Submission to the Inquiry into Access and Affordability of Medical Specialists in Australia

Lung Foundation Australia

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Our vision is healthy lungs for all
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Executive Summary

Medical specialists play an essential role in supporting people with lung diseases, including lung cancer, to manage their condition and maintain their health and wellbeing. However, many people with lung disease face substantial barriers to accessing and affording specialist care when they need it. Drawing on published evidence and the experiences of consumers and health professionals, Lung Foundation Australia's submission identifies the following key findings:

- **People with lung disease can face long and unpredictable waits for specialist respiratory care.** Many patients referred to public services are not seen within clinically recommended timeframes. Private care may offer faster access, but limited and inconsistent data on waiting times prevent a clear understanding of access across the health system.
- **Geographic disparities and insufficient service capacity limit access to specialist respiratory care.** People in regional and remote communities may have few or no local respiratory specialists, requiring long-distance travel or limiting provider choice. Existing services have also not kept pace with emerging demand, including from the National Lung Cancer Screening Program, and require adequate medical, nursing, allied health and administrative workforces to deliver timely, evidence-based care.
- **Delayed recognition of lung disease symptoms can delay referral to specialist care. Once referred, patients may face further barriers progressing through the referral pathway.** One in four participants (28%) in Lung Foundation Australia's 2024 lived experience research presented to a general practitioner more than five times before being diagnosed. After referral, variations in referral information requirements can affect whether patients are triaged and managed on time. Difficulties accessing clinical information from other providers can further impede care, while obtaining and maintaining referrals may place a considerable burden on patients.
- **People with lung disease experience substantial healthcare costs. The direct and indirect costs of specialist care contribute significantly to this burden.** Patients may face substantial out-of-pocket costs for private consultations, diagnostics and procedures. Travel, accommodation, parking and lost income add to the costs of accessing public and private specialist services. These expenses can accumulate, particularly for people who must travel long distances.
- **Gaps in medication subsidies can create inequitable access and additional demand for public specialist services.** As an example, standard treatment for nontuberculous mycobacterial lung disease requires multiple medications over 18 months or longer. Some of these medications must be prescribed "off label", without regulatory approval or subsidies through the Pharmaceutical Benefits Scheme (PBS). Private medication costs may total approximately $9,000 over the course of treatment. Some public hospitals choose to subsidise these medications, increasing demand on public specialist services at these hospitals and contributing to geographic inequities in treatment access.
- **Delayed or missed specialist care can have serious consequences for people with lung disease.** Delays can prolong symptoms, cause distress and uncertainty, defer diagnosis and management, and impede access to specialised treatments. For people with suspected lung cancer, delays may allow the cancer to progress, reducing the chances of survival.
- **Better use of the broader health workforce and stronger connections across care settings could improve access to specialist care.** Specialist and advanced nursing roles can coordinate complex pathways and deliver defined aspects of specialised care. Multidisciplinary primary care can support best-practice management for some lung diseases and preserve specialist

capacity for when specialist expertise is required. Locally appropriate models of care may improve access to specialist expertise in rural and remote communities.

Recommendations

Lung Foundation Australia makes the following recommendations to support more timely, equitable and sustainable access to specialist care for people living with lung disease:

1. **Improve the availability, consistency and transparency of data on specialist service access and performance.** Reporting should enable meaningful comparisons across services and jurisdictions.
2. **Strengthen nationally coordinated specialist respiratory workforce and service planning.** Planning should respond to population needs, geographic maldistribution and changing demands and consider the full multidisciplinary workforce required to deliver effective specialist respiratory services.
3. **Improve national consistency in the clinical information required when referring people with lung disease for specialist care**. Greater consistency should reduce unwarranted variations in triaging and clinical management.
4. **Improve clinical information sharing across the health system.** Explore further improvements to My Health Record that address barriers to uptake and effective use by specialists and support access to the clinical information needed for specialist care.
5. **Review avoidable administrative barriers to obtaining and maintaining specialist referrals**. Consider whether current requirements could be revised to reduce the burden on patients and improve access to and continuity of care.
6. **Improve the affordability and cost transparency of private specialist care.** Reforms should consider the cumulative costs of consultations, diagnostics, procedures and other related services, particularly when ongoing care is required.
7. **Support nationally coordinated improvements to patient travel assistance schemes.** In collaboration with state and territory governments, explore opportunities to improve eligibility criteria, subsidy levels, cultural responsiveness and consistency across jurisdictions.
8. **Continue and strengthen Commonwealth investment in medicines repurposing initiatives that improve access to standard treatments prescribed off label.** These initiatives waive fees associated with regulatory assessment and PBS listing, providing a feasible pathway for critical off-label medicines to be considered for PBS subsidy.
9. **Address the national shortfall in specialist lung cancer nurses**. Specialist nursing support should be available from the point at which lung cancer is suspected.
10. **Implement relevant actions under the *National Nursing Workforce Strategy* to create the conditions needed for effective nursing models of care.** This should include sustainable funding and policy settings that enable nurses to work to their optimum scope of practice.
11. **Enable effective multidisciplinary COPD care in primary care.** Address barriers relating to funding, workforce capability, coordination between services and access to essential assessments such as spirometry, while maintaining timely referral to respiratory specialists when clinically required.
12. **Explore models of care that improve access to specialist care in rural and remote communities.** Work with communities to develop models that reflect local needs, workforce capacity, infrastructure and service availability.

