

Lung Foundation Australia Specialist Lung Cancer Nurse Model of Care



Endorsed
by





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Endorsement statement

This resource meets the Cancer Nurses Society of Australia (CNSA) guidelines and is expected to support nurses in their understanding of specialist lung cancer nursing. Endorsement is provided by CNSA for a period of three years, ending February 2028.

Disclaimer

CNSA has made every effort to ensure that information included within this Model of Care is accurate at the time of endorsement. The information included cannot substitute for the advice or direction of a health care professional, and CNSA makes no guarantees, nor can it assume any legal liability for the accuracy, completeness, or usefulness of such information or for any damage incurred directly or indirectly from the information. Reference to any specific product does not imply its endorsement, recommendation or preference by the Cancer Nurses Society of Australia.



About Lung Foundation Australia

Lung Foundation Australia (LFA) is the leading peak body for respiratory health and lung disease in Australia.

LFA funds life-saving lung health and lung cancer research, and champions programs so Australians with lung disease and lung cancer can live their best lives.

By 2030, LFA's mission is to be recognised as one of the world's **most innovative and effective** lung health charities, and a **fearless leader** of lung health and lung cancer policy, programs and research.

LFA is leading work to improve outcomes for Australians with lung cancer, their carers and families, by working closely with the Australian Government, leading lung cancer experts and people with lung cancer.

In 2019, with support from the Australian Government, LFA developed the **National Strategic Action Plan for Lung Conditions (Strategic Action Plan)**. The Strategic Action Plan highlighted urgent actions required to support Australians living with a lung condition. The Australian Government listed LFA as implementation partner for the Strategic Action Plan, with shared responsibility to implement its actions. Since then, LFA has been leading Action 5.2 to fund specialist lung cancer nurses. In line with the Strategic Action Plan, and based on extensive expert and consumer consultation, LFA developed the **Lung Cancer Blueprint** in 2020 (revised in 2022). The Blueprint outlines six priority areas for lung cancer reform. These include improving access to specialist lung cancer nurses and strengthening survivorship support to enhance quality of life and health outcomes of people at risk of or affected by lung cancer.

The **LFA Specialist Lung Cancer Nurse Model of Care** is an important step in this work. It outlines the critical roles that specialist lung cancer nurses play in addressing the unique needs of people at risk of or affected by lung cancer and in improving lung cancer outcomes.

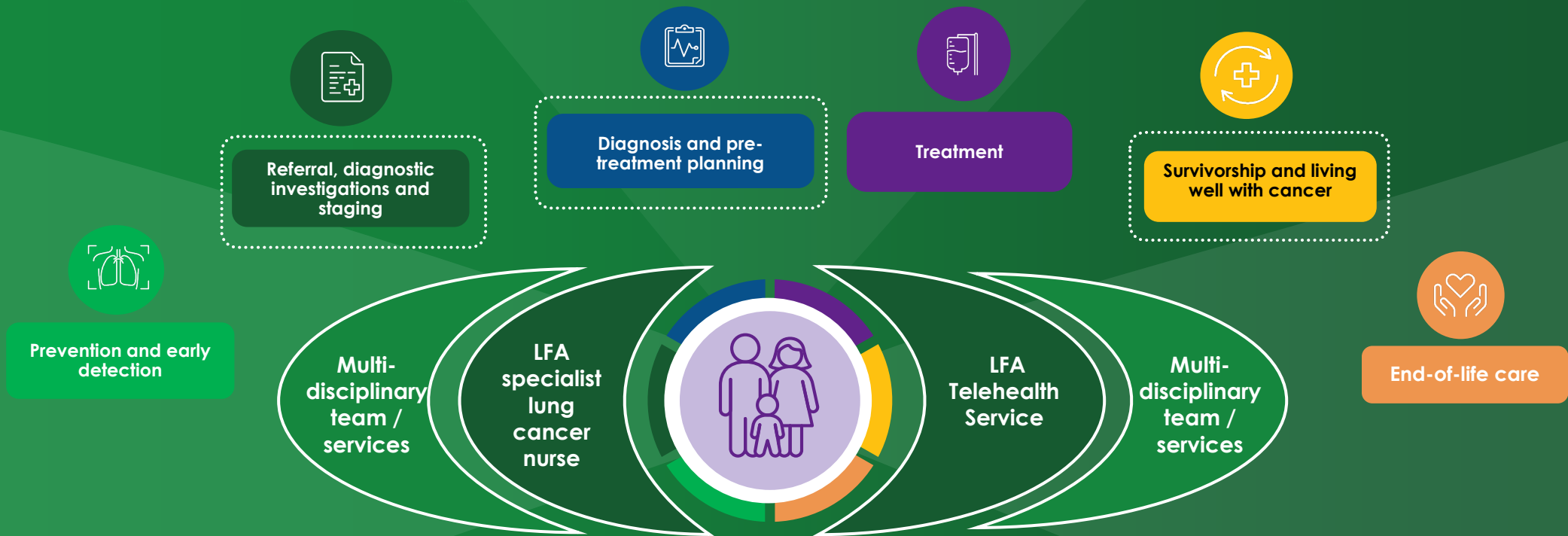
Specialist lung cancer nurse roles are essential for improving the survivorship of people with lung cancer. LFA's goal is to increase the five-year survivorship rate of people affected by lung cancer to 50 per cent.

Glossary of key terms

Terms	Explanation
Nursing advanced practice	The delivery of advanced health practice that involves five domains consisting of clinical care, professional leadership, education, research and support of systems (based on the Advanced Nursing Practice – Guidelines for the Australian Context).
Allied health	Trained experts in specific health fields other than medicine, dentistry or nursing. They provide a range of diagnostic, technical, therapeutic, and support services in connection with health care.
(Cancer) Care Coordinator	An advanced practice registered nurse whose focus is to support patients experiencing cancer and create a seamless experience of cancer care.
Clinical care	Activities carried out on behalf of patients focusing on specific needs including physical care, procedures, health assessments, interpretation of data, care planning and coordination.
Clinical trials	A type of research that studies new tests and treatments and evaluates their effects on human health outcomes.
Comorbidities	The presence of one or more existing diseases or conditions in a person.
Culturally sensitive care	Care that is responsive and respectful to the cultural beliefs, practices, and needs of patients from different cultural backgrounds.
Evidenced based practice	A healthcare approach where care is provided based on the best available current research, clinical expertise, and patient preferences to provide the most effective care.
General Practitioner (GP)	Medical doctors who provide primary care to individuals and are often the first point of contact for people with health concerns.
Metastatic disease	In the context of lung cancer, this refers to the spread of cancer cells from the original site to other parts of the body.
Model of Care	An approach that defines the way health care and services are organised and delivered. Models of care often have a theoretical basis, defined core elements and principles and a structure that allows for implementation and evaluation.
Multidisciplinary teams (MDT)	Teams comprised of multiple health professionals from different disciplines who work collaboratively with a patient and their families / carers to deliver comprehensive care.
Palliative care	Care delivered for a person living with a life limiting or terminal illness, regardless of age. It usually involves the management of symptoms to improve a person's quality of life.
Person-centred care	A healthcare approach where the patient's specific needs, preferences, and values guide all decisions and aspects of their treatment and care.
Primary care	Initial healthcare services that a person receives, usually provided by GPs, nurses or family doctors, with a focus on overall health, and the prevention and treatment of common illnesses.
Recurrent disease	In the context of lung cancer, this refers to cancer cells that have regrown and returned after a period of remission.
Residual disease	In the context of lung cancer, this refers to the presence of cancer cells that remain in a person's body after active treatment.
Supportive care	Refers to support that maintains the quality of life for people living with cancer, cancer survivors, their families / carers, and includes care that supplements clinical treatment modalities.
Survivorship	Refers to supports delivered to address late effects of cancer and its treatment, other chronic illnesses, modifiable risk factors, and monitor cancer recurrence.
Tertiary care	Specialised care delivered in a hospital or similar care setting for patients with immediate, complex needs.
Treatment toxicity management	Support delivered to identify, monitor and mitigate side-effects and adverse reactions that patients may experience from therapies and treatments.

LFA specialist lung cancer nurses improve health outcomes of people at risk of or affected by lung cancer

LFA specialist lung cancer nurses have a stronger focus on pre-diagnosis, diagnosis and post-treatment survivorship.



Core elements of the LFA specialist lung cancer nurse Model of Care.

- Expert, patient-centred and culturally sensitive care
- Integrated service delivery, including with the LFA Telehealth Service
- Timely support, diagnosis and treatment

LFA specialist lung cancer nurses work at the top of their scope of practice across the five domains of advanced nursing practice.

-  **Clinical care**
Ensuring patients receive early, responsive and optimal lung cancer care.
-  **Support of systems**
Contributing to improving local health systems and practices.
-  **Education**
Educating self, other health professionals, patients and broader community.
-  **Research**
Contributing to the evidence base and its implementation in lung cancer care.
-  **Professional leadership**
Operating at the top of the specialist nurse scope of practice.

Where possible, LFA specialist lung cancer nurses are positioned in Respiratory Medicine to enable a core focus on pre-treatment steps of the lung cancer care pathway

1. Introduction to the LFA Specialist Lung Cancer Nurse Model of Care

About the Model of Care

The LFA Specialist Lung Cancer Nurse Model of Care aims to promote consistent, high-quality specialist nursing care for people at risk of or affected by lung cancer.* It provides guidance for LFA, the LFA specialist lung cancer nursing workforce, health services and policy makers.



LFA specialist lung cancer nurses work across the lung cancer care pathway, with a particular focus on pre-diagnosis, diagnosis and post-survivorship, in response to evidence that greatest unmet patient need exists in these steps of the lung cancer care pathway. LFA specialist lung cancer nurses are positioned in Respiratory Medicine where possible.

The Model of Care outlines how LFA specialist lung cancer nurses work to the top of their scope of practice.

The model outlines:

- intended benefits of the role and outcomes that LFA specialist lung cancer nurses work towards
- how LFA specialist lung cancer nurses apply their specialist nursing skills, knowledge and practice across the five domains of advanced nursing practice
- the core roles of LFA specialist lung cancer nurses in each step of the lung cancer care pathway
- knowledge and skills of LFA specialist lung cancer nurses that assist with delivery of a high-quality, specialist service.

The Model of Care informs how LFA specialist lung cancer nurses determine the priorities and focus of their service.

