



Australian Government
Cancer Australia

Best practice approaches to the management of lung cancer in Australia

Final report



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November 2013

Best practice approaches to the management of lung cancer in Australia – Final report.

Cancer Australia

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Foreword

In recognition of the high burden of disease and poorer outcomes of those affected by lung cancer, Cancer Australia has coordinated the Lung Cancer program over the past four years, which aims to improve the early detection of lung cancer; guide health professionals in delivering best practice care; and address inequalities in outcomes. The program has built an accessible evidence base to support the development and implementation of coordinated lung cancer care in Australia.

This report consolidates the research and findings undertaken by Cancer Australia on best practice service delivery approaches to lung cancer care in Australia. This research was conducted over a two year period as part of the Lung Cancer program and included a national map of lung cancer services; a literature review of best practice models of care and patterns of care; and consultation with lung cancer services and consumers. The research findings highlight variations in care, service delivery and experiences of people affected by lung cancer.

Considering the findings and to improve outcomes for people affected by lung cancer, Cancer Australia has developed a set of national best practice principles and elements for lung cancer care in Australia with input from consumers, researchers, clinicians, service providers and jurisdictional representatives. The *Principles for best practice management of lung cancer in Australia* provide an evidence-based approach to best practice lung cancer care in the Australian context.

We recognise the significant input, collaboration and engagement with many stakeholders across the health system to share experiences, information and insights and their collective effort to improving and delivering a coordinated and system-wide approach to improving outcomes for people affected by lung cancer.

Professor Helen Zorbas AO
CEO
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Executive summary

Lung cancer in Australia

In 2012, 11,270 people were diagnosed with lung cancer in Australia.¹ Mortality from lung cancer is high, with only 14% of people diagnosed surviving for more than five years beyond their diagnosis. People with lung cancer also report a high level of unmet need.

While the number of deaths from lung cancer has decreased over time, lung cancer remains the leading cause of cancer death nationally, accounting for 20% of all cancer deaths in men and 17% in women in 2010.¹

Project overview

The *Best practice approaches to the management of lung cancer in Australia* project was a two-year research project funded by Cancer Australia undertaken from July 2011 to June 2013. The project involved a review of published literature on patterns of care for lung cancer in Australia and national and international literature on models of care for lung cancer. The literature review identified key themes that were explored through a comprehensive national process mapping and stakeholder consultation process.

The project findings represent a synthesis of results from the literature together with consultation results from:

- a **national mapping exercise** to identify where lung cancer services are delivered across Australia and overarching elements of these services
- **telephone consultation with 30 public and private health services** (23 public, three private and four public/private services) providing lung cancer care in a range of metropolitan and regional locations around Australia
- in-depth **site visits to eight services** (seven public services and one private service)
- a **national electronic survey of 41 people affected by lung cancer** and their carers
- **telephone interviews with 11 patients** from three of the eight service sites visited
- a **national workshop** with 38 stakeholders, to review project findings and draft principles and elements of best practice lung cancer care.

A series of **22 best practice case studies** were developed based on the evidence elicited through the site consultation process. These case studies are included in Appendix II, with some highlighted within the body of this report. The case studies represent illustrations of how different services have developed approaches that address the *Principles for best practice management of lung cancer in Australia*.

Research findings

The project findings highlight the importance in the lung cancer pathway that includes:

- a **patient-centred approach** that takes account of individual patient and carer needs and preferences
- clear **definition and promotion of the diagnostic referral pathway** for lung cancer to general practitioners (GPs) and other referrers
- an **agreed approach for identifying and fast-tracking diagnostic tests** for patients with symptoms and/or initial test results suggestive of lung cancer
- **formal input from a multidisciplinary team** (MDT) of diagnostic, treatment and supportive care personnel
- referral of all patients with potentially curable lung cancer to a **surgeon with expertise in thoracic surgery**
- access to **medical and radiation oncology services** appropriate to a patient's diagnosis, staging and preferences
- access to **appropriate clinical trials** regardless of patient location
- **inclusion of palliative care** as an integral part of the lung cancer team and early referral for patients with advanced lung cancer
- access to **supportive care services** based on identified needs, including symptom control, psychosocial support and appropriate rehabilitation for patients and/or carers
- **coordination of the lung cancer pathway** from symptom investigation onwards
- **routine feedback** to and involvement of the patient's GP at key points in the patient pathway
- **support for patients after treatment**, including rehabilitation and survivorship care.

There is currently no clear evidence on which to base a 'standard' approach to follow-up for people following treatment for lung cancer.

Mapping lung cancer services in Australia

Best practice approaches to the management of lung cancer in Australia identified that elements of lung cancer care are provided at a range of services and locations across Australia. A total of 191 services were identified that provide some component of care for patients with the disease. However, only 62 MDTs were identified, the majority in metropolitan and public services.

Principles for best practice management of lung cancer

Evidence from the literature and findings from the health service and consumer consultation, have been used to develop:

- a set of **national best practice principles** providing overarching statements of intent for lung cancer care in Australia
- a series of **best practice elements** articulating specific aspects of service delivery required to achieve the principles.

The five ***Principles for best practice management of lung cancer in Australia*** cover the areas of:

Principle 1: Patient-centred care

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

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

Best practice pathways are in place to support timely diagnosis and staging of lung cancer; and appropriate treatment, supportive, follow-up and palliative care are in place.

Principle 3: Multidisciplinary care

Multidisciplinary care is the standard of care for all lung cancer patients.

Principle 4: Coordination, communication and continuity of care

All relevant health professionals, including GPs, provide coordinated delivery of care across the lung cancer continuum of care.

Principle 5: Data-driven improvements in lung cancer care

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

The principles are intended to guide the delivery of lung cancer care irrespective of service delivery setting. They provide the framework which allows for local adaption, recognising that implementation, including specific role allocation, mechanisms for communication, and coordination of services will vary based on local resources.

1 The need to define best practice approaches to lung cancer care

Significant variation exists across Australia in timely access to the resources and expertise required to effectively diagnose, treat and coordinate care for lung cancer patients, which results in variation in survival and quality of life. Only 14% of those diagnosed with lung cancer survive for five years beyond their diagnosis.

Lung cancer is the fourth most common cancer in both Australian men and women, and the fifth most commonly diagnosed cancer overall, accounting for 8.9% of all new cancers in Australia.¹ Lung cancer is the leading cause of cancer death in Australia, with 8,099 deaths recorded in 2010, accounting for 20% of all cancer deaths in men and 17% in women.¹ Lung cancer survival rates are poor, with only 14 out of every 100 people with lung cancer surviving five years beyond their diagnosis. Incidence and mortality rates for lung cancer vary by location, socioeconomic status and Aboriginal and Torres Strait Islander status.²

Symptoms of lung cancer can be vague and non-specific, presenting a challenge for early diagnosis of the disease. Stigma is part of the lung cancer patient experience and influences community, patient and health professional perceptions and responses to the disease.³ People with lung cancer report high levels of unmet need including depression, anxiety and distress.⁴

Timely and appropriate diagnosis, treatment and ongoing care for lung cancer require the input of a number of health professionals, often across a number of delivery settings. There is variation across Australia in timely access to diagnosis, treatment, supportive care and the coordination of care delivered.⁵⁻⁷ This may result in variation in treatment and outcomes, including reduced overall survival and quality of life.

1.1 Project overview

The overall aim of the *Best practice approaches to the management of lung cancer in Australia* project is to define best practice approaches to improve outcomes for people diagnosed with lung cancer in Australia.

The objectives of this project were to:

- identify, collate and review current evidence on best practice approaches to the management of people diagnosed with lung cancer
- to build the evidence-base to inform a national approach to the delivery of best practice lung cancer care.

The project was undertaken in three phases (see Figure 1):

- **phase one:** an in-depth literature review to identify gaps and variations in lung cancer care and best practice themes to be explored through the project, through a review of:
 - Australian studies of lung cancer patterns of care

- national and international literature on models of lung cancer care
- **phase two:** a comprehensive service, health professional and consumer consultation process to explore the themes identified in the literature:
 - development of a national 'map' of where lung cancer services are delivered in Australia, and identification of overarching features of these services
 - telephone consultation with services providing lung cancer diagnosis, treatment and care in different settings and locations across Australiaⁱ (n=30) and an electronic survey of patients with lung cancer and their carers (n=41);
 - in-depth lung cancer service site visits (n=8) to identify challenges, best practice approaches and innovations, including 11 patient interviews at three services

Please see Appendix III for an overview of the consultation methodology for phase two activities.

- **phase three:** findings from the literature, health service and consumer consultation processes informed a set of draft best practice principles and elements for review at a national expert workshop.

Project findings are available in three supplementary reports:

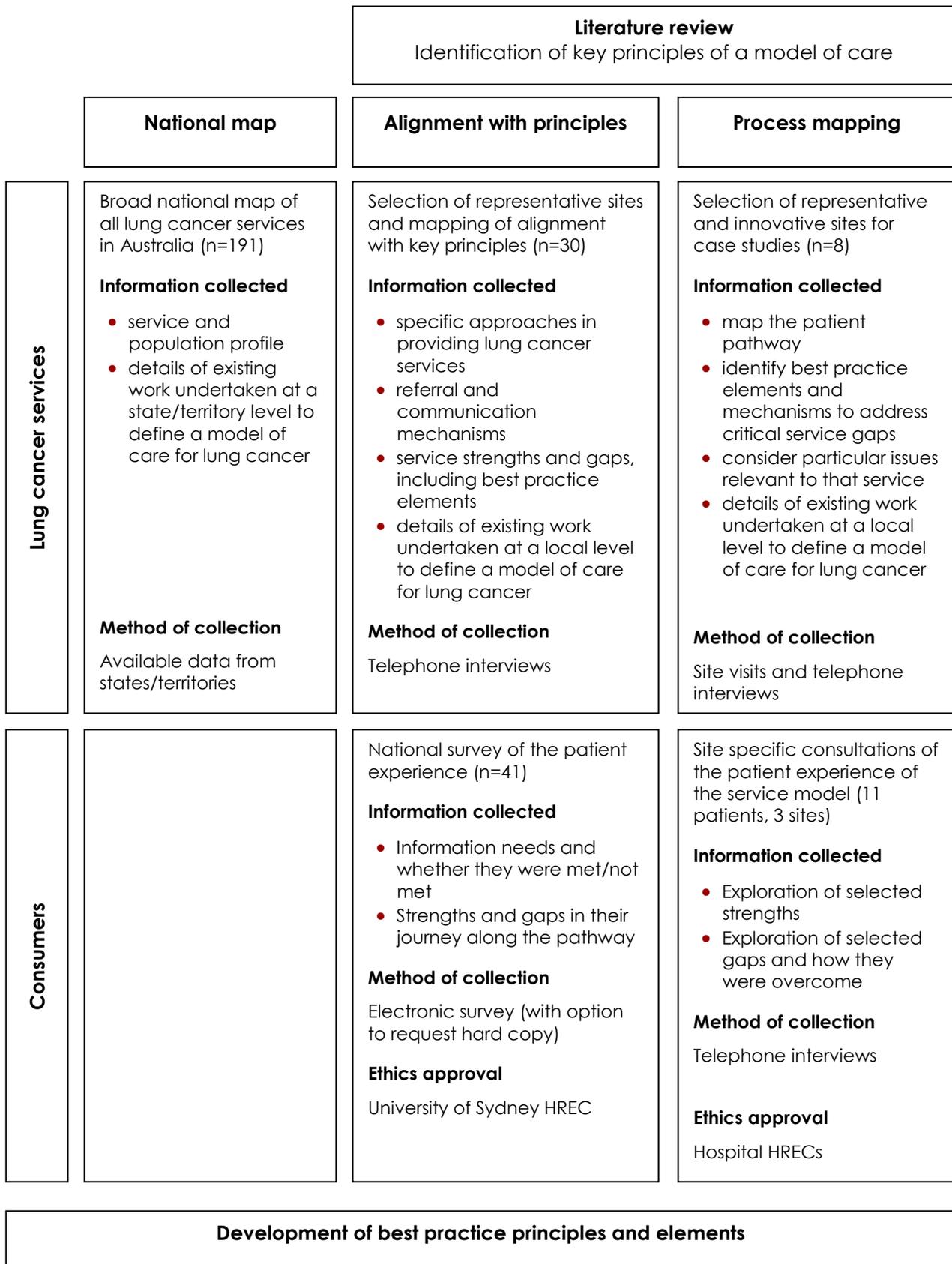
- Cancer Australia. *Best practice approaches to the management of lung cancer – A review of the literature*. Cancer Australia, Surry Hills, NSW, 2013
- Cancer Australia. *Best practice approaches to the management of lung cancer in Australia – Consultation report*. Cancer Australia, Surry Hills, NSW 2013
- Cancer Australia. *Principles for best practice management of lung cancer in Australia*. Cancer Australia, Surry Hills, NSW 2013.