13. **Strengthen national action to prevent lung disease.** The Commonwealth Government should provide sustained leadership and investment to prevent lung disease, helping to alleviate avoidable pressure on medical specialist services and the broader health system.

To discuss Lung Foundation Australia's submission further, please contact Chief Strategy Officer, Paige Preston at paigep@lungfoundation.com.au.

Yours sincerely,



Mark Brooke
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About Lung Foundation Australia

For more than 30 years, Lung Foundation Australia has walked alongside people living with lung disease and lung cancer, helping them navigate some of life's hardest moments with care, knowledge and hope. We provide trusted support through our nurses, peer support programs and social workers. We fund research that leads to better treatments. We speak out for people who need lung health to be taken seriously. Everything we do helps protect the gift of breath, so that more Australians can breathe easier, live well and feel less alone.

The Burden of Lung Disease

Lung diseases affect a substantial proportion of the Australian population and place significant pressure on the health system. Approximately 1 in 3 Australians reports living with a chronic respiratory disease, not including people diagnosed with lung cancer.[1] In 2025, an estimated 15,000 people were diagnosed with lung cancer,[2] making it the second most commonly diagnosed cancer among women and the fourth among men.[3] Chronic lower respiratory diseases, including chronic obstructive pulmonary disease (COPD), were the third leading cause of death in Australia in 2024.[4] Lung cancer was the fifth leading cause of death and caused more deaths than any other cancer.[4]

Lung diseases are also leading causes of potentially preventable hospitalisation, contributing to avoidable demand on health services and significant impacts on communities.[5] This burden is not distributed equally, with higher rates of illness and death among First Nations people, people living in remote areas and people living in the most socioeconomically disadvantaged areas.[5,6] **Preventing lung disease and ensuring timely access to appropriate care, including medical specialist services, are therefore critical to improving health outcomes, reducing inequities and alleviating pressure across the health system.**

Introduction to Submission

Lung Foundation Australia welcomes the opportunity to contribute to the House of Representatives Standing Committee on Health, Aged Care and Disability's Inquiry into access to and affordability of medical specialists in Australia. This submission examines the barriers people living with lung disease experience in obtaining timely, affordable and appropriate specialist care and identifies opportunities to improve access, referral pathways and models of care.

The submission focuses primarily on access to respiratory specialists for people living with lung disease and lung cancer. For simplicity, the term *lung disease* is used collectively throughout the submission to include lung cancer unless lung cancer is discussed explicitly. We recognise that people living with lung disease may also require care from other medical specialists, whether for their lung disease or other conditions.

Similarly, for the purposes of this submission, the term *patient* is used when referring to individuals receiving, seeking, or requiring health care. The term *consumer* is used when referring to individuals with lung disease who participated in consultation activities undertaken to inform this submission.

Our submission draws on published evidence, as well as extensive engagement with consumers and health professionals including:

- **engagement undertaken for this Inquiry** with 18 external consumers and health professionals (including respiratory specialists, nurse consultants, a nurse practitioner, a general practitioner

and allied health professionals), as well as insights from Lung Foundation Australia staff, including nurses who deliver respiratory and lung cancer care through telehealth services;
- **Lung Foundation Australia's 2024 lived experience research**, which included an online survey of 1,034 people living with lung disease and 149 carers, as well as a qualitative online community involving 27 people living with lung disease;[7] and
- **Lung Foundation Australia's 2024 cost-of-living survey** of 703 people living with lung disease, which examined how cost-of-living pressures were affecting this community and explored potential measures to ease these pressures.[8]

This submission was developed with the assistance of generative artificial intelligence and has been extensively reviewed, verified and edited by Lung Foundation Australia.

Acknowledgements

Lung Foundation Australia sincerely thanks the consumers and health professionals who contributed their time and shared their experiences to inform this submission.

We thank the National Rural Health Alliance, Cancer Council Australia and the Leukaemia Foundation for their collaboration during the development of this submission. We acknowledge and support the issues raised in the submissions made by these organisations in areas that align with our own submission.

Responses to the Terms of Reference

a) Examine current access to medical specialists in cities, regional and rural communities, with consideration of workforce distribution, shortages, waiting times and barriers to recruitment, retention and training.

Waiting times for specialist respiratory care

Consumer experiences and publicly available data demonstrate that people with lung disease face long and unpredictable waiting times for public specialist care.

> *"Our main issue is the time it takes to get appointments. My partner has been on a wait list for over a year to see the lung specialist."*
>
> – Lung Foundation Australia 2024 lived experience research participant, Northern Territory

Referrals received by public specialist outpatient clinics are generally assigned an urgency category which is associated with a clinically recommended wait time. Category 1 patients are typically recommended to be seen within 30 days, Category 2 patients within 90 days and Category 3 patients within 365 days. State data suggest that wait times for an initial appointment with a respiratory specialist often exceed these recommended timeframes. For example:

- In **Queensland**, monthly results between January and June 2026 show that only 49% to 54% of patients who attended an initial respiratory specialist appointment were seen within the clinically recommended timeframe.[9] Category 2 patients were least likely to be seen on time, with monthly results over this period ranging from 35% to 41%.[9]
- In **northern Tasmania**, as at 31 July 2026, the reported respiratory specialist clinic waiting time for 75% of patients was up to 360 days for Category 1 patients, up to 1,061 days for Category 2 patients and up to 1,920 days for Category 3 patients.[10] It is not clear whether these figures represent waiting times for people who had attended an appointment or people who were still on the waiting list.
- In **Victoria**, the most recent complete data (Q3 and Q4 2025) indicate that 50% of Category 1 patients attended an initial appointment with a respiratory specialist in the recommended timeframe.[11] However, 90% of Category 1 patients waited up to 222 days to be seen in Q3 and up to 124 days in Q4.[11]

In contrast, consumers and health professionals consulted by Lung Foundation Australia described the private healthcare system as generally providing shorter wait times for specialist care. However, data on wait times for private specialist respiratory care could not be located.

