

Delivering best practice lung cancer care

A summary for health professionals



Cancer Australia's *Lung Cancer Framework: Principles for Best Practice Lung Cancer Care in Australia* (the Lung Cancer Framework) is a national resource for health professionals and service providers involved in the care and treatment of people affected by lung cancer.

This guide provides an overview of the Lung Cancer Framework, which can be accessed at: canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/lung-cancer-framework

The Lung Cancer Framework aims to improve the outcomes and experiences of people affected by lung cancer in Australia by supporting the uptake of five key principles in lung cancer care.

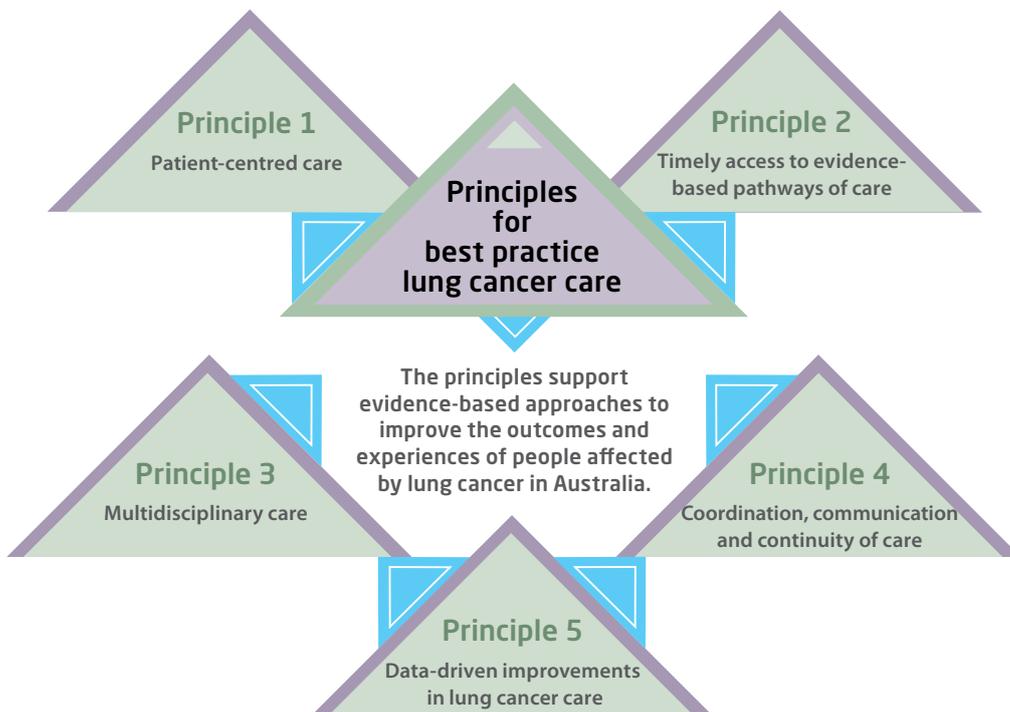
Principles for best practice lung cancer care
Cancer Australia's *Principles for best practice management of lung cancer in Australia* have been informed by evidence from national and international literature, and findings from health service and consumer consultation.

The evidence and consultation combined highlighted unwarranted variations in care, service delivery and experiences of people affected by lung cancer. These variations informed the need for principles to guide best practice lung cancer care.

The Lung Cancer Framework

The Lung Cancer Framework provides evidence-based, best practice information, strategies, tools and resources to support local adoption of the Principles in the delivery of lung cancer care in Australia. The Lung Cancer Framework also incorporates learnings and experiences from people affected by lung cancer, cancer specialists, other health professionals and health service providers.

The examples of best practice in the Lung Cancer Framework are from Cancer Australia's national Lung Cancer Demonstration Project (LCDP), a collaborative project involving 11 health services across Australia.



“ I encourage all those involved in lung cancer care in Australia to adopt the Lung Cancer Framework and the five principles for best practice lung cancer care as part of a national coordinated effort to improve lung cancer outcomes. ”

*Dr Helen Zorbas AO
CEO, Cancer Australia*

Principle 1: *Patient-centred care*

Patients with lung cancer and their carer(s) are the focus of best practice lung cancer care



Essential elements

- ▶ All patients with lung cancer and their carer(s) should be provided with evidence-based information relevant to their clinical and supportive care needs, to support timely shared decision-making.
- ▶ Delivery of optimal lung cancer care considers patient circumstances, beliefs, preferences and supportive care needs.

