Standards of
Service Provision for
Lung Cancer Patients
in New Zealand

National Lung Cancer Working Group

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# Introduction

## Background

Lung cancer has a significant social impact due to the high rates of morbidity and mortality associated with the disease. Lung cancer mortality is higher in New Zealand than in some other Western nations. For example, New Zealand has a five-year relative survival of 11 percent, whereas Australia and Canada have five-year relative survivals of over 14 percent.

There are also significant variations in outcomes across New Zealand, with a range in five-year relative survivals of approximately 4−5 percent to 14 percent. Part of this variation in local outcomes is likely to be due to different standards of care.

Large ethnic disparities are seen not only in the incidence of lung cancer, but also in outcomes. While some of these disparities can be explained by the lower relative socioeconomic status of minority ethnic groups in New Zealand, it is likely that higher tobacco use among Māori and Pacific people is an important contributor to the increased incidence of lung cancer in these populations. Mortality disparities are largely due to a significant number of cases not being diagnosed until the disease is well advanced.

The National Lung Cancer Working Group (NLCWG) developed the *Standards of Service Provision for Lung Cancer Patients in New Zealand* in 2011 in a bid to improve outcomes for lung cancer patients and reduce inequalities associated with this disease. The NLCWG has now reviewed the standards to keep them up to date in the context of New Zealand health care.

The NLCWG developed these standards based on the assumption that the appropriate governing bodies have credentialled the various clinical staff, laboratories and other special investigations involved.

By revising the national standards the NLCWG continues to aim to improve the overall care of all patients with lung cancer.

Although there have been improvements since these standards were first published, delays in access to first specialist assessment, diagnostic tests and definitive treatment remain areas for improvement. Access to palliative care services across New Zealand is currently inequitable, and the ability to capture and audit data for lung cancer patients needs attention.

In general, services are managing patients receiving active cancer treatments appropriately, and so the NLCWG agreed that no major changes were required to the standards relating to active anti-cancer treatment.

By contrast, there is a real need to achieve higher rates of early presentation of lung cancer. Patients with earlier stage lung cancer have improved outcomes. Therefore, primary care is a target audience for the new standards are aimed at primary care, to encourage more chest X-rays in high-risk individuals. The standards also address the issue of imaging that identifies an incidental finding suggestive of cancer. In presenting these standards, the NLCWG acknowledges that more research is required in New Zealand on screening.

Regional reviews against the lung cancer standards identified the lack of measures or performance indicators for each standard. For some standards eg, smoking cessation and advice given to ‘family/whānau’ where gathering achievement data is difficult, the NLCWG has revised or removed such standards. The NLCWG has also revised the standards to more tightly set out definitions and monitoring criteria. It is no longer possible to partially meet a standard; they are now either ‘achieved’ or ‘not achieved’, to avoid confusion.

To keep the monitoring of standards realistic and recognising that some standards require audit of patient notes, the NLCWG has kept required random sample numbers low. A review of achievement against these standards within a particular service is intended to give a snapshot of how that service is performing, and is not necessarily aimed at providing statistically significant samples (which would require dedicated staff).

The standards apply to any person or organisation that provides care and services to patients with lung cancer in New Zealand. The NLCWG also intends that District Health Boards (DHBs) will use them to develop key performance indicators that will be audited and used to drive improvements in services.

The NLCWG would like to emphasise the importance of services providing patients with the opportunity to participate in clinical trials at all stages of their journey.

## How the lung cancer service standards were reviewed

In the original development of these standards, the NLCWG recognised the need for evidence-based practice. Numerous evidence-based guidelines and standards already existed, so the group largely formulated the standards by referring to established international guidelines. These included:

* AGNHMRC and ACN, *Clinical Practice Guidelines for the Prevention, Diagnosis and Management of Lung Cancer* (referred to as ACN 2004)
* BTS and the Society for Cardiothoracic Surgery in Great Britain and Ireland, *Guidelines on the Radical Management of Patients with Lung Cancer* (referred to as BTS 2010)
* NICE, *Clinical Guideline: The diagnosis and treatment of lung cancer (update)* (NICE 2011)
* NHS Wales, *National Standards for Lung Cancer Services 2005* (NHS Wales 2005)
* NHS Scotland, *Clinical Standards – July 2008 [new edition]: Management of lung cancer services* (NHS Scotland 2008)
* NCCN, *Guidelines for Non-Small Cell Lung Cancer* (NCCN 2011).

Where no clear evidence was available, the NLCWG sought expert opinion. It undertook wider consultation with key lung cancer sector stakeholders and relevant professional organisations (including the New Zealand branch of the Thoracic Society of Australia and New Zealand and the Royal New Zealand College of General Practitioners).

For its revision of the *Standards of Service Provision for Lung Cancer Patients in New Zealand* the NLCWG has taken a different approach. For the process of revision of the standards, the NLCWG drafted some changes, as described in the Background, and distributed them for consultation. It then collated feedback from the consultation process and considered it; where appropriate, it accommodated this feedback in the draft document. The consultation process included questions about content, as well as format changes. The NLCWG also reviewed draft standards for the other New Zealand tumour streams, in an attempt to improve consistency across the standards documents.

In undertaking the review, the NLCWG remained of the opinion that the overall number of standards should remain low, and be directed at a high level.