Differences in the availability of wait time data and the definitions used for reporting make it difficult to gain a clear understanding of wait times for specialist respiratory care, but the available data suggest that waiting times can be substantial.

Timely specialist access for suspected lung cancer

Timely access to specialist care is crucial when lung cancer is suspected. The *Optimal care pathway for people with lung cancer* describes the standard of care that should be available to all people with suspected lung cancer in Australia.[12] It specifies that an appointment with a medical specialist linked to a lung cancer multidisciplinary team should occur within two weeks of being referred by a general

practitioner (GP).[12] This is shorter than the general 30-day timeframe for Category 1 referrals. There are limited public data available to understand whether this timeframe is being adhered to. Across four Western Australian hospitals participating in the Lung Cancer Clinical Quality Data Platform from September 2023 to September 2024, between 30% and 65% of patients attended their first specialist appointment within two weeks of referral.[13] This indicates that substantial proportions of patients with suspected lung cancer may not be receiving specialist assessment within the timeframe recommended for optimal care.

> *"I felt extremely frustrated about the lack of information, especially the time between being told I had cancer and my appointment with the oncologist to be told the specific cancer I had and treatment pathway."*
>
> – Lung Foundation Australia 2024 lived experience research participant, Australian Capital Territory

Adequacy and distribution of the specialist respiratory workforce

The *National Medical Workforce Strategy 2021-2031* outlines a vision for a well-distributed, high-quality medical workforce able to meet the increasing health needs of the Australian population.[14] It details a number of strategic priorities and actions to support this vision including initiatives to improve workforce data, planning, supply and distribution.[14] Although some progress has been made in relation to these initiatives,[15] more work is needed to improve access to respiratory specialists and services across Australia.

Geographical variation in access to specialist respiratory services

In Lung Foundation Australia's 2024 lived experience research,[7] 23% of regional respondents reported that the absence of a local respiratory specialist made their condition harder to manage, compared with 9% of respondents in capital cities. This experience aligns with geographic disparities in the broader specialist workforce. In 2023, there were 169 clinical full-time-equivalent medical specialists per 100,000 people in major cities, compared with 43 in medium rural towns, 16 in small rural towns, 77 in remote communities and 31 in very remote communities.[16]

Where appropriate workforce and services are not available locally, patients may need to travel to access specialist care. Long distances create access challenges for people living in regional and remote areas. Some people depend on family members for transport or face difficulties leaving pets, livestock and other responsibilities. Seasonal changes can also impact roads and travel options. These barriers are compounded for patients who must travel repeatedly for specialist appointments, imaging, testing, and multidisciplinary care and can be especially difficult for people with lung disease who may be experiencing breathlessness, fatigue or frailty.

> *"I'm on oxygen 24/7 which means I can't do anything easily."*
>
> – Lung Foundation Australia 2024 lived experience research participant, Victoria

Where few specialist respiratory services are available, patients also have little choice about who provides their care. Restricted choice can be especially harmful for people living with lung disease because conditions such as COPD and lung cancer can be associated with stigma related to smoking history.[17] A person experiencing stigma may be unable to seek a second opinion or find a clinician who better meets their needs. Meaningful access therefore requires not only an available provider, but reasonable access to respectful and person-centric care.

Inadequacies in the availability and capacity of specialist respiratory services

Health professionals consulted by Lung Foundation Australia reported that the availability and capacity of specialist respiratory services is inadequate and has not kept pace with new demands, such as the National Lung Cancer Screening Program introduced in 2025. Health professionals emphasised that increasing the number of medical specialists alone will not be enough to meet current demands for respiratory care.

Health professionals consulted by Lung Foundation Australia indicated that, in New South Wales, many patients discharged from public hospital inpatient care are directed to their treating specialist's private outpatient clinic because the specialist does not operate a public clinic. Health professionals reported a number of barriers to establishing or expanding public respiratory outpatient clinics including limitations on recruiting administrative staff and remuneration arrangements that make working in public clinics less attractive than private practice.

A health professional from another jurisdiction who was consulted by Lung Foundation Australia described how investment in a multidisciplinary workforce substantially improved access to lung cancer care in their hospital. The service recruited additional medical specialists, specialist nurses, and dedicated administrative staff which resulted in significant reductions in wait times for initial appointments, diagnosis and management.

A respiratory specialist consulted by Lung Foundation Australia also emphasised the importance of adequate staffing to support evidence-based multidisciplinary care. Clinical guidelines for many lung diseases recommend treatment by multidisciplinary care teams which can deliver significant benefits to patients and the healthcare system supporting them.[18–20] However, these roles are inconsistently funded.

b) Examine the effectiveness, transparency and equity of referral pathways from the perspective of patients, primary health care practitioners and medical specialists across the public and private health sectors, with consideration of factors affecting referral patterns and any systemic, regulatory or administrative barriers to the appropriate utilisation of these pathways.

