





National Early Detection of Lung Cancer Guidance

National Lung Cancer Working Group November 2017

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Executive summary

Lung cancer remains the leading cause of cancer death in New Zealand. Minimal improvements in lung cancer survival have occurred in the last decade, despite significant effort to improve secondary and tertiary management of lung cancer.

It is recognised that the single most important prognostic factor for lung cancer is stage at diagnosis. Most lung cancer presents at an advanced stage with little or no chance of cure.

International efforts to shift stage at diagnosis to an earlier more curable status have included screening or symptomatic early detection programmes.

Currently, it is felt that New Zealand is not ready to introduce a CT based screening programme due to unknown risks and benefits in our population.

The purpose of this document is to provide high level guidance for the early detection of lung cancer to improve survival rates for New Zealanders with lung cancer.

An early detection programme is considered reasonable, based on local and international evidence suggestive of a beneficial impact in stage at presentation. The early detection programme would include four components:

- 1. Public awareness campaign
- 2. Education for health professionals
- 3. Improved clinical pathways
- 4. Monitoring to evaluate effectiveness

The intention is to introduce the early detection programme as a pilot project in the Midland region, and to develop nationally consistent resources/tools and monitoring indicators to allow for more detailed analysis of data in a smaller cohort.

Due to a strong desire to improve outcomes nationally it is felt that the other regions can use resources developed during the Midland pilot and introduce aspects such as clinical pathways as they see fit.

Although there is some uncertainty around the potential survival benefits of this programme there can be no uncertainty about the ongoing poor outcomes associated with this disease if we do nothing.

Tama tu, tama ora; tama noho, tama mate kai. (He who stands lives; he who sits, perishes.)

Introduction

Purpose

The purpose of this document is to provide high level guidance for the early detection of lung cancer.

This guidance describes a programme to increase early detection of lung cancer in high risk symptomatic people, rather than a screening programme for asymptomatic people (WHO. 2017), through increasing public and health system awareness and improved referral pathways. This guidance aims to improve survival rates for New Zealanders with lung cancer and address unacceptable inequities.

This guidance also provides clear goals and recommendations for implementation based on findings from initiatives implemented overseas and locally (Appendix A).

More work needs to be done on initiatives to encourage earlier presentation and ultimately better survival outcomes in New Zealand. The best opportunity for survival occurs when the cancer is completely removed in an operation. This is most likely when the disease is detected early.

The burden

Lung cancer is the leading cause of cancer deaths in New Zealand and has a lower survival rate than other common cancers. It continues to have the greatest impact on overall cancer morbidity and mortality. For example, New Zealand has a five-year relative survival rate of 11 percent, whereas Australia and Canada have five-year relative survival rates of over 14 percent.

Key Facts

The Cancer: new registrations and deaths 2011 (Ministry of Health. 2014) and Cancer patient survival 1994-2011 (Ministry of Health. 2015) reports show that:

- lung cancer accounted for most of the deaths from cancer, nearly 1 in every 5 deaths were from lung cancer
- for Māori, lung cancer accounts for nearly a third of all Māori cancer deaths
- one and five-year survival rates remain poorer for Māori than non-Māori
- people who live in areas of high deprivation are also disproportionately affected by lung cancer, with men living in deprived areas 3.2 times more likely to be diagnosed with lung cancer than men living in least deprived areas.

Focus on equity

The New Zealand Cancer Plan 2015-2018 aims to improve cancer outcomes for all New Zealanders. This means that people, irrespective of their ethnicity, gender, locality or socioeconomic status, must be able to have every opportunity to access services that will reduce their risk of developing cancer, enable their cancer to be detected earlier as well as getting high-quality cancer treatment quickly.

The impact of cancer is much higher for Māori than the general population. To improve cancer outcomes for Māori, the New Zealand Cancer Plan is guided by the overarching framework and aspirations in the Māori Health Strategy, *He Korowai Oranga* (Ministry of Health 2014).

The four pathways of He Korowai Oranga are core elements that should be integrated into any implementation initiative:

- Te Ara Tuatahi Pathway 1: Development of whānau, hapū, iwi and Māori communities. This pathway supports building Māori capacity to actively contribute to their own communities and long-term health outcomes.
- Te Ara Tuarua Pathway 2: Māori participation in the health and disability sector and in decision-making and service delivery to ensure services are appropriate and effective for Māori.
- Te Ara Tuatoru Pathway 3: Effective health and disability services efforts that focus
 on reducing risk, strengthening prevention and more effectively managing disease
 and long-term conditions, as well as improving overall Māori health and disability
 outcomes.
- Te Ara Tuawhā Pathway 4: Working across sectors that will present opportunities to deliver services more effectively, improve the continuum of care and improve outcomes for Māori across a range of areas.

A useful equity framework has also been developed alongside *He Korowai Oranga* to drive improved equity in health care. This equity framework (refer Appendix B) should be applied to all existing and new approaches that aim to improve cancer outcomes for Māori.