The NLCWG will review these standards three yearly. Researchers and other stakeholders should advise the chair of the NLCWG if they discover important new information that might render an aspect of good practice – and therefore these standards – out of date. The NLCWG will review the information and decide if it is important.

## Summary of changes to 2011 Service Standards

* Total of 20 standards compared to 13 in the 2011 standards.
* Three new standard clusters are:
* prevention and early detection
* supportive care
* clinical performance monitoring and research
* Prevention and early detection cluster has three standards related to referrals for chest X-ray, managing abnormal imaging results and the quit smoking health target.
* Referral and communication standard reworded.
* Investigations cluster is revised to: Investigation, diagnosis and staging.
* Three additional standards are added to the investigations, diagnosis and staging cluster related to access to CT guided biopsy, molecular testing and reporting of tests.
* Follow-up cluster of standards is revised to: Follow-up and surveillance.
* Data collection standard is added to the clinical performance, monitoring and research cluster.
* Equity and Whānau ora statements are added to the introduction.
* A lung cancer standards pathway chart is added to the introduction.
* New format for each standard ie, standard statement is followed by rationale, how we measure the standard, target, and monitoring requirement.
* Wording in some standards is changed.
* Good practice points have been updated or removed.
* High suspicion of cancer (HScan) definition developed in 2016 is referenced.
* Faster Cancer Treatment health target acknowledged in standards.

## Equity and Whānau Ora

Health inequities or health disparities are avoidable, unnecessary and unjust differences in the health of groups of people. In New Zealand, ethnic identity is an important dimension of health disparities. Cancer is a significant health concern for Māori, and has a major and disproportionate impact on Māori communities (Ministry of Health 2008).

Inequities exist between Māori and non-Māori in terms of exposure to risk and protective factors for cancer, incidence and outcomes, and access to cancer services.

Barriers to health care are recognised as multidimensional, and include health system and health care factors (eg, institutional values, workforce composition, service configuration and location), as well as patient factors (eg, socioeconomic position, access to transportation and personal values). Addressing these factors requires a population health approach.

A Whānau Ora approach to health care recognises the interdependence of people; health and wellbeing are influenced and affected by the ‘collective’ as well as the individual. It is important to work with people in their social contexts, and not just with their physical symptoms.

The outcome of the Whānau Ora approach in health will be improved health outcomes for family/whānau through quality services that are integrated (across social sectors and within health), responsive and patient/family/whānau-centred.

These standards address equity for Māori patients with lung cancer in the following ways.

* They focus on improving early detection, timely access to diagnosis and treatment for all patients, including Māori and Pacific people.
* They require practitioners to focus on potential points of delay in diagnosis and management for Māori and Pacific people.
* They require services to identify barriers to attendance (eg, mobility, cost, co‑morbidities and compliance issues) at the earliest opportunity.
* They require services to collect ethnicity data on all measures/indicators, and use it to identify and address disparities.
* They require that family/whānau be involved in care coordination and supportive care.
* Good practice points stipulated in the standards include health literacy and cultural competency training for all health professionals involved in patient care.

## Format of the standards

Each cluster of standards has a title that summarises the step of the patient journey or the area on which the standards are focused. This is followed by the standard itself, which explains the level of performance to be achieved. The rationale section explains why the standard is considered to be important. The ‘How do we measure the standard’ section provides the specific measures for the standard. The target section indicates the level services should aim for to achieve the standard.

Attached to most of the clusters of standards are good practice points. Good practice points are supported by either the international literature, the opinion of the NLCWG or a consensus of feedback from consultation with New Zealand clinicians involved in providing care to patients with lung cancer.

## Standards of service provision pathway

The lung cancer standards are reflected in the following pathway:



## Summary of the clinical standards for the management of lung cancer services

The standards for the management of lung cancer have been divided into 10 clusters:

* prevention and early identification
* timely access to services
* referral and communication
* investigations, diagnosis and staging
* multidisciplinary care
* supportive care
* care coordination
* treatment
* follow-up and surveillance
* clinical performance monitoring and research.

The standards are as follows.

### Cluster 1: Prevention and early identification

**Standard 1.1:** A chest X-ray should be requested for people presenting to general practice or equivalent organisation with symptoms potentially suggestive of lung cancer, or it is documented why this was considered and not requested.

**Standard 1.2:** Every organisation providing health services should have a written policy for managing abnormal results related to thoracic imaging reports with a high suspicion of lung cancer.

**Standard 1.3:** 95 percent of hospital patients who smoke and are seen by a health practitioner in a public hospital are offered brief advice and support to quit smoking. 90 percent of PHO enrolled patients who smoke have been offered help to quit smoking by a health care practitioner in the last 15 months.

### Cluster 2: Timely access to services

**Standard 2.1:** Patients requiring treatment for lung cancer, irrespective of route of referral, should start treatment within 62 days of secondary care receiving a referral.

**Standard 2.2:** Patients with clinical and/or radiological signs and symptoms suggestive of lung cancer should be seen by a specialist with an interest in respiratory medicine within 14 calendar days of secondary care receiving a referral.

### Cluster 3: Referral and communication

**Standard 3.1:** Each cancer centre should provide a lung cancer investigation and management pathway that is easily accessible to all members of the lung cancer service, including primary care general practices.

