Best practice approaches to lung cancer care

A review of the literature
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June 2013
Foreword

Lung cancer is the leading cause of cancer death in both males and females in Australia. Our ability to support best practice approaches to lung cancer care at a national level, and improve lung cancer outcomes is dependent on building the evidence about what comprises best practice care. This literature review commences collection of such evidence.

Best practice approaches to lung cancer care: A review of the literature provides an overview of literature relating to current patterns of care in Australia, and best practice models for the management and care of people with lung cancer both in Australia and internationally. This literature review identifies where gaps and variations exist, important elements of service delivery for best practice lung cancer care, and areas where evidence is unavailable.

This review is a component of Cancer Australia’s Best practice approaches to lung cancer care project that aims to identify best practice approaches to support the consistent management of lung cancer in Australia, and to improve outcomes for people who have been diagnosed with lung cancer. Essential building blocks to inform service delivery include a national map of lung cancer services in Australia; quantitative and qualitative research with patients, health services and key stakeholders; the development of principles of lung cancer care; and identification of essential elements of best practice to support the delivery of care.

We anticipate that this body of evidence and national initiatives being undertaken will assist health services in identifying and implementing best practice lung cancer care, furthering our goal of reducing mortality from lung cancer and improving the wellbeing of people affected by this disease.

Dr Helen Zorbas AO
CEO
Cancer Australia
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Acknowledgements

Cancer Australia acknowledges the contribution of the Best practice approaches to lung cancer care Project Advisory Group (PAG) who provided guidance in the development of the review.

Cancer Australia also acknowledges the input of the ZEST Health Strategies and Cancer Australia staff members who contributed to the development of this literature review.

Project Advisory Group

- Prof David Ball, Chair of Lung Cancer Service, Peter MacCallum Cancer Centre (and National Lung Cancer Program Advisory Group member), VIC
- A/Prof Richard Chye, Director of Palliative Care, Northern Sector, South East Health (and National Lung Cancer Program Advisory Group member), NSW
- Glenda Colburn, Director of the Lung Cancer National Program, Australian Lung Foundation, QLD
- A/Prof Linda Denehy, Head of Physiotherapy, University of Melbourne, VIC
- Dr Haryana Dhillon, Research Co-ordinator Medicine, Central Clinical School and Chair of Australian Psychosocial Oncology Society, NSW
- Prof John Emery, Head of School of Primary, Aboriginal and Rural Health Care, University of WA and Chair of Primary Care Collaborative Cancer Clinical Trials Group, WA
- Prof Kwun Fong, Director of the University of Queensland Thoracic Research Centre (and National Lung Cancer Program advisory group chair), QLD
- Coral Fuata, Carer, NSW
- Meryl Horsell, (Former) Manager of Clinical Service Planning, SA Health, SA
- Dr Cameron Hunter, Clinical Leader of Tasmanian Cancer Network, TAS
- Beth Ivimey, Lung Cancer Care Coordinator, Prince of Wales Hospital and Deputy Chair of ANZ Lung Cancer Nurses Forum, NSW
- A/Prof Paul Mitchell, Senior Specialist at Austin Health Cancer Services and Director of North Eastern Metropolitan Integrated Cancer Service, VIC
- Ashleigh Moore, Patient, Executive Cancer Voices SA
- A/Prof Gary Richardson, Chairman of Private Cancer Physicians of Australia, VIC
- Cindy Sinclair, Indigenous Liaison Officer, Cancer Care Coordination, Cairns Base Hospital, QLD
- Dr Morgan Windsor, Surgical Oncologist, Holy Spirit Northside Medical Centre (and National Lung Cancer Program Advisory Group member), QLD

Research team

- Dr Alison Evans, Director, ZEST Health Strategies
• Holly Fellowes, Senior Project Manager, ZEST Health Strategies
• Sheila Hirst, Sheila Hirst Consulting

Cancer Australia
• Sue Sinclair, General Manager, Service Development and Clinical Practice
• Liz King, Manager, Lung Cancer program
• Kathleen Mahoney, Senior Project Officer, Lung Cancer program
• Natalie Carrangis, Project Officer, Service Development and Clinical Practice
• Lauren Deutsch, Senior Project Officer, Service Development and Clinical Practice
• Ben Brungs, Project Officer, Service Development and Clinical Practice

Funding

The development of this literature review was funded by the Australian Government through the Department of Health and Ageing.
Executive summary

Introduction

This literature review is part of the Best practice approaches to lung cancer care project, which is part of Cancer Australia’s Lung Cancer program. The overall aim of the project is to define a best practice approach to lung cancer, to improve outcomes for people diagnosed with lung cancer in Australia. The project seeks to establish a comprehensive understanding of current patterns of care and best practice models for the management and care of people with lung cancer to inform future service improvement activities.

Lung cancer is the fourth most commonly diagnosed cancer in Australian men and women (excluding basal and squamous cell carcinoma of the skin) and is the leading cause of cancer-related mortality and morbidity for both men and women. In 2007, 9,703 new cases of lung cancer were diagnosed in Australia and 7,626 people died from the disease.Only 14% of those diagnosed with lung cancer survive 5 years after diagnosis.

Objectives

The objectives of this literature review were to:

- summarise patterns of lung cancer care in order to define gaps and variations in the treatment and management of lung cancer in Australia
- identify, collate and review current national and international evidence on best practice models of care for the management of people diagnosed with lung cancer, including clinical and supportive care
- identify evidence-based tools and resources used to support service providers to provide best-practice lung cancer care.

The review of patterns of care literature aimed to establish how patients with lung cancer in Australia currently receive their treatment and care with a view to identifying any known delays in the care pathway and variations in care according to evidence based practice.

The review of models of care literature aimed to establish what models of care for lung cancer are currently in place in Australia and overseas, and to highlight the benefits or challenges associated with these models. This section of the review also aimed to provide evidence of best practice and innovative components of lung cancer care, including tools and resources.
Definition of a model of care

A review of models of care for chronic diseases used in Australia and overseas highlighted the following key elements of a model of care:

- values and principles
- structures and roles
- care delivery process/care management
- referral process/referral patterns
- patient outcomes
- communication structures.

A number of the models of care also included staffing profile and cost-effectiveness as key elements of a model of care; however these elements are outside of the scope of the current project. In addition, the PAG suggested that the following elements may also be relevant:

- data collection and analysis
- research
- governance
- patient satisfaction
- cultural appropriateness.

The definition of a model of care used in this review is:

'A model of care is a multifaceted concept, which broadly defines the way in which health care is delivered including the values and principles; the roles and structures; and the care management and referral processes. Where possible the elements of a model of care should be based on best practice evidence and defined standards and provide structure for the delivery of health services and a framework for subsequent evaluation of care.'

Review methods and data sources

Two main literature searches were conducted using electronic databases (MEDLINE, CINAHL, PsycINFO and Embase) and hand-searching and snowballing searching strategies. Electronic database searching was complemented with extensive searches of national and international lung cancer websites, conference websites, Australian national and jurisdictional health departments, services and organisations, and international depositories of practice guidelines and systematic reviews.
Search timeframe

Articles were included if they were published between 1 January 2000 and 19 October 2011, were in English and available as a full text article.

Many of the studies identified were retrospective studies that utilised data from the 1990s. Health care systems and the treatment of lung cancer are likely to have changed in Australia and internationally since the 1990s and this should be considered when interpreting data from these studies.

Quality of the evidence

In the patterns of care literature review, the majority of the studies were either cohort or case-control studies or descriptive studies. The studies ranged in size from less than 100 subjects to more than 1,000 depending upon whether their focus was on care in an individual setting or across a region or state. No randomised controlled studies were identified.

In the models of care literature review, the majority of studies were descriptive or uncontrolled before and after studies. Few of the studies were randomised controlled trials, cohort studies or case-controlled studies. Of the literature reviews identified, the majority were narrative in style and provided no information about the search strategy or selection criteria used, thereby limiting the applicability of their recommendations or findings.

Patterns of care literature search

Twenty eight articles were identified reporting on patterns of care for lung cancer in Australia. Gaps and variations in treatment and management were identified by 21 studies.

Key findings

Variation/gaps were reported for:

- time to diagnosis
- access to active treatment
- access to re-treatment
- access to palliative care.

Variation in concordance of care with some clinical practice guidelines was also noted.

Components of lung cancer diagnosis reported in the patterns of care literature included:

- time to consult a GP
- time to specialist consultation
- referral to a lung cancer specialist
- pathological/histological diagnosis
- use of staging investigations.
Factors identified as **influencing components of diagnosis** included:
- patient demographics (age, gender, rural location, Aboriginal and Torres Strait Islander status)
- health status (performance status, presence of co-morbidities)
- health service features (presence of a multidisciplinary team (MDT), health service location).

**Components of lung cancer treatment** reported in the patterns of care literature included:
- likelihood of receiving active treatment
- likelihood of receiving specific components of treatment (surgery, radiotherapy, chemotherapy, combination therapy)
- access to re-treatment
- access to palliative care.

Factors identified as **influencing components of treatment** included:
- patient demographics (age, gender, geographical location, Indigenous status)
- disease characteristics (type of lung cancer, degree of spread)
- health status (presence of co-morbidities, stage at diagnosis, performance status)
- health service features (low-volume vs high volume service/specialist, review by an MDT, geographical location of health service).

Some of the identified studies attempted to measure the **impact of variations in care**. These studies suggested that timely diagnosis and treatment, appropriate treatment and multidisciplinary care impacted outcomes at the patient, service and system level.

A number of articles made suggestions about **how variations in lung cancer care could be addressed**. These included:
- more widespread use of multidisciplinary care
- education for medical oncologists and referring specialists regarding the indications and benefits of chemotherapy for stage IV non-small cell lung cancer
- education for GPs and clinicians about options available for the management of lung cancers and on indications and benefits of radiotherapy, especially for small cell lung cancer
- overcome ageist and nihilistic attitudes to lung cancer
- establishment of regional lung cancer services with links to fully resourced multidisciplinary care.
Models of care literature search

Seventy seven papers were identified reporting on models of care for lung cancer in Australia and internationally and 12 articles reported on patient needs and preferences in relation to lung cancer care. The majority of the studies were descriptive or before and after studies.

Key findings

The main areas of focus in the models of care literature were:

- multidisciplinary approaches to treatment planning and care
- the role of specialised and high volume diagnostic and treatment services
- coordination of care/navigation
- appropriate follow-up
- early access to palliative care
- end of life care
- involvement of primary care/community-based care
- patient-centred care
- quality of life issues
- adherence to clinical practice guidelines
- audit/quality measurement.

Studies comparing care and outcomes before and after the introduction/cessation of MDT meetings or clinics demonstrated that MDT teams are associated with reduced time to diagnosis and treatment, and greater use of and more accurate staging.

Involvement of a specialist medical practitioner in the diagnosis and treatment of people with lung cancer has been associated with improved outcomes.

Despite a lack of high-level evidence, many of the studies advocate for a coordinated approach to care delivered in a multidisciplinary fashion, whether via joint conferences, virtual networks, or actual multidisciplinary clinics.

The reported roles of lung cancer care coordinators or navigators vary as do the reported benefits to patient outcomes. Some studies also describe the role of lung cancer nurse specialists. Data from the UK National Lung Cancer Audit suggested that patients seen by a lung cancer nurse specialist were more likely to receive anti-cancer treatment compared to those who were not seen by a lung cancer nurse specialist. The authors conclude that further work is needed to explain this observation.

Evidence appears to be divided as to ideal approaches to follow-up care for people with lung cancer, in particular the role of nurse-led follow-up and whether there is survival benefit to follow-up by specialist health professionals.

Early integration of quality palliative care alongside routine clinical care is feasible and essential from diagnosis. Palliative care is associated with improved survival, improved quality of life, reductions in unnecessary treatment and less aggressive end-of-life care.
Consideration of the role played by primary care professionals in lung cancer care appears to be important. Articles identified in this review suggest that, while most patients would like their GP to be more involved in lung cancer care, GPs are often ‘cut off’ from cancer care during the treatment phase. GPs show preferences for information to be provided electronically from all members of hospital team, in particular information about changes in the patient’s condition, and about key diagnostic and treatment milestones.

Patient preferences to be considered alongside a model of care include:

- perceived areas of unmet needs (outside the acute setting, carers/family, diagnosis, communication)
- patient preferences for information
- style of communication
- patient involvement in decision making.

The models of care literature suggested that patients and carers feel unsupported outside of the hospital setting. Some studies reported a mismatch between what patients want and what their doctors perceive they need with regard to information and involvement in decision making.

Psychosocial and supportive care considerations were explored by some of the identified studies. Non-invasive interventions delivered by health professionals can improve symptoms, psychological functioning and quality of life.

Numerous publications discussed adherence to clinical practice guidelines and pointed out that if published national or international guidelines were adhered to there was less variation/gaps/delays in diagnosis, staging and treatment.

A number of efforts at defining, quantifying and improving quality of care for patients with lung cancer have taken place in the USA, UK, Denmark and the Netherlands. Several quality-of-care indicators for non-small cell lung cancer are available.

Evidence-based tools and resources for lung cancer care

The review set out to identify evidence-based tools and resources that have been used to support service providers to implement and consistently deliver best-practice lung cancer care. No specific tools or resources were identified to support best practice care for the management of lung cancer.

Many countries or jurisdictions use evidence-based guidelines or recommendations to guide lung cancer care or services. Some articles also reported on tools to assess psychosocial distress or information needs; however these were not lung cancer specific.
Conclusions

Variations in lung cancer care are apparent in Australia, including: time to diagnosis, access to active treatment, access to re-treatment and access to palliative care. These variations and gaps appear to be influenced by patient demographics, disease or patient health characteristics and health service features.

Aspects of service delivery that appear to be important in lung cancer care include:

- involvement of an MDT
- involvement of a specialist medical practitioner in diagnosis and treatment
- care coordination, including the role of nurse navigators/care coordinators
- early integration of palliative care
- adherence to guidelines/recommendations and measurement of quality/audit
- consideration of supportive care and quality of life needs
- involvement of primary/community based care.

Literature identified through this review also highlighted the importance of taking account of patient preferences when implementing the model of care.

The literature review has also identified some areas in which evidence is lacking. This includes a clear description of effective service delivery models and health service structures to support best practice lung cancer care and lung cancer-specific tools and resources to support and/or streamline optimal care. These two areas will be explored through the evidence-gathering phase of the Best practice approaches to lung cancer care project.
1. Introduction

1.1 Aims

This literature review is part of the Best practice approaches to lung cancer care project, which is part of Cancer Australia’s Lung Cancer Program. The overall aim of the project is to define a best practice model of care to improve outcomes for people diagnosed with lung cancer in Australia.

This literature review aims to:

- summarise patterns of lung cancer care in order to define gaps and variations in the treatment and management of lung cancer in Australia
- identify, collate and review current national and international evidence on best practice models of care for the management of people diagnosed with lung cancer, including clinical and supportive care
- identify evidence-based tools and resources used to support service providers to provide best-practice lung cancer care.

The review will help to inform recommendations about a best practice approaches to lung cancer care to support the consistent management in Australia of people affected by lung cancer and to identify resources/tools that will support its implementation.

Steps in the lung cancer pathway

- Referral for definitive diagnosis
- Active treatment (surgery, chemotherapy, radiotherapy)
- Follow up until relapse
- Re-treatment
- Follow up until further progression
- Palliative care

The Best practice approaches to lung cancer care project aims to map a best practice pathway from diagnosis onwards, incorporating all relevant components of care.
1.2 Rationale

A comprehensive understanding of current patterns of care and best practice models in relation to the management and care of people with lung cancer will inform service improvement activities in the future. The Best practice approaches to lung cancer care project aims to address the following fundamental questions:

- what is the current pattern of care?
- what is the current model of care?
- does it need to change?
- if so, what should it change to?

The literature review will contribute to answering each of these fundamental questions (Figure 1).

- The patterns of care literature review will help to establish how patients with lung cancer currently receive treatment and will identify any known delays or issues in the care pathway.
- The models of care literature review will establish what models of care for lung cancer are currently in place in Australia and overseas, and highlight the benefits or challenges associated with these models.
- The models of care literature review also aims to provide evidence about best practice approaches to improve outcomes, and to inform the model of care for lung cancer.

1.3 Project scope

The scope of this review, including key questions and the approach to sourcing information, was decided in consultation with Cancer Australia and the Best practice approaches to lung cancer care Project Advisory Group (PAG).

This project aims to define a best practice model of care to improve outcomes for people with lung cancer in Australia. The starting point for the model of care for lung cancer is the point at which the patient has been referred from primary care into specialist (secondary) care for suspected lung cancer for the purpose of investigation of symptoms or for determination of treatment if diagnosis has been undertaken in the primary care setting.

The model will aim to map a best practice pathway from diagnosis onwards, incorporating all relevant components of care.
PHASE 1

Q1. What is the current pattern of care?
- Patterns of care literature review

Q2. What is the current model of care?
- Service mapping
- Consumer survey
- Models of care literature review

Q3. Does it need to change?
- Site visits
- Consumer interviews
- Patterns of care literature review
- Models of care literature review

Q4. What should it change to?
- Site visits
- Consumer interviews

PHASE 2

Proposed model of care for lung cancer in Australia

Consensus phase / stakeholder consultation

Stakeholder Forum

Consensus model of care for lung cancer in Australia

Figure 1 Questions to be addressed in the Best practice approaches to lung cancer care project and sources of information to address these questions
1.5 Organisation of this report

Section 2 describes the methodology used by the project team to gather, review and synthesise literature on patterns of care and models of care for lung cancer.

Section 3 provides an overview of lung cancer incidence and mortality in Australia and how this compares to other comparable countries.

Section 4 presents a synthesis of the results of the literature search relating to patterns of care for the management and treatment of lung cancer in Australia and highlights the gaps and variations that exist in the treatment and management of lung cancer that may impact on outcomes of care.

Section 5 presents a synthesis of the results of the literature search relating to models of care for patients with lung cancer. This section looks at initiatives in Australia and comparable overseas countries that have aimed to improve access to and delivery of comprehensive and appropriate care for patients referred for investigation of symptoms of lung cancer. It also highlights the characteristics of service delivery that have improved patient service and system level outcomes and identifies evidence-based tools and resources that have been used to support service providers to implement and consistently deliver best-practice lung cancer care.

Additional information is provided in the appendices.

- Appendix I lists abbreviations used in the report
- Appendix II outlines key principles and values relating to delivery of cancer services in Australia
- Appendix III details the selection criteria used in the literature review
- Appendix IV details the full search strategy used in the literature review
- Appendix V provides a summary of the regional distribution of articles included in the patterns of care literature review.
2.   Methodology

The scope of this literature review, including the research questions and the approach to sourcing information, was decided in consultation with Cancer Australia and the PAG.

2.1 Definition of ‘Model of care’

To inform the definition of a model of care for lung cancer, a search was run in MEDLINE using the search strategy ‘models of care’ AND ‘definition OR principle’. The search strategy had high sensitivity but poor specificity: although nearly 1,000 articles were retrieved, a scan of the first 100 indicated that articles were not relevant. The search was rerun in Google, the aim being to identify relevant documents in the grey literature. A number of relevant government and non-government articles were identified and the following definition adopted as being relevant to the Best practice approaches to lung cancer in Australia project:

‘A ‘model of care’ is a multifaceted concept, which broadly defines the way in which health care is delivered including the values and principles; the roles and structures; and the care management and referral processes. Where possible the elements of a model of care should be based on best practice evidence and defined standards and provide structure for the delivery of health services and a framework for subsequent evaluation of care.’

2.2 Key elements of model of care

A review of models of care for chronic diseases used in Australia and overseas highlighted the following key elements:2,4-11

- values and principles
- structures and roles
- care delivery process/care management
- referral process/referral patterns
- patient outcomes
- communication structures.

A number of the models of care also included staffing profile and cost-effectiveness as key elements; however these elements are outside of the scope of the current project.

In addition, the PAG suggested that the following elements may also be relevant:

- data collection and analysis
- research
- governance
- patient satisfaction
- cultural appropriateness.
2.3 Strategic direction of cancer service delivery in Australia

The model of care for lung cancer should take into account the strategic direction of cancer service delivery in Australia and align with the values and principles specified by various jurisdictions and agencies involved in health reform and cancer care. A review of documents relating to the strategic direction of cancer service delivery in Australia, at both state and national levels, identified the following guiding principles and values (see Appendix II for full details):12-21

- equity of access
- appropriateness of care, including:
  - culturally appropriate care
  - appropriate care setting
  - governance and leadership
  - patient-centred care
- quality of care, including:
  - patient safety
  - care in line with or exceeding jurisdictional and national care and quality standards
  - use of clinical process and quality outcome indicators
  - a quality improvement ethos
- coordination of care, including:
  - integration of care (tertiary, secondary and primary care services working together to provide cohesive and better care for patients)
  - multidisciplinary care
- evidence-based care
- better outcomes and a reduction in variation in outcomes.

Sub-categories of these elements include:

- multidisciplinary approach
- coordination of care across service sectors
- access to supportive care
- early access to palliative care
- access to trials and research
- quality improvement culture/outlook.
2.4 Formulation of research questions

This report gathered evidence relating to five research questions. These five questions aimed to answer the overarching question ‘What is the best practice model of care to improve outcomes for people diagnosed with lung cancer in Australia?’ The rationale for each of these questions is provided in Table 1.

Table 1 Rationale and potential implications for the research questions addressed through the Best practice approaches to lung cancer literature review

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<tr>
<td>Q1. What are the patterns of care for the management and treatment of patients with lung cancer in Australia?</td>
<td>Examining the current patterns of care for the treatment and management of lung cancer will help to identify any known delays or issues in the care pathway for patients with lung cancer in Australia.</td>
<td>Section 4</td>
</tr>
<tr>
<td>Q2. What gaps and variations exist in the treatment and management of patients with lung cancer in Australia that may have impacted on outcomes of care?</td>
<td>Identifying variations and gaps in care may help to determine what needs to be changed to improve outcomes for patients with lung cancer.</td>
<td></td>
</tr>
<tr>
<td><strong>Models of care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q3. What has been the focus of initiatives in Australia and comparable overseas countries that have aimed to improve access to and delivery of comprehensive and appropriate care for patients referred for investigation of symptoms of lung cancer?</td>
<td>Identifying initiatives that have aimed to improve access to and delivery of care for patients with lung cancer will highlight the strategies that have been employed to date in both Australia and comparable countries.</td>
<td>Section 5</td>
</tr>
<tr>
<td>Q4. What are the characteristics of service delivery for patients with lung cancer in Australia and comparable overseas countries that have improved patient service and system level outcomes?</td>
<td>Identifying what has actually worked from the patient and system perspective.</td>
<td></td>
</tr>
<tr>
<td>Q5. What evidence-based tools and resources have been used in Australia and comparable overseas countries to support service providers to implement and consistently deliver best-practice lung cancer care?</td>
<td>Establishing what has helped in the implementation and monitoring of best-practice models of care for lung cancer.</td>
<td></td>
</tr>
</tbody>
</table>
2.5 Information sources for literature review

2.5.1 Databases

The electronic databases searched were MEDLINE, CINAHL, PsycINFO and Embase.

2.5.2 Grey literature

Electronic database searching was complemented with extensive searches of national and international lung cancer websites, conference websites, Australian national and jurisdictional health departments, services and organisations, and international depositories of practice guidelines and systematic reviews (Table 2).

