



# Foreword

This report presents a brief overview of the findings of the research project '**Identification of barriers to the early diagnosis of people with lung cancer and description of best practice solutions**'. Full findings from this project can be found on the Northern Cancer Network's website located at:

<http://www.northerncancernetwork.org.nz/>

The project was funded by a Health Research Council of New Zealand & District Health Boards New Zealand (HRC\_DHBNZ) grant. It was conducted over a 3 year period from June 2009 until May 2012 and involved 2 Cancer Networks, 3 District Health Boards, and 4 primary care organisations within the Auckland and Lakes regions.

The project aimed to identify the major barriers to the early diagnosis of lung cancer and to develop recommendations to reduce these barriers so as to expedite diagnosis and improve the clinical journey for people with lung cancer and their whānau/family.

A mixed methods design was used to collect both quantitative and qualitative data, so as to fully explore the issues from multiple perspectives. Patients and whānau/family contributed their experiences, and health care professionals from various disciplines contributed their expertise to the project.

Front cover image acknowledgements:

(Left) **Georgina Frazer** (the late) - Georgina is of Te Arawa descent, she was a champion in supporting local initiatives for increasing the awareness of lung cancer in the Lakes community. Georgina lost her battle with Cancer in 2011.

(Right) **Bubsi McFarlane** - Aroha mai Cancer Support Service Rotorua. Aroha mai supports individuals navigate their journey through cancer services from primary healthcare through to tertiary care.

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# Principal Stakeholders

Northern Cancer Network (NCN; Northern DHB Support Agency – NDSA)  
Midland Cancer Network  
Auckland District Health Board (ADHB; participating DHB)  
Counties Manukau District Health Board (CMDHB; participating DHB)  
Lakes District Health Board (LDHB; participating DHB)  
Waitemata District Health Board (WDHB)  
ProCare Health Ltd (participating primary care organisation)  
Total Healthcare Otara and East Tamaki PHO (participating primary care organisation)  
Tamaki Primary Health Organisation  
Rotorua Area Primary Health Services (RAPHS; participating primary care organisation)  
Pinnacle Taupo (participating primary care organisation)  
Māori Health, LDHB  
Māori Leadership Group (NCN)  
Northern Region District Health Boards Māori General Managers Group  
New Zealand Guidelines Group (NZGG)  
University of Auckland (UoA)

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## **Section 1**

# **Introduction**

*What is the project about?*

# Introduction

## Purpose of the Report

This report presents an overview of the findings of the project: *'Identification of barriers to the early diagnosis of people with lung cancer and description of best practice solutions'*. Detailed information about the project, including reports on each research component, is available on the Northern Cancer Network website.<sup>i</sup>

## Lung Cancer

Lung cancer is a major health problem in New Zealand, resulting in approximately 1500 deaths annually.<sup>1-5</sup> It also contributes to ethnic inequalities in health outcomes, as Māori and Pacific peoples have poorer health outcomes from lung cancer than European New Zealanders.<sup>3</sup>

The poor survival from lung cancer is largely attributed to late diagnosis.<sup>6-9</sup> If lung cancer can be diagnosed (and treated) at an early stage, there is a good chance of survival. For example, the five year survival of early stage lung cancer is >50% and with surgical resection >70%.<sup>10</sup> However if lung cancer is diagnosed at an advanced stage, the chance of survival is poor (five year survival is only 3% if distant metastases are present).<sup>10</sup> Earlier

diagnosis of lung cancer therefore has the potential to improve health outcomes. In addition, it lessens patient anxiety and increases patient and whānau/family satisfaction with care.<sup>11</sup>

## Clinical Pathway

The lung cancer pathway is complex. Typically it involves many different services and providers. Although the clinical journey differs for each person with lung cancer, common points in the pathway exist. These include *presentation, investigation, referral, specialist assessment, further investigation and diagnosis*. Problems and delays can occur at any one of these points in the pathway, and frequently delays occur at several points. Delays may be due to patient factors, doctor factors, system factors or to a combination of these.

Barriers that cause delays or prevent optimal care along the lung cancer pathway have the potential to adversely impact on health outcomes.<sup>12</sup> Therefore optimising outcomes involves identifying these barriers and developing solutions to minimise them.

## The Project

The main aim of this Health Research Council of New Zealand & District Health Boards New Zealand (HRC\_DHBNZ) funded project was to develop recommendations to improve the clinical pathway from presentation to diagnosis for people with suspected lung cancer.

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<sup>i</sup> Full information on the project is available at: <http://www.northerncancernetwork.org.nz/>

The project built on work from a previous audit,<sup>13</sup> and drew upon the expertise of a wide variety of health care professionals involved in lung cancer care, as well as on the experiences of lung cancer patients and their whānau/family.

The project used a mixed methods design comprising various research components. It was conducted over a three year period (June 2009 – end May 2012) within the Northern and Midland Cancer Networks. Four primary care organisations and three District Health Boards (DHBs) participated in the research. The primary care organisations covered ~80% of the populations within the participating DHBs.

A particular strength of the project was the extensive involvement of Māori representatives in both the research and development of recommendations. This involvement occurred primarily via an Inequalities Team (IT), comprising one Pacific and five Māori representatives, who worked alongside the Expert Advisory Group (EAG) of the project. The IT was actively involved throughout the project, to ensure that the research was conducted in a culturally appropriate manner and that the research maintained an inequalities focus.

The findings of the project are presented briefly in the following chapters.

## Participating Primary Care Organisations

### *Auckland Region*

- **ProCare Health Ltd** (ProCare)  
Networks Auckland & Manukau
- **Total Healthcare Otago** (THO)

### *Lakes Region*

- **Rotorua Area Primary Health Services** (RAPHS)
- **Pinnacle General Practice Network Taupo** (Pinnacle)

## Participating DHBs

### *Auckland Region*

- **Auckland** (ADHB)
- **Counties Manukau** (CMDHB)

### *Lakes Region*

- **Lakes** (LDHB)

# Research Components of the Project

- 1. Literature Review** of the national and international literature on the barriers to optimal cancer care and the early diagnosis of lung cancer and the interventions recommended to reduce these barriers.
- 2. National Stocktake** of innovative or successful primary or secondary care services that could be relevant to people with lung cancer.
- 3. Clinical Audit** of the clinical records of patients with lung cancer diagnosed in 2008 within the Auckland and Lakes regions, who were registered with one of the participating primary care organisations (*ProCare, THO, RAPHS, or Pinnacle*) and received some component of care at one of the participating DHBs (*ADHB, CMDHB and LDHB*).
- 4. Practice Survey** of general practices affiliated with participating primary care organisations (*ProCare, THO, RAPHS, and Pinnacle*) within the Auckland and Lakes regions.
- 5. Survey and Focus Groups of GPs** affiliated with the participating primary care organisations (*ProCare, THO, RAPHS, and Pinnacle*) within the Auckland and Lakes regions.
- 6. Lung Cancer Patient Interviews and Focus Groups** within the Auckland and Lakes regions.
- 7. Development of Recommendations** based on the findings of the study and development of a best practice assessment tool to assess recommendations for implementation.
- 8. Economic Evaluation of the Recommendations**

Full reports on all these research components are available on the Northern Cancer Network's website at: <http://www.northerncancernetwork.org.nz/>

# What the Project Involved

- 1. Documentation of the current clinical pathway of people with suspected lung cancer and identification of any gaps or delays in care** by an audit of clinical records of people diagnosed with lung cancer in 2008 (according to the New Zealand Cancer Registry (NZCR) who were registered with one of the participating primary care organisations and received some component of secondary care within Auckland (ADHB), Counties Manukau (CMDHB) or Lakes District Health Boards (LDHB).
- 2. Identification of current service provision and processes of care** by:
  - Stocktakes of both primary and secondary care services to identify any innovative or successful services that could be relevant to people with suspected lung cancer.
  - A primary care practice survey and general practitioner (GP) survey of affiliated practices and GPs within participating primary care organisations in the Auckland and Lakes regions to identify current processes of care.
- 3. Identification of barriers to quality care and early diagnosis of people with suspected lung cancer** by:
  - A review of the national and international literature on barriers to optimal cancer care
  - Interviews of patients with suspected or known lung cancer and focus groups of patients with lung cancer and their whānau/family to identify barriers from their perspective.
  - A survey and focus groups of GPs affiliated with participating primary care organisations within the Auckland and Lakes regions to identify local barriers from the GP perspective.
- 4. Identification of potential interventions to improve care of people with suspected lung cancer from initial presentation to healthcare services until diagnosis** by:
  - A review of the national and international literature on services to improve cancer care
  - Stocktakes of both primary and secondary care services to identify any innovative or successful services that could be relevant to people with suspected lung cancer.
  - A survey and focus groups of GPs affiliated with participating primary care organisations within the Auckland and Lakes regions to identify local solutions from the GP perspective.
- 5. Development of recommendations to improve lung cancer care to diagnosis** by:
  - Assessment of the findings of the study and developing recommendations based on these findings.
  - Economic evaluation of the recommendations.

## Section 2

# Lung Cancer Pathway

*What is the current lung cancer pathway?*

# Lung Cancer Pathway

## Clinical Audit

The lung cancer pathway begins when a person first develops symptoms attributable to lung cancer. The *clinical* lung cancer pathway however begins when the person first presents to health care services.

The clinical pathway from initial presentation until diagnosis was documented by an audit of the primary and secondary clinical records of people diagnosed with primary lung cancer in 2008 (identified from a listing obtained from the NZ Cancer Registry) in the Auckland and Lakes regions, who were registered with a participating primary care organisation and who received some component of secondary care within a participating DHB (272 cases).

The audit built on work of a previous audit of all people diagnosed with primary lung cancer in Auckland and Northland in 2004 (565 cases),<sup>13</sup> which documented the secondary care pathway until treatment. This earlier audit did not include the primary care component of the pathway.

Collection of data from the primary care records in the current audit presented considerable logistic issues, as most records were not centralised requiring data collection at individual general practices. Each practice generally had only one case. To ensure accuracy and

consistency in data collection, one GP within each primary care organisation collected the data, and a reliability check was performed on 10% of cases by another GP. Quality of the data collected depended on the quality and completeness of the information in the clinical records.

There were 272 cases in the current audit. The median age was 69 years; 50% were female, 61% were of European ethnicity<sup>ii</sup>, 21% Māori, 9% Pacific and 9% Asian; 10% were never smokers. Many had comorbidities, with ~50% having another respiratory disease and ~30% having cardiovascular disease.

## Initial Presentation

### *Presenting symptoms*

Similar to international findings,<sup>14-18</sup> the most common symptoms at presentation were cough, shortness of breath, chest pain and haemoptysis. Symptoms suggestive of metastatic disease were present in 10% of patients and an incidental finding occurred in 8%. Fatigue and weight loss were also common, usually in combination with other symptoms.

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<sup>ii</sup> Ethnicity for the purposes of this clinical audit was the ethnicity documented in the New Zealand Cancer Registry. This may have led to an undercount of Maori and Pacific compared with self-reported ethnicity classification.

**Most Common Presenting Symptom**  
**Cough** (new or worsened) was the most common presenting symptom - occurring in **49%** of patients

***Haemoptysis occurred in 15%***

The presenting symptoms of lung cancer were similar to those of other respiratory disease, making it difficult for both the patient and doctor to recognise the potential seriousness of the symptoms, particularly as chronic obstructive pulmonary disease (COPD) frequently co-existed.

### *Duration of symptoms*

The duration of symptoms prior to presentation was poorly recorded in both the primary and secondary care records (being unspecified for more than half the patients). In international studies, 50-60% of patients presented to primary care within 3-4 weeks of developing symptoms.<sup>19 20</sup> In the current study for patients for which the duration was specified, 68% had symptoms for one month or less; 7% had symptoms for 1-3 months, 13% for 3-6 months, and 12% over 6 months. Thus 25% of patients (for whom symptom duration was documented) had symptoms for more than three months before presenting to their GP.

### *Primary or secondary care initially*

Approximately three-quarters (76%) of patients initially presented to primary care and one-quarter (24%) presented directly to secondary care. Of those that initially presented to secondary care, more than half (59%) had seen a GP within the preceding six months for other reasons. This suggests the possibility that opportunities may exist within primary care to identify lung cancer symptoms earlier in a substantial number of patients.