Health inequities or health disparities are avoidable, unnecessary and there are unjust differences in the health of different groups of people. In New Zealand, ethnic identity is an important dimension of health disparities. The principles of equity are applied to all aspects of the guidance.

The need to improve access to health services and equity of health outcomes for Māori, Pacific and populations at high risk of lung cancer is acknowledged. There should be effective communication and collaboration between primary and secondary care to support a seamless pathway. The usual pathway for people of all ethnicities is to visit a general practitioner (GP) practice for advice and referral to other services. Access and cost to primary care services is a barrier and can be prohibitive for Māori, Pacific and high risk populations who seek services for early detection of lung cancer.

Key barriers for Māori accessing and engaging with health services have been summarised as follows (Mauri Ora Associates, 2008):

 costs of care – for example, ability to pay for GP visits, chest x-ray and travel to health service

- communication overly technical
- structural for example, distance to travel, waiting time, time-restricted appointments
- cultural issues different kaupapa, stereotypes and assumptions, lack of respect and understanding of Māori values, discouragement of whānau support in consultation

The ability to address these barriers is outside the scope of this guidance document.

Benefits of developing Early Detection of Lung Cancer Guidance

Internationally, early detection of lung cancer programmes have had a positive impact on overall cancer outcomes. Reports from international and local Early Detection of Lung Cancer Guidance (EDOLC) campaigns (refer Appendix C) demonstrate the following benefits:

- increase in the number of patients diagnosed with early stage lung cancer
- diagnosis at an earlier stage increases curative treatment rates and can result in better quality of life and a better experience of care

Broader community benefits include:

- improving capacity and capability of local health providers
- strengthening relationships between health providers for future collaborations
- increased cancer awareness amongst communities, groups and individuals
- · reducing the stigma and fear of lung cancer
- family members living longer to support their younger generation
- building community health literacy
- confidence to talk about cancer

The reports (Appendix C) show that the benefits of earlier detection of lung cancer can be achieved through the following actions:

- promotion of lung cancer awareness in health checks
- consistent messaging to whānau/families to make informed decisions about seeking advice for early detection of lung cancer
- improved access to diagnostics such as chest x-ray
- prompt referrals for early investigation
- education of GPs and health care providers to raise awareness of symptoms and referral pathways

Strategic alignment

The EDOLC guidance aligns with the five strategic themes of The New Zealand Health Strategy: Future Direction (Ministry of Health, 2016).



People-powered

The success of a public awareness initiative is dependent on a variety of activities, including the development of easy to understand health information resources and tools. Consumer

involvement in the development of such resources, and evaluation of public awareness initiatives, is essential to assess the impact of any programme. Understanding barriers to accessing primary health services should help improve health literacy about the symptoms of lung cancer. This, coupled with the benefits of early detection should encourage people to proactively seek health advice earlier.

Closer to home

The guidance recognises the role primary care providers, including community pharmacy and NGOs have in providing information and advice to the community. Information can be delivered via multiple media platforms to ensure it is easily accessible and understood by the target population. Marae based health promotion and health checks will encourage at risk Māori and family/whānau to seek medical advice early. Community health providers who offer low cost access and outreach services will contribute to removing barriers of access to health services.

Value and high performance

There is a clear expectation that the effectiveness of an early detection of lung cancer initiative will be monitored and evaluated to demonstrate improved and equitable health outcomes for the high risk population. Investment in early detection services would, over time, reduce the burden on secondary services, with fewer acute presentations and improved outcomes for patients referred through the primary referral pathway.

One team

The National Lung Cancer Sub-Work Group has developed this guidance in collaboration with primary, secondary, consumer, and regional cancer network input and sought wider consultation with key stakeholders. Working with community/primary care providers and secondary health services to establish seamless processes to access services is an integral part of implementing this guidance. The use of shared care pathways and referral processes are intended to support better decision making and care.

The guidance goals are suitable for use with other tumour streams and have the potential to be used as a template for an all-encompassing early detection of cancer strategy in New Zealand.

Smart system

A robust monitoring and evaluation framework is critical to identify areas for improvement for any early diagnosis of lung cancer initiative. This requires the collection of good quality data and information. The development of key indicators that measure outcomes is necessary to support any decision making. Feedback from patients and their whanau/family is another key process to assess and ensure consumer input into service improvement. A focus on demonstrating equitable outcomes and access to services particularly for Māori and other high risk groups should be incorporated into the reporting system.

In addition to *The New Zealand Health Strategy: Future Direction* this guidance aligns with a number of strategic health plans (see table below).

