists in the
community for disease management.**





Case study: The Lung Learning Framework and Hub

The competency-based Lung Learning Framework is a world-first in respiratory health. It is helping to set best-practice standards in Australia for the prevention, diagnosis and management of lung conditions. The Framework aims to standardise lung health education and training for the Australian primary healthcare sector and covers more than 15 professions within the industry.

The Framework has been consciously designed to reflect the lived experience of lung disease. It reinforces a person-centred approach and shared multidisciplinary support as the fundamentals of high-quality care. The four domains of the framework reflect the lung disease continuum from the promotion of healthy lungs to early detection and diagnosis

through to initial care and planning and self-management and ongoing care.

The Framework is designed for use by providers of lung health education and training, as well as individual health professionals. The accompanying Lung Learning Hub provides interactive access for both audiences to explore the competencies of the framework, as well as a curated collection of quality-assured education.



Scan here to read more and access the Lung Learning Hub.

B Multidisciplinary care in the community

Multidisciplinary care is integral to comprehensive COPD management. The COPD-X guidelines identify the key components of multidisciplinary care for COPD including pulmonary rehabilitation, smoking cessation, self-management training, inhaler technique training, management of mood, chest physiotherapy, nutritional management, symptom management, and palliative care⁴⁶.

Current funding models do not provide adequate access to comprehensive multidisciplinary COPD care in the community and are not adequately funded or designed to support best practice COPD care. For instance, Chronic Disease Management plans provide

only five allied-health consultations per annum, which, for many patients, is insufficient to deliver COPD-specific care and treatment of comorbidities. Mechanisms to support comprehensive team-based COPD care in the community are lacking. New strategies are needed to increase access to multidisciplinary care in the community, using funding mechanisms that are accessible to allied-health professionals and nurses in primary care. Patients repeatedly mention non-pharmacologic opportunities to manage their symptoms as a priority. They require greater access to allied health professionals to access these services.



“Patients greatly value the opportunity to learn about non-pharmacologic interventions for COPD. These include approaches to self-management, breathing techniques, physical activity, fans to help relieve breathlessness, and steps they can take to reduce their risk of getting respiratory infections and so prevent exacerbations. Patients often express their frustration that medications are prescribed too easily while these simple, affordable approaches are often not mentioned by their doctors.”

- Professor Christine Jenkins AM, The George Institute for Global Health and UNSW Sydney



“I would like more services tailored to an ever-growing group of younger Australians, living, working and raising families with COPD. For it to be treated like a chronic disease instead of a terminal illness.”

- Naomi, 48 years, living with COPD

Recommendations

- 3.2. Urgently explore funding models that will provide adequate access to comprehensive multidisciplinary COPD care in the community.
- 3.3. Support a fit-for-purpose model of Voluntary Patient Enrolment (VPE) that encourages continuity of care for patients within their preferred practice. This should include appropriate funding to support GPs and their practices to provide comprehensive and coordinated care for their enrolled patients and improved services enabled by the enrolment process.
- 3.4. Establish processes for earlier referral to symptom management or palliative care for people with lung conditions.
- 3.5. Ensure better access to early and timely supportive and palliative care, together with disease-directed care for people who have increasing needs and/or frequent acute deteriorations of health/admissions.
- 3.6. Fund and continue to evaluate and scale-up Lung Foundation Australia’s Respiratory Care Nurse Program to support people to navigate the health care system, including transition of care and self-management.



Scan here to view the COPD Action Plan. The COPD Action Plan is a template completed by a GP or specialist in conjunction with the patient to outline the best course of treatment in a flare-up or when symptoms are worsening.



“If you’re asking what good would look like, it’s that when somebody is diagnosed, they are handed an information pack about COPD. You just don’t get the time you need in a GP appointment. What are you going to learn in half an hour? They will receive that information pack, and then they can work out a plan as to what’s next. An informed patient is an empowered patient.”

- Ian, 75 years, living with COPD



Case study: Lung Foundation Australia’s Respiratory Care Nurse Program

Lung Foundation Australia’s Respiratory Nurse Program is a nurse-led self-management, education and coaching program for COPD patients delivered via telehealth. A recent evaluation of the program demonstrated the following outcomes:

- Improved patient health
- Improved patient health-related quality of life
- Reduced healthcare utilisation
- Cost-effective, providing an economic benefit to the health care system¹⁰¹.



Scan here to read the full evaluation report.



“People with COPD often have multiple medical problems in addition to COPD, and as result may experience challenging symptoms, social isolation and psychological distress. Offering patients and their carers early access to holistic care from a supportive and palliative team is therefore really important. Palliative care is not just about end-of-life care, it is about supporting patients and their carers, according to their needs, over the last years of life.”

- Associate Professor Natasha Smallwood, The Alfred Hospital and Monash University



“Given the increasing efforts to ensure equity and quality of care for older Australians in the community and in aged care facilities, it is notable that the prevalence of COPD is 30% in Australians aged over 75 years. Many of these people have undiagnosed COPD yet are seriously limited by it, and may suffer exacerbations and hospital admissions as result. Greater awareness and attention to their symptoms of breathlessness, as well as their comorbidities, will help them maintain their independence and improve their quality of life.”