These reports will be available from the Cancer Australia website

www.canceraustralia.gov.au.

ⁱ Services were included from all states and territories, including public and private services managing high and low volumes of patients with lung cancer in metropolitan and regional settings.

Figure 1 Overview of the Best practice approaches to the management of lung cancer in Australia project



2 Evidence from the literature: gaps, variations and themes

The review of published literature on patterns of care and models of care for lung cancer, identified key themes against which the provision of lung cancer care in Australia was explored through consultations with health services and with consumers.

2.1 Gaps and variations

The review of Australian literature on lung cancer patterns of care identified that **variation/gaps** exist for:

- time to diagnosis^{3,4,8-11}
- access to treatment (including curative and palliative treatment)^{3,5,10-15}
- access to re-treatment.¹⁶

Variation in concordance of care with some clinical practice guidelines was also noted.^{11,17}

Factors identified as **influencing components of diagnosis** included:

- patient demographics (age,⁹⁻¹¹ gender,¹¹ rural location,^{3,4,9} Aboriginal and Torres Strait Islander status¹³)
- health status (performance status,¹⁰ presence of co-morbidities¹¹)
- health service features (presence of an MDT,³ health service location^{3,4}).

Factors identified as **influencing components of treatment** included:

- patient demographics (age,^{5,9} gender,⁹ geographic location,^{3,4,17,18} Aboriginal and Torres Strait Islander status¹³)
- disease characteristics (type of lung cancer,⁵ degree of spread⁹)
- health status (presence of co-morbidities,^{5,11} performance status^{5,9,10})
- health service features (low-volume vs. high volume service/specialist,⁹ review by an MDT,^{3,5} geographical location of health service^{3,4,8}).

Studies that have attempted to measure the **impact of variations in care**^{3,8,14,19,27} suggest that timely diagnosis and treatment, appropriate treatment and multidisciplinary care can influence outcomes at the patient, service and system level.

2.2 Themes

Key **service delivery themes** identified as being important to lung cancer diagnosis, treatment and care identified through the review of national and international literature on models of care for lung cancer included:

- **multidisciplinary care**
- **early diagnosis** of lung cancer
- access to **specialist treatment**
- early access to **palliative care**
- **continuity and coordination of care**
- access to **supportive care**
- involvement of **primary care**
- **follow-up and rehabilitation** after lung cancer treatment.

Overarching themes relating to **patient-centred care** and **quality of care** were explored within each of these service delivery themes, as were **differences for specific populations, service locations and service types**.

3 Mapping lung cancer services across Australia

Best practice lung cancer care involves a range of diagnostic, treatment and supportive care services and health professionals at primary, secondary and tertiary levels.

Key lung cancer service components for diagnosis, treatment and care include:

- **diagnosis and staging:** including respiratory medicine, radiology, pathology, nuclear medicine and thoracic surgery
- **treatment:** including thoracic surgery, radiation therapy and/or medical oncology
- **palliative care:** including specialist palliative care providers, members of the lung cancer treatment team, primary care and community care providers
- **supportive care:** including physical, social and practical, psychological, spiritual and information needs and may be provided by medical, nursing and allied health professionals in primary, secondary and tertiary settings
- **primary care:** GPs are key to referral for diagnosis, and are involved in supporting the patient and family members throughout the patient journey.

3.1 Lung cancer services in Australia

Mapping of lung cancer services identified a minimum of 191 services around Australia providing care to people with lung cancer.

The aim of mapping lung cancer services was to achieve a national picture of where lung cancer care is currently being delivered in Australia. This listing was not limited to comprehensive services, but rather was open to all services reporting delivery of one or more components of lung cancer care, and included general cancer specialists and sites providing a single service in isolation (e.g. chemotherapy). Service components were explored by location and volume for the 30 lung cancer services which were subsequently consulted.

Services identified included known specialist lung cancer services, general oncology services providing lung cancer care and chemotherapy day units (see Table 1).ⁱⁱ

Services providing lung cancer care were located in major cities (n=90; capital city n=76), inner regional (n=69), outer regional (n=28) and remote (n=4) locations. Both public (n=135) and private (n=61) services were identified.

A total of 62 lung cancer-specific MDTs were identified, the majority of which were in major cities (n=40) and public services (n=53).

ⁱⁱ It is recognised that other health services may also provide services to lung cancer patients and carers.

Table 1 Summary of identified 'lung cancer services'¹ and key features by state/territory (as at December 2011)

State/ territory	Average new cases pa ²	Total number of lung cancer services ³	Public ⁴	Private ⁴	Rurality classification (as identified via ASGC-RA status)				Located in capital city ⁵	Located in major city in regional/ non- capital city	Known lung cancer MDT	Services providing thoracic surgery
					Major city	Inner regional ⁵	Outer regional ⁵	Remote/ very remote				
ACT	92	4	2	2	4	0	0	0	1	0	1	2
NSW	3090	63	48	16	30	26	8	0	22	7	20	17
NT	59	3	2	1	0	0	2	1	2	1	2	0
Queensland	1790	35	20	15	16	14	4	1	10	6	11	9
SA	771	17	14	3	10	3	2	1	10	0	2	6
Tasmania	280	5	3	2	0	4	1	0	2	0	2	1
Victoria	2329	47	32	18	25	19	4	0	22	1	18	17
WA	880	17	13	6	7	3	6	1	7	0	6	5
Total	9291	191	134	63	91	69	28	4	76	15	62	57

Notes:

- 1 Lung cancer services were identified in the national mapping process.
- 2 Australian Institute of Health and Welfare. Lung cancer in Australia; An overview, 2011.⁶
- 3 'Lung cancer services': this includes a range of health services providing all or part of lung cancer treatment/care to people with lung cancer (e.g. diagnostic, chemotherapy, palliation) and not just services with known MDTs.
- 4 Some services have been classified as both Public and Private for NSW, Queensland, Victoria and WA.
- 5 Four services in NT and Tasmania are classified as being in 'inner or outer regional areas' under ASGC-RA classification but are positioned in the capital.

3.2 Availability of components of lung cancer care in Australia

Lung cancer services were consulted by telephone to elicit information on alignment with best practice principles identified in the literature review. Thirty lung cancer services were consulted, with the following findings:

- the **majority (n=29) reported holding multidisciplinary team (MDT) meetings** at which lung cancer patients are discussed (lung cancer-specific or general cancer meetings)
- **thoracic surgery** was available on site at 18 services (14 metropolitan services and four regional services) and at another site within the health service in one inner regional area
- **radiotherapy** was available on site and/or at another site within the service for 24 services
- **chemotherapy** was available at all 30 service sites, although on-site chemotherapy capacity was limited at two outer regional services
- 24 services were **actively involved in clinical trials** for lung cancer
- **specialist palliative care services** were available on site or at another local site for 27 services
- **cancer care coordinators** were available in 25 services (included lung cancer-specific roles in 15 services and/or general cancer roles in 14 services)
- almost all services indicated that they had **access to most allied health services** particularly in the inpatient setting; psychology services were the least available and access to most allied health services was more limited within the ambulatory setting
- it was rare for **GPs to attend MDT meetings**; where GPs were involved this was typically through a GP liaison role.

Some differences in availability of lung cancer service components and approaches to delivery of lung cancer care were apparent between service locations and service types.

The **metropolitan services** (n=16) consulted appeared more likely than the regional services to:

- treat a higher volume of lung cancer patients
- hold more frequent MDT meetings (for high-volume services)
- have access to all diagnostic technologies (including positron emission tomography [PET] and endobronchial ultrasound [EBUS])
- have all/most treatment components on site or closely located (particularly thoracic surgery and radiotherapy).

Aspects of service availability and delivery for the **regional services**ⁱⁱⁱ (n=14) consulted included:

- increasing use of telehealth for MDT treatment planning and patient consultations

ⁱⁱⁱ The Australian Standard Geographical Classified Remoteness Areas (ASGC-RA) was used to classify the identified services. 'Regional services' include those classified as within inner or outer regional areas, including two services within capital cities.

- greater likelihood of a general rather than lung cancer-specific MDT meeting (particularly for smaller volume services)
- stronger connections between acute care, palliative care and primary care
- limited access to psychologists
- limited access to allied health providers with specific expertise in supporting people with lung cancer and their carers
- increased likelihood of shared care approaches with primary care.

Aspects of service availability and approaches in the **private services** consulted included:

- less well established lung cancer MDT meetings (in some services, private patients are presented at public MDT meetings attended by private providers)
- some protracted diagnostic processes were reported at other private providers; delays were considered to be related to limited referral information, the lack of a rapid referral process and/or nihilistic specialist views
- challenges for involvement of palliative care
- limited access to cancer care coordinators
- limited access to the full range of supportive care services, especially within the ambulatory setting.

Following these telephone consultations, in-depth lung cancer service site visits were conducted, to identify challenges, best practice approaches and innovations, including 11 patient interviews at three services.

4 Approaches to lung cancer service delivery: overview of key themes

Drawing on key research findings across service delivery themes identified in the literature review, findings are presented from health service and consumer consultations. Each theme also identifies a section on innovation and implementation, providing examples of how themes are applied in practice.

4.1 Patient-centred care

4.1.1 Literature review findings

Patient- and family-centred care is a key dimension of high-quality health care. Patient-centred care emphasises and values the individual's experiences in informing their own health care and broader service development, leading to improved patient outcomes.²⁰⁻²²

Evidence indicates that people with lung cancer have high levels of unmet need,⁷ and that patients and carers may feel unsupported outside the hospital setting.²³ The high levels of unmet need as well as stigma and nihilism associated with lung cancer² are likely to exacerbate psychosocial issues experienced in this patient group. It is important that these needs are taken into account throughout the patient journey.