<table>
<thead>
<tr>
<th>Australian</th>
<th>International</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Institute of Health and Welfare (AIHW)</td>
<td>Centres for Reviews and Dissemination DARE (University of York, UK)</td>
</tr>
<tr>
<td>Australian Policy Online (Health)</td>
<td>Cochrane Collaboration</td>
</tr>
<tr>
<td>Cancer Australia</td>
<td>Cochrane Effective Practice and Organisation of Care (EPOC)</td>
</tr>
<tr>
<td>Menzies Research</td>
<td>MacMillan Fund (UK)</td>
</tr>
<tr>
<td>Cancer Institute NSW</td>
<td>International Agency for Research on Cancer (IARC)</td>
</tr>
<tr>
<td>eviQ</td>
<td>International Union for Cancer Control (IUCC)</td>
</tr>
<tr>
<td>National and state Cancer Councils</td>
<td>Scottish Intercollegiate Guidelines Network (SIGN)</td>
</tr>
<tr>
<td>Cancer Voices</td>
<td>National Guideline Clearinghouse (USA)</td>
</tr>
<tr>
<td>Queensland Cancer Control Analysis Team</td>
<td>Turning Research into Practice (TRIP)</td>
</tr>
<tr>
<td>Tasmania Cancer Network</td>
<td>National Institute for Health and Clinical Excellence (NICE) UK</td>
</tr>
<tr>
<td>Department of Health Victoria</td>
<td>SAGE Inventory of Cancer Guidelines and Standards</td>
</tr>
<tr>
<td>Department of Health South Australia</td>
<td></td>
</tr>
<tr>
<td>CanNET Queensland</td>
<td></td>
</tr>
<tr>
<td>Australian Lung Foundation</td>
<td></td>
</tr>
<tr>
<td>Clinical Oncological Society Australia (COSA)</td>
<td></td>
</tr>
<tr>
<td>CareSearch (Palliative care knowledge network)</td>
<td></td>
</tr>
</tbody>
</table>

2.5.3 Hand-searching and snowball searching

The project team, members of the PAG and other jurisdictional contacts also identified a number of reports, articles and references through snowball searching and citation checking.
2.6 Selection criteria

2.6.1 Patterns of care

Articles were included if they were published between 1 January 2000 and 19 October 2011, were in English and available as a full text article. Conference reports, meeting abstracts, posters, opinion pieces, editorials and letters were excluded. The study had to have taken place in Australia and needed to address at least one of the following aspects of patterns of care for lung cancer:

- diagnosis
- staging
- referrals
- treatment
- factors that impact on patterns of care
- outcomes of different patterns of care.

Articles were excluded if they dealt with treatment in the primary health care setting prior to referral to a specialist for diagnosis or treatment. Studies were also excluded if their primary focus was:

- informing clinical practice guidelines or treatment regimes
- assessing the impact and uptake of existing guidelines
- continuing professional education.

2.6.2 Models of care

Articles were included if they were published between 1 January 2000 and 16 November 2011, were in English and available as a full text article. Conference reports, meeting abstracts, posters, opinion pieces, editorials and letters were excluded. The study had to have taken place in Australia or a comparable overseas country (e.g. New Zealand, Canada, USA, UK or other EU country) and needed to address one of the key aspects of a model of care for lung cancer as identified by the project team and PAG:

- values and principles
- cultural appropriateness
- equitable access
- evidence-based care
- patient outcomes
- quality and safety
- structures and roles
- governance and leadership
- IT systems and data systems
• MDT and interdisciplin ary care
• monitoring and evaluation
• care delivery process
• appropriate care setting
• care coordination
• communication
• proximity to care
• patient-centred care
• referral process
• patterns of care
• timeliness of care.

In addition the article also needed to address at least one of the following:
• identify some specific structural aspect of the delivery of care for lung cancer
• explicitly identify, consider or evaluate key structural characteristics of the model of care
• identify reasons for success or failure leading to the model’s uptake or sustainability over time.

Articles were excluded if they dealt with treatment in the primary health care setting prior to referral to a specialist for diagnosis or treatment. Studies were also excluded if their primary focus was:
• informing clinical practice guidelines or treatment regimes
• assessing the impact and uptake of existing guidelines
• continuing professional education.

Full details of the inclusion and exclusion criteria for both literature searches are included in Appendix IV.

2.7 Search strategy

2.7.1 Electronic databases

Electronic reference databases were searched using Medical Subject Heading (MeSH) terms where available in combination with key words (as appropriate). Search terms for the patterns of care literature review included: patterns of care; referral patterns; practice variation; prescribing patterns; health care utilisation; practice patterns; referral and consultation; and treatment planning.

Search terms and search strings for the models of care literature review were more elaborate (reflecting the complexity of the concept under review and the values and attributes identified as being key elements of a model of care). Terms used included: equitable access;
health services accessibility; cultural appropriateness; quality and safety; patient outcomes; outcome assessment (health care); evidence-based practice; evidence-based nursing; evidence-based medicine; governance adherence; quality of health care; patient care team; hospital information systems; regional medical programs; interdisciplinary communication; physician-patient relations; and timeliness. Further details of the search strategy are provided in Appendix IV, and the complete search strategy used by the project team is available on request.

The initial literature selection was based on the paper title, and if this was deemed potentially relevant, followed in turn by review of the abstract or full paper. Publications were considered for inclusion if they addressed at least one of the research questions. Papers had to be in English and a full paper available. Conference abstracts were followed up but only included if a full report was found.

2.7.2 Grey literature

The search strategies employed used ‘lung cancer’ OR ‘lung’ depending on site and search functionality, in combination with ‘care’, ‘management’, ‘multidisciplinary’ or ‘integrated’ as appropriate.

2.8 Search results

2.8.1 Electronic database searches

The patterns of care searches retrieved 164 references from searching four electronic databases (Table 3). After removal of duplicates and assessment of the titles and abstracts, 42 full papers were obtained, of which 27 met the selection criteria for inclusion in the literature review (Table 3 and Figure 2).

For the models of care electronic database search, a total of 4,557 references were identified from searching the four electronic databases (Table 3). After removal of duplicates and assessment of the titles and abstracts, 116 full papers were obtained, of which 53 met the selection criteria for inclusion in the literature review (Table 3 and Figure 3).
Table 3  References identified through searching electronic databases

<table>
<thead>
<tr>
<th>Database</th>
<th>References identified</th>
<th>Patterns of care</th>
<th>Models of care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medline</td>
<td>48</td>
<td></td>
<td>1,854</td>
</tr>
<tr>
<td>CINAHL</td>
<td>6</td>
<td></td>
<td>1,302</td>
</tr>
<tr>
<td>Embase</td>
<td>110</td>
<td></td>
<td>1,217</td>
</tr>
<tr>
<td>PsycINFO</td>
<td>0</td>
<td></td>
<td>184</td>
</tr>
<tr>
<td>Total references retrieved</td>
<td>164</td>
<td></td>
<td>4,557</td>
</tr>
<tr>
<td>Relevant (based on title)*</td>
<td>109</td>
<td></td>
<td>608</td>
</tr>
<tr>
<td>Relevant (based on abstract)*</td>
<td>41</td>
<td></td>
<td>116</td>
</tr>
<tr>
<td>For data extraction</td>
<td>27</td>
<td></td>
<td>53</td>
</tr>
</tbody>
</table>

* After removal of duplicates

2.8.2 Grey literature searches and handsearching

The electronic database searches were complemented by internet-based grey literature searches and hand-searching and snowballing searching strategies by the project team and PAG. After screening for duplicates and assessment against the selection criteria, 1 additional reference was identified for the patterns of care literature review (Figure 2) and 18 for the models of care literature review (Figure 3). In addition, 12 articles about patient preferences were included as context for the models of care literature review (Figure 3).
Figure 2  Results of searches for patterns of care for lung cancer literature review

Electronic database searches n = 164

Titles
  Include n = 109
  Exclude* n = 55

Abstracts
  Include n = 41
  Exclude n = 68

Full reference
  Include n = 27
  Exclude n = 14

Internet-based grey literature searches n = 2

Titles and abstracts
  Include n = 1
  Exclude* n = 1

Full reference
  Include n = 0
  Exclude n = 1

Identified by project team or PAG n = 1 *

Total included references n = 28

*Includes removal of duplicates
Figure 3  Results of searches for the best practice approaches to lung cancer care - a literature review

*Includes removal of duplicates already identified in this search.  †  Includes removal of duplicates already identified in this and other searches.
3. Lung cancer in Australia

Key points

- Lung cancer is the fourth most common cancer in Australian men and women (excluding basal and squamous cell carcinoma of the skin) and the fifth most commonly diagnosed cancer overall.
- In 2007, lung cancer was the leading cause of cancer-related mortality and morbidity in Australia, for both men and women.
- Only 13% of those diagnosed with lung cancer survive five years beyond their diagnosis.
- Between 1982 and 2007:
  - the incidence rate of lung cancer has fallen in males by 32% but risen in females by 72%
  - lung cancer survival has improved but still remains low.
- The differences in incidence rates between men and women reflect changes in patterns of tobacco smoking over time.
- The incidence of lung cancer is strongly related to age. Over 80% of new lung cancers are diagnosed in people aged 60 years and older.
- In the 8 years between 2000–01 and 2008–09, the number of hospitalisations for lung cancer increased by 29%.

Epidemiological data on lung cancer in Australia, including incidence, mortality and survival data, have been sourced from the 2011 Australian Institute of Health and Welfare (AIHW) report Lung cancer in Australia: an overview (NB: Incidence, mortality and survival rates quoted are age-standardised and refer to 2003–2007 unless otherwise stated).1

3.1 Incidence and mortality

3.1.1 Incidence

In 2007:

- 9,703 new cases of lung cancers were diagnosed in Australia (5,948 cases in men, 3,755 cases in women)
- lung cancer was the fourth most commonly diagnosed cancer in men and women (excluding basal and squamous cell carcinoma of the skin), and the fifth most commonly diagnosed cancer overall
- the most common form of lung cancer was non-small cell lung cancer (NSCLC; 64% of lung cancer cases in men and 61% of lung cancer in women)
• small cell lung cancers (SCLC) represented 11% of lung cancer cases in men and 13% in women
• other specified carcinoma and unspecified malignant neoplasm collectively comprised 25% of lung cancers in men and 26% in women.

3.1.2 Mortality

In 2007:
• lung cancer was the leading cause of cancer deaths in men (4,715 deaths) and women (2911 deaths)
• the mortality rate was 46 per 100,000 for men and 24 per 100,000 for women.

Mortality rates have changed over time: between 1982 and 2007 the mortality rate decreased from 79 to 46 per 100,000 for men, and increased from 15 to 24 per 100,000 for women.

3.1.3 Factors influencing incidence and mortality

Incidence and mortality rates for lung cancer vary depending on location, socioeconomic status, and Indigenous status (see Table 4). The likelihood of dying from lung cancer increases with age – the risk of dying from lung cancer by the age of 85 years was 1 in 15 for men and 1 in 29 for women.

Table 4  Factors affecting lung cancer incidence and mortality in Australia¹

<table>
<thead>
<tr>
<th>Factor</th>
<th>Incidence</th>
<th>Mortality</th>
</tr>
</thead>
</table>
| Geographical variation | **Men**
                           Highest in the NT and lowest in the ACT
                           Tended to increase with increasing remoteness
                           **Women**
                           Highest in Tasmania and lowest in the ACT
                           No increase with increasing remoteness | **Highest in the NT and lowest in the ACT for both men and women**
                           Tends to increase with remoteness for both men and women |
| Socioeconomic status   | Decreases with improving socioeconomic status for both men and women     | Tends to decrease with improving socioeconomic status for both men and women |
| Indigenous status      | Significantly higher for Indigenous than non-Indigenous Australians (1.7 times higher in men; 1.6 times higher in women) | Significantly higher for Indigenous than for non-Indigenous Australians (1.6 times higher in men and 1.9 times higher in women) |

Northern Territory (NT); Australian Capital Territory (ACT)
3.2 Lung cancer survival

During 2000–2007 in Australia, people diagnosed with lung cancer were 13% as likely to survive five years after diagnosis as their counterparts in the general population.

Various factors have been identified as being related to survival from lung cancer, including stage of diagnosis, type of lung cancer, gender, age and Indigenous status (Table 5).

<table>
<thead>
<tr>
<th>Factor</th>
<th>Effect on survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage at diagnosis*</td>
<td>Survival decreases with more advanced stage at diagnosis</td>
</tr>
<tr>
<td></td>
<td>In NSW* between 1999 and 2003, the 5-year relative survival estimate was:</td>
</tr>
<tr>
<td></td>
<td>• localised lung cancers: 30%</td>
</tr>
<tr>
<td></td>
<td>• regional lung cancers: 19%</td>
</tr>
<tr>
<td></td>
<td>• distant cancers: 3%</td>
</tr>
<tr>
<td></td>
<td>• unknown stage: 9%</td>
</tr>
<tr>
<td>Gender</td>
<td>Between 2000 and 2007, 5-year relative survival was significantly higher in women (15%) compared with men (11%)</td>
</tr>
<tr>
<td>Age</td>
<td>Between 2000 and 2007, survival decreased with increasing age at diagnosis:</td>
</tr>
<tr>
<td></td>
<td>• 1-year relative survival for those under 30 years was 83% for men and 88% for women compared with 21% for both men and women aged 80 years and over</td>
</tr>
<tr>
<td></td>
<td>• 5-year relative survival for those under 30 years was 68% for men and 73% for women compared with 5% for men and 6% for women aged 80 years and over</td>
</tr>
<tr>
<td></td>
<td>• 10-year relative survival for those under 30 years was 66% for men and 74% for women compared with 4% for both men and women over 80 years of age</td>
</tr>
<tr>
<td>Indigenous status</td>
<td>Between 2000 and 2007, the 5-year crude survival estimate for Indigenous men and women was lower than for non-Indigenous men and women, however, the difference was not statistically significant</td>
</tr>
</tbody>
</table>

*As no national data are available on stage at diagnosis in Australia, national relative survival estimates for lung cancer by stage at diagnosis cannot be calculated. However, to illustrate the trends, data from New South Wales are provided. Data from the USA also indicate that people with NSCLC had a higher 5-year survival than people with SCLC for all stages at diagnosis.

3.3 International comparisons

In Australia, the incidence of lung cancer in men is lower than in other westernised countries, with the exception of New Zealand. The incidence is also higher compared with that in African countries. The incidence of lung cancer in women is significantly higher in Australia compared with most of Europe but lower than in North America and New Zealand.
The mortality rate for men with lung cancer is significantly lower in Australia compared with many regions around the world, with the exception of South America and most African regions. In women, the mortality rate is significantly lower in Australia compared with many regions around the world, with the exception of African and Asian regions (excluding Eastern Asia).

The mortality-to-incidence ratio (MIR) for Australian men and women is lower than all countries and regions with the exception of Micronesia, indicating that Australians have better survival prospects than their counterparts elsewhere in the world (NB: Owing to the wide variation in measures used to estimate survival in different countries, the AIHW report uses the MIR to make international comparisons).
4. Patterns of care literature

Key points

- 28 articles were identified reporting on patterns of care for lung cancer in Australia.
- Variation was reported in time to diagnosis, access to active treatment, access to re-treatment and access to palliative care.
- Factors influencing access to timely diagnosis (including referral to a lung cancer specialist) included: (i) patient demographics (age, gender, rural location, Indigenous status); and (ii) health status (performance status, presence of co-morbidities).
- Factors influencing access to active treatment included: (i) patient demographics (age, gender, geographical location, Indigenous status); (ii) disease characteristics (type of lung cancer, degree of spread); (iii) health status (presence of co-morbidities, stage at diagnosis, performance status); and (iv) health service features (low-volume vs high-volume service/specialist, review by a multidisciplinary team (MDT), geographical location of health service).

4.1 Patterns of care: Key research questions and included articles

This section of the literature review sought to answer research questions 1 and 2 (p.14):

- Q1. What are the patterns of care for the management and treatment of patients with lung cancer in Australia?
- Q2. What gaps and variations exist in the treatment and management of patients with lung cancer in Australia that may have impacted on outcomes of care?

The review identified 28 papers reporting on patterns of care for lung cancer in Australia. Each of the articles contained information about specific aspects of lung cancer management and treatment in Australia. Information extracted from these studies has been used to construct a picture of how lung cancer care is delivered in Australia, including gaps and variations in practice.

This section provides a summary of findings from the key articles, identifies factors that may directly influence or impact on gaps and variations in lung cancer care in Australia, and highlights factors that have been shown to influence patient outcomes.
4.2 Summary of included studies

4.2.1 Geographical distribution

In total, 21 articles identified gaps and variations in treatment and management of lung cancer in Australia, 10 were in NSW, five in WA, three in Victoria and one in SA. Only two studies were national (see Appendix V for further information).

4.2.2 Study locations

The majority of studies reported on patterns of care for patients with lung cancer at a specific hospital or local health authority area, or compared patterns of care between local health authorities, or over a relatively short time period. The exception is a 2011 study in South Australia, which followed two cohorts of patients with SCLC over two consecutive 10-year time periods from 1987 to 2006 at a single oncology unit and measured the impact that changes in patterns of care had on survival.25

4.2.3 Study quality

Of the 28 studies identified for inclusion, none were randomised controlled trials. The majority of the studies were either cohort or case-control studies or descriptive studies. The studies ranged in size from less than 100 subjects to more than 1,000, depending on whether their focus was care in a single setting or across a region or state.

4.2.4 Study timeframes

Articles were included if published between January 2000 and October 2011. Several articles reported on prospective studies started in the 1990s,26, 27 or on retrospective studies utilising data from the 1990s.28-31 The data in this report reflect the most current information relating to patterns of care in Australia; however, it is important to recognise that practices may have changed since the time of data collection. In particular, several jurisdictions have embarked on a cancer reform agenda in the last decade, with a specific focus on MDTs in the last 5 years.

4.3 Diagnostic patterns

Articles reported on a range of components of lung cancer diagnosis, including:

- time to consult a GP
- time to specialist consultation
- referral to a lung cancer specialist
- pathological/histological diagnosis
- use of staging investigations.
Table 6 provides an overview of variables reported to influence these components of diagnosis for lung cancer. Examples from the literature for each component are then described in further detail.

Key variables that appeared to influence components of diagnosis for lung cancer included:

- patient demographics (geographical location, age, gender, Indigenous status, language spoken)
- health status (including performance status, extent of disease and presence of co-morbidities)
- health service features (presence of an MDT, health service location).

Table 6  Factors influencing components of lung cancer diagnosis in Australia

<table>
<thead>
<tr>
<th>Component of diagnosis</th>
<th>Variables negatively influencing access to this component of diagnosis</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time to consult GP</td>
<td>Rural vs metropolitan residence</td>
<td>Hall 2008^32</td>
</tr>
<tr>
<td>Time to specialist consultation</td>
<td>Rural vs metropolitan residence</td>
<td>Hall 2008^32</td>
</tr>
<tr>
<td>Likelihood of receiving a referral to a lung cancer specialist</td>
<td>Older age</td>
<td>Vinod 2003; Vinod 2008^26,33</td>
</tr>
<tr>
<td></td>
<td>Rural vs metropolitan residency</td>
<td>Vinod 2008; Conron 2007^33,34</td>
</tr>
<tr>
<td></td>
<td>Metastatic vs early disease</td>
<td>Conron 2007^34</td>
</tr>
<tr>
<td></td>
<td>Unknown stage</td>
<td>Vinod 2008^33</td>
</tr>
<tr>
<td></td>
<td>Poorer performance status</td>
<td>Vinod 2003^36</td>
</tr>
<tr>
<td>Likelihood of receiving a pathological or histological diagnosis of lung cancer</td>
<td>Male gender</td>
<td>Richardson 2000^28</td>
</tr>
<tr>
<td></td>
<td>Older age</td>
<td>Vinod 2003; Richardson, 2000^26,28</td>
</tr>
<tr>
<td></td>
<td>Poorer performance status</td>
<td>Vinod 2003^26</td>
</tr>
<tr>
<td></td>
<td>Lack of MDT involvement</td>
<td>Conron 2007^34</td>
</tr>
<tr>
<td></td>
<td>Not speaking English</td>
<td>Vinod 2003^26</td>
</tr>
<tr>
<td></td>
<td>Rural vs metropolitan health service</td>
<td>Vinod 2004^27</td>
</tr>
<tr>
<td>Use of staging investigations</td>
<td>Older age</td>
<td>Richardson 2000^28</td>
</tr>
<tr>
<td></td>
<td>Comorbidities</td>
<td>Richardson 2000^28</td>
</tr>
<tr>
<td></td>
<td>Limited disease vs extensive disease</td>
<td>Ellis 2004^29</td>
</tr>
</tbody>
</table>
4.3.1 Examples from the literature

**Time taken to consult a GP**

- A prospective Western Australian (WA) study of 22 rural patients and 21 age- and sex-matched metropolitan patients diagnosed with lung cancer in 2005 found that rural patients took longer to consult their GP compared with metropolitan patients (80.8 vs 10.2 days, respectively). These differences were reported to result in more advanced stage at diagnosis and reduced treatment options, especially surgery (see section on outcomes, page 40).\(^{32}\)

**Referral to a lung cancer specialist**

- The WA study also found that rural patients experienced longer waits for specialist consultation compared with metropolitan patients (24.7 days vs 19.1 days, respectively).\(^{32}\)

**Barriers to specialist referral**

In the WA study, rural GPs indicated that, in general, referral to specialist care at teaching hospitals was the preferred option because of the comprehensiveness of facilities and the availability of MDTs.

Both rural GPs and outer metropolitan GPs reported distance, time and availability of appointments as barriers to specialist referral.\(^{32}\)

- In NSW, a registry-based study of 1,812 patients diagnosed with primary lung cancer between November 1 2001 and December 31 2002 found that 11% of patients had not seen a lung cancer specialist.\(^{33}\)

- In a 2003 study conducted in South Western Sydney (an area with a significantly higher incidence and mortality from lung cancer than the NSW average) of 527 patients treated between 1993 and 1996, 12% did not see a lung cancer specialist.\(^{26}\) The authors concluded that the proportion of patients who are not referred to a lung cancer specialist appears to have remained constant since 1993.\(^{26,33}\)

**Referral bias and therapeutic nihilism**

In 2007, Conron and colleagues found evidence of referral bias and therapeutic nihilism among doctors referring patients to an MDT clinic in Victoria. Referral bias exists in favour of patients with early NSCLC (i.e. patients with good performance status (PS) who are more likely to be referred than patients with metastatic disease). This was particularly noticeable for rural patients, suggesting that further education about advances in metastatic lung cancer management is required.\(^{34}\)

The bias favouring referral of patients with early stage lung cancer increased with the distance of patient residence from the MDT clinic. 40% of patients referred to the clinic with primary lung cancer who lived within the hospital’s metropolitan catchment area presented with early-stage NSCLC, a proportion that approximates what would be expected. At 60% the proportion of patients residing in rural or regional areas who were referred with early-stage NSCLC is well in excess of what would be expected. The difference suggests that patients with widespread disease outside metropolitan areas are less likely to receive the benefits of a lung cancer MDT clinic.
Pathological or histological diagnostic testing

- A 1996 registry-based study conducted in Victoria that reviewed records for 863 people diagnosed with lung cancer between January and July 1993 found that 13% of patients had no histological diagnosis of lung cancer.\(^{28}\)

- In a more recent prospective study of 257 patients diagnosed with lung cancer in a Victorian hospital between September 2002 and September 2004, 92% had a histological diagnosis of lung cancer. The authors cited involvement in an MDT with a greater likelihood of receiving tissue confirmation of malignancy.\(^{34}\)

- The WA study reported that metropolitan patients underwent more thorough diagnostic testing than rural patients.\(^{32}\) However the authors noted that all patients, except one metropolitan patient, had a tissue type recorded, suggesting more diagnostic testing than seen in previous WA studies. The authors proposed that this finding indicates less medical nihilism and a more proactive approach to care than in the past.\(^{32}\)

- The South Western Sydney study found that, between 1993 and 1996, 9% of patients did not have a pathological diagnosis of lung cancer.\(^{26}\) A follow-up study into differences in lung cancer management in three NSW area health services (two metropolitan and one rural) found that residents of the rural area health service were less likely to have pathological confirmation of their lung cancer than those in metropolitan areas (20% for rural residents compared with 9% and 10% for the two metropolitan areas).\(^{27}\)

Use of staging investigations

- The Victorian study by Richardson of 868 patients reported that a number of patients with SCLC were inadequately staged (89% received a chest X-ray; 69% a chest or abdominal computed tomography (CT) scan; 32% a bone scan; 19% a brain CT; 2% a bone marrow biopsy).\(^{28}\) The authors suggested that this may be explained by the older age and generally greater comorbidities of these patients.\(^{28}\)

- A retrospective cohort study of 103 patients with SCLC conducted at a Sydney hospital between January 1996 and July 2000 reported considerable variability in the number of staging investigations performed.\(^{29}\) Patients with localised disease were more likely to have staging investigations than patients with extensive stage disease (ED) at diagnosis (50% of localised disease stage patients vs 27% of ED patients). The authors report that this variation in staging is likely to have a direct impact on treatment.