What are the benefits of a patient-centred approach to lung cancer care?

For patients	For services	For the system
<ul style="list-style-type: none"> ▶ Improved knowledge and recall about information relevant to a patient's care¹⁻⁴ ▶ Decreased anxiety and depression^{4,5} ▶ Improved satisfaction^{1,3,4,6-10} ▶ Improved symptom control and symptom management^{1,4,7,11,12} ▶ Improved participation in consultations¹²⁻¹⁴ ▶ Improved care of psychosocial needs¹⁵ 	<ul style="list-style-type: none"> ▶ Improved communication between the patient and the service provider^{6,12} ▶ Improved documentation and communication of patient's preferences and psychosocial issues¹⁵ ▶ More discussion focused on patient outcomes⁶ ▶ Increased referrals to psychosocial care¹² ▶ Enhanced and better-targeted information-sharing for regional patients, especially concerning their clinical and supportive care needs¹⁵ 	<ul style="list-style-type: none"> ▶ Enhanced partnerships between metropolitan and regional centres¹⁵ ▶ Improvements in the way care is coordinated for patients, including across care settings¹⁴

“ Patient-centred care is about recognising and acknowledging the unique needs of each patient and supporting them throughout their diagnosis, treatment and care. It means asking people about their fears and expectations and answering their questions honestly. It means empowering people to make informed decisions that are right for them. And it means treating people with respect. Importantly, for people with lung cancer, this means providing care without judgement.

Lillian Leigh, Lung cancer patient

Principle 1: *Patient-centred care*

What can help support the delivery of patient-centred lung cancer care?

Strategies to use	Tools and resources that may help
Patient information and education ^{1-5,8,11,16}	
<ul style="list-style-type: none"> ▶ Provide patients and carers with education and information resources about lung cancer care and treatment, including resources developed with consumer input. ▶ Use different formats when presenting information (e.g. written, audio, visual, electronic interactive). 	<p>Information about lung cancer¹⁷</p> <p>What's your cough telling you?¹⁸(brochure)</p> <p>What's your cough telling you?¹⁹(video)</p> <p><i>Cancer Australia</i></p> <p>Understanding Lung Cancer²⁰</p> <p><i>Cancer Council Australia</i></p> <p>Better Living with Lung Cancer - A Patient Guide²¹</p> <p><i>Lung Foundation Australia</i></p>
Patient navigation methods ^{9,22}	
<ul style="list-style-type: none"> ▶ Use nurse-led navigation approaches, or lay people trained as patient navigators, to assist lung cancer patients navigate their treatment pathway. 	<p>Navigation: A Guide to Implementing Best Practices in Person-Centred Care²³</p> <p><i>Canadian Cancer Journey Portfolio</i></p>
Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) ^{6,7}	
<ul style="list-style-type: none"> ▶ Use PROMs and PREMs routinely to measure symptoms, identify what outcomes are important to patients, and help services evaluate patient and carer satisfaction about the care they have received. 	<p>EORTC QLQ-C30²⁴</p> <p><i>European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire - C30</i></p> <p>Electronic Self-Report Assessment for Cancer (ESRA-C)²⁵</p> <p><i>Dana Faber Cancer Centre</i></p> <p>Supportive Needs Screening Tool^{26,27}</p> <p><i>Peter MacCallum Cancer Centre</i></p>
Processes, systems, structures and standard operating procedures	
<ul style="list-style-type: none"> ▶ Use a multidisciplinary team (MDT) meeting patient summary report template to support the identification of patient needs and concerns, and to integrate this type of information into multidisciplinary treatment planning and care. ▶ Implement clear, routinely used referral processes for supportive care services (including when referrals may be triggered) to ensure patients' unique psychosocial needs are considered.¹⁵ ▶ Facilitate shared decision-making between clinicians and patients to allow patient values and preferences to be considered when discussing treatment and care options.²⁸ ▶ Provide communication skills training for health professionals to help staff establish a rapport with patients and carers, and have more effective conversations about patients' health, treatment and prognosis.²⁹ 	<p>Question Prompt Lists^{13,14}</p> <p>Decision aids¹³</p>

Principle 2: *Timely access to evidence-based pathways of care*



Optimal care pathways^{30,31} are in place to support the timely diagnosis and staging of lung cancer, as well as appropriate treatment, supportive, follow-up and end-of-life care.