The model includes:

- principles for determining the focus of their role within their local context, and how to apply them in practice
- evidence of unmet patient needs and of the impact of lung cancer nurses
- key patient needs in each step of the lung cancer care pathway
- contextual considerations that may influence the focus of LFA specialist lung cancer nurse roles in each step of the lung cancer care pathway.

The Model of Care also articulates how the LFA Telehealth Service can complement the services provided by LFA specialist lung cancer nurses in each step of the lung cancer care pathway.

*The Model has been informed by best practice evidence, LFA's work to date with the National Specialist Lung Cancer Nurse Program and multidisciplinary expert clinical advice. The Model aligns with national nursing and cancer specific frameworks and does not replace clinical guidelines or standards of practices underpinning advanced nursing practice or cancer care. See page 41 for more information regarding the development of the Model of Care.

About LFA specialist lung cancer nurses

LFA specialist lung cancer nurses are advanced practice, registered nurses working in the specialist field of lung cancer.

LFA specialist lung cancer nurses are expert practitioners responsible for delivering complex clinical and supportive nursing care to improve outcomes for people at risk of or affected by lung cancer. Their roles are multifaceted.

LFA specialist lung cancer nurses are recruited and supported under the banner of the LFA Specialist Lung Cancer Nurse Program

LFA specialist lung cancer nurses are supported with education, guidance for service establishment, monitoring and evaluation activity and ongoing professional development.

LFA specialist lung cancer nurses work at a senior level across the five domains of advanced practice nursing.



Clinical care

Ensuring patients receive early, responsive and optimal lung cancer care



Support of systems

Contributing to improving local health systems and practices.



Education

Educating self, other health professionals, patients and broader community



Research

Contributing to the evidence base and its implementation in lung cancer care.



Professional leadership

Operating at the top of the specialist nurse scope of practice.

LFA specialist lung cancer nurses work across the lung cancer care pathway, with a particular focus on pre-diagnosis, diagnosis and post-treatment survivorship.



Prevention and early detection



Referral, diagnostic investigations and staging



Diagnosis and pre-treatment planning



Treatment



Survivorship and living well with cancer



End-of-life care

LFA specialist lung cancer nurses care for and support people with small cell lung cancer, non-small cell lung cancer and pleural mesothelioma.

LFA specialist lung cancer nurses are often the first health professional with lung cancer expertise that a patient sees.

Strong involvement pre-diagnosis enables LFA specialist lung cancer nurses to advocate for individual patient health, wellbeing, needs, priorities and preferences in the MDT diagnostic and pre-treatment planning meeting.

LFA specialist lung cancer nurses are core members of multidisciplinary lung cancer teams (MDTs).

LFA specialist lung cancer nurses ensure seamless coordination and transition of care across multiple diagnostic and treatment services and locations.

About the LFA Telehealth Service



The LFA Telehealth Service supports Australians at risk of or affected by cancer (including patients, their families and carers) regardless of where they live, across the entire lung cancer care pathway.

LFA specialist lung cancer nurses refer appropriate patients to the LFA Telehealth Service to extend delivery of specialist care and support.

The LFA Telehealth Service is staffed by specialist lung cancer nurses, social workers and specialist respiratory care nurses, and provides a range of support services:

Specialist Lung Cancer Nurse

- Lung cancer diagnostic and treatment education.
- Comprehensive supportive care assessments, across physical, psychological, social, information and spiritual domains.
- Toxicity assessment.
- Self-management education for lung cancer symptoms and treatment side-effects.
- Referral pathway recommendations.

Lung Cancer Social Worker

- Psychosocial assessment and distress screening.
- Information, support and referral pathways relating to:
 - processing a diagnosis
 - impact on family and relationships
 - financial and housing assistance
 - legal issues and processes
 - coping with progression/recurrence
 - emotional / mental health support.

Specialist Respiratory Care Nurse

- Information, support and referral pathways relating to COPD and Bronchiectasis.
- Self-management education for respiratory disease symptoms and treatment side-effects.
- Guideline recommendations on self-management, including action plans, vaccinations, inhaler delivery, physical activity and diet.

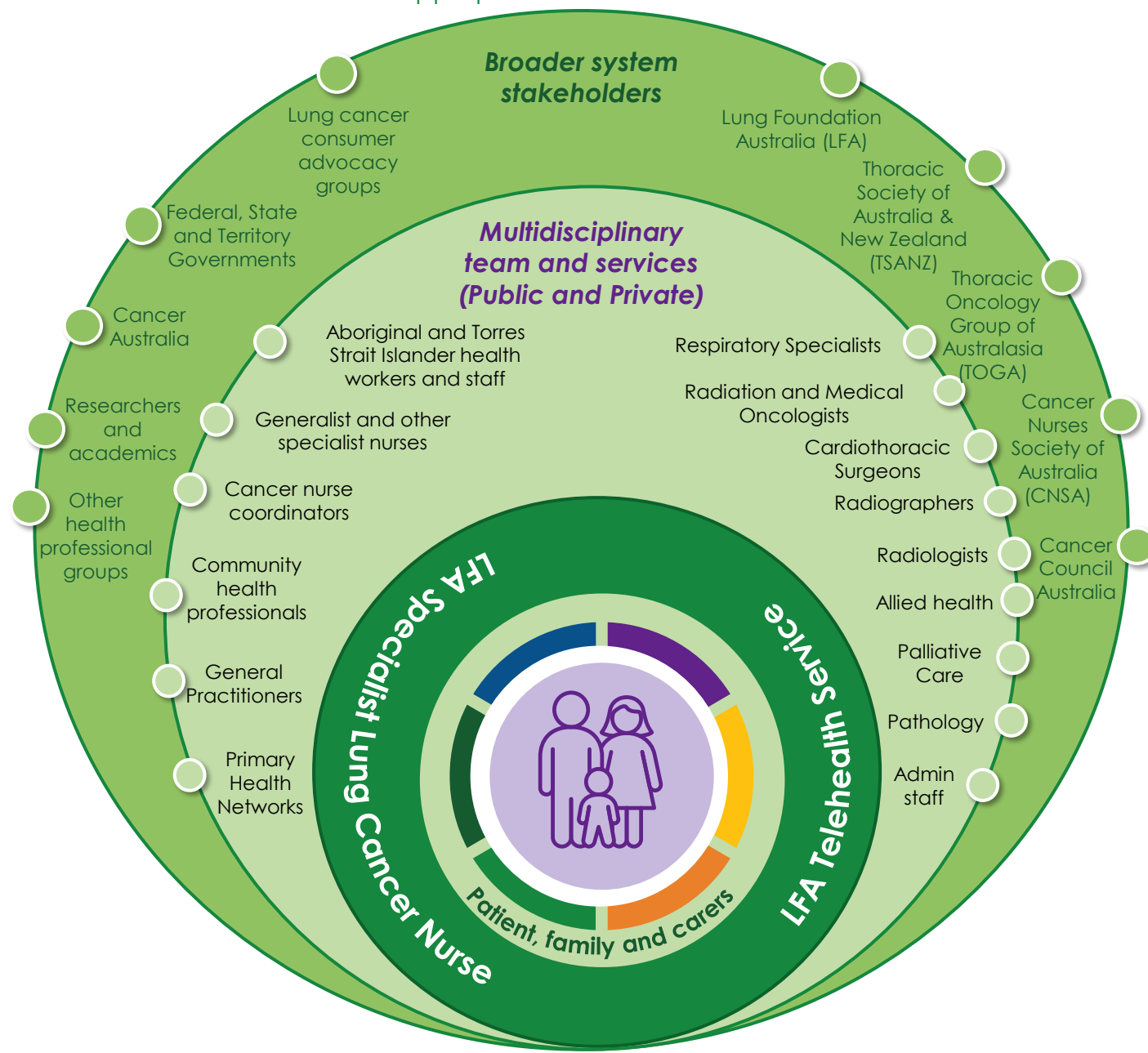
Peer Support

- Connection with lung cancer specific peer-support, including:
 - face-to-face support groups.
 - peer-led online support groups and forums.
 - peer connect (one-on-one) telephone connection.

LFA's Telehealth Service reach and capacity was strengthened in 2024, with Australian Cancer Nursing and Navigation Program funding.

LFA specialist lung cancer nurses work with multidisciplinary teams and services to provide optimal care to people with lung cancer

LFA specialist lung cancer nurses engage with broader stakeholders that influence the context in which they work, ensuring patients have access to the most appropriate services to meet their needs.



Key:

- LFA role or service
- Health services and multidisciplinary teams (incl. tertiary care, primary care and community health services)
- Broader health system stakeholders

National policy and program context of the Model of Care

LFA specialist lung cancer nurses work within a complex system that is undergoing significant change and facing critical issues related to equity, cost, and workforce.

This Model of Care aligns with national policy and program initiatives designed to enhance lung cancer outcomes and better articulate the role of nurses in cancer care.

The Australian Cancer Plan, released November 2023	A national 5-year plan with a focus on equity in cancer outcomes and strategic priorities that include a transformational cancer workforce and enhancing the consumer experience.
The Aboriginal and Torres Strait Islander Cancer Plan, released October 2023	A national plan with a focus on improving cancer outcomes for Aboriginal and Torres Strait Islander peoples.
The Australian Cancer Nursing and Navigation Program (ACNNP)	An initiative announced under the Australian Cancer Plan designed to ensure all people with cancer have access to high quality and culturally safe care, irrespective of their cancer type or location. The Program includes: • Cancer Navigation Service (an extension of the Cancer Council Australia 13 11 20 service) • all-cancer nurse service to be provided by the McGrath Foundation in partnership with the cancer sector • Child and Youth Cancer Hub • Specialist telehealth services, delivered by the cancer NGO sector (including LFA).
Optimal Care Pathways	Nationally endorsed pathways outlining consistent, safe, high-quality and evidence-based care for people with cancer. The <i>Optimal Care Pathway for People with Lung Cancer</i> (2 nd edition) was published in June 2021.
National Lung Cancer Screening Program	Commencing in 2025, targeting people at high risk of lung cancer.
Workforce reform in nursing and cancer nursing	A National Nursing Workforce Strategy undertaken in response to the anticipated nursing workforce shortage in Australia (projected shortfall of 85,000 nurses by 2025 and 123,000 nurses by 2030). Cancer Nursing Workforce Survey undertaken by the Cancer Nurses Society of Australia to better understand the cancer nursing workforce in Australia.