4.4 Lung cancer treatment

Articles reported on a number of components of lung cancer treatment, including:

- likelihood of receiving active treatment
- likelihood of receiving specific components of treatment (surgery, radiotherapy, chemotherapy, combination therapy)
- access to re-treatment
- access to palliative care.
Table 7 provides an overview of variables reported to influence these components of treatment for lung cancer. Examples from the literature for each component are then described in further detail.

Key variables that appeared to influence components of treatment for lung cancer included:

- patient demographics (age, gender, geographical location, Indigenous status)
- disease characteristics (type of lung cancer, degree of spread)
- health status (presence of co-morbidities, stage at diagnosis, performance status)
- health service features (low-volume vs high volume service/specialist, review by an MDT, geographical location of health service).

### Table 7  Factors influencing components of lung cancer treatment in Australia

<table>
<thead>
<tr>
<th>Component of treatment</th>
<th>Variables influencing access to this component of treatment</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Active treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Likelihood of receiving no cancer-specific treatment</td>
<td>Female gender</td>
<td>Vinod 2008(^{33})</td>
</tr>
<tr>
<td></td>
<td>Older age</td>
<td>Vinod 2003; Vinod 2008; Vinod 2010a(^{26,33,35})</td>
</tr>
<tr>
<td></td>
<td>Weight loss</td>
<td>Vinod 2008(^{33})</td>
</tr>
<tr>
<td></td>
<td>Poor performance status (e.g. ECOG ≥ 2)</td>
<td>Vinod 2003; Vinod 2008; Vinod 2010a(^{26,33,35})</td>
</tr>
<tr>
<td></td>
<td>Advanced/unknown stage</td>
<td>Vinod 2008(^{33})</td>
</tr>
<tr>
<td></td>
<td>Consultation with a low-patient-volume lung cancer specialist or a non-lung cancer specialist</td>
<td>Vinod 2008(^{33})</td>
</tr>
<tr>
<td></td>
<td>Presence of comorbidities</td>
<td>Vinod 2010a(^{35})</td>
</tr>
<tr>
<td></td>
<td>Clinician decision/judgement</td>
<td>Vinod 2010a(^{35})</td>
</tr>
<tr>
<td></td>
<td>NSCLC</td>
<td>Vinod 2010a(^{35})</td>
</tr>
<tr>
<td></td>
<td>Non-English language</td>
<td>Vinod 2010a(^{35})</td>
</tr>
<tr>
<td></td>
<td>Rural (vs metropolitan) health service</td>
<td>Vinod 2004(^{27})</td>
</tr>
<tr>
<td>Likelihood of receiving active treatment</td>
<td>Involvement of an MDT</td>
<td>Vinod 2010a; Conron 2007 (^{34,35})</td>
</tr>
<tr>
<td>Component of treatment</td>
<td>Variables influencing access to this component of treatment</td>
<td>Reference</td>
</tr>
<tr>
<td>------------------------</td>
<td>-----------------------------------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>Likelihood of review by an MDT</td>
<td>Metropolitan (vs regional) location (of health service and patient)</td>
<td>Wilcoxon 2011; Stanford 2011; Conron 2007</td>
</tr>
<tr>
<td></td>
<td>Physician nihilistic attitude (more unwell patients judged less likely to benefit so not presented at MDT)</td>
<td>Richardson 2000; Bydder 2009; Tanvetyanon 2009</td>
</tr>
<tr>
<td>Likelihood of receiving surgery</td>
<td>Metropolitan vs rural residence</td>
<td>Hall 2008</td>
</tr>
<tr>
<td></td>
<td>Higher socioeconomic status / locational advantage</td>
<td>Hall 2004a</td>
</tr>
<tr>
<td></td>
<td>Non-Indigenous status</td>
<td>Hall 2004b</td>
</tr>
<tr>
<td>Likelihood of receiving radiotherapy, chemotherapy or combination therapy</td>
<td>Involvement of an MDT</td>
<td>Richardson 2000</td>
</tr>
<tr>
<td></td>
<td>Metropolitan (vs rural) area health authority</td>
<td>Vinod 2004</td>
</tr>
<tr>
<td></td>
<td>Clinician knowledge</td>
<td>Jennens 2004</td>
</tr>
<tr>
<td>Radiotherapy utilisation rates</td>
<td>Attitude of referring physicians</td>
<td>Vinod 2010</td>
</tr>
<tr>
<td></td>
<td>Comorbidities</td>
<td>Richardson 2000; Ellis 2004</td>
</tr>
</tbody>
</table>

**Re-treatment**

<table>
<thead>
<tr>
<th>Component of treatment</th>
<th>Variables influencing access to this component of treatment</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Radiotherapy retreatment rates</td>
<td>Stage of disease</td>
<td>Estall 2007</td>
</tr>
</tbody>
</table>

### 4.4.1 Examples from the literature

**Cancer-specific treatment**

Most of the data on rates of cancer-specific treatment in Australia come from studies in NSW; three Victorian studies were identified. All studies reported that around one-third of the patients studied received no cancer-specific treatment, and that this proportion has remained constant for several years.26,33,45,28

The NSW study of patterns of care in three health areas in 1996 reported that 45% of rural residents received no cancer-specific treatment (especially radiotherapy and chemotherapy) compared with 22–25% in metropolitan areas.27

The authors suggested that patients may not have received cancer-specific treatment because:

- they were not referred to a lung cancer specialist33
- guidelines did not recommend treatment for that patient
- the clinician (or MDT) did not recommend treatment for the patient
- the patient declined treatment35
International comparison

Worldwide, a significant proportion of lung cancer patients receive no anticancer treatment. The Australian figure of 33% compares with 19% in the USA, 37% in Scotland and 50% in Ireland and New Zealand.\textsuperscript{33,35}

Exploring reasons for non-treatment

Vinod and colleagues prospectively reviewed treatment data for 335 patients with lung cancer who presented to a South-West Sydney MDT between December 2005 and December 2007.\textsuperscript{35} They compared:

- the number of patients who should have received treatment (according to guidelines) (n=332, 96%)
- the number of patients for whom the MDT recommended treatment (n=303, 90%)
- the number of patients who actually received treatment (n=269, 80%).\textsuperscript{35}

The difference between the number of patients for whom the guidelines recommended treatment and the number for whom treatment was recommended by the MDT was put down to the presence of co-morbidities and clinician decisions; the difference in the number of patients for whom the MDT recommended treatment and the number who actually received treatment was put down to patient preference and declining performance status. Older age, poorer Eastern Cooperative Oncology Group (ECOG) status, NSCLC, and non-English language were all associated with no treatment.

The authors noted that guidelines cannot account for individual patient factors that determine suitability for treatment. They also noted that MDT discussion may reduce the proportion of patients receiving no treatment and could potentially improve survival and quality of life for lung cancer patients.

Surgery

About surgery for lung cancer

Early stage lung cancers can be treated with surgery alone. For non-small cell lung cancers which have spread to the hilar lymph nodes, the addition of chemotherapy to surgery improves outcomes.\textsuperscript{46} If the cancer has spread to the mediastinal lymph nodes, a combination of chemotherapy and surgery or radiotherapy is more effective than surgery by itself. Surgery is not regarded as a standard of care in patients diagnosed with small cell lung cancer.\textsuperscript{47}

- A registry-based study of investigations and choice of surgery for 668 people diagnosed with lung cancer or mesothelioma in WA in 1996 showed that surgical choices reflected current international guidelines.\textsuperscript{30}
- In contrast, a linkage study of 12,708 people diagnosed with lung cancer in WA between 1982 and 2001 reported that patients were less likely to receive surgery if they:
  - lived in a rural area (Adjusted Odds Ratio (OR) of having surgery for patients living in a very remote area versus a very accessible area: 0.36; 95% CI: 0.14–0.92)\textsuperscript{32,40}
Best practice approaches to lung cancer care - literature review

- presented for a first admission for lung cancer to a rural hospital (OR for people presenting to a rural hospital compared with a metropolitan hospital: 0.26, CI: 0.19–0.36)

- lived in socially, economically or locationally disadvantaged area (vs advantaged area [OR 0.79; 95% CI 0.61–1.04]40

- patients with adenocarcinoma were more likely to be treated surgically as opposed to non-surgically (42% vs 19%, respectively); in contrast, patients with SCLC were less likely to be treated surgically as opposed to non-surgically (1% vs 17%).30

- A second study in the same year reported that fewer Indigenous patients had surgery compared with non-Indigenous patients (9.5% vs 12.9%; NS).41

### Indigenous status and lung cancer surgery

The authors of the 2004 WA study suggest sociocultural and economic factors may influence treatment patterns and outcomes, including:

- financial resources
- cultural and religious barriers
- a preference for traditional healing practices
- concerns that treatment is ineffective and not worthwhile.

The authors suggest that low rates of surgical intervention for lung cancer may indicate that the cancers are more advanced and less amenable to treatment in the Indigenous population or, that patients may have comorbidities or other reasons that led to a decision not to have surgical treatment.

### Radiotherapy

#### About radiotherapy for lung cancer

Radiotherapy plays a major role in the palliation of symptoms in lung cancer, and can improve survival in selected populations of patients with SCLC and NSCLC.28

- The NSW study by Vinod et al.43 found that, between November 1 2001 and December 31 2002, radiotherapy was underutilised by 29% compared with Australian recommendations (Table 8).48,49 The authors suggest that attitudes of referring physicians have an impact on referrals for radiotherapy and thus radiotherapy utilisation rates. The study also demonstrated sub-optimal use of combined-modality treatment for potentially curable lung cancers.43

- Variation in use of radiotherapy for patients with SCLC was also demonstrated in the retrospective cohort study by Ellis and colleagues29 and shortfalls in radiotherapy treatment were reported in Victoria.28

- Reporting on a survey of current practice in radiotherapy departments in Australia and New Zealand, Holloway highlighted variability in treatment of lung cancer between centres. This included variation in planning, delivery, set-up and prescription doses for NSCLC, SCLC and for both radical and palliative treatment doses.50
Table 8  Radiotherapy rates for patients with lung cancer in NSW\(^{43}\)

<table>
<thead>
<tr>
<th>Type of radiotherapy</th>
<th>Actual</th>
<th>Optimal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intent of first radiotherapy episode*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Curative radiotherapy to primary site</td>
<td>20%</td>
<td>50%</td>
</tr>
<tr>
<td>Palliative (to chest)</td>
<td>36%</td>
<td>38%</td>
</tr>
<tr>
<td>Palliative (to metastases)</td>
<td>36%</td>
<td>11%</td>
</tr>
<tr>
<td>Disease stage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NSCLC</td>
<td>43%</td>
<td>68%</td>
</tr>
<tr>
<td>Stage III NSCLC</td>
<td>55%</td>
<td>77–81%</td>
</tr>
<tr>
<td>SCLC</td>
<td>36%</td>
<td>68%</td>
</tr>
<tr>
<td>Limited stage SCLC</td>
<td>46%</td>
<td>94%</td>
</tr>
</tbody>
</table>

* Categories are not mutually exclusive

RT: radiotherapy; NSCLC: non-small cell lung cancer; SCLC: small cell lung cancer

**Radiotherapy re-treatment**

**About radiotherapy re-treatment for lung cancer**

Radiotherapy is a treatment modality with indications in all stages of lung cancer. Most patients present with advanced disease, and there is a high rate of loco-regional and distant recurrence. Studies indicate that re-treatment of local chest disease is effective, with improvement in symptoms in 50% to 80%\(^{44}\); the palliative benefit of treating symptomatic distant metastases is well established.

- A retrospective, longitudinal study in NSW\(^{44}\) was undertaken to identify the indications for and the prevalence of patients with lung cancer undergoing radiotherapy re-treatment. For NSCLC, the likelihood of re-treatment was highest for patients with stage III disease, consistent with the pattern of presentation, initial treatment, and relapse among this group of patients. The rate of re-treatment of recurrent disease was less than the expected incidence of recurrence. Among patients with SCLC, those with limited stage SCLC were more likely to receive re-treatment.

**Chemotherapy**

**About chemotherapy for lung cancer**

Chemotherapy can prolong survival and improve quality of life. Almost all patients with SCLC receive chemotherapy either alone or in combination with radiotherapy. The use of chemotherapy in the management of metastatic NSCLC has increased over the past decade. Chemotherapy has an expanding role in the management of earlier stage disease and is now frequently included in combined modality treatment programs.\(^{51}\)

- An audit of the management of patients with metastatic NSCLC at Royal Melbourne Hospital identified inconsistencies in referral to the Medical Oncology Unit or the Palliative Care Unit and in the choice of chemotherapy.\(^{52}\)
An Australia-wide survey into the gaps and variations in clinician knowledge and bias regarding the role of chemotherapy for stage IV NSCLC, highlighted significant differences in the perceived role of chemotherapy for metastatic disease between various specialty groups involved in the treatment of NSCLC. Many clinicians had a poor understanding of contemporary data regarding the use of chemotherapy in metastatic NSCLC:

- 40% of all clinicians (including 24% of medical oncologists) did not have a good understanding of the survival and response rates to chemotherapy
- there was a significant degree of pessimism regarding the potential benefits of chemotherapy for NSCLC, particularly among pulmonary physicians, radiation oncologists, and palliative care physicians
- almost one-third of respondents did not believe chemotherapy offered symptomatic benefit.

In their retrospective cohort study assessing outcomes of care for SCLC at a teaching hospital in Sydney, the authors raised questions about whether dose calculation for chemotherapy (carboplatin) was undertaken appropriately based on measurement of creatinine clearance. The study also reported a high incidence of febrile neutropenia leading the authors to conclude that consideration should be given to the routine use of antibiotic prophylaxis.

Combined therapy (radiotherapy and chemotherapy)

- A 2011 study in South Australia followed two cohorts of patients with SCLC over two consecutive 10-year time periods from 1987 to 2006. Over the study time frame there was an improvement in survival for limited stage SCLC; the authors noted that this was in part due to combined chemotherapy and radiotherapy treatment.

4.5 Multidisciplinary care/multidisciplinary teams

Several articles identified multidisciplinary care and/or MDTs as a means of addressing the gaps and variations that exist in the care for patients with lung cancer in Australia.

- A 2006 national audit of multidisciplinary care in 155 Australian hospitals across five cancer types (including lung cancer) highlighted significant gaps in implementation of multidisciplinary care, including:
  - two-thirds of teams surveyed did not have an MDT
  - one-third did not inform their patients that their case would be discussed by the team
  - half did not seek patient consent for all cases discussed by the team
  - in one-quarter, the team’s recommended treatment plan was not noted in the patient record
  - routine attendance by the tumour specific minimum core team occurred in less than 1% of teams (this may be because the audit criteria included a GP as an active participant).

It should be noted that this audit took place prior to the introduction in November 2006 of two Medicare Benefits Schedule (MBS) item numbers to support attendance by specialists at
team planning meetings. It is likely that these MBS items may have had a significant impact on implementation of multidisciplinary care.

- A Victorian study conducted in 1996–1997 investigated how lung cancer was being managed in a population-based series of patients diagnosed between January and July 1993. The study reported that most patients with lung cancer were not treated in a multidisciplinary fashion; the authors concluded that the lack of a multidisciplinary approach could result in reduced access to effective treatment options and clinical trials.

- Three articles noted that people living in rural or remote areas of Australia had less access to multidisciplinary care.

### 4.6 Concordance of care with clinical practice guidelines

Several articles compared current practice in Australia with national and international clinical practice guidelines for the management of patients with lung cancer.

- A 2004 population-based study charted the characteristics and treatment outcomes of all patients with lung cancer diagnosed in WA in 1996 in which surgery was the primary treatment. The selection of patients with lung cancer for surgery and their management was compared with international guidelines (British Thoracic Society, SIGN, American College of Chest Physicians, Australian Cancer Network). The authors commented that despite survival of patients with resectable lung cancer being unsatisfactory compared with survival rates in other surgical studies (at 5 years the absolute survival for stage I, II, IIIA, IIIB were 51%, 45%, 12%, 5%, respectively), investigations and choice of surgery in WA in 1996 reflected the current international guidelines. The authors could not find a reason for the unsatisfactory survival rates but suggested that surgical expertise and hospital volume of procedures undertaken at a hospital were an unexplored yet possible explanation.

- Vinod and colleagues compared referral and treatment patterns in NSW with national and international guidelines; and reported that treatment patterns for lung cancer in NSW were in broad concordance with current national guidelines (see Referral to a lung cancer specialist, and Cancer-specific treatment for more information).

- In a 2010 study of patients referred to an MDT in South-West Sydney, Vinod et al. reported that not all patients who should have received treatment for lung cancer according to guidelines actually received treatment. The authors concluded that the ‘non-adherence’ to the guidelines was due to the MDT taking into account individual patient factors (such as comorbidities and patient preferences) that guidelines could not.

- A 2007 survey of current practice in radiotherapy departments in Australia and New Zealand highlighted the need for guidelines for technical aspect of radiotherapy for the treatment of patients with lung cancer.

- A 2011 report found that MDC/MDTs were not being implemented in line with best practice or applied consistently across Australia. Gaps in care delivery existed despite national recommendations about MDC. (See Multidisciplinary care for more information.)
• Reporting on a survey of 868 patients diagnosed with primary lung cancer in Victoria between 1 January 1993 and 31 July 1993, Richardson reported that patterns of management for lung cancer were not uniform, and were inconsistent with published guidelines.28

4.7 Impact of variations in care on outcomes

Several of the studies commented on key variables that appeared to influence components of treatment for lung cancer. A few of these studies also attempted to measure the impact of variations in care on outcomes such as survival.

• A study in 2006 of patients at a WA tertiary hospital who had been diagnosed with NSCLC, inoperable stage III or stage IV NSCLC (n = 98) found that case discussion at an MDT meeting increased survival rates on average by 10 weeks:38
  o median survival was 237 days for patients presented at MDT vs 208 days for those who were not presented (p<0.05)
  o mean survival was 280 days for patients presented at MDT vs 205 days for those who were not presented (p<0.05)
  o 1 year survival was 33% for patients presented at MDT vs 18% for those who were not present (p<0.05).

• A 2011 study in South Australia followed two cohorts of patients with SCLC over two consecutive 10-year time periods from 1987 to 2006.25 Over the study timeframe, there was an improvement in survival for limited stage SCLC. This was thought to be due to:
  o combined chemotherapy and radiotherapy together with standardised radiation delivery
  o improvements in diagnostic imaging leading to more patients being diagnosed with extensive stage not limited stage disease
  o better tolerance of chemotherapy and radiotherapy due to better supportive care.

Variables for poorer outcome included:
• symptomatic treatment alone
• male gender
• poor performance status (ECOG > 2)
• early stage SCLC
• whether the diagnosis was made in the earlier time period (1987–1996).

A prospective WA study of 22 rural patients and 21 age- and sex-matched metropolitan patients diagnosed with lung cancer in 2005 found that rural patients died, on average, 1 month earlier than metropolitan patients (mean days between first GP visit and death: rural = 99.3; metropolitan = 126.1).32
4.7.1 Impact of timely diagnosis and treatment

- In the WA study comparing specialist referral and treatment patterns for rural and metropolitan patients, Hall et al. reported that, compared with metropolitan patients, rural patients: 32
  - had more symptoms on presentation (especially cough, pain or anorexia)
  - were at a more advanced stage at diagnosis compared with metropolitan patients.

Of the seven rural and seven metropolitan patients who died during the study, the rural patients died, on average, 1 month sooner than the metropolitan patients (mean days between first GP visit and death: rural = 99.3; metropolitan = 126.1). 32

- A retrospective cohort study by Hui et al. 31 aimed to explore the associations between socioeconomic factors and lung cancer management and outcomes. Two Sydney area health services (South West Sydney Area Health Service, SWAHS; Northern Sydney Area Health Service, NSAHS) with different socioeconomic profiles were compared for 1996 – in one the population was more affluent, better educated, more likely to speak English and more likely to be employed compared to the other. Overall, patients with lung cancer had similar patterns of care and survival despite differences in socio-economic profiles between the two services. Tumour pathology, stage distribution, performance status, utilisation rates of different treatments and survival rate were all similar.

4.7.2 Impact of multidisciplinary teams

A number of articles discussed the impact of multidisciplinary care on lung cancer outcomes in Australia.

- The 2010 retrospective cohort study conducted in NSW by Vinod concluded that MDT meetings can improve treatment utilisation in lung cancer. 35

- Bydder et al. (2009) explored the impact of MDT discussions on survival for patients with inoperable NSCLC and found that, on average, MDT discussion was associated with 10 weeks’ longer survival. 38

- Conron et al. (2007) found that patients referred to a multidisciplinary clinic at St Vincent’s Hospital in Victoria received timely diagnosis, staging and treatment and that adherence to evidence-based guideline recommendations (the British Thoracic Society Guidelines33) was good. 34 The authors concluded that, compared with patients managed through traditional services, patients managed by a lung cancer MDT are:
  - processed rapidly (i.e. they receive timely diagnosis, staging and treatment)
  - more likely to receive tissue confirmation of malignancy
  - more likely to receive active treatment (87% vs 72%)
  - more likely to complete a radical courses of combined chemotherapy and radiotherapy
  - have a high rate of complete surgical resection
  - have low 30-day postoperative mortality. 34
4.7.3 Impact of appropriate treatment

- The 2011 study by Bishnoi et al. into patterns of care for patients in South Australia analysed data from a single oncology unit to identify temporal trends in patterns of care and their influence on outcomes for people with SCLC. The study followed two cohorts of patients with SCLC over two consecutive 10-year time periods (1987–1996 and 1997–2006). The study reported that outcomes for limited stage SCLC (but not extensive stage SCLC) have improved.  

- The improvement in survival for limited stage SCLC was thought to be due to combined chemotherapy and radiotherapy, better radiation delivery and improvements in diagnostic imaging, leading to more patients being diagnosed with extensive stage not limited stage disease. The outcome for early stage SCLC remains poor. Variables associated with poorer outcomes were: symptomatic treatment alone; male gender; poor performance status (ECOG > 2); extensive stage; and whether the diagnosis was made in the earlier time period (1987–1996).

4.8 The patient experience

Some of the included studies assessed patient views on their experience.

