

**Lung
Foundation
Australia**

New South Wales State Election 2023

**Meeting the respiratory health needs of the
New South Wales Community**

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About Lung Foundation Australia

Lung Foundation Australia (LFA) is the only national charity and leading peak-body dedicated to supporting anyone with a lung disease including lung cancer. For over 31 years we have been the trusted national point-of-call for patients, their families, carers, health professionals and the general community on lung health. There are over 30 different types of lung disease currently impacting 1 in 3 Australians.

Our mission is to improve lung health and reduce the impact of lung disease for all Australians. We work to ensure lung health is a priority for all, from promoting lung health and early diagnosis, advocating for policy change and research investment, raising awareness about the symptoms and prevalence of lung disease and championing equitable access to treatment and care. As a patient representative charity, we have partnered with patients, health professionals, researchers, medical organisations, and the Australian community to drive reform in the delivery of health services in Australia to benefit more than 7 million Australians impacted by lung disease and lung cancer. LFA have offices in Melbourne, Sydney, and Brisbane, and are committed to ensuring that the community have access to timely and accurate information, support, and that we are integrated within the state-based health systems.



Lung disease and lung cancer in New South Wales

Respiratory diseases are responsible for a large burden to the health and economic systems for New South Wales (NSW). More recently, with the COVID-19 pandemic, the burden and number of NSW residents with a respiratory condition grows. Lung disease and lung cancer are responsible for a considerable burden of death and disease, which highlights the need to ensure that people living with these conditions can access tailored information and support for improved self-management of their condition and achieve the best possible outcomes. When including respiratory diseases, which are responsible for a large burden to the health system, the burden and number of NSW residents with a respiratory condition grows. There are over 30 types of respiratory disease, including Chronic Obstructive Pulmonary Disease (COPD). COPD was the 5th leading cause of death in 2018, and second leading cause of avoidable hospital admissions.¹ COPD is preventable and treatable, but not fully reversible. In 2016-2017 (latest figures available), COPD alone was responsible for **+407,350 bed days**, this represents a significant burden to the health system.²

In NSW, lung cancer accounts for almost 1 in 10 of all cancers diagnosed (9%) with 3,985 lung cancer cases in 2018.³ Lung cancer was the fourth most commonly diagnosed cancer in NSW, with around 20,000 cases diagnosed between 2013-2017.⁴ It is also the leading cause of cancer death in NSW – responsible for nearly 20% of total cancer related death.⁵ In 2015-16, this cost the NSW health system \$95.6million and this figure is expected to rise as incidence rises. This figure does not account for the additional indirect costs such as lost work productivity, as well as loss of future productivity due to reduced employment, unemployment, or premature death associated with acute and chronic respiratory diseases.⁶ The emergence of COVID-19 has caused considerable impact on the NSW health system, with a 2022 COVID-19 survey by LFA indicating this will continue as 40% of people reported on-going COVID symptoms. Breathing problems were recorded in 55% of individuals with over 1 in 3 stating their on-going symptoms always or often impacted work, school, or university. The acute phase of COVID-19 infections caused significant economic impacts for NSW, however, as infections increase Long -COVID cases rise resulting in the need for additional health support to ensure the NSW workforce remains strong.

Our recommendations

Lung disease and lung cancer are responsible for a considerable burden of death and disease. NSW residents living with these conditions need tailored information and support to ensure improved self-management of their condition, improved health outcomes, and improved workforce participation. When compounding the potential ongoing respiratory impacts from **long-COVID**, and the **immense strain the hospital system is under**, the need to adopt and implement policies and programs that will protect the lung health of all NSW residents is evident.

In May 2022, the recommendations for the *inquiry into health outcomes and access to health and hospital services in rural, regional, and remote NSW* was published.⁷

The following proposal strongly aligns with **recommendation 8** - that the NSW Government investigate ways to support the growth and development of the primary health sector in rural, regional and remote areas, and support the sector's critical role in addressing the social determinants of health and reducing avoidable hospitalisations for the citizens of NSW, and **recommendation 39** - that NSW Health and the rural and regional Local Health Districts upgrade and enhance their collaborative work with the Primary Health Networks to ensure that high quality health services for rural, regional and remote NSW are cooperatively planned and successfully delivered.⁸