### Cluster 4: Investigations, diagnosis and staging

**Standard 4.1:** Computed tomography (CT) should be performed before a bronchoscopy.

**Standard 4.2:** All patients should have timely access to endobronchial ultrasound (EBUS).

**Standard 4.3:** All patients should have timely access to CT-guided biopsy.

**Standard 4.4:** Staging positron emission tomography and computed tomography (PET-CT) should be performed in patients with suspected or confirmed small-cell lung cancer and non-small-cell lung cancer (NSCLC) suitable for potentially curative treatment.

**Standard 4.5:** All lung cancer patients should have timely access to appropriate molecular testing.

**Standard 4.6:** Reports and recommendations regarding key interventions (eg, radiology investigations and pathology tests) should be communicated to the appropriate member of the lung cancer team (usually referring clinician) within seven days of the intervention.

### Cluster 5: Multidisciplinary care

**Standard 5.1:** All patients with lung cancer should be discussed at a multidisciplinary meeting (MDM).

### Cluster 6: Supportive care

**Standard 6.1:** All patients with lung cancer and their family/whānau should have equitable and coordinated access to appropriate medical, allied health and supportive care services, in accordance with *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand* (Ministry of Health 2010).

### Cluster 7: Care coordination

**Standard 7.1:** All patients with suspected lung cancer should have a nominated point of contact, ideally a nurse who specialises in cancer care, to arrange for provision of psychosocial support, information and coordination of their journey.

### Cluster 8: Treatment

**Standard 8.1:** Patients who cannot be offered curative treatment, or who decline curative treatment, as well as those with a significant symptom burden, should be offered early access to palliative care services.

### Cluster 9: Follow-up and surveillance

**Standard 9.1:** All patients and their general practitioners (GPs) should be given written information regarding a follow-up plan together with a nominated point of contact if there is a clinical concern.

### Cluster 10: Clinical performance monitoring and research

**Standard 10.1:** All patients with lung cancer should be entered into a lung cancer database capturing the provisional national lung cancer core data set.

**Standard 10.2:** Each regional cancer centre or unit managing patients with lung cancer should employ designated lead clinicians with specialist knowledge of lung cancer to provide leadership. A regional lung cancer work group should be established to facilitate this.

**Standard 10.3:** Patients with cancer should be offered the opportunity to participate in research projects and clinical trials where they are available.

# 1 Prevention and early identification

|  |  |
| --- | --- |
| Standard 1.1 | A chest X-ray should be requested for people presenting to general practice or equivalent organisation with symptoms potentially suggestive of lung cancer, or it is documented why this was considered and not requested. |

### Rationale

Chest X-rays can lead to earlier diagnosis of lung cancer.

International initiatives such as the Doncaster project found that 65 percent of patients diagnosed with lung cancer had not had a chest X-ray in the five years prior to diagnosis, even though many had had symptoms warranting investigation. A general practice audit indicated that if services had strictly adhered to the National Institute for Clinical Excellence guidelines (NICE 2005) they could have requested another 20 chest X-rays a week.

The high suspicion of lung cancer definition is set out in the recently updated Faster Cancer Treatment: High suspicion of cancer definitions (Ministry of Health 2016).

### How do we measure the standard

Undertake a review against the standard of 50 consecutive patients or the total number (if less than 50 per annum) for whom referrals to the district health board (DHB) respiratory service (or equivalent) were triaged as a ‘high suspicion of cancer’ and needing to be seen within two weeks.

Undertake a review of associated general practice (or equivalent organisation) and DHB (including emergency department) clinical records to identify prior opportunities to request chest X-rays for high-risk patients or those with red flag symptoms that might indicate a suspicion of cancer. In cases where a chest X-ray was not ordered, there was documentation as to why this was considered and not requested.

### Target

95 percent of eligible patients meet the standard.

### Monitoring requirement

Annual report to regional cancer network and regional lung cancer work group.

|  |  |
| --- | --- |
| Standard 1.2 | Every organisation providing health services should have a written policy for managing abnormal results related to thoracic imaging reports with a high suspicion of lung cancer. |

### Rationale

Early detection and treatment of lung cancer leads to the highest cure rates. A significant proportion of lung cancer is detected incidentally, during work-up for other conditions. These are not often acted on in a timely fashion, as the treating clinical team may be focused on the primary pathology being investigated and not the potential lung cancer.

### How do we measure the standard

Evidence of written policy in place.

### Target

100 percent of organisations meet the standard.

### Monitoring requirement

Annual report to regional cancer network and regional lung cancer work group.

|  |  |
| --- | --- |
| Standard 1.3 | 95 percent of hospital patients who smoke and are seen by a health practitioner in a public hospital are offered brief advice and support to quit smoking.90 percent of PHO enrolled patients who smoke have been offered help to quit smoking by a health care practitioner in the last 15 months. |

### Rationale

There is evidence for improved outcomes in patients with lung cancer who stop smoking. This is self-evident for those patients who are treated with curative intent. Patients with advanced disease, who are being treated with palliative intent, and particularly those being treated with tyrosine kinase inhibitors, also have improved outcomes if they stop smoking. However, at a population level, the greatest gains to be made are from smoking cessation in family/whānau who are current smokers as yet unaffected by lung cancer.

Health practitioners need to approach the topic of smoking cessation with sensitivity. It is important that patients and family/whānau do not experience a sense of blame. This standard is the government health target ‘Better help for smokers to quit’.

### How do we measure the standard

Routine health target reporting**.**

### Target

Rates stated in the standard are achieved.