- Stanford (2008) undertook 10 semi-structured interviews to explore the patient experience of lung cancer in the rural setting, and to determine needs, both met and unmet, throughout the journey. Overall, patients were pleased with the level of service received on a local and metropolitan level, and that the treating teams provided a competent and caring service. All of the participants reported a positive experience with either local or metropolitan hospitals or facilities, and in some cases both. Access to local services was a very positive factor for those patients who received treatment locally. However, concern was expressed for patients not having access to services locally, especially where those services were available and practical and financial issues regarding travel and accommodation when travelling for treatment.

- In the WA study by Hall, rural and metropolitan patients were equally satisfied with their quality of care, but rural patients desired more information and better communication between hospital and GPs.

4.9 Addressing variations in care

A number of articles made suggestions about how variations in lung cancer care could be addressed. These included:

- more widespread use of the MDT

- education for medical oncologists and referring specialists regarding the indications and benefits of chemotherapy for stage IV NSCLC

- education for GPs and clinicians about options available for the management of lung cancers and on indications and benefits of radiotherapy, especially for SCLC

- overcome ageist and nihilistic attitudes to lung cancer

- establishment of regional lung cancer services with links to fully resourced MDTs.
4.10 Summary

The patterns of care literature review aimed to establish how patients with lung cancer in Australia currently receive their treatment and care with a view to identifying any known delays in the care pathway.

4.10.1 Quality of evidence

Twenty eight articles were identified reporting on patterns of care for lung cancer in Australia and 21 of these studies identified gaps or variations in care.

The majority of the studies were either cohort or case-control studies or descriptive studies. None was a randomised controlled trial. The studies ranged in size from less than 100 subjects to more than 1,000 depending upon whether their focus was on care in an individual setting or across a region or state. Two studies were conducted at the national level.

Only studies published between January 2000 and October 2011 were included, however, many articles reported on data gathered during the 1990s. It is important to note that health care provision may have changed since this time, in particular, the instigation of MDTs/multidisciplinary care.

Gaps and variations in treatment and management were reported for:

- access to timely diagnosis
- access to active treatment
- access to re-treatment
- access to palliative care.

Variation in concordance of care with some clinical practice guidelines was also noted.

4.10.2 Diagnosis

Components of lung cancer diagnosis identified in the patterns of care literature included:

- time to consult a GP
- time to specialist consultation
- referral to a lung cancer specialist
- pathological/histological diagnosis
- use of staging investigations.

Key variables that influenced components of diagnosis included:

- patient demographics (age, gender, rural location, Indigenous status, language spoken)
- health status (performance status, presence of co-morbidities)
- health service features (presence of an MDT, health service location).
4.10.3 Treatment

Components of lung cancer treatment reported in the patterns of care literature included:

- likelihood of receiving active treatment
- likelihood of receiving specific components of treatment (surgery, radiotherapy, chemotherapy, combination therapy)
- access to re-treatment
- access to palliative care.

Key variables that influenced components of treatment included:

- patient demographics (age, gender, geographical location, Indigenous status)
- disease characteristics (type of lung cancer, degree of spread)
- health status (presence of co-morbidities, stage at diagnosis, performance status)
- health service features (low-volume vs high volume service/specialist, review by an MDT, and geographical location of health service).

4.10.4 Concordance of care with clinical practice guidelines

Several articles compared current practice in Australia with national and international clinical practice guidelines for the management of patients with lung cancer. Of those studies assessing more recent (after 2000) data, one study found broad concordance with treatment guidelines but others noted either lack of guidelines for technical aspects of treatment; that recommendations were not being adhered to, or that patterns of care were inconsistent with guidelines.

4.10.5 Impact of variations/gaps on outcomes

A few studies measured the impact of variations in care on outcomes such as survival.

Variables that improved survival included:

- timely diagnosis and treatment
- MDT discussion/multidisciplinary care
- appropriate treatment.

4.10.6 Addressing variations in care

Suggestions about how variations in lung cancer care could be addressed included:

- more widespread use of MDTs/multidisciplinary care
- education for medical oncologists and referring specialists regarding the indications and benefits of chemotherapy for stage IV non-small cell lung cancer
- education for GPs and clinicians about options available for the management of lung cancers and on indications and benefits of radiotherapy, especially for small cell lung cancer
- overcome ageist and nihilistic attitudes to lung cancer
- establishment of regional lung cancer services with links to fully resourced multidisciplinary care.
Variations in lung cancer care are apparent in Australia, including: time to diagnosis, access to active treatment, access to re-treatment and access to palliative care. These variations and gaps appear to be influenced by patient demographics, disease or patient health characteristics and health service features.
5. Models of care for lung cancer literature

Key points

- This review identified 77 papers reporting on models of care for lung cancer in Australia and internationally. A further 12 articles reporting on patient needs and preferences in relation to lung cancer care were identified.

- The majority of the studies were descriptive or before and after studies.

- Studies comparing care and outcomes before and after the introduction/cessation of MDT meetings or clinics demonstrated that MDT teams are associated with reduced time to diagnosis and treatment,\(^56\) treatment\(^56-61\) and greater use of and more accurate staging.\(^59,62\)

- Despite a lack of consistent high-level evidence, many of the studies advocate for a coordinated approach to care delivered in a multidisciplinary fashion, whether via joint conferences, virtual networks, or actual multidisciplinary clinics.\(^63\)

- Involvement of a specialist medical practitioner in the diagnosis and treatment of people with lung cancer has been associated with improved outcomes.\(^57,64,65\)

- The roles of care coordinators or navigators vary, as does the reported benefits to patient outcomes.\(^60,66-71\)

- Patients and carers feel unsupported outside of the hospital setting.\(^69,70,72\)

- Patients reported a mismatch between what they want and what their doctors perceive they need with regard to information\(^73-77\) and involvement in decision making.\(^78\)

- Early integration of quality palliative care alongside routine clinical care from the time of diagnosis is feasible and essential.\(^79-83\)

- Palliative care is associated with improved survival, improved quality of life, reductions in unnecessary treatment and less aggressive end-of-life care.\(^81,82\)

- Non-invasive interventions delivered by health professionals can improve symptoms, psychological functioning and quality of life.\(^84,85\)

- Numerous publications discussed guideline adherence and pointed out that if published national or international guidelines were adhered to there was less variation/gaps/delays in diagnosis, staging and treatment.\(^56,59-61,69-71,86-88\)

- A number of efforts at quality defining, quality quantifying and quality improving for patients with lung cancer have taken place in the USA, UK, Denmark and the Netherlands.\(^57\)

- Several quality-of-care indicators for NSCLC are available.\(^39\)

- Evidence is divided as to ideal approaches to follow-up and as to whether there is survival benefit to follow-up by specialist health professionals.\(^86-90\)
5.1 Best practice approaches to lung cancer: key research questions and included articles

This section of the literature review sought to answer research questions 3, 4 and 5 (p.14):

- Q3. What has been the focus of initiatives in Australia and comparable overseas countries that have aimed to improve access to and delivery of comprehensive and appropriate care for patients referred for investigation of symptoms of lung cancer?
- Q4. What are the characteristics of service delivery for patients with lung cancer in Australia and comparable overseas countries that have improved patient service and system level outcomes?
- Q5. What evidence-based tools and resources have been used in Australia and comparable overseas countries to support service providers to implement and consistently deliver best-practice lung cancer?

The following sections of this chapter relate to the research questions as indicated below:

<table>
<thead>
<tr>
<th>Research question</th>
<th>Corresponding chapter reference and page number</th>
</tr>
</thead>
</table>
| Research question 3 | 5.4 Factors impacting on lung cancer outcomes (p.58)  
5.5 Focus of initiatives to improve access and delivery of comprehensive and appropriate care (p.59)  
5.9 Appropriate follow-up (p.74)  
5.13 Clinical practice guidelines and other recommendations (p.94)  
5.14 Quality indicators (p.96) |
| Research question 4 | 5.6 Characteristics of service delivery for patients with lung cancer and impact on patient, service and system level outcomes (p.61)  
5.7 Specialised and high-volume services (p.67)  
5.8 Coordination of care/patient navigation (p.70)  
5.10 Palliative care (p.79)  
5.12 Quality of life (p.88) |
| Research question 5 | 5.5.13 Evidence based tools and resources for lung cancer care (p.102) |

In contrast to the patterns of care section, because of the number of articles and variation in types of studies identified, relevant articles for the models of care section are summarised in table form, with key points provided for each section.

The review identified 77 papers reporting on models of care for lung cancer in Australia. In addition, the review identified 12 articles reporting on patient needs and preferences in relation to lung cancer care that may impact on the optimal model of care. These have been included in this summary as they provide useful context against which information about models of care should be considered.

This section provides a summary of findings from the key articles, identifies factors that may directly influence or impact on gaps and variations in lung cancer care in Australia, and highlights factors that have been shown to influence patient outcomes.
5.2 Summary of included studies

5.2.1 Geographical distribution

The majority of reports were based on studies in the USA, UK or other EU countries (Table 9).

Table 9  Geographical distribution of reports and publications

<table>
<thead>
<tr>
<th>Country/region</th>
<th>Number of studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>26</td>
</tr>
<tr>
<td>UK</td>
<td>22</td>
</tr>
<tr>
<td>Europe</td>
<td>8</td>
</tr>
<tr>
<td>International*</td>
<td>7</td>
</tr>
<tr>
<td>Canada</td>
<td>6</td>
</tr>
<tr>
<td>Japan</td>
<td>4</td>
</tr>
<tr>
<td>Australia</td>
<td>3</td>
</tr>
<tr>
<td>Cuba</td>
<td>1</td>
</tr>
</tbody>
</table>

* Or country/countries not explicitly stated.

5.2.2 Study quality

The majority of the studies were descriptive or uncontrolled before and after studies. Few of the studies were randomised controlled trials, cohort studies or case-controlled studies. Of the literature reviews identified, the majority were narrative in style and provided no information about the search strategy or selection criteria used, thereby limiting the applicability of their recommendations or findings.

5.2.3 Study timeframes

Articles were included if published between January 2000 and October 2011. However, many of the studies identified were retrospective studies that utilised data from the 1990s. Health care systems and the treatment of lung cancer are likely to have changed in Australia and internationally since the 1990s and this should be taken into account when interpreting data from these studies.

5.3 Patient preferences relating to a model of care for lung cancer

Twelve articles were identified which explored patient considerations that may be relevant when considering a model(s) of care for lung cancer in Australia. These articles typically reported results from qualitative studies exploring:

- areas of unmet need\(^{69,70,72,91}\)
- preferences for provision of information about lung cancer\(^{73-77}\)
• communication style
• involvement of patients in decision making.

These articles typically reported results from surveys exploring areas of unmet need, preferences for provision of information and communication style and involvement in decision making. A summary of the identified articles is provided in Table 10 with key points summarised below.

5.3.1 Areas of unmet need

Qualitative research conducted in the UK suggests that:

- patient needs are not met outside hospital/acute setting
- informal carers/family members are typically unsupported
- diagnosis is a particularly difficult time for patients
- communication of diagnosis, treatment and prognosis is not optimal.

As a result of this work, Krishnasamy et al. have identified six key areas for service development:

1. strategies to encourage patients to present earlier to their GP
2. evaluation of rapid diagnostic clinics
3. development and evaluation of a lung cancer care coordinator role
4. evaluation of innovations in delivery of nursing care in the community
5. development of local guidelines to facilitate equitable access to palliative care and social services
6. evaluation of supportive strategies targeted at lay carers.

Another UK-based study suggests that there is no association between hospital (organisational) standards and patient satisfaction.

5.3.2 Patient preferences for information

A literature review reported in 2011 suggests that there is often a mismatch between the information that patients and their doctors consider to be important.

A range of survey- and interview-based studies conducted in the USA, UK, Belgium, Switzerland and Japan suggest that:

- patients would like information on diagnosis, treatment, and life expectancy but often do not feel that they receive this information
- patients want information about treatment, prognosis and cure rate explained in a way they understand
- doctors should inquire about patient preferences for information
- recall of information is often poor in newly diagnosed patients
• nurses are a trusted source of information.\textsuperscript{23}

5.3.3 Communication style

Survey-based studies conducted in the USA and Europe suggest that:

• many patients are dissatisfied with their doctors’ communication\textsuperscript{75}
• more educated patients may focus more on logistics of treatment, while less educated patients may focus more on psychosocial aspects of care\textsuperscript{74}
• patients want family members to be present when information about their cancer is discussed.\textsuperscript{76}

5.3.4 Patient involvement in decision making

Studies conducted in the US, Japan and Europe suggest that:

• there is a mismatch between patient preferences for involvement in decision making and what actually happens\textsuperscript{78}
• patient concerns about side effects are not always factored into decisions about treatment\textsuperscript{92}
• patients vary in their willingness to accept risks for small potential gains\textsuperscript{93}
• physicians can increase patient involvement by using partnering and supportive communication\textsuperscript{94}
• doctors should inquire about patient preferences for involvement in decision making\textsuperscript{76}
• physicians are less prone to giving information relating to death or short life expectancy than information that is more oriented towards ‘dealing with the disease’ or ‘treatment options’.\textsuperscript{77}
Table 10  Patient needs and preferences relevant to a model of care for lung cancer

<table>
<thead>
<tr>
<th>Study description</th>
<th>Design</th>
<th>Country/study period</th>
<th>Description/impact</th>
<th>Reference</th>
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</table>
| Exploration of perceptions of care received and services offered following a     | Cross-sectional survey                      | UK, 1995             | Key areas of unmet need most apparent during periods away from acute care  
40% of patients reported having received as much help as they needed from community services  
Greatest onus of care for patients fell to their lay carers  
Patients who received all diagnostic tests in one hospital were significantly \( p = 0.0001 \) more likely to wait less time between first seeing their GP and diagnosis than patients who had to attend more than one hospital during their diagnostic work-up period  
50% of patients reported experiencing some degree of breathlessness even at rest; only 15% reported having received any advice on living with breathlessness  
Less than one-quarter of hospital consultants identified anxiety as a key problem for patients with lung cancer compared with two-thirds of patients  
Hospital staff largely overlooked the needs of informal carers, who derived support from the community | Krishnasamy 2001 |
<table>
<thead>
<tr>
<th>Study description</th>
<th>Design</th>
<th>Country / study period</th>
<th>Description / impact</th>
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| Exploration of patients’ and family members’ experiences of care provision after a lung cancer diagnosis | Longitudinal interviews In-depth interviews at three time points over a 6-month period with patients diagnosed with lung cancer (n=15) and their carers (n=1) 1 hospital | UK, 1999–2000         | Four key domains of need were identified:  
(1) **diagnosis**: period leading up to and immediately after diagnosis was seen as particularly difficult  
(2) **communication**: of diagnosis, treatment options and prognosis, with inconsistencies highlighted  
(3) **provision of co-ordinated, family-oriented care**: to help families/carers deal with demands of diagnosis and care  
(4) **support away from acute services**: carers and patients felt particularly isolated or unsupported around the 6-month time point, when most patients were living with increasing disability and an increasing consciousness of dying  
Needs were prioritised differently by patients and carers depending on time since diagnosis  
**At diagnosis** needs centred around information, the process of treatment and options  
**Later** patients experienced feelings of greater isolation and physical dependency and were particularly aware of deficiencies in the coordination of supportive care  
Many patients appeared to rely on the relationship with their consultant and, found it difficult to make the transition into palliative care/primary care | Krishnasamy 2007 |
<table>
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<tr>
<th>Study description</th>
<th>Design</th>
<th>Country/study period</th>
<th>Description/impact</th>
<th>Reference</th>
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<tr>
<td>Assessment of satisfaction of people with breast, colorectal and lung cancer with routine inpatient or outpatient cancer care. Comparison of data from a national survey of cancer patients with data about the same hospitals drawn from other national cancer datasets.</td>
<td>Cross-sectional survey</td>
<td>UK, 2000–2001</td>
<td>The majority of recorded standards of hospital care did not show associations with measures of satisfaction, and there were occasional negative associations (dissatisfaction). Higher levels of Respect and Dignity measures (inpatient) were found in hospitals with fewer complaints and slower admission procedures; this may reflect more detailed investigation and higher standards in the admission period. For lung cancer, the measures associated with greater satisfaction with the communication (outpatient) measure were: frequent meetings, operational policy meetings, policy on communicating with GP and policy for urgent referrals. The authors argue that understanding how organisational factors affect quality of care for cancer patients can contribute to planning and management of cancer services. The authors acknowledge that most of the standards measured that are indicators of system performance, were not associated with either of the satisfaction measures. This may be due to low validity (i.e. the measures do not reflect patient orientation) or lack of effect (i.e. the services measured do not influence patient experience).</td>
<td>McCarthy 2009</td>
</tr>
<tr>
<td>Study description</td>
<td>Design</td>
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<tr>
<td>Examination of how beliefs and behaviours of physicians and patients influence clinical communication, doctor–patient interaction and treatment decisions for lung cancer treatment</td>
<td>Literature review – non-systematic Study period stated; search strategy included; selection criteria stated 32 articles included</td>
<td>International, January 1990–February 2011</td>
<td>Wide variability in perceptions of the value of chemotherapy among doctors and patients Patients value survival benefits highly whilst physicians strongly emphasise toxicity and associated symptoms Mismatch has implications for treatment decisions, long-term survival and quality of life in people affected by lung cancer</td>
<td>Davidson 2011&lt;sup&gt;73&lt;/sup&gt;</td>
</tr>
</tbody>
</table>
| Examination of the relationship between the educational level of the patient and the patient’s evaluation of their treatment information Educational level coded as less than high school (n = 45), high school or equivalent (n = 28), and education beyond high school (n = 27) | Patient interviews Structured interview rating the importance of 20 different needs (health, coping, and QOL) for patients with lung cancer (n=100) 1 multidisciplinary clinic | USA, study period not stated | Patients with an educational level less than high school rated as most important:  
- feeling the professional cared for them  
- feeling there was hope  
- knowing when to expect symptoms  
- knowing the names of health professionals  
- having help with their care  
- someone concerned with their health  
- being told who can help  
The authors surmise more educated patients may focus on the logistics of the cancer care rather than psychosocial aspects All participants wanted to know details of treatment, prognosis, and to have questions answered in a way they could understand Health professionals should ensure they speak about cancer and treatment in a language appropriate for the educational level of the patient | Jacobs-Lawson 2009<sup>74</sup> |
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<th>Study description</th>
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| Exploration of recall of information by newly diagnosed patients with lung cancer recall and satisfaction with physicians' communication | Patient survey              | Switzerland, February 2005–February 2006 | Of the 71 patients surveyed:  
  - 90% correctly recalled information about the diagnosis  
  - 83% knew what treatment procedure was proposed  
  - 49% accurately recalled information about the goal of treatment  
  - 76% were highly satisfied with their physician's communication of diagnosis  
  - 73% were highly satisfied with their physician's communication of treatment procedure  
  - 39% were highly satisfied with communication of the treatment goal  
Patients who correctly recalled information regarding the treatment procedure were significantly more satisfied with its communication  
Authors conclude that newly diagnosed patients' recall of information regarding the goal of treatment may be poor, and patients may often feel dissatisfied with physicians' communication. Uncovering the causes of such communication breakdown may lead to the development of useful strategies to improve medical consultations | Gabrijel 2003 |
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<tr>
<th>Study description</th>
<th>Design</th>
<th>Country/study period</th>
<th>Description/impact</th>
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<tbody>
<tr>
<td>Examination of the way patients with lung cancer communicate with physicians at initial lung cancer visits</td>
<td>Post-hoc analysis of transcriptions/recordings of lung cancer consultations Review of physician–patient interactions of patients with lung cancer (n=62) 1 hospital</td>
<td>USA, study period not stated</td>
<td>Physicians can increase patient involvement by using partnering and supportive communication. Greater patient participation and physicians’ patient-centred communication can contribute to longer visits; therefore physicians need to develop strategies to optimally but efficiently address patient’s needs. Clinicians and administrators should assess clinical practices that restrict patient involvement in ways that could affect the quality of decision-making.</td>
<td>Street 2006^24</td>
</tr>
<tr>
<td>Exploration of patient preferences for involvement in treatment decisions and the extent of concordance between the views of patients and physicians</td>
<td>Patient and health professional interviews Interviews with patients recruited for a clinical trial (n=28) and their physicians 6 hospitals</td>
<td>Japan, January–December 2008</td>
<td>Patient and physician perceptions regarding roles in treatment decisions agreed in half of cases. Two-thirds of patients perceived their decision-making process aligned with their initial preference. Overall patients reported moderate levels of depression and anxiety; depression scores were significantly associated with preferred level of control, with patients with passive decision-making preferences having lower depression scores compared with patients with collaborative or active preferences. Concerns and management strategies were insufficiently discussed between patients and physicians. Authors propose that physicians ask about patient preferences at the beginning of each clinical encounter and check on the patient’s level of satisfaction with the decision-making process at the end.</td>
<td>Hotta 2010^28</td>
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<tr>
<td>Study description</td>
<td>Design</td>
<td>Country/ study period</td>
<td>Description/impact</td>
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| Evaluation of patient concerns regarding chemotherapy side effects and physician discussion of these effects for patients with NSCLC | Cross sectional survey  
Survey of patients with NSCLC registered with the Alliance for Lung Cancer Advocacy, Support, and Education (n=464) | USA, 2000–2002          | Most patients would choose a chemotherapy regimen on the basis of the side-effect profile  
Almost half of those patients would choose chemotherapy to avoid nausea; risk of infection and fatigue  
Female physicians were more likely than were male physicians to discuss the different side effects of chemotherapy  
Authors concluded that lung cancer patients have significant and varying concerns about the side effects of chemotherapy and that these concerns are not being uniformly identified by physicians or being integrated into decisions about treatment plans  
Better communication between physician and patient about the likelihood of side effects may reduce chemotherapy-related stress for patients                                                                 | Dubey 2005⁹²      |
| Qualitative study of factors influencing patient treatment choices              | Patient interviews  
Semi-structured interviews with patients with incurable NSCLC within 1 month of consultation with an oncologist (n=5)  
1 oncology unit                                                          | UK, December 2005–January 2007          | Some participants who opted for chemotherapy had made a decision before seeing the oncologist, presented with fewer symptoms, had been more active in seeking information before the consultation, and were willing to accept the risk of side effects  
Participants opting for radiotherapy were not willing to accept the risk of side effects for the possibility of a small survival gain and instead focused on symptom relief  
Nurse navigator performed a valuable role for the patients and was seen as a trusted source of  
<pre><code>                                                                               | Thornton 2011⁹³    |
</code></pre>
<table>
<thead>
<tr>
<th>Study description</th>
<th>Design</th>
<th>Country/study period</th>
<th>Description/impact</th>
<th>Reference</th>
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</thead>
<tbody>
<tr>
<td>Identification of preferences for receiving information and participating in decision-making concerning treatment options, healthcare-setting transfers and end-of-life decision-making for patients with NSCLC (stage IIIb/IV)</td>
<td>Patient interviews</td>
<td>Belgium, February 2007–February 2008</td>
<td>Almost all patients wanted information on diagnosis, treatment and cure rate. Patients desired: information on life expectancy, palliative care, end-of-life care, personal control over treatment, personal control over transfers between healthcare settings (e.g. home, treatment centre or hospice), personal control over end-of-life decisions, personal control over medical decisions in general. Most patients strongly desired their family members to be present when the physician gives them information and when medical decisions were made. Preferences for information may shift depending on changes in the patient’s situation (e.g. patients experiencing pain more likely to want information about life expectancy than patients with no pain). Authors note that as part of a patient-centred approach doctors might do well to inquire up front about patient preferences for information and their desired level of participation.</td>
<td>Pardon 200976</td>
</tr>
<tr>
<td>Study description</td>
<td>Design</td>
<td>Country/study period</td>
<td>Description/impact</td>
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<tr>
<td>Study of patients newly diagnosed with advanced lung cancer about degree to which they wanted to be informed and involved in medical decision-making, and whether the patients felt their preferences were met</td>
<td>Patient interviews Structured interviews with patients with NSCLC (n=128) 13 hospitals</td>
<td>Belgium, 1 year study but study dates not specified</td>
<td>Majority of newly diagnosed patients with advanced lung cancer wanted information about life expectancy; only half of patients reported being informed. Most patients wanted information about palliative care and end-of-life options; only one-quarter reported being informed. For participation in medical decision-making (treatment, transfer between health settings, or end-of-life), patients who preferred the doctor to make decisions often achieved this. Patients who preferred to make the decision themselves often achieved this. Patients who wanted an ‘in-between’ position with some involvement often did not achieve this. No association found between meeting patients’ information and participation needs and quality of life, except with respect to the preference for information about chances of cure. Overall the results show that physicians are less prone to giving information relating to death or short life expectancy than information that is more oriented towards ‘dealing with the disease’ or ‘treatment options’</td>
<td>Pardon 2011</td>
</tr>
</tbody>
</table>


5.4 Factors impacting on lung cancer outcomes

5.4.1 Australian overview

In 2011, Cancer Australia published a literature review and consultation on factors impacting on lung cancer outcomes. The aim of the report was to:

- identify gaps in the optimal management of lung cancer by conducting a review of the evidence and through consultation and research into the investigation, referral, treatment and care of people with symptoms and signs that may indicate lung cancer or who have lung cancer
- identify reasons for variations in outcomes
- identify priority areas for guidance material to improve health outcomes.