The pandemic should be utilised as a catalyst to improve patient empowered disease-management within the community, and we recommend that the NSW Government implement the following recommendations to ensure that every NSW resident can breathe freely and lead healthy and productive lives:

- 1 **Better support for NSW residents with lung cancer in regional and rural areas**
- 2 **Enhanced management of lung disease in the community and out of hospital**
- 3 **Improved health outcomes by reducing smoking rates**
- 4 **Long COVID support for NSW residents**
- 5 **Improving the air we breathe to protect health**

These priorities align with the **NSW State Health Plan: Towards 2021**⁹, will support further successes in the **NSW Health Professionals Workforce Plan**¹⁰, **NSW Cancer Plan**¹¹ (which identifies lung cancer as a particular area of focus and acknowledging the importance of patient-centred care which is paramount at Lung Foundation Australia), and the **NSW Mental Health Commission**.

1. Better support for NSW residents with lung cancer in regional and rural areas

We urge the NSW Government to invest in twelve (12) Specialist Lung Cancer Nurses who can provide vital support to NSW residents diagnosed with lung cancer, particularly those in regional, rural, and remote areas.

Lung cancer can affect anyone, not just smokers, if you have lungs you can get lung cancer. We know there is insufficient support for New South Wales residents with lung cancer who need assistance in navigating their diagnosis and the health system at large, which is unlike patients with other common cancers. LFA has an evidence-based model for specialist lung cancer nurse care, however access to a Specialist Lung Cancer Nurse (SLCN) is limited.

NSW has the second worst patient ratio in Australia for lung cancer

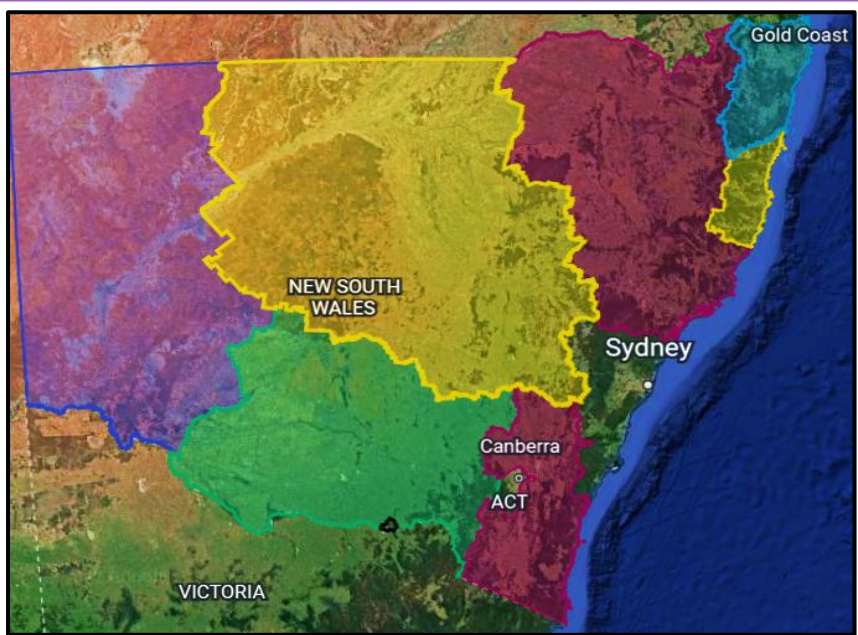
Only 10 nurses currently provide specialist lung cancer care for the entire state

Regional Inequities

In NSW, there is no access to a specialist lung cancer nurse in four of the seven rural and regional local health districts (LHD) (including Far West, Mid North Coast, Murrumbidgee and Southern NSW). Whilst only 28% of NSW residents live in rural or regional LHDs, these regions account for almost 60% of lung cancer cases and these people are unable to receive best practice care.¹² Furthermore, rural, and regional areas account for 92% of the NSW land area, causing many lung cancer patients to travel far distances or simply miss out on vital care, which leads to poorer outcomes.

Lung Cancer Nurse to Patient Ratio in NSW: 1 nurse: 677 patients	Breast Cancer Nurse to Patient Ratio (national): 1 nurse: 168 patients
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REGIONAL INEQUITY
There are only **four** SLCN's in regional and rural LHD's – these four are responsible for 58% of all NSW lung cancer patients (LHD's highlighted)



Lung cancer is costly

Lung cancer is common in NSW, and results in a range of direct and indirect costs. **The total health system costs in NSW associated with lung cancer amount of \$96.5million** in 2015-2016 (latest figures available)¹³, but indirect costs are estimated to be significantly higher as they include absenteeism resulting from the additional time off work taken by people living with lung cancer because of their illness, and a range of other social costs including loss of productivity and loss of life.