- Professor Christine Jenkins AM, The George Institute for Global Health and UNSW Sydney



Scan here to read *The importance of living well in aged care - A COPD case study.*



C Widespread access and uptake of pulmonary rehabilitation

“If pulmonary rehabilitation were a drug, then we would prescribe it to every patient with COPD. Pulmonary rehabilitation is recommended in every COPD guideline across the world, and the benefits for patients and the health system are unquestionable. The absence of an MBS item number is a huge gap for Australians with COPD and is inconsistent with delivery of evidence-based care.”

- Professor Anne Holland, President Elect, The Thoracic Society of Australia and New Zealand

Pulmonary rehabilitation (PR) is the most effective evidence-based intervention to manage breathlessness for people with chronic airways disease, including COPD. PR programs help people breathe more easily, improve their quality of life and keep them out of hospital. See Box 4 for the benefits of PR.

Box 4: Benefits of pulmonary rehabilitation

- Reduces symptoms of breathlessness and fatigue
- Reduces hospital admissions and length of stay
- Reduces re-admissions post exacerbation
- Reduces mortality
- Increases quality of life
- Improves symptoms of anxiety and depression.^{102, 103}

Despite the clear clinical benefits, access to PR is limited in many countries and not available at all in some¹⁰⁴. Access in Australia is extremely limited. In 2013, it was estimated that less than 10 per cent of people with COPD had access to PR¹⁰⁵.

However, recent estimates by Lung Foundation Australia based on the number of services currently available suggest that just 5% of people who would benefit from PR can access it¹⁰⁶.

“We need an [MBS] item number for pulmonary rehabilitation and for maintenance exercise. For the life of me, I cannot understand why it’s so difficult to convince the politicians. Simple reason being, it’s far cheaper to refer a patient to pulmonary rehabilitation than to keep a patient in hospital. That’s just a no-brainer as far as I’m concerned. We know statistically that if you provide pulmonary rehabilitation, you keep people healthier and therefore reduce the burden on the healthcare system. So, why they refuse to ... well, so far, we’ve been unable to convince them ... is beyond me.”

- Ian, 75 years, living with COPD

Even when patients are referred for rehabilitation, not all take up the offer. A range of reasons for this are known¹⁰⁷ but two important factors are that existing programs are limited in number and are predominantly based in hospitals, thus limiting access for people with COPD who are managed in the community. Expanding service delivery of PR beyond the hospital setting into community and home settings would be a cost-effective way to significantly increase access¹⁰⁸. It is critical that PR is available to all Australians who need it.

The pandemic significantly disrupted the delivery of PR. Given the highly vulnerable nature of participants, many services were forced to temporarily shut down or to move to an online format as a contingency measure. As a result, many services now have longer wait lists and patients' conditions have often become more complex by the time they are eventually seen, due to factors such as comorbidities. The urgent re-establishment of PR services offered through hospitals to full-service provision is critical, as is the expansion of PR programs beyond hospital settings into the community.

“Aboriginal and Torres Strait Islander peoples with COPD usually do not access mainstream PR programs due to lack of cultural safety. An MBS item number for PR provided by Aboriginal Community Controlled Health Services is needed so that Aboriginal and Torres Strait Islander peoples have access to PR in a culturally safe environment.”

– Professor Jennifer Alison, University of Sydney

Recommendations

- 3.7. Introduce an MBS item and appropriate reimbursement for the completion of an eight-week program of pulmonary rehabilitation according to national standards for patients with a clinical diagnosis of COPD which is confirmed by spirometry.
- 3.8. Introduce a specific MBS item for Aboriginal Community Controlled Health Services (ACCHS) providing pulmonary rehabilitation.
- 3.9. Establish a national standardised referral mechanism for pulmonary rehabilitation to support access and participation for all people with COPD when referred by a medical practitioner.
- 3.10. Establish quality standards and a national audit for pulmonary rehabilitation delivery, to reduce variation and monitoring the impact of these recommendations on uptake and outcomes of pulmonary rehabilitation for Australians living with COPD.

“Often doctors tell their patients to go home and rest, but I have found that you need to keep active. Keep doing the thing you love, such as doing gardening and any hobbies that you enjoy. Also try and do your rehab exercises and keep learning as much as possible so you keep informed of what’s going on.”

– John, 76 years, living with COPD

“I am currently considering doing a second pulmonary rehabilitation course as I feel that it will help me cope better in the warm weather coming up.”

– Ken, 78 years, living with COPD



Scan to watch Ian's COPD journey and the value of pulmonary rehabilitation.

D Immunisation availability and uptake for all people with COPD

Immunisation is important for people with a lung condition and for the health of the Australian population in general. For people living with COPD, immunisation is recognised as an evidence-based approach to preventing respiratory infections^{109, 110}.

Pneumococcal immunisation is recommended for all patients with COPD⁴⁶. In the current National Immunisation Program (NIP), patients under the age of 65 years with COPD and chronic emphysema are not included in the risk conditions for NIP-funded pneumococcal vaccination. Consequently, they are not eligible for reimbursement.

Incentives and awareness to increase pneumococcal vaccination rates among people with COPD is required, including among those under 65 years old. As demonstrated by the COVID-19 vaccination program, increased awareness and improved access through the removal of barriers such as cost can assist in raising vaccination rates and protecting vulnerable populations from severe illness. The pandemic response has generated increased awareness of vaccines and their ability to prevent severe disease. This increased public trust and acceptance of the importance of vaccines should be leveraged.