## **Initial Presentation to:**

### **Primary Care**

- **76%** of patients

### **Secondary Care**

- **24%** of patients

- 14% self-presented to the Emergency Department (ED)
- 10% were already under secondary care when they developed symptoms or had an incidental finding

***More than half the patients presenting directly to secondary care had seen a GP within the previous 6 months for another problem.***

## Primary Care Management

### *Initial consultation*

At the initial primary care consultation, the main action taken by the GP was as follows: chest X-ray (CXR: 40%); antibiotics only<sup>iii</sup> (16%); symptomatic management only (7%); referral for acute admission (6%); outpatient specialist referral (5%); blood tests only<sup>iii</sup> (5%) or other investigation (6%). Subsequently an additional 25% of patients were referred for a CXR.

### *Raised index of suspicion*

The GP's index of suspicion was raised (either of lung cancer or another serious cause of the patient's symptoms) for 51% of patients at the initial consultation. For 46%, suspicion was raised at a subsequent consultation, usually because of persistent or worsening symptoms. The index of suspicion was raised within two weeks of presentation for 70%; within 2 weeks to 1 month for another 10%; 1-3 months for 10%; and between 3 months to 1 year for 8%. Delayed suspicion was commonly due to symptoms being attributed to other respiratory disease. For 3%, the GP never suspected lung cancer or another serious cause.

As found in other studies,<sup>21 22</sup> an abnormal CXR was often the trigger for raised suspicion and referral to secondary care. However, substantially fewer cases in this study had a GP-ordered CXR than

<sup>iii</sup> Some patients ordered a CXR or referred were also given antibiotics or had blood tests.

reported in an Canadian study (65% vs. 98%),<sup>16</sup> suggesting that NZ GPs may experience more barriers to, or have a higher threshold for, ordering CXRs than GPs elsewhere. In the GP focus groups conducted as part of this study, GPs expressed uncertainty about when they should order CXRs, and commented that they were discouraged from ordering CXRs by hospital radiology departments. Similarly, only 11% of patients had a chest CT scans ordered by a GP compared with 56% in the Canadian study.<sup>16</sup>

## Management within Primary Care

|                     |     |
|---------------------|-----|
| CXR                 | 65% |
| Chest CT scan       | 11% |
| Spirometry recorded | 7%  |

|                     |     |
|---------------------|-----|
| Specialist referral | 55% |
| Acute admission     | 30% |

*10% of patients that had seen a GP with symptoms suggestive of lung cancer subsequently self-presented to ED*

### *Primary Care to Secondary Care*

Lung cancer patients that initially presented to primary care were all seen within secondary care at some stage.

How patients that initially presented to primary care reached secondary care varied as follows:

- 55% of these patients were referred to a specialist outpatient clinic by the GP
  - 34% to a respiratory physician
  - 21% to another specialist
- 30% were referred by the GP for acute admission
  - 6% following the initial consultation
  - 24% following subsequent consultations
- 10% subsequently self-presented to the emergency department (ED) (an additional patient was admitted whilst on holiday outside the region)
- 4% were already under secondary care (although they also consulted their GP).

## Entry to Secondary Care

Patients entered secondary care via a variety of routes:

- 44% of all lung cancer patients were seen acutely by secondary care
  - 23% were referred by a GP for acute admission
  - 21% self-referred to ED (including some patients that had initially presented to primary care)
- 42% of all lung cancer patients were referred by a GP to a specialist
  - 26% to a respiratory physician
  - 16% to another specialist
- 13% were already under secondary care (some of these were also seen in primary care)
  - 2% were under a respiratory specialist
  - 11% were under another specialist

Just over half of all patients were initially seen by secondary care in outpatient clinics. The high proportion (44%) of patients seen acutely by secondary care suggests delayed presentation, at least for some patients. In others, symptoms may

have developed suddenly without prior warning or there may be a sudden exacerbation of symptoms. In a large UK audit,<sup>20</sup> a lower proportion (21%) of lung cancer cases presented as emergencies.

**44% of all lung cancer patients presented acutely to secondary care**

**23% GP-referred for acute admission**

**21% self-referred to ED**

Consistent with the international literature,<sup>14 19 23</sup> the type of presenting symptoms was associated with stage of disease, and influenced GP action and how patients entered secondary care. Patients that presented with respiratory symptoms were more likely to be referred to a respiratory specialist; those with advanced disease were more likely to present acutely to secondary care; and those with an incidental finding were more likely to already be under secondary care for another illness.

## Secondary Care Management

Most commonly, lung cancer patients were initially seen in secondary care by general medicine (42%) or respiratory specialists (35%). Overall, 85% of patients were seen by a respiratory specialist prior to diagnosis; 94% had chest CT scan; 55% had a bronchoscopy; 24% had a CT fine needle aspirate (CTFNA) and 56% were discussed at a multidisciplinary meeting (MDM).

A histological diagnosis of lung cancer was obtained for 85% of patients. The majority (77%) of those with a clinico-radiological diagnosis had metastatic disease. Of cases with a histological diagnosis, this was most commonly obtained by bronchoscopy (44%), CTFNA (26%) or biopsy of metastases (13%).

Thirty-one percent of bronchoscopies were non-diagnostic. Bronchoscopies were more commonly non-diagnostic if a chest CT scan had not been performed prior to the bronchoscopy (88% of cases had a chest CT scan prior to the bronchoscopy).

Management within secondary care varied according to whether patients were in-patients or outpatients when first seen. This was largely due to the differences in stage of disease, as out-patients tended to have earlier stage disease than in-patients. Outpatients were more commonly diagnosed by CTFNA, were slightly more likely to have a histological diagnosis of lung cancer, and were more commonly discussed at an MDM than in-patients.

## Tumour Stage at Diagnosis

The vast majority (74%) of patients had histologically verified non-small cell lung cancer (NSCLC); 15% had a clinico-radiological diagnosis of lung cancer; and 11% had small cell lung cancer (SCLC). Of those with histologically verified NSCLC, 51% had adenocarcinoma; 26% had squamous carcinoma and the remainder had NSCLC *not further defined* (18%) or *other* (5%).

Of all cases with histologically verified NSCLC or a clinico-radiological diagnosis, over half (51%) had metastatic (stage IV) disease at diagnosis; 19% had locally advanced (stage III); 19% had localised (stage I/II) disease; and 10% had unknown stage. Of all cases with SCLC, 72% had extensive disease and 28% had limited disease.

At diagnosis, of those with known stage, 71% had incurable disease (stage IIIB/IV NSCLC or extensive SCLC). Similar results were found in a Canadian study<sup>16</sup> which reported that only 20-30% of lung cancer patients had potentially curable disease at diagnosis.

Delays in presentation and delays to diagnosis are thought to contribute to the high frequency of advanced disease at diagnosis.<sup>16</sup>

## At Diagnosis

**71% of patients with known stage had incurable disease**

*Less than 30% of lung cancer patients had potentially curable disease*

## Time to Diagnosis

### *Symptoms to presentation*

Time from development of symptoms until presentation to health care services was poorly recorded in the clinical records. For those with documented

symptom duration, two-thirds of patients presented within one month but one-quarter had symptoms for more than three months before presenting to their GP (half of these taking longer than 6 months to present).

### *Presentation to diagnosis*

The time to diagnosis varied considerably, with some patients being diagnosed rapidly whilst others had prolonged times to diagnosis.

Although almost half of the patients presenting initially to primary care were diagnosed within two months of presentation, one-quarter of patients took longer than four months to be diagnosed. (The median time from presentation to primary care until diagnosis was 65 days (interquartile range (IQR) 31; 123).)

In-patients (when first seen by secondary care) were diagnosed more rapidly than outpatients. In particular, patients that presented acutely to secondary care (either self-referred or GP-referred for acute admission) were diagnosed rapidly, with a median time (from presentation to secondary care until diagnosis) of only 13 days (IQR: 8;27). Acute presentation to secondary care was strongly associated with stage of disease, being much more common in those with metastatic disease.

Patients with advanced disease were diagnosed much more rapidly than those with early stage (potentially curable) disease. The median time from presentation to primary care until diagnosis was 49 days (IQR 23; 97) for those with metastatic NSCLC compared

with 100 days (IQR 57; 231) for those with early (I/II) stage disease.

*Patients with metastatic disease were diagnosed much more rapidly than those with early stage potentially curable lung cancer*

### *Presentation to referral*

The median time from presentation to primary care until the referral (either outpatient clinic or acute admission referral) was received by secondary care was twenty-one days (IQR 6; 73). For 25% of patients it took over ten weeks from initially presenting to the GP until specialist referral.

### *Referral to FSA*

The median time from receipt of referral until the first specialist appointment (FSA) was eleven days (IQR 5; 17).

Patients referred as outpatients to a respiratory specialist took a median of eleven days (IQR 6; 15) to be seen following receipt of the referral, whereas in-patients were seen by a respiratory specialist the same day that they were referred.

### *FSA to diagnosis*

The median time from the FSA until diagnosis was fifteen days (IQR 8; 36) and comprised the time to complete diagnostic investigations. This was somewhat longer than reported in a Swedish study (median 9 days).<sup>19</sup> The median time was a week shorter for those

who were in-patients at the FSA than for out-patients (13 days versus 20 days).

For patients that had a chest CT scan following the FSA, the median time from the FSA until the CT was fourteen days (IQR 3; 27) for out-patients, but only three days (IQR 1; 6) for in-patients.

Patients were first discussed at an MDM approximately one month following the FSA (median 33; (IQR 20; 52)).

## Factors which influenced Times to Diagnosis

Various factors expedited or impeded transit along the clinical pathway.

As reported internationally,<sup>14 15</sup> the type of symptoms influenced patient and GP action, the time to presentation, referral and specialist assessment. Haemoptysis was an important trigger for both patient and GP action. However cough (the most common presenting symptom of lung cancer) tended to be ignored initially by both the patient and the GP, presumably because cough is a common symptom, especially in smokers.

An abnormal CXR, especially if suspicious of lung cancer, was an important trigger for urgent specialist referral. Although a normal initial CXR was uncommon (3%), it resulted in prolonged delay to referral and diagnosis with a median time from primary care presentation to diagnosis of 7.5 months (222 days; IQR 156; 263).

Within the clinical records, there was evidence of system delays in 10% of patients with i) an additional referral

being required, as the original referral had been lost; ii) an additional referral being required or an acute presentation due to the patient's condition deteriorating prior to the FSA or iii) abnormal results not being followed up, especially abnormal CXR results from an attendance at ED. Those patients that deteriorated prior to their FSA had experienced prolonged times within primary care with a median time from presentation to referral of 81 days (IQR 27; 121) compared with 21 days (IQR 6; 73) overall for all patients. However, their median time from referral to FSA was the same as for patients overall.

As mentioned previously, stage of disease and in-patient / out-patient status influenced time to diagnosis. In-patients especially those with metastatic disease were assessed, investigated and diagnosed more rapidly than those with early stage potentially curable disease. This likely reflects the fact that in-patients had easier access to specialists and investigations, thereby reducing time to diagnosis.

A non-diagnostic initial bronchoscopy (which occurred in 17% of all patients) increased the median time from FSA to diagnosis by a month (45 days (IQR 17; 73) vs. 15 days (IQR 8; 36) for patients overall). The majority of cases with a negative initial bronchoscopy required a second bronchoscopy (35%) or a CTFNA (47%) resulting in delay. A histological diagnosis was not made for 18% of those with an initial non-diagnostic bronchoscopy.

Patient-related delays were documented in the clinical records for 11% of patients. Delays resulted from patients not attending appointments (DNAs), postponing appointments because of holidays, or initially declining investigation or referral.

Delays could occur at one or multiple steps along the pathway and could be due to patient, doctor or system factors or a combination of these.

## Did Missed Opportunities for Diagnosis Exist?

An American study reported that 38% of patients had missed opportunities to establish a diagnosis of lung cancer.<sup>24</sup> Such missed opportunities included failure to recognise clinical clues and failure to action a requested follow-up within a month.<sup>24</sup>

Although it was difficult to quantify missed opportunities for earlier diagnosis in the current study, there was evidence of delays to diagnosis in 11% of patients due to delays caused by the patient; and in 10% of patients from lost referrals, failure of follow-up of abnormal results and prolonged time within primary care such that the patient's condition deteriorated prior to the FSA (see the previous section). It is likely that not all such events would have been documented in the clinical records; therefore 21% was likely to be an underestimate of patients that could have been diagnosed earlier.