Variations in referral requirements for lung diseases

There can be considerable variation in the completeness of referrals made to respiratory specialists. Referrals that lack sufficient clinical information create barriers to appropriate triage and effective clinical management. There are differences in referral information requirements across services that may contribute to this variation.

For Medicare-funded specialist services, Services Australia states that referring practitioners have legal obligations when referring a patient for treatment by a medical specialist.[21] Referrals must include relevant clinical information about the patient's condition and must be dated and signed by the

referring practitioner.[21] However, these requirements are broad and do not guarantee that a referral will contain the clinical information needed to assess urgency or provide care efficiently.

Public patients attending public specialist outpatient services are not treated under the same Medicare billing arrangements. Public clinics may apply more detailed referral requirements, but these requirements can vary across states and territories. For example, Queensland and Western Australia have disease-specific referral criteria for bronchiectasis and chronic suppurative lung disease,[22,23] whereas Victoria does not.[24] Bronchiectasis and chronic suppurative lung disease are long-term lung conditions in which ongoing infection and inflammation cause excess mucus production, persistent wet cough, and progressive damage to the airways. In Queensland, the results of sputum (mucus) cultures must accompany referrals for these conditions but are only listed as highly desirable for referrals in Western Australia. Similarly, spirometry, a type of lung function testing, is mandatory for referrals in Western Australia but only listed as useful in Queensland.[22,23]

While some variation in referral requirements may be reasonable, it can lead to uncertainty for referrers, delays in care, and geographic inequities in access to and experiences of care for patients with the same condition.

Information sharing between healthcare providers

Delayed or insufficient information sharing between healthcare providers is a significant barrier to efficient and effective referral pathways into specialist care. Health professionals consulted by Lung Foundation Australia reported continued reliance on faxing and multi-step administrative processes that could substantially delay referrals. Others described difficulties accessing information from previous clinical investigations. Respiratory specialists reported particular challenges locating imaging held across a growing number of private radiology systems, often requiring multiple platform logins and patients' assistance to identify the relevant provider. Without access to both imaging reports and images, specialists may lack the information needed to make timely, informed clinical decisions. This can result in repeat investigations, delayed care, additional patient costs and avoidable demand on health services. When clinical information systems do not support reliable communication between providers, the coordination burden often falls to patients. Consumers described repeatedly explaining their history and ensuring that hospitals, specialists and GPs had access to relevant information.

My Health Record has the potential to help address these information-sharing challenges across the health system. However, uptake and use remain lower among medical specialists than among GPs, pharmacies and public hospitals. As at July 2026, 76% of specialists were registered for My Health Record, but only 45% had used it.[25] Reported barriers include poor usability and limited integration with existing clinical systems.[26] Even where rates of registration and use are higher, it remains unclear whether My Health Record adequately supports information sharing and clinical care. The feedback received from consumers and health professionals consulted by Lung Foundation Australia suggests that further improvements may be needed to address persistent information-sharing challenges, particularly in specialist care.

Distribution of care across the health workforce

Effective referral pathways make appropriate use of capabilities across the health workforce. Health professionals consulted by Lung Foundation Australia reported that some patients referred for specialist input could have been appropriately managed in primary care, without specialist involvement. Other health professionals emphasised the role of nurses in supporting effective specialist referral pathways. A specialist lung cancer nurse consulted by Lung Foundation Australia described a structured model in which specialist nurses contact patients following referral, coordinate investigations, monitor appointment timelines and support progression through diagnosis and treatment. This coordination can

help patients navigate the pathway, reduce delays and ensure that care progresses in a timely and organised way.

Use of emergency pathways to access public specialist services

Public patients can access specialist care through different pathways, including referral from primary care and follow-up after a hospital admission. The pathway used can affect how quickly a patient receives specialist care. Health professionals consulted by Lung Foundation Australia reported that, in some services, patients requiring respiratory specialist follow-up after a public hospital admission can obtain appointments relatively quickly. While timely follow-up after admission may be clinically appropriate, consumers and health professionals consulted by Lung Foundation Australia also reported instances in which patients were directed to emergency departments primarily to expedite specialist access. One consumer reported spending a day in an emergency department for this purpose.

Patient barriers to entering and navigating referral pathways

People living with lung disease can experience substantial delays in having their symptoms recognised and appropriately investigated. This can prevent or delay access to appropriate specialist care. In Lung Foundation Australia's 2024 lived experience research,[7] 28% of participants reported presenting to a GP with symptoms more than five times before their lung condition was diagnosed.

> *"My condition became worse as it was constantly misdiagnosed. It wasn't until I was hospitalised that a specialist found I had COPD. I have had many years suffering and being given antibiotics. My sister died of lung cancer because of the same situation."*
>
> – Lung Foundation Australia 2024 lived experience research participant, New South Wales

Barriers for patients may also continue after the need for specialist care has been identified. GPs play a central role in coordinating care and facilitating access to medical specialists.[27] However, patients may need multiple GP appointments to obtain and maintain referrals which can be confusing and burdensome for patients. Patients may need to return to their GP if ongoing specialist care is required after a referral expires, if they wish to change specialists, or if the reason for treatment changes.[28] If GP appointments are difficult to access because of cost, waiting times or limited availability, this can impact access to and continuity of specialist care. These administrative requirements can also constrain patient choice and autonomy in their health care.

c) Examine the affordability of specialist services, including out of pocket costs for consultations, diagnostics, procedures, and patient access to specialists through public health services, as well as factors influencing fee setting by specialists in the public and private health sectors.