Funding twelve (12) specialist lung cancer nurses, at a total cost of \$1.2m per year, will assist in significantly **reducing the extreme inequities** across cancer care, and will see significant benefits to the thousands of NSW residents who are diagnosed with lung cancer each year, their families and friends, the health system, and the economy.

What is a Specialist Lung Cancer Nurse

Specialist lung cancer nurses are highly qualified registered nurses who add significant value to the coordination of care, support, guidance, and advice to patients experiencing lung cancer. They support patients by directing care and providing information and education throughout the course of treatment, from diagnosis to palliative care. Evidence shows that there are 75% fewer avoidable emergency department presentations when a specialist lung cancer nurse is involved in the care. Lung Foundation Australia's model of care for the specialist lung cancer nurse is evidence-based and draws on international and national research programs and includes an evaluation framework. **This evidenced-based model of care closely aligns with the strategies and priorities outlined in the NSW Cancer Plan 2022-2027 and works towards achieving person-centred care with equity of access.**⁵

2. Enhanced management of lung disease in the community and out of hospital

Respiratory disease and occupational lung disease is responsible for a significant amount of health system strain and currently in NSW, this is worsened by the challenging influenza season and COVID-19, putting added pressure on the already burdened hospital and healthcare workforce.

Care outside of hospital, and continued care in the community, is vital to ease this demand. LFA can offer this health system support through our Respiratory Care Nurse and Lungs in Action programs. These ready to implement programs supports improved disease management, which in turn can assist in preventing exacerbations and avoidable emergency department presentations, and support more equitable access across NSW. **We recommend a holistic approach to respiratory care in the community, at total of \$1.15m per year.**

Respiratory Care Nurse Program

As part of a comprehensive approach to respiratory and occupational lung disease management in the community, LFA recommends the immediate funding of **five** respiratory care nurses, at \$1m per year, to support NSW residents with respiratory disease. This also directly aligns with the *NSW Health Strategic Framework for Integrating Care* by providing care that target their needs and support for individuals with complex needs.¹⁴

Preventable hospital admissions are contributing to hospital bed shortages, ambulance ramping, poor patient outcomes, staff burnout and growing health system and economic costs. COPD is the second leading cause of preventable hospitalisations, which has been increasing over the years in NSW.^{15 16} Lung Foundation Australia's dedicated respiratory care nurses can reduce this burden on hospitals and improving health and well-being of those living with a lung disease like COPD.

"She helped me with my medications, vaccination, technique, doctor questions etc.... She made me feel in control of my health and able to help myself."
- Patient who used the Respiratory care nurse service

Program evaluation¹⁷ found: <ul style="list-style-type: none">• reduction in disease flare-ups• significant reduction in ED presentations• reduced smoking rates• increased physical activity• correct inhaler use• increased medication adherence	Community demand – Lung Foundation service delivery update: Community demand far exceeds capacity – the current wait time to speak to a respiratory care nurse is <u>4 weeks</u> .
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Lungs in Action Program

Lungs in Action (LIA) provides a continuum of care through a community exercise program designed to help people living with a chronic lung disease maintain the health and wellbeing benefits achieved by participating in pulmonary and cardiac rehabilitation. The program is available to patients with a variety of lung and heart conditions, including patients with COPD, bronchiectasis, asthma, lung transplant, interstitial lung disease (including silicosis), and lung cancer.

The NSW Strategic Framework and Workforce Plan for Mental Health 2018-2022 highlights inequitable access to mental health services arising due to geographical isolation and the need for integrated care within all communities.¹⁸ Rural patients also experience longer waiting times to access mental health support services and specialist care for respiratory conditions. LIA plays an integral role in reducing social isolation and facilitates relationships with those with a lived experience of lung and heart disease, enhancing community connectedness and belonging. The program also increases participants' independence and quality of life, by increasing their exercise capacity (which helps to reduce the severity of their symptoms, such as breathlessness), making activities of daily living easier and reducing the burden on participants families and carers. Currently, only 12 LIA programs are facilitated across the state with 60% located in metropolitan local health districts, and as such individuals from regional and rural communities are unable to access this beneficial service.