In an attempt to identify whether patients had clinical clues that were not recognised, the GPs collecting the data from the primary care records were asked to assess when the patient presented with symptoms or signs that *in retrospect (with the knowledge that the patient had lung cancer)* could be attributed to the lung cancer. This was not necessarily when a GP would be expected to suspect lung cancer, but it would indicate the earliest time that lung cancer could be suspected. It would tend to overestimate missed opportunities.

For 80% cases, the *retrospective date of presentation* was the same as the actual date of presentation. For another 10%, the retrospective date was within three months of the actual presentation date, and for the remaining 10% the retrospective date was between three months to one year earlier. Thus with the benefit of hind sight, 20% of lung cancer cases could have been suspected of having lung cancer earlier. This suggests that for at least some of these 20%, clinical clues of lung cancer could have been missed.

Thus, although it was not possible in this study to accurately quantify missed opportunities to diagnose lung cancer earlier, it is likely that the diagnosis could have been made earlier for 20-40% of patients (21% with documented delays plus some of the 20% that could possibly have been suspected earlier).

## Missed Opportunities to diagnose lung cancer earlier occurred mostly because of:

### • Doctor or system delays:

- Failure to recognise clinical clues especially in the presence of comorbidities
- Diagnostic difficulty- non diagnostic bronchoscopy
- Lost referrals
- Failure to follow-up abnormal results

### • Patient-related delays

- DNAs
- Initially declining investigations
- Postponing appointments due to holidays or for other reasons

## Ethnic Differences

Considerable differences existed between patients from different ethnic groups in age at diagnosis (p 0.0005); gender (p 0.04); socioeconomic status (NZDep: p 0.04); comorbidity burden (Charlson Comorbidity Index (CCI): p 0.02); smoking history (p 0.002); tumour subtype (p 0.02) and stage (not significant for ethnic groups overall).

Māori patients tended to be younger at diagnosis, were more commonly female, current smokers and more commonly had squamous carcinoma; whereas European and Pacific patients more commonly had adenocarcinoma. Pacific patients had a

higher comorbidity burden and more commonly had metastatic disease than European or Māori patients.

Despite these substantial differences in the characteristics of patients there were few ethnic differences evident in the clinical pathway. Differences that did occur related to acute admissions, in-patient status and do not attend (DNAs).<sup>iv</sup>

Pacific patients were more likely to be referred for an acute admission (p 0.04). Half of these patients presented to the GP acutely and were immediately referred for admission, and the other half had consulted the GP previously regarding symptoms related to lung cancer. The more frequent referral of Pacific patients for acute admission was explained by more advanced disease at presentation (when tumour stage was adjusted for in the analysis the association between ethnic groups and acute admissions became not significant). Pacific patients were also more likely to be in-patients when first seen by secondary care, consistent with their more advanced disease and acute admission rate.

Although DNAs were not common pre-diagnosis occurring in only 7% of all patients, the majority occurred in Māori or Pacific patients. Sixteen percent of Māori and 8% Pacific patients did not attend an appointment, compared with

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<sup>iv</sup> Do not attend were defined as specialist or investigation appointments not attended prior to diagnosis, as documented in the clinical records. DNAs in the current audit did not include re-scheduled or cancelled appointments.

3% European patients (p 0.01). Reasons for these ethnic differences in DNAs could not be ascertained in this audit, although socioeconomic factors, attitudes, and practical factors such as transport difficulties could be contributory.

There was no significant difference between ethnic groups in the investigations performed, the proportion with a histological diagnosis; the proportion seen by a respiratory specialist or discussed at an MDM; or in the median time to diagnosis.

## Few differences in the clinical pathway existed between ethnic groups

- **Pacific patients** were more commonly referred for an **acute admission** and were more commonly **in-patients** when first seen by secondary care due to more advanced disease at presentation
- **Māori & Pacific patients** were more likely **not to attend** appointments

## Regional Differences

There were substantial differences between the Auckland and Lakes regions in the demographic and tumour characteristics of their patients, consistent

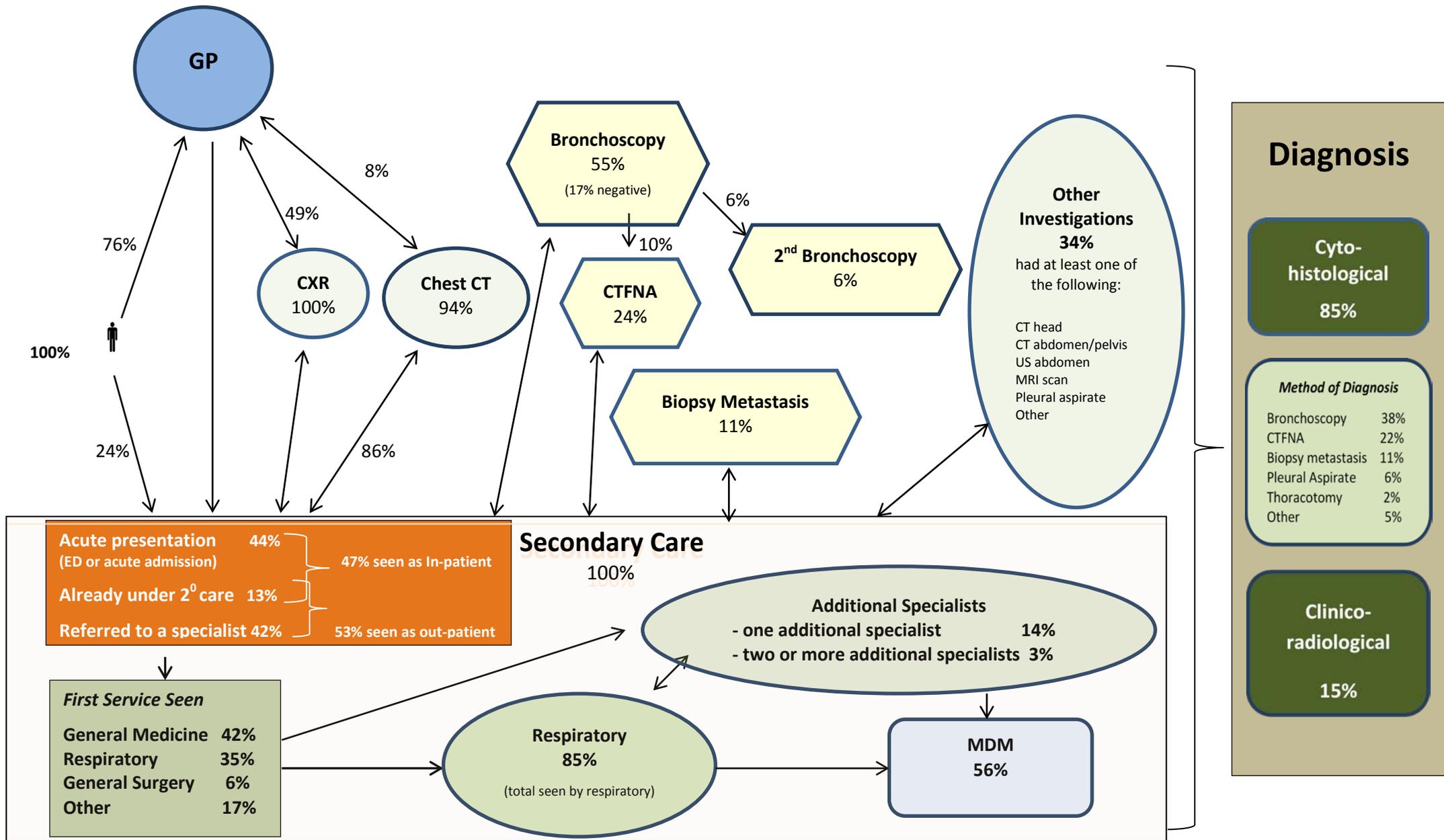
with the different ethnic mix of their populations. Differences in tumour stage were difficult to ascertain as stage was unknown for 9% of patients (17% in the Lakes region and 9% in Auckland). Although fewer cases in Lakes had early stage (I/II) NSCLC than in Auckland (13% vs. 21%), there was no statistically significant difference in tumour stage between the two regions.

The clinical pathway was very similar in the Auckland and Lakes regions. The main difference was that in the Lakes region, patients with suspected lung cancer were generally referred to general medicine and then to respiratory medicine, rather than being referred directly to a respiratory specialist. There was no other significant difference between the regions in the type or timeliness of management pre-diagnosis.

## The clinical pathway was similar in the Auckland & Lakes regions

- **Fewer patients at Lakes** had **early stage disease** at presentation (however tumour stage was unknown for a high proportion of patients)
- **Fewer patients at Lakes** were initially **referred to a respiratory specialist** instead they were referred to general medicine.

# Lung Cancer Clinical Pathway to Diagnosis



% = % of the total lung cancer cases

## Section 3

# Current Services & Processes of Care

*What lung cancer care is currently provided  
in NZ & what new initiatives been tried?*

# Current Services & Processes of Care

Current services and processes of care were identified using a:

i) **Practice Survey** of all (170) general practices within the Auckland and Lakes regions, that were affiliated with one of the participating primary care organisations. Data collected included details of services provided, referral processes for investigations and specialist appointments, and processes for dealing with abnormal results and do not attends. The majority (80%) of the practices were located in an urban area. Practices differed considerably in their staff profiles and patient populations, particularly in the ethnic mix of their enrolled patients. The response rate was 78%.

ii) **GP Survey** of (102) GPs affiliated with two participating primary care organisations within the Auckland and Lakes regions. The response rate was 89%.

iii) **National Stocktake** of primary and secondary care services that could be relevant to people with lung cancer and their whānau/family.

- A *National Stocktake survey of primary care services* was sent to all Primary Health Organisations (PHOs). The PHO response rate was 43%. In addition the stocktake was sent to Māori and Pacific community health and social services that were identified by the Inequalities Team of the current project using their

network of contacts within the health sector.

- A *National Stocktake survey of secondary care services* was sent to all (21) DHBs. The response rate was 100%.

## Primary Care Services *Processes of care*

Services and processes of care varied between practices, as did the on-going training of their GPs. Only 34% of practices reported that most or all of their GPs had attended a meeting on respiratory medicine and/or lung cancer within the past two years.

Variability between practices in services and process of care is of concern. Whilst some differences may be appropriate to cater for different patient populations and local conditions, it is important that patients seen at one practice receive the same quality of care available elsewhere. How patients are referred for investigation and specialist assessment is particularly important as it impacts on the timeliness of assessment and diagnosis.

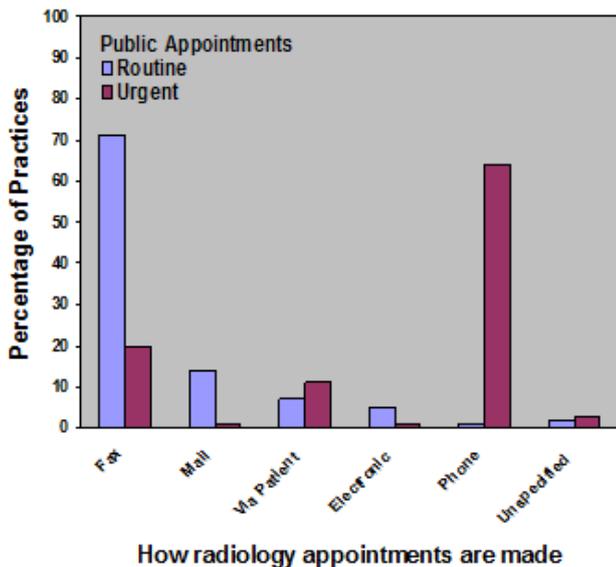
### **Radiology Referral**

X-ray appointments were made differently by different practices, and varied according to whether the test was considered urgent, and whether it was to be performed in the public or private sector. Many (87%) practices referred patients to private radiology services to expedite investigation and also for convenience of location.

Most (71%) practices made routine public radiology appointments by fax. Others

referred by mail (14%); via the patient (7%); electronic referral (e-referral: 5%) or by phone (3%). If the test was considered urgent, 64% of practices phoned for an appointment (sometimes also sending a referral by mail or fax). Another 20% faxed the referral; 11% sent the referral via the patient and one practice used e-referral.

Routine private radiology appointments were predominantly made via the patient (67%) or by phone (20%). Urgent private radiology appointments were most commonly made by phone (72%) or via the patient (19%). No practice reported using e-referral to make either a routine or urgent appointment with private radiology.