Recommendations

- 3.11. Fund free access to pneumococcal vaccinations for all people with COPD under the National Immunisation Program.
- 3.12. Deliver awareness and education campaigns on the benefits of immunisation in order to increase uptake.



Research priorities for priority area 3: Community management

- Models of comprehensive multidisciplinary COPD care across the health spectrum, including primary to tertiary care, that tailor approaches for populations disproportionately affected by COPD (e.g. Aboriginal and Torres Strait Islander peoples, people living in areas of socioeconomic disadvantage and rural and remote areas).
- Examine new models of integrated respiratory and palliative care in primary and secondary care, and how these could be offered to people with COPD in regional or remote areas.
- Examine the cost-effectiveness of new models.
- Examine comorbidities and multi-morbidity, including related impacts (e.g. psychological, employment and productivity, loneliness, costs etc.), and identifying and treating cardiovascular disease and other comorbidities early in COPD.
- Identify the essential components of self-management interventions.
- Examine remote monitoring and digital interventions in COPD self-management.
- Examine strategies to reduce exacerbation risk, such as how to avoid viral respiratory tract infections (RTIs) in winter.
- Examine strategies to increase physical activity and reduce sedentary behaviour in COPD, such as the use of urban walking circuits.
- Examine approaches to incentivise GPs to undertake spirometry in everyone with a respiratory history (significant exposures) or persistent symptoms.
- Conduct research specific to Aboriginal and Torres Strait Islander peoples, including 48 hour follow-up after hospital discharge and referral to and uptake of pulmonary rehabilitation (especially after an exacerbation and hospitalisation).
- Examine new effective non-pharmacological management approaches and pharmacological treatments for people with distressing symptoms and severe COPD.

Priority area 4

Acute care management

Priorities

A

Ensure optimal access and delivery of acute care for people with COPD.

B

Increase adherence to guidelines-based acute management of COPD through national standards of care.

C

Transform acute COPD care with virtual and digital innovations.



“People living with COPD deserve access to the best care at the right time. Qualitative research and frequent reports from people with COPD to the Lung Foundation confirm the too-frequent experience of fragmented and siloed care. A focus on solutions that deliver coordinated and integrated care, and effectively transition care between acute, specialist, and community health care services, is critical to improving both the experience of people living with COPD and their health outcomes.”

- Harry Patsamanis, General Manager Clinical Programs, Research and Innovation, Lung Foundation Australia

Outcomes

- People with COPD provided with access to the right services, at the right time, in the right place as their needs change.
- Acute care for people with COPD is consistently based on best-practice guidelines.
- Acute care for people with COPD enhanced by virtual care and digital innovations.

Overview

COPD hospitalisations are frequent and largely preventable. In 2018, COPD was the leading cause of potentially preventable hospitalisations in Australia²⁹.

Data shows wide variations in COPD care across the nation. For example, in 2017-18, the rate of hospitalisation for COPD was 18 times higher in the area of the country with the highest rate compared with the area with the lowest rate²⁹. Variation in acute care, and in particular diagnostic delays, worsens outcomes for Australians with COPD.

COPD care in Australia is informed by evidence-based clinical practice guidelines⁴⁶. Although there is currently no national data assessing adherence with these guidelines, it is recognised from the adverse COPD outcomes measured in the limited number of audit studies to date that the uptake of guidelines is sub-optimal^{46, 111}, particularly in relation to managing COPD exacerbations^{28, 112}.

Australia's health care system is often perceived as poorly integrated and fragmented, and care pathways between primary and tertiary care are not well coordinated¹¹³. Patients with COPD who are discharged from hospital following an exacerbation should receive the care they need and deserve, including comprehensive follow-up led by the primary healthcare team⁴⁶.

Acute care management

Acute care relates to emergency (i.e., not stable) care delivered across different settings, such as primary care, community services, pre-hospital emergency services, emergency departments, hospital inpatient care, Hospital in the Home, and virtual care.

Exacerbations are serious complications of COPD that often require acute care from pre-hospital and emergency department (ED) services¹¹⁴.

“My first big exacerbation was the most terrifying night of my life. Went to sleep a little unwell, woke up at 1am and couldn't breathe. My first ever trip in an ambulance. I couldn't even work out how to ring 000 because I couldn't speak. I live alone, too. The more I couldn't breathe the more I panicked, which just made it so much worse. Nine days in hospital, five weeks to recover back to some semblance of normal and a setback on my lungs that I won't recover from. I was petrified of going to sleep for weeks after in case it happened again, so I ended up an absolute zombie from lack of sleep. I'm still nervous at night.”

- Cathy, 61 years, living with COPD

A Ensure optimal access and delivery of acute care for people with COPD

Patients may require admission to hospital for severe exacerbations of COPD. Exacerbations may be managed outside a respiratory unit, including by non-respiratory physicians in general medicine.

Exacerbations of COPD (flare-ups) are frequently due to respiratory tract infections. They have also been associated with increases in exposure to air pollution. During episodes that are life threatening patients may sometimes require temporary assistance with breathing². The frequency of severe exacerbations (i.e., those requiring hospital admission) has decreased by approximately 50% since the beginning of the COVID-19 pandemic, coinciding with the widespread

adoption of public health measures such as the wearing of face coverings, improved hand hygiene and social distancing^{59, 115}. This is not widely appreciated in the COPD community, and greater awareness is needed of the ongoing role these simple but crucial strategies play in reducing infection.