People from regional and rural locations, individuals from Aboriginal and Torres Strait Islander or culturally and linguistically diverse communities and older people can have specific needs in relation to the management and care of lung cancer.

4.1.2 Health service consultation findings

Services use a range of approaches to provide information and support to patients with lung cancer and their carers, including:

- verbal discussions with specialist medical, nursing and allied health professionals
- provision of general and lung cancer-specific information resources
- education sessions with nursing staff prior to treatment (radiotherapy, chemotherapy)
- use of screening tools to identify areas of unmet supportive care need
- 'family conferences' (more common for palliative care).

No services reported formally seeking feedback from patients with lung cancer and their carers. However, some reported mechanisms to gain feedback from all health service consumers or from cancer patients within a cancer service.

Improvements suggested by services that would assist in supporting a patient-centred approach to care included:

- increasing awareness by staff without specific lung cancer expertise (e.g. surgical nurses and radiation therapists) about issues for people with lung cancer
- ensuring all staff have appropriate skills to respond sensitively to patients' and carers' needs, to facilitate informed decision-making and respect their choices.

One service described particular issues in relation to elderly patients with lung cancer, in particular, the need to ensure that the decisions to treat or not to treat are taken on the best available evidence. This includes careful assessment of the patient's health status including co-morbidities and functional capacity and of the need for additional support for the patient and carer through treatment.

4.1.3 Consumer consultation findings

Consumer survey feedback highlighted that improvements could be made in:

- communication of information about treatment options to patients and carers
- the amount of information provided about diagnosis, treatment and what to expect during and after treatment
- support provided to carers of people with lung cancer
- coordination of diagnosis and treatment
- the way in which palliative care is introduced and discussed with patients and carers.

"I would have liked more information while I was going through everything actually on the cancer itself. Like you know you've got cancer, but I had to Google a lot how the cancer grows and how it actually works in your body, and what it takes to not get cancer."

"I appreciated the honesty, you know, there was no fluffing around the issues, I was told up front as to what the situation was. The only thing that I was left in the dark a little bit about I guess was the extent of the effects of the treatment on myself and the severity, the harshness of it."

"I must say that from the minute I walked in the door of that clinic every member of staff just made me feel so welcome and the only way I can explain it is they made me feel worthwhile."

4.1.4 Innovations and implementation

One large metropolitan service has developed a geriatric oncology service as a component of medical oncology, with treatment decisions informed by a geriatric assessment. The service is offered to all patients over 70 years of age. For more information see Case study 1 in Appendix II.

4.2 Patient-centred care: issues for specific populations

Key evidence presented below relates to populations that may have specific needs in relation to lung cancer care diagnosis, treatment and care: people from regional and rural Australia; people from Aboriginal and Torres Strait Islander peoples; people from culturally and linguistically diverse backgrounds; and older people.

Many of the challenges and needs identified for people from these populations are not unique to people with lung cancer and may have broader application to people with other cancer types and/or other health conditions. However, it is likely that some of the issues identified may be particularly relevant for people with lung cancer and their families because of:

- the high number of co-morbidities and complex care needs of people with lung cancer
- the fact that lung cancer is often diagnosed at an advanced stage
- the significant symptoms associated with lung cancer and the side effects of treatment.

It is important to note that, as with the overall population, considerable diversity exists within specific populations. This highlights the importance of a patient-centred approach that tailors care to individuals and their families.

4.2.1 Literature review findings

Within Australia:

- 31% of the population live outside major cities (19% in inner regional areas, 9% in outer regional areas and just over 2% in remote or very remote areas):
 - the incidence of lung cancer in men and mortality from lung cancer in men and women tends to increase with increasing geographic remoteness⁶
- 3% of the population in Australia identifies as being of Aboriginal or Torres Strait Islander descent
 - incidence and mortality from lung cancer are significantly higher for people from Aboriginal and Torres Strait Islander communities compared with the rest of the Australian population⁶
- 19% of the Australian population speak a language other than English at home
 - the incidence of lung cancer for people from culturally and linguistically diverse backgrounds varies (higher in people born in North-West Europe and lower in people from Southern and Central Asia compared with the Australian-born population)⁶
- The occurrence of lung cancer was strongly related to age in 2007, with 84% of new lung cancers in males and 80% in females diagnosed in the age range of 60 years and over. While the mean age at diagnosis was 71 years for males and 70 years for females, the highest rate was in those aged 80 to 84 years.⁶

4.2.2 Health service consultation findings

Challenges identified by some regional services providing care for **regional and rural patients** included:

- the need for patients and their carers to travel for diagnostic and treatment services and the associated cost and disruption to their home life
- the fact that city-based services may be unfamiliar and confusing (particularly for patients from Aboriginal and Torres Strait Islander communities – see below)
- the challenge of implementing specific strategies to facilitate timely access to diagnostic services for patients living in regional or rural Australia, e.g. inpatient admission was constrained by competing service demands.

Challenges identified by services providing care for patients from **Aboriginal and Torres Strait Islander communities** included:

- the diversity of patients and carers and the need to respond flexibly to their needs
- the high proportion of patients diagnosed with advanced disease, resulting in limited treatment options
- the need to build trust between patients, their family members and service providers
- the importance of a clear follow-up plan for patients when they return to country.

Overall, most services had access to Aboriginal and Torres Strait Islander Health Liaison Officers who were available to support all Aboriginal and Torres Strait Islander Health patients and carers accessing the health service (not just cancer). Two services had Aboriginal Cancer Care Coordinators to provide additional support to Aboriginal and Torres Strait Islander patients with cancer and their carers.

About half of all services reported treating people from **culturally and linguistically diverse communities** frequently or very frequently within their service. These services identified:

- the need for access to interpreters
- the challenge of disclosing personal health information via an interpreter in smaller communities in which the interpreter is known personally to community members
- the importance of cultural awareness by health professionals in relation to breaking bad news, disclosing a diagnosis and approaches to making decisions about treatment.

4.2.3 Consumer consultation findings

Consumer survey feedback from some respondents living in regional and rural communities indicated dissatisfaction with waiting times, access to information about travel and accommodation and care coordination. However, numbers were not high enough to determine whether there were significant differences compared with people receiving care in metropolitan locations.

One consumer survey respondent identified as being from an Aboriginal and Torres Strait Islander community and six reported speaking a language at home other than English. No specific cultural issues or differences were identified for these respondents.

“But we had to do a lot of travelling and were never offered any help with that or accommodation.”

4.2.4 Innovations and implementation

One major regional tertiary hospital servicing a large geographic area, including rural and remote towns, is successfully using telehealth to facilitate local access to chemotherapy. This requires relevant videoconference technology to be available at all sites as well as a local physician or GP to support patient management. Telehealth consultations include the patient (and carers), supported by a local nurse or allied health provider as well as any relevant medical personnel. For further information, see Case study 2 in Appendix II.

One regional cancer service provides cancer services to people from Aboriginal and Torres Strait Islander communities from urban, rural and very traditional cultural backgrounds. In addition to the general Aboriginal Health Workers/Liaison Officers available for the whole health service population, an Aboriginal Cancer Care Coordinator role has been developed. This role has specific knowledge of cancer services and care, as well as the culture, language and patient-centred needs of these diverse communities. For more information about this approach to managing care for people from Aboriginal and Torres Strait Islander communities see Case study 3 in Appendix II.

4.3 Early diagnosis of lung cancer

4.3.1 Literature review findings

Symptoms of lung cancer are vague and non-specific. A delay in diagnosis can affect treatment choices and result in sub-optimal patient outcomes, including reduced functional status, quality of life and mortality for patients with potentially curative disease.^{4,8,9}

A key factor in the timeliness^{iv} of the diagnostic process is appropriate referral for investigation of symptoms. Involvement of a specialist medical practitioner in the diagnosis and treatment of people with lung cancer has been associated with improved outcomes.²⁴ In 2012, Cancer Australia released a guide for GPs on investigating symptoms of lung cancer. The guide encourages urgent referral of patients with signs or symptoms of lung cancer to a specialist linked to a lung cancer MDT.²⁵

4.3.2 Health service consultation findings

The service consultation highlighted the complexity of the pathway to definitive lung cancer diagnosis and staging. Entry points for people with suspected or confirmed lung cancer included referral from a GP, hospital emergency departments or another hospital department or specialist.

^{iv} The project explored from a consumer and health service perspective the 'timeliness' of diagnosis and treatment. It was noted by a number of health services that, while for some patients a delay in diagnosis or treatment may not ultimately influence outcomes, it can have a significant effect on emotional wellbeing.

Diagnosis and staging involves multiple specialties and access to specialist imaging technology, including positron emission tomography (PET) and endobronchial ultrasound (EBUS). While diagnostic and staging tests for lung cancer were common across services, the approach to triage and coordination of the diagnostic pathway varied considerably. A number of services reflected on the need for patients to return several times for tests before a definitive diagnosis and stage could be confirmed.

Key challenges associated with timely diagnosis and staging for lung cancer included:

- awareness of referring doctors regarding the appropriate referral pathway and information required prior to diagnostic investigations
- coordination of a complex diagnostic pathway for patients with significant co-morbidities
- timely access to diagnostic and staging technologies (including delays in on-site access to services used by other departments, e.g. CT scanning and bronchoscopy, and lack of on-site access to all diagnostic technologies for regional services)
- perceived nihilism of some referring doctors, diagnostic clinicians and/or health services
- sharing of information from multiple providers across different information platforms
- access to adequate samples for molecular testing.

Key enablers for facilitating timely diagnosis and staging for lung cancer included:

- an agreed triage approach (e.g. review and prioritisation of cases at point of entry by registrars or medical consultants, rapid access clinics)
- coordination of diagnostic and staging procedures (e.g. scheduling same-day appointments for regional patients, planning tests on a 'what if' basis for patients with a high suspicion of lung cancer)
- common information platforms to facilitate streamlined transfer of test results
- good communication across public and private sectors
- provision of clear direction provided in advance to radiologists and respiratory physicians about how pathology samples should be collected and used, with a view to limiting the need for repeat sampling.

4.3.3 Consumer consultation findings

Feedback from the consumer survey highlighted that:

- time to first specialist appointment ranged from two weeks to two months
- time to definitive diagnosis ranged from two weeks to two to three months; the majority of consumers who reported a longer wait for diagnostic results felt this timeframe was too long.

"I don't smoke. I had a productive cough for more than 12 months. I was treated as if I had an infection or asthma because the GPs did not relate lung cancer to a non-smoker."

"...it's a very, very long day [to have a PET]. I mean I suppose some people go down and stay overnight but I found I couldn't afford to do that. But apart from that it was okay. The test itself was okay."

"I was very, very lucky that I have got an excellent GP.... actually the surgeon commented about that when I first met him. He was looking at the X-ray. He said "You must have a good GP to pick it up so early."

4.3.4 Innovations and implementation

Two examples of rapid access clinics were described through the site visits. These were both designated lung cancer diagnostic clinics – one held weekly and one twice weekly. Views about the value of rapid access clinics varied. For further information see Case study 5 in Appendix II.

