



**Australian Government**  
**Cancer Australia**

# Lung Cancer Framework

Principles for Best Practice  
Lung Cancer Care in Australia



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Lung Cancer Care in Australia



*Lung Cancer Framework: Principles for Best Practice Lung Cancer Care in Australia* was prepared and produced by:

Cancer Australia  
Locked Bag 3 Strawberry Hills NSW 2012 Australia  
Tel: +61 2 9357 9400 Fax: +61 2 9357 9477  
canceraustralia.gov.au

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ISBN Print: 978-1-74127-325-0 ISBN Online: 978-1-74127-326-7

#### **Recommended citation**

Cancer Australia, 2018. *Lung Cancer Framework: Principles for Best Practice Lung Cancer Care in Australia*, Cancer Australia, Surry Hills, NSW.

*Lung Cancer Framework: Principles for Best Practice Lung Cancer Care in Australia* can be downloaded or ordered from the Cancer Australia website: [canceraustralia.gov.au/resources](http://canceraustralia.gov.au/resources)

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# Foreword

As the Government's lead national agency in cancer, Cancer Australia works to reduce the impact of cancer and improve the wellbeing of people affected by cancer.

Lung cancer is the leading cause of cancer burden in Australia. People affected by lung cancer experience significant impacts, not only on life expectancy but they may also experience considerable psychological distress and reduced quality of life. Additionally, variations in lung cancer incidence and outcomes exist by remoteness and socio-economic status, and for Aboriginal and Torres Strait Islander people.

The *Lung Cancer Framework: Principles for Best Practice Lung Cancer Care in Australia* (the Lung Cancer Framework) is a national resource for health professionals, service providers and policy makers who are involved in the care and treatment of people affected by lung cancer across Australia.

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 Principles: patient-centred care; multidisciplinary care; timely access to evidence-based care; coordination, communication and continuity of care; and data-driven improvements. Evidence-based information, strategies, tools and resources are included in the Lung Cancer Framework to support local adoption of these Principles in the delivery of best practice lung cancer care.

The development of the Lung Cancer Framework was guided by systematic reviews of the evidence and a national demonstration project undertaken with health service collaborations across Australia, supported by an Expert Steering Group and Cancer Australia's Lung Cancer Advisory Group. We thank these contributors for their invaluable experience, which has been incorporated into the Lung Cancer Framework.

We hope that the uptake of the Lung Cancer Framework will help inform and support efforts at the local, health service and system levels, to ensure the provision of best practice care and ultimately to improve outcomes and experiences for people affected by lung cancer across Australia.

Dr Helen Zorbas AO

CEO Cancer Australia

## Statement of Acknowledgment

We acknowledge the traditional owners of Country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to the traditional owners and their cultures, and to Elders both past and present.

Cancer Australia acknowledges that there is no single Australian Aboriginal and Torres Strait Islander culture or group and that there are many diverse communities, language groups and kinships throughout Australia. However, when presenting data we will be respectfully using the term Indigenous Australians.





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# Acknowledgements

Cancer Australia would like to thank the health professionals, Advisory Group members, and consumers that have contributed to the development of the Lung Cancer Framework. Their contribution has involved the provision of strategic advice and guidance. For a full list of acknowledgements please see Appendix A.

## Lung Cancer Advisory Group

Chaired by Professor David Ball from 2013 to 2017, Cancer Australia's Lung Cancer Advisory Group provided high-level expert advice on the development and implementation of Cancer Australia's *Principles for Best Practice Management of Lung Cancer in Australia* (the Principles). The Advisory Group consists of members with relevant multidisciplinary expertise including respiratory medicine, radiation oncology, medical oncology, cardiothoracic surgery, general practice, lung cancer nursing and lung cancer consumer representation. The development of the Lung Cancer Framework and strategic support for its national implementation has also been guided and supported by the expert Advisory Group.

## Steering Group of the Lung Cancer Demonstration Project

The Steering Group provided high-level strategic advice regarding the implementation and evaluation of Cancer Australia's National Lung Cancer Demonstration Project. Chaired by Professor David Ball, the Steering Group supported the national demonstration project through provision of guidance and advice on the conduct and evaluation of the best practice initiatives. Examples of best initiatives to support implementation of the Principles are included in the Lung Cancer Framework.

## Lung Cancer Demonstration Project Collaborations

There were four health service Collaborations encompassing 11 sites that participated in Cancer Australia's National Lung Cancer Demonstration Project. The Collaborations were instrumental in developing and demonstrating best practice approaches to lung cancer treatment and care in service delivery settings in order to improve outcomes for people affected by lung cancer. Elements of the approaches demonstrated by the Collaborations are provided in the Lung Cancer Framework as examples of best practice.

## Clinical Leadership Group of the Lung Cancer Demonstration Project

The Clinical Leadership Group comprised representation from the four health service Collaborations involved in the Lung Cancer Demonstration Project. The Clinical Leadership Group provided an opportunity for health services to share key learnings, report on progress and examine relevant operational aspects of the Principles in the Australian cancer care context. The work of the Leadership Group assisted in the development of the best practice strategies that are presented in the Lung Cancer Framework and also the development of evidence to support the use of these strategies across Australia in order to improve outcomes.



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## Aim of the 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 Cancer Australia's *Principles for Best Practice Management of Lung Cancer in Australia* (the Principles).<sup>1</sup> Improved outcomes and experiences are required as lung cancer is the leading cause of cancer death in Australia.<sup>2</sup> Also, patients affected by lung cancer may experience high levels of unmet need,<sup>3</sup> which can contribute to psychological distress for patients, and this has the potential to affect their quality of life.<sup>4</sup>

The Lung Cancer Framework is a national resource for health professionals and service providers who are involved in the care and treatment of people affected by lung cancer across Australia. 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 best practice lung cancer care in Australia.

## Lung Cancer in Australia

### Incidence, mortality and survival

In 2017, lung cancer was estimated to be the fifth most commonly diagnosed cancer and the leading cause of cancer death in Australia.<sup>2+</sup> The estimated number of new cases diagnosed in 2018 for lung cancer is 12,741 cases. These cases account for nine per cent of all new cancer cases estimated to be diagnosed in Australia in 2018.<sup>5</sup>

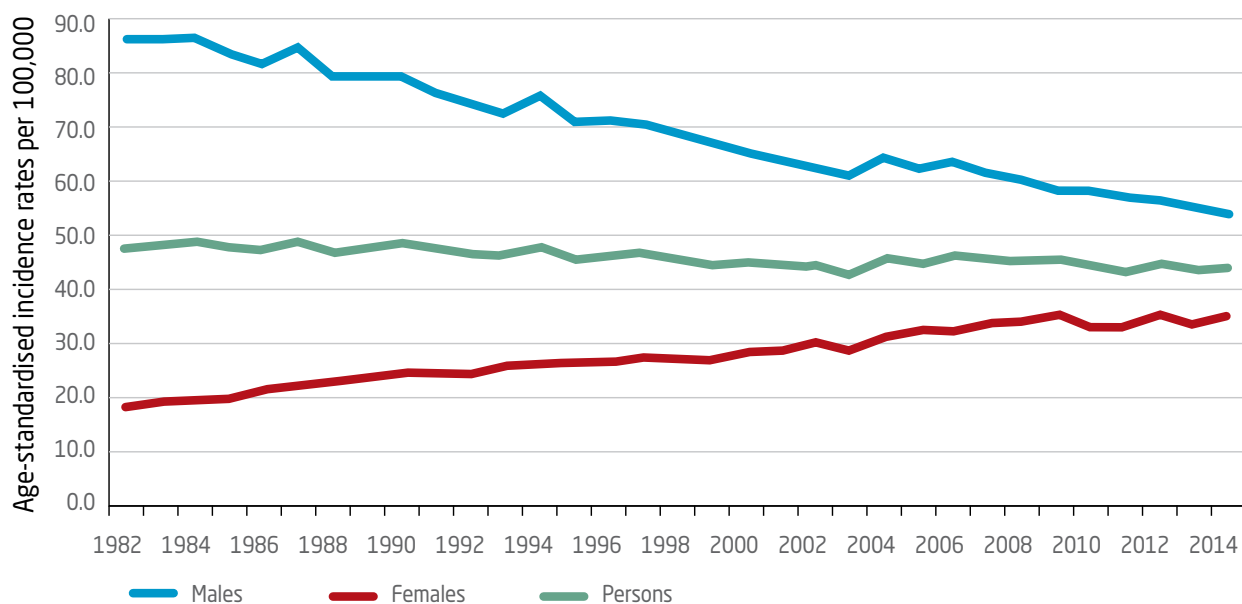
Between 1982 and 2014, the age-standardised lung cancer incidence rate decreased in males from 85.1 to 53.3 per 100,000 and increased in females from 18.2 to 34.4 per 100,000. In this 32-year period, the age-standardised lung cancer incidence rate for all persons in Australia decreased from 47.0 to 42.9 per 100,000.<sup>5</sup> (See Figure 1)

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<sup>+</sup>National and sub-national data presented in the Lung Cancer Framework excludes basal cell and squamous cell carcinomas of the skin, as these diseases are not included in the Australian Cancer Database because they are not notifiable diseases.



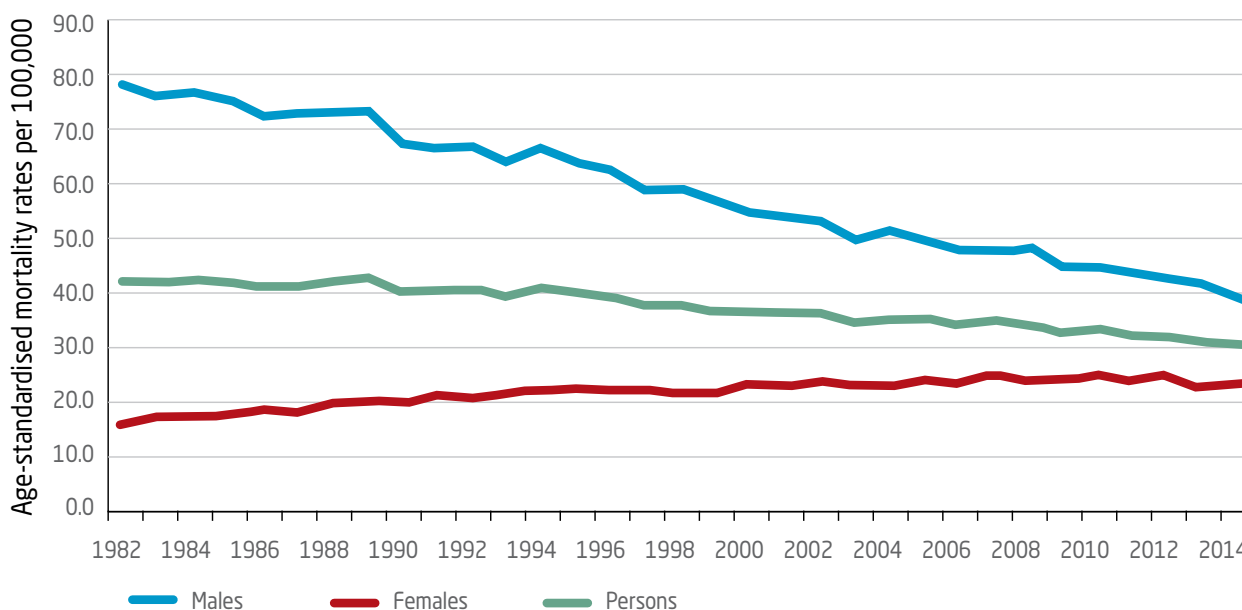
Figure 1 - Age-standardised incidence rates per 100,000 for those diagnosed with lung cancer (1982–2014) in Australia, by sex



Source: Australian Institute of Health and Welfare (AIHW) 2017. Australian Cancer Incidence and Mortality (ACIM) books: Canberra: AIHW. <<http://www.aihw.gov.au/acim-books>>.