The report summarises factors associated with the diagnosis and referral processes for lung cancer, priority areas for clinical guidelines and implications for patients, providers and health care system. It also identifies priority areas to decrease variations in lung cancer management in Australia and describes initiatives that need to be addressed in order to decrease the burden of lung cancer. Strategies identified by experts as priority areas to improve lung cancer care included:

- educational initiatives for general practitioners with strategies to increase the awareness and recognition of symptoms
- referral and access to MDTs to assist in diagnosis, staging and treatment
- evidence-based guidance to promote timely investigation and diagnosis of lung cancer
- strategies to increase public awareness of lung cancer, diagnostic strategies and available therapies
- recommendations to assist clinicians in monitoring patients with ongoing symptoms when investigations do not initially confirm lung cancer
- guidelines for MDTs specific to lung cancer
- strategies to improve communication across the public and private sectors
- information targeted at consumers and health care professionals on the benefits of chemotherapy and radiotherapy for managing symptoms and improving quality of life
- monitoring of quality indicators, such as time from diagnosis to treatment
- identification of incentives for the private sector to participate in MDTs
- promotion of lung cancer specialists in surgery and oncology
- guidelines on the indications for surgery in lung cancer
- access to information identifying the location of lung cancer specialists
- algorithms to calculate co-morbidity risk for all types of lung cancer treatments.
5.4.2 International context

In 2000, Fergusson and Borthwick\textsuperscript{96} presented an overview of the important issues surrounding the organisation of services at each stage of the cancer journey for lung cancer patients in the UK, acknowledging that the process of care for lung cancer patients is changing. Key points included:

- the availability of guidelines for lung cancer management
- the fact that MDT approaches were starting
- recognition of the important role of lung cancer specialist nurses
- the need for routine data collection for clinicians to ‘measure’ their service.

UK approaches

Naidu and Rajesh (2008)\textsuperscript{97} provide a comprehensive review of developments in the management of patients with lung cancer in the UK with a particular focus on the impact on quality of life. The review describes how dissemination of the NICE (National Institute for Health and Clinical Excellence) and SIGN (Scottish Intercollegiate Guidelines Network) lung cancer guidelines into clinical practice is the remit of cancer networks.

An overview is given of the four core objectives of cancer networks with special focus given to the key objective – MDTs. An audit of networks is undertaken by the National Clinical Audit Support Program (NCASP).

The paper finishes by describing the UK Lung Cancer Consortium (UKLCC) aim to ‘\ldots\textit{double one-year lung cancer survival by 2010 and five-year survival by 2015\ldots}\textsuperscript{.}\;’ A 12-point plan outlines an aggressive strategy for prevention, screening, awareness, information and support, diagnosis and staging, treatment, end of life care, MDT management, workforce capacity, research, and data collection.

5.5 Focus of initiatives to improve access and delivery of comprehensive and appropriate care

The literature describes a range of approaches with a focus on improving access to and delivery of comprehensive and appropriate care for people with a diagnostic referral for lung cancer. The main areas of focus were:

- multidisciplinary approaches to treatment planning and care
- the role of specialised and high volume diagnostic and treatment services
- coordination of care/navigation
- appropriate follow-up
- early access to palliative care
- end-of-life care
- involvement of primary care/community-based care
- patient-centred care
• quality of life issues
• adherence to clinical practice guidelines
• audit/quality measurement.

These areas are also reflected in clinical practice guidelines identified through the review. Further detail about each of these areas of focus is provided in the next section, together with results of studies that have explored the impact of different approaches/initiatives.

**Canadian case study: an integrated lung cancer network**

In the mid-2000s, clinicians from three institutions in the Greater Toronto Area of Canada led an initiative to redesign lung cancer services offered to patients with lung cancer. The clinicians wanted to integrate regional and community lung cancer services in order to improve patient care and to provide greater access to specialist lung cancer teams.

**Aims**
The initiative aimed to:

- establish links with primary care
- manage patient referrals to the hospital-based lung cancer team
- provide local access to multidisciplinary lung cancer clinics
- offer a multidisciplinary rapid-access clinic for potentially curable patients
- aid knowledge transfer
- facilitate working to generally agreed guidelines
- benefit clinical trial recruitment.

**Features of model adopted**

A non-hierarchical clinical network was established that consolidated the lung cancer team, with a multi-institutional and multidisciplinary tumour board and comprehensive thoracic oncology clinics, with specialists integrated across all three institutions. Key features of the initiative included:

- consolidated referral pathway between family medicine, respirology and thoracic surgery for patients with suspected lung cancer that aimed to reduce time to diagnosis
- patient-flow coordinator responsible for booking all consultations and investigations
- weekly rapid-access MDT clinic specifically for patients with resected and locally advanced lung cancer to fast-track decision-making and to coordinate multimodal treatment in patients who may be being managed with curative intent.

The initiative succeeded in increasing the number of patients seen with early stage disease and when they are candidates for curative-intent treatment, and to increase the opportunities to offer patients clinical trials.

Challenges included the need to invest considerable time and effort into the redesign work, and the equitable delivery of local multidisciplinary services to an ethnically and economically diverse population.
5.6 Characteristics of service delivery for patients with lung cancer and impact on patient, service and system level outcomes

5.6.1 Multidisciplinary teams/multidisciplinary care

Multidisciplinary care and involvement of MDTs in diagnosis and treatment planning has been a major focus of cancer service improvement approaches in recent years.

Development of multidisciplinary approaches to lung cancer diagnosis and treatment was a focus of 13 articles.56-62,71,99-103 Studies comparing components of care and outcomes before and after the introduction (or in some cases cessation) of MDT meetings and/or multidisciplinary clinics have demonstrated that MDTs are associated with:

- decrease in time to evaluation from presentation56
- more accurate staging/increased use of pathological staging59,62
- shorter time from diagnosis to treatment56-61
- increased use of aggressive therapy with curative intent101
- increased progression-free and overall survival58,71,99,101
- decreased use of palliative care only101
- increased referral for palliative care56
- increased adherence to guidelines60
- increased patient satisfaction56
- improved practitioner satisfaction56
- increased clinical trial enrolment.54

One study suggested no difference in time to diagnosis or treatment but indicated the presence of confounders that may have influenced the study results.100

Two studies (by the same authors) concluded that MDT meetings do not improve decision making or accuracy of survival predictions for individual team members, but do improve aspects of physician learning/understanding and increase team performance overall.102,103

Table 11 provides a summary of the studies that explored the impact of MDTs/clinics on components of care and outcomes for people with lung cancer.
Table 11  Impact of multidisciplinary care and multidisciplinary teams on outcomes for people with lung cancer

<table>
<thead>
<tr>
<th>Study description</th>
<th>Design</th>
<th>Country/study period</th>
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<tbody>
<tr>
<td>Literature review of evidence of benefits of a multidisciplinary approach to diagnosis and management of thoracic malignancy</td>
<td>Narrative review</td>
<td>USA, not specified</td>
<td>MDTs result in more timely assessment and accurate staging of disease, higher rates of procedures to confirm pathologic staging, and increased use of aggressive therapy, including curative intent radiation therapy, surgery, and chemotherapy</td>
<td>Bauman 2010^{62}</td>
</tr>
<tr>
<td>Literature review of the attributes contributing to superior outcomes in the surgical management of early stage lung cancer and examples of implementing improvement</td>
<td>Narrative review</td>
<td>USA, not specified</td>
<td>Multidisciplinary care has positive influence on management and survival, shortens time to therapy, improves staging, increases rate of surgery, increases quality of surgery, increases compliance with guidelines, and improves decision making</td>
<td>Handy 2011^{57}</td>
</tr>
<tr>
<td>Retrospective comparison of MDT recommendations with clinical management and assessment of impact on patient outcomes</td>
<td>Retrospective case review</td>
<td>USA, February 2006–October 2009</td>
<td>37% concordance between team recommendations and clinical management 61% of all discordant care attributed to clinicians’ decisions Patients whose clinical management was concordant with MDT recommendations had a significantly shorter time to clinical intervention (14 days vs 25 days, p&lt;0.01), and longer median overall survival (2.1 years vs 1.3 years, p&lt;0.01) and progression-free survival (1.3 years vs discordant = 0.8 years, p&lt;0.05) than those who received discordant care</td>
<td>Osarogiagbon 2011^{58}</td>
</tr>
<tr>
<td>Study description</td>
<td>Design</td>
<td>Country/ study period</td>
<td>Impact</td>
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| Prospective analysis of concordance between proposed and administered treatment for patients presented at a weekly MDT meeting over 1 year | Prospective case review Evaluation of planned vs administered treatments for patients with lung cancer presented to a weekly MDT (n=344) 1 multidisciplinary team | France, July 2003–March 2005                                                                                                             5% discordance between proposed and administered treatment  
Trend toward a survival benefit from implementing recommendations  
Patients with discordance of treatment had a lower survival rate but not significant (p=0.07) | Leo 2007⁹⁹ |
| Retrospective before and after study comparing time to diagnosis and time to treatment after a multidisciplinary thoracic oncology clinic ceased to operate | Retrospective pre-/post-case review Comparison of timeliness of treatment decisions for patients with lung cancer discussed before (n=244) and after (n=101) the closure of the clinic Identified through tumour registry | USA, 1999–2003                                                                                                                             No difference in time to diagnosis (p=0.09) or time to treatment (p=0.71)  
NB. Clinic did not involve a thoracic surgeon, and the non-clinic era had an active MDT throughout, which probably confounded the study results | Riedel 2006¹⁰⁰ |
| Retrospective before and after study comparing components of care for patients after initiation of a multidisciplinary conference for patients with NSCLC | Retrospective pre-/post-case review Comparison of components of care for patients with NSCLC treated before (n=535) and after (n=687) the introduction of a multidisciplinary conference 1 hospital | USA, 2001–2007                                                                                                                             Significant increase in number of patients receiving a complete staging evaluation, pre-therapy multidisciplinary evaluation and adherence to National Comprehensive Cancer Network treatment guidelines⁴⁶ (p<0.0001)  
Significant decrease in time from diagnosis to treatment (p<0.0001) | Freeman 2010⁵⁹ |
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<th>Study description</th>
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</table>
| Retrospective before and after study comparing components of care for patients after the introduction of an MDT for patients with inoperable NSCLC | Retrospective pre-/post-case review                                     | UK, 1997 and 2001             | Increase in patients receiving chemotherapy (p<0.001)  
Decrease in patients receiving palliative care only (p<0.001)  
Increase in median survival from 3.2 months to 6.6 months (p<0.001) | Forrest 2005[10] |
| Comparison of components of care for patients with lung cancer following the introduction of a multidisciplinary clinic | Descriptive article  
Description of the approach to and benefits of a multidisciplinary clinic  
Detailed methodology not stated | USA, study period not stated | Decrease in time from initial referral to evaluation (2–3 weeks to 5 days)  
Increase in referral to palliative care (88% vs 100%)  
Increase in review by both interventional pulmonologist and radiologist (14% vs 100%)  
Decrease in time to treatment (19 vs 8.5 days)  
Improvement in patient satisfaction  
More presentation at cancer conferences  
Improvement in practitioner satisfaction | Horvath 2010[56] |
| Development of a multidisciplinary lung cancer clinic in a community cancer clinic to enhance patient care | Descriptive article  
Description of changes attributed to introduction of a multidisciplinary cancer clinic  
Detailed methodology not stated  
46 patients described as being seen at the clinic | USA, 2007–2009 | Significant improvements in time from diagnosis to initiation of treatment = 18 vs 24 days before multidisciplinary lung cancer clinic  
Increase in community lung cancer clinic patient care of 28%  
75% increase in referrals from the multidisciplinary lung cancer clinic geographic area  
Initial work-up met national guidelines | Bjegovich-Wiedman 60 |
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<th>Study description</th>
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</table>
| Comparison of outcomes for patients with lung cancer following the introduction of a multidisciplinary lung cancer program in a community hospital | Descriptive article Description of the approach to and benefits of a multidisciplinary clinic | USA, study period not stated          | Steadily improving survival rates: much higher than those observed nationally for patients diagnosed with lung cancer since the program began  
Key components:  
- thoracic surgeons skilled in video-assisted thoracoscopic surgery  
- nurse navigator/coordinators  
- utilisation of treatment guidelines  
- formal continuing medical education  
- emphasis on early detection that includes consideration of CT screening of former smokers  
- cancer centre with many services to be offered at a single location  
- access to research protocols  | Fischel 2009^[71]                           |
| Investigation of impact of telemedicine on MDT involvement by surgeons and specialist thoracic radiologist where time and/or distance constraints prevented attendance in person | Audit of MDT meetings and case review  
Review of cases discussed via telemedicine (n=62) over 28 MDT meetings  
1 hospital | UK, November 2000–November 2001         | Increase in resection rate by 30%; these patients would previously have been referred to a surgical outpatient clinic for investigations  
Decrease in time from diagnosis to treatment from 69 to 54 days (NS, p>0.05)  
Telemedicine saved 112 hours (equivalent to 3 working weeks) of thoracic surgical time during the year, resulting in cost savings | Davison 2004^[61]                           |
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<th>Study description</th>
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<tr>
<td>Clinician survey pre- and post-MDT discussion for 50 newly diagnosed patients to determine whether team discussion improves the quality or outcome of clinician decision making</td>
<td>Prospective case review and health professional survey Survey of health professionals to ascertain views on management of 50 cases of lung cancer before and after an MDT meeting 1 hospital</td>
<td>UK, December 1999–January 2003</td>
<td>In only 23 of 87 instances (26%) in which an individual specialist’s initial treatment preference differed from the final group judgment did the specialist finally concur with the group treatment choice after discussion Findings did not support the theory that team discussion improves the quality of decision making overall Authors concluded that doctors are poor at judging quality-of-life and treatment outcomes in lung cancer</td>
<td>Kee 2004&lt;sup&gt;102&lt;/sup&gt;</td>
</tr>
<tr>
<td>Descriptive study exploring clinician views on whether MDT discussion changes prognostic accuracy of individual clinicians and improves the accuracy of the team’s aggregated prediction for 50 cases discussed</td>
<td>Prospective case review Survey of health professionals to ascertain views on management of 50 cases of lung cancer before and after an MDT meeting 1 hospital 15 clinicians</td>
<td>UK, December 1999–January 2003</td>
<td>Group discussion did not significantly change the accuracy of survival prediction for any one clinician The team as a whole improved its calibration and discrimination of prognostic estimates after the team meeting</td>
<td>Kee 2007&lt;sup&gt;103&lt;/sup&gt;</td>
</tr>
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5.7 Specialised and high-volume services

The importance of specialist involvement in lung cancer diagnosis and treatment was identified in three articles. These studies focused on:

- the role of a respiratory physician in diagnosis
- the role of a thoracic surgeon in planning and delivery of surgical treatment
- the benefits of treatment in high-volume centres.

Involvement of a specialist medical practitioner in the diagnosis and treatment of people with lung cancer has been associated with improved outcomes. This includes:

- increases in resection rate, surgery in the elderly and extended resections for people treated by a specialist thoracic surgeon
- improvements in patient outcomes, safety, cost and long-term survival for people treated by a specialist thoracic surgeon
- more rigorous diagnostic and staging procedures and greater likelihood of active treatment for people whose diagnosis and treatment is managed by a respiratory physician.

Table 12 provides a summary of the studies that explored the impact of specialised/high-volume services on components of care and outcomes for people with lung cancer.
## Impact of involvement of specialist care on outcomes for people with lung cancer

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<tr>
<th>Study description</th>
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| Literature review into the attributes contributing to superior outcomes in the surgical management of early-stage lung cancer and examples of implementing improvement | Narrative review Study period, search strategy and selection criteria not stated | USA, study period not specified | The attributes contributing to superior clinical outcomes include: high clinical volumes, specialised care and MD care. In summary:  
- **operative volume** – high surgical volume improves mortality and patients should choose their care setting and provider based on this  
- **specialisation** (e.g. specialist thoracic surgeon versus general surgeon) – improves patient outcomes, safety, cost and long-term survival | Handy 2011\(^{57}\) |
| Before and after study into the effect of appointment of a specialist thoracic surgeon on surgical practice for lung cancer previously provided by cardio-thoracic surgeons | Retrospective case review Review of cases of patients undergoing surgical resection for lung cancer before (n=65) and after (n=175) the appointment of a specialist thoracic surgeon 1 health authority | UK, 1994-1999 | Treatment by specialist thoracic surgeons (as opposed to cardio-thoracic surgeons) was associated with an increase in:  
- resection rate (from 12.2 to 23.4%, \(p < 0.001\))  
- operations in the elderly (4 vs 18% over 75 years old, \(p = 0.02\))  
- extended resections  
- no significant difference was found in:  
  - stage distribution  
  - in-hospital mortality  
  - stage-specific survival after surgery | Martin-Ucar 2004\(^{64}\) |
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<th>Study description</th>
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<th>Country/study period</th>
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| Investigation of the effect of involvement by a respiratory physician on the diagnosis, staging, treatment and survival of a large unselected group of lung cancer patients | Retrospective case review Review of cases of lung cancer from the Scottish Cancer Registry (n=3855) | UK, 1995             | Nearly three-quarters of patients managed initially by a respiratory physician Patients managed by a respiratory physician more likely to have:  
- cancer diagnosis confirmed by histological methods  
- stage of disease recorded  
- more rigorous staging investigations (e.g. CT scans and bronchoscopy)  
- active treatment with surgery, radiotherapy or chemotherapy  
- longer 1-year and 3-year survival for those seen by respiratory physician  
This result supports published national guidelines that lung cancer patients benefit from the involvement of a respiratory physician | Fergusson 2003 |
5.8 Coordination of care/patient navigation

Literature variously describe the role of specialist lung cancer nurses, care coordinators and/or nurse navigators in supporting people with lung cancer and their families throughout the cancer journey. Roles described include providing a continuous point of contact for patients and their families, offering medical guidance and social and emotional support.

UK guidelines suggest that each cancer centre/unit should have at least one lung cancer nurse specialist (NICE, 2011; Scottish Intercollegiate Guidelines Network (SIGN), 2005). The role and attributes of these roles include coordination of care, assessment of patients’ needs and coping skills, education in ways to identify and cope with symptoms, and provision of support.

Four articles were identified that discussed the role of care coordinators/nurse navigators in the care of people with lung cancer.

The identified articles presented a mixture of description of the roles of care coordinators as well as some articles describing the benefits of nurse coordinator or navigator roles on patient outcomes (Table 13). A Canadian study reported no significant differences in symptom distress, fatigue, quality of life, and health care usage (unscheduled clinic visits, emergency department visits, and hospitalisations) after introduction of a nurse navigator.

Where benefits of nurse coordinator/navigator roles are described, these included:

- CALD patients: American Indians being treated with curative radiotherapy who received navigation assistance missed fewer days of treatment compared to those who did not receive navigation (1.7 vs 4.9 days) (p = 0.0001) and were more likely to enrol in a clinical trial.

- A reduction in avoidable re-admissions per month after introduction of nurse-led proactive care in a UK hospital in 2009 (0.3 vs 4 avoidable readmissions per month).

A number of articles identified in previous sections also concluded that nurse navigators are an essential part of multidisciplinary lung cancer care.

Data from the UK National Lung Cancer Audit also indicate that patients seen by a lung cancer nurse specialist (LCNS) were more likely to receive anti-cancer treatment compared to those that were not seen by an LCNS (64.8 % of patients seen by an LCNS received anti-cancer treatment vs 30.4 per cent of those who were not seen by an LCNS). The audit notes that although this highlights the importance of the LCNS, further work is needed to explain this observation.

The role of specialist lung cancer nurses in follow-up care is also described in the next section.
Table 13  Description of the role of care coordinators/nurse navigators and impact of involvement of these roles on outcomes for people with lung cancer

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<tr>
<th>Study description</th>
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<th>Country/study period</th>
<th>Description/Impact</th>
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<tbody>
<tr>
<td>Description of the role requirements of a nurse navigator</td>
<td>Descriptive article</td>
<td>USA, study period not stated</td>
<td>Nurse navigator identifies and manages patients with suspected or confirmed NSCLC, meets with patients during all follow-up appointments, and completes all paperwork, summaries and follow ups with the family physician. Authors outline a number of attributes that effective nurse navigators must possess including: knowledgeable about health system, knowledge about all aspects of oncology care, ability to act as patient advocates, compassionate, organised and able to work with an MDT.</td>
<td>Seek 2007¹⁰⁶</td>
</tr>
<tr>
<td>RCT comparing impact on continuity of nursing care delivered by a pivot nurse/nurse navigator to improve symptom relief and outcomes for patients with lung or breast cancer</td>
<td>Randomised controlled trial</td>
<td>Canada, study period not stated</td>
<td>The nurse coordinated care, assessed patients' needs and coping skills, taught specific ways to identify and cope with symptoms and offered education and support. No significant differences in symptom distress, fatigue, quality of life, and health care usage (unscheduled clinic visits, emergency department visits, and hospitalisations) between groups. The nurse navigator did not have an impact on the patient outcomes measured in this study.</td>
<td>Skrutkowski 2008⁶⁶</td>
</tr>
<tr>
<td>Study description</td>
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<tr>
<td>Descriptive study comparing a patient navigation program providing culturally</td>
<td>Prospective case review</td>
<td>USA, February 2004–September</td>
<td>American Indians from the Northern Plains of the US have higher rates of cancer mortality, present with more advanced stages of cancer, demonstrate lack of trust of health care systems, almost half live in poverty and unemployment is high compared with the rest of the US population. Patients had a median of 12 contacts with their navigator; the first contact lasted for a median time of 40 minutes and for 15 minutes for every subsequent contact. Patients who received navigation assistance and who were treated with radiotherapy with curative intent missed fewer days of treatment compared to those who did not receive navigation (1.7 vs 4.9 days) (p = 0.0001). Such patients were more likely to enrol in a clinical trial than those who did not receive navigation. Note that treatment interruption is a predictor for loco-regional relapse.</td>
<td>Guadagnolo 2011</td>
</tr>
<tr>
<td>Study description</td>
<td>Design</td>
<td>Country/study period</td>
<td>Description/impact</td>
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<td>Descriptive before and after study comparing the impact of proactive case management on the nature and frequency of re-admission</td>
<td>Descriptive before and after study comparing the impact of proactive case management on the nature and frequency of re-admission</td>
<td>UK, January 2009–mid-March 2010</td>
<td>Proactive case management helps avoid re-admissions and prevent unscheduled care</td>
<td>Baxter 2011</td>
</tr>
<tr>
<td>Proactive case management defined as: a patient-centred way to promote care within defined best practice, such as national guidelines requires input and agreement on management from the MDT, with the clinical nurse specialist as the key worker or key accessible professional</td>
<td>Proactive case management helps avoid re-admissions and prevent unscheduled care</td>
<td>Benefits of adopting proactive case management and national guidance on nursing management in lung cancer</td>
<td></td>
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<td></td>
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<td>Avoidable re-admissions per month were lower after introduction of proactive care (0.3 vs 4 per month), giving an average rate of admission avoidance as 3.7 per month</td>
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<td>33 re-admissions were avoided in 9 months</td>
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<td>At an average stay of 6 days, this represents 198 saved bed days over 9 months, or 266 bed days per year as a result of outpatient proactive case management alone</td>
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Proactive case management helps avoid re-admissions and prevent unscheduled care. Benefits of adopting proactive case management and national guidance on nursing management in lung cancer. Avoidable re-admissions per month were lower after introduction of proactive care (0.3 vs 4 per month), giving an average rate of admission avoidance as 3.7 per month. 33 re-admissions were avoided in 9 months. At an average stay of 6 days, this represents 198 saved bed days over 9 months, or 266 bed days per year as a result of outpatient proactive case management alone.
5.9 Appropriate follow-up

Five articles described approaches to follow-up care for people with lung cancer and the role of different health professionals in providing this care (Table 14).\(^\text{86-90}\)

5.9.1 Medical follow-up

Two studies compared outcomes for patients with lung cancer who are followed up by a thoracic surgeon, chest physician and other health professionals, such as a GP.\(^\text{86,87}\) Evidence appears to be divided as to whether there is survival benefit to follow-up by specialist health professionals.