Program evaluation indicates 92% of attendees see LIA as being an important part of managing their condition and 96% would recommend the program to others with similar health conditions.

LFA recommends an investment of \$150,000 per year for 3 years to expand the Lungs in Action program into areas with an identified need, including those with a high Indigenous and Culturally and Linguistically Diverse population and low-socioeconomic status, who have a higher rate of chronic disease (and limited access to health services).



"I love working with clients who need help to get motivated to exercise and stay active. Classes also help clients to be more mobile and independent which benefits their physical and mental health. Most attend twice a week and many say if they don't attend these sessions, their health deteriorates." - Aileen, Lungs in Action Instructor

Integration with occupational lung health screening

We highlight that NSW also must move into the next stage of occupational lung screening, with new technologies like the Australian-made mobile CT scanner on a truck making rural and regional access to these important services possible. Screening retired mine workers and other at-risk occupations with the appropriate technology is now a gap in NSW, and we reiterate the value that the respiratory care nurse positions can offer through telehealth in tandem with this type of regional service.

3. Improved health outcomes by reducing smoking rates

Reducing harm from smoking products is integral to support the health and wellbeing of NSW residents. LFA recommend the NSW Government implement a positive licencing scheme for tobacco and e-cigarettes as a matter of urgency.

Tobacco smoking is the leading preventable cause of death and disease in NSW, causing the loss of 6,285 lives in 2020.¹⁹ In 2006-2007 the estimated annual social cost of tobacco use in NSW was \$8.4 billion, however more recent data from 2015-2016 indicated social costs of smoking for Australia to be \$136.9 billion, indicating an increased and substantial economic burden due to smoking.²⁰ Despite NSW reducing tobacco smoking rates to 8.2%, smoking rates remain high amongst socially and economically disadvantaged groups (19%) in regional and rural areas (21%) and amongst First Nations people (29%), demonstrating significant gaps in tobacco rates and the need for ongoing and enhanced support.²¹ Further to this, the use of e-cigarettes is on the rise in youths, creating a new public health concern and causing additional health harms.²²

Tobacco Licensing Scheme

NSW must urgently shift from a negative licensing scheme and implement a positive licensing scheme as this will aid in reducing smoking rates and the adverse effects of tobacco in line with the *NSW State Health Plan: Towards 2021*.²³ Licensing of retailers provides a register of tobacco and e-cigarette retailers and wholesalers and can be used to assist in reducing persistently high smoking rates in vulnerable populations.²⁴ Furthermore, the positive scheme raises considerable revenue which can be utilised to offset and enhance enforcement efforts. We also note the current Public Health (Tobacco) Act 2008 is insufficient in protecting NSW residents and must be reviewed and updated to reflect the current state of tobacco and e-cigarette use. These steps are not mutually exclusive.

It is well understood that the use of e-cigarettes has been on the rise particularly among youths, with significant concern being raised by parents, schools, health professionals, and public health experts.²⁵ A positive licensing scheme is essential to tackle the growing e-cigarette crisis by strengthening enforcement and monitoring of unlawful advertising, sale, contents, and access to these dangerous products, and changes to the Act enable stronger penalties and enforcement for repeat offenders to be fairly penalised. NSW is set to be the last Australian state to implement a positive licensing scheme, with Queensland and Victoria beginning the process of implementing positive licensing schemes. Consistency between states and territories makes for a co-ordinated approach, allowing national efforts possible which is needed to address e-cigarettes and other emerging threats to the significant gains made in tobacco control to date.

82% of NSW residents think more needs to be done to protect children from vaping²⁷

E-cigarettes cause:
smoking uptake, nicotine addiction, poisoning, seizures, trauma, burns and lung injury²⁶

4. Long COVID support for NSW residents

As the number of NSW residents who experience long-term respiratory impacts from COVID-19 grows, tailored support is desperately needed.

COVID-19 remains a significant challenge for NSW residents, as the nation transitions to the new 'COVID normal.' Millions of NSW residents have been infected with COVID-19 and subsequently are at risk of experiencing long-term respiratory impacts.²⁸ It is estimated that at least 1 in 5 will experience long COVID with symptoms of fatigue, shortness of breath and cognitive dysfunction, lasting for months and impacting everyday life.^{29,30} The risk of developing long-COVID is higher for individuals with more severe disease, however, many individuals with even a mild illness are being diagnosed with long COVID.