2. The demonstrated need for and impact of specialist lung cancer nurses

There are significant inequities in outcomes for people affected by lung cancer

Lung cancer is the fifth most diagnosed cancer and the leading cause of cancer death in Australia.¹

In 2024, it is estimated that over 15,000 people will be diagnosed with lung cancer in Australia, accounting for about 9 per cent of all cancer cases. The number of new lung cancer cases is increasing and over the next 10 years almost 168,000 people will be diagnosed with lung cancer. Lung cancer has the lowest 5-year survival rate of the five most common cancers in Australia and claims more lives than breast and prostate cancer combined.

Only one in four people diagnosed with lung cancer today will be alive in five years.

Significant disparities exist in lung cancer outcomes.²

Lung cancer outcomes vary across the country. Some population groups are disproportionately affected and more likely to be diagnosed with and die from lung cancer.



Aboriginal and Torres Strait Islanders	are twice as likely to be diagnosed with and die from lung cancer compared to non-Indigenous Australians. In addition, they are more likely to be diagnosed with lung cancer that has progressed to an advanced stage.
People experiencing socio-economic (SES) disadvantage	are twice as likely to be diagnosed with and die from lung cancer than people from higher socioeconomic backgrounds.
Australian's living in regional, rural and remote areas	experience 12% lower survival rates and 31% more lung cancer cases, compared to those living in major cities and report limited or non-existent access to specialist cancer treatment.
People from culturally and linguistically diverse backgrounds	experience inequitable access and outcomes. Lung cancer incidence in some communities is expected to increase greatly based on smoking trends.

There are many complexities in the diagnostic work-up, staging and treatment of lung cancer

Lung cancer is often diagnosed at a late stage or not staged at all.³

Only 12 per cent of Australians are diagnosed with lung cancer at an early stage (Stage I or II). In contrast, about four times as many are diagnosed with incurable Stage IV disease, where the five-year survival rate is less than 5 per cent. The National Lung Cancer Screening Program aims to increase early diagnosis and improve five-year survival rates for lung cancer patients.

Nearly a third of lung cancer patients are not staged at diagnosis, potentially missing out on life-changing treatment and care.



Experiences of
people affected by
lung cancer^{4, 5, 6}

**3+
month**

wait for a diagnosis of lung cancer after presentation of lung cancer symptoms.

48%

experience a wait time greater than the recommended 42 days from GP referral to commencing treatment.

28.5%

of people are not staged when diagnosed, potentially missing life-changing treatment.

The lung cancer care pathway is long, complex and difficult to navigate.⁷

The diagnostic and staging pathway for lung cancer is lengthy and complex, requiring multiple diagnostic tests. In Australia, people with suspected lung cancer often spend 3 months or more undergoing diagnostic and staging testing before receiving a diagnosis. The high number of tests required to accurately diagnose, stage the disease and plan appropriate treatment influences this timeline. Limited availability and capacity of in-house diagnostic services, and complexity of accessing outsourced services, contribute further to these delays.

Critical aspects of lung cancer diagnosis, treatment and care occur outside cancer services.⁸

Investigations, diagnosis, and surgery for lung cancer typically occur in Respiratory Medicine and cardiothoracic services rather than in cancer services, where specialist cancer nurses are traditionally based. This can limit early access to available lung cancer support, information and coordination services and increases the complexity of navigating care.

People affected by lung cancer experience significant challenges requiring specialist lung cancer nursing support

People with lung cancer experience significant physical, psychosocial and financial distress and many needs go unmet. [9](#), [10](#), [11](#), [12](#), [13](#)



People affected by lung cancer experience:

- **significant stigma, that can manifest as guilt, shame, anxiety and depression.** Stigma affects how people seek help, access health services and advocate for their needs
- **debilitating symptoms and side-effects of lung cancer and its treatment.** Common symptoms such as breathlessness, coughing and fatigue, reduced exercise capacity and mobility have a significant impact on physical health and quality of life. Symptoms contribute to feelings of fear, depression and anxiety, often leading to social isolation
- **higher prevalence of poor mental health** (29.6% higher compared to other cancers)
- **increased risk of suicide.** Compounded by stigma, rates of suicide are 5 times higher among people with lung cancer than the general population and 8 times higher than in people with breast, prostate and colorectal cancers
- **complex health needs.** People with lung cancer often have multiple comorbidities, many of which are associated with social and economic disadvantage (e.g. chronic obstructive pulmonary disease). Comorbidities can influence timely access to treatment.

Lung cancer is costly and causes financial burdens for patients, their families and carers. ¹⁴

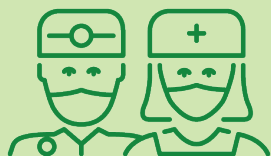
People affected by lung cancer experience significant financial burdens. Direct costs of lung cancer cost \$448 million in 2022 including treatment, out-of-hospital expenses and out-of-pocket expenses. Indirect costs of lung cancer in 2022 totalled \$14.9 million, including costs associated with people taking time off work.

Healthcare for lung cancer in Australia is the third mostly costly of all cancer types, with a case of lung cancer costing an average of \$52,000 to the health system (from one-year pre-diagnosis to three years post-diagnosis).

Access to a specialist lung cancer nurse improves patient outcomes and experience of care

The involvement of a specialist lung cancer nurse in the care of lung cancer patients leads to significant improvements in timely diagnosis and timely access to treatment, improved outcomes and wellbeing.

Involvement of a specialist lung cancer nurse leads to:^{15, 16, 17}



44%
more likely to have access to needed treatment

75%
fewer presentations to an Emergency Department due to symptom assessment and management provided by specialist lung cancer nurses



significantly shorter wait times from referral to treatment, which increases the potential for positive health outcomes

International quality standards recognise the importance of a specialist lung cancer nurse role pre-diagnosis. Access to a specialist lung cancer nursing during diagnostic work-up enhances patient experience and outcomes. Patients with a specialist lung cancer nurse are more likely to access timely, recommended treatment.¹⁸

Specialist lung cancer nurses improve patient outcomes and overall wellbeing.¹⁹

They:

- improve the value and quality of patient-centred lung cancer care
- improve access to lung cancer treatment and timeliness of treatment
- increasing receipt of anticancer therapy
- strengthen patient capacity to self-manage lung cancer symptoms
- improve outcomes for patients / carers affected by lung cancer (cancer outcomes, quality of life and wellbeing)
- improve cancer service alignment with optimal lung cancer care
- reduce avoidable emergency department presentations.



I hope that one day there will be less ignorance about the causes of lung cancer, and that others living with the disease will be able to access the support they need, including the specialist care only a specialist lung cancer nurse can deliver.



Having been through two different cancer diagnoses, I have experienced many contrasts in my journey. For example, when I had breast cancer, I had ready access to breast cancer nurses, while as a lung cancer patient, I'm yet to meet one in the course of the four years of my treatment.

3. The role of LFA specialist lung cancer nurses

Overview of the LFA specialist lung cancer nurse role

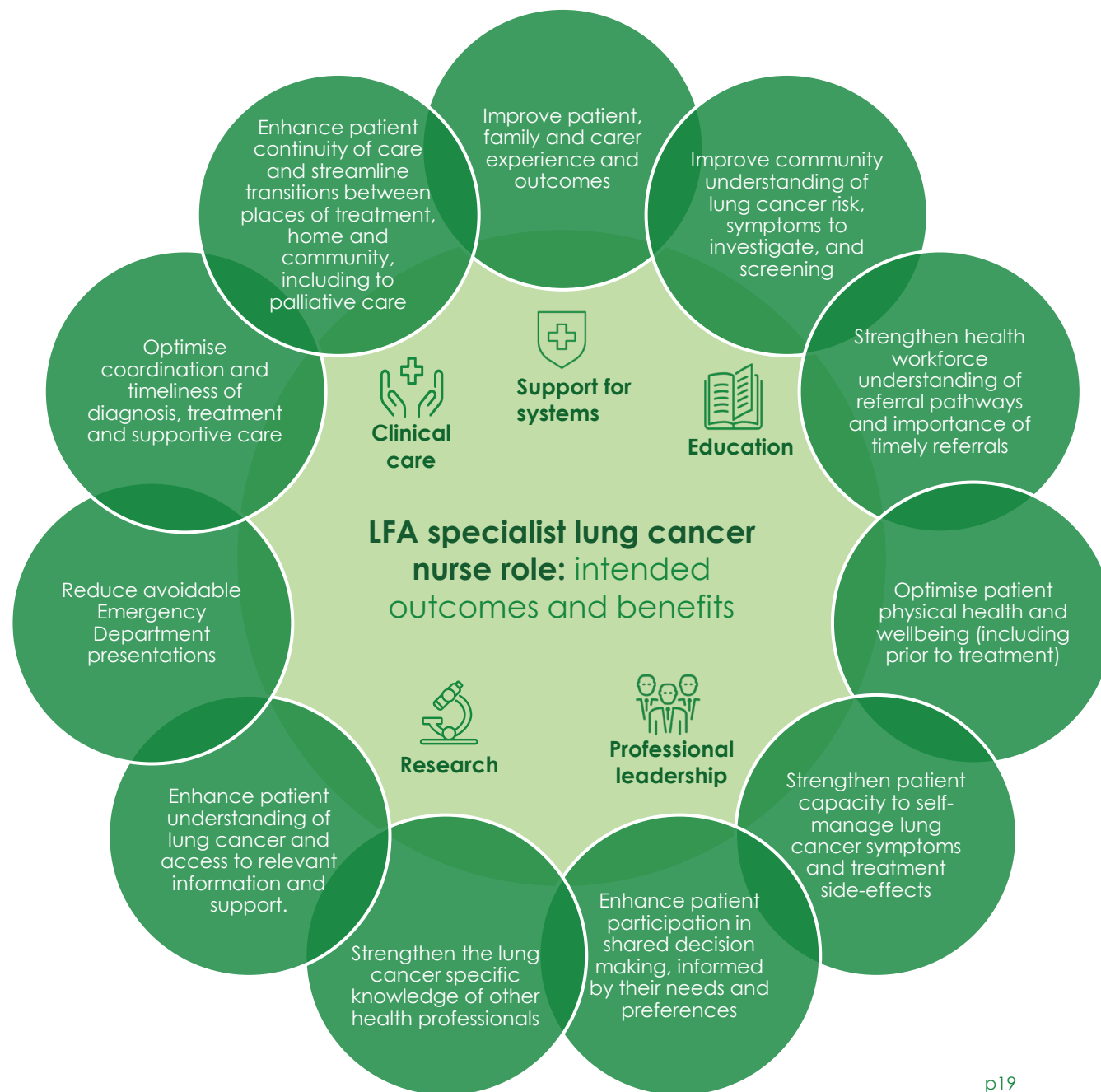
LFA specialist lung cancer nurses work at the level of a Clinical Nurse Consultant (CNC).