In 2018, an estimated 9,198 people are expected to die from lung cancer in Australia, accounting for 19% of all cancer deaths in 2018.<sup>5</sup> Between 1982 and 2015, the age-standardised lung cancer mortality rate decreased in males from 78.9 to 39.0 per 100,000 and increased in females from 15.4 to 23.5 per 100,000. In this 33-year period, the age-standardised lung cancer mortality rate for all persons in Australia decreased from 42.3 to 30.5 persons per 100,000.<sup>5</sup> (See Figure 2)

Figure 2 - Age-standardised mortality rates per 100,000 for those diagnosed with lung cancer (1982–2015) in Australia, by sex

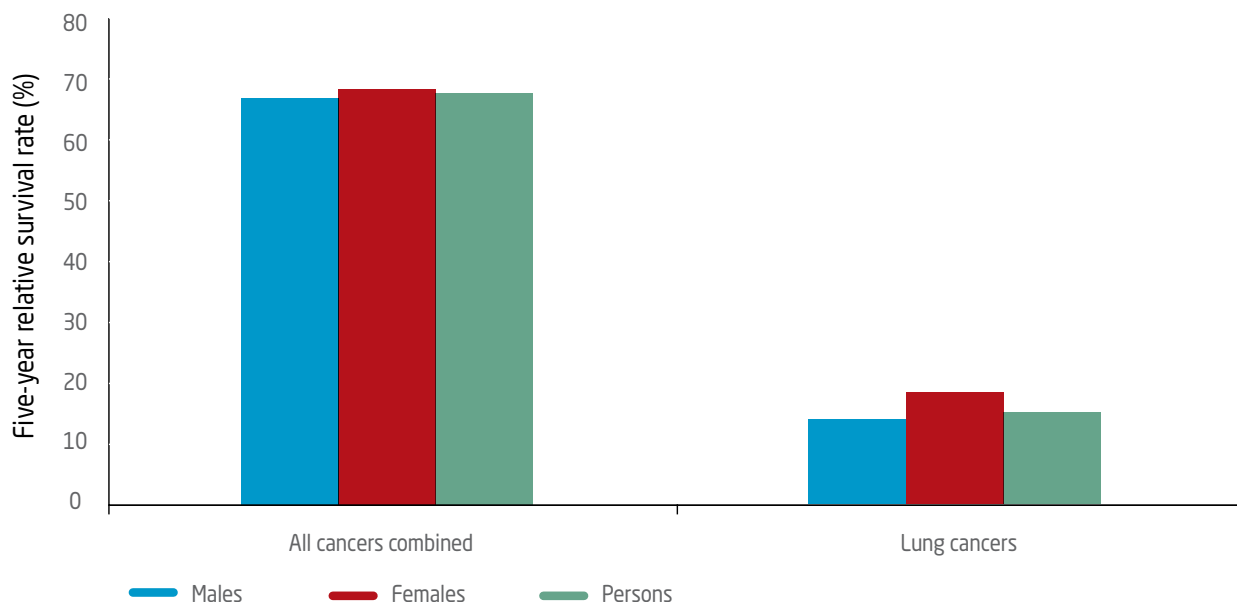


Source: Australian Institute of Health and Welfare (AIHW) 2017. Australian Cancer Incidence and Mortality (ACIM) books: Canberra: AIHW. <<http://www.aihw.gov.au/acim-books>>.



Between 2009 and 2013 the five-year relative survival rate for lung cancer was 16%. In comparison, the five-year relative survival rate for all cancers combined between 2009–2013 was 68%. The survival for lung cancer for females was higher than for males between 2009–2013.<sup>2</sup> (See Figure 3)

**Figure 3 - Five-year relative survival (%) for all cancers combined and lung cancer in Australia (2009–2013), by sex**



Source: Australian Institute of Health and Welfare (AIHW). *Cancer in Australia 2017. Cancer series no.101. Cat. no. CAN 100.* Canberra: AIHW, 2017.

## The burden of disease

Cancer is responsible for the highest burden of disease in Australia – that is premature death or disease-related disability.<sup>6</sup> Lung cancer is the leading cause of cancer burden,<sup>6</sup> accounting for almost one-fifth (19%) of the national cancer burden in 2011.<sup>6</sup> For lung cancer, 98% of the burden of disease is due to premature mortality. The Australian Burden of Disease Study 2011 reported that the greatest years of life lost for lung cancer were in those aged 75 to 79 years in males and females.<sup>6</sup>

## Variations in incidence and outcomes

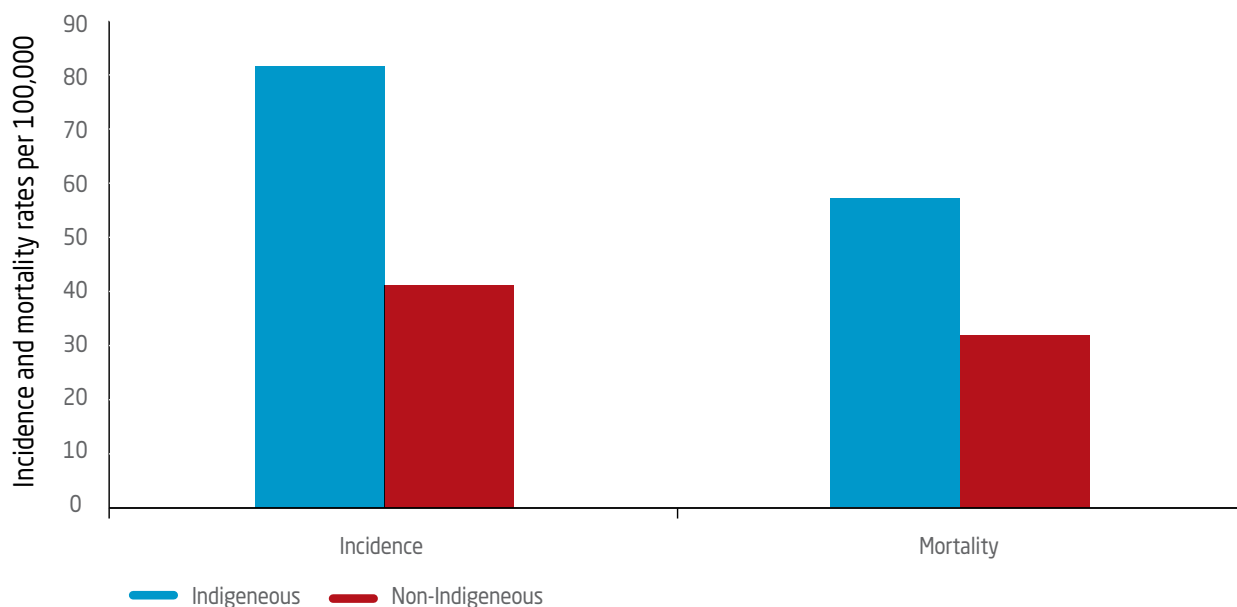
For all Australians, lung cancer incidence decreases with improvements in socio-economic status.<sup>2</sup> The lung cancer incidence rate generally increases with remoteness for males, but varies little by remoteness for females.<sup>7</sup> The rate of lung cancer burden<sup>†</sup> in the lowest socio-economic group is almost twice the rate in the highest group.<sup>6</sup>

Between 2008 and 2012, lung cancer was the most commonly diagnosed cancer among Indigenous Australians.<sup>2</sup> The age-standardised incidence rate was 2.0 times higher for Indigenous Australians than non-Indigenous Australians.<sup>2</sup> Between 2010 and 2014, lung cancer also accounted for the highest number of cancer-related deaths in Indigenous Australians.<sup>2</sup> The age-standardised mortality rate from lung cancer was 1.8 times higher for Indigenous Australians than non-Indigenous Australians.<sup>2</sup> (See Figure 4) Indigenous males experience 2.3 times, and Indigenous females 2.6 times, greater lung cancer burden than non-Indigenous Australians.<sup>6</sup>

<sup>†</sup> Burden of lung cancer disease refers to the combined impact of dying prematurely, as well as living with lung cancer.



Figure 4 - Age-standardised incidence (2008–2012) and mortality (2010–2014) rates per 100,000 for those diagnosed with lung cancer in Australia, by Indigenous status



**Notes:**

1. The rates were age-standardised to the 2001 Australian Standard Population and are expressed per 100,000 population.
2. Some states and territories use an imputation method to determine Indigenous cancers, which may lead to differences between these data and those shown in jurisdictional cancer incidence reports.
3. Incidence data is for New South Wales, Victoria, Queensland, Western Australia and the Northern Territory.
4. Mortality data is for New South Wales, Queensland, Western Australia, South Australia and the Northern Territory.

**Source: Australian Institute of Health and Welfare. Cancer in Australia 2017. Cancer series no.101. Cat. no. CAN 100. Canberra: AIHW, 2017.**

## Lung cancer care expenditure

Health system expenditure on lung cancer care in Australia was \$122.5 million in 2008–09, constituting five per cent of total cancer expenditure for that Financial Year. The majority of this expenditure was due to hospital-admitted patient costs (91% of expenditure), followed by out-of-hospital services (5.6%) and prescription pharmaceuticals (approximately three per cent).<sup>8y</sup> Lung cancer was the most common principal diagnosis reported for palliative care episodes of care in 2015–16 in both private and public hospitals.<sup>9\*\*</sup>

<sup>y</sup> Apart for the incidence, mortality and survival section, percentages have been rounded up or down throughout the Lung Cancer Framework document.

<sup>\*\*</sup> Lung cancer is the most common principal diagnosis in the 3-character International Classifications of Disease Version 10th Edition – Australian Modification (ICD-10-AM) groupings for palliative care separations, public and private hospitals, 2015–2016.





## Development of the Lung Cancer Framework

The Lung Cancer Framework has been informed by a program of work undertaken by Cancer Australia (See Appendix B: Program of Work). This program of work included:

- ▶ The development of the *Principles for Best Practice Management of Lung Cancer in Australia* as part of the Best Practice Approaches to the Management of Lung Cancer in Australia project
- ▶ A national Lung Cancer Demonstration Project (LCDP), which demonstrated the delivery of lung cancer care according to the Principles across a range of service delivery settings across Australia. The LCDP also identified key factors contributing to the uptake and ongoing use of the Principles (See Appendix C: Methodology of the Lung Cancer Demonstration Project and the Systematic Reviews)
- ▶ Five systematic reviews of international evidence published from 2000–2017 (one systematic review for each Principle) to identify and synthesise the evidence base regarding the effectiveness of the Principles in improving lung cancer care processes and/or outcomes (See Appendix C: Methodology of the Lung Cancer Demonstration Project and the Systematic Reviews)
- ▶ A rapid scoping of the published peer-reviewed literature regarding the factors that assist in sustaining the implementation of best practice strategies over time.

**The quantitative and qualitative evidence from this program of work has been combined to inform the development of the Lung Cancer Framework.**

Additionally, the Lung Cancer Framework is in alignment with the *Optimal Care Pathway (OCP) for People with Lung Cancer*. The OCP for People with Lung Cancer describes the key principles and practices required at each stage of the lung cancer care pathway to guide the delivery of consistent, safe, high-quality and evidence-based care.<sup>10</sup> The Lung Cancer Framework complements these key principles and practices along the care continuum.

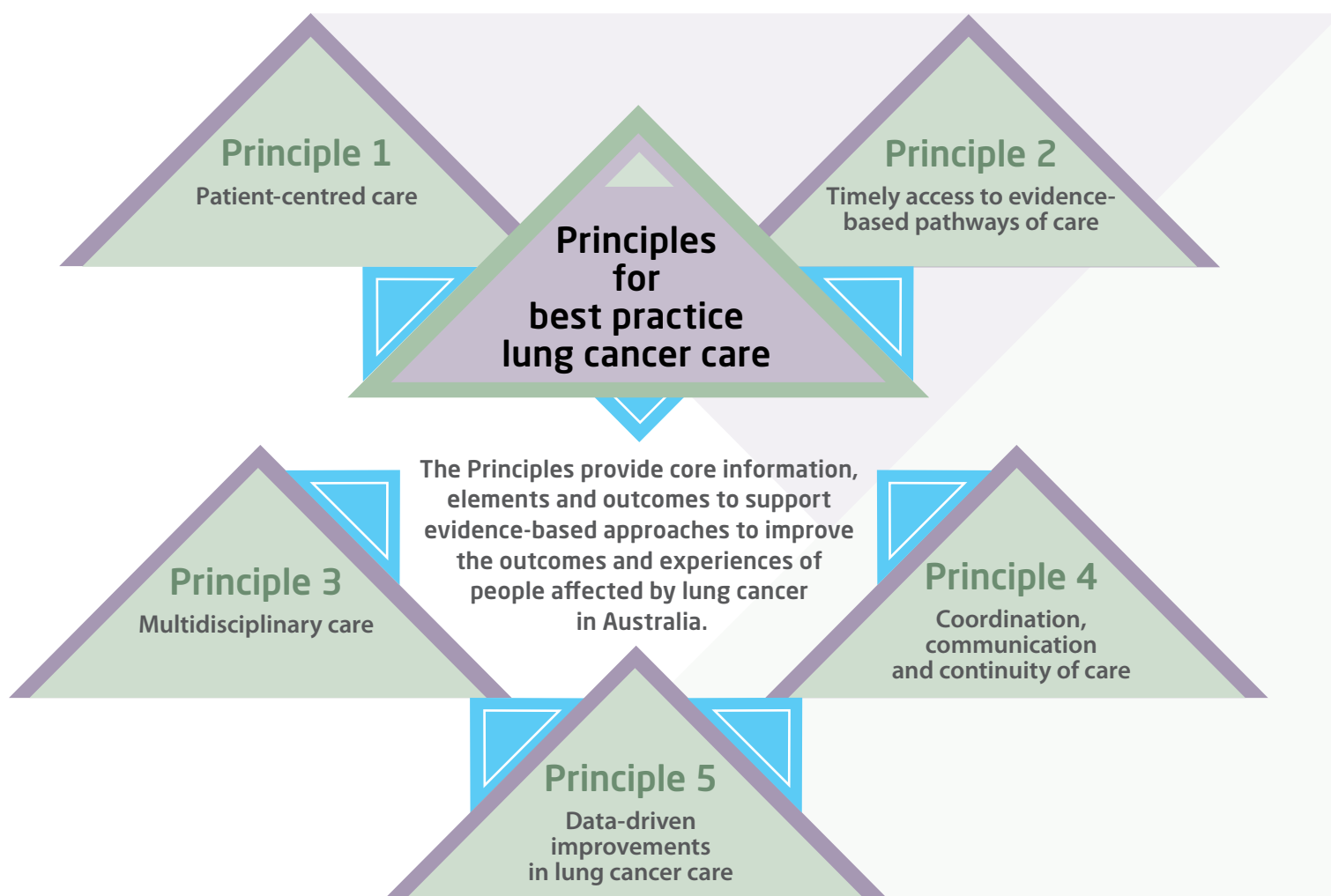
## Principles for best practice lung cancer care

The five *Principles for Best Practice Management of Lung Cancer in Australia* (the Principles) consist of elements and outcomes, which inform evidence-based, best practice information, strategies, tools and resources to improve the outcomes and experiences of people affected by lung cancer in Australia.