Many people with COPD have concurrent multimorbidities and have complex presentations.

Typically, as COPD worsens, patients have multiple and increasingly frequent admissions. Without evidence-based care, they will continue to deteriorate then die, highlighting the importance of supportive and palliative care.



“Compared to other common chronic diseases, people with COPD have a high number of comorbidities. It is vital that these are sought and treated, as they are associated with worse quality of life, increased hospitalisation and greater mortality.”

Professor Christine McDonald, The Austin Hospital and The University of Melbourne

Recommendations

- 4.1. Fund a supported-discharge service pilot program with hospital-based Respiratory Nurse Navigators and GP education in Primary Health Networks with high COPD burden. The Respiratory Nurse Navigators to provide clinical care coordination to strengthen the transition of care from hospitals and emergency departments to general practice and integration with pulmonary rehabilitation services.
- 4.2. Explore remote healthcare/telemedicine and develop and test models of virtual care for COPD patients who are discharged from rural-regional hospitals in order to facilitate remote but prompt specialist review.
- 4.3. Integrate the Managing COPD Exacerbation Checklist (See Box 5) into hospital discharge summaries for patients admitted with a COPD exacerbation, to enable evidence-based management actions.

Box 5: Managing COPD Exacerbation Checklist

The Managing COPD Exacerbation Checklist is a resource that lists the steps that need to be actioned during and following a COPD exacerbation. The actions are broken up into

three sections: in hospital; prior to leaving hospital; and one to four weeks post discharge.



Scan here to view the resource.



Case study – Supported discharge service for COPD in Western Australia

COPD Support Service is a service for non-oxygen-dependent COPD patients discharged from hospitals across Perth where patients referred from eight metropolitan hospitals are provided with clinical care coordination through a COPD Supported Discharge Service for up to three weeks after being discharged from hospital.

Through a combination of supported discharge and community-based care, the COPD service connects patients with primary care, including general practice. It aims to reduce unplanned

hospital admissions by providing a safety net for patients to receive effective care, closer to home. Each patient receives a telephone consultation within a week of discharge, followed by a home visit. Patients are supported with their hospital discharge plan, with a focus on medications, pulmonary rehabilitation, managing exacerbations, and links to other community services, if required. The program provides both face-to-face and virtual visits with a strong focus on education¹¹⁶.



“I’ve had a couple of bad exacerbations, probably picked them up at the gym. And, of course, that’s one thing we are prone to as patients, because we just find it very hard to escape those sort of bugs that other people breathe in and out and don’t even notice.”

– Ian, 75 years, living with COPD

B

Increase adherence to guidelines-based acute management of COPD through national standards of care

Adherence to evidence-based guidelines is critical to improving COPD outcomes. See priority area 5B: Implement COPD-X guidelines.

The development of national COPD clinical-care standards for managing COPD exacerbations is underway by the Australian Commission on Safety and Quality in Health Care (ACSQHC). It is anticipated that this work will commence as part of the Commission’s 2022-2023 Work Plan. These standards, once developed, will set the benchmarks for acute care for COPD, especially for emergency and hospital care. They are also likely to address appropriate personalised treatment (as listed in Box 5: Managing COPD Exacerbation Checklist), location of care, and care pathways. Processes for education, implementation and audit of adherence to the national standards will then need to follow.

Workforce education should be promoted across the continuity of care, to enhance COPD

management in line with the use of and adherence to guidelines, particularly guidelines-based exacerbation management and use of COPD action plans. Reducing the frequency of COPD exacerbations is a crucial step on the path towards the reduction of COPD burden⁵⁹. This work would include education of primary care practitioners, community health professionals, the emergency medicine workforce and other hospital-based teams with a view to improving early identification and, therefore, the timely treatment of COPD exacerbations. See priority area 3A: Workforce education and training.

Recommendations

- 4.4. Develop and support adherence to national COPD clinical care standards for managing COPD exacerbations.

C

Transform acute COPD care with virtual and digital innovations

Virtual care for patients with COPD exacerbations could help bridge the gap between primary care and hospital care. Virtual Wards are presently operated by several hospital and health services. The approach involves health care professionals from hospitals delivering acute care to patients within their own homes via videoconferencing. In this way, it resembles Hospital in the Home (HITH) services, but without the home visits. This approach represents an additional model of care that could be useful for patients with mild to moderate exacerbations whose daily care needs are beyond those of a GP consultation but not severe enough to warrant hospital admission. This approach could also apply to patients who require home monitoring after early discharge from hospital – in other words for delivering virtual HITH or virtual Post-Acute Care models.

The digital transformation of acute care for COPD could be achieved using clinical decision support systems (CDSS). This approach involves the provision of digital health tools to help primary care practitioners, emergency department teams and hospital teams to more appropriately diagnose and manage patients with COPD exacerbations according to the COPD-X guidelines. The embedding of evidence-based clinical algorithms would support clinical decision-making in the acute setting.

Recommendations

- 4.5. Urgently explore opportunities and innovative strategies to transform acute COPD care with virtual and digital innovations.