They are highly skilled and senior nurses, usually located in Respiratory Medicine departments to enable a strong role during referral, diagnostic investigations and staging, diagnosis and pre-treatment planning

Working across the domains of advanced nursing practice, LFA specialist lung cancer nurses improve outcomes for people at risk of or affected by lung cancer in each step of the lung cancer care pathway by:

- providing timely and comprehensive clinical and psychosocial care
- strengthening relevant knowledge of health professionals, patients, family and community
- improving health service processes and systems
- coordinating and streamlining key elements of diagnosis, treatment and care.

See **Section 4** (on pages 26 – 38) for further detail regarding the LFA specialist lung cancer nurse's role across the lung cancer care pathway.



Guiding principles for the LFA specialist lung cancer nurse role

LFA specialist lung cancer nurses develop a comprehensive map of local lung cancer care pathways and services (usually in the first three months of the role) to inform the focus of their service. The principles described below also guide LFA specialist lung cancer nurses to identify their priorities for the role.

Provide culturally safe clinical care and support for people affected by or at risk of all types of lung cancer.

- LFA specialist lung cancer nurses provide clinical care and support to patients, their family and carers affected by non-small cell lung cancer, small cell lung cancer and pleural mesothelioma.
- LFA specialist lung cancer nurses demonstrate culturally competent and safe approaches to engagements with patients, families and community.

Deliver clinical care and support from the earliest possible step in the lung cancer care pathway.

- LFA specialist lung cancer nurses are positioned in Respiratory Medicine departments (where available) rather than in Cancer Services to facilitate early, ongoing, timely and responsive clinical and supportive care across the lung cancer care pathway.

Focus on addressing unmet needs of lung cancer patients, including priority populations.

- LFA specialist lung cancer nurse roles focus on the pre-diagnosis, diagnosis and post-treatment survivorship steps of the lung cancer care pathway as evidence suggests this is where patients have the highest unmet needs.
- LFA specialist lung cancer nurses apply an equity lens to their service delivery.

Prioritise application of specialist nursing knowledge and skills.

- LFA specialist lung cancer nurses work to the top of their scope of practice. They prioritise the application of specialist nursing knowledge and skills, over roles that can be carried out by less senior or less specialised nursing and / or administration staff.
- Examples include involvement in triaging referrals and establishing nurse-led clinics.

Add capacity to available nursing services.

- LFA specialist lung cancer nurse roles complement existing nursing services in a local health service.^A
- The roles are not intended to replace any pre-existing capacities or roles (e.g. by replacing the lung cancer component of a cancer care coordinator's role) or provide cover for general nursing and /or administration roles. This is especially relevant during the acute treatment phase and at end-of-life, where care should continue to be provided by nurses employed within a health service to deliver this service.

^A LFA specialist lung cancer nurses may operate in health settings outside of Respiratory Medicine, where this service is not available in a local area.

LFA specialist lung cancer nurses work to their scope of practice, aligned to the domains of advanced nursing practice

1. Clinical care

2. Support of systems

3. Education

4. Research

5. Professional leadership



Clinical care

Clinical care encompasses activities completed with or on behalf of patients to address their needs, including physical care, procedures, health assessments, interpretation of data and care planning and coordination.

LFA specialist lung cancer nurses play a critical role in ensuring lung cancer patients have access to and receive early, responsive and optimal lung cancer care across all steps of the lung cancer care pathway.

Examples

Completing comprehensive supportive care assessments.

- Screening and re-screening across all domains of supportive care, including physical, social, psychological, information and spiritual domains.
- Using validated, standardised tools to complete assessments.^B
- Connecting patients to the right treatment at the right time and delivering nurse-led interventions.

Delivering evidence-based interventions.

- Facilitating non-pharmacological, evidence-based, symptom management strategies.
- Monitoring and advising patients and carers about evidence-based, pharmacological symptom management.
- Delivering behavioural change interventions for modifiable lifestyle related topics (e.g. variations of the "Ask, Advise Help" model).

Participating as a core member of the lung cancer MDT.

- Ensuring all lung cancer patients are discussed at MDT meetings and meeting outcomes are actioned in a timely manner.
- Advocating for patients at MDT meetings, to assist delivery of care that is responsive to the individual patient's needs, priorities and preferences.
- Strengthening communication between MDTs, health services, patients and families / carers.

Establishing and delivering specialist lung cancer nurse-led clinics.

Examples include clinics for:

- comprehensive supportive care assessment
- triage and rapid access
- pulmonary nodule surveillance
- symptom management and survivorship.

A. Adapted from Chief Nursing & Midwifery Officers Australia, Advanced Nursing Practice Guidelines for the Australian Context.

B. LFA specialist lung cancer nurses may use this potential list of standardised tools (see page 43) to complete comprehensive supportive care assessments.

LFA specialist lung cancer nurses work to their scope of practice, aligned to the domains of advanced nursing practice

1. Clinical care

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Support of systems

LFA specialist lung cancer nurses collaborate with MDT members and services across the lung cancer care pathway to identify opportunities to improve service delivery that will benefit lung cancer patient experience and outcomes.

Examples

Reviewing local lung cancer processes and systems, identifying gaps and opportunities to streamline service delivery, in collaboration with health service leaders

Introducing initiatives to improve processes and systems e.g. streamlining booking processes for bronchoscopy.

Implementing quality improvement initiatives and standards of care through participation in evaluations of clinical practice.

Contributing to process and system redesign initiatives and change management.

LFA specialist lung cancer nurses work to their scope of practice, aligned to the domains of advanced nursing practice

1. Clinical care

2. Support of systems

3. Education

4. Research

5. Professional leadership



Education

LFA specialist lung cancer nurses have a commitment to their own education and professional development and the education of others. They are actively involved in developing, delivering and participating in educational initiatives for patients, their families / carers, nursing colleagues and other health professionals.

Examples

Developing and delivering education

- Identifying clinical education needs with the health service and collaborating with other staff to develop and deliver education.
- Developing and updating of specialised health professional education resources.
- Delivering thoracic oncology-related education to upskill health professionals (including Respiratory Medicine, medical oncology, general practice and primary care).
- Educating patients, families and carers about lung cancer and its treatment, including diagnostic investigations, lung cancer symptoms and treatment side-effects.

Participating in education

- Understanding developments in respiratory and thoracic oncology fields and translating these into clinical practice.
- Actively seeking out and engaging in self-education and professional development opportunities (including LFA specialist lung cancer nurse training).
- Attending respiratory and thoracic oncology conferences and participating in symposia as relevant.

LFA specialist lung cancer nurses work to their scope of practice, aligned to the domains of advanced nursing practice

1. Clinical care

2. Support of systems

3. Education

4. Research

5. Professional leadership



Research

LFA specialist lung cancer nurses play a key role in clinical research within the lung cancer setting, in collaboration with health service leaders and researchers. They support a culture of inquiry and innovative problem solving, which contributes to improved lung cancer outcomes and health care systems.

Examples

Adapting and applying related scientific research to their own specialist lung cancer nurse service approach.

Working with health service leads, clinicians and researchers to support research projects (e.g. identifying clinical research questions, developing and implementing clinical evaluation plans).

Working in collaboration with others as a co-researcher to test the effects of a lung cancer service innovation.

Encouraging patient participation in clinical trials and health services research.

LFA specialist lung cancer nurses work to their scope of practice, aligned to the domains of advanced nursing practice

1. Clinical care

2. Support of systems

3. Education

4. Research

5. Professional leadership



Professional leadership

LFA specialist lung cancer nurses are leaders in thoracic oncology nursing. They advocate for patients within the health system, promote their profession and disseminate lung cancer nursing knowledge.

Examples

Contributing to the ongoing development and management of lung cancer pathways and clinical processes.

Advocating for patient needs, system enhancements and service succession planning.

Being a professional role model/ mentor for nursing (and other) colleagues.

Demonstrating clinical expertise in relation to the complex needs and care of lung cancer patients.

Providing consultation and advice to general practitioners and other health professionals.

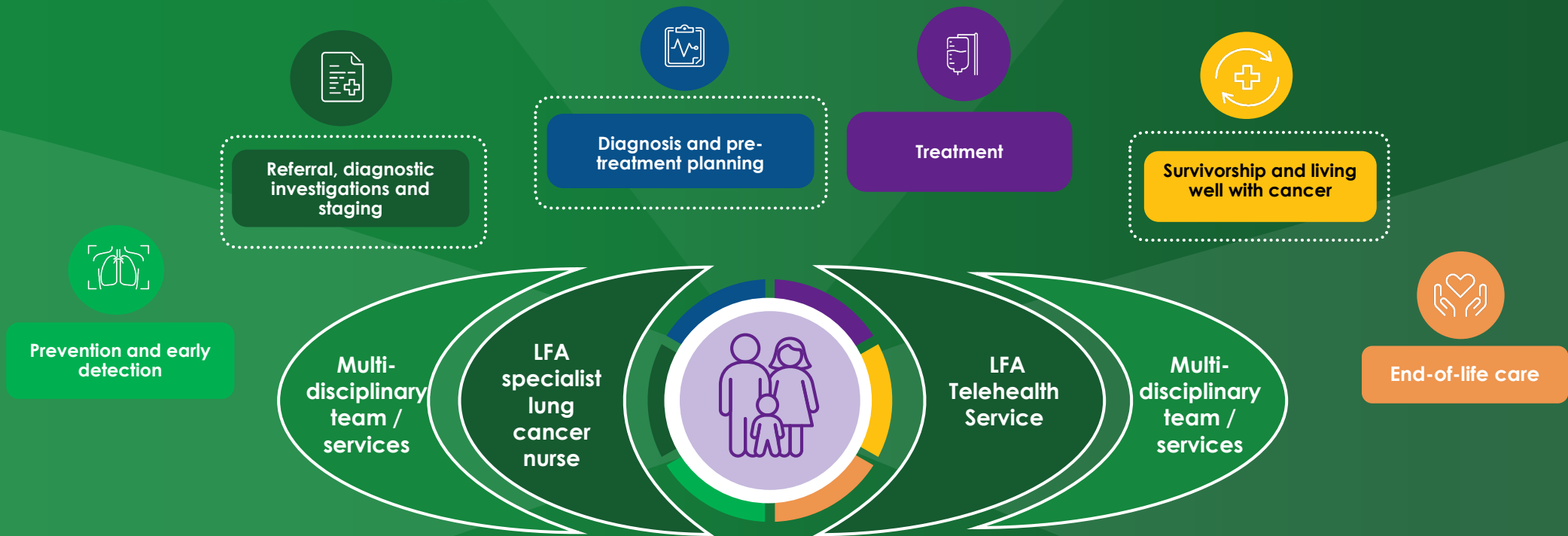
Participating in relevant committees and planning groups for the broader advancement of lung cancer nursing.