Essential elements

- ▶ Patients with suspected lung cancer should have access to all critical components of the lung cancer pathway appropriate to diagnosis and staging.
- ▶ General Practitioners (GPs) should assess, investigate and refer patients with symptoms that may be lung cancer according to best practice evidence.³²
- ▶ Services should have clearly documented pathways and facilitate timely and streamlined referral of patients into the specialist lung cancer team for diagnosis, staging and treatment in line with the national Optimal Care Pathway.^{30,31}
- ▶ Clearly defined evidence-based treatment pathways for patients with lung cancer should be developed according to disease stage.
- ▶ All patients with a diagnosis of lung cancer should be considered for clinical trial participation.

What are the benefits of timely access to evidence-based pathways of lung cancer care?

For patients	For services	For the system
<ul style="list-style-type: none"> ▶ Improved survival³³⁻³⁵ ▶ Improved quality of life, increased satisfaction and reduced distress^{34,36-38} ▶ Improved symptom management and psychosocial support for patients and families^{34,38} ▶ Improved continuity of care¹⁵ 	<ul style="list-style-type: none"> ▶ Reduction in unnecessary treatment and less aggressive care at the end of life^{34,38} ▶ Enhanced communication and collaboration among clinical and administrative staff¹⁵ ▶ Improved patient waiting times³⁶ 	<ul style="list-style-type: none"> ▶ Strengthened GP partnerships with relevant administrative and managerial staff, clinicians and organisations¹⁵ ▶ Increased knowledge among primary care providers about referral pathways and the role of clinical and administrative staff in secondary care settings¹⁵ ▶ Reduced health service costs¹⁵

“Timely access to care is critical across the care continuum – whether at the point of diagnosis, or in terms of access to treatment or access to palliative care. We have to look for ways to recognise and act on symptoms quickly, and to work in a coordinated and streamlined way to triage care and anticipate patient needs.”

Professor Patsy Yates, Professor of Nursing

Principle 2: Timely access to evidence-based pathways of care

What can help support timely access to evidence-based pathways of lung cancer care?

Strategies to use	Tools and resources that may help
Identifying clinical trials and patient eligibility	
<ul style="list-style-type: none"> ▶ Include information on available clinical trials in the lung cancer MDT meeting agenda and minutes as this can prompt consideration of trial eligibility. Regular attendance of a clinical trial nurse at meetings can facilitate this. 	<p>Australian Cancer Trials website³⁹ Cancer Australia</p>
Telemedicine to link health professionals across distances ^{40,29}	
<ul style="list-style-type: none"> ▶ Use technology to support participation of staff in the treatment and care of patients. For example, virtual participation of a specialist thoracic radiologist in an MDT meeting has been shown to decrease the time from diagnosis to treatment.⁴⁰ 	<p>Information on resources to support telehealth⁴¹ Department of Health</p>
Information, templates and processes to support timely lung cancer diagnosis and staging ³⁹	
<ul style="list-style-type: none"> ▶ Implement a rapid referral lung lesion template and use rapid referral directories to facilitate direct referral to the hospital's thoracic/respiratory medicine department or multidisciplinary lung lesion clinic for timely assessment, diagnosis and staging of lung cancer. ▶ Use of a localised online referral pathway, based on the <i>Map of Medicine or HealthPathways Referral Portal</i>, can also support timely referral from primary care for patients, in line with the <i>Optimal Care Pathway for People with Lung Cancer</i>.³⁰ 	<p>Optimal care pathway for people with lung cancer³⁰ Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer³¹ Process mapping the patient journey through health care: an introduction⁴²</p>
<ul style="list-style-type: none"> ▶ Set up dedicated interventional radiology (CT-guided biopsy) appointments to improve timely access for people with suspected lung cancer. A similar process can be used to support access to dedicated specialist palliative care appointments. 	
GP education and information on referral pathways and best practice lung cancer care	
<ul style="list-style-type: none"> ▶ Provide information sessions for GPs to promote local referral pathways and best practice lung cancer management. Sessions can be organised with the support of GP liaison staff. 	<p>Investigating symptoms of lung cancer: a guide for GPs³² Cancer Australia</p>
Timely and preferred communication of the treatment plan to GPs	
<ul style="list-style-type: none"> ▶ Provide GPs with input about their patients' treatment plan, for example, in a multidisciplinary patient summary report.³² ▶ Establish a reasonable timeframe to communicate with GPs about their patients following diagnosis and discussion at an MDT meeting. 	

Principle 3: *Multidisciplinary care*



An integrated team approach used across the lung cancer pathway to ensure that each patient's individual treatment plan considers all relevant treatment and care options.