### Monitoring requirement

Routine health target reporting**.**

## Good practice points

1.1.1 Referral to quit smoking treatment services are a key component of the ‘ABC’ approach (**A**sk about and document every person’s smoking status; give **B**rief advice to stop; strongly encourage people to use **C**essation support). More information on quitting smoking can be found at www.moh.govt.nz/tobacco.

1.1.2 Health providers should improve people’s health literacy by increasing public awareness of the signs and symptoms of lung cancer.

1.1.3 Primary care providers should be upskilled to increase their awareness of lung cancer, lung cancer symptoms, risk factors and benefits of early detection.

1.1.4 In a general practice or an equivalent organisation:

* practitioners should refer patients with red-flag symptoms of lung cancer to a respiratory physician (or equivalent), even if they are in a low risk group. In addition, they should request a chest X-ray
* if the chest X-ray is reported as normal and the patient is not referred, practitioners should give the patient a documented management plan of what to do if the symptoms persist or worsen, and/or a follow-up review date.

# 2 Timely access to services

|  |  |
| --- | --- |
| Standard 2.1 | Patients requiring treatment for lung cancer, irrespective of route of referral, should start treatment within 62 days of secondary care receiving a referral. |

### Rationale

Patients referred urgently with suspected cancer should be seen promptly and should complete their diagnostic investigations and start treatment within an acceptable timeframe. This is because delayed treatment can result in disease progression, resulting in some potentially curable patients becoming incurable. Palliative patients also require timely treatment, as most of the benefit from systemic treatment is achieved in patients with good performance status.

The degree of benefit varies according to prognostic factors and performance status. The most significant gains in outcomes will be with early-stage NSCLC and small-cell lung cancer; services should prioritise these patients for treatment.

The aim in setting waiting time targets is to encourage a culture of timely work-up in which treatment is initiated as soon as possible. Where waiting times are longer than the time specified in the standard, local or regional services should work to reduce them to achieve the target. If the service is already meeting the target, it needs to maintain and further improve performance.

This standard refers to all patients diagnosed with lung cancer not only the Faster Cancer Treatment Health Target cohort.

### How do we measure the standard

**Numerator:** Number of patients with ECOG 0–2 performance status who started treatment within 62 calendar days of referral.

**Denominator:** All patients with ECOG performance status 0–2 with confirmed lung cancer.

### Target

More than 90 percent of patients meet the standard.

### Monitoring requirement

Annual report to regional cancer networks and regional lung cancer work groups.

|  |  |
| --- | --- |
| Standard 2.2 | Patients with clinical and/or radiological signs and symptoms suggestive of lung cancer should be seen by a specialist with an interest in respiratory medicine within 14 calendar days of secondary care receiving a referral. |

### Rationale

See Rationale for Standard 2.1 above.

### How do we measure the standard

**Numerator:** Number of patients seen by a specialist with an interest in respiratory medicine within 14 calendar days of referral.

**Denominator:** All referrals with a high suspicion of lung cancer received at secondary services.

### Target

95 percent of patients meet the standard.

### Monitoring requirement

Six-monthly report to regional cancer network and regional lung cancer work group.

## Good practice points

2.1.1 Routine recording of key intervention points is necessary, to enable identification and monitoring of bottlenecks in the patient pathway.

2.1.2 Practitioners should perform CT scans of the lower neck, chest and upper abdomen as early as possible.

2.1.3 Patients should have open access (a same-day or no-wait service within the public system) to chest X-services inside working hours.

2.1.4 Practitioners should prioritise patients with early-stage disease quickly through the cancer treatment pathway.

2.1.5 Practitioners should refer small-cell cancer patients to radiation oncology and/or medical oncology as soon as they have established the diagnosis.

# 3 Referral and communication

|  |  |
| --- | --- |
| Standard 3.1 | Each cancer centre should provide a lung cancer investigation and management pathway that is easily accessible to all members of the lung cancer service, including primary care general practices. |

### Rationale

The purpose of the referral pathway is to ensure that all patients with suspected lung cancer are referred to the most appropriate health care service, and that appropriate standardised information is available in the referral.

### How do we measure the standard

Pathway is available to members of the lung cancer team including primary care general practices.

### Target

100 percent of all lung cancer service members, including primary care general practices, can access lung cancer pathway information. This implies universal availability of information.

### Monitoring requirement

Evidence of an annual review of regional lung cancer pathway (eg, minutes of work group meetings).

### Good practice points

3.1.1 Referrals should contain the words ‘high suspicion of cancer’ (HSCan) to help with prioritisation.

3.1.2 Practitioners should make electronic proforma-based referrals.

3.1.3 Practitioners should maintain two-way communication between primary, secondary and tertiary care during patients’ lung cancer journey.

# 4 Investigations, diagnosis and staging

|  |  |
| --- | --- |
| Standard 4.1 | CT should be performed before a bronchoscopy. |

### Rationale

CT prior to bronchoscopy improves the positive diagnostic yield, thereby reducing the requirement for repeat investigation.

### How do we measure the standard

**Numerator:** Number of patients with lung cancer undergoing bronchoscopy where CT chest was performed prior to bronchoscopy.

**Denominator:** All patients with lung cancer undergoing bronchoscopy.

A sample of 20 patients seen in the six-month period.

### Target

More than 95 percent of patients meet the standard.

The tolerance within this target is designed to account for factors of patient choice and patients unable to undergo CT due to comorbidities.