Research priorities for priority area 4: Acute care management

- Investigate innovative models of acute-care coordination and navigation, including undertaking research to further understand exacerbations and how they are addressed by emergency medical services.
- Undertake implementation research to drive the uptake of best evidence into routine patient care.
- Investigate best practice in use of oral steroids in exacerbations. Undertake research into whether this should be based on blood inflammatory cell counts (eosinophils). Such work might lead to more accurate characterisation of exacerbations, fewer oral steroid courses in the community, and a reduction in acute oral steroid effects (such as elevated blood-glucose levels) and long-term side effects.
- Explore optimal use of antibiotics in exacerbations of COPD, including when to use, duration and class.
- Undertake multimorbidity assessment during exacerbations, including the use of tests for cardiac effects (NT-proBNP), blood glucose levels, and procalcitonin to indicate bacterial infections.
- Investigate the role of the clinician navigator, a knowledgeable clinician (nurse or specialist) assigned to be the contact person for the day to pre-empt issues and to talk to patients, carers and primary care practitioners.
- Explore opportunities to maximise the impact of telehealth in delivering best care for people with COPD. This includes patients who are discharged from rural and regional hospital and may require specialist review. These range from earlier diagnosis to lifestyle interventions and best practice management. The goal should be to ensure equitable healthcare and reduce the disparities that currently affect people with COPD and at risk of COPD in the diverse geographies and communities in Australia. The research should determine whether routinely implemented telehealth achieves optimal care for people with COPD.



“Making appointments has now become a joke. If you need to see a specialist, or another GP, X-rays etc... you have to wait days, and, in some cases, months for an appointment. This area needs to be addressed urgently. In some cases, we can lose our breath and sometimes would love to speak to someone urgently [then and there] on what else can be done, rather than go to the hospital and waste taxpayers’ money being looked after for what can be done over the phone.”

- John, 76 years, living with COPD

Priority area 5

COPD research and translation

Priorities

A

Significantly boost investment in COPD research.

B

Optimise the implementation of COPD guidelines.

C

Invest in national data infrastructure for COPD.



“People with COPD constantly seek reassurance from the Lung Foundation that more is being done to prevent, treat and cure their disease. COPD research investment from the benchtop to the bedside has lagged behind the burden of disease for too long. Governments must act now to increase funding for COPD research, taking into account the priorities of people living with COPD as described in this Blueprint.”

- Mark Brooke, Chief Executive Officer, Lung Foundation Australia

Outcomes

- Increased investment in COPD research and translation of research outcomes into policy and practice.
- Greater adherence to evidence-based COPD guidelines to improve COPD outcomes.
- Enhanced national data infrastructure for COPD in Australia and increased knowledge about COPD.

Overview

There has been little improvement in how we diagnose, treat, and manage COPD in recent decades, and even less attention focused on how to prevent COPD. Subsequently, improvement of outcomes has largely stagnated, and needs to be urgently addressed through greater investment in research and translation of outcomes.

Research is essential to strengthening the knowledge base to effectively prevent, diagnose and manage COPD, and to create a path towards prevention and cure.

Given the impact that the disease has on the nation's health, COPD research does not receive a fair share of funding. Numerous gaps exist between evidence and practice. Stigma and the consequent under-recognition of COPD has led to a significant underinvestment in better understanding the disease, and this is contributing to tragic and unacceptable poor outcomes for people living with COPD. The underfunding of COPD research is a global problem. This blueprint provides Australia with an opportunity to lead by example and address the major deficiencies that are evident in sub-optimal outcomes and research investment to date.

A Significantly boost investment in COPD research

“Compared with other diseases with similar or less morbidity and mortality, the investment of financial and intellectual resources from both the public and private sector to advance understanding of COPD, reduce exposure to known risks, and develop new therapeutics has been woefully inadequate.”

– Towards the elimination of chronic obstructive pulmonary disease: a Lancet Commission⁵⁹

Research funding in Australia typically delivers significant ‘bang for the buck’. The country spends a lower percentage of GDP on research than the OECD average, and yet it achieves a higher quality and quantity of research outputs than its international peers¹¹⁷.

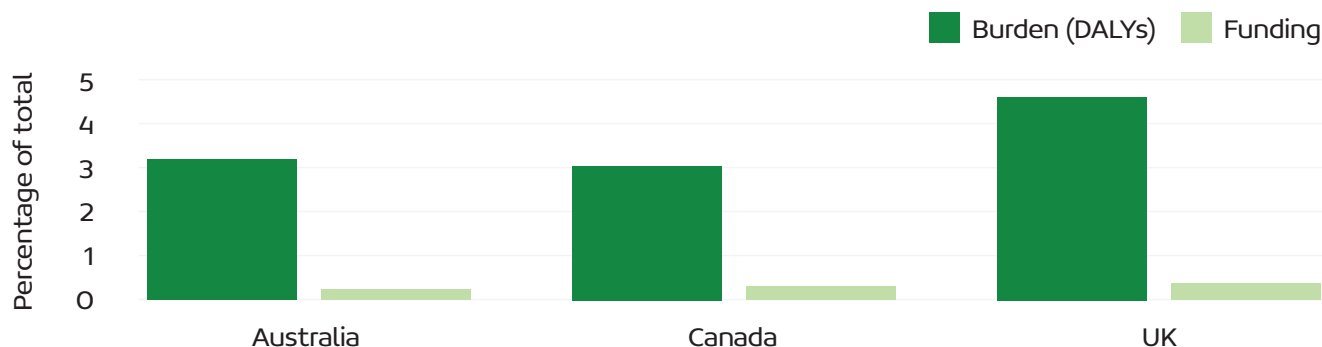
Despite the vital role of research in changing and saving lives, COPD research does not receive the investment and support warranted by its outcomes or at a level relative to the disease's burden. COPD research funding has been disproportionately low relative to the impact of the disease for many decades, and this fraction has declined even further in recent years. For no other chronic disease is there such a mismatch between funding and public health burden^{59, 118, 119}.