3 in 4 New South Wales residents think the government should invest in increasing support and information for people with ongoing COVID symptoms

Lung Foundation Australia's community survey on COVID-19 – NSW perspective

- 87% of people who reported ongoing COVID-19 symptoms, are still experiencing symptoms
- The majority of those still experiencing symptoms reported fatigue, breathing problems and a cough, and 26% said that their health professional referred to their ongoing symptoms as "long-COVID"
- 58% of NSW residents surveyed reported having a chronic health condition prior to the pandemic, half of which reported having a lung disease, lung cancer, or asthma.
- 1 in 2 had an appointment, test or procedure cancelled or delayed due to COVID. In addition, 72% of these people who had a cancellation or delay reported impacts such as worsened condition, hospital presentation, worse mental health, and physical pain.
- 55% of NSW residents with a chronic disease reported being moderately or very concerned about managing their condition and the risk of future COVID infection.
- 63% of NSW residents were interested in accessing a Lung Foundation Australia free COVID-19 specific respiratory nurse to help manage ongoing symptoms.

Lung Foundation Australia are trusted by the community in the provision of accurate and reliable information of respiratory illness. With 1 in 3 people experiencing a respiratory disease, COVID infection and the long-term respiratory impacts resulted in significant concern in the community. The need for information and support grew significantly through the pandemic:

- a 62% increase in LFA website traffic during the peak of the pandemic
- over 134,000 visits to our digital COVID resources and information
- increase in calls and requests for information on COVID-19 and their disease
- surge in reports of distress among both patients and carers.

We recommend an investment of \$150,000 to enable LFA to support NSW residents experiencing long COVID and for those who have concerns or need support to manage their pre-existing lung disease. This funding will enable LFA to provide a broad range of information and support, and as the peak lung health organisation we are best placed to deliver this comprehensive program of work.

"The pandemic brought on new feelings of anxiety. After having covid, I struggled for a while with shortness of breath and brain fog and as did many of the people I knew. However, we had no information on this and when it would clear." - NSW resident who had COVID-19

5. Improving the air we breathe to protect health

Air pollution is an emerging threat to health, and we encourage the NSW Government to:

- **Create a climate resilient community who can prepare, respond, and recover from natural disasters**
- **Strengthen standards for clean air**

Create a climate resilient community who can prepare, respond, and recover from natural disasters

Climate change is causing a significant disruption to the NSW community at an increasingly frequent rate with severe natural disasters occurring in unprecedented numbers. Each of these climate disasters has put the community's health at risk, and we note in these times a lack of consistent and proactive messaging from a range of government and non-government sources. **We recommend an investment of \$120,000 for LFA to create and disseminate educational resources to fill this vital gap and to better understand the needs and challenges in times of climate crisis related to air quality (fires), mould (floods), and broader issues that cause breathing difficulties (including heatwaves).**

Strengthen standards for clean air

We urge the NSW EPA to strengthen the ambient air quality standards for ozone, nitrogen dioxide and sulfur dioxide and adopt the World Health Organisation (WHO) Air Quality Guidelines, as the current Australian national standards fail to protect NSW residents from the harmful impacts of air pollution. Additionally, we urge the NSW EPA to publish the outcomes from the review of the Clean Air Regulation review and update the legislation immediately to reduce air pollution. Whilst this review is welcomed, more needs to be done to protect NSW residents from poor air quality.

What is the impact of air quality?

In Australia, air pollution causes around 3000 deaths (equivalent to about 28,000 years of life lost).³¹ Short term health impacts of air pollution include worsening of existing respiratory conditions like COPD, bronchiectasis, and asthma, as well as pneumonia and irritation to the nose, throat, eyes, or skin.³² Long term health impacts include heart disease, lung cancer, respiratory diseases and can cause damage of nerves, brain, kidneys, liver, and other organs. ³³ In NSW, industry, motor vehicle, other transport activities, and domestic wood smoke are the main sources of anthropogenic air pollution and within Sydney, domestic wood heating causes the greatest amount of PM2.5 pollution. ^{34,35} PM2.5 particles pose the greatest risk to health as they are small enough to go deep into the lungs and can enter the bloodstream, causing significant health implications.³⁶

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