The development of the Principles was informed by evidence from national and international literature, and findings from health service and consumer consultation that highlighted variations in care, service delivery and experiences of people affected by lung cancer.

The implementation of the Principles aims to improve outcomes for people affected by lung cancer, and reduce the burden of lung cancer in Australia.<sup>11</sup> (See Figure 5)

Figure 5 - The Principles for Best Practice Management of Lung Cancer in Australia



# Principle 1

## Patient-centred care

Patient-centred care is a Principle of best practice lung cancer care in Australia.

Patient-centred care means that the patient with lung cancer and their carer(s) are the focus of best practice lung cancer care.

There are two elements essential to this Principle:

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

The outcome of a patient-centred care approach is that the patient with lung cancer and their carer(s) feel supported, informed and respected across the cancer care continuum.

This chapter outlines the importance of patient-centred care and how it improves lung cancer care. It also describes evidence-based, best practice information, strategies, tools and resources that support the implementation of this Principle into practice.

## Why the Principle matters

Patient-centred care provides a focus on the unique needs of each patient affected by lung cancer.

Patients affected by lung cancer can experience high levels of unmet need,<sup>3</sup> which can contribute to psychological distress for patients, and this has the potential to affect their quality of life.<sup>4</sup> There can be a mismatch between what patients with lung cancer prefer and what their doctors perceive they need with regards to information<sup>12-16</sup> and their involvement in decision making.<sup>17</sup> This mismatch can have implications for treatment decisions, the long-term survival of patients and also their quality of life.<sup>15</sup>

Best practice patient-centred lung cancer care uses each individual patient's experience to inform the care they receive, and this can contribute to improving their outcomes.<sup>18,19</sup>

## What improves when the Principle is used

Findings from both the peer-reviewed published literature and the Lung Cancer Demonstration Project show that patient-centred care is associated with improvements in consumer-, service- and system-level outcomes. These include:

### Consumer-level outcomes

- ▶ **Improved patient knowledge and improved recall in patients about information that is relevant to their care:** associated with staff sharing evidence-based information with patients, and education initiatives that target patients and includes information about clinical and supportive care needs<sup>20-23</sup>



- ▶ **Decreased patient anxiety and reduced depression:** associated with improved knowledge in patients about aspects of their cancer treatment<sup>23, 24</sup>
- ▶ **Improved patient satisfaction across the lung cancer care continuum:** associated with patient-centred interventions that seek to increase patient knowledge about their diagnosis and processes of care.<sup>20, 22, 23</sup> Improvements in patient satisfaction are also linked with improved patient-provider communication<sup>25, 26</sup> and enhanced care-coordination<sup>27-29</sup>
- ▶ **Improved symptom control and the management of symptoms:** associated with the use of patient-centred education and information.<sup>20, 23, 30</sup> This includes education regarding pain management during treatment,<sup>30</sup> and the routine use of Patient-Reported Outcome Measures (PROMs) to improve symptom control,<sup>26</sup> the earlier detection of symptoms<sup>30</sup> and the earlier referral of patients<sup>26, 31</sup>
- ▶ **Improved patient participation in consultations:** associated with the use of Question Prompt Lists.<sup>32, 33</sup> Question Prompt Lists significantly increase the mean number of questions asked by patients during consultations,<sup>32, 33</sup> including questions about their prognosis, tests and the side effects of treatment<sup>31</sup>
- ▶ **Improved psychosocial care for regional patients referred to metropolitan centres for lung-specific services:** associated with the use of a specially developed information resource to improve regional patients' understanding about lung-specific services in metropolitan centres<sup>34</sup>

## Service-level outcomes

- ▶ **Improved patient-provider communication:**<sup>25, 31</sup> associated with use of PROMs with cancer patients. Discussions about patient outcomes during consultations occur more frequently,<sup>26</sup> and communication about emotional functioning, health-related quality of life and sensitive issues is also enhanced<sup>26, 31</sup>
- ▶ **Improved documentation and communication to the care team of patients' preferences and psychosocial issues:** associated with the raising of these issues at multidisciplinary team meetings<sup>34</sup>
- ▶ **Increased frequency of discussions regarding patient outcomes:** associated with the use of PROMs. PROMs also assist patients and their doctors in developing a shared view of treatment goals, the status of the patient and the patient's reason for visiting their doctor<sup>25</sup>
- ▶ **An increase in referrals to psychosocial care:** associated with the use of PROMs with patients affected by lung cancer<sup>31</sup>
- ▶ **Enhanced and better-targeted information supplied to regional patients, especially information that concerns clinical and supportive care needs:** associated with the development and implementation of material that specifically targets regional patients who are referred for lung-specific services provided in metropolitan centres<sup>34</sup>

## System-level outcomes

- ▶ **Enhanced partnerships between metropolitan and regional centres:** associated with the development of a shared understanding of what information patients need in order to be able to navigate between and through different treatment centres<sup>34</sup>
- ▶ **Improvements in the way that care is coordinated for patients, including across care settings:** associated with increased patient knowledge of lung services<sup>3</sup>





# Strategies

This section contains evidence-based, best practice information, strategies, tools and resources, which support the delivery of patient-centred care for patients with lung cancer at the consumer- and service-levels in Australia. The tools and resources listed in this section can be accessed using the details provided in the References section, unless otherwise noted.

**Table 1 - Consumer-level strategies, and examples of strategies, tools and resources to support the delivery of patient-centred care for those affected by lung cancer in Australia**

Consumer-level strategies	Examples of best practice strategies	Additional examples of relevant tools and resources
<p>Patient information and education in written, audio, visual and/or electronic interactive formats<sup>11, 20-24, 27, 30</sup></p>	<ul style="list-style-type: none"> <li>▶ A best practice example from the LCDP is the development and implementation of Sydney Local Health District's <i>Lung Services Patient Information Guide</i> (Information Guide) for regional patients referred for lung-specific services at the Royal Prince Alfred Hospital in Sydney. The Information Guide was designed to build patients' knowledge about the care and treatment that regional patients may receive, including in different treatment centres, as well as information they may need when they are visiting Sydney, such as Sydney transport options. The Information Guide was drafted following a wide consultation process with patients and also their carer(s) to determine areas of need and what would best suit this need. Pilot testing was conducted with consumers prior to full implementation, and feedback was gathered and then actioned. Once completed, the Information Guide was distributed to a range of services located in regional centres in Dubbo and Coffs Harbour.<sup>34</sup></li> </ul>	<ul style="list-style-type: none"> <li>▶ Cancer Council Australia's <i>Understanding Lung Cancer</i> brochure assists patients and their families to understand more about a lung cancer diagnosis and its treatment.<sup>35</sup></li> <li>▶ Palliative Care Australia's <i>Asking Questions Can Help: An Aid for People Seeing the Palliative Care Team</i> information brochure. This resource was developed after extensive discussions with people referred to a specialist palliative care service, their families and with health professionals working in the area of palliative care.<sup>36</sup></li> <li>▶ Cancer Australia's <i>What's Your Cough Telling You?</i> video and brochure identifies lung cancer symptoms that consumers should be aware of and provides information on the importance of early assessment by a GP or healthcare worker.<sup>37</sup></li> </ul>



<p>Patient navigation methods, involving healthcare professionals or lay persons who are trained as patient navigators<sup>38</sup></p>	<ul style="list-style-type: none"> <li>▶ Nurse-led patient navigation programs to assist lung cancer patients to navigate treatments, including radiotherapy and/or chemotherapy treatments.<sup>28</sup></li> </ul>	<ul style="list-style-type: none"> <li>▶ Canadian Cancer Journey Portfolio's <i>Navigation: A Guide to Implementing Best Practices in Person-Centred Care</i><sup>39</sup> describes the different types of navigation programs (including professional-led, lay- or peer-led, online, and system-based navigation methods) to improve the delivery and accessibility of patient-centred care, and includes a number of tools and resources to support these navigation methods.</li> </ul>
<p>The routine use of assessment measures, PROMs to measure the patient's health status and Patient-Reported Experience Measures (PREMs)<sup>25, 26</sup></p>	<ul style="list-style-type: none"> <li>▶ PROMs to measure lung cancer patient symptoms and how satisfied patients are with the care they receive.<sup>25, 26</sup></li> </ul>	<ul style="list-style-type: none"> <li>▶ <i>The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30 (EORTC QLQ-C30)</i><sup>40</sup> was developed to assess the quality of life of cancer patients, and is supplemented by disease-specific modules (including for lung cancer).</li> </ul>

**Table 2 - Service-level strategies, and examples of strategies, tools and resources to support the delivery of patient-centred care for those affected by lung cancer in Australia**

Service-level Strategies	Examples of best practice strategies	Examples of relevant tools and resources
<p>Development of processes, systems, structures, and standard operating procedures to improve timely access to, and the delivery of, patient-centred care across the care continuum</p>	<ul style="list-style-type: none"> <li>▶ A best practice example from the LCDP is the <i>Patient Multidisciplinary Team Meeting Summary Template</i> used by QLD's Metro North Hospital and Health Service. This resource was used by clinicians during their consultations with patients to support the identification and integration of patients' needs and concerns and/or their needs regarding their treatment into multidisciplinary treatment planning and care. Collaboration with clinicians was undertaken at all steps in the process, from designing the approach to implementation, piloting the summary template and interpreting the findings before wider rollout.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Decision support interventions, such as the use of Question Prompt Lists<sup>32, 33</sup> and decision aids.<sup>27, 32</sup></li> </ul>





	<ul style="list-style-type: none"><li>▶ Clear referral process for supportive care services, including 'trigger points' for when a patient should be referred for supportive care, was also used in the LCDP. The development of this referral process included the gathering of expert advice from a Psychosocial Working Group, and all relevant referral processes were documented in a <i>Standard Operating Procedure Manual</i>. The referral process was endorsed by staff, and was used routinely with all patients affected by lung cancer.</li><li>▶ Shared decision making between clinicians and patients allows for the clinical knowledge and advice from clinicians to be discussed and considered together with the values and preferences held by patients when considering options for treatment.<sup>41</sup></li><li>▶ Communication skills training for health professionals, with topics including building a relationship with the patient, information gathering, breaking bad news, and shared decision making.<sup>42</sup></li></ul>	
<p>The routine use of assessment measures and PROMs to measure the patient's status<sup>25,26</sup></p>	<ul style="list-style-type: none"><li>▶ Routine use of PROMs to measure lung cancer patient symptoms and how satisfied they are with the care they receive.<sup>25,26</sup></li></ul>	<ul style="list-style-type: none"><li>▶ <i>Electronic Self-Report Assessment for Cancer (ESRA-C)</i>.<sup>43</sup> This web-based program can be used by patients to report health information, such as symptoms and quality of life issues, to their care team.</li><li>▶ Peter MacCallum Cancer Centre's validated <i>Supportive Needs Screening Tool</i> to be used by health care professionals to determine the care for cancer patients.<sup>44,45</sup> The tool asks cancer patients specific questions related to their physical health and well-being.</li></ul>



## Principle 2

### *Timely access to evidence-based pathways of care*

Timely access to evidence-based pathways of care is a Principle of best practice lung cancer in Australia.