Essential elements

- ▶ All patients should be considered by a lung cancer multidisciplinary team regardless of location and delivery setting.
- ▶ The outcome of treatment recommendations of the multidisciplinary team should be clearly documented.
- ▶ The outcome of the multidisciplinary team meeting should be discussed with the patient and a treatment plan agreed.

What are the benefits of taking a multidisciplinary approach to lung cancer care?

For patients	For services	For the system
<ul style="list-style-type: none"> ▶ Improved survival⁴³ ▶ Reduction in time to treatment after diagnosis and improved satisfaction⁴³⁻⁴⁶ ▶ Increased likelihood of receiving curative treatment including radiotherapy or chemotherapy^{45,47-49} ▶ More frequent referrals to specialist palliative or hospice care and increased opportunities for clinical trial participation⁵⁰ ▶ Improved quality of life and reduced hospitalisation at the end of life⁵¹ 	<ul style="list-style-type: none"> ▶ Increased likelihood of patients receiving guideline-adherent care⁴⁸⁻⁵¹ ▶ Improved cancer treatment planning, and more accurate and complete pre-operative staging^{44,47,50} ▶ Improved documentation of treatment plans and patient preferences¹⁵ 	<ul style="list-style-type: none"> ▶ Improved communication between secondary care and primary care providers¹⁵

“As healthcare professionals we need to diagnose lung cancer early and provide rapid referral to a specialist associated with a lung cancer multidisciplinary team to ensure best outcomes for our lung cancer patients.”

Professor Shalini Vinod, Radiation Oncologist

Principle 3: *Multidisciplinary care*

What can help support the delivery of multidisciplinary lung cancer care?

Strategies to use	Tools and resources that may help
Multidisciplinary lung cancer clinic⁵²	
<ul style="list-style-type: none"> ▶ Establish multidisciplinary lung cancer clinics during which patients with lung cancer can meet with their main treating doctor and other members of the team as needed. The clinic can also support the patient to make informed decisions and to obtain a second opinion if needed. 	<p>Cancer Australia's multidisciplinary care hub⁵³ provides a range of evidence-based resources and tools to support multidisciplinary cancer care. The hub is based on the resources which allow for variation in implementation according to cancer type and location of service provision.</p>
Use of video or teleconferencing to support multidisciplinary care in regional settings	
<ul style="list-style-type: none"> ▶ Use video or teleconferencing to enable specialists from regional and rural locations to participate in MDT meetings when distance or time prevents attendance in person.^{39,52} 	
Documentation processes to support multidisciplinary care	
<ul style="list-style-type: none"> ▶ Establish and use a patient summary report to standardise documentation from MDT meetings. The summary can be included in the patient's medical notes and shared with relevant team members, including the GP. 	
Standard operating procedures for multidisciplinary care	
<ul style="list-style-type: none"> ▶ Develop and agree on team protocols to standardise and improve the efficiency and transparency of MDT processes. 	

“Multidisciplinary care is central to delivery of best practice lung cancer care. However, we are still challenged by how to ensure all patients have access to a multidisciplinary team. In WA, videoconferencing plays a significant part in linking regional and metropolitan sites, and electronic databases allow us to enter data anywhere in the state and access that data in real time during our MDT meetings and clinics.”

Dr Annette McWilliams, Respiratory Physician

Principle 4: *Coordination, communication and continuity of care*



All relevant health professionals, including GPs, provide coordinated delivery of lung cancer care across all services and settings, and along the cancer care pathway.

Essential elements

- ▶ A care plan should be developed for every lung cancer patient, which integrates the delivery of care across services and settings, including a nominated key point of contact and entry point back into the system.
- ▶ At a systems level, services should implement processes that support timely communication, continuity and coordination of care.

What are the benefits of improved communication, coordination and continuity of lung cancer care?