### Monitoring requirement

Six-monthly report to regional cancer network and regional lung cancer work group.

|  |  |
| --- | --- |
| Standard 4.2 | All patients should have timely access to EBUS. |

### Rationale

Successful treatment of lung cancer depends on the accurate diagnosis and staging of the lung cancer; EBUS facilitates this.

### How do we measure the standard

**Numerator:** Number of patients with lung cancer who had an EBUS within seven days of receipt of referral.

**Denominator:** All patients with lung cancer who had an EBUS.

### Target

95 percent of patients meet the standard.

### Monitoring requirement

Six-monthly report to regional cancer network and regional lung cancer work group.

|  |  |
| --- | --- |
| Standard 4.3 | All patients should have timely access to CT-guided biopsy. |

### Rationale

Successful treatment of lung cancer depends on the accurate diagnosis and staging of the lung cancer; CT-guided biopsy facilitates this.

### How do we measure the standard

**Numerator:** Number of patients with lung cancer who had a CT-guided biopsy within seven days of receipt of referral.

**Denominator:** All patients with lung cancer who had a CT-guided biopsy.

### Target

95 percent of patients meet the standard.

### Monitoring requirement

Six-monthly report to regional cancer network and regional lung cancer work group.

|  |  |
| --- | --- |
| Standard 4.4 | PET-CT should be performed in patients with suspected or confirmed small-cell lung cancer and NSCLC suitable for potentially curative treatment. |

### Rationale

Successful treatment of lung cancer depends on the accurate diagnosis and staging of the lung cancer; PET-CT facilitates this.

### How do we measure the standard

**Numerator:** Number of patients with lung cancer who are treated with curative intent (through radical radiotherapy, radical chemoradiotherapy or surgical resection) who undergo PET-CT prior to the start of their treatment.

**Denominator:** All patients with lung cancer who are treated with curative intent.

### Target

95 percent of patients meet the standard.

### Monitoring requirement

Six-monthly report to regional cancer networks and regional lung cancer work groups.

|  |  |
| --- | --- |
| Standard 4.5 | All lung cancer patients should have timely access to appropriate molecular testing. |

### Rationale

Patients with incurable lung cancer whose tumours have targetable oncogenic mutations (eg, activating mutations of the epidermal growth factor receptor gene (EGFR) or rearrangements of anaplastic lymphoma kinase (ALK)) experience the best outcomes when treated with targeted therapies. The presence or absence of mutations cannot be determined by demographic features, but only through molecular analysis of tumour tissue.

### Specifications

**Numerator:** Patients with a new diagnosis of incurable non-squamous NSCLC who had molecular testing of their tumour for EGFR mutation.

**Denominator:** All patients with a new diagnosis of incurable non-squamous NSCLC.

### Target

95 percent of patients meet the standard.

### Monitoring requirement

Six-monthly report to regional cancer network and regional lung cancer work group.

|  |  |
| --- | --- |
| Standard 4.6 | Reports and recommendations regarding key interventions (eg, radiology investigations and pathology tests) should be communicated to the appropriate member of the lung cancer team (usually referring clinician) within seven days of the intervention. |

### Rationale

This standard promotes timely treatment.

Health and Disability Services Standard criterion 3.3.4 requires that services be coordinated in a manner that promotes continuity in service delivery and a team approach.

### How do we measure the standard

Percentage of random sample of 20 patient records with key intervention reports communicated to the lung cancer team within seven days.

### Target

95 percent of reports and recommendations meet the standard.

### Monitoring requirement

Annual report to regional cancer network and regional lung cancer work group.

## Good practice points

4.1.1 Health practitioners should choose investigations that give the most information about diagnosis andstaging with least risk to the patient. They should think carefully before performing a test that gives only diagnostic pathology when information on staging is also needed to guide treatment.

4.1.2 In appropriate patients, practitioners should carry out non-ultrasound guided transbronchial needle aspiration (non-US TBNA) at the time of bronchoscopy, guided by CT or PET scan.

4.1.3 In appropriate patients, practitioners should use EBUS-TBNA or non-US TBNA as the preferred diagnosis and staging tests, based on information provided by CT or PET-CT scans.

4.1.4 Practitioners should confirm the diagnosis pathologically where they think a patient has N2/N3 disease (mediastinal nodal involvement), based on information provided by the PET-CT scan, unless the patient has obvious distant metastatic disease or multiple nodal stations, in keeping with locally advanced lung cancer.

4.1.5 Practitioners should assess lung function and perform gas transfer diffusing capacity of the lung for carbon monoxide (DLCO) studies in patients considered suitable for potentially radical treatment.

4.1.6 Selected patients undergoing surgery for lung cancer will require cardiopulmonary exercise testing.

4.1.7 Practitioners should consider CT of the head as part of staging investigation in patients with small-cell lung cancer or locally advanced NSCLC.

4.1.8 Practitioners should take the tissue requirements for molecular testing into account when obtaining and handling biopsy specimens in patients with suspected lung cancer. Core biopsy is preferable to fine needle aspiration where it is feasible and safe.

4.1.9 Practitioners should use molecular testing to select patients suitable for targeted therapies, and should not exclude patients with non-squamous NSCLC from testing on clinical characteristics.

4.1.10 Molecular test results should include a results and interpretation section readily understandable by clinicians and non-specialist pathologists.