Timely access to evidence-based pathways of care means that best practice pathways are in place to support the timely diagnosis and staging of lung cancer; and appropriate treatment, supportive, follow-up and end-of-life care.

The elements essential to this Principle are:

- ▶ Patients with suspected lung cancer should have access to all critical components of the lung cancer pathway appropriate to diagnosis and staging
- ▶ General Practitioners should assess, investigate and refer patients with symptoms that may be lung cancer according to best practice evidence
- ▶ Services should have clearly documented pathways and facilitate timely and streamlined referral of patients with suspected lung cancer into the specialist lung cancer team for diagnosis, staging and treatment
- ▶ 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.

The outcomes associated with this Principle are that:

- ▶ All patients have timely access to all critical components of the lung cancer pathway regardless of location and service delivery setting
- ▶ Defined pathways are in place for lung cancer diagnosis that include access to Positron Emission Tomography (PET) and Endobronchial ultrasound (EBUS)
- ▶ All patients with potentially curable lung cancer are referred for assessment by a surgeon with expertise in thoracic/lung cancer surgery
- ▶ Palliative care is introduced early when treatment has non-curative intent.

This chapter outlines the importance of timely access to evidence-based pathways of care and how it improves lung cancer care. It also describes evidence-based, best practice information, strategies, tools and resources that support the implementation of this Principle into practice.

## Why the Principle matters

The Principle of timely access to evidence-based pathways of care supports timely patient access to all critical components of the lung cancer pathway across the care continuum, including: early detection; diagnosis, staging, treatment planning, treatment, supportive care, survivorship, palliative care and/or end-of-life care.<sup>10</sup> For example, timely access to evidence-based pathways of care early in the care pathway is important because symptoms of lung cancer can be vague and non-specific, potentially resulting in a delay in diagnosis. A delay in diagnosis can affect treatment options and result in sub-optimal patient outcomes, including reduced functional status and quality of life for patients with potentially curative disease.<sup>46-48</sup>



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## What improves when the Principle is used

Findings from both the peer-reviewed published literature and the Lung Cancer Demonstration Project show that timely access to care is associated with improvements in consumer-, service- and system-level outcomes. These include:

### Consumer-level outcomes

- ▶ **Improved survival:** associated with early involvement of a specialist medical practitioner, such as a respiratory physician or a cardiothoracic surgeon, in the diagnosis and treatment of people with lung cancer.<sup>49</sup> Improved survival is also associated with early access to specialist palliative care<sup>50</sup> and enrolment in clinical trials<sup>51</sup>
- ▶ **Improved quality of life, increased patient satisfaction, and reduced patient distress:** associated with use of rapid diagnostic pathways<sup>52,53</sup> and/or early access to specialist palliative care<sup>50,54</sup>
- ▶ **Improved symptom management and psychosocial support for patients and their families:** associated with improved referral to a hospice at the end of life, which is facilitated by early access to specialist palliative care<sup>50,54</sup>
- ▶ **Improved continuity of care for patients:** associated with enhanced communication among specialists, and across primary and secondary care<sup>34</sup>

### Service-level outcomes

- ▶ **Reduction in unnecessary treatment and less aggressive care at the end of life:** associated with early access to specialist palliative care<sup>50,54</sup>
- ▶ **Enhanced communication and collaboration among clinical and administrative staff:** associated with the provision of information to improve awareness of the roles of various health practitioners and administrative staff in the lung cancer patient pathway<sup>34</sup>
- ▶ **Improved patient waiting times:** associated with use of rapid diagnostic pathways. A Fast-Track CT pathway following abnormal lung imaging reduces diagnostic delays and makes more effective use of clinic appointments<sup>52</sup>

### System-level outcomes

- ▶ **Strengthening of General Practitioner partnerships with relevant administrative and managerial staff, clinicians and organisations:** associated with the launch and use of Lung Cancer Pathways for General Practitioners<sup>34</sup>
- ▶ **Increased knowledge among primary care providers about referral pathways and the role of clinical and administrative staff in secondary care settings:** associated with improved information provision to primary care providers<sup>34</sup>
- ▶ **Reduced health service costs:** associated with a reduction in avoidable hospital admissions through the Emergency Department by improved management of referrals, early detection and patients' investigations<sup>34</sup>

## Strategies

This section contains evidence-based, best practice information, strategies, tools and resources, which support timely access to evidence-based pathways of care for patients with lung cancer at the consumer-, service-, and systems-levels in Australia. The tools and resources listed in this section can be accessed using the details provided in the References section, unless otherwise noted.

**Table 3 - Consumer-level strategies, and examples of strategies, tools and resources to support timely access to evidence-based pathways of care for those affected by lung cancer in Australia**

Consumer-level strategies	Examples of best practice strategies	Examples of relevant tools and resources
Identifying clinical trials and eligible patients for participation in clinical trials	<ul style="list-style-type: none"> <li>▶ A best practice example from the LCDP is the listing of all available clinical trials on the lung cancer multidisciplinary team meeting agenda and minutes. Also, routine attendance of a clinical trial nurse at each lung cancer multidisciplinary team meeting allowed screening of patients for their eligibility to participate in identified lung cancer trials.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Cancer Australia's <i>Australian Cancer Trials</i> website provides a database of cancer clinical trials in Australia. This website is an information resource for consumers and health professionals and can support a discussion between a consumer and their specialist.<sup>55</sup></li> </ul>

**Table 4 - Service-level strategies, and examples of strategies, tools and resources to support timely access to evidence-based pathways of care for those affected by lung cancer in Australia**

Service-level strategies	Examples of best practice strategies	Examples of relevant tools and resources
<p>The use of Telemedicine to link health professionals across distances</p>	<ul style="list-style-type: none"> <li>▶ Telemedicine to support timely access to care. For example, enabling participation of a specialist thoracic radiologist in a multidisciplinary team meeting where time constraints and/or distance prevented attendance in person, decreased time from diagnosis to treatment and also resulted in a saving in time equivalent to three working weeks of thoracic surgical time during a 12-month period.<sup>56</sup></li> </ul>	<ul style="list-style-type: none"> <li>▶ Telehealth resources to support the delivery of Telemedicine include videoconferencing, as well as other services to transmit voice, images, data, and other information between health professionals, services, and locations.<sup>57</sup></li> </ul>
<p>The development of referral information, templates and processes to support the provision of timely diagnosis and staging of lung cancer</p>	<ul style="list-style-type: none"> <li>▶ A best practice example from the LCDP is the development of the Metro North Hospital and Health Service's Prince Charles Hospital's Rapid Referral – Lung Lesion rapid referral process for General Practitioners. This Rapid Referral Template was used to refer patients with a suspicious lung lesion (suspected lung cancer) directly into thoracic medicine at the hospital for a more rapid assessment. The development of this resource required a thorough consultation with staff, clinicians and organisations. A Referral Directory was developed to help ensure patients were referred to the appropriate specialist. All relevant physicians that worked within a multidisciplinary team environment were identified and listed in the Referral Directory. A regular review of the list of physicians was established to ensure that contact details were correct and current.</li> </ul>	<ul style="list-style-type: none"> <li>▶ <i>Process Mapping the Patient Journey Through Health Care: an Introduction</i>. This is a practical framework to assist services wishing to undertake a process mapping exercise for reconfiguring the patient's journey in the hospital setting from the perspective of the patient.<sup>58</sup></li> </ul>



<p>Pathway to support timely and streamlined referrals for patients with suspected and known lung cancer</p>	<ul style="list-style-type: none"><li>▶ A best practice example from the LCDP is the development and implementation of an Online Referral Pathway. This was developed using the <i>Map of Medicine</i> or <i>HealthPathways</i> online clinical and referral information portals with the aim of ensuring timely referrals for patients with suspected lung cancer, in line with the <i>Optimal Care Pathway for People with Lung Cancer</i>.<sup>9</sup> The Online Referral Pathway highlighted appropriate timeframes to investigate patients' symptoms for the purposes of diagnosis. Promotion of the Online Referral Pathway was undertaken to alert General Practitioners of its availability. Listing Respiratory Physicians that are multidisciplinary team members in the Rapid Referral Template - Referral Directory as the first point of contact for referrals from General Practitioners to assist General Practitioners in their use of the Online Referral Pathway.</li></ul>	<ul style="list-style-type: none"><li>▶ <i>The Optimal Care Pathway for People with Lung Cancer</i><sup>10</sup> and its <i>Quick Reference Guide</i>.<sup>59</sup> This optimal cancer care pathway is intended to guide the delivery of consistent, safe, high-quality and evidence-based care for people with lung cancer. The pathway aligns with key service improvement priorities, including providing access to coordinated multidisciplinary care and supportive care and reducing unwanted variation in practice.</li><li>▶ The Northern Territory Government's <i>Cancer Journeys in the Northern Territory: NT Patient Cancer Care Referral Pathway - Trachea/ Lung</i>.<sup>60</sup> This pathway booklet assists people with cancer to understand and navigate the cancer journey through the public health system in the Northern Territory, including information on early detection, initial diagnosis, treatment planning and treatment options.</li><li>▶ <i>South Australian Lung Cancer Pathway</i>.<sup>61</sup> This pathway outlines requirements and recommendations to guide delivery of optimal and consistent care and support of cancer patients and their families across South Australia.</li><li>▶ Western Australia (WA) Cancer and Palliative Care Health Network – <i>Thoracic Cancer Model of Care</i>.<sup>62</sup> This evidence-based model of care describes how patient-centred thoracic cancer care should be delivered in WA.</li><li>▶ Queensland Health's <i>Changing Models of Care Framework</i>.<sup>63</sup> This guide provides step-by-step principles for reviewing and changing a model of care. It is a collation of combined expertise and experience from clinicians and managers who have been involved in changing models of care delivery.</li></ul>
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<p>Timely communication of treatment plan with the General Practitioner to aid access to supportive and follow-up care</p>	<ul style="list-style-type: none"> <li>▶ A best practice example from the LCDP is the timely provision of the Multidisciplinary Treatment Planning Summary Report to the General Practitioner by their preferred method of communication (e.g. by fax or email). Timely receipt was defined as occurring within one week following the multidisciplinary team meeting, in alignment with the <i>Optimal Care Pathway for People with Lung Cancer</i>.<sup>10</sup></li> </ul>	<ul style="list-style-type: none"> <li>▶ Cancer Australia's <i>Investigating Symptoms of Lung Cancer: A Guide for GPs</i>.<sup>64</sup> A guide to assist General Practitioners to manage people who have or may have lung cancer and support their early and rapid referral into the cancer care pathway. The guide is based on the best available evidence and expert consensus and can be accessed via the Cancer Australia website.</li> </ul>
<p>The provision of information sessions to educate General Practitioners about referral pathways and best practice lung cancer care</p>	<ul style="list-style-type: none"> <li>▶ A best practice example from the LCDP is the provision of information sessions for General Practitioners about referral pathways and best practice lung cancer treatments. Implementation of these information sessions was supported by consultation with General Practitioner Liaison Staff to discuss the organisation, structure and timing of the information sessions. After-hours education sessions were required to accommodate the working schedules of General Practitioners.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Please note: this strategy provides general guidance and as such there are no specific tools and resources.</li> </ul>
<p>The introduction of dedicated appointment slots</p>	<ul style="list-style-type: none"> <li>▶ A best practice example from the LCDP is the introduction and embedding of dedicated interventional radiology (CT-guided biopsy) and specialist palliative care appointments slots. Implementation of this required engagement with radiology and specialist palliative care physicians to champion the introduction of dedicated appointment slots for their respective disciplines. The embedding of dedicated appointment slots into routine practice helped ensure this remained an ongoing process.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Please note: this strategy provides general guidance and as such there are no specific tools and resources.</li> </ul>



**Table 5 - System level strategies, and examples of strategies, tools and resources to support timely access to evidence-based pathways of care for those affected by lung cancer in Australia**

System-level strategies	Examples of best practice strategies	Examples of tools and resources
Continuing Professional Development	<ul style="list-style-type: none"><li>▶ The LCDP explored the use of Continuing Professional Development points to encourage greater participation amongst General Practitioners in activities, such as information sessions for best practice lung cancer care.</li></ul>	<ul style="list-style-type: none"><li>▶ Please note: this strategy provides general guidance and as such there are no specific tools and resources.</li></ul>



## Principle 3

### Multidisciplinary care

Multidisciplinary care is a Principle of best practice lung cancer care in Australia.

There are three elements essential to this Principle:

- ▶ 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 should be discussed with the patient and a treatment plan agreed.

The outcomes related to multidisciplinary care are that:

- ▶ All patients, regardless of their disease stage, have access to all relevant treatment and supportive care options
- ▶ All patients are fully informed of their treatment choices and are supported to have input into their treatment plan
- ▶ An agreed treatment plan is documented and communicated with all members of the treatment team and General Practitioner.