Sharing specialist lung cancer nursing knowledge through presentations and publications.

4. The LFA specialist lung cancer nurse's role across the lung cancer care pathway

LFA specialist lung cancer nurses improve health outcomes of people at risk of or affected by lung cancer

LFA specialist lung cancer nurses have a stronger focus on pre-diagnosis, diagnosis and post-treatment survivorship.



Core elements of the LFA specialist lung cancer nurse Model of Care.

- Expert, patient-centred and culturally sensitive care
- Integrated service delivery, including with the LFA Telehealth Service
- Timely support, diagnosis and treatment

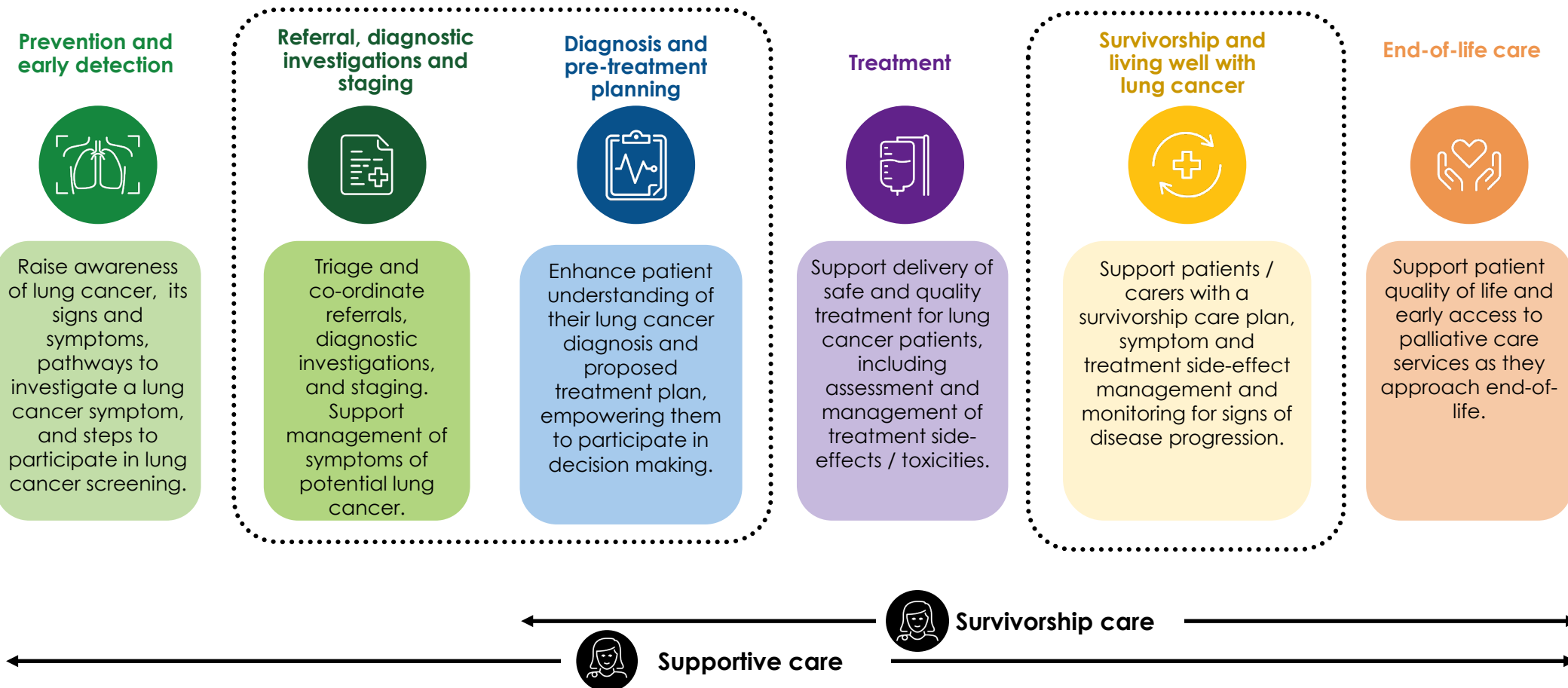
LFA specialist lung cancer nurses work at the top of their scope of practice across the five domains of advanced nursing practice.

-  **Clinical care**
Ensuring patients receive early, responsive and optimal lung cancer care.
-  **Support of systems**
Contributing to improving local health systems and practices.
-  **Education**
Educating self, other health professionals, patients and broader community.
-  **Research**
Contributing to the evidence base and its implementation in lung cancer care.
-  **Professional leadership**
Operating at the top of the specialist nurse scope of practice.

Where possible, LFA specialist lung cancer nurses are positioned in Respiratory Medicine to enable a core focus on pre-treatment steps of the lung cancer care pathway.

LFA specialist lung cancer nurses enhance optimal care across the lung cancer care pathway

LFA specialist lung cancer nurses work across the lung cancer care pathway, with a particular focus on pre-diagnosis, diagnosis and post-treatment survivorship.^A



The following pages outline indicative roles and responsibilities of LFA specialist lung cancer nurses in each step of the lung cancer care pathway.

A. This lung cancer care pathway aligns with the Optimal Care Pathway for people with lung cancer. This model specifically reflects key contributions delivered by specialist lung cancer nurses, and is adaptable across varied service contexts, and for diverse patient needs that LFA specialist lung cancer nurses respond to.

Prevention and early detection



ABOUT THIS STEP

LFA specialist lung cancer nurses tend to have minimal involvement in this step of the lung cancer care pathway.

LFA specialist lung cancer nurses:

- improve health professional and community understanding of lung cancer risk factors, and strategies to reduce risk
- strengthen health professional and community awareness of lung cancer signs and symptoms
- strengthen understanding of the steps to participate in screening and to investigate suspected lung cancer.

Role of the LFA Telehealth Service | 1800 654 301



- How to interpret surveillance results and recommended actions.
- Lung cancer screening pathway.

Key patient / community needs

- Understanding of personal risk of lung cancer and how to reduce it.
- Motivation and support to take action to reduce personal lung cancer risk.
- Awareness of signs and symptoms of lung cancer.
- Awareness of when and how to seek advice from a health professional.
- Motivation and understanding of how to participate in lung cancer screening.
- Understanding of the importance and urgency to act on recommendations from lung cancer screening and / or surveillance.

Contextual considerations

- Culturally sensitive approaches to community engagement and education are essential for effective engagement with priority population groups.

LFA specialist lung cancer nurse roles

Educate and advise the general community and health professionals, including those working in Aboriginal and Torres Strait Islander health about:

- lung cancer and signs / symptoms
- steps and local referral pathways to investigate suspected lung cancer
- the local LFA specialist lung cancer nurse service offered
- how to reduce lung cancer risk, including via locally available smoking cessation services
- the importance of early detection of lung cancer
- the national lung cancer screening program, its importance and how to access it.

LFA specialist lung cancer nurse knowledge and skills

- Lung cancer risk factors.
- Signs and symptoms of lung cancer and recommended steps and local pathways for investigations.
- Lung cancer screening criteria and the participant pathway.
- The impact of stigma on help-seeking behaviour and how to negate it.
- Lifestyle modifications to reduce lung cancer risk.
- Locally available smoking cessation support services.
- How to apply behaviour change models that offer brief interventions (e.g. variations of the 'Ask, Advise, Help' model).
- How to provide culturally sensitive education and engagement.

Referral, diagnostic investigations and staging



ABOUT THIS STEP

ROLES, RESPONSIBILITIES AND SKILLS

LFA specialist lung cancer nurses play a key role in this step of the lung cancer care pathway.

LFA specialist lung cancer nurses:

- improve timeliness of diagnostic investigations and appointments
- strengthen patient capacity to self-manage lung cancer symptoms
- optimise patient health and wellbeing prior to treatment.

Key patient needs^A

- Timely investigation of lung cancer signs and symptoms.
- Practical information and support to help access tests, plan appointments, navigate travel, accommodation.
- Proactive, culturally safe support (particularly for vulnerable patients).
- Support to manage anxiety, distress and sense of overwhelm while undergoing tests and awaiting results.
- Support to manage distressing lung cancer symptoms affecting quality of life, such as breathlessness, cough, pain and fatigue.
- Timely and relevant referrals to supportive care.
- A key point of contact for information and support.

Contextual considerations

- The diagnostic pathway is often lengthy, complex and a highly anxious time for patients.^B
- Diagnostic investigations occur under the supervision of a respiratory physician, meaning that patients do not yet have access to the cancer-specific information and support available through cancer services.
- Depending on the health service, an LFA specialist lung cancer nurse may be the only health professional involved during this step who has strong, lung cancer specific expertise.
- Many public health services rely on private diagnostic testing providers (often in different locations) to meet service demand.
- Completion of comprehensive genomic profiling influences treatment options, timeframe to starting treatment and patient outcomes.

Role of the LFA Telehealth Service | 1800 654 301



- Guidance for lung cancer diagnostic pathway and optimal timeframes.
- Education about diagnostic investigations and tests – what to expect.
- Advice on navigating appointments.
- Guidance on important questions to ask specialists.
- Support to self-manage underlying respiratory conditions e.g. COPD, bronchiectasis.
- Lung Cancer symptom assessment and self-management education.

A. Refer to **Section 2** (on pages 13 – 17) for further information about the unmet needs and challenges experienced by people undergoing investigations for lung cancer.

B. Refer to **Section 2** (on pages 13 – 17) for further information about the complex factors affecting the diagnostic pathway and delays in treatment for people at risk of or affected by lung cancer.

Referral, diagnostic investigations and staging



ABOUT THIS STEP

ROLES, RESPONSIBILITIES AND SKILLS

LFA specialist lung cancer nurse roles

Facilitate timely triage and diagnostic testing

- Enable timely, appropriate triage of suspected lung cancer referrals.
- Facilitate comprehensive, timely diagnostic investigations, including coordination support and identify potential gaps in work-up.
- Support nodule surveillance and management.
- Streamline referral, triage and diagnostic testing pathways and processes.