For patients	For services
<ul style="list-style-type: none"> ▶ Improved survival is associated with coordination through MDT care and with the early introduction of specialist palliative care when relevant^{34,54,55} ▶ Reduced anxiety¹⁴ ▶ Improved independence⁵⁶ ▶ Reduced symptom severity is associated with care continuity provided by nurse-led follow-up⁵⁷ ▶ Improved survival due to early integration of specialist palliative care³³ ▶ Reduced distress due to care continuity and home-based nursing care^{56,57} ▶ Greater satisfaction with follow-up care interventions, such as nurse-led navigation,⁹ survivorship care plans^{58,59} and nurse- or GP-led integrated care plans^{8,57} ▶ Reduced patient burden is associated with telephone-based follow-up care by eliminating the need to travel⁶⁰ 	<ul style="list-style-type: none"> ▶ Improved healthcare professional communication and increased empathy^{29,61} ▶ Improved access to a care coordinator¹⁵ ▶ Improved access to supportive healthcare professionals through the use of cancer care plans that incorporate a patient needs assessment and psychosocial screening¹⁵

“GPs play a central role in coordinating care for people with lung cancer. Our patients often have their care delivered in different services and locations and may be dealing with a range of other health conditions and comorbidities. We are often answering questions from the patient and their carers, and coordinating tests and appointments, so it’s critical that we are kept informed about treatment plans and outcomes.”

Dr Kerry Hancock, GP

Principle 4: *Coordination, communication and continuity of care***What can help support improvements in coordination, communication and continuity of lung cancer care?**

Strategies to use	Tools and resources that may help
Lung cancer care plans	
<ul style="list-style-type: none"> ▶ Use lung cancer care plans as these can help with coordination, communication and continuity of care. Plans include details for key points of contact, as well as links to information resources. <ul style="list-style-type: none"> – Treatment plans include information about diagnosis and treatment, possible treatment side effects and how to manage them. – Follow-up plans include information about future appointments, ongoing supportive care and potential long-term effects of treatment. 	
Fast-track respiratory clinics	
<ul style="list-style-type: none"> ▶ Establish and use fast-track respiratory clinics with local diagnostic testing to expedite clinical assessment and diagnosis of people with suspected lung cancer, particularly for patients in regional areas. 	
Care coordination evaluation	
<ul style="list-style-type: none"> ▶ Implement care coordination questionnaires for patients and carers to evaluate patients' experiences and to facilitate quality improvement activities. 	
Information to improve experience, outcomes and satisfaction with services	
<ul style="list-style-type: none"> ▶ Provide patients with Question Prompt Lists as these can assist in overcoming communication barriers and enhance the information that is shared during consultations.¹⁴ 	<p>EORTC OUT-PATSAT35⁶² <i>European Organisation for Research and Treatment of Cancer</i></p> <p>Question prompt lists for people with cancer⁶³ <i>Cancer Institute NSW</i></p> <p>Asking questions can help: An aid for people seeing the palliative care team⁶⁴ <i>Palliative Care Australia</i></p>
Provide training to ensure best practice support for patients	
<ul style="list-style-type: none"> ▶ Provide communication skills training as this can assist health professionals to improve their skills in key interactions, such as when delivering bad news and facilitating shared decision-making.²⁸ 	<p>Patient-clinician communication in hospitals: Communicating for safety at transitions of care⁶⁵ <i>Australian Commission on Safety and Quality in Health Care</i></p>
<ul style="list-style-type: none"> ▶ Use trained patient navigators to guide people with lung cancer through the health system.²² Navigators can help patients schedule appointments and understand their care pathway. 	<p>Helping patients make informed decisions: communicating benefits and risks⁶⁶ <i>Australian Commission on Safety and Quality in Health Care</i></p>

Principle 5: *Data-driven improvements in lung cancer care*



Lung cancer data are collected, monitored and reviewed regularly to support continuous improvement in the delivery of best practice lung cancer care.

Essential elements

- ▶ Services should collect data using the agreed national lung cancer clinical data set, and measure patient experience to monitor and review practice.
- ▶ Services should have mechanisms in place for regular monitoring and review processes and outcomes to support the delivery of best practice lung cancer care.
- ▶ Services should engage with consumers to ensure that their feedback is used to inform service delivery and outcomes.

What are the benefits of routinely collecting, monitoring and reviewing lung cancer data?

For patients	For services	For the system
<ul style="list-style-type: none"> ▶ Improved survival⁶⁸ ▶ Reduced symptom severity⁶⁹ ▶ Reduced post-operative pain⁶⁹ ▶ Improved quality of life⁷⁰ 	<ul style="list-style-type: none"> ▶ Improved communication between patients and service providers^{69,71-74} ▶ Improved understanding of gaps related to psychosocial screening and referral processes for supportive care and specialist palliative care¹⁵ ▶ Increased referral to psychosocial care^{72,75} ▶ Increased monitoring of treatment responses^{74,76} ▶ Improved service delivery models¹⁵ ▶ Improved equity and equality in access to care for patients¹⁵ 	<ul style="list-style-type: none"> ▶ Improved resource use (e.g. a reduction in imaging)⁶⁸ ▶ Reduction in hospital length of stay and re-admissions⁷⁰

“ There must be no sweeter reward for a health care provider than knowing that they truly helped a fellow human through toil and compassion. Technology now enables such knowledge to further improve lung cancer and indeed health care generally.