# 5 Multidisciplinary care

|  |  |
| --- | --- |
| Standard 5.1 | All patients with lung cancer should be discussed/registered at an MDM. |

### Rationale

The cornerstone of best practice in cancer care is multidisciplinary treatment planning and multidisciplinary care. An effective multidisciplinary approach can result in survival benefits, increased recruitment into clinical trials, reduction in service duplication and improved coordination of services. Further guidance on this topic is set out in the *Lung Cancer Multidisciplinary Meeting Toolkit* (National Lung Cancer Working Group 2014).

### How do we measure the standard

**Numerator:** Number of lung cancer registrations discussed at an MDM.

**Denominator:** Number of all lung cancer registrations.

### Target

90 percent of patients meet the standard, excluding those who died before first their treatment.

### Monitoring requirement

Six-monthly report to regional cancer network and regional lung cancer work group.

## Good practice points

5.1.1 All referrals to a MDM should include demographic data, provisional staging and clinical factors such as: current symptoms, performance status, weight loss, medical co-morbidity, bronchoscopy, relevant imaging, pathological diagnosis (if available) and lung function, to maximise the MDM’s ability to make appropriate clinical decisions.

5.1.2 The multidisciplinary discussion report should include treatment recommendations and intent, where possible, as well as reasons for any variation from standard practice.

5.1.3 Where the treating clinician does not following the treatment plan recommended by the multidisciplinary team, he or she should record the reason.

5.1.4 The recommendations of the multidisciplinary discussion should be available as an electronic record accessible to other members of the health care team.

# 6 Supportive care

|  |  |
| --- | --- |
| Standard 6.1 | All patients with lung cancer and their family/whānau should have equitable and coordinated access to appropriate medical, allied health and supportive care services, in accordance with *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand* (Ministry of Health 2010). |

### Rationale

The psychological, social, physical and spiritual needs of cancer patients are many and varied. To a large extent, these needs can be met by the multidisciplinary health care teams in hospitals and in the community.

Non-government organisations, including the Cancer Society, perform an important role in providing supportive care.

### How do we measure the standard

The DHB has a psychosocial assessment tool. There is evidence of appropriate use of the tool in a random sample of 20 lung cancer patient records.

### Target

95 percent of patients have their supportive care and psychosocial needs assessed and documented.

### Monitoring requirement

Annual report to regional cancer network and regional lung cancer work group.

## Good practice points

6.1.1 Practitioners should refer patients and their family/whānau experiencing significant distress or disturbance to health practitioners with the requisite specialist skills (Ministry of Health 2010).

6.1.2 Support services including spiritual services should be culturally appropriate (eg, it may be appropriate to refer Māori patients and their family/whānau to whānau supportive services and Māori patient navigators/cancer coordinators) (Ministry of Health 2010).

6.1.3 Supportive care assessments and interventions should be undertaken in suitable facilities and locations that take into consideration people’s needs for privacy, comfort and mobility.

# 7 Care coordination

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| Standard 7.1 | All patients with suspected lung cancer should have a nominated point of contact, ideally a nurse who specialises in cancer care, to arrange for provision of psychosocial support, information and coordination of their journey. |

### Rationale

The cancer journey is complex; it is not uncommon for a patient to be seen by many specialists within and across multiple DHBs and across the public and private sectors.

Care coordination refers to a system or a role primarily intended to expedite patient access to services and resources, improve communication and the transfer of information between services, address patients’ informational needs and improve continuity and coordination of care throughout the cancer continuum. Services need to ensure they have strategies in place that improve the coordination of care. Care coordination is the responsibility of the entire multidisciplinary team.

One person should available as a single point of contact for patients and caregivers through the various stages of the lung cancer journey.

### How do we measure the standard

**Numerator:** Number of patients triaged with high suspicion of lung cancer contacted by a cancer nurse within 14 calendar days of referral.

**Denominator:** Total number of high suspicion of lung cancer referrals received.

**Or** random sample of 20 lung cancer patient records (to capture acute presentation patients) – evidence of contact with clinical nurse specialist or cancer care coordinator within 14 days of referral.

### Target

95 percent of patients meet the standard.

### Monitoring requirement

Annual report to regional cancer network and regional lung cancer work group.

## Good practice points

7.1.1 All regional cancer centres should employ a dedicated lung cancer nurse specialist.

7.1.2 The person acting as the point of contact should keep each patient informed about all the processes involved in diagnosing and treating lung cancer, in a manner appropriate to their individual needs.

7.1.3 The information, treatment and care patients are given should be culturally appropriate.

# 8 Treatment

The NLCWG recognises that timely active anti-cancer treatment is fundamental. However, the group has not defined specific standards for active treatment. Instead, it has incorporated the principle of timeliness in the 62-calendar-day waiting time target between receipt of a referral and start of treatment (see Standard 2.1).

The degree of benefit of treatment for a particular patient varies according to prognostic factors and performance status. The most significant gains in improved outcomes will be in patients with early-stage NSCLC and small-cell lung cancer, and therefore practitioners should prioritise these patients for treatment.

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| Standard 8.1 | Patients who cannot be offered curative treatment, or who decline curative treatment, as well as those with a significant symptom burden, should be offered early access to palliative care services. |

### Rationale

The role of palliative care in patients with lung cancer is particularly important. The majority of patients with lung cancer will ultimately die of their disease; most experience a significant symptom burden during their cancer journey. Palliative care interventions can prolong survival in patients with NSCLC.