Document name	Publication date	Publisher
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The New Zealand Health Strategy: Future Direction	2016	Ministry of Health
Pharmacy action plan 2016-2020	2016	Ministry of Health
Standards of Service Provision for Lung Cancer Patients	2016	Ministry of Health
National Criteria for Access to Community Radiology	2015	Ministry of Health
The New Zealand Cancer Plan Better, Faster Cancer Care 2015-2018	2014	Ministry of Health
He Korowai Oranga - Māori Health Strategy	2014	Ministry of Health
The Primary Health Care Strategy 2001	2001	Ministry of Health

Potential impact of an early detection of lung cancer initiative

Findings from the evaluation of the 'Be Clear on Cancer: Lung cancer' campaign (Cancer Research UK, 2014) can be used as an indication of increased resource requirements and outcomes that could occur should a similar programme be implemented in New Zealand. Significant findings from the evaluation were:

An increase in patients accessing GP services

There was an increase in the number of patients aged over 50 accessing GP services that equated to approximately 3.1 additional visits per practice per week.

• An increase in two week referrals

Two week referrals for suspected lung cancer increased to approximately 1.5 extra referrals per hospital, per week.

• Increased demand for radiology services

Results also showed a 20% increase in the number of patients referred by a GP for a chest x-ray in the first month of the national campaign. In addition, there was an 8% rise in GP referred CT scans per working day in May 2012, compared with April 2012.

• An increased diagnosis of patients with early stage disease

An increase of 3.1 percentage points for the proportion of non-small cell lung cancers diagnosed at Stage I. There was also a corresponding 3.5 percentage point decrease in the proportion of people diagnosed at Stage IV.

• An increase in the proportion of patients receiving surgery as first treatment

An increase of 2.3 percentage points (13.7% to 16.0%) for the proportion of patients receiving surgical resections as a first definitive treatment.

Findings from the Midland Cancer Network and Lakes DHB 'cough, cough, cough' campaign and the Northern Cancer Networks "the sooner, the better" campaign are further explained in Appendix C.

Implementation of this guidance document requires not only the development of a work plan but also a commitment by the Ministry of Health to fund the proposed early detection of lung cancer pilot to develop, test and refine national resources and ongoing initiatives.

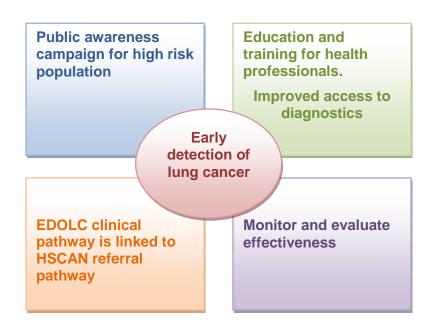
Guidance overview

This guidance focuses on four high level goals for early detection of lung cancer. These goals address the people and systemic changes needed to improve lung cancer outcomes. Successful implementation of the guidance should include actions that address all four goals simultaneously, as well as improve access to health care services for Māori, Pacific and high risk of lung cancer population.

Goals

- 1. People are aware of important symptoms of lung cancer prompting them to seek medical advice.
- 2. All providers are aware of who in their population is at high risk for lung cancer. These patients should be assessed for symptoms and referred for further investigations as appropriate.
- 3. All providers have an integrated early detection of lung clinical pathway that links to the high suspicion of cancer (HSCAN) referral pathway and implement an early detection of lung cancer model of service.
- 4. All early detection activities are monitored and evaluated to ensure they are contributing to improved lung cancer outcomes.

Early Detection of Lung Cancer Guidance



Goal 1. People are aware of important symptoms of lung cancer prompting them to seek medical advice

Recommendation:

Implement a public awareness campaign highlighting the symptoms that may lead to the early diagnosis of lung cancer.

Why is this goal important?

Findings from lung cancer campaigns implemented in the UK (Cancer Research UK, 2014) indicate that raising public awareness of the signs and symptoms of lung cancer can influence people to seek medical advice. Early diagnosis and treatment has the potential to save lives as well as improve the quality of life.

Earlier equitable access to treatment for lung cancer can result in improved quality of life and longer survival.

Who is the target group?

Those at high risk of lung cancer¹, their family members, friends and other key influencers who can prompt person to seek medical advice. Public awareness campaigns should also target groups where inequities exist, particularly for Māori where the evidence shows that cancer registration and mortality rates are three times those of non-Māori (Ministry of Health, 2015).

Low health literacy affects a person's ability to access health services and make informed health decisions.

Māori have much poorer health literacy skills compared with non-Māori, regardless of age, gender, level of education, labour force status, household income or rural/urban location. These have a negative impact on health status.

When making a decision to refer, assess and document risk factors for lung cancer. These include:

- smokers or ex-smokers
- history of exposure to asbestos
- pre-existing lung disease particularly COPD or interstitial lung disease
- history of cancer
- family history of lung cancer

It should be noted the incidence of non-smoking related cancer is increasing particularly in women and East Asians.

¹ High risk factors

What needs to happen?

