

# **National Guidance**

**Follow up and supportive care of lung cancer patients after curative-intent therapy.**

**National Lung Cancer Working Group**

**July 2017**

## Introduction

Lung cancer remains the leading cause of cancer death in New Zealand. Traditionally, lung cancer patients treated with curative intent are routinely followed up by the treating specialist for up to five years post treatment.

Nationally, there is no agreed process or frequency of when follow up appointments and imaging surveillance should occur. Nor is there convincing proof that intensive follow-up approaches based on regular laboratory and radiological investigations improve outcomes in asymptomatic patients.

A study undertaken by the Department of Respiratory Services, Auckland City Hospital (Curtis E, Christmas T) concluded that routine follow up of non-small cell lung cancer (NSCLC) treated with curative intent does not appear to be beneficial to the majority of patients and that follow up of this group needs to be more targeted if it is to be cost effective.

Advances in diagnostic procedures, treatment techniques and improved survival rates has meant survivorship models and supportive care pathways for lung cancer survivors need to be included in this guidance.

One of the expectations of the New Zealand Cancer Plan 2015-2018 in relation to follow up care is that:

- More people will be accessing the psychological and social support they need
- People will have access to easily understood and nationally consistent information resources
- Patients will receive consistent follow-up and surveillance from all clinicians (eg, general physicians, primary care providers, senior nurses)
- Integrated palliative care services will be available.

## NZ Health Strategy - 2016



The 2016 New Zealand Health Strategy supports a new way of working to support the health and wellbeing of New Zealanders to 'live well, stay well, get well'. The five strategic themes are:

- people powered
- closer to home
- value and high performance

- one team
- smart system

### **People Powered**

- It is important to consider what matters most to the lung cancer patient during their recovery phase and take into account their personal wishes. Follow up and supportive care should be planned taking into consideration the person's desire to either extend life or to have quality of life in case of a recurrence.
- Partnering with whānau to identify follow up supportive care needs will support self management and whānau decision making.
- Initiating advance care planning ensures individuals have a chance to say what's important to them. It helps people understand what the future might hold and to say what treatment they would and would not want.
- If we asked a group of patients with the same type of lung cancer, same treatment and similar demographics whether they want to have further treatment if recurrence happens, the response will undoubtedly vary due to their personal values and beliefs.

### **One Team**

- Effective implementation of the patients' follow up and recovery plan is reliant on a collective approach with all health professionals understanding their role. Follow up can be facilitated by the patients' own GP, a clinical nurse specialist/practitioner, supported by the secondary/tertiary care specialist and should be as agreed by the patient. Encouraging and involving whānau in decision making recognises the importance of whānau in a patient's recovery.

### **Closer to home**

- With advances in technology, the need to travel to hospital for a clinic appointment may not be necessary. Virtual clinic appointments have numerous cost benefits to the patient in terms of time saved by not having to travel to appointments, not having to take time off work, travel costs and more. This situation empowers the patient to make decisions in a familiar environment and supported by as many people as they want present. Follow up appointments at a GP clinic close to where people live or works will be easier for patients who already receive much of their medical advice in the primary care setting.

### **Value and high performance**

- Due to the increasing demands on secondary and tertiary imaging services, patients expected to have a positive outcome if a recurrence happens should be targeted. All providers should work with patients and their whānau/family to evaluate the follow up and supportive care services received so improvements can be made.
- Routine imaging of all curative intent patients is not supported by the National Lung Cancer Work Group.

### **Smart system**

- An integrated system that allows for health records (including referrals) to be shared between primary, secondary and tertiary care will support the one team concept. Reminder systems for follow up appointments should reduce the number of patients who for various reasons do not attend their appointment.

# Principles<sup>1</sup>

## *Equitable and Accessible*

Follow-up should be similar throughout the country so that all patients have equitable access. All patients should have access, both in terms of location and cost.

## *Evidence-based to improve outcomes*

While some cancers have evidence supporting specific follow-up regimes, others lack supporting evidence and are done for reasons such as reassurance rather than because they are shown to improve survival. The magnitude of the change in patient outcomes needs to be clearly defined and considered.