### How do we measure the standard

**Numerator:** Number of patients referred from a secondary/tertiary service for specialist palliative care for symptom management.

**Denominator:** Number of patients shown to have died from lung cancer.

**Or** evidence found in random sample of 20 patient records of patients known to have died from lung cancer.

### Target

95 percent of patients meet the standard.

### Monitoring requirement

Annual report to regional cancer network and regional lung cancer work group.

## Good practice points

Good practice points for this cluster are grouped under the headings ‘palliative care’, ‘surgery’, ‘radiation oncology’ and ‘systemic therapy’.

### Palliative care

8.1.1 Most patients with lung cancer would benefit from a palliative care team helping with symptom management, psychosocial support and attention to spiritual needs.

8.1.2 Palliative care should be provided by a patient’s lead practitioner and, when assessed as necessary, a specialist palliative care provider.

8.1.3 Practitioners should identify patients who may benefit from specialist palliative care services and refer them without delay.

8.1.4 An integrated care pathway for the dying should be implemented in hospitals, hospices and other care settings (including residential care homes and patients’ homes).

8.1.5 Patients should have access to cultural and spiritual support if required.

8.1.6 Practitioners should encourage patients to consider advance care planning where cure is not possible. Wherever possible, they should avoid leaving this discussion until the terminal stages of the illness.

### Surgery

8.1.7 Practitioners should undertake and record assessments of the operative risks using standard scoring tools, for audit purposes.

8.1.8 Practitioners should perform systematic nodal dissection in all patients undergoing resection for lung cancer. They should sample a minimum of six nodes/nodal stations at the time of surgery, to improve the accuracy of pathological staging.

8.1.9 A multidisciplinary team should review post-surgical pathological findings for all patients.

### Radiation oncology

8.1.10 Practitioners should consider and manage external and internal target motion, particularly in curative settings.

8.1.11 Practitioners should record prescribed doses to the planning target volume and at-risk organs (at least the volume of lung receiving greater than 20 Gy, mean lung dose) for future analysis.

8.1.12 Practitioners should consider suitable patients with early-stage lung cancer not fit for surgery or who decline surgery for stereotactic ablative body radiation therapy.

8.1.13 Practitioners should consider patients with stage II or III NSCLC receiving radiation with curative intent for concurrent chemotherapy.

8.1.14 Practitioners should consider patients with limited-stage small-cell lung cancer (broadly staged as T1–4, N0–3, M0) for concurrent or sequential chemoradiation. Radiotherapy should ideally be started during the first or second cycle of chemotherapy.

8.1.15 Practitioners should consider patients with small-cell lung cancer for prophylactic cranial irradiation if their disease has not progressed on first-line treatment.

### Systemic therapy

8.1.16 Practitioners should offer post-operative platinum-based combination chemotherapy to post-surgical NSCLC patients with good performance status and T1-3, N1-2, M0 pathological disease.

8.1.17 Practitioners should consider patients with stage II or III NSCLC and good performance status who are not candidates for surgery by virtue of stage or co-morbidity for concurrent chemoradiation.

8.1.18 Practitioners should consider patients with (broadly staged as T1-4, N0‑3, M0) small-cell lung cancer and good performance status for concurrent chemoradiation.

8.1.19 Practitioners should consider patients with stage III or IV NSCLC and good performance status for platinum-based combination chemotherapy to improve survival, disease control and quality of life. Practitioners may offer single-agent chemotherapy with a third-generation drug to patients who cannot tolerate platinum-based combination chemotherapy.

8.1.20 Practitioners should consider patients with extensive-stage small-cell lung cancer for platinum-based combination chemotherapy up to a maximum of six cycles.

8.1.21 Practitioners should offer treatment with targeted therapies to patients with incurable NSCLC and known targetable mutations (eg, activating mutations of the EGFR or ALK rearrangements).

8.1.22 Practitioners should not treat patients with EGFR or ALK targeted therapies in the absence of an identified oncogenic mutation.

# 9 Follow-up and surveillance

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| Standard 9.1 | All patients and their general practitioners should be given written information regarding a follow-up plan and a nominated point of contact if there is a clinical concern. |

### Rationale

The main objective of follow-up care is to detect distant recurrence at an early stage so that treatment for any relapse can be started. The NLCWG notes that there is insufficient evidence to recommend any particular schedule of follow-up of patients after treatment for lung cancer.

There is no convincing proof that intensive follow-up approaches based on regular laboratory and radiological investigations improves outcomes in asymptomatic patients. The NLCWG discourages routine testing beyond a plain chest X-ray in asymptomatic patients, to free up resources for and reduce delays in diagnosing new cancers.

### How do we measure the standard

Each cancer centre has a formalised follow-up template available.

Random sample of 20 curatively treated lung cancer patient records indicating evidence of the follow-up plan.

### Target

95 percent of patients meet the standard.

### Monitoring requirement

Annual report to regional cancer network and regional lung cancer work group.

## Good practice points

9.1.1 There is no evidence that the routine use of CT and PET-CT, tumour markers or bronchoscopy in asymptomatic patients has any effect on outcome. The NLCWG discourages routine use of these tests in follow‑up of asymptomatic patients.

9.1.2 Practitioners should inform patients whether they will offer them regular follow-up appointments after completing treatment; they should also inform them whether the clinical follow-up will be carried out through a hospital outpatient service or in the community by a GP.