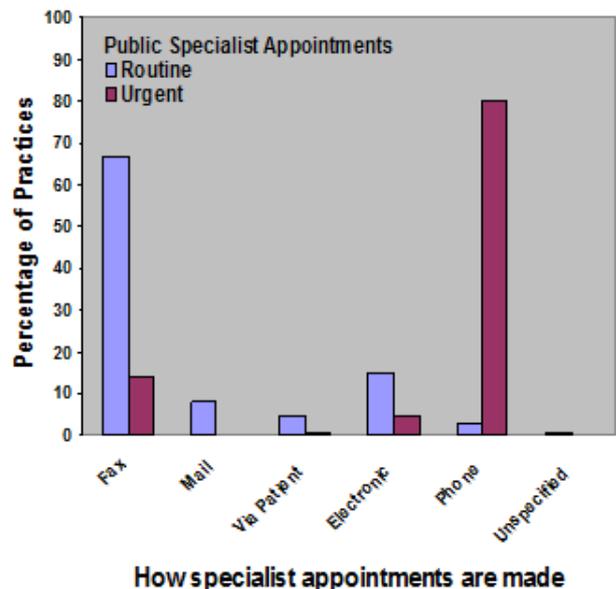
GPs ability to order a chest CT scan in the presence of an abnormal CXR varied, with only 29% of GPs reporting that they could order a chest CT scan (with specialist pre-approval). Interestingly 15% of GPs did not know if they were able to order a CT scan or not.

### Specialist Referral

The majority (82%) of GPs reported that they had ready access to specialist respiratory advice, mostly (77%) by phone. None of the GPs had access to virtual specialist consultations and only 6% had email access to specialists.

Most practices reported making a routine specialist appointment in the public sector by fax (67%); 15% used e-referral; 8% posted the referral; 2% used a courier and the remainder sent the referral via the patient. Urgent referrals to a specialist in the public sector were most commonly (80%) made by phone (either alone or in combination with fax/mail/courier); an additional 14% were made by fax alone; 5% by e-referral.

Routine private specialist appointments were made via the patient (37%), by phone (26%) or fax (24%), 5% by mail and 5% by e-referral. Most practices made urgent appointments with a private specialist by phone (79%); 8% via the patient and 8% by fax. Only one practice reported using e-referral.



Thus referral processes for radiology and specialist appointments varied considerably, with few GPs currently using e-referrals. Many referrals were faxed and some were still posted to the hospital. Faxing of referrals has been associated with loss of the referral and the mixing of patient information between faxes. Postage may also lead to lost referrals and produce considerable delay.

Replacement of existing referral methods by e-referrals has the potential to provide standardised referral information, reduce the incidence of lost referrals, avoid the mixing of patient information that can occur with faxing, improve the timeliness of referral receipt and facilitate triaging, thereby expediting investigation and specialist assessment, and in addition can permit tracking of the referral and on-line decision support. Some regions are currently developing e-referral systems and in the future e-referral should be used more widely.

### ***Radiology results***

Results from radiology were most commonly received electronically (public; 64%; private: 65%) or by fax (public: 24%; private: 18%) or by phone or courier.

If there was an abnormality suggestive of lung cancer on the CXR, 71% of practices were usually phoned by the private radiologist but only 47% were phoned by a radiologist in the public sector.

The time until GPs received notification of a CXR result suggestive of lung cancer varied considerably: 87% of GPs received the result within 4 days (36% the same

day) but 6% did not receive notification for over a week.

### ***Specialist feedback***

Only 42% of GPs considered that they received timely feedback following the FSA in the public sector, whereas 70% received timely feedback from a private FSA.

Feedback from specialists was received electronically (public 52%; private; 53%), by mail (public: 18%; private: 13%) or by fax (public: 10%; private: 10%), and the remainder by phone or courier.

### ***Do not attends***

The vast majority of practices reported that they followed up DNAs, usually by phone or by both a phone call and a letter. Although follow up routinely occurred at many practices for regular patients, some practices stated that they did not follow up casual patients. Other practices did not contact patients, but made a note on the file to discuss the DNA with the patient at the next consultation.

Lack of follow-up (or waiting until the next appointment to discuss the DNA) may result in delayed investigation or specialist assessment thereby delaying diagnosis.

## ***Service improvement***

### ***Cancer specific services***

Only a small proportion (14%) of general practices reported an initiative or service that could potentially benefit to people with (or suspected of having) lung cancer. These included nurse led clinics with risk

assessment and smoking cessation support; and phone support for cancer patients.

### **General services**

Whilst the vast majority of primary care organisations did not provide any cancer specific service, there were some general services or initiatives reported that could be relevant to people with lung cancer and their whānau/family.

Some practices were working with secondary care to improve investigation and referral processes (for example: e-referrals and referral pathways).

Other practices were attempting to improve the patient centeredness and cultural safety of care by:

- Tikanga best practice and Pacific cultural competency training for staff. (28% of practices reported that all or most of their non-Māori non-Pacific staff had attended such training; 45% reported that none of their staff had attended.)
- Use of an interpreter service usually over the phone or in person. (44% of practices used an interpreter service although only 3% used an interpreter often.)
- A whānau ora approach to care with initiatives to involve the family in healthcare; marae-based or church-based health promotion and education sessions; nursing outreach clinics to the marae; whānau ora nurses in the community; community health co-ordinators; and cultural

liaison roles. (28% of practices reported at least one of these services.)

- Provision of complimentary or traditional medicine including acupuncture, massage, herbal treatments, homeopathy, spiritual healing and mirimiri. (21% of practices reported providing such services.)
- Obtaining patient feedback regarding their health care experience via a patient survey; a comments and suggestion box in the waiting room; or by the GP or nurse routinely asking the patient about their experiences. (69% of practices sought patient feedback: 51% by patient survey.)

### **Innovation within primary care**

Much of the innovation within primary care to improve services was occurring either in conjunction with secondary care (e.g. e-referrals) or was by Māori and Pacific providers.

Thematic analysis of the responses from Māori and Pacific providers suggested that five main themes flowed through their innovation. These were:

#### **i) The people**

Organisations reported that they were underfunded, and were only able to provide some services because of the dedication and commitment of their staff and others, such as volunteers.

‘Aunties’ who acted as primary care coordinators, as well as *Kaumtua* and *Kuia* (elderly men and women) were

significant people involved in improving health education and access to and through health care services, including cancer care.

'Aunties' were respected members of the community, often community health care workers, who not only assisted with transport and other practical needs, but provided information and education about health, and motivated patients to seek care and attend appointments. These 'aunties' operated as '*health champions*' within their communities.

### **ii) Kaupapa or traditional knowledge**

Kaupapa and tikanga were considered essential for community engagement and much innovation focused on improving care by building relationships with the community, involving the patient, whānau/family and community in care, and delivering care in culturally appropriate ways in traditional, convenient and comfortable settings, such as marae- and church-based services. In addition kaupapa-based social marketing sought to improve engagement with health services.

### **iii) Integrated and holistic care**

Other innovation involved a whānau ora approach to address *all* needs of the patient and their whānau/family (not only the health care needs of the patient). This involved integration of health care services with rongoa (traditional healing), social services and non-health services. Inter-service collaboration and networking were used to optimise access to health, social and support services.

Improving health literacy was considered key to a whānau ora approach, so that patients and their whānau/family were empowered to manage their own health care. Another initiative used to involve the patient and whānau/family in care was the development of *agreed care plans*.

### **iv) Access**

Some initiatives facilitated access to information about health, health care services and support. Health messages and health care related information were commonly incorporated into various events (such as sporting events) and were provided in a variety of settings (e.g. work, school, marae, church). Provision of health education helped to involve the patient and whānau/family in care and empowered them.

Other initiatives to improve access involved reduced fees, transport assistance and outreach clinics as well as cultural competency of providers and services. Respectful and culturally safe providers and services were considered essential to improve acceptability and therefore access to health care.

### **v) Rural and urban differences**

*Whānaungatanga* and *whakapapa* (tribal connectedness) in rural-based Māori services permitted a level of community connection that was difficult to duplicate in the urban settings. Urban-based organisations attempted to build connections by employing Māori and Pacific staff or working with Māori and Pacific organisations.

## Primary care provided few cancer specific initiatives or services

### General initiatives involved:

- Improving referral processes by e-referral
- Improving the patient-centeredness and cultural safety of care

Much of the **service innovation** was by **Māori & Pacific providers** and involved the following themes:

- The People
- Kaupapa or traditional knowledge
- Integrated and holistic care
- Access
- Rural and urban differences

## Secondary Care Services

Secondary care services and processes of care varied across DHBs. Some variation was expected, as services and processes evolve within the local context in response to local needs. However equitable access to care and national consistency in the quality of health care provided is an important aim of the NZ Health System.

## *Processes of care*

### *Specialist appointment and feedback*

Referral processes for a FSA for people with suspected lung cancer were similar across all the DHBs. Referrals were triaged on a daily to twice weekly basis by a respiratory physician; although some of the smaller DHBs reported difficulties with triaging (e.g. no triage roster; physician leave). At most DHBs, referrals were tracked by clerical staff of the Central Referral Office. At others, referrals were tracked by the nurse specialist or consultant, or not at all.

Patients with suspected lung cancer were prioritised to be seen within two weeks. Performing a chest CT scan prior to the FSA to expedite lung cancer diagnosis was a recent initiative at many, but not all, DHBs. The CT was commonly requested on receipt of the referral. However some DHBs reported that although a chest CT scan was requested on receipt of the referral, CT scans were often not performed by the time of the FSA due to long waiting times for CT scans. At one DHB, the first investigation performed was a bronchoscopy, which was scheduled as the first specialist appointment; and the chest CT was performed subsequently.

Most DHBs reported sending appointment reminders to patients, usually by post or phone. Fewer DHBs reported notifying the referring GP of the appointment date. Approximately one-third (35%) of GPs reported that they were 'often' notified of the date of the

respiratory FSA and 25% were 'sometimes' notified.

### ***Do not attends***

DHBs generally followed-up did not attends (DNAs) by contacting the patient by phone or post. Usually, clerical staff contacted the patient to re-schedule the appointment. Several DHBs also routinely informed the GP of DNAs; although others only contacted the GP if they could not contact the patient or the patient declined another appointment. The majority (80%) of practices and GPs reported commonly being notified if a patient did not attend (DNA) an investigation or appointment in the public sector; however fewer (47%) were notified of DNAs in the private sector.

### ***Multidisciplinary care***

The majority (71%) of DHBs participated in a multidisciplinary meeting (MDM). Most used a standard MDM referral and management plan form and most collected data via the MDM. Only one DHB accessed a MDM via a videolink, although another planned to do so in the near future.

### ***Service improvement***

Considerable differences existed between DHBs in the services available for people with (or suspected of having) lung cancer and their whānau/family. Notable variations occurred in access to: chest CT scans; dedicated lung cancer clinics with expedited investigation; lung cancer care co-ordinators; MDMs; and Kaupapa Māori services. There also seemed to be a general deficiency in pre-diagnostic information resources, and

none of the available information was targeted to Māori.

### ***Improved referral processes***

Some DHBs were working with primary care organisations to improve referral processes. Initiatives included the development of referral and investigation pathways, and e-referral systems with standardised referral templates and (in the future) electronic triage and on-line decision support.

## **Services differed between DHBs relating to:**

- Access to chest CT scans
- Dedicated lung cancer clinics with expedited investigation
- Lung cancer care co-ordinators
- MDMs
- Kaupapa Māori services

Initiatives to improve lung cancer care included:

### ***Improved access to chest CT scans***

Waiting times for CT scans and CTFNAs were reported to vary across DHBs, with several DHBs reporting considerable delays to obtain these investigations. Initiatives to expedite CT scans included:

- Booking of the chest CT by the radiologist or GP (in conjunction with a hospital specialist) if the CXR was suggestive of lung cancer.

- Booking of the chest CT scan on receipt of referral (if not already booked) so that it would be performed prior to the FSA.
- Walk-in appointments for chest CT scans for patients referred by a respiratory specialist.
- Designated chest CT slots for suspected lung cancer patients prior to the bronchoscopy list.

### **Expedited FSA & investigation**

Initiatives to expedite assessment and investigation of patients with suspected lung cancer included:

- Dedicated clinics for suspected lung cancer. Some of these were *same day* or *one stop* clinics with investigations such as chest CT scans, spirometry, and bronchoscopy performed on the day of the FSA. Others involved investigations performed within the week of the FSA, rather than on the same day.
- Investigation pathways for rapid diagnostic workup.
- Lung cancer coordinator / navigator – many, but not all, DHBs had a care coordinator. However the role and qualification of the coordinator varied across DHBs, as did the time period over which the coordinator was involved. At some DHBs there was a lung cancer coordinator, but at others the role extended across all cancers, and at other DHBs there was no care coordinator. At some DHBs, the role was specifically targeted to Māori and Pacific patients. Typically the coordinator became involved after the FSA. The role of the care coordinator usually involved coordinating investigations, tracking results, collating information for the

MDM, and informing the patients of services and providing support.