5.9.2 Nurse-led follow-up

Three articles had a specific focus on the role of nurses in follow-up of patients with lung cancer.\(^\text{88-90}\)

Moore and colleagues\(^\text{89}\) described the process and experience of developing the nurse specialist role in lung cancer in relation to follow-up care. Data were collected from case records and semi-structured interviews. Four themes emerged related to the development of these roles:

- **training**: nurses acknowledged that much of their learning could only occur experientially, through the actual ‘doing’ of the role
- **credibility**: most nurses experienced a degree of hostility from some colleagues as it took time for the new model to become accepted
- **emotional burden**: the emotional burden of working closely with a population of patients whose prognosis is poor was repeatedly acknowledged and additional support strategies for nurses were put in place
- **making a difference**: nurses perceived the new model of follow-up was associated with huge benefits for patients.

This study illustrates that developing nurse-led follow-up is challenging and there are many practical and emotional hurdles to be overcome for nurses who take on the role. The authors note that comprehensive preparation, and continuing support and supervision are essential to ensure sustainability of nurse navigator roles.
### Table 14  Impact of different approaches to follow-up of people with lung cancer

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<th>Study description</th>
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<th>Country/ study period</th>
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| Retrospective cohort study of patients diagnosed with NSCLC between 1980 and 2008 in which post-operative follow-up was managed by a thoracic surgeon or a chest physician | Retrospective cohort study Review of records for patients with NSCLC (n=1398) 2 hospitals  | Japan, 1980–2008     | Follow-up by thoracic surgeons included physical examination and chest radiogram 1 month post-operatively and every 3–4 months for 3 years  
Follow-up by chest physicians also included chest CT scan every 6 months  
Over the study period, longer survival for patients in the chest physician group than in the thoracic surgeon group, particularly those with advanced disease  
- stage IA-B – no difference  
- stage IIA-IIIB – chest physician = 42.9% vs surgeon = 33.8% ($p=0.0008$)  
Difference in 5-year survival not statistically significant for the more recent time period (1994–2008)  
Early detection of asymptomatic disease by regular follow-up including chest CT scan may improve the chance of treatment with curative intent and thus may increase survival, irrespective of the doctor in charge of follow-up | Nakamura 2010$^{66}$ |
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<th>Study description</th>
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<th>Country/study period</th>
<th>Description/impact</th>
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</table>
| Retrospective cohort study into survival of surgically treated stage IA to IIB NSCLC patients in which post-operative follow-up was with a thoracic surgeon or other health professional | Retrospective cohort study Review of patient records for patients with NSCLC (n=245) 1 hospital | Canada, January 1988–December 1995 | Patients followed up at clinic visits every 3–4 months for first 2 years, biannually from years 2–5 and yearly thereafter  
Despite clinic follow-up, 66.7% (60 of 90) recurrences identified by the family GP, 28.9% (26 out of 90) by the surgeon  
A 75% cost savings could ensure if patients were followed up by their family physician  
No 5-year survival benefit for patients whose recurrence was detected by the surgeon  
Raises questions regarding the rationale and efficiency of follow-up by the thoracic surgeon  
Authors suggest it is difficult to support regular thoracic clinic follow-up after tumour resection if most recurrences are detected outside this setting, i.e. by the GP  
Long-term follow-up after limited-stage NSCLC resection could possibly be performed by the family GP without compromising overall survival | Gilbert 2000[87] |
| RCT comparing nurse-led follow-up and conventional medical follow-up for patients with lung cancer who had completed their initial treatment and were expected to survive for at least 3 months  
Conventional follow-up consisted of routine outpatient appointments (one post-treatment) | Randomised controlled trial  
Comparison of nurse-led and conventional approaches to follow-up for patients with lung cancer (n=203)  
1 specialist hospital and 3 cancer units | UK, study period not stated | Nurse-led follow up versus conventional medical follow up resulted in the following statistically significant outcomes:  
- patients scored significantly better in most satisfaction subscales at 3, 6, and 12 months (p<0.01 for all subscales at 3 months)  
- less severe dyspnoea at 3 months (p=0.03)  
- less peripheral neuropathy at 12 months (p=0.05)  
- better scores for emotional functioning and | Moore 2002[88] |
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<th>Study description</th>
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<td>appointment, then appointments at 2- or 3-month intervals for medical assessment and investigations to monitor disease</td>
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<td></td>
<td>greater satisfaction at 3, 6, and 12 months (p=0.03)</td>
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<td>Nurse-led follow up consisted of:</td>
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<td>• patients attended fewer consultations with a hospital doctor during the first 3 months (p=0.004)</td>
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<td>• open access to nurse specialists Monday–Friday and contact through open access clinic, telephone, and message pager service</td>
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<td>• patients had fewer radiographs during the first 6 months (p=0.04)</td>
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<td>• telephone assessment or clinic appointment 2 weeks after baseline, then every 4 weeks while patient is stable; no routine investigations</td>
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<td>• patients had more radiotherapy within the first 3 months (p=0.01)</td>
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<td>• weekly, open access nursing clinics with same day appointments available</td>
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<td>• patients more likely to die at home rather than in a hospital or hospice (p=0.04)</td>
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<td>• emphasis on rapid and comprehensive communication GP and primary health care team</td>
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<td>No differences were seen in survival or rates of objective progression, although nurses recorded progression of symptoms sooner than doctors (p=0.01)</td>
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<td>• regular discussion with and referral to medical</td>
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<td>Both patients and general practitioners were highly satisfied with the nurse led model of follow up</td>
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<td></td>
<td>Authors concluded that, overall, follow-up of patients with lung cancer by clinical nurse specialists is safe, acceptable, and cost effective</td>
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<td>Study description</td>
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<td>team on detection of any new symptom or rapid worsening of condition</td>
<td>Cross-sectional survey and interviews</td>
<td>UK, study period not stated</td>
<td>Patients, carers, staff, and GPs asked to rate the acceptability of nurse-led follow-up, telephone follow-up, GP-led follow-up, and standard medical follow-up through surveys and in-depth interviews. All four groups interviewed would be happy with nurse-led follow-up as long as there was medical backup and the nurse had the ability to refer if needed, order X-rays, and ensure appropriate medication was prescribed. Although medical-led follow-up was often preferred by patients and relatives, nurse-led follow-up was preferred for discussion of emotional and psychological problems. Staff saw benefits of the nurse-led clinic, including: redirection of resources, more appropriate addressing of the patient needs, freeing up of time for those patients who needed to see the doctor. Staff also noted the importance of clear protocols, training, and easy access to medical review.</td>
<td>Cox 2006⁹⁰</td>
</tr>
<tr>
<td>• documentation from nurse-led clinic held in notes and sent to GP, home care team or hospice, and consultant in charge of patient</td>
<td>Questionnaire containing vignette scenarios of nurse-led, telephone, GP-led, and standard (hospital, medical) follow-up was completed by 34/54 (63%) of eligible patients, 10/20 (50%) carers, 20/31 (65%) staff, and 11/38 (29%) GPs.</td>
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5.10 Palliative care

Palliative care is focused on symptom management and improving quality of life for people with a terminal illness.

- Six publications were identified that described the role of palliative care in lung cancer.\textsuperscript{79-83, 108}
- Two of these provided evidence relating to the benefit of early integration of palliative care with standard oncologic care in patients with metastatic non-small-cell lung cancer.\textsuperscript{80, 82}

Key articles are summarised in Table 15.

The literature highlights that:

- early integration of quality palliative care alongside routine clinical care is feasible and essential from diagnosis\textsuperscript{79-83}
- among patients with metastatic non-small-cell lung cancer, early palliative care as opposed to standard care led to significant improvements in both quality of life and mood:
  - improved survival (11.6 months vs 8.9 months, \( p = 0.02 \))
  - improved quality of life (FACT-L scale of 98.0 vs 91.5, \( p = 0.03 \))
  - fewer depressive symptoms (16% vs 38%, \( p = 0.01 \))
  - reductions in unnecessary treatment and less aggressive end-of-life care (33% vs 54%, \( p = 0.05 \))\textsuperscript{82}
- the concept of palliative care/education should be introduced early in the journey.\textsuperscript{83}

5.10.1 Guidelines for palliative lung cancer care

The American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care\textsuperscript{109} addresses the integration of palliative care services into standard oncology practice at the time of diagnosis of metastatic or advanced lung cancer.

Based on seven randomised controlled trials, the authors conclude: “Based on strong evidence from a phase III RCT, patients with metastatic non–small-cell lung cancer should be offered concurrent palliative care and standard oncologic care at initial diagnosis. While a survival benefit from early involvement of palliative care has not yet been demonstrated in other oncology settings, substantial evidence demonstrates that palliative care - when combined with standard cancer care or as the main focus of care - leads to better patient and caregiver outcomes. These include improvement in symptoms, QOL, and patient satisfaction, with reduced caregiver burden. Earlier involvement of palliative care also leads to more appropriate referral to and use of hospice, and reduced use of futile intensive care.”
5.10.2 End-of life care: use of advanced care directives

In addition to the palliative care studies, one article described results from a pilot of an advance care planning (ACP) intervention for lung cancer nurses to use in discussing end-of-life preferences and choices for care with patients diagnosed with inoperable lung cancer.110

ACP is the process by which a dialogue is initiated with patients and carers about their understanding of the patient’s medical history, condition and prognosis and their preferences for future care and treatment options.

Nine patients who took part in ACP discussions with their nurse were interviewed.

Patients’ reactions to the ACP process varied. Key findings were:

- the nurses’ attributes aided the discussion about future care and treatment
- patients appreciated the information and explanation offered to them
- patients accepted the recording of their preferences which were shared with their health care team.

5.10.3 End of life care: use of intensive care units

A USA-based study111 analysed database records to examine changes over time in outpatient-to-inpatient continuity of care in individuals hospitalised with advanced lung cancer and its relationship to end-of-life intensive care unit (ICU) use.

Outpatient-to-inpatient continuity of care was defined as: an inpatient visit by the patient’s usual care provider during the last hospitalisation. Outpatient-to-inpatient continuity significantly decreased from between 1992 and 2002. Factors associated with decreased continuity included male sex, black race, low socioeconomic status, being unmarried, treatment by a hospitalist, and treatment in a teaching hospital. Continuity of care or being seen by a usual care provider (e.g. GP, internist, or geriatrician) during hospitalisation was associated with a lower chance of an ICU stay.

After adjustment for patient characteristics, patients with outpatient-to-inpatient continuity of care had a 25.1% reduced odds of entering the ICU during their terminal hospitalisation. The authors conclude that efforts to improve outpatient-to-inpatient continuity of care may reduce end-of-life ICU use in terminally ill patients.
Table 15  Impact of early introduction of palliative care on outcomes for people with lung cancer

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<th>Country/study period</th>
<th>Description/impact</th>
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<tr>
<td>Narrative review of the evidence for palliative symptom management</td>
<td>Narrative review</td>
<td>USA, no study period stated</td>
<td>Palliative care is multidisciplinary, begins at the time of diagnosis of a serious disease; continues throughout treatment, cure, or until death; and involves the family during the bereavement period. Quality of life needs are assessed for both patients and family caregivers with a focus on four domains: physical, psychological, social, and spiritual well-being. Integration of quality palliative care into routine clinical care of patients with lung cancer after surgical intervention is essential for preserving function and optimising quality of life.</td>
<td>Ferrell 2011</td>
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<tr>
<td>Summary of strategies in supportive care for patients with metastatic lung cancer in particular tumour-directed therapy (radiation and chemotherapy), supportive treatment of symptoms and early integration of palliative care</td>
<td>Narrative review</td>
<td>Canada, no study period stated</td>
<td>Longer-course radiation treatment offers a survival and symptom benefit over short-course treatment in patients with good performance status. Palliative chemotherapy improves quality of life and survival, however, the optimal drug combination, number of courses of chemotherapy are not yet known, and proper stratification of patients is essential. Early integration of specialised palliative care shows promise as a means of improving patient care and limiting unnecessary treatment.</td>
<td>Freedman 2009</td>
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<tr>
<td>Non-blinded, randomised, controlled trial of 151 patients with metastatic NCSLC who received either early palliative care integrated with standard oncologic care and (n=77) or late palliative care integrated with standard oncologic care</td>
<td>Randomised controlled trial (non-blinded)</td>
<td>USA, June 2006–July 2009</td>
<td>Quality of life and mood assessed at baseline and at 12 weeks using the Functional Assessment of Cancer Therapy–Lung (FACT-L) scale and Hospital Anxiety and Depression Scale.</td>
<td>Temel 2010</td>
</tr>
<tr>
<td>Study description</td>
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| care or standard oncologic care alone | standard oncologic care alone (n=74) 1 hospital | | Compared with patients receiving standard care, those assigned to early palliative care had:  
- better quality of life (QOL score 98 vs 91.5, $p<0.03$)  
- fewer depressive symptoms (16% vs 38%, $p=0.01$)  
- less aggressive care at the end of life* (33% vs 54%, $p=0.05$)  
- improved survival (11.6 months vs 8.9 months, $p=0.02$)  
The authors conclude that:  
- early integration of palliative care for patients with metastatic NSCLC is a clinically meaningful and feasible care model that has effects on survival and quality of life  
- aggressive end-of-life care might produce sufficiently high levels of psychological distress that treatment produces more harm than good  
- palliative care might directly reduce psychological distress at the end of life which in turn might produce salutary benefits that extend life  
*Aggressive end-of-life care was classified as chemotherapy within 14 days before death, no hospice care, or admission to hospice 3 days or less before death reduced chemotherapy and longer hospice care | |
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<tr>
<td>Study to assess the feasibility of early palliative care in the ambulatory setting and its impact on quality of life (QOL) in patients newly diagnosed with NSCLC. Participants were expected to meet with the palliative care team at least every other month during the study period; the majority of patients met with the team at least monthly.</td>
<td>Cross-sectional survey Survey of patients with NSCLC (n=50) 1 hospital</td>
<td>USA, October 2003–June 2005</td>
<td>Good compliance (86%) with palliative care visits QOL and mood analyses confirmed high symptom burden in patients with newly diagnosed advanced NSCLC (50% of participants experienced some degree of shortness of breath, cough, difficulty breathing, appetite loss, weight loss, or unclear thinking at baseline assessment) Integrating palliative and oncology care is feasible. Although palliative care guidelines were provided, no data were collected on the palliative care team’s involvement in specific domains or their associated interventions; it would be useful to gain insight into which components of palliative care were provided most frequently.</td>
<td>Temel 2007</td>
</tr>
<tr>
<td>Longitudinal descriptive study examining associations between QOL and each of the following: symptom distress, symptom frequency, symptom severity, depression, anxiety, functional status, and medical and demographic characteristics in patients with advanced lung cancer.</td>
<td>Longitudinal descriptive study (interviews) Interviews with patients with lung cancer (n=80) 1 hospital; 2 private clinics</td>
<td>USA, no study period stated</td>
<td>High attrition rate: of the 80 patients enrolled, only 50% were alive at the 4-month data collection point Highlights the need for palliative care to begin at diagnosis Patients reported a relatively high QOL that did not change significantly as they approached the end of life. Significant determinants of QOL were: symptom distress, symptom severity, symptom frequency, and depression. Interventions for symptom management must be implemented at diagnosis because patients in this population may approach the end of life quickly.</td>
<td>Hermann 2011</td>
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<td>Study description</td>
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| Preliminary study of caregivers and physician of lung cancer patients’ regarding their perceptions of hospice care and timing of enrolment | Cross sectional survey                      | USA, 2000–2004       | Caregivers’ reasons for deferred hospice enrolment included: patients’ unanticipated rapid transition from well to sick and the belief that hospice care means giving up hope  
Physicians’ reasons for deferred hospice enrolment were: patients and caregivers overestimate survival from lung cancer and the (incorrect) assumption that patients need to be ‘do not resuscitate/do not intubate’ prior to hospice enrolment  
The authors conclude that lung cancer patients may benefit from earlier introduction to the concepts of hospice care and more education regarding hospice care to support earlier and easier transition to palliative care | Ford 200883 |
5.11 Involvement in primary care/community-based care

Five articles discussed the issue of GP involvement in lung cancer patient care. Three have been reviewed elsewhere in this report.

Two additional publications (one from Canada and one from Australia) are summarised in Table 16.

Key findings in relation to involvement of primary care in lung cancer care included:

- GPs are often ‘cut off’ from cancer care during the treatment phase, but become involved again in later aspects of care.
- Most patients would like their GP to be more involved in lung cancer care.
- Most GPs would like to be more involved in cancer care and show preferences for:
  - Information to be provided from all members of hospital team.
  - Information to be provided about changes in the patient’s condition; following initial outpatient consultation; at time of admission and discharge; and at treatment milestones.
  - Information to be provided electronically.
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<th>Study description</th>
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<tr>
<td>Prospective longitudinal study of patients with lung cancer to assess family physician (GP) involvement in follow-up during different phases of cancer</td>
<td>Longitudinal descriptive study (n=395) Patients with a recent diagnosis of lung cancer (n=395) Survey every 3–6 months for 18 months to assess aspects of their family GP involvement in cancer care 5 hospitals</td>
<td>Canada, May 2005–July 2008</td>
<td>The majority of patients (92%) had a regular GP and in 60% of these cases, the GP referred to a specialist for diagnosis of lung cancer For most patients the oncology team was responsible for their cancer care A large proportion of patients continued to see their GP throughout their cancer journey, but the GP was more involved once treatment ceased. At all phases of cancer, most patients would have liked their family physician to be more involved than he/she actually was in all these aspects of care The authors conclude that their research reinforces the importance of good communication and collaboration between GPs and the oncology team in order to keep the former involved at all phases of cancer and to promote shared care in cancer follow-up</td>
<td>Aubin 2011</td>
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</table>

<p>| Interviews with a hospital-based lung cancer team in a teaching hospital and a sample of GPs in the hospital catchment to ascertain what information GPs need to care for patients with lung cancer, | Cross-sectional survey (health professionals) Survey of GPs (n=242) 1 Division of General Practice | Australia, February–April 2009 | GPs would like to receive information from all members of the hospital team including the medical officer, palliative care nurse, psychologist and social worker Key triggers for communication included: changes in the patient’s condition; following initial outpatient consultation; at time of admission and discharge; and at treatment milestones. GPs would prefer information electronically and both medical and social information were seen as important. | Rowlands 2010 |</p>
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<td>GPs wish to receive information from all members of the hospital-based lung cancer team if it is relevant to the ongoing care of their patient. Authors suggest technology-enabled solutions, such as an electronic multidisciplinary discharge summary, electronic health record and person-controlled electronic health record, may be strategies to improve both timeliness and access to information.</td>
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</table>
5.12 Quality of life

Interventions and approaches to improve patient quality of life were the focus of six articles identified through this review; these articles discussed a range of issues that impacted on a patient’s quality of life including those relating to treatment side-effects as well as psychosocial issues.84,85,91,114-117

A US study in 2001 indicated that lung cancer patients diagnosed with lung cancer possessed higher levels of distress than patients with other cancer diagnoses.91 The authors suggested that this added distress may in part be because of the poor prognosis and because these patients may feel responsible for their diagnosis through lifestyle behaviours, and for the difficulties that confront their families. They suggested that lung cancer patients should be recognised as a high risk group in terms of psychological distress, and special attention in terms of early detection and intervention is warranted, such as psychosocial screening.91

Two related literature reviews assessed the effectiveness of non-invasive interventions delivered by health professionals in improving symptoms, psychological functioning and quality of life in patients with lung cancer.84,114 The most recent was the 2011 Cochrane review published in the Cochrane Library.84

In summary:

- nurse follow-up programmes and interventions to manage breathlessness may produce beneficial effects
- counselling may help patients cope more effectively with emotional symptoms, but the evidence is not conclusive
- other psychotherapeutic, psychosocial and educational interventions can play some role in improving patients’ quality of life
- exercise programmes and nutritional interventions have not shown relevant and lasting improvements of quality of life
- reflexology may have some beneficial effects in the short term.84

The other studies concluded that:

- most patients would like advice on coping with fatigue, physical distress, treatment, and coping with day-to-day life115
- there is often misunderstanding/misinformation about issues relating to quality of life, especially fatigue116
- non-pharmacological techniques for the management of breathlessness can result in significant improvements in quality of life65
- strategies such as education about potential symptoms of excessive stress, ways to alleviate or moderate stress (e.g. cognitive behavioural therapy or relaxation training) and social support systems should be implemented for at-risk patients117
- nurses are in an ideal position to assess, intervene, and reduce or alleviate the detrimental effects of stress among patients with lung cancer.117
### Table 17  Impact of interventions to improve quality of life for people with lung cancer