Dedicated and substantial research investment that is commensurate with the scope of the problem is required. This Blueprint calls for a significant boost to investment to ensure the creation of

meaningful opportunities for COPD research. A recent Lancet Commission intended to catalyse momentum and provide a much-needed new vision to set the course towards the elimination of COPD. It recommended that funding agencies should increase financial investments to adapt to the burden of COPD. It also urged that by 2030 the total public and private global research and development expenditures for COPD should increase by 50%⁵⁹. Such an increase would not bring funding to a level commensurate with the disease burden, but it would create an opportunity to make inroads on it.

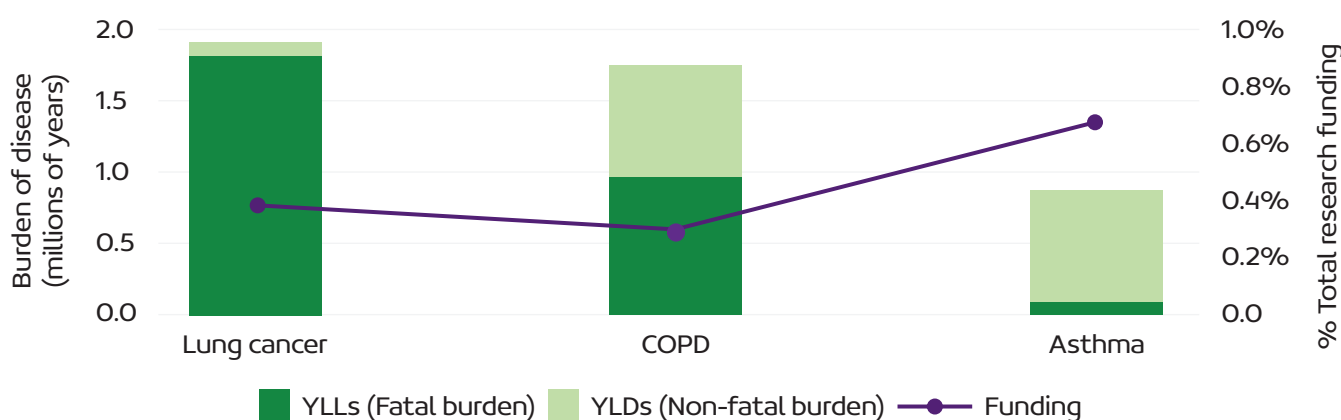
In the absence of a global respiratory research strategy¹²⁰, Australia has the opportunity to lead the world by developing a national research strategy for COPD that prioritises the areas of greatest need and sets goals and targets to address the deficiencies of research funding and reach the improvement of 50%, at least, by 2030.

COPD funding compared to total burden (Australia, Canada and the UK between 2008 and 2017)¹²¹



Fatality of disease burden compared to proportion of total funding awarded – Australia, 2008-2017¹²¹

Diseases with a higher fatal burden, like COPD and lung cancer, are proportionally less well funded than those with a less fatal burden, like asthma.



The recent Medical Research Future Fund (MRFF) targeted call for research, *Preventive and Public Health Research Initiative 2021 Chronic Respiratory Conditions Grant Opportunity*, is welcome however this is an isolated opportunity for respiratory research with very narrowly defined areas of research mostly suitable to asthma.

Recommendations

- 5.1. Introduce targeted Medical Research Future Fund (MRFF) COPD funding to drive transformative and innovative research. The focus of this work should be on preventing and optimally managing COPD across the life course, starting from preconception. Funding to include:
 - Interventions to prevent, diagnose, treat and manage COPD (e.g. strategies to support GPs in performing Lung Health Checks, and the establishment of respiratory diagnostic hubs).
 - Research to generate knowledge on determinants of variations in care, and components of quality care for COPD.
 - COPD research fellowships, scholarships and grant schemes for early and mid-career researchers to build the capacity of the health and medical research workforce.
 - Optimal non-pharmacologic interventions to manage COPD, including physical activity, optimal implementation of community-based Pulmonary Rehabilitation, breathing techniques and training, and infection prevention. Pharmacological treatments for people with distressing symptoms and severe COPD.
 - Economic evaluations to determine the cost-effectiveness of new models and approaches to improving COPD care and outcomes.
- 5.2. Develop a national research strategy for COPD that prioritises the areas of greatest need and addresses the current deficiencies of research funding. Its goal should be to achieve an increase of at least 50% in funding for COPD research by 2030. The research strategy should incorporate the COPD research priorities identified in this Blueprint.