It is recommended that a mixed media communications campaign be developed to communicate messages of symptom awareness to people in the target group. Media channels could include:

- 1. a social media campaign
- 2. a local print and radio campaigns
- 3. stories from local survivors or champions
- 4. a tool that provides further symptom information and advice on when to seek medical advice
- 5. sharing stories and the use of local champions or warriors for lung health
- 6. an informative website
- 7. a note regarding the incidence of non-smoking related cancer is increasing particularly in women and East Asians

It is envisaged that local/regional initiatives will be co-designed in collaboration with the community. Empowering people to be involved at the planning and developing stage of the campaign will help to overcome barriers faced by the target population.

What are the key messages and themes for a public awareness campaign?

Primary message

The aim is to raise awareness of a persistent cough as a symptom of lung disease and encourage people to seek medical advice.

Cancer Research UK (Cancer Research UK, 2014) identified that more than 90% of patients with lung cancer are symptomatic at diagnosis, with a cough being the most common presenting symptom. 'Cough, cough, cough' - If you or someone you know has a cough for more than 3 weeks, see your doctor.

Themes

The use of themes can assist in overcoming potential barriers that may prevent those at risk of lung cancer visiting their GP. Themes can counteract access barriers to early detection; specific barriers include the financial cost of being checked, fear of the outcome and a lack of knowledge of symptoms (Cancer Research UK, 2014).

Examples of themes are:

- 'Be brave, be strong, be there for your family'
- 'It's about lung health not disease'
- 'Early diagnosis increases your chance of cure'.

The pilot will need to develop national tools and resources to support this goal for national implementation.

Goal 2. That providers identify, assess and refer for investigation, symptomatic patients who are at high risk of lung cancer

Recommendations:

- 1. Develop and deliver education and training for early detection of lung cancer to multidisciplinary health professionals in the community.
- 2. Ensure there are no barriers to access for lung assessments and chest x-rays for people identified at high risk of cancer.

Why is this goal important?

Findings from the UK show that those who provide health care and advice in the community are pivotal to the success of early detection of lung cancer campaigns (Cancer Research UK, 2014). It is vital that health professionals in the community understand how they can support an early detection of lung cancer initiative.

Two studies have reported that early detection of lung cancer campaigns can increase the proportion of patients presenting with earlier stage lung cancer (Appendix C Doncaster & Liverpool). Overall survival is improved in patients presenting with early stage lung cancer.

Who is the target group?

Primary health organisations, pharmacists, clinical nurse specialists, public health nurses, radiologists, GPs, nurse practitioners, non-government organisations, Māori health providers, health care assistants and other health workers as necessary.

What needs to happen?

- 1. Develop and deliver early detection education and training for the target group (identified above) that includes:
 - a. significant input and/or partnership with primary health organisations
 - b. clarification of who in the population is high risk
 - c. best practice guidelines to support decision making and better care, including mapped pathways and eReferral systems to secondary care services
 - d. training to collect consistent information about high risk patients
- Simplify systems to expedite the diagnosis of patients with early stage disease including formalised referral pathways and streamlined patient access to diagnostics, such as chest x-ray and CT from primary care (refer Appendix D). Diagnostic reports should be made available to the patients GP within 24 hours and support timely communication of results to the patient.

What are the key messages for education and training?

All people at high risk of lung cancer should have a lung assessment completed and where possible same day access to a fully subsidised chest x-ray if:

 the patient has never had a chest x-ray or hasn't has had one in the previous 12 months or

if the patient presents with new symptoms.
There needs to be equitable and timely access to chest x-ray referred from primary care.
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Goal 3. All providers have an integrated early detection of lung cancer (EDOLC) clinical pathway that links to the high suspicion of cancer 2(HSCAN) referral pathway

Recommendation:

EDOLC clinical pathway is documented, linked to the HSCAN referral guidance and is readily available to all primary and secondary health providers.

Why is this goal important?

Clear pathways for referral are vital to ensure that a patient's transition along the treatment pathway is seamless. To achieve this all patient referrals to imaging and secondary care need to be consistent, complete, contain appropriate information and follow a recommended pathway.

The intent of the Faster Cancer Treatment programme supports improvements in the clinical pathway for lung cancer patients by reducing waiting times for diagnostics, treatment and support.

Who is the target group?

All health professionals who refer patients to secondary care for imaging and other services.

What needs to happen?

- 1. Formalised lung clinical referral pathway is established and includes reference to the national HSCAN definition.
- 2. Electronic referral systems that link primary care to secondary services.
- 3. Standardised eReferral forms are developed and implemented.

The following definition has been developed by the National Lung Cancer Working Group -(Ministry of Health, 2016) to support achievement of the faster cancer treatment (FCT) health target by clarifying what constitutes a 'high suspicion of cancer' for lung cancer.