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<th>Study description</th>
<th>Design</th>
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| Systematic review (Cochrane review) assessing the effectiveness of non-invasive interventions delivered by health professionals in improving symptoms, psychological functioning and quality of life in patients with lung cancer | Systematic literature review 15 trials | International, search criteria and selection period stated | Nurse follow-up programmes and interventions to manage breathlessness may produce beneficial effects  
Counselling may help patients cope more effectively with emotional symptoms, but the evidence is not conclusive  
Other psychotherapeutic, psychosocial and educational interventions can play some role in improving patients’ quality of life  
Exercise programmes and nutritional interventions have not shown relevant and lasting improvements of quality of life  
Reflexology may have some beneficial effects in the short term                                                                 | Rueda 2011\(^84\)                                                                 |
| A prospective survey of patients with cancer who completed the Brief Symptom Inventory (BSI) to determine the prevalence of psychological distress among cancer patients. Variations in distress among 14 cancer diagnoses were examined | Prospective patient survey Survey of patients with cancer (n=4496) | USA, 1987 and ending in 1993 | The overall prevalence rate of distress was 35.1%. The rate varied from 43.4% for lung cancer to 29.6% for gynaecological cancers  
In a comparison of the 14 cancer diagnoses, lung cancer patients experienced the highest level of distress  
This study offers support for the need to identify high-risk patients (such as lung cancer patients) through psychosocial screening in order to provide early intervention  
Failure to detect and treat elevated levels of distress jeopardises the outcomes of cancer therapies, decreases patients’ quality of life, and increases health care costs                                                                 | Zabora 2001\(^91\)                                                                 |
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<tr>
<th>Study description</th>
<th>Design</th>
<th>Country/ study period</th>
<th>Description/impact</th>
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<tr>
<td>Pilot of educational models to reduce barriers to pain and fatigue management (‘barriers study’) and an interdisciplinary palliative care approach to manage Quality of life concerns for patients with lung cancer (‘QOL pilot’)</td>
<td>Quasi-experimental comparative study (Barriers) Descriptive study (QoL) Barriers study: usual care (n=18) and nurse-led educational intervention to address pain and fatigue (n=28) QOL study: nurse met with patient to assess QOL concerns followed by an MDT conference to initiate supportive care and address the patient’s QOL and symptom concerns (n=10)</td>
<td>USA, study period not stated</td>
<td><strong>Barriers study</strong> Common beliefs such as the inevitability of fatigue, lack of effective treatment for fatigue, the lower priority given to managing fatigue, and concerns of being a complainer when reporting fatigue all improved for the intervention group Patients in the intervention group also revised their incorrect belief that there is a danger of addiction from pain medication Findings suggest that the educational intervention helped to reduce patient barriers related to pain and fatigue management and improved patients’ beliefs on common and pervasive pain barriers, such as tolerance and fear of addiction. <strong>QoL study</strong> Patients have multiple QOL concerns - disease and treatment-related symptoms (fatigue, cough, pain, dyspnea), psychological concerns (anxiety, fear, depression, anger), social concerns (family distress, relationship changes, isolation, disruption of life), and spiritual concerns (meaning, focus on the present) MDT palliative care approach rated as very helpful by both physicians and patients Authors concluded that attention to barriers of symptom management, early referral to supportive care services, and coordination of interdisciplinary care are essential to supporting the QOL of patients with lung cancer</td>
<td>Borneman 2008</td>
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<th>Study description</th>
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<tr>
<td>Description of experiences during radiotherapy of patients suffering from lung cancer</td>
<td>Patient interviews</td>
<td>Sweden, study period not stated</td>
<td>Fatigue was a major experience (for all but one patient) and was expressed in terms of low energy levels and low fitness, sometimes leading to social isolation. All respondents experienced some kind of physical distress during RT – most often pain or breathlessness. To manage the situation during a course of RT, support in the form of assistance from family or friends was described as essential and capable nurses and doctors were also identified as important. Almost all of the patients used some kind of mental pastime (e.g. TV, knitting, reading) and tried to perform activities routinely to manage daily life. Most of the respondents reported different kinds of fear hindered their ability to manage their lives during RT. The authors suggest a new focus (from nurses) on energy levels, fitness and fatigue, patients’ own resources for managing daily life during RT, and a comparison and evaluation of patients’ strategies for overcoming fatigue.</td>
<td>Ekfors 2004</td>
</tr>
</tbody>
</table>
| Prospective cohort study on the development of non-pharmacological techniques and strategies for the management of breathlessness in lung cancer patients in a specialist palliative care setting | Prospective cohort study                             | UK, study period not stated    | Significant changes between first and last visit:  
- frequency of reported dyspnoea ($p<0.001$)  
- functional capacity (walking 100m/stairs) ($p<0.001$)  
- physical symptom distress score ($p<0.01$)  
- activity level score ($p<0.001$)  | Hately 2003 |
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<th>Study description</th>
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<tr>
<td>3x 90 min sessions with a palliative care physiotherapist who provided strategies to reduce breathlessness: breathing retraining simple relaxation techniques activity pacing psychosocial support</td>
<td>Non-systematic literature review Search strategy not detailed, selection criteria not stated, study period unclear</td>
<td>Not stated</td>
<td>Numerous other intervention scores e.g. accepting situation, positive thinking, activity pacing, organising day, relaxing exercises – all improved (p&lt;0.001) Improvements were also noted in other QOL scores such as: patients perception of QOL, hours per day spent lying down, bodily strength, being able to do what you wanted, and things that made patients happy (p&lt;0.01) Overall significant improvements in quality of life and high levels of satisfaction with the interventions</td>
<td>Hansen 2008\textsuperscript{117}</td>
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<tr>
<td>Overview of stress in patients diagnosed with lung cancer</td>
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<td>Patients with lung cancer experience stress related to diagnosis, symptom management issues, and having an illness with an increasing societal stigma The Human Response to Illness Model\textsuperscript{118} gives nurses a comprehensive framework for assessment and management of stress in lung cancer patients. The model explains how psychosocial factors interact with physiological processes. The physiologic stress response is a normal adaptive response elicited by social, psychological, physiologic, or biologic stress. Sufficiently intense and unresolved stress responses may lead to pathophysiologic consequences. Patients with a coexisting illness such as lung cancer are at high risk Nurses are in an ideal position to assess, intervene, and reduce or alleviate the detrimental effects of stress among patients with lung cancer Psychosocial stressors should be determined</td>
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<td>Study description</td>
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<td>during an initial patient assessment to determine whether an individual is particularly vulnerable for a pathologic stress response. Appropriate strategies should be implemented for at risk patients such as education about potential symptoms of excessive stress, ways to alleviate or moderate stress (e.g. cognitive behavioural therapy or relaxation training) and social support systems.</td>
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### 5.13 Clinical practice guidelines and other recommendations

Two clinical practice guidelines that discussed issues relating to models of care were identified through this review, as well as two articles providing clinical practice recommendations. These are briefly summarised below.

England’s [NICE lung cancer guidelines 2011](105) contain the following key priorities for implementation relevant to a model of care:

- **early diagnosis**: the need for increased public awareness about symptoms and signs of lung cancer
- **communication**: the need for a lung cancer clinical nurse specialist to be available at all stages of care to support patients and carers
- **diagnosis and staging**: use of investigations that give the most information about diagnosis and staging with the least risk (including use of PET-CT, EBUS-guided TBNA, EUS-guided FNA, or non-ultrasound-guided TBNA)
- **treatment**: ensure all patients potentially suitable for multimodality treatment (surgery, radiotherapy and chemotherapy in any combination) are assessed by a thoracic oncologist and thoracic surgeon; patients with SCLC should be assessed by a thoracic oncologist within 1 week of recommending treatment
- **managing symptoms**: patients should have rapid access to a team capable of providing interventional endobronchial treatments
- **follow-up and patient perspectives**: offer all patients a specialist follow-up appointment within 6 weeks of completing treatment to discuss ongoing care with regular appointments thereafter.

Scotland’s [SIGN guidelines 2005](53) contain the following recommendations relevant to a model of care for lung cancer:

- **multidisciplinary care**:
  - all patients with a diagnosis of lung cancer should have their treatment and management planned and directed by an MDT
  - allied health professional services should be offered to all patients with lung cancer
- **follow-up**:
  - follow-up by clinical nurse specialists should complement conventional arrangements
  - hospital follow-up should be continued where hospital treatment or specialist advice is still required, or whilst clinical trials are ongoing
  - after surgery, the surgeon should follow up all patients initially; later follow up should be according to local policy
  - after palliative therapy is completed, follow-up should be agreed between the oncologist, respiratory physician, GP and palliative care team
- **communication**:
  - communication skills training should be provided across the MDT.
5.13.1 Other clinical practice recommendations

A commentary by Alberts et al. (2003) provides thirteen, evidence-based recommendations for practice organisation relating to the multidisciplinary approach, referral patterns, management decisions, communication, and ongoing care in the USA. Their recommendations take into consideration the quality of the evidence available and the possible benefit that might be gained. 63

Despite a lack of objective proof for a coordinated approach to care, they concluded that:

- care is best delivered in a multidisciplinary fashion, whether that be via joint conferences, virtual networks, or actual multidisciplinary clinics
- patients with suspected lung cancer should be expeditiously evaluated and referred for management
- clear and understandable information on the diagnosis, treatment options, and possible outcomes should be provided to patients
- treatment recommendations should be based on locally agreed-on adaptations of clinical practice guidelines
- provisions for ongoing care should be apparent to all concerned. 63

A 2010 review by Bauman and Arenburg 62 of current evidence for the diagnostic workup and treatment of lung cancer concluded that:

- it should be assumed all lung nodules or masses are lung cancer until proven otherwise using PET/CT
- the likelihood of malignancy can be estimated using the Swensen model - based upon three radiologic features of the lesion (location, size, and border character) as well as three clinical characteristics of the patient (tobacco use, age, and history of prior malignancy) 119
- determining whether a suspicious lesion is surgically resectable requires accurately estimating the clinical stage of the tumour and the ‘physiologic’ stage of the patient
- the clinical stage determined by CT scan and PET-CT scan should be used for planning surgical intervention (if the patient appears to have disease restricted to the lung) or for determining whether a biopsy is indicated before pursuing any further therapy (in medically unresectable patients, or those with stage III or IV disease)
- good surgical candidates should be referred directly to surgery if evaluation suggests they do not have metastatic or locally advanced disease
- spirometry is recommended in all patients considered for lung cancer resection; both to estimate the patient’s baseline pulmonary function, and to aid in estimating the predicted post-operative pulmonary function
- medically unresectable patients should be considered for radiotherapy.
5.13.2 Compliance with guidelines

Numerous publications discussed guideline adherence and pointed out that if published national or international guidelines were adhered to there was less variation/gaps/delays in diagnosis, staging and treatment.\textsuperscript{56,59-61,69-71,96,98,99}

Stinchcombe and colleagues (2007)\textsuperscript{120} surveyed 347 physicians to assess and compare their beliefs against the American College of Chest Physicians (ACCP) guidelines for the evaluation and treatment of patients with lung cancer.

Most reported having read, consulted, or used the guidelines to set practice policies, and found the guidelines helpful. However, a significant percentage of respondents’ practice beliefs differed from the guidelines on issues such as screening for lung cancer, the survival benefit of chemotherapy in stage IV disease, and postoperative radiation therapy. This indicates that practice beliefs differ from the guidelines in select areas.

5.14 Quality indicators

Quality-of-care indicators are measurable elements of practice performance that can be used to assess the quality or change in quality of the care provided. A summary of the identified articles is provided in Table 18. Two literature reviews addressed quality of care indicators for NSCLC\textsuperscript{39,121} and one review looked at what attributes contribute to good outcomes in the surgical management of early-stage lung cancer and provided examples of implementing improvement.\textsuperscript{57}

The 2011 narrative review by Handy and colleagues noted that quality of medical care is complex to define or explain.\textsuperscript{57} Handy noted a number of efforts at quality defining, quality quantifying and quality improving that have taken place in the USA, UK, Denmark and the Netherlands. Both Tanvetyanon (2009)\textsuperscript{39} and Lennes and Lynch (2009)\textsuperscript{121} noted that quality indicators generally fall into three categories based on the aspect of the care they assess: structure of care, process of care, outcome of care.

Several quality-of-care indicators for NSCLC are available. The use of these indicators to measure practice performance holds the promise of improving outcomes of patients with NSCLC.\textsuperscript{39}

5.14.1 Clinical trials

One randomised trial was conducted to test the effect of an educational video on positively changing patients’ knowledge and attitudes regarding clinical trials thereby increasing trial enrolment.\textsuperscript{122} The brief educational video seemed to be effective in positively changing lung cancer patients’ attitudes about participation in clinical trials. Whilst higher enrolment rates were also observed in the intervention group versus the standard care group, the difference did not reach statistical significance.
5.14.2 Audit/evaluation of service

A number of papers mentioned in discussion that self-assessment or audit of the service was essential to providing effective patient care.69,99,103
Table 18  
Studies exploring quality of lung cancer care

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| Assessment of determinants influencing the quality of care, and variations in the actual quality of integrated care, for NSCLC patients Measurement of quality indicators of professional, organisational, and patient-oriented quality | Prospective survey  Study of patients with NSCLC (n=276) 6 hospitals | Netherlands, September 2004–February 2005 | Patient characteristics proved to have more influence on the scores than professional or hospital characteristics  
Patients with more advanced disease went through the diagnostic course more quickly and began therapy earlier, but were less likely to be discussed at MDT meeting  
Overall the study showed large variation between hospitals with regard to scores for the quality indicators, and that the quality of integrated patient-oriented care for NSCLC patients’ needs improvement                                                                                                                                 | Ouwens 2007 |
| Quality indicators in cancer care: development and implementation for improved health outcomes in non-small-cell lung cancer Review of the current state of quality indicators for NSCLC. Proposed quality metrics focus on diagnosis and staging, timeliness of care, supportive care and patient satisfaction | Narrative review     | USA, no study period stated | Non–small-cell lung cancer (NSCLC) care is multidisciplinary and complex in nature. There are few quality indicators that are widely accepted by the physicians who treat lung cancer. Quality indicators generally fall into three categories based on the aspect of the care they assess: structures, processes, or outcomes  
Summary of quality indicators proposed by:  
- National Cancer Care Network (NCCN) NSCLC Quality Indicators  
- Quality Oncology Practice Initiative (QOPI) from American Society of Clinical Oncology (ASCO)                                                                                                                                                                                                                                                                 | Lennes 2009 |
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<tr>
<td>Quality-of-care indicators for non-small cell lung cancer</td>
<td>Literature review</td>
<td>International, January 2003–May 2009</td>
<td>Several quality-of-care indicators for NSCLC are available. Process-of-care indicators are the most studied. The use of these indicators to measure practice performance holds the promise of improving outcomes of patients with NSCLC. The most common indicators for aspects of service provision were:</td>
<td>Tanvetyanon 2009[^39]</td>
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<td>- structure-of-care quality indicators – the quality of lung surgery, e.g. National Cancer Institute-designated cancer centres or high-volume hospitals</td>
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<td>- process-of-care quality indicators – the receipt of surgery for early-stage NSCLC and the administration of chemotherapy for advanced-stage NSCLC</td>
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<td>- outcome-of-care quality indicators – postoperative morbidity or mortality after lung surgery</td>
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<tr>
<td>Literature review of the attributes contributing to superior outcomes in the surgical management of early stage lung cancer and examples of implementing improvement</td>
<td>Narrative review</td>
<td>USA, not specified</td>
<td>Elements of audit included:</td>
<td>Handy 2011[^57]</td>
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<td></td>
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<td></td>
<td>- problem identification and prioritisation</td>
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<td>- development of evidence based indicators and standard</td>
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<td>- data collection and analysis</td>
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<td>- feedback to providers and managers</td>
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<td>- implementation of quality improvement</td>
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<td>- public release of data</td>
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</tbody>
</table>
5.15 Summary

5.15.1 Quality of the evidence

Seventy seven papers were identified reporting on models of care for lung cancer in Australia and internationally and 12 articles reported on patient needs and preferences in relation to lung cancer care. The majority of the studies were descriptive or before and after studies.

5.15.2 Key findings

The main areas of focus in the models of care literature were:

- multidisciplinary approaches to treatment planning and care
- the role of specialised and high volume diagnostic and treatment services
- coordination of care/navigation
- appropriate follow-up
- early access to palliative care
- end of life care
- involvement of primary care/community-based care
- patient-centred care
- quality of life issues
- adherence to clinical practice guidelines
- audit/quality measurement.

Multidisciplinary care

Studies comparing care and outcomes before and after the introduction/cessation of MDT meetings or clinics demonstrated that MDT teams are associated with reduced time to diagnosis and treatment, and greater use of and more accurate staging.

Specialist care

Involvement of a specialist medical practitioner in the diagnosis and treatment of people with lung cancer has been associated with improved outcomes.

Coordination of care

Despite a lack of high-level evidence, many of the studies advocate for a coordinated approach to care delivered in a multidisciplinary fashion, whether via joint conferences, virtual networks, or actual multidisciplinary clinics.
The reported roles of **lung cancer care coordinators or navigators** vary as do the reported benefits to patient outcomes. Some studies also describe the role of **lung cancer nurse specialists**. Data from the UK National Lung Cancer Audit suggested that patients seen by a lung cancer nurse specialist were more likely to receive anti-cancer treatment compared to those who were not seen by a lung cancer nurse specialist. The authors conclude that further work is needed to explain this observation.

**Follow-up care**

Evidence appears to be divided as to ideal approaches to **follow-up care for people with lung cancer**, in particular the role of nurse-led follow-up and whether there is survival benefit to follow-up by specialist health professionals.

**Early integration of palliative care**

**Early integration of quality palliative care** alongside routine clinical care is feasible and essential from diagnosis. Palliative care is associated with improved survival, improved quality of life, reductions in unnecessary treatment and less aggressive end-of-life care.

**Involvement of primary care**

Consideration of the **role played by primary care professionals in lung cancer care** appears to be important. Articles identified in this review suggest that, while most patients would like their GP to be more involved in lung cancer care, GPs are often ‘cut off’ from cancer care during the treatment phase. GPs show preferences for information to be provided electronically from all members of the hospital team, in particular information about changes in the patient’s condition, and about key diagnostic and treatment milestones.

**Patient-centred care**

**Patient preferences** to be considered alongside a model of care include:

- perceived areas of unmet needs (outside the acute setting, carers/family, diagnosis, communication)
- patient preferences for information
- style of communication
- patient involvement in decision making.

The models of care literature suggested that patients and carers feel unsupported outside of the hospital setting. Some studies reported a mismatch between what patients want and what their doctors perceive they need with regard to information and involvement in decision making.

**Quality of life**

**Psychosocial and supportive care considerations** were explored by some of the identified studies. Non-invasive interventions delivered by health professionals can improve symptoms, psychological functioning and quality of life.
Adherence to clinical practice guidelines

Numerous publications discussed adherence to clinical practice guidelines and pointed out that if published national or international guidelines were adhered to there was less variation/gaps/delays in diagnosis, staging and treatment.

Quality of care

A number of efforts at defining, quantifying and improving quality of care for patients with lung cancer have taken place in the USA, UK, Denmark and the Netherlands. Several quality-of-care indicators for non-small cell lung cancer are available.

5.15.3 Evidence-based tools and resources for lung cancer care

The review set out to identify evidence-based tools and resources that have been used to support service providers to implement and consistently deliver best-practice lung cancer care. No specific tools or resources were identified to support best practice care for the management of lung cancer.

Many countries or jurisdictions use evidence-based guidelines or recommendations to guide lung cancer care or services. Some articles also reported on tools to assess psychosocial distress or information needs; however these were not lung cancer specific.
6. Conclusions

This literature review was conducted as part of the Best practice approaches to lung cancer care project, a Cancer Australia National Lung Cancer Initiative. The overall aim of the project is to define a best practice model of care to improve outcomes for people diagnosed with lung cancer in Australia. The project seeks to establish a comprehensive understanding of current patterns of care and best practice models for the management and care of people with lung cancer to inform future service improvement activities.

The literature review aimed to:

- summarise patterns of lung cancer care in order to define gaps and variations in the treatment and management of lung cancer in Australia
- identify, collate and review current national and international evidence on best practice models of care for the management of people diagnosed with lung cancer, including clinical and supportive care
- identify evidence-based tools and resources used to support service providers to provide best-practice lung cancer care.

Consideration of the findings from this review should take account of the quality of evidence and the time periods over which the data reported in the literature were collected.

- In the patterns of care literature review, the majority of the studies were either cohort or case-control studies or descriptive studies. The studies ranged in size from less than 100 subjects to more than 1,000 depending upon whether their focus was on care in an individual setting or across a region or state. No randomised controlled studies were identified.
- In the models of care literature review, the majority of studies were descriptive or uncontrolled before and after studies. Few of the studies were randomised controlled trials, cohort studies or case-controlled studies. Of the literature reviews identified, the majority were narrative in style and provided no information about the search strategy or selection criteria used, thereby limiting the applicability of their recommendations or findings.

Variations in lung cancer care are apparent in Australia, including: time to diagnosis, access to active treatment, access to re-treatment and access to palliative care. These variations and gaps appear to be influenced by patient demographics, disease or patient health characteristics and health service features.

Aspects of service delivery that appear to be important in lung cancer care include:

- involvement of an MDT
- involvement of a specialist medical practitioner in diagnosis and treatment
- care coordination, including the role of nurse navigators/care coordinators
- early integration of palliative care
- adherence to guidelines/recommendations and measurement of quality/audit
- consideration of supportive care and quality of life needs
- involvement of primary/community based care.

Patient preferences should be an important consideration alongside the development of a model of care for lung cancer.