“I was misdiagnosed for eight years. Treated for pneumonia and asthma. Looking back now, with the lack of available treatment for COPD and the stigma that surrounds this disease, I worry that there isn’t much that could have been done if I had been correctly diagnosed earlier. This is the sad part about the lack of research and treatment for COPD.”
 – Cathy, 61 years, living with COPD

“As for the Government, I want them to accept the problem, and then understand the size of the problem. And then fund it accordingly.”
 – Ian, 75 years, living with COPD

B Optimise the implementation of COPD guidelines

Translating clinical evidence into prevention behaviours and healthcare practice is complex and difficult. Implementation requires behaviour change. We know that changing behaviour is difficult, but not impossible.

Despite helpful guidelines for preventing, diagnosing and managing COPD, there is room for improvement in clinical practice and patient behaviour. This is consistent with many other clinical fields in which there is strong evidence that guidelines, while necessary, are seldom sufficient on their own to change practice. Further support in the form of behavioural implementation strategies may be required to optimise care and to support patients and families in their attempts to prevent exacerbations and effectively self-manage COPD¹²².

Australia has robust evidence-based guidelines for the management of COPD: *COPD-X Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease*⁴⁶ (See Box 6).

While there are a range of different COPD guidelines in place around the world, there has been little evaluation of optimal approaches to their implementation and uptake into clinical practice, or their impact on clinical outcomes.

We know from the limited studies available and the poor COPD outcomes experienced that the uptake of guidelines is sub-optimal^{46,111}, and there is poor adherence to COPD-X recommendations for managing exacerbations^{28,112}. A significant gap exists between what is known to be effective (evidence) and what is happening (practice). Our greatest challenge lies in guideline implementation, which includes objective assessment, accurate diagnosis and evidence-based practice in COPD.

Our key goal is to translate the evidence-based recommendations in COPD-X into everyday practice across Australia⁴⁶.

Education, upskilling and support of health professionals will be critical to increasing the uptake and use of COPD guidelines across the spectrum of Australian health care settings.

Recommendations

- 5.3. Conduct ongoing revision, dissemination and implementation of national, evidence-based clinical practice guidelines and tools for COPD, including:
 - Workforce training and upskilling delivered by traditional and innovative techniques. See priority area 3.
 - Funding the development of additional tools, documents and campaigns to encourage awareness and use of the guidelines, including a refreshed COPD-X concise guide for primary care.
 - Investing in digital health initiatives. Examples

include integrated software for clinical decision support systems and prompts in electronic health records that aid with management decisions. These should be integrated with the COPD standards of care being developed nationally.

- 5.4. Fund implementation science research to explore the barriers to adoption of COPD-X and how to overcome them, and to drive the uptake of best evidence into routine patient care. Research should include the impact of the uptake of the guidelines, the reach and impact of key recommendations and the maintenance of knowledge translation.

Box 6: Australia's guidelines for the management of COPD

Australia's guidelines for the management of COPD, *COPD-X Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease* (commonly abbreviated as COPD-X), were first published in 2003¹²³ and are the only guidelines specific to the Australasian context. The guidelines are updated quarterly and recognised by independent national review as being high-quality living guidelines¹²⁴.

The aim of the COPD-X guidelines is to improve health outcomes and optimise quality of life for people with COPD.



Scan here to view the COPD-X Guidelines.

C Invest in national data infrastructure for COPD

“To make progress on the burden of COPD in Australia, we need to know exactly where the problems lie, so we can focus our effort and seek funding appropriately. Rapid access to high-quality data is essential to ensure this. At present, we do not have a systematic approach to gathering data about lung health in Australia, unlike many countries similar to ours in the OECD who are doing it far better than we are. We urgently need to address this, in order to catch up and to start to tackle the root causes as well as the consequences of COPD for all Australians.”

– Professor Christine Jenkins AM, The George Institute for Global Health and UNSW Sydney

Robust and nationally consistent data and supportive infrastructure are fundamental to understanding population level patterns and trends in COPD. They are also key for identifying emerging population health needs.

Work in the area of COPD suffers from a lack of comprehensive data. This shortfall hinders awareness and our understanding of the condition as well as the ability of policy and decision-makers to effectively plan for the current and future impacts of COPD. For example, the prevalence of COPD is difficult to determine from routine health surveys. This is because COPD is formally defined in terms of an abnormality of lung function, and clinical testing is required to accurately estimate the prevalence of the disease².

Important work is underway by the Australian Institute of Health and Welfare (AIHW) to develop a new method for calculating COPD prevalence that links different forms of administrative data, such as that from the Pharmaceutical Benefits Scheme, Medicare Benefits Schedule and from hospitals and aged care¹²⁵.

Additional COPD data-challenges exist. These include gaps in data relating to the implementation of and access to best-practice care, as well as the nature and prevalence of early retirement, reduced productivity, absenteeism and loss of employment. Another gap is around respiratory health in children, especially as it pertains to healthy lungs and factors such as early-life respiratory infections, nutrition, and exposure to smoke, which is all directly relevant to future COPD.