Chest x-ray or other imaging suggestive/suspicious of lung cancer (including new pleural effusion, pleural mass, and slowly resolving consolidation)

Persistent or unexplained haemoptysis in high risk individuals over 40 years of age

New pathological diagnosis of lung cancer

² *HSCAN definition

Goal 4. Monitor and evaluate the effectiveness of early detection of lung cancer initiative

Recommendation:

District health boards and primary health organisations monitor initiatives to ensure they contribute to improving outcomes.

Why is this goal important?

Monitoring and evaluation to track the effectiveness of the programme is critical. It helps to determine exactly when a programme is on track and when changes may be needed. Monitoring and evaluation forms the basis for modification of interventions and assessing the quality of activities being conducted.

What will be achieved?

More people will be aware of the need for early detection of lung cancer to reduce the impact of lung cancer in the 'at risk' population. Health providers will understand the resourcing requirements necessary to support early diagnosis and improve outcomes for the 'at risk' population.

How do we implement?

Components of monitoring and evaluation include:

- 1. A review of patient staging migration information to assess any shifts.
- 2. Identification of increases in the number of patients discussed at MDM for whom treatment recommendations have curative intent versus non curative intent.
- 3. Monitoring of plain chest x-ray demand i.e. number of DHB GP referred chest x-rays per month.
- 4. A qualitative component to assess the impact of research around marketing penetration within the target market.
- 5. A quantitative measurement of uptake of early detection of lung cancer initiatives by district health boards.
- 6. A review in equity of access for people who live rurally as well as, those who access low cost GP practices.
- 7. A review of one year and five year survival rates.

Current systems to support monitoring the effectiveness of the programme will need to be adapted, which will require additional resource.

The pilot will need to develop monitoring indicators for implementation nationally.

Note: All measures will include ethnicity for Māori and other high risk ethnicities.

Conclusion

It is recommended that the Ministry of Health incorporate the principles of this guidance into the cancer work plan for 2017/18 and beyond. This will strengthen the National Cancer Programme's focus on early detection activities. An increased focus on early detection of lung cancer is likely to reduce the survival gap of lung cancer in New Zealand compared to Australia.

Because Māori are more likely to present with later stage disease, improved early detection of lung cancer has the potential to reduce the disparities of lung cancer outcomes between Māori and non Māori.

This guidance aligns with the direction set out in the New Zealand Health Strategy to support the development and implementation of regional early lung cancer detection programmes.

A high level summary of options for implementation is in Appendix A.

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Appendix A – Implementation of guidance

Introduction

Implementation of the early detection of lung cancer guidance links with other Ministry of Health cancer programmes such as Faster Cancer Treatment (FCT) programme.

The early detection of lung cancer guidance document is consistent with the initiatives established for the FCT programme which includes:

- improving the diagnosis, treatment and experience of care for lung cancer patients
- improving clinical outcomes from lung cancer
- improving the coordination of lung cancer patient care and streamline access to different treatment and services
- improving the timeliness of referrals
- ensuring best practice in treatment and care for lung cancer patients
- · enabling international comparison of data
- identifying and improving any bottlenecks and delays in access to diagnostic procedures and treatment

Local, regional and national initiatives in progress include:

- · formalising clinical pathways
- eReferrals to secondary services
- collection of data and patient information
- establishment of the cancer and psychological and social support service

Options for implementation

Option 1

Implement an Early Detection of Lung Cancer programme in one region prior to rollout across other regions.

Option 2

Implement a phased rollout of the Early Detection of Lung Cancer programme by DHB.

Option 3

Implement simultaneous rollout of an Early Detection of Lung Cancer programme across all regions.

Preferred option for action

The National Lung Cancer Working Group endorses option 1 for regional implementation of an early detection of lung cancer programme in the Midland region which can be refined, following the evaluation, prior to national implementation.

To ensure there is a nationally consistent approach the pilot will need to develop, test and refine:

- communication campaign resources and tools
- EDOLC monitoring indicators to evaluate the programme.

The rationale for selecting the Midland region is that both Lakes and Waikato DHBs have had experience in developing and delivering an early detection of lung cancer initiative. The Lakes 'Cough, cough, cough' campaign provided learnings that can be transferred to a regional EDOLC campaign. The Midland Cancer Network Executive and Midland Lung Cancer Work Group supported the establishment of a Midland EDOLC Work Group in 2015 and this group merged with the National Lung Cancer Sub-Work Group to develop the guidance.

This does not preclude other regions progressing goals 2 and 3 in their regional service plans.

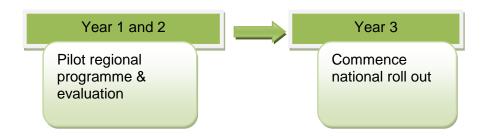
What are the benefits of implementing a regional programme?

The implementation of a regional programme would enable local and therefore contained testing of any resource requirements and methods used to deliver the EDOLC initiative. These resources and methods can then be refined before national rollout, increasing the likelihood of success.

How should the programme be implemented?