Optimise patient health

- Work with MDT members to assess and optimise patient health status (including management of comorbidities), to enable investigations and maximise possible treatment options.
- Advocate for appropriate treatment and other decisions (to other members of the MDT), to align with patient physical health status, psychosocial factors and preferences.
- Assess symptoms, educate about evidence-based self-management strategies and advise on evidence-based pharmacological management.

Facilitate comprehensive supportive care

- Complete comprehensive, supportive care assessments of patient health, symptoms, and psychosocial status.
- Assess and deliver brief behaviour change interventions to support appropriate lifestyle modifications, including smoking cessation.
- Assess and provide stigma counselling where appropriate.
- Make appropriate referrals to internal and external services e.g. LFA Telehealth Service, pulmonary rehabilitation, respiratory physiotherapy, exercise physiology, dietetics, social work, psychology, palliative care.

Nurse-led clinic examples

- Pulmonary nodule surveillance clinic
- Triage and rapid access clinic
- Holistic assessment clinic
- Symptom management clinic

LFA specialist lung cancer nurse knowledge and skills

Clinical knowledge and skills

- Types of lung cancer and their signs and symptoms.
- Lung cancer triage categories and rapid access pathways.
- Lung cancer histology, staging and genomic mutations.
- Comprehensive genomic profiling process.
- Lung cancer investigations and what is involved.
- Understanding of lung cancer treatments (and the investigations / health status needed to access them).
- Management of common lung cancer comorbidities and complexities influencing diagnostic processes and treatment options (e.g. COPD).
- Lung cancer symptom assessment.
- Pharmacological and non-pharmacological lung cancer symptom management strategies / treatments.
- How to use validated, standardised tools to complete comprehensive supportive care assessments.
- How to apply behaviour change models that offer brief interventions.
- Smoking cessation counselling skills.
- Stigma counselling skills.
- How to have culturally sensitive conversations about a potential cancer diagnosis and accessing diagnostic tests.

Health service and system knowledge

- Local referral, triage and diagnostic pathways and work-flows.
- Up-to-date knowledge of local service providers for diagnostic and other relevant tests and how to access them.
- Local transport and accommodation options for those travelling for testing.
- Local MDT meeting processes.
- Local smoking cessation support services.
- Local lung cancer supportive care referral pathways.

Diagnosis and pre-treatment planning



ABOUT THIS STEP

ROLES, RESPONSIBILITIES AND SKILLS

Where possible, treatment nurses are the key point of nursing contact for patients in this step of the pathway. The LFA specialist lung cancer nurses provide expert advice and intervene where more advanced, specialist nursing knowledge and skills are required.

LFA specialist lung cancer nurses:

- strengthen MDT member understanding of patient health status, circumstances and preferences for treatment
- strengthen patient capacity to participate in shared decision making
- optimise patient receipt of relevant practical and psychosocial supportive care.

Key patient needs^A

- Understanding of individual lung cancer diagnosis.
- Practical and psychosocial support to process a diagnosis of lung cancer.
- Understanding the recommended treatment options, what is involved, the intended benefits and possible side-effects.
- Treatment decision making support.
- Timely referral for most appropriate treatment(s).
- Practical support for accessing pre-treatment planning appointments.
- A point of contact for expert, evidence-based information and support.

Contextual considerations

- Cardiothoracic and radiation oncology services are not available onsite in all health services.
- Referral between health services (e.g. for assessment of suitability for surgery) increases risks of patients being 'lost' in the health system and treatment delays. Careful coordination and monitoring is needed.
- The introduction of neoadjuvant chemotherapy has increased the complexity of treatment planning (across multiple teams and locations) and requires a strong focus on patient health optimisation in preparation for treatment.
- LFA specialist lung cancer nurses often act "as a bridge", facilitating faster and smoother transitions for patients between Respiratory Medicine and cancer services / cardiothoracic surgical services.

A. Refer to **Section 2** (on pages 13 – 17) for further information about the unmet needs and challenges experienced by people with a lung cancer diagnosis

Role of the LFA Telehealth Service | 1800 654 301



- Connection with lung cancer information, resources and services.
- Support with processing the diagnosis.
- Information about clinical trials and how to access them.
- Lung cancer symptom assessment and self-management education.
- Emotional and mental health support.
- Connection with Peer Support.
- Support for self-management of underlying respiratory disease (e.g. COPD), in preparation for treatment.
- Lifestyle modification advice.
- Guidance for accessing / referral to Palliative Care.
- Education and support for family members and carers.
- Information and support with legal issues and processes.

Diagnosis and pre-treatment planning



ABOUT THIS STEP

ROLES, RESPONSIBILITIES AND SKILLS

LFA specialist lung cancer nurse roles

Inform treatment options offered

- Share insights with the MDT about patients' health status and their likelihood of coping well with proposed treatments.
- Identify and advocate for patients to be considered for appropriate clinical trials.
- Advocate in lung cancer MDTs for patients' physical, mental and emotional wellbeing. This includes consideration of patients' personal circumstances, preferences for treatment, and goals whilst receiving care.

Educate and support patients and their families about:

- the lung cancer diagnosis and implications for treatment options and daily living
- proposed MDT treatment plan, including practical considerations and potential side-effects, to empower them to participate in decision making.

Optimise patient health

- Work with MDT members to assess and optimise patient health (including management of comorbidities), to maximise possible treatment options.
- Assess symptoms, educate about evidence-based self-management strategies and advise on evidence-based pharmacological management.

Facilitate comprehensive supportive care

- Complete comprehensive, evidence-based assessments of patient health, symptoms, and psychosocial status.
- Assess and deliver brief behaviour change interventions to support appropriate lifestyle modifications, including smoking cessation.
- Commence survivorship wellbeing care plan with patients.
- Deliver low intensity psychological care, including stigma counselling where appropriate.
- Facilitate peer support groups and / or connection with peer support.
- Make relevant referrals to internal and external support services, and further navigation services as needed.
- Assess appropriateness of a referral to palliative care services, according to patient need and wellbeing.

Nurse-led clinic examples

- Symptom management clinic

LFA specialist lung cancer nurse knowledge and skills

Clinical knowledge and skills

- Types of lung cancer, histology, staging and genomic mutations.
- Detailed understanding of different lung cancer treatments for different types and stages of lung cancer; and what is involved from clinical and practical perspectives.
- Strong understanding of the physical and psychosocial challenges commonly experienced by people with lung cancer.
- Legal pathways available for people with occupational lung cancer.
- Management of common lung cancer comorbidities and complexities (e.g. COPD).
- Lung cancer symptom assessment.
- Pharmacological and non-pharmacological lung cancer symptom management strategies / treatments.
- How to use validated, standardised tools to complete comprehensive supportive care assessments.
- How to apply behaviour change models that offer brief interventions.
- Smoking cessation and stigma counselling skills.
- How to have culturally sensitive conversations about a cancer diagnosis and treatment options.

Health service and system knowledge

- How to find out about current clinical trials and how to access them.
- Up-to-date knowledge of local service providers / locations for different treatment modalities (including in relevant regional centres).
- Local transport and accommodation options for those travelling for treatment.
- Relevant lung cancer supportive care referral pathways (e.g. to local smoking cessation services, allied health services, pulmonary rehabilitation, palliative care, peer support).

Treatment



ABOUT THIS STEP

ROLES, RESPONSIBILITIES AND SKILLS

Where possible, treatment nurses are the key point of patient contact and play a leading role in this step of the lung cancer care pathway. LFA specialist lung cancer nurses provide expert advice, and intervene where more advanced, specialist nursing knowledge and skills are required.

LFA specialist lung cancer nurses:

- strengthen and supplement the lung cancer specific knowledge of treating nursing teams
- optimise patient health and wellbeing while undergoing treatment
- increase timely access to treatment services
- reduce avoidable Emergency Department presentations.

Key patient needs

- Practical support to access treatment (e.g. booking and coordination, transport, travel, accommodation if required) and to coordinate multiple treatment modalities where relevant.
- Support to help prepare for, recognise and manage side-effects of treatment, lung cancer symptoms and the impact of other comorbidities on health and wellbeing.
- Practical and psychosocial support (for patients and their families) during treatment period.
- Point of contact for information and support.

Contextual considerations

- Multiple factors may increase the need for LFA specialist lung cancer nurse involvement during treatment, including:
 - neoadjuvant treatment, which increases complexity of care coordination across multiple departments / sites and requires monitoring and optimising health in preparation for surgery
 - any treatment provided in an offsite health service and / or department outside cancer services (e.g. cardiothoracic surgery), which risks patient being 'lost' in the health system
 - targeted therapy treatment, which means the patient does not come into the health service regularly
 - travel to treatment facilities
 - high levels of supportive care needs
 - lung cancer-specific expertise of treating nurses.
- Treatment for people with lung cancer is often distributed over multiple departments, health services and locations.

Role of the LFA Telehealth Service | 1800 654 301



- Connection with lung cancer treatment information and resources.
- Education on lung cancer treatment protocols and related side-effects.
- Support to self-manage lung cancer symptoms and treatment related side-effects.
- Connection with Peer Support.
- Advice around finances, transport, housing and legal issues.
- Supportive care assessment and referral pathway recommendations.
- Emotional and mental health support.

Treatment



ABOUT THIS STEP

ROLES, RESPONSIBILITIES AND SKILLS

LFA specialist lung cancer nurse roles

Strengthen health professional knowledge of lung cancer

- Educate treatment nurses about lung cancer and management of symptoms of lung cancer and underlying lung disease.
- Advise treatment nurses on supportive care referral pathways.

Optimise patient health (where needed*)

- Provide patient consultations / advice to treatment nurses regarding lung cancer specific symptoms and treatment toxicity assessment and management.
- Assess symptoms and toxicities; educate patients about evidence-based self-management strategies and advise on additional management (including for management of lung cancer comorbidities).

Coordinate care (where needed*)

- Support coordination of complicated treatment plans e.g. neoadjuvant treatment.
- Support access to treatment for patients with high support needs.
- Raise any concerns to the MDT around a patient's tolerability for proposed therapies.
- Review and update patient survivorship wellbeing care plan, including communication of surveillance and follow-up.
- Provide detailed handovers to medical oncology / radiation oncology services, where needed.

Facilitate supportive care (where needed*)

- Complete comprehensive, evidence-based assessments of patient health, symptoms, and psychosocial status.
- Facilitate peer support groups and / or connection with peer support.
- Assess appropriateness of a referral to palliative care services, according to patient need and wellbeing.
- Advise on or make appropriate referrals to internal and external services.