This chapter outlines the importance of multidisciplinary care and how it improves lung cancer care. It also describes evidence-based, best practice information, strategies, tools and resources that support the implementation of this Principle into practice.

## Why the Principle matters

Multidisciplinary care underpins optimal lung cancer care across the care pathway, providing an integrated team approach to support the timely delivery of coordinated, patient-centred, evidence-based lung cancer care.

Multidisciplinary care for lung cancer patients is associated with improved, if not equivalent, survival in patients affected by lung cancer compared to care where multidisciplinary care is not offered to these patients.<sup>65-70</sup>

Evidence also indicates that multidisciplinary care is associated with improved access to treatments by patients affected by lung cancer, including radiotherapy and chemotherapy<sup>71</sup> and higher rates of treatment for patients with cancer overall.<sup>65,\*\*</sup>

## What improves when the Principle is used

Findings from both the peer-reviewed published literature and the Lung Cancer Demonstration Project show that multidisciplinary care is associated with improvements in consumer-, service- and system-level outcomes. These include:

<sup>10</sup> \*Multidisciplinary teams should involve core disciplines integral to the provision of best practice lung cancer care, with core team members attending most meetings either in-person or remotely. Core team members can include a care coordinator (as determined by multidisciplinary team members), medical oncologist, nuclear medicine physician, nurse (with appropriate expertise), pathologist, radiation oncologist, radiologist/imaging specialists, respiratory physician, and thoracic surgeon. Non-core team members can include a clinical psychologist, clinical trials coordinator, dietitian, general practitioner, occupational therapist, palliative care specialist, pharmacist, physiotherapist, psychiatrist and social worker.<sup>10</sup>



## Consumer-level outcomes

- ▶ **Improved survival:** associated with delivery of care that is concordant with the patient's multidisciplinary team's recommendations<sup>72</sup>
- ▶ **Reduction in time to treatment after diagnosis and improved patient satisfaction:** associated with delivery of multidisciplinary care<sup>66, 67, 72, 73</sup>
- ▶ **Increased likelihood of receiving curative treatment, including radiotherapy or chemotherapy:** associated with discussion of patients at multidisciplinary team meetings<sup>65, 67, 71, 74</sup>
- ▶ **More frequent referral to specialist palliative or hospice care and increased opportunities for clinical trial participation:** associated with delivery of care that is coordinated via a multidisciplinary care team<sup>75</sup>
- ▶ **Improved quality of life and reduced hospitalisations at the end of a patient's life:** associated with discussion of patients at multidisciplinary palliative care team meetings<sup>76</sup>

## Service-level outcomes

- ▶ **Increased likelihood of receiving guideline-adherent care:** associated with care coordination at cancer centres which implement multidisciplinary care at higher levels<sup>71, 74, 75, 77</sup>
- ▶ **Improved cancer treatment planning and more accurate and complete pre-operative staging:** associated with discussion of patients at multidisciplinary team meetings<sup>65, 66, 76</sup>
- ▶ **Improved documentation of patients' treatment plans:** associated with recording of outcomes from multidisciplinary team meetings and inclusion in the patient medical record<sup>34</sup>
- ▶ **Improved documentation of patient preferences:** associated with an increased number of treatment plans discussed with the patient and patient preferences documented in Multidisciplinary Treatment Meeting Summaries<sup>34</sup>

## System-level outcomes

- ▶ **Improved communication between secondary care and primary care providers:** associated with provision of a Multidisciplinary Team Meeting Summary to the patient's General Practitioner<sup>34</sup>

## Strategies

This section contains evidence-based, best practice information, strategies, tools and resources, which support the delivery of multidisciplinary care for patients with lung cancer at the consumer-, service-, and systems-levels in Australia. The tools and resources listed in this section can be accessed using the details provided in the References section, unless otherwise noted.



**Table 6 - Consumer-level strategies, and examples of strategies, tools and resources to support the delivery of multidisciplinary care for those affected by lung cancer in Australia**

Consumer-level strategies	Examples of best practice strategies	Examples of relevant tools and resources
<p>Multidisciplinary Clinic for lung cancer patient management<sup>78</sup></p>	<ul style="list-style-type: none"> <li>▶ A best practice example from the LCDP is the establishment and implementation of a Multidisciplinary Lung Cancer Care Clinic (Clinic) for patients diagnosed with lung cancer. The Clinic was established to improve patient contact with clinicians involved in their care or treatment and to assist patients in making informed treatment decisions and/or to be referred for second opinions (if requested or required). Successful implementation of the Clinic required all necessary diagnostic information to be available for participating clinicians prior to day of the Clinic commencing. The lead clinician performing the consultation with the patient/and or their carer(s) and other specialists essential to their care, also needed to be available to meet with the patient at the Clinic visit. Additionally, other clinicians involved in undertaking the treatment needed to be available to see patients when they were visiting the Clinic, including a lung cancer nurse to help guide patients through the Clinic. Patients were provided with clear, evidence-based treatment recommendations at the time of attending the Clinic.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Please note: there are no tools and resources listed for this strategy.</li> </ul>

**Table 7 - Service-level strategies, and examples of strategies, tools and resources to support the delivery of multidisciplinary care for those affected by lung cancer in Australia**

Service-level strategies	Examples of best practice strategies	Examples of relevant tools and resources
<p>Improved access for regional patients to multidisciplinary care using video or teleconferencing</p>	<ul style="list-style-type: none"> <li>▶ Supplementing face-to-face multidisciplinary treatment planning meetings with video or teleconferencing.<sup>78</sup> This can also enable attendance of specialists when time and/or distance prevents them from attending in person.<sup>55</sup></li> </ul>	<ul style="list-style-type: none"> <li>▶ Telehealth services can assist in the provision of Telemedicine by using information and communication technologies to transmit health information over distances and support the timely delivery of health services. Examples of Telehealth resources to support the delivery of Telemedicine include videoconferencing, as well as other services to transmit voice, images, data, and other information between health professionals, services and locations.<sup>56</sup></li> </ul>



**Table 8 – System-level strategies, and examples of strategies, tools and resources to support the delivery of multidisciplinary care for those affected by lung cancer in Australia**

System-level strategies	Examples of best practice strategies	Examples of relevant tools and resources
<p>Development of documentation processes to improve delivery of and outcomes from multidisciplinary care</p>	<ul style="list-style-type: none"> <li>▶ A best practice example from the LCDP is the standardisation of a process to document treatment recommendations arising from multidisciplinary team meetings, regardless of their location. Documentation of multidisciplinary team meeting outcomes aimed to improve data collection, monitoring and evaluation capacity, and continuity and quality of care for patients. Successful implementation of the documentation process involved completion and inclusion of a Multidisciplinary Team Meeting Summary in the patient’s medical records. This was to be done in a timely manner after the meeting and the summaries were shared with all relevant stakeholders involved in the patient’s care and treatment, including General Practitioners. Further, there was support for others to adopt the lung cancer team’s Multidisciplinary Summary Template in order to strengthen partnerships throughout cancer care within Health Districts. For example, teams working in other tumour streams were assisted to use the Multidisciplinary Summary Template across the Health District to improve the overall documentation of multidisciplinary care processes, outcomes and treatment planning. Feedback processes were also incorporated for quality improvement, such as administering and reporting on an evaluation survey to General Practitioners aimed at improving summaries of multidisciplinary team meetings.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Cancer Australia’s <i>Multidisciplinary Care Hub</i>.<sup>80</sup> An online multidisciplinary care information hub to support the uptake of multidisciplinary cancer care in regional and metropolitan cancer centres. This hub is based on the <i>Principles of Multidisciplinary Care</i> which provides a definition of multidisciplinary care, allowing for variation in implementation according to cancer type and the location of service provision. The hub provides a single point of access to tailored, evidence-based information and resources for health professionals including tools, pro formas and case studies, to assist health professionals and health service managers to implement multidisciplinary care, including a: <ul style="list-style-type: none"> <li>▶ Checklist for planning a multidisciplinary team meeting</li> <li>▶ Checklist for communicating with a patient</li> <li>▶ Checklist for principles of multidisciplinary care</li> <li>▶ Checklist for running a multidisciplinary team meeting</li> <li>▶ Checklist for suggested meeting resources</li> <li>▶ General Practitioner Notification</li> <li>▶ Register of information source providers</li> <li>▶ List of core and non-core multidisciplinary care team members</li> <li>▶ Team meeting attendance register</li> <li>▶ Treatment plan pro forma</li> <li>▶ Information Sheet</li> </ul> </li> </ul>
<p>Standard Operating Procedures for multidisciplinary care</p>	<ul style="list-style-type: none"> <li>▶ A best practice example from the LCDP is the development and implementation of Standard Operating Procedures for multidisciplinary team meetings. The provision of protocols aimed to improve efficiency, transparency and standardisation of multidisciplinary team processes and systems.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Please note: there are no tools and resources listed for this strategy.</li> </ul>



## Principle 4

### *Coordination, communication and continuity of care*

Coordination, communication and continuity of care is a Principle of best practice lung cancer care in Australia.

Coordination, communication and continuity of care means that all relevant health professionals, including General Practitioners, provide coordinated delivery of care across the lung cancer continuum of care.

There are two elements essential to the Principle:

- ▶ 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.

The outcomes of this Principle are that:

- ▶ Patients have well-coordinated lung cancer care tailored to their needs
- ▶ Systems are established to facilitate timely and effective information exchange.

This chapter outlines the importance of coordination, communication and continuity of care and how this improves lung cancer care. It also describes evidence-based, best practice information, strategies, tools and resources that support the implementation of this Principle into practice.

## Why the Principle matters

Coordination, communication and continuity of care strengthen the delivery of lung cancer care provided across all services and settings along the cancer care pathway.

People with lung cancer, and their carer(s), navigate a complex diagnostic and treatment pathway that may span different services and locations.<sup>11</sup> Information can be shared across departments and services by multiple providers using different information platforms.<sup>11</sup>

Across the care continuum, lung cancer patients are also required to process and integrate information from numerous health care providers, including a multidisciplinary team of specialists.<sup>28</sup>

Additionally, when lung cancer patients are outside the hospital or acute setting they can have high levels of unmet needs, and communication regarding diagnosis, treatment and prognosis may be inconsistent.<sup>81</sup>

## What improves when the Principle is used

Findings from both the peer-reviewed published literature and the Lung Cancer Demonstration Project show that coordination, communication and/or continuity of care is associated with improvements in consumer- and service-level outcomes. These include:



## Consumer-level outcomes

- ▶ **Improved survival:** associated with coordinated delivery of lung cancer care through multidisciplinary care<sup>82, 83</sup> and with coordination of care across specialties, specifically with the early integration of specialist palliative care with standard lung cancer care.<sup>50</sup> The latter is also associated with reduced depression<sup>84</sup>
- ▶ **Reduced anxiety:** associated with use of Question Prompt List interventions to improve patient-provider communication<sup>33</sup>
- ▶ **Improved patient independence:** associated with care continuity provided by home-based nursing care. This improves patient independence by patients being able to perform a greater number of routine activities without assistance<sup>85</sup>
- ▶ **Reduction in symptom severity:** associated with care continuity provided by nurse-led follow up. Nurse-led follow-up of lung cancer patients is associated with a reduction in the severity of their dyspnoea and peripheral neuropathy<sup>86</sup>
- ▶ **Reduced patient distress:** associated with care continuity provided by nurse-led follow up<sup>86</sup> and home-based nursing care<sup>85</sup>
- ▶ **Greater patient satisfaction:** associated with follow-up care interventions, such as nurse-led patient navigation programs,<sup>28</sup> survivorship care plans<sup>87, 88</sup> and integrated care plans that incorporate follow-up care led by a nurse<sup>86</sup> or General Practitioner<sup>27</sup>
- ▶ **Reduction in patient burden:** associated with telephone follow-up interventions for symptom assessment which reduce the need for patients to travel for hospital-based assessments<sup>89</sup>

## Service-level outcomes

- ▶ **Improved healthcare professional communication and increased empathy:** associated with healthcare professionals that receive communication skills training. Trained healthcare professionals ask patients more open questions and show increased empathy<sup>42, 90</sup>
- ▶ **Improved access to a care coordinator:** associated with the nomination of a staff member, as part of a patient's cancer care plan, to assist in coordination of their care across the cancer care continuum<sup>34</sup>
- ▶ **Increased numbers of referrals to a supportive healthcare professional:** associated with the use of cancer care plans which incorporate Patient Needs Assessment including information from psychosocial screening<sup>34</sup>





## Strategies

This section contains evidence-based, best practice information, strategies, tools and resources, which support coordination, communication and continuity of care for patients with lung cancer at the consumer- and service-levels in Australia. The tools and resources listed in this section can be accessed using the details provided in the References section, unless otherwise noted.