- Monitoring times from referral until the FSA (with a target of 2 weeks from receipt of referral until the FSA).

### **Information resources**

There was a paucity of pre-diagnostic information for patients other than information on some investigations (such as bronchoscopy) and Cancer Society leaflets. None of the available information resources targeted Māori or Pacific patients. An initiative to improve access to information was the development of an online resource ‘HealthPoint’ to provide information on lung cancer and investigations, and on local services in some regions.

### **GP education sessions**

Only a small number of DHBs provided GP education sessions on lung cancer in conjunction with local respiratory specialists.

### **Cultural safety of services**

Most DHBs reported that their staff attended Tikanga training courses to improve cultural understanding and responsiveness. Other initiatives included: Māori and Pacific liaison, advisory or support services; Māori cancer care coordinators; marae-based services and Māori cancer nurses.

**Summary** *Some DHBs had many initiatives to improve lung cancer care whilst others had none. National and regional standards are required to promote consistency in the care provided by DHBs.*

## Section 4

# Barriers to Early Diagnosis & Optimal Care

*Which barriers to quality lung cancer care  
are important locally?*

# Barriers to Early Diagnosis & Optimal Lung Cancer Care

Barriers to optimal lung cancer care have the potential to delay diagnosis, reduce satisfaction with care, and adversely impact on health outcomes.

Barriers are numerous and whilst some occur at a particular point in the clinical pathway, many operate throughout the pathway. As barriers commonly coexist, their aggregate impact needs to be considered. Barriers tend to have a disproportionate impact on Māori and Pacific peoples, and other minority or disadvantaged groups.<sup>25 26</sup>

Only by recognising the barriers and their impact can strategies be developed to improve the quality of care and subsequent outcomes.<sup>27</sup>

Barriers were identified by a:

i) **Literature Review** which involved a comprehensive search of the national and international literature to identify barriers within the clinical cancer pathway from presentation until diagnosis.<sup>28 29</sup>

ii) **GP Survey** which involved a survey of (102) GPs affiliated with two participating primary care organisations within the Auckland and Lakes regions (89% response rate).

iii) **GP Focus Groups** which involved focus groups of (33) GPs affiliated with the other two participating primary care organisations within the Auckland and Lakes regions.

iv) **Patient Interviews** which involved interviews of (19) patients with suspected or confirmed lung cancer who initially presented to a hospital emergency department (ED).

v) **Patient Focus Groups** which involved focus groups of (20) patients who had a confirmed diagnosis of lung cancer and their families/whānau.

Much was already known about barriers to quality cancer care. The literature on barriers is vast with numerous studies from many different countries repeatedly documenting similar barriers. However little was known about which of these barriers were important in the NZ context. The *GP Survey & Focus Groups*, and the *Patient Interviews & Focus Groups* aimed to identify which barriers were the most important locally, and included both the GP and patient perspective.

## Types of Barriers

Barriers can be categorised in various ways.

Quality of care is a multidimensional concept and these dimensions provide a useful framework for categorising barriers and assessing their impact. Such dimensions include: accessibility and timeliness; efficiency; effectiveness and safety; and equity and patient

centeredness. The various types of barriers impacting on each of these dimensions are listed below.

**Accessible and timely care:** Barriers reported in the literature to accessible and timely care include: financial barriers (particularly transport and travel costs); geographic barriers; service availability barriers; and information barriers.

**Efficient care:** Barriers that impair the efficiency of care include: fragmentation of care; sub-optimal mix of providers; poor integration of services and providers; and disruption to continuity of care.

**Safe and effective care:** Barriers to safe and effective care include lack of available evidence on best practice; ineffective communication of the evidence to providers; out-dated knowledge of providers; and lack of multidisciplinary care.

**Equitable and patient-centred care:** Barriers to equitable and patient-centred care include lack of health system responsiveness, poor provider communication skills and sub-optimal cultural competence; and also to patient factors such as beliefs, preferences and health literacy.

Barriers can also be categorised as system, doctor or patient.<sup>25 27 30 31</sup>

**System barriers** include: inadequate capacity or poor coordination resulting in prolonged waiting times for investigations and specialist services; inadequate processes to ensure effective communication leading to referrals not

being actioned or results being unavailable when required; inappropriate staff mix and lack of cultural safety. Such barriers influence the physical accessibility of services, waiting times and appropriateness of services.

**Doctor barriers** predominantly relate to lack of clinical knowledge and expertise leading to failure to recognise diagnostic clues, leading to delayed referral or investigation; or to poor communication or cultural skills. Such barriers affect transit along the pathway and may delay diagnosis and influence the ability providers to effectively address the needs of patients and their whānau/family.

**Patient barriers** relate to demographic factors, social context, culture, beliefs, attitudes and knowledge. Such barriers commonly inhibit the seeking of care and impair entry into the health system as well as influencing transit along the pathway, by non-compliance or non-attendance at investigations or appointments.

Alternatively barriers can be categorised according to where in the lung cancer pathway they predominantly occur: *at presentation* or *throughout* the pathway; within *primary care* or within *secondary care*. This latter categorisation will be used below to present the main barriers operating in the Auckland and Lakes regions.

## Important Barriers Locally

### *Barriers to presentation & throughout the pathway*

Barriers to early presentation and transit along the clinical pathway include:

- *Knowledge barriers* such as lack of information about lung cancer, its symptoms, investigation, treatment and prognosis; and *attitude barriers* such as mistrust of the health service or fatalistic or stoical attitudes towards lung cancer.
- *Cultural barriers* such as lack of culturally appropriate providers or services.
- *Practical barriers* to accessing healthcare services, such as lack of geographically convenient services, lack of suitably timed appointments, transport or financial difficulties.

Lack of recognition of the presenting symptoms of lung cancer was considered a major barrier to early presentation and diagnosis of lung cancer by both GPs and patients. GPs considered that lack of recognition by the patient of the seriousness of their symptoms delayed presentation to health care services in general, but particularly for Māori and Pacific patients. Some patients admitted that they delayed presenting to the GP because they initially thought their symptoms were not serious, attributing them to COPD or bronchitis. Participants in the focus groups appeared to have little prior knowledge about the symptoms of lung cancer. However fear and fatalism also contributed to delays in

help seeking; and some patients commented that they had been afraid to present in case their symptoms were due to cancer. Older smokers tended to expect poor health with cough and breathlessness. Health beliefs were considered by patients to strongly influence presentation. Similarly GPs considered that fear, beliefs, mistrust and past negative experiences with health care delayed presentation and that this was a particular barrier for Māori patients. A US study supported the notion that minority ethnic groups were more likely to have beliefs and perceptions about lung cancer that interfered with presentation and treatment.<sup>32</sup> Gender as well as ethnic differences in help seeking were commented upon in the focus groups; specifically it was suggested that male culture tended to delay presentation to the GP.

Not only were beliefs and perceptions considered to influence presentation but also to strongly impact on compliance with management and attendance at appointments. Māori and Pacific patients were considered much more likely to DNA than other patients. GPs commented on the frustration of having organised an urgent appointment and then the patient did not attend the appointment. Twenty-eight percent of GPs reported that their management was influenced by this perception of non-compliance. GPs considered that DNAs were an important barrier that delayed diagnosis for Māori and Pacific patients.

Inadequate information and poor communication was felt to contribute to delays, frustration and stress for patients and their whānau/family. Focus group participants stated that information was often not available when it was needed. Patients commonly saw multiple doctors and often clinical information and investigation results had not been communicated between providers. Also patients were often required to repeat their history which they found exhausting. Patients and their whānau/family considered that provision of appropriate information about investigations and lung cancer could reduce uncertainty and distress. They also commented that the way that information was provided and the environment in which it was provided were also important.

Consultation and travel costs were considered by GPs to a barrier for Māori and Pacific patients, but not for patients in general. Patients did not mention cost as a particular barrier.

Lack of convenient health care services was not seen as a barrier by GPs. However, patients in the Lakes region talked about the additional stress caused by the necessity to travel for a specialist appointment.

### *Barriers within primary care*

Within primary care, delays to diagnosis may occur due to lack of recognition of clinical clues and the failure to consider lung cancer as a possible diagnosis; lack of continuity of care; inadequate access

to diagnostic tests to confirm or exclude cancer as the underlying cause of the patient's symptoms; fatalistic attitudes to lung cancer of either the GP or patient; or lack of compliance or non-attendance (DNA) by the patient.

Patients recounted making numerous visits to their GP, presenting with the same symptoms or an escalation of symptoms; usually being initially treated with antibiotics, inhalants or other medications before being referred for a CXR. Focus group participants suggested that time pressure in GP consultations contributed to delays in investigation. Also patients and their whānau/family felt that lack continuity of care by seeing different GPs (because of unavailability of the patient's own GP or the use of drop-in centres) increased the risk of delayed investigation and referral as often information sharing between providers was poor. In contrast, an on-going doctor-patient relationship was thought to engender trust, facilitate patient disclosure and compliance, and engender timely action.

Patients expressed frustration at the long time between presenting to the GP and being referred for CXR or specialist assessment. Many held GPs accountable for delayed diagnosis. Whilst patients and whānau/family considered that lack of GP expertise was an important barrier to the early diagnosis of lung cancer, other patients felt that GP expertise and concern had expedited their investigation and specialist assessment.

Missed opportunities for the early diagnosis of lung cancer were attributed in the literature to GP failure to recognize potential diagnostic clues or to the inability to complete the diagnostic work-up in a timely manner.<sup>19 24 33 34</sup> COPD was strongly associated with missed opportunities and delays to diagnosis.<sup>24</sup>

GPs themselves considered that the non-specific nature of lung cancer symptoms caused diagnostic difficulty (especially in patients with COPD) and was an important barrier to early diagnosis. This was compounded by the fact that less than half of the GPs had seen a newly diagnosed lung cancer patient in the past year, whilst respiratory symptoms were common-place. GPs felt pressured not to 'over-order' CXRs and expressed uncertainty regarding when they should order a CXR. GPs considered that current referral guidelines were not useful clinically, and they needed clear and practical investigation and referral guidance.

An abnormal CXR was an important trigger for referral in the current study and in the international literature. The literature suggested that physicians tended to be 'over-reliant' on CXRs to diagnose lung cancer,<sup>15 33 35</sup> and that a major contributor to delayed diagnosis was a false-negative CXR.<sup>36</sup> A normal CXR was associated with substantial delay to referral and diagnosis in the *Clinical Audit* of this project. In a large UK audit, GPs considered a CT scan was the most useful investigation in the diagnosis of lung cancer.<sup>20</sup>

If a CXR was suspicious of lung cancer, less than one-third of GPs reported that they were able to order a chest CT scan. Difficulty accessing chest CT scans was the most important barrier to the timely diagnosis of lung cancer from the GP perspective. Although GPs considered that the chest CT scan should be performed prior to the FSA to expedite diagnosis, they were less concerned about who ordered the chest CT scan. Whilst some GPs preferred to order the CT themselves, most were happy for the radiologist or specialist to order the scan, provided the GP received a copy of the report. Currently if a specialist ordered the CT, the GP frequently had difficulty obtaining a copy of the report.

### *Barriers within secondary care*

Within secondary care, delays may occur due to lost referrals or communication problems between primary and secondary care; long waiting times for specialist appointments or radiological or other investigations such as bronchoscopy and CTFNA; lack of appropriate information or results at appointments; multiple appointments or investigations; diagnostic difficulty (such as non-diagnostic bronchoscopy); lack of multidisciplinary care; or lack of compliance and DNAs (possibly related to fatalistic attitudes to lung cancer).

Patients and GPs suggested that delays occurred at all points within the lung cancer pathway.

GPs felt that difficulty in accessing timely specialist appointments within the public

sector was an important barrier to timely diagnosis. GPs thought that specialist clinics were filled by follow-up patients that prevented new patients from being seen promptly. Patients felt that a lack of resources, particularly a shortage of specialists, contributed to delays in the system.