Evidence from EDOLC campaigns in the UK (Cancer Research UK, 2014) shows that early detection of lung cancer strategies should be implemented on an annual basis for a set period of time. It is recommended that a minimum commitment of two years be made and to commence a national roll out in year three.

Implementation timeframe



Key actions for implementation

Year One

- 1. Appoint an agency to lead the development of the work programme
- 2. Lead agency develops a project plan for delivery
- 3. Lead agency develops resources and tools required to deliver the strategy
- 4. Regional delivery of early detection initiative

Year Two

- 1. Continue regional delivery of early detection of lung cancer initiative
- 2. Review and refine early detection of lung cancer resources and tools
- 3. Evaluation of programme

Year Three

- 1. Lead agency supports national training of early detection strategy utilising regional cancer networks
- 2. National delivery of early detection lung cancer initiative
- 3. National monitoring and evaluation of initiative
- 4. Final report

Appendix B - Background

At this time, New Zealand does not support introducing a lung cancer screening programme. However, public awareness campaigns for early detection of lung cancer have been run in the United Kingdom since 2012. Results have been encouraging in terms of increased awareness amongst the public of the early signs of lung cancer and increased number of patients referred for chest x-ray for potential early diagnosis. In New Zealand, the Northern Cancer Network, Midland Cancer Network / Lakes DHB have also run campaigns to raise awareness of and promote early detection of lung cancer (refer Appendix C).

Lung cancer screening

In November 2013 a literature review explored international and national lung cancer screening and/or early detection of lung cancer initiatives (National Lung Cancer Working Group. 2013). The National Lung Cancer Working Group (NLCWG) agreed that New Zealand is not ready for a lung cancer screening programme at this stage, but it should keep a watching brief on emerging research. Some of the reasons for this are:

- the need for more preliminary research in this area
- high false positive results
- unknown uptake of the New Zealand population in such a programme
- the substantial infrastructure and investment required

Early detection of lung cancer

In May 2014 a concept paper was submitted to the Ministry of Health on early detection of lung cancer initiatives (NLCWG. 2014). The concept paper proposed development of a national early detection initiative for lung cancer based on overseas and local initiatives that encourage earlier presentation, diagnosis and treatment of lung cancer, and ultimately improving survival outcomes in New Zealand. In general, feedback from stakeholders was supportive of the concept. Some of the issues raised include:

- unknown costs and infrastructure required to support such a programme
- relatively minimal evidence to support the investment
- whether encouraging chest x-ray in high risk individual amounts to screening when this has not been shown to be beneficial to other populations

These are all valid concerns but the alternative to the proposal, which is continue to do nothing, seems more likely to harm our population.

Standards of service provision for lung cancer

The recently published Standards of Service Provision for Lung Cancer Patients in New Zealand (May 2016) include a section on prevention and early detection. The late presentation of lung cancer is the major determinant of mortality. There is a real need to drive early presentation, as stage migration has been shown to improve outcomes for lung cancer. The standards aimed at primary care to encourage more chest x-rays in high risk individuals.

To support the implementation of the national lung cancer standards, the NLCWG has developed a High Suspicion of Lung Cancer Definition (April 2016) for triaging clinicians. The definition also provides guidance for referrers to identify high risk patients.

These include:

- smokers or ex-smokers
- history of exposure to asbestos
- pre-existing lung disease particularly COPD or interstitial lung disease
- history of cancer

It should be noted the incidence of non-smoking related cancer is increasing particularly in women and East Asians.

How the national early detection of lung cancer guidance was developed

The Ministry of Health commissioned the NLCWG to develop national guidance on the opportunities for early detection of lung cancer including:

- organising and holding a national workshop for stakeholders to discuss an early draft of the national guidance
- establishing a sub-group (including nomination of a chair and providing ongoing secretariat support and management) to complete the development of the guidance including:
 - o terms of reference for the sub-group
 - ensuring there are at least two primary care representatives, a consumer and an equity perspective on the sub-group
 - o hold at least two face to face meetings of the sub-group
- the scope of the early detection guidance is expected to include a small number of high level recommendations with high level guidance on implementation. Detailed recommendations and implementation approaches and strategies are outside the scope requirements of the Ministry of Health. The scope includes:
 - o scoping options and high level analysis of options
 - o recommendations to the Ministry of two or three options to implement. Recommendations must be ranked in priority for implementation. Realistic cost estimates for the Ministry and service providers needs to be considered in the analysis of which options will result in greatest gains in outcomes for spend. The cost estimates indicates what resources are needed to implement the recommendations.
 - o a high level implementation plan
- the NLCWG and sub-group will endorse the final guidance before submission to the Ministry.

- the guidance will link with any New Zealand lung cancer screening research initiatives to share knowledge and ensure the guidance reflects the latest research findings.
- the Ministry's approval is required for all final documents.

What do we mean by national early detection of lung cancer guidance

A national detection of lung cancer programme includes the following strategic components.