## *Safe*

All follow-up should be safe and not place the patient at undue risk for no additional benefit. The amount of radiation that a cancer survivor is exposed to should be limited to the minimum that may help identify treatable recurrence, metastases or second primary cancers.

## *Optimal use of health care resources*

In our resource-limited environment clinicians “have a responsibility to the community at large to foster the proper use of resources and must balance their duty of care to each patient with their duty of care to the population”<sup>2</sup>. This includes equity of access for new patients and non-cancer patients where resource (e.g. CT machine time) is limited.

## *Clear and Concise*

Simplicity is important for patients and clinicians, so follow-up plans should be simple and clear enough for people to understand.

## *Address psychological factors*

Follow-up should be an agreed plan between the patient and clinician. Deciding not to undergo follow-up should also be supported as a valid option (particularly where there is evidence of minimal benefit from follow-up). Cancer survivors may fear the possibility that their cancer could return, and value ongoing follow-up in secondary care for reassurance. However, this can prolong the time that they consider themselves a “patient”, rather than a well person who has survived cancer. Follow-up plans should allow people to resume their normal life while providing support where needed.

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<sup>1</sup> Whanganui DHB, Development of Individualised Cancer Follow-up Booklets for Breast, Colorectal and Melanoma Cancers, FCT Service Improvement Project

## **Guideline Objectives**

The primary objective of this document is to provide guidance on follow up and supportive care of lung cancer patients who have completed curative-intent treatment.

### **TARGET POPULATION**

The target population is both small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC) patients after curative-intent treatment.

### **INTENDED USERS**

This guidance is targeted to thoracic surgeons, medical and radiation oncologists specialising in lung cancer, radiologists, general practitioners, respiratory physicians, cancer nurse specialists, nurse practitioners, other primary care providers and psychosocial support care providers.

### **AIM**

The aim of follow-up and supportive care after curative intent treatment of lung cancer is intended to:

- monitor for cancer recurrence or spread at an early stage so that treatment for any relapse can be started
- provide information to the primary care team to support implementation of the patient recovery plan
- utilise a key contact person to facilitate and coordinate primary and secondary/tertiary care health professionals to manage side effects, complications of treatment and referral back into the secondary/tertiary care if necessary
- educate and encourage patient self-management and healthy lifestyle options.

### **SCOPE OF GUIDANCE**

This guidance covers the period prior to discharge from final curative intent treatment and includes recommendations for:

- treatment summary
- recovery plan based on health needs assessment
- clinical care reviews
- psychosocial and support services
- imaging surveillance.

A consensus approach of the expert opinion of the National Lung Cancer Working Group (Appendix 2) was used to determine the appropriate timing of follow up imaging surveillance. This is due to little high level research or evidence that this approach is effective either for the patient or clinician.

### **SURVIVORSHIP**

Cancer survivors can face post treatment challenges to physical health, finances, relationships, emotions, identity and future prospects. There are various survivorship models aimed at supporting the patient post treatment around the themes of shared care,

survivorship care plans, and supported self management intervention (Cancernet April 2016).

Basic survivorship care plans include the following:

- summary of cancer diagnosis and treatment
- recommendations for specific action to monitor for recurrence and secondary cancers
- information about possible long-term late effects of treatment
- advice for living a healthy lifestyle
- who will follow up patient
- psychosocial and support services
- patient information resources.

Discussion has commenced on developing an agreed national survivorship model for cancer patients which will change the way routine follow up of cancer survivors will occur. This will continue to evolve as an agreed survivorship model is developed and changes of practice are implemented. This guidance should be reviewed and updated at least two yearly or as changes occur.

The national *Standards of Service Provision for Lung Cancer Patients in New Zealand* (2<sup>nd</sup> edn) will also need to be updated to align with this guidance.

## **COORDINATION OF FOLLOW UP**

The purpose and intent of follow up and supportive care should be clearly understood by both the patient and health professional.