4.4 Multidisciplinary care

4.4.1 Literature review findings

Diagnosis, treatment and care for people with lung cancer requires input from a range of disciplines. Evidence indicates that a multidisciplinary approach to cancer care (and lung cancer care) can improve patient survival and quality of life, improve access to active treatment and the delivery of best practice care, and facilitate the provision of information and support for patients.^{3,5,26–30}

4.4.2 Health service consultation findings

Disciplines commonly represented at lung cancer-specific MDT meetings included respiratory medicine, thoracic or cardiothoracic surgery, medical and radiation oncology, radiology, nuclear medicine, pathology and lung cancer nursing/cancer nurse coordinators.

Variations were apparent in MDT meeting processes, including frequency and duration of meetings, attendees and approach to setting meeting agendas and documenting outcomes. The majority of services consulted did not have formal criteria to decide which patients with lung cancer are discussed at the MDT meeting.

Key challenges associated with lung cancer MDT meetings included:

- the need for formalised processes/systems for effective MDT meetings
- the need for common access across services to patient information and test results
- the need for access to or availability of specific specialists in some contexts
- how to identify patient supportive care needs within limited MDT meeting times
- reliance on individuals rather than embedded systems to drive improvements.

Key enablers associated with lung cancer MDT meetings included:

- a clear MDT meeting agenda listing patients to be discussed and reason for presentation
- access to all relevant diagnostic and staging information for each patient presented

- use of telehealth for facilitating MDT meetings across different sites within a health service or network or to enable input from a metropolitan specialist into a regional MDT with no local access to that specialist input
- an experienced Chair who seeks input from all attendees and confirms recommendations
- a collegiate atmosphere to facilitate communication within and outside the MDT meeting
- timely documentation and communication of meeting outcomes to all relevant team members, including the patient's GP.

In addition to MDT meetings, multidisciplinary outpatient clinics were also identified as an important mechanism for facilitating multidisciplinary input, reducing patient burden of unnecessary appointments and enhancing coordination of care.

4.4.3 Consumer consultation findings

Feedback from the consumer survey highlighted that patients and carers understood that their diagnosis and treatment would be discussed with other health professionals. Over half of the respondents to the electronic survey indicated awareness that their care would be discussed at an MDT meeting.

4.4.4 Innovations and implementation

One metropolitan lung cancer service had developed a lung cancer database specifically for that service to better merge MDT meetings and decision-making processes. The database is web-based and MDT members have a login and password. For more information see Case study 15 in Appendix II.

4.5 Access to specialist treatment

4.5.1 Literature review findings

The disciplines involved in optimal treatment and care for lung cancer depend on individual patient and disease characteristics. Evidence indicates that:

- involvement of medical practitioners with a specialist interest in lung cancer treatment (and linked to an MDT) provides better access to appropriate treatment and improved patient outcomes^{3,15,28,31}
- lung cancer treatment may be influenced by service volume and level of specialty of treating clinicians, with higher volume and specialist lung cancer services/service providers more likely to promote active treatment.⁹

Factors that appear to influence components of treatment for lung cancer include patient demographics, disease characteristics, health status, and health service features (see page 14).

4.5.2 Health service consultation findings

Overall, services reported that, once diagnosed, lung cancer treatment is offered in a timely manner.

Key challenges relating to timely provision of specialist treatment for lung cancer included:

- how to provide integrated, coordinated care involving different medical specialists (respiratory medicine, thoracic surgery, medical/radiation oncology and palliative care)
- sharing of information from multiple providers across different information platforms
- local access to all treatment modalities (especially for regional services)
- access to clinical trials.

Key enablers for timely access to specialist treatment for lung cancer included:

- joint clinics (e.g. medical and radiation oncology, oncology and palliative care)
- co-location of services
- personal relationships and informal/formal networks between health professionals
- triage processes (e.g. prioritising radiation therapy for spinal cord compression)
- common databases/information platforms facilitating shared access to information.

4.5.3 Consumer consultation findings

Feedback from the consumer survey highlighted that time to treatment ranged from one week to two months after diagnosis. Views on the appropriateness of the longer waiting times varied.

"Initially I felt a whole month to wait for treatment was too long but when it was explained that everything needed to be set up so the treatment ran concurrently and smoothly, I settled down."

"...each specialist involved made me feel that I was in good hands...just as long as my diagnosis and the start of chemotherapy fitted their timetable."

4.5.4 Innovations and implementation

One site in a regional city reported that the appointment of two new cardiothoracic surgeons with a pro-active approach to the surgical management of people with lung cancer has changed local service delivery even though lung cancer surgery remains a small part of their overall workload. The two surgeons alternate attendance at the weekly lung cancer MDT meeting to accommodate a cardiac surgery operating list at the same time. For more information see Case study 8 in Appendix II.

4.6 Early access to palliative care

4.6.1 Literature review findings

Early integration of quality palliative care alongside routine clinical care is essential from the point of diagnosis of advanced lung cancer. Evidence indicates that early access to palliative care is associated with improved survival and quality of life, reduction in unnecessary treatment and less aggressive end-of-life care.^{32,33}

4.6.2 Health service consultation findings

Referral of people with lung cancer to palliative care services was reported to occur through formal and informal pathways. Referral was most common for people with advanced stage lung cancer for whom active treatment is no longer appropriate and for patients with significant pain or symptom control issues, regardless of treatment status.

Services acknowledged that elements of the palliative approach may be undertaken by other members of the lung cancer team and do not rely on specialist palliative care support.

Key challenges in relation to timely access to palliative care included:

- barriers to referral and uptake of palliative care from health professionals and consumers because of a perception it means giving up hope and a reluctance to transfer care from treating clinicians
- recognition of the benefits and optimal time for involvement of palliative care for people with lung cancer
- the need for palliative care services to be available
- the need for a shared understanding of the role of GPs in palliative care.

These challenges are not specific to lung cancer but may be more relevant for people with lung cancer and their carers because of the high proportion of patients diagnosed with advanced disease, and the significant associated symptoms and co-morbidities.

Key enablers for timely access to palliative care included:

- an 'all of service' approach to some aspects of palliative care (e.g. discussion of goals of care and advance care planning)
- co-location of palliative care within a cancer service to support informal appointments and introduction to team members for people still receiving active treatment
- introduction of the benefits of palliative care on the basis that services may not need to be accessed until later
- description of palliative care as a service that can assist with control of symptoms and living with lung cancer rather than as a service associated with end-of-life care.

4.6.3 Consumer consultation findings

Of the 41 respondents to the electronic consumer survey:

- 20 reported being given information about palliative care services; of these, half reported being given this information early in the patient pathway
- only three reported that provision of palliative care information was 'too soon'
- two respondents indicated the information was provided too late.

"It was confronting to think about palliative care when I was first receiving treatment but I think it's all confronting when talking about our mortality especially as I was relatively young (age 54). It is important I think to look at the whole picture and possibilities, however daunting."

4.6.4 Innovations and implementation

In one cancer service within a regional city, a nurse practitioner role is evolving to work at the interface of oncology and palliative care services. Within another service a similar model was being used for neuro-oncology patients where a nurse coordinator was linked with all patients with poor prognosis brain tumours. For more information see Case study 17 in Appendix II.

4.7 Continuity and coordination of care

4.7.1 Literature review findings

Continuity of care is defined as the delivery of services by different providers in a coherent, logical and timely fashion, consistent with the patient's medical needs and personal context. Three key approaches are required to ensure continuity and coordination of care: informational approaches, management/organisational approaches and interpersonal approaches.³⁴

Australian research has identified a range of challenges associated with specific cancer care coordinator roles, including limited resources to meet increasing service demand.^{35,36} However, evidence suggests the need for coordination of care to be provided by a designated member of the team to manage the care process at different points in the pathway, including the development and communication of a care plan and ensuring that all the care needed is arranged and delivered.³⁷

4.7.2 Health service consultation findings

Services typically reported that elements of lung cancer care coordination are undertaken by one or more individuals some of whom were in designated lung cancer care coordinator roles. Other mechanisms to support continuity and coordination of care included systems for information transfer across and within services, organisational arrangements and interpersonal relationships.

Key challenges associated with continuity and coordination of care included:

- how best to help people with lung cancer and their carers navigate a complex diagnostic and treatment pathway that may span different services and locations

- sharing information across departments and services using different information platforms
- determining key points at which care coordination is needed, with recognition that much of the coordination is required during the diagnostic phase
- whether continuity and coordination of care requires a dedicated cancer care coordinator role and, if so, whether such positions are sustainable.

The complexity of the diagnostic and treatment pathway and the fact that patients diagnosed typically have complex care needs, does indicate a need to identify optimal approaches to ensure coordination of care.

Key enablers for continuity and coordination of care for people with lung cancer included:

- shared information systems/platforms
- processes to support information sharing between service providers and health professionals, e.g. MDT meetings
- professional relationships and networks between providers within and across services
- good written documentation about the patient
- approaches that support empowerment of patients and carers to actively participate in the coordination of the journey and to identify times at which they need assistance from the health care team
- identification of care coordination tasks that can be undertaken by staff other than designated cancer care coordinators, e.g. appointment scheduling by clerical staff and liaison with other services the patient may be accessing.

4.7.3 Consumer consultation findings

Around three-quarters of the consumer survey respondents said they felt well informed about where to go and about next steps. However, around one-third reported feeling confused or frustrated by the hospital system and indicated they did not know who to contact if they had concerns.

"... [it would have helped] being guided through a mine field of information and where to go and what to do."

"When you first go to the specialist and then you agree, yes I'll have chemotherapy. Then you meet with an oncology person who's your person all the way through who you can ring and ask questions and they find out everything for you and they're really, really good."

4.7.4 Innovations and implementation

In one regional area, a system of Cancer Link Nurses has been established to support patients from a large geographic area. A similar model is available in one state where a system of central cancer care coordinators have been established with regional cancer care coordinators in key towns throughout the state. For more information see Case studies 19 and 20 in Appendix II.

4.8 Access to supportive care

4.8.1 Literature review findings

Supportive care services have a significant role to play in the care of people with lung cancer, given these patients have the highest level of psychosocial distress among cancer patients and there is a high level of co-morbidities for these patients.^{7,12} There is increasing evidence of the role and value of using formal screening processes to identify patients' supportive care needs to facilitate appropriate referral, and of the range of interventions in improving physical symptoms, social and psychological functioning and quality of life.³⁸

4.8.2 Health service consultation findings

Access to allied health disciplines to address specific supportive care issues for people with lung cancer was reported to occur on a referral basis in both inpatient and ambulatory care settings, regardless of location. Timeliness of access appeared to be constrained by resource issues in at least some services.

Approaches to identify patient supportive care needs included general assessment processes and formal screening for supportive care needs.

The cancer care coordinator (where available) and other cancer-specific nursing roles (e.g. radiotherapy nurses) and medical professionals were seen as key providers of at least base level supportive care for people with lung cancer.

Key challenges in relation to access to supportive care included:

- how best to identify patient and carer supportive care needs
- how to address identified supportive care needs if available services are limited
- how to integrate supportive care into a medically focused service delivery model
- how to ensure that patients take up supportive care referrals when made
- how to coordinate supportive care needs for patients and carers travelling from rural and regional settings for treatment.

Key enablers in relation to access to supportive care included:

- use of validated supportive care screening tools as part of standard practice
- promotion of psychosocial care as 'everyone's business' with inclusion of specific questions about supportive care needs included in standard patient consultations
- reinforcement by all health professionals of the importance of supportive care in improving patient and carer outcomes to normalise referrals
- routine provision of information about available accommodation and transport support to people from regional and rural areas
- use of supportive care approaches such as peer support models that do not rely on allied health services

- acknowledgement of carer support needs as part of consultations.