- Local and/or regional clinical leadership and governance is critical to assist with changing the minds and hearts. There is a need to gather information to shape a local/regional strategy and to provide a baseline for future monitoring and evaluation.
- Awareness campaign of the early symptoms of lung cancer and the benefits of making the diagnosis early within the general population is a vital starting point.
- Development and use of nationally consistent messages.
- A high level awareness in primary care through education is also required in addition to good access to diagnostic and specialist treatment services.
- Ensuring general practice has ready access to diagnostics is crucial.
- A high level awareness for community pharmacy teams is required as the community pharmacy maybe the first point of contact if a person has a chronic and persistent cough.
- Optimise clinical practice and systems with agreed local and/or regional clinical pathways and resources/tools to ensure that the systems and processes are aligned between primary, diagnostics and secondary services to meet the population need.
- Nationally consistent monitoring and evaluation of initiatives.

Equity Framework - Ministry of Health

Equity of Health Care for Māori: A framework guides health practitioners, health organisations and the health system to achieve equitable healthcare for Māori.



There are three actions that support the framework:

- Leadership: by championing the provision of high quality health care that delivers equitable health outcomes for Māori.
- Knowledge: by developing a knowledge base about ways to effectively deliver and monitor high quality health care for Māori.
- Commitment: to providing high quality health care that meets the health care needs and aspirations of Māori.

Appendix C – Summary of national and international EDOLC initiatives

Internationally there has been a move towards increasing lung cancer awareness such as the United Kingdom's Doncaster campaign and others. Overseas evidence indicates that valuable research has been conducted to identify early detection strategies in countries such as Scotland, Ireland, Australia, and Canada. In New Zealand, similar lung cancer awareness campaigns have been held in the Midland and Northern regions.

Midland Cancer Network and Lakes DHBs 'cough, cough, cough' campaign

The Lakes "Cough, cough, cough" campaign aim was to improve lung cancer outcomes for the Rotorua community. This was a pilot study in Lakes with the aim of using:

- social marketing to encourage earlier presentation to a health care provider
- GP education sessions
- provide Māori Health providers and community education sessions and information
- align systems and processes for improved access to chest x-ray and CT, and establish a rapid access respiratory clinic.

Key messages were developed in partnership with Māori. Key local faces represented the local campaign. Although the numbers were small there appeared to be an associated rise in early stage lung cancer diagnosed in 2011 when compared to 2009. This project was low cost (\$30k) and specifically targeted to a high risk community. In addition, the campaign resulted in education and capacity building for health providers and development of important relations for future collaborations.

A similar but smaller project was held in Hamilton, Waikato DHB. This project focused on a social marketing campaign (a success was advertising on local buses) and working with pharmacies when people presented with a cough. The budget for this project was \$10k. However there were no measures to evaluate effectiveness. Waikato also incorporated the key messages into locally run Kia Ora E Te Iwi community health literacy programmes in partnership with Cancer Society and Māori health providers.

Northern Cancer Network (NCN)

The NCN completed "the sooner, the better" campaign in 2010 to promote detection of lung cancer symptoms. The objective was to raise awareness of lung cancer symptoms among Māori and Pacific people aged 45-64 years and to encourage early presentation while there is still an opportunity for curative treatment. The campaign used radio, print and posters. There were no measures to evaluate effectiveness.

NCN completed a three year research project (Stevens et al) in 2012 to identify barriers to early detection of lung cancer and description of best practice solutions. The barriers identified for early detection of lung cancer from a patient/whānau perspective include a lack of awareness of lung cancer symptoms and benefits of early treatment; fatalistic attitude to lung cancer and mistrust of healthcare system; the diagnostic period being the worst part of the pathway due to wait times; poor support and information.

Irish Cancer Society's annual lung cancer awareness campaign from 2011 to 2013

In 2011 the Irish Cancer Society launched a three year advertising and PR campaign to raise awareness of lung cancer. Instead of targeting tobacco users with frightening messages and imagery normally associated with lung cancer, the campaign decided to

focus on the use of an empowering message. This resulted in more people engaged with the campaign. Using traditional as well as online advertising mediums, PR and social media platforms also worked well to reach a wide audience and campaign evaluations show traction with both young and old. Market research using a quantitative survey was undertaken in 2011 and 2013 to evaluate the impact of the campaign.

UK Department of Health "Be Clear on Cancer" campaign

This campaign was to raise public awareness of a persistent cough as a lung cancer symptom, and to encourage people with the symptom to visit their GP. The campaign ran nationally in England during May and June 2012, following a regional pilot in 2011. It included TV, press and radio advertising. National campaigns have been held each subsequent year.

Ironmonger et al. (2014) reported that, following the national campaign, public awareness of a cough as a symptom of lung cancer increased, as did the number of patients presenting to GPs with a cough; urgent GP referrals for suspected lung cancer; GP referred chest x-rays and lung cancers diagnosed, and an increase in the proportion of non small cell lung cancers diagnosed at stage I and II.

