Somerset, Wiltshire, Avon and Gloucestershire Cancer Alliance

Clinical Protocol

FOLLOW UP PROTOCOL AND SCHEDULE AFTER RESECTION OF COMMON INTRATHORACIC MALIGNANCIES INCLUDING PRIMARY LUNG CANCER, PULMONARY CARCINOID AND THYMIC TUMOURS

SETTING	Thoracic Cancer Surgery
FOR STAFF	Thoracic Consultants, Respiratory consultants, Cardiothoracic registrars, Thoracic Clinical Fellows, Lung Clinical Nurse Specialists (Lung CNS)
PATIENTS	Patients under follow up for intrathoracic malignancies including primary lung cancer, pulmonary carcinoid and thymic tumours, excluding small cell lung cancer (SCLC) within Somerset, Wiltshire, Avon and Gloucester Cancer Alliance (SWAG CA)

Background

University Hospitals Bristol and Weston is the referral centre for Lung Cancer surgical resection for all SWAG sites except Salisbury. UHBW clinical and imaging follow up protocols post-surgery are based on ESMO clinical practice guidelines, with NSCLC patients followed for 5 years post-surgery. NICE guidelines recommend that protocol driven nurse led follow up is offered to all patients following lung cancer diagnosis and treatment.

The delivery of network wide, locally delivered nurse led follow up is being established for patients within the Somerset, Wiltshire, Avon and Gloucester Cancer Alliance (SWAG CA) to reduce treatment variation in lung cancer, to deliver NICE recommendations, and to free up thoracic consultant surgical time for cancer surgery. This protocol sets out who is responsible for patient follow up and timing of imaging and follow up appointments, for resected NSCLC, thymic tumours and pulmonary carcinoid. The appendices contain suggested questions to be asked within follow up appointments, and best practice learning points from Trusts who have transitioned to a localised nurse led follow up process.

The purpose of follow up is to detect lung cancer recurrence and second primary lung cancers that might be amenable to further treatment. The risk of relapse of NSCLC is 6-10% per year initially but drops considerably after 4 years post-surgery, with local relapse most likely within the first 2 years and distant relapse thereafter. The risk of second primaries remains stable at 1-6% per year throughout. Surveillance for these is only of value if the patient is able and willing to undergo treatment, hence at each appointment their fitness for treatment and wishes should be assessed.

This protocol refers to all new patients undergoing Lung Cancer Surgery once approved.

This protocol applies to completely resected tumours. Management of incompletely resected tumours is more complex and these patients may require adjuvant treatment, additional early interval CT scans and bespoke management plans made on a case by case basis. These patients may be able transition back into nurse led surgical follow up, once adjuvant treatment has been completed and follow up schedule is able to proceed as per protocol.

This protocol has been reviewed and agreed by consultant surgeons, lung cancer leads and lead CNSs from each Trust within the SWAG CA, and will continue to be reviewed.

Model

This protocol allows for both face to face and telephone/remote nurse led follow up appointments, to account for differing local geography, patient demographics, patient preferences and service delivery models.

Medical support for CNS led clinics should be readily and immediately available from either the visiting thoracic surgical consultant, or the local lung cancer consultants, depending on local agreement.

Where a telephone or other remote model is being delivered, the ability to offer patients a prompt appointment in a CNS or consultant face to face clinic should be maintained.

The network is supportive of sites who elect to deliver follow up remotely by CT scan followed by a letter if the scan is clear, and recognise that where resource is limited, this could help increase LCNS input into other parts of the lung cancer service. However, if a CT + letter model is considered it is recommended that: that this applies to CT scans from year 3 onwards; this is agreed with the patient at the preceding appointment; the patient does not have complex cancer treatment related symptoms or psychological needs; patients can activate face to face appointments promptly if needed; outcomes and patient experience of the pathway are subjected to audit.