Nurse-led clinic examples

- Lung cancer symptom and treatment toxicity management clinic

LFA specialist lung cancer nurse knowledge and skills

Clinical knowledge and skills

- Detailed up-to-date understanding and knowledge of different lung cancer treatments and developments across cancer stages and types; and what is involved from clinical and practical perspectives.
- How to recognise and respond to lung cancer-specific symptoms and toxicities associated with different lung cancer medical oncology treatments.
- Immune related adverse events related to immunotherapy treatment for lung cancer and critical responses required.
- Strong understanding of the physical and psychosocial challenges commonly experienced by people with lung cancer.
- Guidelines for management of common comorbidities and complexities (e.g. COPD).
- Assessment and management of lung cancer symptoms, including facilitation of non-pharmacological management strategies and advice on pharmacological symptom management.
- How to use validated, standardised tools to complete comprehensive supportive care assessments.
- Smoking cessation and stigma counselling skills.
- How to facilitate a culturally sensitive treatment process.

Health service and system knowledge

- Up-to-date knowledge of local service providers / locations for different treatment modalities (including in relevant regional centres).
- Local transport and accommodation options for those travelling for treatment.
- Local smoking cessation support services.
- Relevant lung cancer supportive care referral pathways (e.g. to allied health services, pulmonary rehabilitation, palliative care, peer support).

*Examples of higher needs for LFA specialist lung cancer nurse involvement are described in Contextual Considerations on the previous page.

Survivorship and living well with lung cancer



ABOUT THIS STEP

ROLES, RESPONSIBILITIES AND SKILLS

LFA specialist lung cancer nurses play a key role in this step of the lung cancer care pathway, including facilitating shared care within MDTs and supporting patient transitions to primary care.^A

LFA specialist lung cancer nurses:

- strengthen continuity of care for patients
- improve patient confidence and capacity to self-manage long-term lung cancer symptoms, treatment side-effects, and to live well
- improve timely detection of recurrence and facilitate rapid service re-entry.

Key patient needs

- Support to help navigate and manage physical and psychosocial symptoms and side-effects of lung cancer and its treatment.
- Information and support to optimise health and wellbeing.
- Early identification of recurrent, residual or metastatic disease.
- Support to navigate follow-up care and live well following treatment for lung cancer.
- Support to manage physical, emotional, financial, and social issues that are different from those experienced during active treatment.

Contextual considerations

- Survivorship focuses on the health and wellbeing of a person with cancer (and their family / carers) from the time of diagnosis until the end-of-life. This includes the physical, mental, emotional, social, and financial effects of lung cancer.^B
- Enhancements in lung cancer detection and screening will drive an increase in lung cancer survival rates. This means more lung cancer patients will need ongoing survivorship and follow-up support, including over the long-term.
- Post treatment, lung cancer patients have significant unmet needs that are often not addressed or followed up on.

The level of LFA specialist lung cancer nurse involvement in this step will be dependent on patient need and the local supportive care resources and services available. Some people may require regular, ongoing specialist lung cancer nursing support, whilst others may be discharged from the nurse service.

Role of the LFA Telehealth Service | 1800 654 301



- Connection with survivorship information and resources.
- Support to complete a survivorship care plan.
- Education around self-management of longer-term lung cancer symptoms and treatment related side-effects.
- Connection with a peer support group.
- Supportive care assessment and referral pathway recommendations.
- Emotional and mental health support.
- Support to manage anxiety.
- Advise on post-treatment follow-up and assessment for signs of recurrence / relapse.

A. Survivorship and living well with cancer also underpins delivery of supports across the lung cancer care pathway (visually described on page 27).

B. Refer to **Section 2** (on pages 13 – 17) for more information on the multi-faceted effects of lung cancer on people at risk of or affected by lung cancer and their families / carers.

Survivorship and living well with lung cancer



ABOUT THIS STEP

ROLES, RESPONSIBILITIES AND SKILLS

LFA specialist lung cancer nurse roles

Facilitate healthcare team communication

- Establish systems and processes for MDT follow-up with patients at the end of treatment.^A
- Share and communicate patient survivorship wellbeing care plan with relevant MDT members.
- Facilitate and deliver post-treatment follow-up, surveillance and shared care in conjunction with the MDT, Primary Care and other community organisations / services.

Optimise patient health

- Assess and support management of common long-term lung cancer symptoms and treatment side-effects, including but not limited to impaired pulmonary function, breathlessness, chronic cough, reduced exercise capacity, fatigue, pain, neuropathy and mental health issues.
- Monitor for signs of disease progression / recurrence and intervene early.
- Review and update survivorship plans with patients on a regular basis.
- Facilitate patient compliance with follow-up schedule.

Facilitate comprehensive supportive care

- Complete ongoing and timely comprehensive care assessments (across the 5 supportive care domains).
- Assess and deliver brief behaviour change interventions to support appropriate lifestyle modifications, including smoking cessation support, to reduce risk of lung cancer recurrence.
- Assess, advise and support management of underlying comorbidities (e.g. COPD, diabetes, cardiovascular disease) via referral to relevant specialists (as needed).
- Deliver low-intensity psychological care, including stigma counselling.
- Facilitate or provide expert support for face-to-face or virtual lung cancer peer support groups.
- Facilitate referrals to palliative care services when appropriate, according to patient need and wellbeing.
- Facilitate access to survivorship tools and information.
- Make appropriate referrals to internal and external support services, including community-based support.

Nurse-led clinic examples

- Post-treatment survivorship clinic - for follow-up, comprehensive supportive care assessment, symptom and toxicity management
- Symptom management and survivorship clinic

LFA specialist lung cancer nurse knowledge and skills

Clinical knowledge and skills

- Survivorship wellbeing care plans and how to use them.
- How to recognise and respond to lung cancer-specific symptoms and toxicities associated with different lung cancer treatments.
- Immune related adverse events linked to immunotherapy treatment for lung cancer and critical responses required.
- Deep understanding of the physical and psychosocial challenges commonly experienced by people with lung cancer.
- Guidelines for management of common comorbidities and complexities.
- Respiratory Function Tests (Spirometry) and interpretation of results.
- Pharmacological and non-pharmacological lung cancer symptom and treatment toxicity assessment and management strategies / treatments.
- How to use validated, standardised tools to complete comprehensive supportive care assessments.
- Smoking cessation and stigma counselling skills.
- How to facilitate culturally sensitive approaches to survivorship.

Health service and system knowledge

- Up-to-date knowledge of local service providers / locations for investigation of suspected recurrence (including relevant regional centres).
- Local smoking cessation support services.
- Relevant lung cancer supportive care referral pathways (e.g. to allied health services, pulmonary rehabilitation, palliative care, peer support).

A. The population of people affected and living with lung cancer is growing, with estimates that nearly 168,000 people will be diagnosed with lung cancer in Australia over the 10-year period from 2022 to 2032.

End-of-life care



ABOUT THIS STEP

Palliative care services play a leading role in this step of the lung cancer care pathway. LFA specialist lung cancer nurses support delivery of an appropriate handover, and may provide additional support to patients and their families and carers as needed.^A

LFA specialist lung cancer nurses:

- enhance patient / carer understanding and decision-making for palliative care and end-of-life support
- increase timely access to palliative care (where clinically indicated)
- facilitate a smooth transition to palliative care services and end-of-life support.

Role of the LFA Telehealth Service | 1800 654 301



- What to expect at end-of-life.
- Grief and bereavement support.
- Guidance for accessing palliative care support.
- Family and carer emotional support.

Key patient / community needs

- Understanding of palliative care and end-of-life support services available.
- Timely access to palliative care and end-of-life support services.
- Support to manage end-stage lung cancer symptoms and comfort care.
- End-of-life care decision making support.

Contextual considerations

- 42% of people are first diagnosed with Stage IV lung cancer. They may be suitable for palliative care referral at diagnosis.²⁰
- Lung cancer is the second most common type of cancer associated with hospitalisation for palliative care.²¹
- Culturally sensitive approaches to discussions about palliative care and end-of-life care are essential.

LFA specialist lung cancer nurse roles

Educate and support patients and carers

- Educate patients, families and carers about available palliative and end-of-life care support and services.

Optimise patient wellbeing

- Ensure palliative care and end-of-life services understand the patient's needs, end-of-life care directives and preferences.

Facilitate supportive care

- Facilitate appropriate referrals to palliative care services.
- Connect patients and family members with grief and bereavement services.

LFA specialist lung cancer nurse knowledge and skills

Clinical knowledge and skills

- How to facilitate a conversation about palliative care, end-of-life care and related concepts such as advanced care planning and directives.
- Culturally sensitive approaches to discussing end-of-life.