For people with lung disease, the collective costs of health care can be substantial. An analysis of 2013 survey data found that adults living with asthma or COPD in Australia had household out-of-pocket healthcare expenditure 109% higher (95% CI: 50% – 193%) than people without a health condition.[29] This was the highest difference in household out-of-pocket healthcare expenditure reported across the chronic conditions studied.[29] Consequently, people with asthma or COPD had odds of skipping health

care that were 6.16 times higher (95% CI: 3.30-11.50) than people without a health condition.[29] The costs associated with specialist care can be especially unaffordable for people with lung disease.

Specialist consultations

Cost-of-living pressures have made specialist consultations less affordable for many people with lung disease. In Lung Foundation Australia's 2024 cost-of-living survey, around 2 in 5 participants reported that these pressures had a moderate to severe impact on their ability to afford specialist appointments for their lung condition (38%), specialist appointments for other conditions (40%) and private health insurance (40%).[8] Almost one-quarter (24%) had cancelled or delayed specialist appointments, while 15% had changed from private to public specialist care.[8] Cancelling or delaying specialist appointments was more common among participants in rural or remote areas (32%) and regional cities (26%) than among those in capital cities (19%).[8]

Available evidence indicates that respiratory and sleep medicine specialists may charge lower fees than some other specialties.[30] However, their services can still involve material out-of-pocket costs. Grattan Institute analysis found that more than 10% of initial respiratory and sleep medicine consultations were charged at two to three times the Medicare Benefits Schedule (MBS) fee.[30] Between 2018 and 2023, the median out-of-pocket cost of an initial respiratory medicine consultation approximately doubled in real terms, from around $50 to around $100.[30] These costs may be particularly difficult to absorb when consultations are needed regularly or alongside the high collective healthcare costs experienced by many people with lung disease.

Diagnostics and procedures

Access to lung function testing and medical imaging supports the timely diagnosis and management of many lung diseases.[12,19,20,31,32] When these tests and procedures are not available through the public health system, patients may face substantial private out-of-pocket costs that accumulate over the course of their care.

> *"It is the financial burden of the costs of tests, scans and ultrasounds to assess my condition that I find stressful."*
>
> – Lung Foundation Australia 2024 lived experience research participant, New South Wales

A GP consulted by Lung Foundation Australia described significant challenges accessing affordable lung function testing in their region. Public outpatient services in the region involve long waits and bulk-billed or low-cost visiting services are infrequent. The region's only private provider offers the most timely access but involves high out-of-pocket costs for patients.

This experience reflects broader challenges in accessing lung function testing, particularly spirometry. Although spirometry can be performed in general practice and reimbursed under Medicare, the high costs of equipment, infection control compliance, and low reimbursement rates make in-house testing difficult for many practices. These barriers have contributed to a decline in spirometry testing for lung diseases in general practice,[33] further limiting the services available to perform this testing.

Access to subsidised medications through public specialist services

Although medication affordability extends beyond the principal focus of this Inquiry, it is relevant where access to specialist care and the setting in which that care is provided influences whether a patient can obtain standard medications affordably.

A medication may be considered standard clinical treatment for a particular condition, but its use for that condition may not be approved by the Therapeutic Goods Administration (TGA) and listed on the Australian Register of Therapeutic Goods (ARTG). This often means the medication cannot be subsidised through the Pharmaceutical Benefits Scheme (PBS), even if it is listed on the ARTG for another indication. In this situation, the medication must be prescribed "off label" for the condition and patients must pay for it privately. These costs can vary substantially depending on the medication.

To improve access to off-label medications, public hospitals can decide to subsidise the costs of these treatments for their patients. This can create a financial incentive, or necessity, for patients to seek specialist care through the public healthcare system to be able to afford essential medications. Whether or not a medication is subsidised and to what extent varies across state and territory public healthcare systems, contributing to substantial inequities and adverse outcomes for patients and the health system. These impacts are illustrated in the management of nontuberculous mycobacterial (NTM) lung disease.

Nontuberculous mycobacteria are bacteria found in the environment that can cause chronic lung disease, often in people with an existing lung disease or a weakened immune system. NTM is an under recognised public health challenge in Australia. The incidence of NTM infections has been increasing and now exceeds tuberculosis incidence.[34–36] Although NTM infections do not always result in NTM lung disease, an increase in the incidence of these infections is correlated with increases in NTM lung disease prevalence.[37]

Patients with suspected NTM lung disease will be referred to a medical specialist for management. Treating NTM lung disease effectively is challenging. It involves a multi-medication regimen that must generally be continued for 18 months or more. Clarithromycin is the only medication that can be provided as part of this treatment regimen that is subsidised by the PBS for NTM lung disease. Clarithromycin is poorly tolerated, with most patients having to change to azithromycin to improve tolerability and compliance. All other medications, including azithromycin, must be prescribed off label, which can result in substantial costs for patients. An example of a standard regimen of azithromycin, ethambutol and rifampicin has an **approximate out-of-pocket cost of $500 per month over an 18-month course, totalling $9,000**. The unaffordability of these medications can contribute to delays in treatment initiation, reduced treatment adherence, and the use of medications or regimens that conflict with standard practice. This can lead to treatment failure. It also increases the risk of antibiotic resistance which can compromise the ongoing effectiveness of standard treatment options for NTM lung disease where few alternatives exist.