The literature review has also identified some areas in which evidence is lacking. This includes a clear description of effective service delivery models and health service structures to support best practice lung cancer care and lung cancer-specific tools and resources to support and or streamline optimal care. These two areas will be explored through the evidence-gathering phase of the Best practice approaches to lung cancer care project.
# Appendix I: Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>ACCP</td>
<td>American College of Chest Physicians</td>
</tr>
<tr>
<td>ACP</td>
<td>advanced care planning</td>
</tr>
<tr>
<td>ACT</td>
<td>Australian Capital Territory</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>ASCO</td>
<td>American Society of Clinical Oncology</td>
</tr>
<tr>
<td>ATSI</td>
<td>Aboriginal and Torres Strait Islander</td>
</tr>
<tr>
<td>BSI</td>
<td>Brief Symptom Inventory</td>
</tr>
<tr>
<td>CALD</td>
<td>Cultural and Linguistic Diversity</td>
</tr>
<tr>
<td>CanNET</td>
<td>Cancer Service Networks National Program</td>
</tr>
<tr>
<td>CINAHL</td>
<td>Cumulative Index to Nursing and Allied Health Literature</td>
</tr>
<tr>
<td>COSA</td>
<td>Clinical Oncological Society Australia</td>
</tr>
<tr>
<td>CT</td>
<td>computerised tomography</td>
</tr>
<tr>
<td>DARE</td>
<td>Database of Abstracts of Reviews of Effects</td>
</tr>
<tr>
<td>EBUS</td>
<td>endobronchial ultrasound</td>
</tr>
<tr>
<td>ECOG</td>
<td>Eastern Cooperative Oncology Group</td>
</tr>
<tr>
<td>ED</td>
<td>extensive stage disease</td>
</tr>
<tr>
<td>EPOC</td>
<td>Cochrane Effective Practice and Organisation of Care</td>
</tr>
<tr>
<td>EU</td>
<td>European Union</td>
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<tr>
<td>EUS</td>
<td>endoscopic ultrasound</td>
</tr>
<tr>
<td>FACT-L</td>
<td>Functional Assessment of Cancer Therapy–Lung</td>
</tr>
<tr>
<td>FNA</td>
<td>fine needle aspiration</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<tr>
<td>IARC</td>
<td>International Agency for Research on Cancer</td>
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<tr>
<td>ICU</td>
<td>intensive care unit</td>
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<tr>
<td>IT</td>
<td>information technology</td>
</tr>
<tr>
<td>IUCC</td>
<td>International Union for Cancer Control</td>
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<tr>
<td>LCNS</td>
<td>lung cancer nurse specialist</td>
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<tr>
<td>MBS</td>
<td>Medicare benefit scheme</td>
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<tr>
<td>MeSH</td>
<td>Medical subject heading</td>
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<tr>
<td>MDC</td>
<td>Multidisciplinary Care</td>
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<tr>
<td>MDT</td>
<td>Multidisciplinary Team</td>
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<td>MIR</td>
<td>mortality-to-incidence ratio</td>
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<tr>
<td>MOC</td>
<td>model of care</td>
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<td>n</td>
<td>number</td>
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<tr>
<td>NCCN</td>
<td>National Cancer Care Network</td>
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<tr>
<td>NICE</td>
<td>National Institute for Health and Clinical Excellence (UK)</td>
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<tr>
<td>NSCLC</td>
<td>non-small cell lung cancer</td>
</tr>
<tr>
<td>NSW</td>
<td>New South Wales</td>
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<tr>
<td>NT</td>
<td>Northern Territory</td>
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<tr>
<td>Abbreviation</td>
<td>Definition</td>
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<tr>
<td>NSAHS</td>
<td>Northern Sydney Area Health Service</td>
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<td>OR</td>
<td>adjusted odds ratio</td>
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<tr>
<td>PAG</td>
<td>Project Advisory Group</td>
</tr>
<tr>
<td>PET-CT</td>
<td>positron emission tomography – computerised tomography</td>
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<tr>
<td>POC</td>
<td>patterns of care</td>
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<td>PS</td>
<td>performance status</td>
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<tr>
<td>QOL</td>
<td>quality of life</td>
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<tr>
<td>QOPI</td>
<td>Quality Oncology Practice Initiative</td>
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<tr>
<td>RCT</td>
<td>randomised clinical trial</td>
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<tr>
<td>RT</td>
<td>radiotherapy</td>
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<tr>
<td>SA</td>
<td>South Australia</td>
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<tr>
<td>SAGE</td>
<td>Standards and Guidelines Evidence</td>
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<tr>
<td>SCLC</td>
<td>small cell lung cancer</td>
</tr>
<tr>
<td>SE</td>
<td>socioeconomic status</td>
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<tr>
<td>SIGN</td>
<td>Scottish Intercollegiate Guidelines Network</td>
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<tr>
<td>SWSAHS</td>
<td>South West Sydney Area Health Service</td>
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<tr>
<td>TBNA</td>
<td>transbronchial needle aspiration</td>
</tr>
<tr>
<td>TRIP</td>
<td>Turning Research into Practice</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
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<tr>
<td>UKLCC</td>
<td>UK Lung Cancer Consortium</td>
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<tr>
<td>USA</td>
<td>United States of America</td>
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<td>vs</td>
<td>versus</td>
</tr>
<tr>
<td>WA</td>
<td>Western Australia</td>
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</table>
Appendix II: Key principles and values relating to delivery of cancer services in Australia

| Organisation | Principles | Key elements of a model of care | | | | | | | | | |
|--------------|------------|---------------------------------|---|---|---|---|---|---|
| **Australian government** | | | | | | | | | | |
| National Health Priority Action Council National Service Improvement Framework for Cancer, 2006 | Placing people, families and communities affected by chronic disease at the centre of care | | | | | | | | | |
| | Spanning the continuum of care and life course for the condition | | | | | | | | | |
| | Spanning different clinical and community settings | | | | | | | | | |
| | Supporting the application of evidence-based practice | | | | | | | | | |
| | Focusing on disadvantaged and special population groups having appropriate health services | | | | | | | | | |
| | | | | | | | | | |
| **State and Territory governments’ health departments** | | | | | | | | | | |
| Victoria Victoria’s Cancer Action Plan, 2008-2011 | Multidisciplinary cancer care to ensure effective and efficient patient management | | | | | | | | | |
| | Maximal geographic access for patients and their carers/families | | | | | | | | | |
| | High quality and safe cancer services | | | | | | | | | |
| | Care coordination and supportive care | | | | | | | | | |
| | Reducing unwanted variation in practice (quality monitoring and support) | | | | | | | | | |
### Key elements of a model of care

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Principles</th>
<th>Equitable access</th>
<th>Appropriate care</th>
<th>Governance &amp; leadership</th>
<th>Person-centred care</th>
<th>Quality of care</th>
<th>Coordination of care</th>
<th>Evidence based</th>
<th>Better outcomes / reduce variation in outcomes</th>
<th>Data, IT systems and monitoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer services framework overview, 2003</td>
<td>A commitment will be made to an effectively managed, integrated Statewide cancer program People with cancer will have access to high-quality services, and care will be available as close to their homes as possible, taking account of local population density. Services will be population based Individuals will have access to the full range of services All cancer patients will have the benefit of multidisciplinary, multi-modality coordinated care High-quality cancer care depends upon the achievement of a ‘critical mass’ of expertise and academic leadership Information systems and data collection for the monitoring of cancer services and outcomes will be given a high priority</td>
<td>✓</td>
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<tr>
<td>Cancer Institute NSW, NSW Cancer Plan 2011-15</td>
<td>Reduce variations in cancer outcomes in NSW Reduce the gap between established best evidence, and the care actually provided Patient-centred health systems Facilitate uptake of new evidence into clinical practice A reporting cycle on the performance of cancer services High quality, coordinated and multidisciplinary care</td>
<td>✓</td>
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<td>Organisation</td>
<td>Principles</td>
<td>Key elements of a model of care</td>
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</table>
| NSW Health Optimising cancer care in NSW, 2003[16]                          | Implementation, monitoring and review of standards for cancer care in NSW  
An area-wide approach to optimising cancer care  
Patient-centred care  
Access to appropriate clinical services  
Multi-disciplinary care  
Communication between primary, secondary and tertiary services  
Education, training and continuing professional development                                                                                                                                  | **Equitable access** | **Appropriate care** | **Governance & leadership** | **Person-centred care** | **Quality of care** | **Coordination based on evidence** | **Better outcomes / reduce variation in outcomes** | **Data, IT systems and monitoring** |
<p>|                                                                              |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | ✓ | ✓ | ✔ | | | | | ✓ |
| Queensland Strategic directions for cancer prevention and control, 2009-2012  | No specific principles stated                                                                                                                                                                                                                                                                                                                                                                                                           | - | - | - | - | - | - | - | - | - |</p>
<table>
<thead>
<tr>
<th>Organisation</th>
<th>Principles</th>
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</thead>
</table>
| Western Australia WA Health Cancer Services Framework, 2005 | Safety and quality in cancer care  
Patient focused care with appropriate information and transparency  
Accessibility and timeliness of care  
Addressing all elements of the patient pathway including partnerships with patients, carers and families  
Ensuring multidisciplinary care  
Addressing issues of facilities and workforce  
Supporting staff education and development  
Linking research to care and providing opportunities for enhanced data collection  
Evidence-based therapy |

<table>
<thead>
<tr>
<th>Key elements of a model of care</th>
<th>Equitable access</th>
<th>Appropriate care</th>
<th>Governance &amp; leadership</th>
<th>Person-centred care</th>
<th>Quality of care</th>
<th>Coordination</th>
<th>Evidence based</th>
<th>Better outcomes/reduce variation in outcomes</th>
<th>Data, IT systems and monitoring</th>
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<tr>
<td>Western Australia WA Health Cancer Services Framework, 2005</td>
<td>✓</td>
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### Key elements of a model of care

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<th>Appropriate care</th>
<th>Governance &amp; leadership</th>
<th>Person-centred care</th>
<th>Quality of care</th>
<th>Coordination of care</th>
<th>Evidence based</th>
<th>Better outcomes / reduce variation in outcomes</th>
<th>Data, IT systems and monitoring</th>
</tr>
</thead>
</table>
| South Australia (SA Health in association with Cancer Council SA) SA Statewide cancer control plan, 2011-2015<sup>18</sup> | Save more lives by reducing the number of new cases of cancer and improving rates of survival when cancer does occur  
Ensure people receive effective support as well as the best treatment and care  
Improve the quality of life of people with cancer, cancer survivors and carers  
Address inequalities between more and less advantaged sectors of the community in cancer risk and cancer outcome by addressing the causes  
Build for the future through investment in the cancer control workforce, infrastructure and strong cancer research  
Cancer care is patient-centred and is focused on meeting the needs of people with cancer, their families and carers  
The model of care in SA is evidence based and reflects best practice  
Cancer care reflects consumer principles, in particular as described within the Cancer Australia consumer Group Consensus Values Statement and as described within the Charter of Paris Against Cancer, 2000 | ✓    | ✓   | ✓   | ✓   | ✓   | ✓   | ✓   | ✓   | ✓   | ✓   |
### Key elements of a model of care

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Principles</th>
<th>Equitable access</th>
<th>Appropriate care</th>
<th>Person-centred care</th>
<th>Quality of care</th>
<th>Coordination based</th>
<th>Evidence based</th>
<th>Better outcomes / reduce variation in outcomes</th>
<th>Data, IT systems and monitoring</th>
</tr>
</thead>
</table>
| Tasmania Cancer Framework and Strategic Cancer Plan 2010-2013 | Improving cancer prevention  
Detecting cancers earlier  
Creating an integrated and sustainable system  
Providing a contemporary model of care  
Ensuring a well-governed system | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| ACT Draft Cancer services plan, 2008-2012* | Person centred care and optimal self-care  
Quality, safe and cost effective interventions that build on current best practice models  
Addressing the needs of disadvantaged groups  
Integrated multidisciplinary care  
Cross sectoral partnerships and collaboration | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| NT NT cancer plan (in development) | In development | – | – | – | – | – | – | – | – |

* Quoting principles outlined in ACT Health Primary Care Strategy 2005-2008
<table>
<thead>
<tr>
<th>Organisation</th>
<th>Principles</th>
<th>Key elements of a model of care</th>
</tr>
</thead>
</table>
| Cancer Australia Strategic Plan 2011-2014[^20](p22) | Health outcomes  
Reduced mortality  
Improved equity of outcomes  
Increased access  
Reduced gaps  
Improved wellbeing | Equitable access  
Appropriate care  
Governance & leadership  
Person-centred care  
Quality of care  
Coordination of care  
Evidence based  
Better outcomes / reduce variation in outcomes | ✓ | ✓ | ✓ | ✓ | ✓ | |
| CanNet (Cancer Australia)[^21]  
Cancer Services Network Elements, 2008 | Person-centred care  
Equitable access  
Better coordinated cancer services  
Best available evidence for practice | Equitable access  
Appropriate care  
Governance & leadership  
Person-centred care  
Quality of care  
Coordination of care  
Evidence based  
Better outcomes / reduce variation in outcomes | ✓ | ✓ | ✓ | ✓ | ✓ |
## Appendix III: Selection criteria

### Selection criteria for patterns of care literature review

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
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<tr>
<td>Time period</td>
<td>2000–2011</td>
<td></td>
</tr>
<tr>
<td>Language</td>
<td>English</td>
<td></td>
</tr>
<tr>
<td>Type of article</td>
<td>Full text article available</td>
<td>Conference abstract</td>
</tr>
<tr>
<td>Place of study</td>
<td>Australia</td>
<td>A country other than Australia</td>
</tr>
<tr>
<td>Population</td>
<td>Humans</td>
<td></td>
</tr>
<tr>
<td>Disease area</td>
<td>Lung cancer</td>
<td>Mesothelioma</td>
</tr>
<tr>
<td>Aspects of patterns of care</td>
<td>1. Diagnosis (e.g. genetic testing)</td>
<td>Care in the primary health care setting prior to referral to specialist for diagnosis or treatment (secondary health care setting)</td>
</tr>
<tr>
<td></td>
<td>2. Staging (e.g. uniformity of staging, accuracy of staging)</td>
<td>Palliative care per se (rather than access to palliative care)</td>
</tr>
<tr>
<td></td>
<td>3. Referrals (education of referring physicians, effects of prolonged waiting times on referral patterns)</td>
<td>Studies whose primary focus is informing clinical practice guidelines/treatment regimes</td>
</tr>
<tr>
<td></td>
<td>4. Treatment - surgery - chemotherapy - radiotherapy - palliative care</td>
<td>Studies whose primary focus is assessing the impact and uptake of existing guidelines</td>
</tr>
<tr>
<td></td>
<td>5. Factors that impact on patterns of care (SE status, age, symptoms, performance status, MDT involvement)</td>
<td>Studies whose focus is continuing professional education</td>
</tr>
<tr>
<td></td>
<td>6. Outcomes of differing patterns of care (overall survival; time to relapse; quality of life)</td>
<td></td>
</tr>
<tr>
<td>Objectives</td>
<td>Identifies or addresses specific aspect of patterns of care, referral patterns or practice variation for lung cancer</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Identifies gaps and variations in patterns of care, referral patterns or practice variation in treatment of lung cancer</td>
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</table>
### Selection criteria for models of care literature review

<table>
<thead>
<tr>
<th>Criteria</th>
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</tr>
<tr>
<td>Type of article</td>
<td>Full text article available</td>
<td>Conference abstract</td>
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<tr>
<td>Place of study</td>
<td>Australia or comparable overseas country (New Zealand, Canada, USA, UK and other EU countries)</td>
<td>A health system that is not comparable to the health system in Australia</td>
</tr>
<tr>
<td>Population</td>
<td>Humans</td>
<td></td>
</tr>
<tr>
<td>Disease area</td>
<td>Lung cancer</td>
<td>Mesothelioma</td>
</tr>
<tr>
<td>Aspect of model of care</td>
<td>1. Values and principles 2. Structures and roles 3. Care delivery process 4. Referral process</td>
<td>Care in the primary health care setting prior to referral to specialist for diagnosis or treatment (secondary health care setting). Palliative care per se (rather than access to palliative care) Treatment guidelines</td>
</tr>
<tr>
<td>Objectives</td>
<td>Identifies or addresses some specific structural aspect of the delivery of care for lung cancer Key structural characteristics of the model of care are explicitly identified, considered or evaluated Identifies reasons for success or failure leading to model’s uptake or sustainability over time</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>Education or training initiatives that do not inform model of care directly</td>
</tr>
</tbody>
</table>

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Best practice approaches to lung cancer care - literature review
### Appendix IV: Search strategy

#### Search strategy for patterns of care literature review

PubMed searches were performed using the free text search terms in combination with the Medical Subject Headings (MeSH, the controlled vocabulary used by the National Library of Medicine for indexing articles). CINAHL, PsycINFO and Embase were searched using the same free text search terms and similar controlled search terms (as appropriate for each database).

<table>
<thead>
<tr>
<th>Element</th>
<th>Free text search terms</th>
<th>Examples of PubMed, CINAHL or PsycINFO indexed terms</th>
<th>Relevant terms that might appear in an article</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patterns of care</td>
<td>Patterns of care</td>
<td>Prescribing patterns/ Cancer care facilities/ Multidisciplinary care team/ Health care services/ Health care utilisation/ Primary health care/ Health care delivery/</td>
<td>Variation in outcomes (overall survival, time to relapse, quality of life) Factors that impact on patterns of care (SE status, ECOG performance status, MDT involvement, symptoms, age, rural/remote/metropolitan location, caseload volume) Treatment (surgery, chemotherapy, radiotherapy, palliative care) Provider practices impacting on outcomes Optimal model</td>
</tr>
<tr>
<td>Referral patterns</td>
<td>Referral patterns</td>
<td>Prescribing patterns/ Practice patterns/ Referral and consultation/ Professional referral/</td>
<td></td>
</tr>
<tr>
<td>Practice variation</td>
<td>Practice variation</td>
<td>Practice variation/ Advanced nursing practice/ Utilisation reviews/ Treatment planning/</td>
<td></td>
</tr>
</tbody>
</table>
Search strategy for model of care literature review

PubMed searches were performed using the free text search terms in combination with the Medical Subject Headings (MeSH, the controlled vocabulary used by the National Library of Medicine for indexing articles). CINAHL, PsycINFO and Embase were searched using the same free text search terms and similar controlled search terms (as appropriate for each database).

<table>
<thead>
<tr>
<th>Element</th>
<th>Free text search terms</th>
<th>PubMed MeSH terms</th>
<th>Relevant terms that might be used in an article</th>
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<tbody>
<tr>
<td>Values and principles</td>
<td>Equitable access</td>
<td>Health services accessibility/</td>
<td>equity, access, private, public, rural, remote, tertiary services</td>
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<td></td>
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<td>Health care disparities/</td>
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<tr>
<td></td>
<td>Cultural appropriateness</td>
<td>Cross-cultural comparison/</td>
<td>cultural competency, cultural awareness, cultural safety, ATSI, CALD, ethnic groups</td>
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<tr>
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<td>Quality and safety</td>
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<tr>
<td></td>
<td>Patient outcomes</td>
<td>Outcome assessment (health care)/</td>
<td>patient satisfaction, patient perception of care/treatment, patient awareness of lung cancer nurse services, quality of life, outcome indicators (morbidity, mortality, complications, promptness of treatment, management of physical, psychosocial and psychological symptoms, enrolment in clinical trials)</td>
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<tr>
<td></td>
<td></td>
<td>Patient outcome assessment/</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Outcomes research/</td>
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<tr>
<td></td>
<td></td>
<td>Outcome measures/</td>
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<td>Evidence-based practice/</td>
<td>evidence-based, clinical practice guideline, protocol</td>
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<tr>
<td></td>
<td></td>
<td>Evidence-based nursing/</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Evidence-based medicine/</td>
<td></td>
</tr>
<tr>
<td>Structures and roles</td>
<td>Governance OR leadership</td>
<td>Guidance adherence/</td>
<td>Governance, leadership</td>
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<td></td>
<td></td>
<td>Practice guidelines/</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Outcome</td>
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<tr>
<td>Element</td>
<td>Free text search terms</td>
<td>PubMed MeSH terms</td>
<td>Relevant terms that might be used in an article</td>
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<td>------------------------------------------------</td>
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<tr>
<td></td>
<td></td>
<td>assessment/</td>
<td>multidisciplinary care, interdisciplinary care, case conference, case management, case follow-up data collection</td>
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<tr>
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<td>Multidisciplinary care OR interdisciplinary care</td>
<td>Treatment outcome/</td>
<td>incidence, mortality, cancer registry, stage, treatment modalities, recurrence, population-based data, data sets, monitoring, evaluation, outcomes, quality of care</td>
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<tr>
<td></td>
<td>IT systems AND data systems</td>
<td>Quality of health care/</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Monitoring and evaluation</td>
<td>Patient care team/</td>
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<td></td>
<td></td>
<td>Patient care planning/</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Information systems/</td>
<td></td>
</tr>
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<td></td>
<td></td>
<td>Medial records systems, computerised/</td>
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<tr>
<td></td>
<td></td>
<td>Hospital information systems/</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Quality assurance, health care/</td>
<td></td>
</tr>
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<td>Care delivery process</td>
<td>Proximity to care</td>
<td>Case management/</td>
<td>rural, remote, metropolitan, accessibility of care</td>
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<td></td>
<td>Care coordination</td>
<td>Disease management/</td>
<td>care coordination, continuity of care, care coordinator, integrated care, comprehensive care, organisation of care, shared care</td>
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<tr>
<td></td>
<td></td>
<td>Regional medical programs/</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nursing team/</td>
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<td></td>
<td>Appropriate care setting</td>
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</tr>
<tr>
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<td>Person-centred care OR needs-based cancer care delivery</td>
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Best practice approaches to lung cancer care - literature review
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<tr>
<th>Element</th>
<th>Free text search terms</th>
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<th>Relevant terms that might be used in an article</th>
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<td>cancer services, cancer organisations, support</td>
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<td>communication, written</td>
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<td>relations/</td>
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<td>communication/documentation/</td>
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<td>Nurse–patient</td>
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<td></td>
<td>relations/</td>
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<td>timeliness, waiting time, promptness of</td>
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<td>OR referral patterns</td>
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<td>treatment</td>
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<td>OR practice variation</td>
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<td>patterns of care, referral patterns, practice</td>
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<td></td>
<td></td>
<td></td>
<td>variation</td>
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## Appendix V: Regional distribution of patterns of care studies

<table>
<thead>
<tr>
<th>Study location</th>
<th>No. of studies</th>
<th>Reference</th>
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<tbody>
<tr>
<td>National</td>
<td>2</td>
<td>Wilcoxon 2010</td>
<td>MDC for cancer treatment and planning(^{36})</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Jennens 2004</td>
<td>Clinician knowledge and bias regarding the role of chemotherapy for stage IV NSCLC(^{42})</td>
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<tr>
<td>NSW</td>
<td>10</td>
<td>Vinod 2008</td>
<td>Referral to lung cancer specialist</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Receiving cancer-specific treatment(^{33})</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Vinod 2010b</td>
<td>Referral for RT(^{43})</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Simonella 2009</td>
<td>Receiving cancer-specific treatment(^{45})</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Vinod 2003</td>
<td>Referral to lung cancer specialist</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>Receiving a pathological diagnosis</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Receiving cancer-specific treatment(^{24})</td>
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<tr>
<td></td>
<td></td>
<td>Vinod 2004</td>
<td>Receiving cancer-specific treatment(^{27})</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Estall 2007</td>
<td>RT retreatment utilisation rates(^{44})</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ellis 2004</td>
<td>Adequacy of staging investigations</td>
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<td></td>
<td></td>
<td></td>
<td>RT utilisation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Accuracy of chemotherapy dose calculations(^{29})</td>
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<tr>
<td></td>
<td></td>
<td>Vinod 2010a</td>
<td>Receiving cancer-specific treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>MDT or MDC involvement(^{35})</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stanford 2008</td>
<td>People living in rural or remote areas of Australia had less access to MDC(^{37})</td>
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<tr>
<td></td>
<td></td>
<td>Hui 2005</td>
<td>Patients with lung cancer had similar patterns of care and survival despite differences in socio-economic profiles(^{31})</td>
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<tr>
<td>Vic</td>
<td>3</td>
<td>Richardson 2000</td>
<td>Histological diagnosis</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Treatment type (radiotherapy, chemo or combined)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>MDT involvement</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>treated in a multidisciplinary fashion(^{28})</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Conron 2007</td>
<td>Patients referred to a multidisciplinary clinic received timely diagnosis, staging and treatment and there was good adherence to evidence-based guideline recommendations compared with the traditionally managed Australian lung cancer population(^{34})</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wong 2004</td>
<td>Referral to the Medical Oncology Unit or Palliative Care Unit</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Inconsistency in the choice of chemotherapy(^{52})</td>
</tr>
<tr>
<td>Study location</td>
<td>No. of studies</td>
<td>Reference</td>
<td>Gaps and/or variations identified</td>
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<td>----------------</td>
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<tr>
<td>WA</td>
<td>5</td>
<td>Bydder et al. (2009)</td>
<td>Discussion at MDT meeting(^{38})</td>
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<tr>
<td></td>
<td></td>
<td>Hall 2004a</td>
<td>Socially, economically and locationally disadvantaged groups were less likely to receive surgery(^{40})</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hall 2004b</td>
<td>Non-Indigenous patients were less likely to receive surgery for their lung cancer(^{41})</td>
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<tr>
<td></td>
<td></td>
<td>Hall 2008</td>
<td>Fewer treatment options for rural patients(^{32})</td>
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<tr>
<td></td>
<td></td>
<td>Mina 2004</td>
<td>Survival of patients with operable cancer(^{30})</td>
</tr>
<tr>
<td>SA</td>
<td>1</td>
<td>Bishnoi 2011</td>
<td>Use of combined chemo-radiotherapy radiotherapy delivery Improvements in diagnostic imaging(^{25})</td>
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</tbody>
</table>
References

2. NSW Health, Rehabilitation Redesign Project 2010.
5. WA Health Networks, Model of care overview and guidelines. 2007, Department of Health, Western Australia: Perth.