9.1.3 If a GP is responsible for longer-term follow-up, practitioners need to document an agreed assessment and investigation plan.

# 10 Clinical performance monitoring and research

|  |  |
| --- | --- |
| Standard 10.1 | All patients with lung cancer should be entered into a lung cancer database capturing the national lung cancer core dataset. |

### Rationale

The aim of this standard is to standardise data collection for lung cancer to integrate demographic, diagnostic, treatment, outcome and other medical information, to contribute to service and clinical performance monitoring and research. Ultimately, this will improve patient outcomes.

There is currently no national cancer database other than the New Zealand Cancer Registry. Until a national cancer database is available, services should collect information on patients with lung cancer systematically in a local or regional lung cancer database, to support multidisciplinary cancer care and to allow future local, regional and national collation and analysis.

### How do we measure the standard

**Numerator:** The number of patients entered into the lung cancer database per network region (for a defined period of time).

**Denominator:** The number of New Zealand Cancer Registry-identified patients diagnosed with lung cancer per network region.

### Target

100 percent of patients meet the standard.

### Monitoring requirement

Six-monthly report to regional cancer network and regional lung cancer work group.

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| Standard 10.2 | Each regional cancer centre or unit managing patients with lung cancer should employ designated lead clinicians with specialist knowledge of lung cancer to provide leadership. A regional lung cancer work group should be established to facilitate this. |

### Rationale

Clinical leadership enables services to direct resources to where they will have the greatest impact.

### How do we measure the standard

Presence of a clinical leader and evidence of regular regional lung cancer work group meetings.

### Target

All relevant centres and units appoint clinical leaders and demonstrate evidence of at least one annual regional lung cancer work group meeting.

### Monitoring requirement

Annual report to regional cancer network and regional lung cancer work group.

|  |  |
| --- | --- |
| Standard 10.3 | Patients with cancer should be offered the opportunity to participate in research projects and clinical trials where they are available. |

### Rationale

Patients who take part in clinical trials have better outcomes, and units actively engaging in clinical trials tend to provide better care for all their patients.

### How do we measure the standard

**Numerator:** Number of lung cancer patients entered into clinical trial, research or audit.

**Denominator:** Total number of lung cancer patients discussed at an MDM meeting over an annual period.

### Target

Evidence that 5 percent of patients are entered into clinical trials, research or audits in each sub-specialty within each region.

### Monitoring requirement

Annual report to regional cancer network and regional lung cancer work group.

## Good practice points

10.1.1 Practitioners should inform patients that their information is being recorded in a lung cancer database to help the multidisciplinary team recommend a treatment plan and to monitor and evaluate access to services.

10.1.2 Where data is collected, it should comply with the National Cancer Core Data Definitions (National Health IT Board 2011).

# Appendix 1:National Lung Cancer Working Group Membership

### Chair

Dr Charles de Groot, radiation oncologist, Waikato Hospital

### Members

Dr Scott Babington, radiation oncologist, Christchurch Hospital

Dr Ben Brockway, consultant and senior lecturer in respiratory medicine, Dunedin Hospital and Dunedin School of Medicine, University of Otago, Dunedin

Professor Richard Edwards, professor of public health and head of department, University of Otago, Wellington School of Medicine and Health Services

Dr Paul Dawkins, respiratory physician, Counties Manukau DHB

Dr James Entwisle, clinical leader, radiology department, Wellington Hospital

Dr Tana Fishman, senior lecturer, University of Auckland Department of General Practice and Primary Health Care; Greenstone Family Clinic, Manurewa, Auckland

Dr Greg Frazer, respiratory and general physician, Christchurch Hospital; clinical senior lecturer, University of Otago, Christchurch

Dr David Hamilton, radiation oncologist, Capital & Coast DHB

Dianne Keip, clinical care coordinator, Hawke’s Bay DHB

Dr Chris Lewis, respiratory specialist, Auckland DHB

Dr Brendan Luey, consultant medical oncologist, Capital & Coast DHB

Bubsie Macfarlane, Aroha Mai Cancer Support Services, Rotorua

Dr Kim McAnulty, radiologist, Waikato Hospital, Waikato Clinical School, University of Auckland

Dr Felicity Meikle, thoracic surgical fellow, Dunedin

Dr Ziad Thotathil, radiation oncologist, Regional Cancer Centre, Waikato Hospital

# Appendix 2:Abbreviations used in this document

|  |  |
| --- | --- |
| ACN | Australian Cancer Network |
| ALK | anaplastic lymphoma kinase |
| BTS | British Thoracic Society |
| CT | computed tomography |
| DHB | District Health Board |
| EBUS | endobronchial ultrasound |
| EBUS-TBNA | endobronchial ultrasound − transbronchial needle aspiration |
| EGFR | epidermal growth factor receptor |
| ECOG | Eastern Cooperative Oncology Group |
| GP | general practitioner |
| Gy | Gray (unit), an international unit of absorbed radiation dose of ionising radiation |
| MDM | multidisciplinary meeting |
| NCCN | National Comprehensive Cancer Network |
| NHS  | National Health Service |
| NICE | National Institute of Clinical Excellence |
| NLCWG | National Lung Cancer Working Group |
| NSCLC | non-small cell lung cancer |
| non-US TBNA | non-ultrasound guided transbronchial needle aspiration |
| PET-CT | positron emission tomography and computed tomography |

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