The exceptional costs of standard medications for NTM lung disease force many patients to seek specialist care through public hospitals that subsidise these treatments, even for patients who would otherwise like to be managed in the private healthcare system. This can increase demand on public specialist services and delay treatment given the long wait times for many public services. If a patient lives far away from the public hospitals that provide these subsidies, they may face additional barriers accessing these medications or may not be able to access them at all (**see Case Study: Regional patient journey accessing affordable medications for NTM lung disease**). These challenges are particularly concerning given the disproportionate burden of NTM infections in regional and remote areas of Australia.[34,38]

Case Study: Regional patient journey accessing affordable medications for NTM lung disease

A Brisbane-based respiratory specialist with expertise in managing NTM lung disease was consulted by Lung Foundation Australia. The specialist described the experience of a patient with NTM lung disease living in regional Queensland who faced substantial financial and geographic barriers accessing the medications required to treat their condition.

The patient was initially referred to a regional public hospital for specialist assessment and management. However, after being advised of the long wait time, the patient sought care from a private respiratory specialist. Following assessment, the private respiratory specialist contacted the Brisbane specialist for advice about how the patient could access the medications required to treat NTM lung disease. As almost all the medications required to treat their condition were not subsidised through the PBS, it became clear the patient would not be able to initiate treatment privately.

The Brisbane specialist was able to assess the patient through a public telehealth appointment. The Brisbane specialist deemed the patient to have severe disease that required immediate treatment, and further delays would result in significant disease progression and morbidity. The Brisbane specialist was able to facilitate subsidised access to the required medications. However, the patient had to make regular 50-minute trips each way to a different public hospital to collect the medications. Over the course of prolonged treatment, these journeys imposed additional travel costs and practical burdens on the patient.

The Brisbane specialist noted that the high cost of standard NTM medications means that patients who have already been assessed privately may still need to attend a public specialist service solely to access subsidised treatment. This increases demand on already stretched public outpatient services, delays treatment and may further reduce the availability of public specialist care for patients with more urgent or complex needs.

As part of its 2023-24 Federal Budget, the Australian Government introduced the Medicines Repurposing Program which aims to improve patient access to off-label medications.[39] For a medication to be listed on the ARTG for a particular indication, it must undergo regulatory assessment by the TGA. To be listed on the PBS, the Pharmaceutical Benefits Advisory Committee (PBAC) must also make a recommendation in favour of its listing. Fees are incurred at each of these stages and can deter listing of medicines on the ARTG for a new indication, particularly where there is low commercial incentive to do so.[39] The Medicines Repurposing Program offers to waive these fees for medications that are selected under the program,[39] providing a feasible pathway for these medications to be subsidised under the PBS. Program applications can be made by clinicians, health organisations, patient groups, pharmaceutical companies, and researchers.[39] However, funding for the Medicines Repurposing Program will cease on 30 June 2027.[39] Since its commencement, 29 medications have been nominated for the Program, but only 3 have been selected to date.[39] An independent evaluation of the Program was completed in June 2026 and is now under consideration.[39] If implemented effectively, medicines repurposing initiatives offer significant potential for improving access to medications that must be prescribed off label despite being standard care.

Travel costs

Although discussions of affordability often focus on the direct costs of specialist services, the indirect costs of accessing these services are also an important consideration and can substantially affect

whether patients can afford care. These costs may include travel, accommodation and parking expenses, as well as lost income or leave for patients, families and carers. These costs can accumulate over the course of care and place a particular burden on people who must travel long distances.

In Lung Foundation Australia's 2024 cost-of-living survey, 34% of participants reported that cost-of-living pressures had a moderate to severe impact on their ability to afford travel for appointments relating to their lung condition.[8] This impact was more commonly reported by participants in rural or remote areas (47%) than those in regional cities (33%) or capital cities (30%).[8]

State and territory patient assisted travel schemes provide eligible patients, and sometimes their escorts, with financial assistance for travel and accommodation when approved specialist services are not available locally.[40] However, despite these schemes, significant travel-related barriers remain. Some people are ineligible even when poor health, breathlessness, social isolation or financial constraints make independent travel difficult. For those who are eligible, subsidies have not kept pace with the actual costs of travel and accommodation, leaving patients with significant out-of-pocket costs.[41(p5)] The assistance available also varies considerably between jurisdictions. While some variation may reflect differences in geography and public transport availability, patients with comparable travel and care needs can receive materially different levels of support depending on where they live. Concerns have also been raised about the cultural responsiveness of these schemes for Aboriginal and Torres Strait Islander peoples.[42] Further improvements to these schemes are needed to support affordable and equitable access to specialist care.

d) Examine the impact on patient outcomes by delays due to cost, distance and waiting times, and broader system impacts on primary care, emergency departments, public hospitals, chronic disease management, as well as impacts on people due to deferred or missed care.