International guidelines generally recommend that follow up should be coordinated by a multidisciplinary team, and, if possible, coordinated by the treating specialist who initiated the curative-intent therapy for the primary lung cancer. The treating specialist should personalise ongoing management and frequency of follow up as agreed with each lung cancer survivor. It is possible for the GP to follow up patients who are treated for early stage lung cancer therefore the patient's GP should receive a written treatment summary and recovery plan.

There is evidence to suggest that nurse led follow up provides an acceptable, appropriate and effective service to patients affected with lung cancer with no difference in survival or time to progression compared to the control group. Nurse led follow up is associated with cost savings and higher patient satisfaction. Virtual follow up has the potential to be utilised.

## **FREQUENCY OF FOLLOW UP**

In New Zealand, there is variability around the country of follow up and surveillance of curatively treated lung cancer patients. This document is the starting point towards supporting a nationally consistent approach to follow up and supportive care for these patients.

Follow up and supportive care should be based on the individualised needs of the patient as patients quality of life expectations and a range of other factors may determine whether the patient wants to pursue ongoing vigorous treatment if there is recurrence of cancer.

For all patients, initial follow up clinic appointment by treating specialist should be at 4-6 weeks post treatment to assess patient for complications.

In both NSCLC and SCLC, the majority of recurrences are diagnosed in the first two years following curative treatment and more intense follow up schedules do not result in overall survival time.

Follow-up after five years needs to be undertaken in collaboration with the patient and their GP.

Note: patients with known indeterminate lung nodules (normally contra-lateral) may be followed up under the normal lung nodule surveillance programme.

## **IMAGING**

Routine use of CT and PET-CT, tumour markers or bronchoscopy in the follow up of asymptomatic patients is discouraged. This should free up current resources to improve access to imaging services and reduce delays in diagnosing new cancers.

Routine testing beyond a plain chest x-ray in asymptomatic patients is not recommended.

The optimal frequency and timing of surveillance imaging is not clearly defined by current evidence. Any new and persistent or worsening symptom warrants the consideration of a recurrence therefore appropriate imaging for diagnosis.

Consultation document

## Follow up & supportive care

- Primary care team and whānau with support from secondary/tertiary care
- Offer lifestyle changes e.g. smoking cessation, immunisations, rehabilitation
- Single point of contact
- Easy way back into system
- Patient and whānau experience to gauge quality of services

### Factors:

- **Patient:** priorities and preferences, co-morbidities, fragility, geography and whanau support
- **Procedure:** expected and un-expected complications
- **Cancer:** stage and prognosis, effectiveness adjuvant and 2<sup>nd</sup> line intervention, surveillance
- **Access:** available local versus regional resources

Focus area Clinical, tumour marker and imaging surveillance	Focus area Additional psychosocial support	Focus area Additional treatment recommended	Focus area Existing conditions that need secondary care
Recommendation	Minimum requirement		Lead responsibility
1. Prior to discharge a treatment summary is completed	<ul style="list-style-type: none"> <li>• Primary treating specialist is responsible for completing the treatment summary.</li> <li>• The summary should include as a minimum: <ul style="list-style-type: none"> <li>➢ diagnosis</li> <li>➢ treatment type</li> <li>➢ long term side effects</li> <li>➢ signs and symptoms of recurrence</li> <li>➢ key single point of contact and contact details</li> <li>➢ follow up appointment frequency and location – local provider, community, primary or secondary</li> </ul> </li> <li>• A standardised format should be used.</li> <li>• Patient and whānau who support them understands the written summary information.</li> <li>• A copy is given to the patient and their GP.</li> </ul>		Treating specialist
2. A recovery and support plan based on health needs assessment is developed in consultation with the patient and whānau support members.	<ul style="list-style-type: none"> <li>• Holistic health needs assessment of supportive care requirements is initiated when curative intent treatment starts.</li> <li>• Advance care plan is initiated.</li> <li>• Developed in consultation with the multidisciplinary team</li> <li>• A copy of the recovery and support plan is given to the patient and their GP</li> <li>• Referrals to other services as required.</li> </ul>		Cancer nurse specialist - Lung
3. Psychosocial and	<ul style="list-style-type: none"> <li>• Psychosocial assessment and counselling as</li> </ul>		Clinical psychologist