4.8.3 Consumer consultation findings

Feedback from the consumer survey highlighted that:

- at least half reported that emotional needs (patient and/or carer) were addressed all or most of the time
- fewer than half reported involvement of allied health professionals (including dietitians, physiotherapists and counsellors) in their treatment and care.

"I haven't seen any physios, I haven't seen any dieticians. I haven't had any advice on that whatsoever. And my, quite candidly, my food intake has been atrocious."

4.8.4 Innovations and implementation

In one private service, access to allied health services was very constrained (with the exception of pastoral care). To support improved access to allied health services, two family trusts have provided funding support. As part of this initiative, a psycho-oncology service for all cancer patients with a research focus was established in collaboration with the Psychology Department at the University linked with the health service. For more information see Case study 10 in Appendix II.

4.9 Involvement of primary care

Involvement of primary care is integral to the lung cancer pathway, from the point of referral for investigation of symptoms, to provision of supportive care and palliative care, overall coordination of care and follow-up care. Primary care is therefore relevant to each of the different *Principles for best practice management of lung cancer in Australia*.

4.9.1 Literature review findings

While most patients would like their GP to be more involved in lung cancer care, GPs are often 'cut off' from cancer care.³⁹ 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.⁴⁰

4.9.2 Health service consultation findings

Effective and timely communication with and involvement of primary care in the care pathway of patients with lung cancer and their carers can be challenging. Communication between services providing care for people with lung cancer and the patient's GP was reported to occur most commonly in writing at key points in the patient pathway. However, the approach does not appear to be routine or consistent across services.

Key challenges relating to the involvement of primary care in diagnosis and care of people with lung cancer and their carers included:

- GPs having knowledge about lung cancer signs, symptoms and referral pathways
- administrative delays in sending information to GPs
- GPs having adequate time available to participate in MDT meetings
- mobile GP workforce and lack of GPs in some regional and rural areas
- variation in skills of GP to provide supportive and palliative care to people with cancer
- variation in quality of communication to GPs during diagnosis and treatment
- focus of service delivery models on provision of care within the tertiary setting.

Key enablers relating to the involvement of primary care in the diagnosis and care of people with lung cancer and their carers included:

- use of GP Liaison Officers associated with Medicare Locals as an interface between tertiary care providers and primary care
- attendance by specialist lung cancer team members at GP education meetings
- incorporation into lung cancer databases of systems to support routine, timely generation of GP summary letters at key pathway points (e.g. following MDT meetings)
- opportunistic provision to GPs of information about lung cancer (e.g. feedback about appropriate referral pathways if referrals come through inappropriate entry points)
- shared access to information across tertiary and primary care settings.

4.9.3 Consumer consultation findings

Feedback from the consumer survey and consumer interviews highlighted a strong involvement by the patient's GP in their treatment and care. While some respondents indicated that their GP was involved in their care and/or follow-up or that they cared for their family member at home during the palliative phase, no quantitative information was identified about the GP role in these specific aspects of the patient pathway.

"The only health professional in five years to say anything to me [a carer] about me was our GP."

"I see my GP quite regularly. And every time I think that I need for him to see me, I don't hesitate, I take what I need to take and show him. And he records all these things, and I'm quite sure the doctors (specialists) are in contact with him. They need to be as well."

4.9.4 Innovations and implementation

A Cancer Services GP Liaison role has been established within a large regional health service that includes a regional cancer centre. This role links with the General GP Liaison role responsible for facilitating communication between the health service and Medicare Local. For more information see Case study 18 in Appendix II.

4.10 Improving life after treatment for lung cancer

4.10.1 Background

Evidence appears to be divided about ideal approaches to follow-up care for people with lung cancer, in particular the role of nurse-led follow-up and whether there is a survival benefit to follow-up by specialist health professionals.^{41–45}

Evidence is emerging that specific rehabilitation interventions using tailored exercise programs may improve functional capacity of patients post-surgery and reduce functional decline in patients having chemotherapy/radiotherapy for more advanced cancer.^{46,47}

There is also growing evidence that survivorship following a cancer diagnosis and treatment can present challenges as people adjust to the short- or long-term physical and psychosocial consequences of their disease and treatment.⁴⁸

4.10.2 Health service consultation findings

Key challenges in relation to life after treatment for lung cancer included the need:

- to define and agree on a streamlined approach to follow-up for people with lung cancer
- to develop ways to share information, in order to facilitate shared access to previous imaging or test results at follow-up appointments
- for recognition of the value of rehabilitation post-surgery and/or to reduce functional decline during treatment
- for greater priority to be placed on long-term survivorship issues for lung cancer patients; survivorship tends to have less focus because a high proportion of patients with lung cancer are diagnosed at an advanced stage.

Key enablers in relation to life after treatment for lung cancer included:

- shared access to information
- effective communication between members of the treatment team to agree on follow-up approaches for individual patients and avoid unnecessary duplication
- a research focus on the benefits of rehabilitation following surgery for lung cancer.

4.10.3 Consumer consultation findings

Feedback from the consumer survey highlighted that patients see a range of health professionals at follow-up, and the need for support following treatment for lung cancer.

"I felt abandoned after my treatment finished. I joined an online forum which helped to some degree but I found all the deaths upsetting."

"...it was just like you'd been surrounded by such caring people for so long and then suddenly you're just out on your own again. And I found it really difficult because as I

said we don't have a lot of visitors, there'd probably be a lot of people in the same situation."

"I didn't understand, it's just taken me a long time to get over the chemotherapy. I'm only just starting to feel good actually. So I just didn't understand what was going to happen after. I thought a week after I'd be fine, which I wasn't. So that sort of took my nerves a little bit."

4.10.4 Innovations and implementation

A small number of services had undertaken or are commencing research into the value of rehabilitation following lung cancer surgery to prevent functional decline in patients receiving chemotherapy and radiotherapy.

These services tended to be large volume services with a strong focus on supportive care research and with links with University physiotherapy research departments.

4.11 Quality of lung cancer care

4.11.1 Literature review findings

Numerous publications refer to the importance of clinical practice guidelines in ensuring the quality of cancer care, with efforts to define, quantify and improve quality of care developed in Australia and overseas.^{3,9,30,49,50} This includes using patient experiences to inform service development and ensure improved patient outcomes.²⁰⁻²²

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.⁵⁰ Following endorsement by the National Health Information Standards and Statistics Committee, a lung cancer data set specification is to be published by Cancer Australia, to guide data collection in clinical practice settings. This will enable services to review lung cancer management and outcomes over time.⁵¹

Services reported that they had no formal mechanisms to proactively gain consumer feedback on how patients and carers experienced their care; some services mentioned patient feedback surveys designed to capture feedback from all hospital patients but noted that these are not specific to lung cancer care.

4.11.2 Health service consultation findings

Key challenges for quality improvement initiatives included the need :

- to identify data collection systems/tools to collect data with which performance can be measured
- for agreed indicators against which practice can be measured.

Key enablers for quality improvement initiatives included:

- administrative/clerical/data support to undertake quality review and quality improvement initiatives
- the importance of clinical champions to drive quality improvement initiatives.

Quality initiatives identified through the consultations included:

- patterns of care studies and/or quality reviews including time to diagnosis and/or treatment
- palliative care research and quality activities
- contribution by thoracic surgeons to an Australian lung cancer database
- use of Cancer Institute NSW eviQ protocols to guide chemotherapy provision and provide up-to-date information for patients.

Areas identified in which improvements could be made included:

- agreed standards/measures around time to diagnosis and treatment within a model of care as a way of leveraging service improvement
- agreed standards/measures to consider specific aspects of care, e.g. surgical management
- a comprehensive lung cancer dataset to enable ongoing review of practice and patient outcomes^v
- systematic approaches to gaining feedback from patients with lung cancer and their families.

4.11.3 Innovations and implementation

All of the case studies included Appendix II reflect health service approaches to improving the quality of their lung cancer services for patients and carers.

Several services reported a past or current review of the diagnostic pathway and timeliness (see Case study 6 [Timely diagnosis and staging]) of the collection of data to enable retrospective review of practice (see Case study 15 [Multidisciplinary care]).

^v It should be noted that following a parallel Cancer Australia project, a minimum dataset has been recently published that will be useful to guide future lung cancer data collection.⁵¹

5 Conclusions

Best practice lung cancer care involves a range of diagnostic, treatment and supportive care services and health professionals at primary, secondary and tertiary levels. This national project has highlighted the importance of specific expertise and experience in managing the diagnosis, treatment and care of people with lung cancer across all disciplines.

The proposed best practice approaches to lung cancer care that have been identified through this project reflect areas for which there is a body of evidence within published literature and/or strong support identified through health service consultations and consumer feedback. This includes areas in which services already appear to have good processes in place and/or areas of priority, identified by services and consumers.

The proposed best practice approaches that have been integrated into the *Principles for best practice management of lung cancer in Australia* reflect the importance in the lung cancer pathway of:

- a **patient- and family-centred approach** to lung cancer care from the point of investigation of symptoms onwards
- clear **definition and promotion of the diagnostic referral pathway** for lung cancer to GPs and other referrers
- an **agreed approach for identifying and fast-tracking diagnostic tests** for patients with symptoms and/or initial test results suggestive of lung cancer
- **formal input to treatment planning from a multidisciplinary team** of diagnostic, treatment, supportive and palliative care personnel
- referral of all patients with potentially curable lung cancer to a **surgeon with expertise in thoracic surgery**
- equitable access to **medical and radiation oncology services** appropriate to a patient's diagnosis, staging and preferences
- **inclusion of palliative care** as an integral part of the lung cancer team and early involvement of palliative care for people with advanced disease
- equitable access to **appropriate clinical trials**
- equitable access to **supportive care services**, based on identified needs
- **coordination of the lung cancer pathway** from symptom investigation onwards
- written communication with **routine feedback** to the patient's GP at key points in the patient pathway
- agreed and consistent approaches to **quality review and quality improvement**.

There is currently no clear evidence on which to base a 'standard' approach to follow-up for people following treatment for lung cancer.

As part of the health service consultation process, a number of systemic issues were identified that may influence delivery of best practice lung cancer care in Australia. Areas for improvement include access to shared information platforms, consistency in documentation, and approaches to optimise use and access to human resources and the physical infrastructure required to deliver best practice care.

In developing and implementing best practice approaches for lung cancer service delivery, there are likely to be considerations at a service level based on service type and location. These considerations also link to the volume of lung cancer cases treated within the service per year, with metropolitan and public services more likely to treat a higher volume of cases.

The long-term goal is for all services providing lung cancer care in Australia to use findings from the *Best practice approaches to the management of lung cancer in Australia* project to inform changes at a local service delivery level to ensure that lung cancer patients are receiving the best possible lung cancer care now and in the future. This will ultimately improve survival and quality of life and reduce the burden of lung cancer on the Australian community.