Professor Kwun Fong, Respiratory Physician

Principle 5: *Data-driven improvements in lung cancer care*

What can help support data-driven improvements in lung cancer care?

Strategies to use	Tools and resources that may help
Patient-targeted data collection to inform service delivery changes	
<ul style="list-style-type: none"> ▶ Use electronic self-reporting systems to prompt patient–provider discussion of symptoms and quality of life issues.⁷⁷ ▶ Use online data collection and feedback systems to help patients self-score their symptoms. The online system can then generate a trigger for the treating oncologist once a symptom burden threshold has been reached.⁷⁸ 	<p>Electronic Self-Report Assessment for Cancer (ESRA-C)²⁵ a web-based program for patients to report health information to their care team Dana Faber Cancer Centre</p>
Multidisciplinary team meeting dashboard	
<ul style="list-style-type: none"> ▶ Establish and consolidate the use of electronic dashboards to support MDT meetings and treatment planning. ▶ A focus on clinical trial enrolment, referral to specialist palliative care, and patient profile data can be useful to include in the dashboard. ▶ Nominate an MDT member to be responsible for ongoing data collection and monitoring using the lung cancer clinical data set specification. 	<p>Lung cancer clinical data set specification⁷⁹ Cancer Australia and Australian Institute of Health and Welfare</p>
Analysis of patient records	
<ul style="list-style-type: none"> ▶ Conduct an analysis of patient records to identify opportunities for improvement, particularly relating to the timeliness of symptom investigation, diagnosis and treatment, assessed in line with the <i>Optimal Care Pathway for People with Lung Cancer</i>.³⁰ <p>These findings can be used to inform service-level changes.</p>	<p>Lung cancer demonstration project clinical audit tool⁸⁰ Cancer Australia</p>
Identifying gaps and areas for improvement through data-assisted quality improvement	
<ul style="list-style-type: none"> ▶ Identify gaps and areas for data-driven improvement. For example, this may involve examining data on the assessment and reporting of ECOG performance status, the number and appropriateness of psychosocial assessments, and referral processes for supportive care and specialist palliative care. ▶ Engaging consumers to inform service delivery improvements can help. 	<p>ECOG Performance Status⁸¹ ECOG-ACRIN Cancer Research Group</p> <p>Lung cancer demonstration project self-assessment tool⁸² Cancer Australia</p> <p>National Framework for Consumer Involvement in Cancer Control⁸³ Cancer Australia</p>

Cancer Australia's Lung Cancer Demonstration Project identified several elements that can contribute to the successful implementation and sustainability of strategies to embed the *Principles for best practice management of lung cancer in Australia* into practice over time.

A quality improvement program or activity is more likely to be sustainable if it is well planned, with targeted goals that take account of influencing factors. Capacity for planning and implementation is also important.⁸⁶

Best practice examples of strategies to sustain the Principles in practice

For consumers

- ▶ Engagement of consumers through advice and input to program directions

For services

- ▶ Active communication between all those involved in lung cancer care
- ▶ Leadership from clinical experts
- ▶ A culture of organisational leadership
- ▶ Embedding new practice, innovation and strategies into routine health service delivery
- ▶ Communication and dissemination strategies
- ▶ Clear role delineation and training of staff in new processes
- ▶ Engagement of clinicians and key stakeholders
- ▶ Dedicated staff member(s) to initiate and lead changes
- ▶ Staff members to collect and review data
- ▶ Executive discussions about the impact of changes on workforce capacity

For the system

- ▶ Routine education and training for staff
- ▶ Access to evidence-based information on best practice lung cancer care
- ▶ Embedding formalised processes for review of quality improvement processes
- ▶ Development of contingencies for program continuation
- ▶ Funding and budget planning to support ongoing implementation
- ▶ Adequate information technology infrastructure and data systems

“ We know that many programs face challenges in sustaining improvements over time. Often, when programs conclude, hard-won improvements in public health and clinical care dissipate. Understanding and supporting the sustainability of improvement activities positions efforts for long-term success.

*Adjunct Associate Professor Christine Giles
Executive Director, Cancer Australia*

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