1) Resected Non-Small Cell lung cancer (excluding carcinoid)

Event	Timing	Team Member	Imaging
Telephone follow up	1 week post discharge	UHBW Lung CNS	None
First outpatient clinic: – Check pathology and MDT outcome, referral to oncology if needed – Consultant to complete letter in NCSI end of treatment summary format – Give patient lung cancer leaflet – Refer to oncology if candidate for adjuvant treatment	2-3 weeks post discharge	UHBW Consultant	CXR

Offer holistic need assessment (HNA) Give patient HNA Leaflet and book onto HNA telephone clinic.	6 weeks post discharge	Macmillan Cancer Support Worker	None
Outpatient clinic	4 months post discharge	UHBW Lung CNS/Consultant	CXR
Outpatient clinic - UHBW CNS to send letter to patient explaining transition to local CNS clinic	8 months post discharge	UHBW Lung CNS/Consultant	CXR
Outpatient clinic *	12 months post discharge	Peripheral Hospital Lung CNS	Contrast chest CT **
Outpatient clinic *	2 years post discharge	Peripheral Hospital Lung CNS	Contrast chest CT **
Outpatient clinic *	3 years post discharge	Peripheral Hospital Lung CNS	Contrast chest CT **
Outpatient clinic *	4 years post discharge	Peripheral Hospital Lung CNS	Contrast chest CT **
Outpatient clinic *	5 years post discharge	Peripheral Hospital Lung CNS	Contrast chest CT **

* Appointments from 12 months onwards can be face to face or telephone/remote

** CT scans booked for following year at appointment

***Call patient one week before the appointment to have CXR completed so report is available on time for follow up apt. For patients living further away and save them an additional trip, you could complete X -ray on the way out from clinic and then call with the results.

2) Resected Pulmonary Carcinoid Tumours

After initial follow up, low dose CT scans and clinic appointments as below in typical and atypical carcinoid. Follow up should be life-long or until comorbidity or performance status makes further follow up inappropriate. Consider sharing Neuroendocrine cancer UK (Formerly NET patient foundation) information leaflet and link https://www.neuroendocrinecancer.org.uk/ in clinic letters.

If incomplete resection then discuss at Neuroendocrine MDT, with management and follow up to be decided on a case by case basis.

Typical carcinoid (TC) clinic timeline.

Event	Timing	Team Member	Imaging
Telephone follow up	1 week post discharge	UHBW Lung CNS	None
First outpatient clinic: – Check pathology and MDT outcome – Consultant to complete letter in NCSI end of treatment summary format – UHBW Consultant to send letter to patient explaining transition to local CNS clinic.	2-3 weeks post discharge	UHBW Consultant	CXR
Offer holistic need assessment (HNA) Give patient HNA Leaflet and book onto HNA telephone clinic	6 weeks post discharge	Macmillan Cancer Support Worker	None
Outpatient clinic*	1 year post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	2 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	5 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	8 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	11 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	14 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	Every 5 years	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **

* Offer annual clinic appointments from year 1. Appointments from 12 months onwards can be face to face or telephone/remote.

** CT scans booked for following year at appointment

Atypical Carcinoid (AC) clinic timeline

Scan annually for five years, then 2-3 yearly to 15 years. Consider using this protocol for LNECs.

If incomplete resection then discuss at Neuroendocrine MDT, with management and follow up to be decided on a case by case basis.

Event	Timing	Team Member	Imaging
Telephone follow up	1 week post discharge	UHBW Lung CNS	None
First outpatient clinic: – Check pathology and MDT outcome – UHBW Consultant to send letter to patient explaining transition to local CNS clinic.	2-3 weeks post discharge	UHBW Consultant	CXR
Offer holistic need assessment (HNA) Give patient HNA Leaflet and book onto HNA telephone clinic.	6 weeks post discharge	Macmillan Cancer Support Worker	None
Outpatient clinic*	1 year post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	2 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	3 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	4 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	5 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	7 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	9 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **

Outpatient clinic*	11 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	13 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	Every 2-5 years	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **

* Offer annual clinic appointments from year 1. Appointments from 12 months onwards can be face to face or telephone/remote.

** CT scans booked for following year at appointment

3) Resected Thymic Malignancies

Clinic timeline: low risk (stage I/II AND completely excised R0)

Event	Timing	Team Member	Imaging
Telephone follow up	1 week post discharge	UHBW Lung CNS	None
First outpatient clinic: – Check pathology and MDT outcome – UHBW Consultant to send letter to patient explaining transition to local CNS clinic	2-3 weeks post discharge	UHBW Consultant	CXR
Outpatient clinic*	1 year post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	2 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	3 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	4 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	5 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **

Outpatient clinic*	7 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	9 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	11 years post discharge	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **
Outpatient clinic*	Every 5 years	Peripheral Hospital Lung CNS	Low radiation Contrast chest CT **

* Offer annual clinic appointments from year 1. Appointments from 12 months onwards can be face to face or telephone/remote.