The diagnostic phase was characterised by multiple visits for investigations and specialist appointments and the time taken waiting for appointments for the various visits contributed to diagnostic delay. Time taken to complete diagnostic investigations (such as scans, bronchoscopy, CTFNA and other investigations) was often lengthened by tests being ordered sequentially by different physicians, and the tests and appointments not being coordinated, such that results were commonly not available at specialist appointment.<sup>16</sup> Waiting for appointments and results added to patient and whānau/family uncertainty and distress.

Patients spoke about getting stalled at particular points due to the unavailability of staff or services at holiday times, or cancellation of investigations or procedures because of equipment breakdown, industrial action or other reasons. Some patients attempted to circumvent delays in the public system by paying for diagnostic tests; however they felt that this shouldn't be necessary and had the potential to lead to inequalities in care.

Focus group and interview participant accounts revealed differential access to

timely care according to whether they were inpatients or outpatients when initially seen by secondary care. Inpatients were rapidly assessed and investigated, whereas outpatients tended to experience delays to diagnosis. This difference in the time to diagnosis between inpatients and outpatients was also evident in the *Clinical Audit*.

Transition between different providers or settings of care was considered high risk for communication breakdowns, coordination problems and failure of effective follow-up. Few GPs were routinely notified of appointment dates and few received timely feedback from specialists, which hampered their follow-up of patients. Many patients commented about problems relating to follow-up of abnormal CXRs performed in ED. This finding was supported by the literature.<sup>33</sup> Patients discharged from hospital prior to the completion of diagnostic tests stated that they experienced added delays and stress.

Diagnostic difficulty also contributed to delays. In particular a non-diagnostic bronchoscopy usually necessitated further investigation by repeat bronchoscopy or CTFNA thereby prolonging the time to diagnosis. It was considered that performance of a chest CT scan prior to bronchoscopy could increase the diagnostic yield and identify which patients would benefit from CTFNA as the initial diagnostic investigation.

## *In summary*

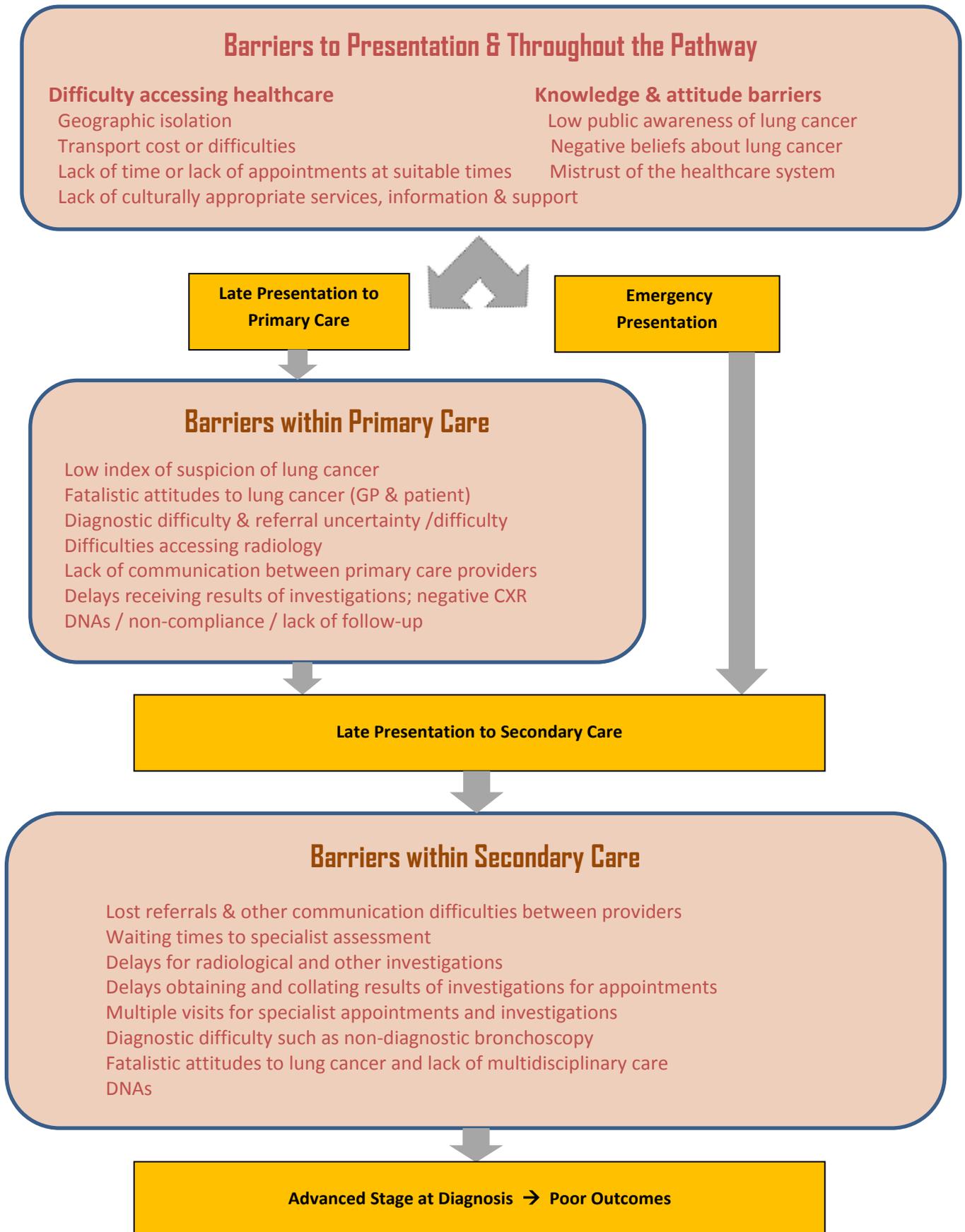
Numerous barriers were considered to exist to the timely diagnosis of lung cancer. The most important barriers were considered to be

- late presentation because of a lack of appreciation of the seriousness of symptoms or conversely because of the fear of having cancer
- GPs' difficulty knowing which patients to investigate and refer, as most patients present with symptoms similar to other respiratory disease, rather than with classic 'alarm' symptoms
- GPs' inability to access chest CT scans
- communication problems, especially relating to referral and communication between providers
- outpatient waiting times for specialist assessment and diagnostic investigations.

Patients and their whānau/family considered that delays in seeking care and delays in investigation and referral played a greater role in delaying diagnosis than problems within secondary care. However despite this, they felt that waiting times within secondary care, coupled with lack of information, were the most stressful part of their diagnostic experience.

GPs considered that poor access to chest CT scans and delays within secondary care were the most important barriers to early diagnosis; although difficulty knowing which patients to investigate and refer was also considered an important within primary care.

## Barriers within the Lung Cancer Pathway



**Section 5**

**Best Practice  
Recommendations**

*What can be done to  
Facilitate lung cancer diagnosis in NZ  
and how much will it cost?*

# Best Practice Recommendations

The recommendations presented below aim to address gaps and deficiencies in the lung cancer pathway as identified through the current project. Where possible the recommendations have been based on international and national guidelines and standards, and on best practice as identified through the *Literature Review* and the *National Stocktake*.

The recommendations have been categorised into:

- i) those to facilitate presentation and improve the overall patient journey throughout the pathway
- ii) those predominantly relating to primary care
- iii) those predominantly relating to secondary care.

## 1. Recommendations to Improve the Patient Journey

These recommendations aim to facilitate entry into and transit along the lung cancer pathway by improving the patient centeredness and cultural appropriateness of lung cancer care.

### **Recommendation 1.1**

***Improve health literacy, especially for Māori and Pacific peoples, by improving public awareness of lung cancer and developing information resources.***

### **1.1.1 Improved public awareness**

Low awareness of the symptoms of lung cancer, guilt about smoking, fear and pessimistic attitudes towards lung cancer outcomes and possible mistrust of the health system are currently reported to lead to late presentation of people with lung cancer.

Improving public awareness and knowledge of lung cancer could be achieved by coordinated social marketing campaigns, particularly directed towards Māori and Pacific communities. These should aim to increase awareness of the symptoms of lung cancer and the benefits of early diagnosis, and to reduce the fear of presenting to healthcare services. Key messages should be consistent and should be developed in conjunction with Māori and Pacific communities. Culturally appropriate community workers should be educated and supported to help inform the population. In addition, it is important that the health system has sufficient capacity to 'follow through'.

### **1.1.2 Improved information resources**

The time from initial presentation to healthcare services until diagnosis is particularly stressful for patients and their whānau/family, and is associated with much uncertainty and anxiety. Yet information and support are often lacking at this time, commonly being provided only after the diagnosis of lung cancer has been made.

Written and non-written information resources should be developed by primary and secondary health services in collaboration with Māori and Pacific

communities and other stakeholders. The information should be a national resource, consistent with guidelines and standards.

The information and messages provided should be culturally appropriate and easy to understand, being provided in multiple formats and languages. Information should be consistent and aligned with that provided to health professionals. It should include information on lung cancer, its symptoms, investigations, treatment, and outcomes; traditional medicine (CAM); who to see/contact, who the patient will be referred to, where to go and what to expect when; support and financial assistance; details on local services and transport/parking arrangements.

The information should be delivered in an integrated manner and should be reinforced face-to-face by health professionals (such as primary and secondary care coordinators and community health workers). The appropriate information should be provided at various points in the pathways to ensure relevance and to avoid the patient and their whānau/family becoming overwhelmed by 'information overload'.

### **Recommendation 1.2**

***Adequately credentialed, supported and culturally appropriate primary and secondary cancer care coordinators should be available to coordinate the patient journey and provide support.***

Cancer care coordinators / navigators are being used internationally and nationally to facilitate and coordinate the patient journey. In NZ, care coordinators have been shown to promote engagement of Māori with mainstream services by assisting with communication and access; and their use has been associated with increased patient and provider satisfaction and reduced DNAs.<sup>29 37 38</sup> However, there is considerable regional variation in the availability of primary and secondary care coordinators,<sup>37</sup> and often involvement of the secondary care coordinator does not commence until after diagnosis.<sup>37</sup>

#### **1.2.1 Establish primary care coordinator role**

The use of community health workers should be promoted by establishing a primary care coordinator role ('Aunty') to coordinate and facilitate the patient journey and provide support for 'at risk' patients.

Aunties currently act as primary care coordinators within some Māori communities. These Aunties are greatly respected for their knowledge and networks within the community, and their persona enables them to motivate individuals and their whānau. Currently few Aunties are employed in clinical roles; most being in community health worker roles, Kaumatua support, or some are simply active concerned individuals within their community.<sup>39</sup> Aunties should be employed in paid community health worker positions. They need to be adequately educated and supported with information and other resources. In

particular, they should be well-versed in the issues that affect Māori and Pacific people's health, well-being and ability to manage their own health and well-being. They should receive targeted education regarding cancer and national guideline recommendations, so that they can assist with the early identification of patients with possible cancer.

The primary care coordinator role should commence early in the pathway on suspicion of cancer (e.g. at the time of a suggestive CXR or chest CT scan if not previously) so as to support the patient and their *whānau*/family during the difficult period prior to diagnosis. The primary care coordinator should provide information, support and transport assistance to patients with or suspected of having cancer. The primary care coordinator should work closely with the secondary care coordinator / cancer nurse to avoid service gaps and to provide continuity of care and support. The primary care coordinator should establish close collaborative links with other healthcare providers and with social /community /support services.

### **1.2.2 Establish secondary care coordinator**

A secondary care cancer coordinator / cancer nurse role should be established within each DHB to coordinate the patients' journey and provide information and psychosocial support to the patient and their *whānau*/family.

The secondary care coordinator / cancer nurse should be the single point of contact within the hospital system for the

patient and their *whānau*/family throughout the lung cancer journey (from referral to secondary care until transfer of care to an oncology or palliative care nurse). The coordinator should be aware of all referrals for suspected lung cancer and they should be notified by radiology of any patient with an abnormality suggestive of lung cancer on CXR or CT scan performed in secondary care.

The coordinator should make contact with the patient within one week of the FSA. They should improve continuity and co-ordination of care by expediting access to services, facilitating communication and appropriate transfer of information between services, and should support the patient and their *whānau*/family by addressing their informational and support needs. Appropriate information and other resources should be available to assist the coordinator in their role.

The secondary care coordinator should work closely with the primary care coordinator to promote continuity of care and support. The coordinator needs to establish close links with other healthcare providers and with social/community/support services.

It would be desirable for all patients to have access to a *lung* cancer nurse specialist within secondary care; however smaller DHBs may not have sufficient numbers of lung cancer cases to warrant this. All patients should at least have access to a *cancer* nurse.