**Table 9 - Consumer-level strategies, and examples for strategies, tools and resources to provide coordination, communication and continuity of care for those affected by lung cancer in Australia**

Consumer-level strategies	Examples of best practice strategies	Examples of relevant tools and resources
<p>The provision of a Lung Cancer Care Plan to patients and their General Practitioner</p>	<ul style="list-style-type: none"> <li>▶ A best practice example from the LCDP is the development and implementation of a Lung Cancer Care Plan (Care Plan). This was designed for use with patients diagnosed with non-small or small-cell lung cancer. Information included in the Care Plans were the contact details of the Lung Cancer Nurse; information regarding diagnosis, treatment, treatment side-effects and how to manage them, and follow-up care; along with links to other information resources relevant to patient care and treatment.</li> </ul> <p>In order to aid comprehension, the Lung Cancer Care Plans were divided into 'Treatment plans' and 'Follow-up plans'. The Care Plans were updated in the patient's medical records at each patient visit, incorporating information informed by the patient's needs assessment.</p> <p>The updated Care Plans were provided to the General Practitioner, as well as to the patient.</p>	<ul style="list-style-type: none"> <li>▶ Please note: there are no tools and resources listed for this strategy.</li> </ul>
<p>Information to improve patients' satisfaction with services</p>	<ul style="list-style-type: none"> <li>▶ A best practice example demonstrated in the LCDP is the development and implementation of a Patient Satisfaction Survey. To ensure patients' feedback was used to improve services after the Principle was implemented, the feedback from the patients was collated with the results provided to Executive-level staff, clinicians and other stakeholders to inform recommendations for service delivery improvements.</li> </ul>	<ul style="list-style-type: none"> <li>▶ The European Organisation for Research and Treatment of Cancer's <i>EORTC IN-PATSAT32</i><sup>91</sup> is a 32-item satisfaction with care questionnaire to measure patients' appraisal of hospital doctors and nurses, as well as aspects of care organisation and services.</li> </ul>



<p>Information to improve patients' experience and outcomes</p>	<ul style="list-style-type: none"> <li>▶ The provision of a Question Prompt List to patients before a consultation may assist in overcoming communication barriers, such as the patient forgetting questions and doubting whether it is legitimate to ask certain questions. A Question Prompt List can enhance information provision during consultation, and contain questions regarding the disease and treatment such as 'What kind of symptoms will this cancer cause?' and 'What kind of treatment do I need?'<sup>33</sup></li> </ul>	<ul style="list-style-type: none"> <li>▶ <i>Questions to Ask a Medical or Radiation Oncologist</i> is a resource that was produced by the Centre for Medical Psychology and Evidence-based Decision-making at the University of Sydney with funding from the Cancer Institute NSW.<sup>92</sup></li> <li>▶ Palliative Care Australia – <i>Asking Questions Can Help: An Aid for People Seeing the Palliative Care Team</i>:<sup>36</sup> this booklet provides information about palliative care and suggested questions for patients and carers seeing a specialist palliative care team to ask to aid decision making and care planning.</li> </ul>
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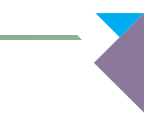
**Table 10 - Service-level strategies, and examples of strategies, tools and resources to provide coordination, communication and continuity of care for those affected by lung cancer in Australia**

Service-level strategies	Examples of best practice strategies	Examples of relevant tools and resources
<p>The evaluation of a Fast-Track Respiratory Clinic</p>	<ul style="list-style-type: none"> <li>▶ A best practice example from the LCDP is the development, implementation and evaluation of a regional Fast-Track Respiratory Clinic. The aims of the clinic included expediting the clinical assessment and diagnosis of patients with suspected lung cancer, and improving access to Sydney-based multidisciplinary team meetings. Evaluation was conducted through interviews with General Practitioners who referred patients to the Respiratory Clinic and other healthcare professionals who worked within the health service. Feedback was summarised and provided to the Respiratory Physician onsite, allowing for the examination of the care coordination, communication and continuity of care being provided.</li> </ul>	<ul style="list-style-type: none"> <li>▶ Please note: there are no tools and resources listed for this strategy.</li> </ul>





<p>The evaluation of needs related to care coordination</p>	<ul style="list-style-type: none"><li>▶ A best practice example demonstrated in the LCDP is the development and implementation of Sydney Local Health District's <i>Cancer Care Coordination Questionnaire for Patients</i>.<sup>93</sup> A postal survey was sent to lung cancer patients at a time after their diagnosis, and aimed to measure patients' experience of cancer care coordination. The survey was administered to evaluate current patient practices, and assess and recommend service delivery improvements in order to develop information to support the coordination of patient care.</li></ul>	<ul style="list-style-type: none"><li>▶ Please note: there are no tools and resources listed for this strategy.</li></ul>
<p>Providing appropriate training to ensure best practice support for patients</p>	<ul style="list-style-type: none"><li>▶ Reviewing communication skills training for healthcare professionals caring for patients with cancer. This can be achieved using interactions with real and/or simulated patients, incorporating learning techniques such as role-play, and including topics such as breaking bad news and shared decision-making.<sup>42</sup></li><li>▶ Inclusion of trained patient navigators to assist lung cancer patients in navigating the healthcare system across the care continuum is another best practice strategy.<sup>37</sup> In cancer care overall, patient navigators can assist with the scheduling of appointments, and help the patient to understand their diagnosis, treatment plans and expectations regarding treatment in a way that is in line with their treatment plans and goals that are agreed with the healthcare team.<sup>94</sup></li></ul>	<ul style="list-style-type: none"><li>▶ Please note: there are no tools and resources listed for this strategy.</li></ul>



## Principle 5

### *Data-driven improvements in lung cancer care*

Data-driven improvements in lung cancer care is a Principle of best practice lung cancer care.

Data-driven improvements in lung cancer care means that lung cancer data are collected, monitored and reviewed regularly to support continuous improvement in the delivery of best practice lung cancer care.

There are three elements essential to the Principle:

- ▶ 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.

The outcome of data-driven improvements is that improvements in lung cancer care are driven by process and outcome data, and patient experience.

This chapter outlines the importance of data-driven improvements in lung cancer care and how these improve lung cancer care. It also describes evidence-based, best practice information, strategies, tools and resources that support the implementation of this Principle into practice.

## Why the Principle matters

Data-driven improvements in lung cancer care inform best practice, patient-centred service delivery, and support continuous improvements in the delivery of lung cancer care.

Data-driven improvements in lung cancer care are associated with improved patient outcomes, such as overall survival<sup>95</sup> and processes of care outcomes, including better diagnostic and treatment pathways.<sup>96</sup> Quality of care also improves for people with lung cancer<sup>97</sup> when data-driven improvements are implemented. For example, patients are more likely to receive care based on their needs<sup>98,99</sup> and the care they receive is more likely to be more focussed on their concerns<sup>97</sup> when data to measure processes, outcomes, and the patient's experience is used to inform their care.

## What improves when the Principle is used

Findings from both the peer-reviewed published literature and the Lung Cancer Demonstration Project show that data collection, monitoring and review are associated with improvements in consumer-, service- and system-level outcomes. These include:



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## Consumer-level outcomes

- ▶ **Improved survival:** associated with web-mediated patient symptom data collection and feedback. Improved survival is attributed to the early detection of relapse and better performance status at the point at which relapse was detected, allowing for optimal salvage treatment to be provided<sup>95</sup>
- ▶ **Reduction in symptom severity:** associated with the use of validated patient-reported outcome and assessment measures such as the EORTC QLQ-C30.<sup>100</sup> Completion of a computerised version of the EORTC QLQ-C30 and provision of this data to staff prior to consultations is reported to improve physical functioning and decrease dyspnoea<sup>100</sup>
- ▶ **Reduced postoperative pain and improved quality of life:** associated with implementation of a multidisciplinary care pathway for patients undergoing thoracic cancer surgery coupled with continuous patient data collection and clinical audit<sup>101</sup>

## Service-level outcomes

- ▶ **Improved patient-provider communication:** associated with the routine collection and feedback of PROMs data.<sup>97, 100, 102</sup> Specific improvements include an increase in symptom-focussed discussion between patient and staff during consultations,<sup>100</sup> detection of previously unrecognised problems<sup>103</sup> and assistance with referrals based on the needs that were identified<sup>97, 102</sup>
- ▶ **Improved understanding of gaps related to psychosocial screening and referral processes for supportive care and specialist palliative care:** associated with collection of relevant data and its analysis<sup>34</sup>
- ▶ **Increased referral to psychosocial care:** associated with use of PROMs<sup>98, 99</sup>
- ▶ **Increased monitoring of treatment responses:** associated with electronic symptom reporting and feedback interventions, particularly with respect to outpatient symptoms following surgery<sup>103</sup> and toxicity when receiving chemotherapy<sup>104</sup>
- ▶ **Improved service delivery:** associated with examination of audit data and its comparison against the *Optimal Care Pathway for People with Lung Cancer* timeframes<sup>34</sup>
- ▶ **Improved equity and equality in access to care for patients:** associated with the review, analysis and discussion of patient profile data presented in multidisciplinary team meetings<sup>34</sup>

## System-level outcomes

- ▶ **Improved resource use:** associated with a web-mediated patient symptom data collection and feedback intervention for enabling early detection of relapse. The intervention led to a reduction in the rate of imaging by 49% per patient per year<sup>95</sup>
- ▶ **Reduction in hospital length of stay and re-admissions:** associated with implementation of a multidisciplinary care pathway coupled with continuous patient data collection and clinical audit<sup>101</sup>

## Strategies

This section contains evidence-based, best practice information, strategies, tools and resources, which support the delivery of data-driven improvements for patients with lung cancer at the consumer-, service-, and systems-levels in Australia. The tools and resources listed in this section can be accessed using the details provided in the References section, unless otherwise noted.

**Table 11 - Consumer-level strategies, and examples of strategies, tools and resources to provide data-driven improvements for those affected by lung cancer in Australia**

Consumer-level strategies	Examples of best practice strategies	Examples of relevant tools and resources
<p>Patient-targeted data collection to inform service delivery changes</p>	<ul style="list-style-type: none"> <li>▶ Use of an electronic self-reporting system where patients completed validated questionnaires in clinic waiting rooms before starting treatment. Follow-up with the questionnaires can occur four to six weeks later, when treatment-related cancer symptoms and quality-of-life issues may present. The use of questionnaires can prompt discussion of symptoms and quality-of-life issues, and focus patient-provider conversations on issues relevant to each patient's experience.<sup>97</sup></li> <li>▶ Use of a web-mediated data collection and feedback system, where patients self-scored their symptoms using an online 'e-follow-up application,' and an automated email was sent to the treating oncologist once a set threshold for symptom burden was reached by the patient.<sup>95</sup></li> </ul>	<ul style="list-style-type: none"> <li>▶ <i>Electronic Self-Report Assessment for Cancer (ESRA-C)</i>.<sup>43</sup> This web-based program can be used by patients to report health information, such as symptoms and quality of life issues, to their care team.</li> </ul>

**Table 12 - Service-level strategies, and examples of strategies, tools and resources to provide data-driven improvements for those affected by lung cancer in Australia**

Service-level strategies	Examples of best practice strategies	Examples of relevant tools and resources
<p>The development of a dashboard to be used to support Multidisciplinary Team Meetings and treatment planning</p>	<ul style="list-style-type: none"> <li>A best practice example demonstrated in the LCDP is the development and implementation of an electronic dashboard. Key steps involved in the development included identifying what data to capture in the dashboard, and the development of a minimum dataset. Special attention was paid to determining what data to include in the dashboard about clinical trial enrolment and eligibility, referrals to specialist palliative care and information regarding the profile of patients. Successful implementation involved a multidisciplinary team member identified and nominated to be responsible for the ongoing collection and monitoring of the data available in the multidisciplinary team meeting.</li> </ul>	<ul style="list-style-type: none"> <li><i>Lung Cancer (Clinical) Data Set Specification</i>.<sup>105</sup> The data set defines data standards for the national collection of lung cancer clinical data so that data collected is consistent and reliable. It aims to facilitate more consistent data collection while enabling individual treatment centres or health service areas to develop data extraction and collection processes and policies that are appropriate for their service settings.</li> </ul>
<p>The collection and analysis of patient records to improve the timeliness of evidence-based pathways of care</p>	<ul style="list-style-type: none"> <li>A best practice example from the LCDP is the collection and analysis of patient records. Included was the collection and review of data around timeliness of diagnosis to investigation to treatment in patients that had been diagnosed with stage III lung cancer. To ensure appropriate service-level changes could be considered, the results were presented to the Hospital's Lung Cancer Steering Group, with a report that included recommendations regarding how to modify practice to improve timeliness of care, while ensuring alignment with <i>Optimal Care Pathway for People with Lung Cancer</i> timeframes.</li> </ul>	<ul style="list-style-type: none"> <li><i>Lung Cancer Demonstration Project Clinical Audit Tool</i>.<sup>106</sup> This tool was used to provide data for the evaluation of the LCDP including measuring the impact of the strategies implemented in the LCDP and providing information about current practice and service delivery.</li> </ul>
<p>Analysis of service-level data to support quality improvement</p>	<ul style="list-style-type: none"> <li>Use of reciprocal peer-to-peer review where multidisciplinary teams from treatment centres with results that contrasted to national averages were paired together to review each other's processes and identify areas for improvement. This was followed by 12 months of supported quality improvement and collaborative working to improve quality.<sup>96</sup></li> </ul>	<ul style="list-style-type: none"> <li>Please note: there are no tools and resources listed for this strategy.</li> </ul>