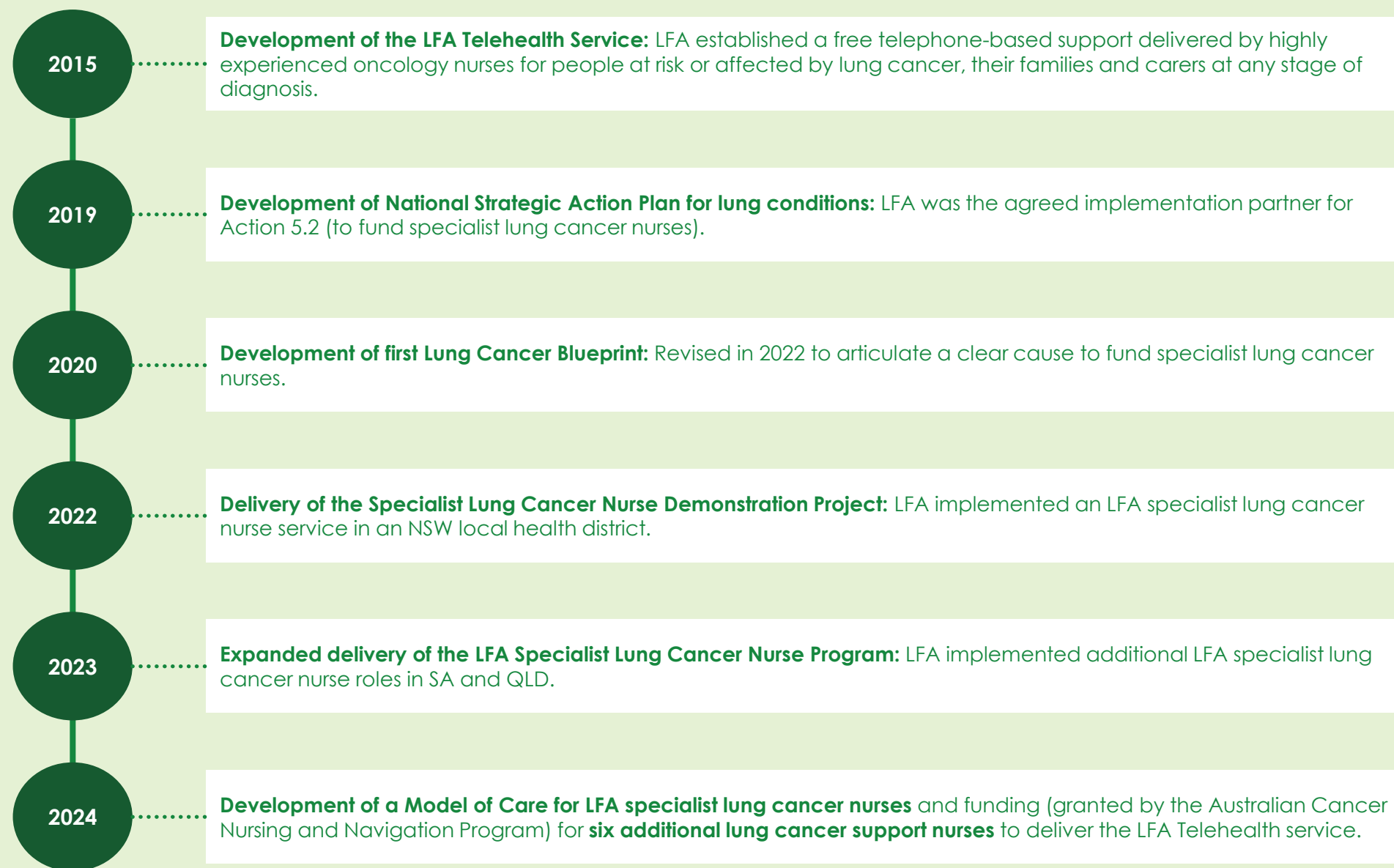
Health service and system knowledge

- Local palliative care services, key contacts and referral pathways.
- Grief and bereavement services.
- Processes around end-of-life care directives, specific to the health service and state where care is provided.

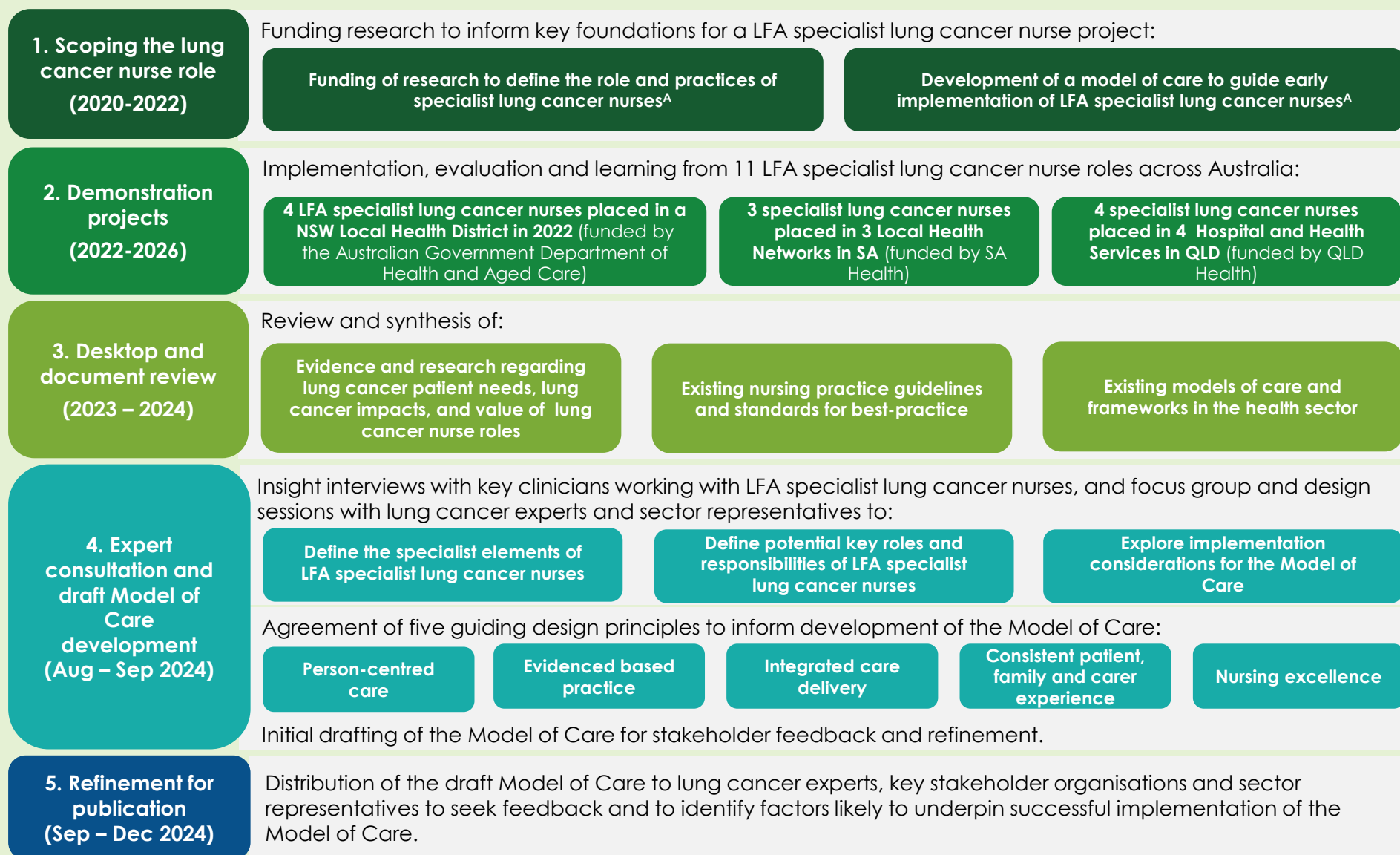
A. LFA specialist lung cancer nurses often build strong relationships with patients and their families, who continue to look to the nurses for support during end-of-life.

Supporting information

Timeline of key initiatives led by LFA in support of specialist lung cancer nursing



How the Model of Care was developed



A. See: Brunelli, V.N. (2024). Connecting the data-driven practice of specialist lung cancer nurses to a holistic model of patient-centred care. Australian Journal of Cancer Nursing, 25(1): 5-6 <https://journals.cambridge.org/ajcn/volume-25-number-1/oral-abstracts>. Brunelli, V.N., & Yates, P. (2023). From little things, big digital things grow: Expectations, Standards and Performance Framework for the Australian Specialist Lung Cancer Nurse. Respiriology, 28(S3):11-12 <https://onlinelibrary.wiley.com/doi/10.1111/resp.14471>

Stakeholders consulted in the development of the Model of Care

Development of the Model of Care was led by an LFA project working group, with support by Nous Group. Consultations, co-design sessions and a written feedback process were facilitated with many different stakeholder groups.

The Model of Care was developed in close collaboration with:

- the Education Council of the Australia and New Zealand Lung Cancer Nurses Forum; and
- LFA specialist lung cancer nurses.

Organisations that participated in consultations and contributed to the Model of Care include:

Cancer Council Australia
Cancer Nurses Society of Australia
The Australian & New Zealand Society of Cardiac & Thoracic Surgeons
Thoracic Oncology Group Australasia

Insights into the benefits and roles of specialist lung cancer nurses and / or input into the Model of Care were provided by other (non-LFA) lung cancer nurses and clinicians currently working with LFA specialist lung cancer nurses, including radiologists, respiratory physicians, medical oncologists, radiation oncologists, cardiothoracic surgeons.

LFA very much values the considered contributions made by all individuals and organisations involved.

Validated, standardised tools for comprehensive supportive care assessments.

LFA specialist lung cancer nurses use validated, standardised tools to complete comprehensive supportive care assessments.^A The table below highlights appropriate tools specialist lung cancer nurses may use to complete holistic patient assessments across the five supportive care domains.

Supportive Care Domain	Physical	Psychological	Social	Information	Spiritual
Standardised assessment tool	Edmonton Symptom Assessment Scale	Brief Symptom Inventory Scale	SF36	Test of Health Literacy in Adults Scale	The Scottish PROM of Spiritual Care
	Lung Cancer Symptom Scale	Distress Thermometer	HRQoL	Information Scale	Existential Concerns Scale
	Dyspnoea Scale	Anxiety and Depression Scale			

A. Brunelli, VN (2020), A model of engagement to enhance the capacity of specialist cancer nurses to support people living with lung cancer to self-manage (<https://eprints.qut.edu.au/157472>), Brisbane: Queensland University of Technology; Brunelli, VN, Kochovska S, Ferreira D, & Currow D (2023), Expectations, standards and performance framework for specialist lung cancer nurses, (<https://doi.org/10.1111/resp.14459>); Australian Commission on Safety and Quality in Health Care (2024), Comprehensive Care Standard (<https://www.safetyandquality.gov.au/standards/nsqhs-standards/comprehensive-care-standard>).

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2. Lung Foundation Australia (2022), The Next Breath Accelerating Lung Cancer Reform in Australia 2022-2025 (https://lungfoundation.com.au/wp-content/uploads/2022/08/OYO220615_LFA_Lung-Cancer-Blueprint-2_Digital.pdf).
3. Ibid, 12.
4. Lisy K, Langdon L, Piper A, Jefford M (2019), Identifying the most prevalent unmet needs of cancer survivors in Australia: A systematic review, (<https://doi.org/10.1111/ajco.13176>), Asia-Pacific journal of clinical oncology.
5. Lung Foundation Australia (2024), SA Specialist Lung Cancer & Specialist Respiratory Nurse Project Evaluation Progress Report 1.
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Lung Foundation Australia acknowledges the Traditional Custodians of the lands on which we work throughout Australia and their unceded sovereignty of and continuing connection to land and sea. We pay our respects to their cultures and to Elders both past and present. We acknowledge that Aboriginal and Torres Strait Islander people across Australia are significantly overrepresented in lung disease and lung cancer. In the spirit of reconciliation, we recommit to working with communities to close the gap on lung health and build on the strengths of communities to lead and guide the path to healthy lungs for all.

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