### **Recommendation 1.3**

***Promote a whānau ora approach by integration of care, including the development of networks between health care, social and community services to enable holistic care for health and non-health needs of patients and their whānau/family.***

A key element of *whānau ora* is the establishment of appropriate links across health and social related services to provide a seamless service that supports and acknowledges the social, economic and cultural needs of the patient and their whānau/family. However currently lung cancer care focuses on the health needs of the individual patient, and social needs and the needs of whānau/family are commonly neglected.<sup>38 39</sup>

Primary and secondary care coordinators should assess patient and whānau/family needs and provide appropriate information and referral to the appropriate support services. Both the health and non-health needs of the patient should be assessed; and in addition, the needs of the whānau/family should be addressed.

### **Recommendation 1.4**

***Promote the on-going involvement of patients and their whānau / family in health care by obtaining feedback regarding their experiences.***

On-going feedback from patients and whānau/family is required to 'give voice' to their experience within the lung cancer pathway, and to ensure that care is patient-centred and delivered in accordance with community and cultural values.

Healthcare providers should routinely use a regionally agreed patient satisfaction survey to document and respond to patient and whānau/family issues.

## **2. Recommendations to Reduce Barriers within Primary Care**

These recommendations aim to facilitate investigation and referral so as to expedite diagnosis.

### **Recommendation 2.1**

***Up skilling of primary care providers to increase awareness of lung cancer, its risk factors, and the benefits of early treatment.***

GPs may not have a high index of suspicion of lung cancer as they only see a patient with newly diagnosed lung cancer every 1-2 years, yet they commonly see patients with respiratory symptoms.<sup>38 40</sup> GP up skilling sessions with local respiratory physicians have the potential to increase GP awareness of lung cancer presentation, treatment and outcomes, and also familiarise the GPs with local specialist services.<sup>37</sup> However, only a few DHBs have held GP educational initiatives in lung cancer. Also currently, Māori health workers, whānau ora workers, and navigators/coordinators do not have access to continuing medical education sessions or other educational activities.

DHBs should work with primary care organisations and local respiratory specialists to facilitate education sessions in lung cancer for GPs, nurses and other

healthcare workers. These education sessions should address issues such as lung cancer risk factors, key symptoms of lung cancer, local investigation and referral pathways, lung cancer treatment and outcomes by tumour stage. Information and messages should be consistent and aligned with national guidelines and standards.

In addition to up skilling, GPs should be supported by clear and practical referral guidelines as part of their workflow.

### **Recommendation 2.2**

***Smoking status should be routinely recorded in the primary care records to facilitate identification of those at risk of lung cancer, and to promote action to encourage smoking cessation.***

Risk assessment within primary care could be improved by the routine documentation of smoking status (never smoker; ex-smoker or current smoker) in the clinical records.

Risk assessment should also include spirometry (as COPD is an independent risk factor for lung cancer).<sup>41</sup> Spirometry should be recorded for smokers and ex-smokers (with a >20 pack year smoking history).

GPs should have a high index of suspicion of lung cancer in those patients with risk factors of lung cancer who present with new or worsening respiratory symptoms.<sup>29</sup> In addition, many lung cancer patients that initially present directly to secondary care, have previously seen a GP within six months of diagnosis.<sup>42</sup> Therefore direct questioning

of at risk patients about the symptoms of lung cancer when they present for another reason may alert the GP to the possibility of lung cancer and reduce emergency presentations. Smoking cessation support should be offered to current smokers.<sup>37</sup>

### **Recommendation 2.3**

***Improve GP utilisation of CXRs.***

Currently in NZ, GPs request CXRs reactively. The current threshold for ordering a CXR may be too high with considerable delay before a CXR is ordered in some patients and with others not having a CXR performed prior to being seen in secondary care.<sup>42</sup> Poor access to publicly funded radiology has been considered a barrier to the timely diagnosis of lung cancer by GPs.<sup>40</sup> Approximately 50% of GPs considered that their patients experience inappropriately long waiting times for a CXR within the public sector and the vast majority felt that waiting times for chest CT scan are inappropriately long.<sup>40</sup> In addition, GPs have reported that some hospital radiology departments actively discourage them from ordering CXRs.<sup>38</sup>

GPs should have a lower threshold for ordering a CXR in high risk patients, especially if a CXR has not been performed within the preceding 12 months. In addition, guidelines note that repeated presentations for the same symptom/s or combinations of symptoms are likely to be more important than a single presentation or single symptom.<sup>12</sup> It is important that GPs be aware of the

patient's prior history (including previous presentations). Therefore access to complete records is essential. Yet currently GPs do not have access to the records if the patient has been seen at another practice.

CXRs should be performed for those with a history of smoking and significant chest symptom/s (not limited to haemoptysis or weight loss) in the absence of a CXR within the preceding 12 months. The CXR should be performed and reported to the GP within 7 calendar days of receipt of the request. Ideally, the findings of a CXR suggestive of lung cancer should be phoned through to the ordering doctor by the radiologist within 24 hours and the report should be automatically copied to both respiratory referrals and the secondary care coordinator at the DHB. If the CXR is normal, but the doctor is suspicious of lung cancer, the patient should be referred to a physician with an interest in respiratory medicine or lung cancer.

#### **Recommendation 2.4**

***Appropriate systems and safety nets should be in place to follow up patients with un-resolving symptoms, abnormal results and DNAs.***

Currently processes and systems differ greatly between practices.

All practices should have appropriate systems in place to follow-up and manage patients with un-resolving symptoms or abnormal results, and patients who do not attend appointments or investigations.

#### **Recommendation 2.5**

***Develop regionally consistent investigation & referral pathways across all DHBs that are aligned with national guidelines and standards, and integrated with workflow support tools.***

Symptoms which could be due to lung cancer are common and similar to those of other respiratory disease. GPs are often uncertain which patients to further investigate and refer.<sup>38 40</sup> GPs have reported that they do not find the NZGG Guidelines for *Suspected Cancer in Primary Care* useful for lung cancer. The guidelines are currently not integrated with the GPs' workflow support tools limiting their usefulness.

GPs often have to deal with several different DHBs therefore consistency of referral processes across DHBs is required.<sup>37 38 40</sup>

GPs have requested clear investigation and referral pathways that are integrated with their patient management systems.<sup>38 40</sup> National standards for patient management systems (PMS) should include context-sensitive, background search functionality so that GPs can be prompted with relevant clinical guidance at the point of care

#### **Recommendation 2.6**

***An e-referral system with standardised referral information template should be available to all GPs.***

GPs currently refer patients to secondary care by a variety of ways (e.g. fax, courier, letter via the patient, post, phone, electronically),<sup>40</sup> most of which

are paper-based, some being more expedient than others. Referrals currently contain variable information, get lost, take variable time to be received, and faxed referrals can mix up information on different patients. Current referral processes predispose to delays to specialist assessment and diagnosis. It is well recognised that paper-based referral processes tend to be inefficient and prone to errors.

An electronic referral system, incorporating decision support, referral and investigation guidelines and pathways, should be available to all GPs as part of their patient management software. Clear details should be provided on how to refer patients, what clinical information should be provided, and which investigations should be ordered prior to the FSA.

Referral processes should be consistent nationally across all DHBs (as GPs commonly deal with more than one DHB). The e-referral template should also be consistent nationally across all DHBs and should be integrated with national guideline recommendations. Electronic triage of referrals should be conducted by the appropriate specialist and the GP should receive immediate acknowledgement of the referral. On-line tracking of referrals should be available, so that the GP is kept fully informed of progress.

**Recommendation 2.7**  
*An audit tool for the assessment of GP lung cancer referral should be developed to provide feedback on appropriate referral.*

Consistency of GP referrals with national guidelines (including NZGG's 'Suspected Cancer in Primary Care' clinical guideline) and standards should be audited. In particular, a 'significant event audit' toolkit should be developed to aid retrospective assessment of the pathway of lung cancer cases that were not GP-referred (i.e. self-presented to ED). This would enable practitioners to reflect on practice and identify any opportunities for earlier diagnosis, and alter their approaches to lung cancer risk management for enrolled populations.

### 3. Recommendations to Reduce Barriers within Secondary Care

**Recommendation 3.1**  
*Improve access to timely outpatient CT scans for suspected lung cancer.*

Whilst inpatients commonly have ready access to investigations including chest CT scans, outpatients often have to wait for a chest CT. GPs consider poor access to CT scans is a major barrier to the early diagnosis of lung cancer.

In some DHBs, a chest CT can be requested by the GP in consultation with a radiologist or specialist, if the CXR is suggestive of lung cancer.<sup>37 38 40</sup> In other DHBs the CT scan is requested following referral to secondary care whilst at other DHBs it is requested at the first specialist appointment.<sup>37</sup> Radiologists may state on

a CXR report that a chest CT scan is recommended, however in many DHBs the GP cannot action this, leading to frustration.<sup>38</sup>

Whereas a chest CT is usually performed prior to bronchoscopy at most DHBs, at some DHBs this is not the case.<sup>37</sup> Chest CT waiting times vary greatly across DHBs with inappropriately long waiting times in some regions.<sup>37</sup> Such delay for CT scans may result in a chest CT requested pre-FSA not being performed by the time of the FSA, or a bronchoscopy being performed prior to the chest CT scan so as to expedite diagnosis.<sup>37</sup>

A contrast enhanced CT scan of the chest, lower neck and upper abdomen should be performed prior to: i) the first specialist assessment (FSA) if the CXR is suggestive of lung cancer and ii) bronchoscopy.

An outpatient chest CT scan should be performed within 10 days of receipt of referral so as not to delay the FSA. The secondary care coordinator / cancer nurse should ensure that the chest CT report and films are available at the FSA. A chest CT scan should be performed prior to the bronchoscopy to ensure that a bronchoscopy is the most appropriate diagnostic investigation.

Ideally, the radiologist should telephone the referring doctor regarding an abnormal CXR suggestive of lung cancer, and the chest CT should be booked at that time, in conjunction with the referring doctor. If the radiologist has not booked the chest CT scan in conjunction with the GP, the GP should be able to

request a chest CT, provided agreed criteria are met, following an abnormal CXR suggestive of lung cancer. This process would be facilitated by an e-referral system. Criteria for GP ordered CT scans should be developed in conjunction with GPs, respiratory physicians and radiologists. If a chest CT has not been requested by the GP, the specialist triaging referrals should order the scan on receipt of the referral for suspected lung cancer to enable it to be performed pre-FSA.

Discharge recommendation for a follow-up CXR at 6 weeks or chest CT scan should be booked by the hospital; and the patient and GP should be notified of the booking.

### **Recommendation 3.2**

***Develop a systematic approach to action referrals for suspected lung cancer to ensure the time from receipt of GP referral to FSA is <2 weeks.***

Referrals should be triaged by the appropriate specialist daily. The secondary care coordinator / cancer nurse should be notified of all cases with suspected lung cancer on triage of the referral so that she/he can coordinate appointments and ensure all relevant information is available at the FSA.

Rapid access clinic (i.e. a dedicated lung cancer clinic) should be available in each cancer centre to facilitate rapid assessment of suspected lung cancer. Timely access to FSA could be improved by reducing hospital-based follow-ups.

Timely access to diagnostic investigations (particularly CTFNA) should be improved.

**Recommendation 3.3**

***Cases with symptoms/signs of lung cancer should be promptly transferred to the care of a physician with an interest in respiratory medicine or lung cancer.***

Cases with symptoms or signs of lung cancer admitted acutely or admitted under a non-respiratory specialist should have their care transferred as soon as possible to an appropriate member of the lung cancer team. All such patients should be presented at an MDM and have access to the secondary care coordinator / cancer nurse.

**Recommendation 3.4**

***Systems should be developed to identify and manage cases with an incidental finding of lung cancer on radiological imaging.***

A nominated member of the lung cancer team (e.g. the secondary care coordinator or cancer nurse) should be informed of every radiology report where new lung cancer is mentioned as a differential diagnosis.

Hospital and community radiology providers should develop systems so that notification of possible new lung cancer occurs routinely (preferably electronically). Notification should be to the nominated member of the lung cancer team.

**Recommendation 3.5**

***Cases with possible early stage lung cancer should be prioritised for rapid transit through the pathway as survival gains are likely to be greatest for these patients.***

Potentially curable patients should be identified and fast-tracked for subsequent management.

Timely access to investigations such as CTFNA, EBUS, CT-PET should be improved as waiting times for these commonly delay the management of potentially curable patients.