support services	<p>required</p> <ul style="list-style-type: none"> <li>• Referrals to support services – carer/home support, meals, housing etc.</li> <li>• Health promotion and wellness.</li> <li>• Review of immunisation schedules such as annual flu vaccination.</li> <li>• Counselling &amp; stop smoking support for patients who have completed curative intent therapy.</li> </ul>	<p>Social Worker</p> <p>Primary care provider</p> <p>Stop smoking practitioners</p>
4. Clinical care review is undertaken at initial post treatment appointment.	<ul style="list-style-type: none"> <li>• Medical history, physical exam and imaging as determined by treating specialist. <ul style="list-style-type: none"> <li>➤ Surgery - at least one clinic visit to assess for surgical complications.</li> <li>➤ Medical oncology – if chemotherapy given following adjuvant chemotherapy post-surgery.</li> <li>➤ Medical oncology – if at least one chemo-radiation given.</li> <li>➤ General or respiratory physician – any ongoing significant medical or respiratory co-morbidity.</li> </ul> </li> </ul>	<p>Treating specialist initial review then ongoing follow up by GP or cancer nurse specialist.</p>
5. Patient education	<ul style="list-style-type: none"> <li>• Written patient information on post treatment, follow up process and what to expect following curative treatment.</li> <li>• Symptom recognition i.e. advice on who to contact should symptoms appear in the interval between scheduled reviews.</li> <li>• Survivorship information.</li> <li>• Palliative care services.</li> </ul>	<p>Lung cancer nurse specialist</p> <p>Hospice</p>
6. Imaging modality specific to patient's symptoms	<ul style="list-style-type: none"> <li>• Chest x-ray at 3 months post treatment</li> <li>• CT baseline at 6 months post treatment for patients who had: SABR treatment and chemo-radiotherapy.</li> </ul>	<p>Treating specialist to order</p>

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# Appendix 1

## New Zealand and International Benchmarking and Guidelines

The *Standards of Service Provision for Lung Cancer Patients in New Zealand (2016)* Standard 9.1 Follow up and surveillance recommends:

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

### Good Practice Points

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

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

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

### Imaging surveillance

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

The 2011 UK NICE guidelines have a similar approach.

The European Society of Medical Oncology recommends more intensive follow up with computerised tomography (CT) carried out every 6 months for two years and yearly afterwards for three years. The evidence both for and against intensive follow up is poor.

New techniques (e.g. SABR) will need to have a more intense CT based serial follow up imaging program as part of the quality assurance program. This will result in a less intense CT based program also as part of the standard follow up as a good second line therapy option (surgery) will likely be available in many on evidence of local progression. This would normally be approved by the Clinical Practice Committee and resourcing included in the business case.

Patients may wish to be scanned as they feel reassured when scanned. As with any test there is the danger of false reassurance and potential harm of repeated CT scans. There is also the psychological impact of detecting recurrent disease in patients without symptoms who would not normally be offered immediate treatment. Limited resources may mean the wishes of the individual patient who don't meet the criteria for follow up imaging surveillance are not met. The option of private scanning is available to those who really do want it.

American Society of Clinical Oncology (ASCO) guidelines specifically state that there is no proven value for either chest X-ray roentgenogram or CT in surveillance and therefore advocates imaging only upon the development of symptoms. Guidelines from other organisations recommend periodic chest imaging.

No randomised controlled trials evaluating the role of surveillance CT imaging for the follow-up of patients with lung cancer have been published. Evidence from a large, retrospective, uncontrolled comparison study suggests that there may be a survival benefit to follow-up with periodic CT scans vs CXR for patients with resected stage I to IIIB lung cancer, whilst extrapolation from the National Lung Cancer Screening Trial would also suggest CT is superior to CXR in surveillance for metachronous lung cancers.

## **Appendix 2**

### **National Lung Cancer Working Group Guidance Team**

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