References

1. Australian Institute of Health and Welfare (AIHW). *Cancer in Australia: an overview*. Canberra: AIHW, CAN 70, 2012.
2. Australian Institute of Health and Welfare (AIHW). *Lung cancer in Australia: an overview*. Canberra: AIHW, CAN 58, 2011.
3. Chambers SK, Dunn J, Occhipinti S *et al*. A systematic review of the impact of stigma and nihilism on lung cancer outcomes. *BMC Cancer* 2011; 12–184.
4. Zabora J, Brintzenhofesoc K, Curvow B *et al*. The prevalence of psychological distress by cancer site. *Psycho-Oncology* 2001; 10: 19–28.
5. Conron M, Phuah S, Steinfort D *et al*. Analysis of multidisciplinary lung cancer practice. *Intern Med J* 2007; 37(1): 18–25.
6. Vinod SK, Hui AC, Esmaili N *et al*. Comparison of patterns of care in lung cancer in three area health services in New South Wales, Australia. *Intern Med J* 2004; 34(12): 677–83.
7. Vinod SK, Sidhom MA, Gabriel GS *et al*. Why do some lung cancer patients receive no anticancer treatment? *J Thorac Oncol* 2010; 5(7): 1025–32.
8. Hall SE, Holman CDJ, Threlfall T *et al*. Lung cancer: an exploration of patient and general practitioner perspectives on the realities of care in rural Western Australia. *Aust J Rur Health* 2008; 16(6): 355–62.
9. Vinod SK, O'Connell DL, Simonella L *et al*. Gaps in optimal care for lung cancer. *J Thorac Oncol* 2008; 3(8): 871–9.
10. Vinod SK *et al*. Lung cancer patterns of care in south western Sydney, Australia. *Thorax* 2003; 58(8): 690–4.
11. Richardson GE, Thursfield VJ, Giles GG. Reported management of lung cancer in Victoria in 1993: comparison with best practice. Anti-Cancer Council of Victoria Lung Cancer Study Group. *Med J Aust* 2000; 172(7): 321–4.
12. Hall SE, Holman CD, Sheiner H. The influence of socio-economic and locational disadvantage on patterns of surgical care for lung cancer in Western Australia 1982–2001. *Aust Health Rev* 2004a; 27(2): 68–79.
13. Hall SE *et al*. Treatment patterns for cancer in Western Australia: does being Indigenous make a difference? *Med J Aust* 2004b; 181(4): 191–4.
14. Bydder S *et al*. The impact of case discussion at a multidisciplinary team meeting on the treatment and survival of patients with inoperable non-small cell lung cancer. *Intern Med J* 2009; 39(12): 838–41.
15. Jennens RR, De Boer R, Irving L *et al*. Differences of opinion: A survey of knowledge and bias among clinicians regarding the role of chemotherapy in metastatic non-small cell lung cancer. *Chest* 2004; 126(6): 1985–93.

16. Estall V, Barton MB, Vinod SK. Patterns of radiotherapy re-treatment in patients with lung cancer: A retrospective, longitudinal study. *J Thorac Oncol* 2007; 2(6): 531–36.
17. Wilcoxon H *et al.* Multidisciplinary cancer care in Australia: a national audit highlights gaps in care and medico-legal risk for clinicians. *Asia Pac J Clin Oncol* 2011; 7(1): 34–40.
18. Stanford C. The needs of rural lung cancer patients. 2008, North Coast Cancer Institute: Coffs Harbour.
19. Bishnoi S *et al.* Small Cell Lung Cancer: Patterns of care and their influence on survival - 25years experience of a single Australian oncology unit. *Asia Pac J Clin Oncol* 2011; 7(3): 252–57.
20. Institute of Medicine. Crossing the Quality Chasm: a new health system for the twenty first century. Washington: National Academies Press, 2001.
21. Frampton S, Guastello S, Brady C *et al.* Patient centred Care Improvement Guide. Planetree Inc. and Picker Institute, USA, 2008.
22. Australian Commission on Safety and Quality in Health Care. Patient-centred care: improving quality and safety through partnerships with patients and consumers. Sydney: ACSQHC, 2011.
23. Krishnamany M, Wilkie E, Haviland J. Lung cancer health care needs assessment; patients' and informal carers' responses to a national mail questionnaire survey. *Pall Med* 2001; 15(3): 287–94.
24. Fergusson RJ *et al.* Lung cancer: the importance of seeing a respiratory physician. *Eur Resp J* 2003; 21(4): 606–10.
25. Cancer Australia Investigating symptoms of lung cancer: a guide for GPs. Sydney: Cancer Australia, 2012.
26. Bauman K, Arenberg D. Multidisciplinary evaluation of patients with suspected lung cancer. *Clin Pulm Med* 2010; 17(1): 35–41.
27. Saini KS, Taylor C, Ramirez AJ *et al.* Role of the multidisciplinary team in breast cancer management: results from a large international survey involving 39 countries. *Ann Oncol* 2012; 23(4): 8453–9.
28. Freeman RK, Van Woerkom JM, Vyverberg A *et al.* The effect of a multidisciplinary thoracic malignancy conference on the treatment of patients with lung cancer. *Eur J Cardio-Thorac Surg* 2010; 38(1): 1–5.
29. Bjegovich-Weidman M, Haid M, Kumar S *et al.* Establishing a community-based lung cancer multidisciplinary clinic as part of a large integrated health care system: aurora health care. *J Oncol Pract* 2010; 6(6): e27–30.
30. Handy JR. Attributes contributing to superior outcomes in the surgical management of early-stage lung cancer and examples of implementing improvement. *Cancer J* 2011; 17(1): 57–62.

31. Martin-Ucar AE, Wallera DA, Atkins JL *et al.* The beneficial effects of specialist thoracic surgery on the resection rate for non-small-cell lung cancer. *Lung Cancer* 2004; 46: 227–32.
32. Temel JS, Jackson VA, Billings JA *et al.* Phase II study: integrated palliative care in newly diagnosed advanced non-small-cell lung cancer patients. *J Clin Oncol* 2007; 25(17): 2377–82.
33. Smith TJ, Temin S, Alesi ER *et al.* American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care. *J Clin Oncol* 2012; 30: 880–7.
34. Haggerty JL, Reid RJ, Freeman GK *et al.* Continuity of care: a multidisciplinary review. *BMJ* 2003; 327(7425): 1219–21.
35. Cancer Institute NSW. Evaluation of the role of the cancer care coordinator. Sydney: Cancer Institute NSW. 2011.
36. Skrutkowski M, Saucier A, Eades M *et al.* Impact of a pivot nurse in oncology on patients with lung or breast cancer: symptom distress, fatigue, quality of life, and use of healthcare resources. *Oncol Nurs For* 2008; 35(6): 948–54.
37. Yates P. Cancer care coordinators: realising the potential for improving the patient journey. *Cancer Forum* 2004; 28(3).
38. Pigott C, Pollard A, Thomson K, Aranda S. Unmet needs in cancer patients: development of a supportive needs screening tool (SNST). *Supp Cancer Care* 2009; 17: 33–45.
39. Aubin M *et al.* Family physician involvement in cancer care follow-up: the experience of a cohort of patients with lung cancer. *Ann Fam Med* 2010; 8(6): 526–32.
40. Rowlands S, Callen J, Westbrook J. What information do general practitioners need to care for patients with lung cancer? A survey of general practitioners perceptions. *Health Info Manag J* 2010; 39(1): 8–16.
41. Nakamura R *et al.* Postoperative follow-up for patients with non-small cell lung cancer. *Onkologie* 2010; 33(1–2): 14–8.
42. Gilbert S *et al.* Who should follow up lung cancer patients after operation? *Ann Thorac Surg* 2000; 69(6): 1696–700.
43. Moore S *et al.* Nurse led follow up and conventional medical follow up in management of patients with lung cancer: Randomised trial. *BMJ* 2002; 325(7373): 1145–7.
44. Moore S *et al.* Nurse specialist led follow-up in lung cancer: The experience of developing and delivering a new model of care. *Eur J Oncol Nurs* 2006; 10(5): 364–77.
45. Cox K *et al.* Preferences for follow-up after treatment for lung cancer: assessing the nurse-led option. *Cancer Nurs* 2006; 29(3): 176–87.
46. Granger CL, McDonald CF, Berney S, Chao C, Denehy L. Exercise intervention to improve exercise capacity and health related quality of life for patients with non-small cell lung cancer: a systematic review. *Lung Cancer* 2011; 72(2):139–53.

47. Jones LW, Eves ND, Peterson BL, Garst J *et al.* Safety and feasibility of aerobic training on cardiopulmonary function and quality of life in post-surgical non-small cell lung cancer patients: a pilot study. *Cancer* 2008; 113(12): 3430–9.
48. Jefford M. Improving outcomes for cancer survivors in Australia. *Cancer Forum* 2009; 33(3): 159–63.
49. Lennes IT, Lynch TJ. Quality indicators in cancer care: development and implementation for improved health outcomes in non-small-cell lung cancer. *Clin Lung Ca* 2009; 10(5): 341–6.
50. Tanvetyanon T. Quality-of-care indicators for non-small cell lung cancer. *Cancer Control* 2009; 16(4): 335–41.
51. Cancer Australia. Lung Cancer Data Set Specification. Surry Hills: Cancer Australia 2013 (to be published).
52. NEMICS North Eastern Metropolitan Integrated Cancer Service. Overview of primary lung cancer patients admitted to Victorian public and private health services: Victorian Admitted Episodes Dataset (VAED); Statewide dataset 2007/2008 to 2009/2010. Unpublished report, 2011.

Appendix I: Participating health services

NSW

Orange General Hospital

Royal Prince Alfred, Sydney Cancer Centre

Calvary Mater Newcastle

Wollongong Hospital/Illawarra Cancer Centre

Liverpool Hospital

Nepean Cancer Centre

Queensland

The Prince Charles Hospital

Toowoomba Hospital

John Flynn Hospital, Gold Coast

Nambour Hospital

Townsville Hospital

Victoria

Albury Wodonga Health

Peter MacCallum Cancer Institute

Austin Health

Central Gippsland Health Service

Cabrini Hospital

Barwon Hospital, Geelong

Western Australia

Bunbury Health Service

Albany Health Service

Sir Charles Gairdner Hospital

ACT

The Canberra Hospital

Northern Territory

Royal Darwin Hospital

South Australia

Adelaide Cancer Centre/ Ashford Private Hospital

Flinders Medical Centre

Queen Elizabeth Hospital

Whyalla Regional Hospital

Royal Adelaide Hospital

Tasmania

Royal Hobart Hospital

NW Health Service, Burnie

Launceston Hospital

Appendix II: List of case studies from the health service consultations

Principle 1: Patient-centred care

Case study 1: A geriatric oncology service

A large metropolitan service has developed a geriatric oncology service as a component of medical oncology, with treatment decisions informed by a geriatric assessment. The service is offered to all patients over 70 years of age and includes:

- a medical oncologist with an interest in geriatric medicine, specialist nurses/coordinators and allied health professionals
- a specific multidisciplinary meeting
- nurse-led 'geriatric screening' of patients to assess their current health status (apart from the cancer), functional capacity and psychosocial supports and needs
- access to additional supports provided to optimise the patient's and carer's ability to manage at home.

Since the program was fully operationalised, the median length of inpatient stay for geriatric cancer patients has fallen from 6.23 days to 5.93 days.