Role of the Australian Institute of Health and Welfare in the monitoring of COPD

The Australian Institute of Health and Welfare's (AIHW) vision is to provide stronger evidence (data and information) for better decisions and improved health and welfare. The AIHW has a long history of monitoring and reporting on chronic conditions, including COPD. This monitoring aims to cover the continuum of care; and can include the measurement of risk and protective factors, incidence and prevalence, comorbidities, the use of primary care, hospital and aged care services by people living with COPD, and the burden of disease, mortality and expenditure. The AIHW aims to take a population or person-centred approach across the life course and over time and considers the broader health context, including social, economic, geographic and environmental factors that impact on the development and progression of the condition.

Recommendations

- 5.5. Fund a national COPD Centre of Excellence that can incorporate the development of national infrastructure and standards of care; the systematic synthesis of evidence on prevention and management of COPD; best practice implementation; and an annual reporting mechanism, including the potential for a National COPD Registry.
- 5.6. Advocate for COPD data to be a greater priority in national health surveys, such as the Longitudinal Study of Australian Children (LSAC) and the Longitudinal Study of Indigenous Children (LSIC), in recognition of the burden of disease, especially in Aboriginal and Torres Strait Islander communities. Review and update respiratory questions in national health surveys. Address data gaps around children's health, especially with reference to healthy lungs which is directly relevant to future COPD.
- 5.7. Ensure that relevant strategies (such as chronic conditions plans) in each Australian jurisdiction contain a specific focus and target for COPD. This should include data capture, linkages, and timely reporting. The targets to be embedded in performance indicators for hospitals.
- 5.8. Establish Respiratory Networks in each state and territory to oversee data on exacerbations admissions.



John's story

I am 76, married, with three sons and six grandchildren. I have lived in the same home for the last 50 years where we raised our children and watched them grow up and [then] leave home and have families of their own. I live with COPD.

I suffered from asthma when I was a child. I very seldom went to a doctor because of work commitments, and I rarely went to the same doctor more than a few times. If I became ill, I would attend a medical centre to collect any scripts that I might need, usually for bronchitis.

I was a senior auditor with the Federal Public Service until ill health forced me to retire. In my last years at work, I found I could hardly walk any distance and had a continuous cough. I finally gave in and went to a doctor who took me in hand. In March 2000, I was diagnosed with COPD. I assumed COPD was another type of flu, but when my wife and I did further research we found it was a non-curable lung disease.

Since 2005, other medical problems have started. My left carotid artery was blocked, which caused a stroke on my right side. It was replaced in February 2006. Since then, I have now had five stents to clear blockages in my heart and they continue to monitor

more blockages. I have had further vascular problems, mainly in my legs and have had several angiograms on them with different procedures taking place.

I currently use oxygen with exertion, such as when I do gardening or travel any distance. And when I have a shower, as I find this really difficult to do without oxygen. My specialist has now prescribed Kapanol, [which] is a low dose morphine that lasts for eight hours and helps with breathlessness. Also, Ordine, another morphine medication which is quick acting but only last for a couple of hours.

I also have anxiety attacks when I can't get my breath which causes me to become incontinent.

Whilst, I might have all these problems, I really need to thank my wife. Without her persistence, time and effort, I don't think I would be here today. I consider other people are worse off than myself as I have a great team of people working with me on this journey.

My motto is live each day as best as you can and enjoy it.

Pictured: John, 76 years, living with COPD and his wife Lennette.

Glossary

List of relevant terms and acronyms, with accompanying definitions.

ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Services
ACSQHC	Australian Commission on Safety and Quality in Health Care
AIHW	Australian Institute of Health and Welfare
AMS	Aboriginal Medical Services
Burden of disease	Burden of disease measures the impact of living with illness and injury and dying prematurely. The summary measure ‘disability-adjusted life years’ (or DALY) measures the years of healthy life lost from death and illness.
CDM	Chronic Disease Management
CRE	Centre of Research Excellence
COPD	Chronic Obstructive Pulmonary Disease
COPD-X	COPD-X. Australia’s guidelines for the management of COPD. An abbreviation of COPD-X Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease
DALYs	Disability-adjusted life years
ED	Emergency Department
FCTC	Framework Convention on Tobacco Control
GHRN	Global Health Respiratory Network
GPs	General Practitioners
HCP	Health Care professional
HITH	Hospital in the Home
HIV	Human immunodeficiency virus
LDCT	Low-dose computed tomography
LSAC	The Longitudinal Study of Australian Children
LSIC	The Longitudinal Study of Indigenous Children
MBS	Medicare Benefits Schedule
MRFF	Medical Research Future Fund

NHS	National Health Survey
NIP	National Immunisation Program
OECD	Organisation for Economic Co-operation and Development
PBS	Pharmaceutical Benefits Scheme
PDA	Patent ductus arteriosus, a condition involving problematic blood flow between the heart and lungs.
PIP	Practice Incentives Program
PPH	Potentially Preventable Hospitalisations
PR	Pulmonary Rehabilitation
QI	Quality Improvement
RDH	Respiratory diagnostic hub
RTI	Respiratory tract infection
SDGs	Sustainable Development Goals
SEIFA	Socio-Economic Indexes for Areas is an ABS product that ranks areas in Australia according to relative socio-economic advantage and disadvantage.
TB	Tuberculosis
TGA	Therapeutic Goods Administration
TSANZ	The Thoracic Society of Australia and New Zealand
WHO	World Health Organization
YLLs	Years of life lost
YLDs	Years of healthy life lost due to disability

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