Consequences of delayed or missed care for people with lung cancer

Timely diagnosis and treatment are critical for people with suspected lung cancer because delays may allow the cancer to progress. Five-year survival for lung cancer decreases substantially with advancing stage at diagnosis. Among people diagnosed between 2011 and 2016, five-year survival was 68% for stage 1, falling to 32% for stage 2, 17% for stage 3 and 3.2% for stage 4.[43]

Reflecting the importance of timely intervention, the *Optimal care pathway for people with lung cancer* sets an expectation that patients see a specialist within two weeks of their initial referral, complete diagnostic investigations within two weeks of their first specialist appointment and begin treatment within six weeks of their initial referral.[12] These timeframes provide benchmarks for consistent, safe and high-quality care. However, delayed or compromised access to specialist services can affect whether they are achieved.

Available data indicate that many people with lung cancer are not diagnosed and treated within these recommended timeframes. Among four Western Australian hospitals participating in the Lung Cancer Clinical Quality Data Platform between September 2023 and September 2024, only 50% to 61% of patients underwent their first diagnostic procedure within the recommended timeframe, while only 12% to 30% commenced treatment on time.[13] Similarly, the Victorian Lung Cancer Registry, which covers approximately 80% of the Victorian population, reported that 69% of patients met the relevant measure for timely diagnosis in 2024 and only 34% met the measure for timely treatment.[44] Delayed or compromised access to specialist care can contribute to delays in diagnosis and treatment initiation, with serious clinical consequences and considerable distress for patients, families and carers.

Consequences of delayed or missed care for people with other lung diseases

The consequences of delayed or missed specialist care are not limited to lung cancer. For people with other lung diseases, delays can prolong symptoms, distress and uncertainty, defer diagnosis and management, and restrict access to specialised treatments.

> *"With that news [of diagnosis] we went away and made a phone call to book an appointment to see another specialist. Two months later we were in. So, I had two months to consult with Dr Google and read about this thing [occupational lung disease] I had and live with the symptoms that hit me like a truck and made life, the process of breathing, a painful and unpleasant experience."*
>
> – Lung Foundation Australia 2024 lived experience research participant, Queensland

People with suspected interstitial lung disease, a complex group of conditions involving inflammation or scarring of the lungs, require referral to specialist services to establish a diagnosis and appropriate management plan.[20,45] Delayed access to specialist services can therefore prolong the diagnostic process and defer condition-specific care. For people with interstitial lung disease, diagnostic delays have been associated with poorer quality of life, more frequent hospital admissions following diagnosis, and earlier disease progression or death.[46]

For some lung diseases, certain treatments can only be accessed via a specialist. If access to a specialist is compromised, this affects when or if these specialised treatments are made available to patients in need. For example, monoclonal antibody therapies can benefit some people with specific types of severe asthma[47]. However, treatment subsidised through the PBS must be prescribed by a specialist and patients generally must be under the care of the same specialist for at least six months before they are eligible for treatment[47]. The monoclonal antibody mepolizumab has recently been listed on the PBS for some people with uncontrolled COPD and also requires prescription by a respiratory specialist or general physician.[48] People with COPD may also require specialist care to be able to access home oxygen and other specialised therapies.[49] Delayed or missed specialist care can have significant consequences for patients who stand to benefit from these treatments.

e) Assess innovative and emerging models of care that may improve access to medical specialists.

Nursing models of care

Australia's nursing workforce has broad capabilities across different health settings and specialties. The recently released *National Nursing Workforce Strategy* recognises the contribution of nurses to evidence-based care.[50] However, it also identifies regulatory, funding and policy barriers that can prevent nurses from working to their full scope of practice.[50] There is significant potential for nurses to help address some of the challenges associated with access to specialist care if they are enabled to do so.

Specialist lung cancer nurses

Lung cancer care is particularly complex and time sensitive. It requires around twice the diagnostic tests of other common cancers and relies on comprehensive genomic testing to inform treatment

decisions.[42] Care must therefore be carefully coordinated if patients are to progress from suspected lung cancer to specialist assessment, diagnosis and treatment within the recommended timeframes.

Specialist lung cancer nurses are essential in this process. They can coordinate referrals and investigations, provide education and symptom management, prepare patients for appointments and maintain contact between medical reviews. Evidence demonstrates the benefits of specialist lung cancer nurses in supporting timely, coordinated care and access to treatment,[51,52] which is why their involvement in lung cancer care is recommended in national and international clinical guidelines.[12,53] For optimal benefit, specialist lung cancer nurses should be available from the point at which lung cancer is suspected given the complexity of the pre-diagnosis period.[54] This is the model of care adopted by Lung Foundation Australia.[54]

Despite their recognised importance, access to specialist lung cancer nurses in Australia remains inadequate. A 2023 survey found that only 57% of participating Australian health services had a specialist lung cancer nurse involved in the lung cancer multidisciplinary team.[55] Some of these nurses were also required to care for patients with other cancer types.[55] The survey was repeated in 2025 and early findings suggest specialist lung cancer nurse involvement may have worsened over time.[56]

There are currently approximately 55 specialist lung cancer nurses in Australia, representing 48 full-time equivalent positions, and only 11 start supporting patients before diagnosis.[42] This workforce supports an estimated 15,100 people newly diagnosed with lung cancer each year, equating to approximately one full-time equivalent specialist nurse for every 314 newly diagnosed patients.[42] Lung Foundation Australia estimates that an additional 120 specialist lung cancer nurses are required nationally to meet patient needs.[42]

Expanding the specialist lung cancer nurse workforce would help patients reach and navigate specialist services more efficiently and effectively, provide vital clinical support and continuity between medical appointments, and allow medical specialists to focus on the care that requires their expertise. In the absence of adequate face-to-face lung cancer nurse workforce in Australia, we acknowledge the importance of Lung Foundation Australia's Lung Cancer Nurse Telehealth Service, funded by the Department of Health, Disability and Ageing. This service complements specialist care, providing patients and carers with trusted information, navigation support and self-management tools across their lung cancer journey.