Case study 2: Use of telehealth for regional patients

One major regional tertiary hospital servicing a large geographic area, including rural and remote towns, is successfully using telehealth to facilitate local access to chemotherapy. This requires relevant videoconference technology to be available at all sites as well as a local physician or GP to support patient management. Telehealth consultations include the patient (and carers), supported by a local nurse or allied health provider as well as any relevant medical personnel.

The extent to which telehealth is used depends on the patient's individual situation:

- patients with potentially curative disease travel to the regional centre for initial assessment, treatment planning and/or treatment such as surgery or radiotherapy
- patients with stage IV disease requiring chemotherapy only may have all care facilitated through telehealth
- follow-up care is often provided via telehealth.

Telehealth is also being used to support local delivery of some chemotherapy regimens. Oncology nurses at the main site supervise local nurses in the provision of chemotherapy via telehealth, starting with low risk chemotherapy.

Telehealth was reported to be beneficial for patients and carers, reducing the need for unnecessary travel. It was also seen to be beneficial for staff, in particular building the skills

and capacity of remote staff and contributing to attracting and retaining staff in these areas.

The telehealth approach was based on a strong understanding of the impact of travel on patients and carers; it was noted that a 10-minute telehealth consultation may save a patient five hours of travel.

Key requirements identified for the lead site included:

- a culture of trust and sharing:
 - the lead site should assume they are better resourced than the remote site and specific telehealth funding should be shared equally
 - the lead site should be flexible in making time available to the remote site; specific clinic times can be adjusted once trust is built and the process is established
- telehealth patients should be discussed at the lead site MDT meeting
- the importance of clinical leadership to drive the initiative
- advanced medical trainees should become familiar with the technology and processes.

Key requirements identified for the remote site included:

- a doctor to take instruction and support local patient management
- local nurses and allied health providers
- a protocol about how to access the lead site urgently if needed
- local capability to provide required care and interventions, with education/supervision provided via telehealth if required.

Case study 3: Aboriginal cancer care coordinator role

In one regional referral service an Aboriginal cancer care coordinator role had been established to support Aboriginal patients with cancer (including lung cancer) and their carers. Referrals to the Aboriginal Cancer Care Coordinator come from health professionals within the service and from the referring service as well as directly from patients and carers.

Working with other providers as appropriate, the coordinator's role may include:

- organising transport and accommodation, including financial support and accessing Centrelink
- providing information and cultural support to the patient and carer
- sitting in on medical consultations and day oncology appointments
- providing information about the range of services available within the regional city
- linking with local GPs to ensure access to appropriate medication with appropriate financial support using the 'Closing the Gap' scheme
- facilitating telehealth links so that the patient can talk with family at home, especially if they are hospitalised for long periods
- links with other providers including the Aboriginal and Torres Strait Islander palliative care worker and other general Aboriginal health workers within the service, within the patient's

local community and with similar roles in the capital city, should patients need to be referred.

A culturally appropriate teaching aid has been developed which local community workers can go through with the patient and family to familiarise them with the health service before leaving their community.

In eight months since January 2012, the Aboriginal Cancer Care Coordinator has supported 60 patients with nearly 700 occasions of service. Only one patient has not completed the recommended treatment.

Some challenges in the role include:

- the need for better coordination of appointments to ensure the patient does not get lost between appointments
- limited additional skills training particularly around cancer issues available for the worker because of resource issues.

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

Case study 4: The respiratory CNC

At least two sites described the role of a respiratory clinical nurse consultant (CNC, or lung cancer CNC) in coordinating the diagnostic process for people with suspected lung cancer. Common roles included:

- scheduling appointments to minimise burden of time and number of visits for patients
- organising travel and accommodation for patients from regional centres
- identifying potential psychosocial issues during the diagnostic phase
- facilitating a smooth transition across respiratory medicine and cancer services through liaison with the cancer service
- provision of feedback to the referrer about diagnosis.

Discussion at one site highlighted that the role is being reviewed to determine any aspects that could be undertaken by administrative or clerical staff (e.g. scheduling appointments) to provide greater opportunity for the role to focus on clinical requirements.

Case study 5: The rapid access clinic

Two examples of rapid access clinics were described through the site visits. These were both designated lung cancer diagnostic clinics – one held weekly and one twice weekly. Both services indicated that patients requiring urgent referral could be seen outside these clinics if required.

Views about the value of rapid access clinics varied. Some services did not see the benefit of a designated weekly clinic, indicating that this reduced the flexibility in undertaking rapid investigations. One service reported that although the weekly rapid access clinic was useful

in streamlining diagnostic services, it was seen as a '*choke point*' if there were large referral numbers in a given week.

Case study 6: Review of the diagnostic pathway

Several services reported a past or current review of the diagnostic pathway and timeliness. One large metropolitan service compared its diagnostic service with the following NHS (UK) targets:

- all suspected cancers should be seen by a specialist within 14 days of GP referral
- treatment should begin within 31 days of diagnosis, and within 62 days of GP referral.

Based on the evidence from the review, the service is now undertaking a range of strategies to improve timely access to services, where needed.

Case study 7: GP education sessions

One large metropolitan service runs twice yearly GP education sessions within its immediate catchment area, with other sessions held occasionally in the wider catchment. Sessions are usually multidisciplinary in nature, with various specialists participating. The sessions provide updates on current diagnosis and management of lung cancer.

Reported benefits include:

- enhancing relationships between primary care and tertiary care providers
- encouraging timely referral into diagnostic services
- facilitating referral into local rather than more distant metropolitan services
- promoting availability of the care coordination service.

Case study 8: Access to surgical services in a regional centre

One site in a regional city with an estimated 50–100 new lung cancer cases per year reported that the appointment of two new cardiothoracic surgeons with a pro-active approach to the surgical management of people with lung cancer has changed local service delivery even though lung cancer surgery remains a small part of their overall workload.

Both surgeons had experience of working with a major thoracic unit as part of their training program and maintain links with this service for advice as required. The two surgeons alternate attendance at the weekly lung cancer MDT meeting to accommodate a cardiac surgery operating list at the same time. Every effort is made to see lung cancer patients as soon as possible for the initial surgical assessment, work-up and decision-making.

Lack of access to designated theatre time (only a fortnightly list) is overcome by using an out-of-hours list to ensure timely surgical intervention.

Case study 9: Supportive care meetings

At least two regional services have established formal supportive care meetings in which patients and carers' supportive care needs are identified and addressed.

These meetings are usually attended by nursing staff, allied health professionals and palliative care staff. In one service with a strong mix of public and private service delivery, medical oncologists attend the first part of the meeting to provide an update on all new patients. In the other service, staff from smaller services within the region can link in via video-conferencing.

Case study 10: Access to psychology services in a private setting

In one private service, access to allied health services was very constrained (with the exception of pastoral care). To support improved access to allied health services, two family trusts have provided funding support. As part of this initiative, a psycho-oncology service (for all cancer patients) with a research focus was established in collaboration with the Psychology Department at the University linked with the health service.

Key activities include:

- a clinical psychology service for cancer patients with identified needs, funded through access to the Medicare Psychology Item numbers and accessed through GP referral
- provision of psycho-educational programs with other key service providers
- provision of specific sessions on managing fatigue, pain and stress supported by Master's psychology students with supervision
- mindfulness programs supported by Master's students
- research, including trialling of a screening tool through day oncology services and evaluation of specific interventions.

Key challenges have included:

- educating oncologists and other providers about the role of psychology services and that a level of emotional distress is appropriate for all cancer patients and strategies that they can use to respond to 'normal' distress
- negotiating roles and responsibilities between the psychology, social work and pastoral care services.

Case study 11: A comprehensive palliative care service in the private sector

One large private health service developed an integrated palliative care model as part of a Government private funding initiative to pilot how private funds could support different aspects of patient management, including primary or community-based services.

This service has continued primarily under the same funding model and has strong Executive support. While successful, ongoing funding sustainability is a significant challenge for this service.

Key features of the service include:

- a 22-bed inpatient facility near the main acute service site to which patients can be transferred while still having active cancer treatment
- a palliative care nurse and medical consultancy service for patients at the acute health site
- a community-based palliative care service for home visits.

Further work is being undertaken to:

- optimise early referral to palliative care, including the use of a palliative care trigger tool within acute care settings, and work with oncologists and other specialists to clarify the role and benefits of the palliative care service
- develop and promote a charter to guide palliative care service delivery and its interface with acute services.

Case study 12: Improving functional capacity during and after treatment

A small number of services had undertaken or are commencing research into the value of rehabilitation following lung cancer surgery or to prevent functional decline in patients receiving chemotherapy and radiotherapy.

These services tended to be large volume services with a strong focus on supportive care research and with links with university physiotherapy research departments.

Principle 3: Multidisciplinary care

Case study 13: The MDT Coordinator

One regional service uses an MDT Coordinator. This is an administrative role; where the person undertaking the role has extensive experience working in cancer services. Roles include:

- prompting of team members to add cases to the electronic agenda
- sourcing of imaging results and submission in advance of meeting to radiology for review
- transfer into the MDT database of relevant patient history from the patient notes
- circulation of final agenda to MDT members
- documentation during the meeting of key decisions and recommendations
- circulation of meeting attendance sign-on sheet during meeting
- quality check of meeting records post-meeting
- distribution of meeting summary post-meeting (saved into patient record, distributed electronically to MDT members, faxed to patient's GP).

MDT members view the MDT Coordinator as central to the efficiency of the meetings and a core facilitator of seamless transfer of information across the public and private sectors.

Case study 14: Building multidisciplinary relationships

One metropolitan service identified the need to foster a sense of collegiality and teamwork among MDT meeting members. Approaches described included:

- acknowledgement of all team members on conference abstracts and journal articles and encouragement of all members to review and input into such publications
- participation of multiple team members in conferences and other fora
- social team-based activities throughout the year.

A strong sense of team was viewed as important to encourage open discussion within MDT meetings, support communication outside MDT meetings and encourage quality initiatives by the team.

Case study 15: Development of a lung cancer database to support the MDT

An example of a lung cancer database was a bespoke database developed specifically for a metropolitan lung cancer service. The database is web-based and MDT members have a login and password. The database:

- lists a calendar of meetings, allowing the user to add a patient to a meeting agenda
- is used to record information for each patient to be presented (patient history, symptoms, co-morbidities, investigations conducted and results, tumour site and size, metastases and reason for MDT presentation)
- generates the meeting agenda
- automatically calculates the stage
- captures recommended next steps agreed in the MDT meeting
- includes a resource section providing access to protocols.

Patients remain on the list until the treatment plan has been implemented. The records are then maintained on the database, allowing retrospective review of the data collected for quality improvement processes.

Case study 16: Facilitating multidisciplinary discussion across small regional services

In one small health region, video-conferencing has been successful in facilitating a fortnightly MDT:

- the MDT Chair (respiratory physician) and MDT meeting coordinator are located in one of the smaller health services within the region
- medical and radiation oncologists are present at the regional cancer centre located in the major regional town
- a visiting thoracic surgeon from a metropolitan health service also attends the meeting and provides a consultation clinic at the cancer centre on the same day
- a specialist palliative care physician links in via a metropolitan palliative care service

- any service providers across the region can submit a case for MDT discussion.

Critical success factors include strong commitment by individual providers and administrative support through the broader cancer reform agenda within the region.