**Table 13 – System-level strategies, and examples of strategies, tools and resources to provide data-driven improvements for those affected by lung cancer in Australia**

System-level strategies	Examples of best practice strategies	Examples of relevant tools and resources
<p>Identifying gaps and areas to improve through data-assisted quality improvement processes</p>	<ul style="list-style-type: none"> <li>▶ A best practice example demonstrated in the LCDP is the collection of information about current practice in lung cancer care to analyse and highlight any gaps to improve processes.</li> </ul> <p>Information collected included monitoring and evaluating whether ECOG performance status was being assessed and reported for all patients in the Multidisciplinary Team Meeting Summary. Another example included reviewing the number and appropriateness of referrals for psychosocial assessment so that this information could be established to improve assessment practice and determine resourcing. In addition, referral processes for supportive care and specialist palliative care were also examined to improve access, processes and the quality of care provided.</p> <p>All information was used to promote informal discussion among lung cancer team members so that systems and measures could be implemented to improve the quality of care provided to all patients.</p>	<ul style="list-style-type: none"> <li>▶ ECOG-ACRIN Cancer Research Group – <i>ECOG Performance Status</i>.<sup>107</sup> This scale was developed by the Eastern Cooperative Oncology Group to measure a patient’s level of functioning in terms of their ability to care for themselves, daily activity and physical ability.</li> <li>▶ <i>Lung Cancer Demonstration Project Clinical Audit Tool</i>.<sup>106</sup> This tool was used to provide data for the evaluation of the LCDP including measuring the impact of the strategies implemented in the LCDP and providing information about current practice and service delivery.</li> <li>▶ <i>Lung Cancer Demonstration Project Self-Assessment Tool</i>.<sup>108</sup> The self-assessment tool is designed to assist in reviewing and monitoring current practice against the five <i>Principles for Best Practice Management of Lung Cancer in Australia</i>. The tool is designed to consider how practice across the whole setting aligns with each Principle and review the systems and processes used relevant to each Principle.</li> </ul>







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## Sustainability

Many programs face challenges in sustaining their improvements and impact. Often when programs conclude, hard-won improvements in public health and clinical care outcomes dissipate. Understanding and supporting program sustainability positions efforts for long-term success.

Some models of sustainability focus on identifying factors or conditions that increase the likelihood of a specific strategy being continued. Other models examine sustainability from a systems perspective,<sup>109</sup> focusing on the interplay of environmental factors, contextual influences and the strategy.<sup>110</sup>

In reality, it is a combination of both perspectives that produces the greatest insights about sustainability. The sustainability of a program is more likely to succeed if it is well planned, with targeted goals related to influencing factors and sufficient capacity exists or is planned to support program implementation and evaluation. Integrating sustainability strategies into programs ensures that benefits are maintained beyond the duration of the program or initiative.<sup>111</sup>

The following elements have been identified by the health services that participated in the LCDP. These elements enable the implementation and sustained use of the strategies that support the Principles in practice over time. They are presented at the consumer-, service-, and systems-level.

### Consumer-level elements

- ▶ **Engagement of consumers**, through seeking their advice and input, to develop and maintain trust and partnerships through shared decision-making

### Service-level elements

- ▶ **Active communication** between all those involved in the treatment of a patient across the lung cancer care continuum to foster a shared understanding of the positive outcomes of undertaking service-delivery changes
- ▶ **Leadership from clinical experts** to drive change, create and sustain buy-in from clinicians and key stakeholders, make the case for the value of innovation, and to drive any initiative through established clinical, auxiliary and managerial networks
- ▶ **A culture of active leadership** to ensure the provision of structures to establish routine practice and improve efficiency
- ▶ **The embedding of new and/or improved strategies into routine health service delivery and existing service systems** to aid sustainability through the changing of organisation policy, processes and roles
- ▶ **The development and implementation of a communication and dissemination strategy for new/ improved processes** to sustain momentum through a shared and fostered knowledge regarding the new and/or improved processes being implemented
- ▶ **Clear role delineation and focussed training of staff around new processes** to increase staff confidence in sustaining implementation, and to support staff in taking more ownership of the change being undertaken
- ▶ **Engagement of clinicians and key stakeholders** including General Practitioners to ensure support and feedback is used to inform delivery and outcomes
- ▶ **A dedicated staff member(s) that can invest time to initiate service delivery changes** to lead and help sustain the strategies related to care coordination, communication and care continuity



- ▶ **Availability of staff members and teams** to co-ordinate the capture and analysis of data, and the subsequent coordination and implementation of service delivery changes
- ▶ **Promotion of Executive discussions of workforce capacity** to focus on measuring the capacity of services to support the implementation of changes before they occur

## Systems-level elements

- ▶ **Routine education and training for staff** to ensure all staff are versed in new care processes that are to be implemented and sustained
- ▶ **Access to an evidence base** to provide a better understanding of the gaps in the delivery of lung cancer care
- ▶ **The embedding of formalised processes for the review of quality improvement processes** to ensure targets are being met
- ▶ **The development of contingencies for program continuation** to ensure the Principles are sustained over time
- ▶ **Adequate Information Technology (IT) infrastructure and support and other systems** to assist in systems being able to adequately capture data, provide analysis, monitoring and subsequent evaluation
- ▶ **Funding and budget planning** to support ongoing implementation of strategies





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## Appendix A: Acknowledgements

### Membership of the Lung Cancer Advisory Group (2013-2017)

Professor David Ball  
Professor David Barnes  
Professor Michael Boyer AM  
Professor Phyllis Butow AM  
Professor Suzanne Chambers  
Ms Mary Duffy  
Dr Peter Flynn  
Ms Renae Grundy  
Dr Kerry Hancock  
Professor Kwun Fong  
Dr Kathryn Kirkpatrick  
Ms Melanie Lane  
Ms Sue McCullough  
Associate Professor Paul Mitchell  
Professor Dorothy O'Keefe PSM  
Professor Jane Phillips  
Dr Briony Scott  
Mr Michael Sullivan  
Associate Professor Shalini Vinod  
Dr Michael Worthington  
Associate Professor Gavin Wright

### Membership of the Steering Group of the Lung Cancer Demonstration Project

Professor David Ball  
Mr Ross Hogan  
Mr Colin Hornby  
Dr Cameron Hunter  
Dr Liz Kenny  
Dr Kathryn Kirkpatrick  
Ms Glenna Parker  
Mr Michael Sullivan  
Dr Julie Thompson  
Professor Patsy Yates



## Lung Cancer Demonstration Project Collaborations

Western Australia Cancer and Palliative Care Network, WA

- ▶ Royal Perth Hospital, WA
- ▶ Fiona Stanley Hospital, WA
- ▶ South West Health Campus/ Bunbury Cancer Network, WA
- ▶ Sir Charles Gairdner Hospital, WA

Sydney Local Health District, NSW

- ▶ Royal Prince Alfred Hospital, NSW
- ▶ Concord Repatriation General Hospital, NSW
- ▶ Coffs Harbour Health Campus, NSW
- ▶ Mid North Coast Cancer Institute, NSW
- ▶ Western NSW Local Health District, NSW

Metro North Hospital and Health Service, QLD

- ▶ The Prince Charles Hospital, QLD

Tasmanian Health Organisation – Southern Region, TAS

- ▶ Royal Hobart Hospital, TAS

## Membership of the Clinical Leadership Group of the Lung Cancer Demonstration Project

Professor David Barnes

Ms Catherine Bettington

Dr Allison Black

Ms Gemma Collett

Ms Kim Doran

Professor Kwun Fong

Ms Renae Grundy

Dr Cameron Hunter

Ms Jacqueline Logan

Dr Annette McWilliams

Ms Barbara Page

Dr Nicole Rankin





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## Cancer Australia Staff that contributed to the development of the Lung Cancer Framework

Dr Helen Zorbas AO

A/Associate Professor Christine Giles

Dr Cleola Anderiesz

Ms Melissa Austen

Dr Harleen Basrai

Mr Jack Bird

Ms Janessa Catto

Ms Jennifer Chynoweth

Ms Melinda Daley

Dr Barbara Daveson

Ms Karen Evans

Ms Le-Tisha Kable

Ms Liz King

Dr Vivienne Milch

Ms Caroline Nehill

Ms Nathaya Nguyen

Ms Lauren Ognenovski

Ms Doriane Ranaivoharison

Ms Deshanie Rawlings

Mr David Salvestrin

Ms Sue Sinclair

Dr Nerissa Soh

Mr Scott Turnbull



## Appendix B: Program of Work

### Principles for Best Practice Management of Lung Cancer in Australia

The *Principles for Best Practice Management of Lung Cancer in Australia* were developed as part of the Best Practice Approaches to the Management of Lung Cancer in Australia Project, undertaken during 2011–2013. This project included a national mapping exercise of lung cancer services across Australia; a literature review of best practice models of care and patterns of care; and consultation with lung cancer services and consumers.<sup>11</sup> Based on these findings, Cancer Australia developed the Principles for best practice lung cancer care in Australia. This included the core elements and outcomes for each Principle. The development of the Principles involved input from consumers, researchers, clinicians, service providers and representatives from all states and territories throughout Australia.<sup>11</sup>

### Lung Cancer Demonstration Project

The Lung Cancer Demonstration Project (LCDP) was conducted from 2014–17 to demonstrate the delivery of lung cancer care according to the Principles across a range of service delivery settings, and to identify key factors contributing to the uptake and ongoing use of the Principles. The LCDP involved four health service collaborations (Collaborations) in four Australian states (New South Wales, Queensland, Tasmania and Western Australia). Collaborations were chosen, based on their ability to deliver comprehensive lung cancer care across a mix of geographical locations including urban, regional and rural sites; supported by clinical leadership and opportunities to undertake strategies to implement the Principles. The Collaborations spanned eleven sites, and included metropolitan providers and providers outside of major capital cities, which together delivered comprehensive lung cancer care.

As part of the LCDP, the Collaborations chose the most appropriate strategies to implement the Principles in their settings. They then implemented these strategies in a staged approach over the three years of the LCDP. In addition to demonstrating all of the five Principles for best practice lung cancer care, the Collaborations generated information regarding the processes and systems required for their implementation, and this was evaluated through the use of a mixed methods methodology. (See Appendix C for details of methodology)

### Systematic reviews of international evidence

In 2017, five systematic reviews of the peer-reviewed literature were conducted. One systematic review was undertaken for each Principle. The reviews were completed to identify and synthesise the best available evidence regarding the effectiveness of Cancer Australia's Principles in improving lung cancer care processes and/or outcomes. (See Appendix C for details of methodology)





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# Appendix C: Methodology of the Lung Cancer Demonstration Project and the Systematic Reviews

## Lung Cancer Demonstration Project

### Project Aim

In 2014, the Lung Cancer Demonstration Project was established by Cancer Australia with an aim to:

- ▶ Demonstrate the delivery of lung cancer care according to the *Principles for Best Practice Management of Lung Cancer in Australia*, and
- ▶ Identify key factors that facilitate the ongoing delivery of best practice lung cancer care.

### Study Design

A mixed methods study design was used for evaluating outcomes of the LCDP. This involved the collection of:

- ▶ Clinical audit data from across all of the Collaborations involving 152 patients diagnosed with lung cancer
- ▶ Practice survey data with one survey completed for each Collaboration
- ▶ Interview data from key informants from each Collaboration, including interviews with nine staff (Clinical Leaders, Projects Coordinators and Research Staff).

Data was collected at three time points in the 2014 to 2017 period.

### Participants

The LCDP consisted of four health service Collaborations across Australia, including services in New South Wales, Western Australia, Queensland and Tasmania. The Collaborations implemented best practice lung cancer care in accordance with Cancer Australia's Principles over the 2014 to 2017 period.

### Data Analysis

A thematic analysis was undertaken for qualitative evidence from the Practice Survey and Key Informant interview data. A descriptive analysis was undertaken for quantitative evidence from the clinical audits and Practice Survey, where available. Findings were synthesised using a case study approach with each Collaboration considered to be one case study. For the clinical audit, findings were additionally synthesised across Collaborations.