The role of nurses in other lung diseases

Appropriately qualified nurses and nurse practitioners can also improve access to specialised assessment, treatment and ongoing care for people with other lung diseases. In COPD care, nurses and nurse practitioners are valued members of the multidisciplinary team and, with appropriate training and expertise, can provide or support specialised care such as lung function testing and oxygen therapy.[57] Funding and policy settings that enable nurses to undertake these roles within specialist services or other appropriate care settings could improve access to aspects of specialised care that may otherwise be limited or substantially delayed.

An example from the closely related field of allergy and immunology provides one example of how expanded nursing roles could work in practice. The Rural Allergy Group is an independently operated, nurse practitioner-led service that was established in response to limited access to specialist allergy care in rural and regional Victoria.[58] Between June 2023 and June 2025, the service recorded 2,708 patient encounters, principally concerning food allergy and allergic rhinitis.[59] A wide range of services were successfully delivered, including 715 initial assessments, 647 immunotherapy injections, 302 oral immunotherapy appointments, 882 phone consultations, and 10 patch tests.[59] This model demonstrates how nurse practitioners can manage defined patient cohorts in a regional setting while maintaining pathways for referral or escalation to medical specialists when required.[59]

Funding and policy settings that enable nurses to work to their full scope of practice

Realising the potential of nursing models to improve access to specialist care requires supportive funding, workforce and policy settings. The *National Nursing Workforce Strategy* identifies several relevant priorities, including nationally coordinated workforce planning, sustainable funding for nurse-led models of care, and the removal of barriers that prevent nurses from working to their optimum scope of practice.[50]

Funding structures present a particular barrier. For example, although nurse practitioners can access MBS items for professional attendances, current arrangements may not adequately reflect the complexity, duration or scope of nurse practitioner-led care. Rebates remain substantially lower than those available for comparable medical practitioner services, while access to MBS-funded investigations, procedures and other relevant items remains limited.

Implementing relevant actions under the Strategy would help create the conditions needed to establish and sustain effective nursing models and expand access to specialised care across Australia.

Multidisciplinary models of care in primary care settings

Effective COPD management in primary care could improve access to diagnosis and treatment while preserving respiratory specialist capacity for patients who require specialist expertise. Many aspects of COPD diagnosis and management can be delivered in primary care, with referral to a respiratory specialist recommended in defined clinical circumstances.[60,61] However, implementing best-practice COPD care in Australian primary care settings has been challenging because it requires input and coordination across a range of health professionals and services. Barriers include Medicare funding arrangements, workforce capability, communication between services and access to essential assessments such as spirometry. Addressing these barriers could support earlier diagnosis and treatment, enable more patients to receive appropriate care in primary care and reduce referrals that do not require medical specialist involvement.

Canada's Best Care COPD program provides a practical example of this approach.[62] The program brings together the patient, their primary care provider and a certified respiratory educator case manager to deliver evidence-based assessment, individualised care planning, education and self-management support, with referral for specialised respiratory care when required.[62] An integrated electronic health record also guides and standardises patient encounters.[62] The program has been associated with sustained reductions in COPD-related hospitalisations and emergency department presentations, with these reductions increasing over multiple years.[62]

This example demonstrates the potential benefits of structured, multidisciplinary COPD management in primary care. Applying similar principles in Australia would require coordinated action to make best-practice care feasible and sustainable in primary care settings. This should complement, rather than restrict access to, respiratory specialist care by supporting patients to receive care in the most appropriate setting and facilitating timely referral when specialist assessment or management is clinically required.

Models of care for rural and remote communities

Models of care that strengthen connections between local health professionals and medical specialists may improve access to care in rural and remote communities and support specialist involvement at the appropriate level.

One such model is secondary consultation in which a GP seeks advice from a medical specialist about a specific clinical question to guide local health care provision. The specialist may advise on diagnosis or management or recommend direct referral for specialist care. Grattan Institute identifies secondary

consultation as a potential way to strengthen primary care and reduce the need for conventional specialist appointments where patients can be appropriately managed locally.[30] Models operating in the United States and Canada have demonstrated benefits, and similar initiatives have been implemented in parts of Australia.[30] This approach may warrant further exploration in respiratory care, particularly where local access to medical specialists is limited.

When direct specialist involvement is required, telehealth can connect patients with specialists without every consultation needing to occur in person. This may be particularly valuable in rural and remote communities where distance and limited local specialist availability create substantial access barriers. Health professionals consulted by Lung Foundation Australia emphasised that telehealth works best when an appropriately skilled local health professional is available to support the consultation.

As detailed in the National Rural Health Alliance's submission to this Inquiry, no single model will be suitable for every community. Models should be place-based and developed with communities to reflect local needs, workforce capacity, infrastructure and service availability. Lung Foundation Australia supports further exploration of these approaches in line with the principles outlined in the National Rural Health Alliance's submission.

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