Principle 4: Coordination, communication and continuity of care

Case study 17: The oncology-palliative care nurse practitioner

In one cancer service within a regional city, a nurse practitioner role is evolving to work at the interface of oncology and palliative care services. It is envisaged that this role will see many cancer patients (across tumour groups) in the ambulatory setting and assist with symptom relief and advanced care planning, as well as facilitating transition to palliative care services as needed.

Within another service a similar model was being used for neuro-oncology patients where a nurse coordinator was linked with all patients with poor prognosis brain tumours. This coordinator had specific palliative care skills and was able to support the patient and family during the early stages of their illness, linking them in with appropriate community-based services. As the patient deteriorates she can facilitate their transition to palliative care services.

Case study 18: The GP Liaison Officer

A Cancer Services GP Liaison role has been established within a large regional health service that includes a regional cancer centre. This role links with the General GP Liaison role responsible for facilitating communication between the health service and Medicare Local.

The Cancer Services GP Liaison role is filled by different GPs for the key cancer groups. Its establishment was driven by the Regional Cancer Centre and Medicare Local with the aim of facilitating clear, active and functional communication lines with GPs. The role is funded through the Medicare Local.

The current GP Liaison Officer for lung cancer services is an experienced GP who has worked in the region for a long time and has strong connections with other GPs and local palliative care service providers.

Key features of the role include:

- participation in the lung cancer MDT meeting (one hour per week)
- liaison with relevant GPs before and after the MDT to invite input and provide (and seek) feedback about the agreed treatment plan (30–40 minutes per week).

A summary of the meeting is also faxed to the GP – usually within 90 minutes of the MDT. The GP Liaison Officer is seen as an equal member of the MDT and feels able to ask questions and contribute to the discussion.

GPs are themselves invited to attend the MDT (face-to-face or via teleconference), although it is rare for them to participate. If they do attend it is often for patients with complex medical and / or social issues.

Feedback from GPs about the GP Liaison Officer is reported to have been positive, enabling them to respond to questions from the patient or family member about their lung cancer journey.

Case study 19: Regional cancer care coordinator network

In one state, a network of cancer care coordinators has been established with support from the State Department of Health to support all cancer patients, with a particular emphasis on regional and rural patients. The network includes rural cancer care coordinators, one metropolitan-based regional cancer care coordinator, along with a number of metropolitan tumour-specific cancer care coordinators.

The rural cancer care coordinators support the patient and family prior to referral to a major metropolitan service and after their return home. This may include organisation of referral to the metropolitan service, ensuring the timing of appointments is coordinated, advising on transport and accommodation and providing information about the cancer care coordination service. The rural cancer care coordinators tend not to give specific cancer information.

The metropolitan-based regional cancer care coordinator works closely with the tumour-specific cancer care coordinators in the metropolitan service, e.g. the lung cancer care coordinator. For regional cancer patients with complex needs, the regional cancer care coordinator may provide additional support. The regional cancer care coordinator will also liaise with the rural cancer care coordinators and the patient's GP when the patient returns home.

The cancer care coordinators across the State have common access to electronic information systems to facilitate communication. They also hold monthly meetings via videoconference to discuss management and strategic issues. An evaluation of the cancer care coordinator network has identified benefits of the service and guided future directions.

Case study 20: Cancer Link Nurses

In one regional area, a system of Cancer Link Nurses has been established to support patients from a large geographic area. Patients may travel distances of more than 200km to attend the regional cancer centre for treatment. The Cancer Link Nurse within the Cancer Centre provides support to patients while at the Cancer Centre and refers to the local Cancer Link Nurse when the patient returns home. The local Cancer Link Nurse will contact the patient and family and provide information and support, and link them with local community services as needed.

A similar model is available in one state where a system of central cancer care coordinators have been established with regional cancer care coordinators in key towns throughout the state (see also Case study 19).

Case study 21: The metropolitan cancer care coordinator

In one large metropolitan service, the lung cancer care coordinator contacts lung cancer patients once their diagnosis is confirmed. The role links closely with the social worker.

At diagnosis, the lung cancer care coordinator meets the patient, undertakes supportive care screening, provides information and support, makes appropriate referrals and facilitates appointments. The cancer care coordinator is the key contact point for the patient and family and tries to have contact at least weekly by phone or face-to-face during treatment. The coordinator also plays a significant role in symptom management and facilitating transition to palliative care services, when needed. However, service demand is exceeding role capacity.

Case study 22: Information systems to facilitate care coordination

A number of services indicated that they use electronic information systems to facilitate communication and coordination within and across services. Identified systems included Queensland Oncology Online (QOOL), Mosaic and CanMap. These systems support documentation of the patient treatment plan, are used to plan clinical appointments and to facilitate supportive care referrals.

Where electronic systems were not available, some cancer care coordinators reported using hard-copy templates to facilitate communication between providers in metropolitan and regional services.

Principle 5: Data-driven improvements in lung cancer care

Relevant case studies that reflect this principle include case study 6, 13, 15 and 22.

Appendix III: Methodology and profile of consultation respondents

An overview of the project methodology and key features of the consultation respondents including the profile of the participating services and consumers is identified below.

Health service consultation

National map

Development of the National Map of Lung Cancer Services was informed by a range of national and local documents, including:

- a 2011 Victorian report⁵² reported 3-year data on the number of patients and admissions for lung cancer across all Victorian public and private health service and individual public health services.^{vi} Approximately 80% of all lung cancer patients were admitted to a public health service. This report identified 29 Victorian public health services that admitted more than 20 patients with lung cancer per annum; 11 of these services admitted more than 200 patients per annum
- in NSW, service data were accessed through the recently developed the Cancer Institute NSW Cancer Service Directory³⁵, which enabled the identification of 16 lung cancer multidisciplinary teams, 21 radiotherapy services and 64 chemotherapy units in NSW.

These Victorian and NSW data sources (along with a WA online cancer service directory) provided a basis to build the service map for these States. They also clearly demonstrated the large number of services involved in the management of people with lung cancer.

An initial listing and brief profile of Australian lung cancer services was developed for all states and territories drawing on the above documents and other local resources. Listings for each state and territory were forwarded to relevant personnel to ensure that no major lung cancer services were omitted from the listing.

^{vi} Data for individual private hospitals is available only with permission of the individual private service

Telephone interviews

A purposive sample of 36 lung cancer services was chosen to represent lung cancer services across Australia, including:

- all states and territories
- metropolitan and regional locations
- public and private services
- small and large lung cancer services.

Prior to the scheduled telephone interview, sites were asked to complete a short pre-interview survey to explore key aspects of their service.

Telephone interviews were conducted with representatives from 30 lung cancer services^{vii} during May–August 2012. Telephone interviews were either one-to-one or group interviews with up to four representatives of the service (participants chosen by the service). Most interviews were conducted with one to two personnel. Participants included thoracic surgeons, medical oncologists, radiation oncologists, respiratory or general physicians, palliative care professionals, lung cancer nurses and/or relevant nursing executives.

Answers from the pre-interview survey were used as a basis to explore aspects of the lung cancer service provided at that site. Services were asked to comment on challenges and enablers of good service delivery at the site.

Telephone interviews typically ran for 60 minutes. Interviews were recorded and notes entered into a data collection tool developed to capture responses in both quantitative and qualitative ways.

Site visits

From the sample of lung cancer services, a subset of eight services was chosen to participate in the site visit consultations. These services were chosen to reflect the range of lung cancer services across Australia and to provide insight into key aspects of lung cancer service delivery. The aim was to use these sites as case studies to inform *Best practice approaches to the management of lung cancer in Australia*.

Eight site visits were conducted during July–September 2012. Site visits were adapted to suit each service, dependant on services available at each site and availability of staff on the day(s) of the site visit, but focused on exploring the following four areas:

- current systems and processes to provide optimal patient care
- innovative/best practice approaches, as well as challenges and strategies undertaken or considered to address these

^{vii} Because of various organisational issues, telephone interviews were not undertaken with two services who agreed to participate.

- the use of any quality mechanisms and /or best practice guidelines to guide and review local practices
- key features that should be included in a national best practice approaches to the management of lung cancer.

In developing the approach to the site visits, the following core research elements were included:

- observation of a multidisciplinary team (MDT) meeting (if applicable at the site)
- individual or group interviews with a range of different providers including:
 - different members of the MDT providing care at different points in the pathway
 - other relevant internal providers, including quality or research staff, Aboriginal liaison/health workers, interpreter staff
 - external providers involved in any 'shared-care' arrangements, joint MDT processes or the provision of community-based palliative care or other services
 - general practitioners
- review of readily available documentation, including:
 - established policies and protocols
 - standard patient information resources
 - any relevant service reports or publications (e.g. recent quality reports or published papers).

Consumer consultation

The purpose of the consumer consultation was to gain an insight into the experiences of consumers of lung cancer services in Australia, including their views on the quality of treatment and care, and those factors that influenced their care.

Electronic survey

The consumer survey was open to all people who had experienced lung cancer in Australia. The survey was also open to carers to complete on behalf of people with lung cancer with a small section included to capture their own experiences of being a carer of someone with lung cancer.

The survey did not specifically exclude patients with mesothelioma.

The online survey was open for six weeks during July–September 2012. In total, 61 respondents commenced the online survey. One request was received for a hard copy survey. No completed hard copy surveys were returned.

There was a 34% dropout rate (n=20) in completion of the online survey, with 41 people completing the survey in its entirety. This dropout rate, which was spread equally across patients and carers, may in part reflect the length of the survey.

The 41 complete responders represent a spread of patients and carers across Australia, with only a few differences between patients and carers. Key features of the sample included:

- more women (n=29) than men (n=12) completed the survey
- for both genders, approximately half of the respondents were patients and half carers
- the largest number of respondents came from NSW with no respondents from Tasmania or the Northern Territory
- twenty one patients reported their age as being over 40 years at diagnosis, with eight aged over 60 years at diagnosis
- over half of respondents (23/41) reported that they or the person they cared for had been diagnosed with lung cancer at least two years ago; of these, half had been diagnosed more than five years ago
- promotion of the survey through the Australian Lung Foundation and state/territory Cancer Councils means that there may be some bias in respondents towards people who are active users of support networks and therefore results may not be representative of all people affected by lung cancer.

Telephone interviews

The purpose of the consumer consultations was to focus on the experiences of people treated at the eight sites to gain an insight into their personal views on the quality of treatment and care. This was aimed to inform the detailed site-specific case-studies on the process for lung cancer treatment and care. The sample represented a different group of participants to the electronic survey.

The consumer interview schedule was developed with input from the Consumer Reference Group to explore four key themes related to the patient experience of treatment and care for lung cancer.

Telephone interview participants were selected to include:

- patients diagnosed with lung cancer, currently undergoing treatment at the site, or treated within the past 12 months
- carers of relatives with lung cancer who were currently undergoing treatment or whose relatives had died up to two to three years ago.

The following process was used to invite participants, ensuring that participants confidentiality was maintained:

- site clinicians identified potential consumers and invited them to participate through a personal letter from their Unit Head (or relevant person)
- interested consumers mailed their completed consent and details form (reply paid) to the research team
- the research team contacted individuals to conduct a telephone interview at a convenient time

- the research team only had access to information from participants who agreed to participate; health services had no information about who had responded to the letter of invitation unless volunteered directly by the consumer.

Effort was made to recruit participants from diverse ages, genders and cultural backgrounds. Eleven telephone interviews were conducted in September – November 2012.