Results to date indicate that "Be Clear on Cancer" is changing levels of public awareness. There are also early indications that clinical outcomes are improving. These are some of the statistically significant findings following the first national lung cancer campaign in 2012, comparing figures with the same period in the previous year:

- Around 700 more people were diagnosed with lung cancer.
- Around 400 more people had their cancer diagnosed at an early stage.
- Around 300 additional patients had surgery as a first treatment of diagnosed lung cancer, giving them the best chance of prolonged survival.

https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2013/05/bcocresp-apr-16.pdf

Doncaster campaign

This was a social marketing campaign based on raising awareness of the symptoms of lung cancer and the benefits of early detection - Customer 'Push' and preparing health care professionals for the initiative in terms of sharing insights, training and capacity management in GP surgeries - Service 'Pull'. Participants included 17,837 people living within the priority communities and 11 general practices, March to April 2008. Post campaign results demonstrated success by the number of people who would visit their GP with a bad cough and also ask for a chest x-ray, an increase referrals from GP for chest x-ray and the number of patients with stage I and II diagnoses improved.

The results of this project include:

- people who had a bad cough increased visits to their GP from 82% to 87%
- people requesting a chest x-ray increased from 54% to 67%
- targeted practices increased their chest x-ray referral rates by 22%
- stage I or II lung cancer diagnosis increased from 21% pre-campaign to 23% post campaign

Liverpool campaign

In Liverpool, a campaign for early detection of lung cancer using national and local media through radio, television and celebrity involvement was completed at Merseyside in 2012.

The impact of the campaign was reviewed through the referral rate at the rapid access lung cancer service from general practice. The results were analysed from April to December 2012 and compared with the same months in 2010 and 2011.

- The 2012 results indicated a total of 323 patients were referred to the rapid access clinic and 32% diagnosed with lung cancer, of these:
 - o 33% had stage I or II disease
 - o 29% had treatment that was potentially curable.
- In 2011, 283 patients were referred, of these:
 - o 31% had a lung cancer diagnosis
 - o 21% had stage I or II disease
- In 2010, 274 patients were referred, of these:
 - o 39% had lung cancer
 - o 20% had stage I or II disease

The above results demonstrate that between 2010 to 2012, there was an increase of at least 8% of patients diagnosed with stage I or II disease.

Scotland campaign

Scotland introduced a "Detect Cancer Early" programme in 2013 which aimed to increase the proportion of people who are diagnosed in the early stages of breast, bowel and **lung cancer** by 25% by the end of 2015. It is reported (16 November 2015 http://www.bbc.com/news/uk-scotland-34833278) that the percentage of people diagnosed with the earliest stage one lung cancer has increased by 24.7% since the adverts were first screened.

New South Wales Australia

A public education campaign 'Listen out for lung cancer' (LOFLC) was launched in 2013 aimed at improving the survival rates of people diagnosed with lung cancer by encouraging early detection. Now in its third year, the campaign encourages people to listen out for symptoms of lung cancer: persistent cough, change in cough and coughing up blood; across their family, friends, community and colleagues and also encourages people with suspect symptoms to request a chest x-ray to improve early detection rates. LOFLC delivered a 60.5% prompted recall and significant increase in unprompted awareness of key lung cancer symptoms.

Manchester mobile CT pilot

More than 2,500 people with a history of smoking took part in the month-long Manchester Lung Health Checks which saw CT scanners set up in shopping centre car parks from June 2016.

Smokers and ex-smokers aged between 55 and 74 in three deprived areas - Harpurhey, Gorton and Wythenshawe - were offered a free health check followed by an on-the-spot scan.

- The number of patients discovered at stage four which is nearly always incurable reduced from nearly 50% to just over 10%
- Over 2,500 people were checked, with about half then being offered an immediate CT scan - those scans led to 42 cancers being discovered

- Nearly 90% of those diagnosed were offered curative treatment
- A further 20% of those who attended were diagnosed with chronic obstructive pulmonary disease.

Appendix D – Radiology recommendations for EDOLC initiative

Recommendations to streamline radiology services in an EDOLC initiative			
Action	Recommendations		
Access to chest x-ray	Ensure fully subsidised and timely access		
	Access to chest x-ray should be same day		
	Referral for chest x-rays can be from a clinical nurse specialist, nurse practitioner or GP		
	Travel costs should be funded (in rural and remote areas)		
	Chest x-rays should be as close as possible to home		
Standardisation of chest x-ray	If there is a high suspicion of cancer on chest x-ray a CT should be recommended		
	If the finding is indeterminable, cancer is a differential then recommend a referral to respiratory physician		
Patient communication	Ensure the patient understands that more imaging is required		
Access to CT	Within 2 weeks		
	Chest x-ray report can be used for referral		
	Travel costs are funded via the national travel and accommodation (NTA) policy (rural and remote areas)		