For calculation of changes over time, clinical audit data collected over three time-points in 2014 to 2017 was analysed with data from the first time-point (2014) set as baseline. When the sample size was sufficient, changes were assessed by logistic regression analysis and odds ratios were computed. However, in the case of small sample sizes chi-squared measures of association were conducted and the results interpreted qualitatively.

# Systematic Reviews

## Systematic Review Aim

In 2017, a systematic review of the published peer-reviewed literature was conducted with an aim to:

- ▶ Identify and synthesise the best available evidence on the effectiveness of Cancer Australia's Principles in improving lung cancer care and/or outcomes

## Research Questions

The research questions for the systematic review were:

What is the evidence that in lung, AND/OR other cancer care:

1. Patient-centred care is effective in improving outcomes?
2. Timely access to care, specifically through the provision of evidence-based or best-practice care pathways, is effective in improving outcomes?
3. Multidisciplinary care is effective in improving outcomes?
4. Coordination, communication and continuity of care are effective in improving outcomes?
5. Data-driven improvements are effective in improving outcomes?

## Search Strategy

The search strategy consisted of a three-step process:

1. Search for authoritative systematic reviews identified from the following repositories:
  - ▶ Centres for Reviews and Dissemination DARE (University of York, UK)
  - ▶ Cochrane Collaboration
  - ▶ Joanna Briggs Institute Library of Systematic Reviews
  - ▶ Cochrane Effective Practice and Organisation of Care (EPOC)
2. Search for systematic reviews using search terms targeted to each Principle in the databases:
  - ▶ OVID (Medline, EMBASE and PsychINFO)
  - ▶ PubMed
3. Search for primary studies (randomised controlled trials, cohorts, case-control studies and ecological studies) as per step 2 with a defined search strategy agreed before execution.



For each step, lung cancer studies published from 2011–2017 were searched for first. If this time period yielded insufficient results to determine effectiveness of the Principle in relation to lung cancer patients, the search was broadened to cancer care 2011–2017, followed by lung cancer to cover 2000–2017, and then cancer care 2000–2017. The search was progressed to the next step only when results from the previous step were insufficient with respect to the number and quality of articles found. Articles outside the defined criteria including non-English language, non-Human studies, retrospective studies, grey and unpublished literature were excluded.

Articles were screened for inclusion by two independent reviewers and any conflicts resolved by a third reviewer. This was first done first by title, second by abstract and third by full-text. Systematic reviews and primary studies were quality appraised using validated checklists (AMSTAR and CASP). Those rated as moderate quality or higher were included in the review. Moderate and or higher quality criteria were established before appraisal.

## Data Synthesis

Data from the systematic reviews and primary studies was extracted into tables and findings were grouped according to outcomes for each Principle. Using guidance and analytical steps outlined in the UK Economic and Social Research Council's Methods on narrative synthesis, findings were synthesised into narrative summaries for each Principle. The analysis of the data involved tabulation, grouping and clustering, and the transformation of the findings into a common rubric.<sup>112</sup>

A mixed methods methodology was used to evaluate the LCDP. This included collecting and analysing clinical audit data (which included data from 152 patients diagnosed with lung cancer), Practice Survey data from the Collaborations and Key-informant interview data from clinical leaders across the Collaborations. A thematic analysis was undertaken for the qualitative data from the practice surveys and Key-informant interviews. Descriptive statistical analysis was completed for the numerical data, which was collected at three time points.

## Abbreviations

<b>ACRIN</b>	American College of Radiology Imaging Network
<b>AMSTAR</b>	Assessing the Methodological Quality of Systematic Reviews
<b>CASP</b>	Critical Appraisal Skills Programme
<b>Collaborations</b>	Lung Cancer Demonstration Project Health Service Collaborations
<b>CT</b>	Computed Tomography
<b>EBUS</b>	Endobronchial Ultrasound
<b>ECOG</b>	Eastern Cooperative Oncology Group
<b>ESRA-C</b>	Electronic Self-Report Assessment for Cancer
<b>EORTC</b>	European Organisation for Research and Treatment of Cancer
<b>IT</b>	Information Technology
<b>LCDP</b>	Lung Cancer Demonstration Project
<b>OCP</b>	Optimal Care Pathway
<b>PET</b>	Positron Emission Tomography
<b>the Principles</b>	Principles for Best Practice Management of Lung Cancer in Australia
<b>PREMs</b>	Patient-Reported Experience Measures
<b>PROMs</b>	Patient-Reported Outcome Measures



## Glossary

<b>Aboriginal and Torres Strait Islander</b>	A person of Aboriginal and/or Torres Strait Islander descent who identifies as such and is accepted as such by the community with which he or she is associated
<b>Biopsy</b>	The removal of a small amount of tissue from the body, for examination under a microscope, to help diagnose a disease
<b>Burden (of disease)</b>	The quantified impact of a disease or injury on a population. Burden of disease analysis measures the combined impact of dying prematurely or disease-related disability
<b>Cancer continuum</b>	The full spectrum of cancer control services from prevention and early detection efforts, through diagnosis and treatment, to rehabilitation and support services for people living with cancer and/or palliative care
<b>Care coordination</b>	The delivery of services by different providers occurs in a coherent, logical and timely manner, consistent with the person's medical needs and personal context
<b>Care pathway</b>	A care pathway describes the management and its sequence of a well-defined group of patients during a well-defined period of time
<b>Chemotherapy</b>	The use of drugs, which kill or slow cell growth, to treat cancer. These are called cytotoxic drugs
<b>Clinical trial</b>	Research conducted with the patient's permission, which usually involves a comparison of two or more treatments or diagnostic methods. The aim is to gain better understanding of the underlying disease process and/or methods to treat it. A clinical trial is conducted with rigorous scientific method for determining the effectiveness of a proposed treatment
<b>Cohort study</b>	A study that samples a cohort (a group of people who share a similar defining characteristic, such as their age) and performs a cross-section at intervals through time. Cohort studies are used in medicine to investigate risk factors and causes of diseases
<b>Consumers (in LCDP)</b>	A term that can refer to: patients and potential patients; carers; organisations representing cancer consumer interests; members of the public who are targets of cancer promotion programs; and groups affected in a specific way as a result of cancer policy, treatments or services
<b>CT (computerised tomography) scan</b>	The technique for constructing pictures from cross-sections of the body, by x-raying the part of the body to be examined from many different angles
<b>Dyspnoea</b>	The sensation of shortness of breath, difficulty breathing, or breathlessness



<b>ECOG performance status</b>	A scale developed by the Eastern Cooperative Oncology Group to measure a patient's level of functioning in terms of their ability to care for themselves, daily activity and physical ability
<b>Health outcome</b>	A health-related change due to a preventive or clinical intervention or service. The intervention may be single or multiple, and the outcome may relate to a person, group or population, or be partly or wholly due to the intervention
<b>Hospice</b>	A place that provides specialist palliative care for people with a life-limiting illness. Hospices provide inpatient medical care, respite care, and end-of-life care to manage pain and symptoms and attend to the emotional and spiritual needs of people who are unable to be cared for at home, or don't wish to die at home
<b>Lung cancer</b>	<p>Lung cancer occurs when abnormal cells in one or both lungs grow in an uncontrolled way. There are several types of lung cancer, each beginning in a different type of cell in the lung:</p> <ul style="list-style-type: none"> <li>▶ Small cell carcinoma (around 12% of lung cancer) usually arises from epithelial cells that line the surface of the centrally located bronchi.</li> <li>▶ Non-small cell carcinoma (over 60% of lung cancer) consists of a different group of cancers that tend to grow and spread more slowly than small cell carcinoma. It mainly affects cells lining the bronchi and smaller airways.</li> </ul> <p>Other types account for around 25% of lung cancer</p>
<b>Multidisciplinary care</b>	An integrated team approach to cancer care. This happens when medical, nursing and allied health professionals involved in a patient's treatment together consider all treatment options and personal preferences of the patient and collaboratively develop an individual care plan that best meets the needs of that patient
<b>Multidisciplinary team</b>	<p>A health care team consisting of a group of experts, including doctors, nurses and other health professionals who specialise in the treatment of specific types of cancer. Most doctors who treat the common types of cancer work with experts in a multidisciplinary team</p> <p>A multidisciplinary team can include a general practitioner, a surgeon, a medical oncologist, a radiation oncologist, a palliative care specialist, a nurse consultant, nurses, a dietitian, a physiotherapist, an occupational therapist, a social worker, a psychologist, a counsellor and a pastoral care worker</p>
<b>Oncologist</b>	A doctor who specialises in the study and treatment of cancer



<b>Palliative care</b>	<p>Treatment to relieve symptoms without trying to cure the disease. Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with a life-threatening illness. Prevention and relief of suffering is provided through early identification and impeccable assessment and treatment of pain and other problems such as physical, psychosocial and spiritual</p> <p>Palliative Care Australia defines a Palliative Care Provider to be a medical, nursing or allied health professional who provides primary care with a palliative approach to patients with a life-limiting illness. A Specialist Palliative Care Provider is a medical, nursing or allied health professional, recognised as a specialist by an accrediting body (or who primarily works in palliative care if an accrediting body is not available), who provides primary or consultative care to patients with a life-limiting illness<sup>112</sup></p>
<b>Patient-centred care</b>	<p>Patient-centred care considers patients' cultural traditions, their personal preferences and values, their family situations, and their lifestyles. It makes patients and their families an integral part of the care team who collaborate with health care professionals in making clinical decisions. Patient-centred care provides an opportunity for patients to decide important aspects of self-care and monitoring. Patient-centred care ensures that transitions between providers, departments, and health care settings are respectful, coordinated, and efficient. When care is patient-centred, unneeded and unwanted services can be reduced</p>
<b>Peer review (of literature)</b>	<p>A process in which research is checked by independent, impartial experts in the same field to make sure it is accurate and reliable prior to being published</p>
<b>Peripheral neuropathy</b>	<p>Weaknesses numbness or pain that causes a tingling, burning or stabbing sensation, usually in the hands and feet, which is caused by damage to the peripheral nerves which send information from the brain and spinal cord to the rest of the body</p>
<b>PET scan</b>	<p>Positron emission tomography. A technique used to build up clear and detailed cross-section pictures of the body. The person is injected with a glucose solution containing a small amount of radioactive material. The PET scanner can 'see' the radioactive substance. Damaged or cancerous cells show up as areas where the glucose solution is being used</p>
<b>Psychosocial care</b>	<p>Care that relates to one's practical, social and psychological needs with the aim of helping to control symptoms or distress and increase satisfaction with life. It can include practical advice, motivational, social and vocational training, structured counselling, support and guidance. The term psychosocial care may be used interchangeably with supportive care, although does not include physical aspects of care</p>



<b>Qualitative evidence</b>	Descriptive information from the examination, analysis, and interpretation of observations of the feelings, thoughts, meanings, and understandings of people (describing the 'how' and 'why')
<b>Quality of life</b>	An individual's overall appraisal of their situation and subjective sense of wellbeing. Quality of life encompasses symptoms of disease and side effects of treatment, functional capacity, social interactions and relationships, and occupational functioning. Key psychological aspects include subjective distress, satisfaction with treatment, existential issues, and the impact of illness and treatment on sexuality and body image
<b>Quantitative evidence</b>	Numerical or statistical information that provides a good overall picture of a population or geographical region, as well as trends over time (describing the 'who,' 'what,' 'where' and 'when')
<b>Radiotherapy</b>	The use of radiation, usually x-rays or gamma rays, to kill tumour cells or injure them so they cannot grow or multiply
<b>Randomised controlled trial</b>	A trial in which participants are randomly allocated to receive the new treatment or the standard treatment (the control)
<b>Specialist</b>	A doctor who specialises in a particular area of medicine
<b>Staging</b>	Tests to find out, and also a means of describing, how far a cancer has spread. Conventionally refers to the allocation of categories (0, I, II, III, IV) to groupings of tumours defined by internationally agreed criteria. Frequently these are based on the tumour, the nodes and the metastases. Staging may be based on clinical or pathological features
<b>Supportive care</b>	Improving the comfort and quality of life for people with cancer
<b>Survivorship</b>	In cancer, survivorship focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to follow-up care, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also part of the survivorship experience
<b>Telehealth</b>	The use of information and communication technologies to provide clinical health care from a distance
<b>Telemedicine</b>	The use of advanced telecommunication technologies to exchange health information and provide health care services across geographic, time, social and cultural barriers
<b>Thoracic</b>	Relating to the thorax (the chest), which includes the cavity enclosed by the rib cage which protects organs such as the heart and lungs



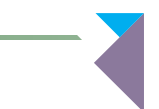
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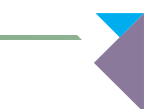
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