**Recommendation 3.6**

***All lung cancer patients should be presented at a multidisciplinary meeting.***

In order to establish a culture of multidisciplinary care, all patients with lung cancer be presented at a MDM. Recommendations from multidisciplinary discussion should be available in the electronic clinical record and should be accessible to other members of the healthcare team. Patients and their GP should be informed of the recommendations of the multidisciplinary discussion within 2 working days of the meeting.

### **Recommendation 3.7**

***Communication between secondary and primary care providers and with the patient should be appropriate and timely.***

Although it is essential that the GP and the patient are fully informed of the management plan,<sup>29</sup> variability currently exists in the quality and timeliness of this information.<sup>37</sup> Communication from secondary care to GPs is often paper-based, with GPs in most regions not able to access to hospital records, or the records of other GPs (that have seen the patient on a casual basis).<sup>40</sup> In addition, communication to the patient and whānau/family is often deficient such that the patient may not understand the reason for follow-up investigations or appointments.<sup>38</sup>

All GPs should have electronic access to community and hospital consultation reports and results of investigations. Innovative methods for sharing of records have been developed by private IT vendors and these may assist the tracking of multiple presentations. Other initiatives which may assist include TestSafe and the GP2GP project.

TestSafe (<http://www.testsafe.co.nz/>) is part of a regional initiative by Auckland DHBs to improve information sharing among community and hospital healthcare providers for the benefit of patients. TestSafe gives healthcare providers access to diagnostic results and reports for their patients. It brings together results from DHBs and community laboratories, and work is

underway to include medications dispensed by community pharmacists.

The GP2GP project is a current Ministry of Health initiative to enable the electronic transfer of consultation records from an after-hours doctor or hospital emergency department back to the patient's regular GP. The initiative provides the patient's regular GP with a more complete clinical history, thereby promoting awareness of any persistent or non-resolving symptoms and facilitating earlier diagnosis. In addition, the regular GP is aware of investigations and referrals initiated by another doctor enabling follow-up.

On discharge from hospital, the patient should be provided with a management plan and a discharge summary and follow-up plan should be transmitted to the GP.

## **Economic Evaluation**

The current project sought to develop recommendations to facilitate earlier diagnosis of lung cancer. An economic evaluation was performed to evaluate the cost-effectiveness of expediting the diagnosis of lung cancer.

A cost-utility analysis (CUA) compared changes in costs and quality-adjusted life-years (QALYs) across different timings of service delivery. Patients' progression to Stage IV disease was modelled in a time-dependent Markov process.

In the current study, the difference in time to diagnosis between primary care and secondary care approached 5 weeks, with most of the additional time related to the extra time that outpatients waited for a CT scan.

The monthly rate of progression to Stage IV lung cancer for untreated patients at the time of diagnosis was estimated as 17%. This means that each month about 1 in 6 patients will develop Stage IV disease.

Reduction in time to diagnosis was associated with favourable changes in stage distribution, increase in life expectancy, and increase in costs.

The aggregated cost per QALY for 31 days' earlier diagnosis across the entire lung cancer cohort was \$1,963, excluding any costs of accelerated care. Costs per QALY ranged up to \$7,355, depending on the expense and efficiency of programmes to accelerate diagnosis.

## Earlier diagnosis

- Improves stage distribution
- Increases life expectancy
- Increases costs

*Cost of earlier diagnosis: \$1963*

*(by 31 days) over the entire lung cancer cohort*

*Costs per QALY: <\$7,355*

# In Conclusion

Many barriers to the early diagnosis of lung cancer exist locally; and the complexity of the healthcare system poses major challenges to attempts to reduce these barriers and improve lung cancer care.<sup>43</sup> To be effective, best practice solutions need to incorporate not only specific lung cancer initiatives, but also broader initiatives. A system-wide approach with a focus on improving information, reducing inefficiencies and improving coordination and integration across services and sectors is required.<sup>43</sup> Many of the recommendations from this project apply not only to lung cancer, but also to other cancers and other diseases.

In order to ensure regional equity and consistency in care, improvements need to be implemented nationally across all regions, although some contextualisation may be required. It should be noted that many of the recommended initiatives are already occurring within some DHBs.

The economic evaluation indicated that the recommended initiatives to improve timely lung cancer diagnosis are both equitable and economically competitive. Therefore they should be considered for implementation. Implementation however, was not part of this project. It is hoped that the National Lung Cancer Work Group and the Regional Cancer Networks will take the lead in implementation of the recommendations arising from this project.

## Summary of the Lung Cancer Project Recommendations

| <b>RECOMMENDATIONS TO FACILITATE THE OVERALL PATIENT JOURNEY</b><br>including entry into and transit along the lung cancer pathway by improving the patient centeredness and cultural appropriateness of lung cancer care  |  |
|--|--|
| <b>Recommendation 1.1</b><br><b>Improve health literacy, especially for Māori and Pacific peoples, by improving public awareness of lung cancer and developing information resources</b>   |  |
| <b>1.1.1</b>   | Coordinated social marketing campaign directed towards target populations (particularly Māori and Pacific communities) to increase awareness of the symptoms of lung cancer, benefits of early diagnosis and reduce the fear of presenting to healthcare services. |
| <b>1.1.2</b>   | Development of written and non-written information resources by primary and secondary health services in collaboration with the target population (particularly Māori and Pacific communities) and other stakeholders.   |
| <b>Recommendation 1.2</b><br><b>Adequately educated, supported and culturally appropriate primary and secondary cancer care coordinators should be available to coordinate the patient journey and provide support</b>   |  |
| <b>1.2.1</b>   | Promote the use of community health workers by establishing a primary care coordinator ( <i>Aunty</i> ) role to coordinate the patient journey and provide support for 'at risk' patients.   |
| <b>1.2.2</b>   | Establish a secondary care cancer coordinator / cancer nurse role within each DHB to coordinate the patient journey and information and psychosocial support to the patient and their whānau/family  |
| <b>Recommendation 1.3</b><br><b>Promote a whānau ora approach by integration of care, including the development of networks between health care, social and community services to enable holistic care for health and non-health needs of patients and their whānau/family</b> |  |
| <b>1.3.1</b>   | Primary and secondary care coordinators should assess patient and whānau/family needs and provide them with appropriate information and referral to the appropriate support services   |
| <b>Recommendation 1.4</b><br><b>Promote the on-going involvement of patients and their whānau / family in health care by obtaining feedback regarding their experiences</b>  |  |
| <b>1.4.1</b>   | Healthcare providers should routinely use a regionally agreed patient satisfaction survey to document and respond to patient and whānau/family issues  |

## RECOMMENDATIONS TO REDUCE BARRIERS WITHIN PRIMARY CARE

### **Recommendation 2.1**

**Up skilling of primary care providers to increase awareness of lung cancer and the benefits of early treatment**

**2.1.1** DHBs should work with primary care organisations and local respiratory specialists to facilitate education sessions in lung cancer for GPs, nurses and other healthcare workers

### **Recommendation 2.2**

**Smoking status should be routinely recorded in primary care records to facilitate identification of those at risk of lung cancer, & promote action to encourage smoking cessation**

**2.2.1** Routine documentation with regular updating of smoking status (never smoker; ex-smoker or current smoker) in the clinical records for all adult patients

### **Recommendation 2.3**

**Improve GP utilisation of CXRs**

**2.3.1** CXR should be performed for those with a history of smoking and significant chest symptom/s (not limited to haemoptysis or weight loss) in the absence of a CXR within the preceding 12 months.

**2.3.2** Discharge recommendation for a follow-up CXR at 6 weeks should be booked by the hospital and the patient and GP should be notified of the booking

### **Recommendation 2.4**

**Appropriate systems and safety nets should be in place to follow up patients with un-resolving symptoms, abnormal results and DNAs**

### **Recommendation 2.5**

**An e-referral system with standardised referral information template should be available to all GPs**

**2.5.1** An e-referral system with standardised referral template should be available to all GPs as part of their patient management software

### **Recommendation 2.6**

**An audit tool for the assessment of GP lung cancer referral should be developed to provide feedback on appropriate referral**

## RECOMMENDATIONS TO FACILITATE AND EXPEDITE DIAGNOSIS WITHIN SECONDARY CARE

### **Recommendation 3.1**

**Regionally consistent investigation & referral pathways aligned with national guidelines and standards should be developed across DHBs**

**3.1.1** Regionally consistent investigation & referral pathways should be developed in collaboration with respiratory physicians, radiologists, GPs and NZGG

**3.1.2** Guideline commissions should include funding to integrate guidance with workflow support tools (such as PMS, decision support systems, e-referral systems)

**3.1.3** National standards for PMS systems should include context-sensitive, background search functionality so that practitioners are prompted with relevant clinical guidance at the point of care; this can assist with a decision to make an e-referral

### **Recommendation 3.2**

**Improve access to timely outpatient CT scans for suspected lung cancer**

**3.2.1** A contrast enhanced CT scan of the chest, lower neck and upper abdomen should be performed prior to: i) the first specialist assessment (FSA) if the CXR is suggestive of lung cancer and ii) bronchoscopy

### **Recommendation 3.3**

**Develop a systematic approach to action referrals for suspected lung cancer to ensure the time from receipt of GP referral to FSA is  $\leq 2$  weeks**

**3.3.1** A chest CT scan should be booked prior to the FSA (if not already done)

**3.3.2** Improve timely access to the FSA and diagnostic investigations for suspected lung cancer (e.g. rapid access clinic)

### **Recommendation 3.4**

**Cases with symptoms/signs of lung cancer should be promptly transferred to the care of a physician with an interest in respiratory medicine or lung cancer**

### **Recommendation 3.5**

**Systems should be developed to identify and manage cases with an incidental finding of lung cancer on radiological imaging**

**3.5.1** A nominated member of the lung cancer team (e.g. the secondary care coordinator / cancer nurse) should be informed of every radiology report where lung cancer is mentioned as a differential diagnosis

### **Recommendation 3.6**

**Cases with possible early stage lung cancer should be prioritised for rapid transit through the pathway as survival gains are greatest for these patients**

**3.6.1** Potentially curable patients should be identified at the MDM and fast-tracked for subsequent management

**3.6.2** Improve timely access to investigations such as CTFNA, EBUS, CT-PET as waiting times for these commonly delay the management of potentially curable patients

### **Recommendation 3.7**

**All lung cancer patients should be presented at a multidisciplinary meeting**

### **Recommendation 3.8**

**Communication between secondary and primary care providers and with the patient should be appropriate and timely**

**3.8.1** Electronic access for all GPs to community and hospital consultation reports and results of investigations

**3.8.2** Following the MDM, a management plan should be provided in a timely manner to both the patient and the GP

**3.8.3** On discharge from hospital, the patient should be provided with a management plan and a discharge summary and follow-up plan should be transmitted to the GP

# Abbreviations

|            |  |
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| ADHB       | Auckland District Health Board   |
| CAM        | Complimentary Alternative Medicine   |
| CCI        | Charlson Comorbidity Index   |
| CMDHB      | Counties Manukau District Health Board   |
| CME        | Continuing Medical Education   |
| CNE        | Continuing Nursing Education   |
| CT         | Computer Axial Tomography  |
| CTFNA      | CT Fine Needle Aspirate  |
| CUA        | Cost-Utility Analysis  |
| CXR        | Chest Xray   |
| COPD       | Chronic obstructive pulmonary disease  |
| DHB        | District Health Board  |
| DNA        | Did Not Attend   |
| EAG        | Expert Advisory Group  |
| ED         | Emergency Department   |
| E-referral | Electronic referral  |
| FSA        | First Specialist Appointment   |
| GP         | General Practitioner   |
| HRC_DHBNZ  | Health Research Council of New Zealand and District Health Boards<br>New Zealand |
| IQR        | Interquartile Range  |
| IT         | Inequalities Team  |
| KPI        | Key Performance Indicator  |
| MDM        | Multidisciplinary Meeting  |
| MOH        | Ministry of Health   |
| NCN        | Northern Cancer Network  |
| NSCLC      | Non-Small Cell Lung Cancer   |
| NZ         | New Zealand  |
| NZGG       | New Zealand Guidelines Group   |
| PHO        | Primary Health Organisation  |
| PMS        | Patient Management Systems   |
| QALY       | Quality-Adjusted Life-Year   |
| RAPHS      | Rotorua Area Primary Health Services   |
| SCLC       | Small Cell Lung Cancer   |
| THO        | Total Healthcare Otago   |
| UK         | United Kingdom   |

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