** CT scans booked for following year at appointment

Higher risk (stage III/IV OR thymic carcinoma OR incomplete excision (R1/R2)

Discuss in MDT regarding further treatment and follow up strategy. May need adjuvant treatment and early interval CT. Only suitable for nurse led follow up once any planned adjuvant treatment is complete, and scanning protocol can proceed as per low risk patients.

Reference Guidance

Nurse led follow up clinics

Offer CNS-led follow up to all patients (based on NICE Guidance https://www.nice.org.uk/guidance/cg121)

Follow up of non-resected lung nodules

Use British Thoracic Society guidelines, available at; Guidelines | British Thoracic Society | Better lung health for all (brit-thoracic.org.uk) or use the App "pulmonary nodule risk" in Apple App Store or Google Apps, from Cancer Research UK

Carcinoid

European Society of Medical Oncology (ESMO) Clinical Practice Guideline Neuroendocrine bronchial and thymic tumours: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up available at; https://www.esmo.org/guidelines/endocrine-and-neuroendocrine-cancers/lung-and-thymic-carcinoids

"Follow-up for Lung Carcinoid should be life-long, since recurrences remain very common over time."

After radical resection of Lung Carcinoid, life-long follow-up with low- radiation imaging procedures and increasing interval of time, adjusted to prognostic factors, is recommended.

"Follow-up focuses on tumour and functioning syndrome evaluations long-term toxicity evaluations specific conditions including DIPNECH or MEN-1."

"By local consensus, serum biomarkers not currently recommended."

Thymic Tumours

European Society of Medical Oncology (ESMO) Clinical Practice Guideline on thymic epithelial tumours available at; https://www.esmo.org/guidelines/endocrine-and-neuroendocrine-cancers/lung-and-thymic-carcinoids

"Follow-up of Thymic Cancer is recommended in all patients in a similar manner to Atypical Carcinoid."

"No prospective data are available to build recommendations about post-treatment oncological follow-up of patients."

"While a relapse might still be treatable in a curative-intent, patients should benefit from a regular radiological assessment."

Appendix 1- Suggested questions for follow up visit

- Document current performance status.
- Have they developed any other serious medical conditions that would make follow up inappropriate
    - Patients fit to be offered further active treatment if diagnosed with asymptomatic recurrence will usually be WHO PS 0-2.
- Check that the patient still wants to be followed up;
    - Would they consider further active treatment if recurrence was diagnosed?
- Discuss the benefits and harms of follow up, particularly in patients with; performance status 3 or 4, frailty, or with diagnoses limiting life expectancy.
- “Have you had your flu injection this year?”
- “Have you had Pneumovax” if over 65.
- Check smoking status.
- If motivated to make a quit attempt, offer smoking cessation referral +/- nicotine replacement or other pharmacological support in line with Trust* and NICE advice
- If not ready to quit, suggest harm reduction (e.g. transition to vaping) in line with NICE advice
- Document smoking status at every visit

Smoking cessation advice is based on Trust Clinical Guideline and NICE smoking cessation guideline 2018.

Excerpts below;

“At every opportunity, ask people if they smoke and advise them to stop smoking in a way that is sensitive to their preferences and needs”

“People using e-cigarettes should stop smoking tobacco completely, because any smoking is harmful”

“The evidence suggests that e-cigarettes are substantially less harmful to health than smoking but are not risk free”

“The evidence in this area (ecigarettes) is still developing, including evidence on the long-term health impact”

(5) Prescribing nicotine replacement therapy

*Trust protocol includes prescription of a short acting nicotine replacement product AND acting product e.g. Transdermal patch 7-21mg daily titrated to cigarette use.

PLUS

Nicorette Quickmist mouth spray **OR** NiQuitin strips **OR** Nicorette inhalator Check DMS for details; Nicotine Replacement Therapy (NRT) Clinical Guideline

Appendix 2- Patient Communications

The following are template for communicating the transition to a nurse led follow up process to patients.*

Letter template for new patients:

Dear XXX

We are writing to inform you that your next and subsequent appointments will be run by one of the Lung cancer Clinical Nurse Specialists (CNS) based at your local hospital.

Clinical Nurse Specialist clinics for lung cancer surveillance are the recommended model by the National Institute for Health and Care Excellence (NICE). These clinics offer a complete holistic approach to your specific needs after cancer treatment and consistency. Patient experience surveys have highlighted the benefits and positive impact of having this clinic follow up model, which is well established in many cancer centres nationally.

Your local hospital will automatically organise your next due appointment with the Clinical Nurse specialist, and they will continue with the same schedule of appointments and scans as initially planned for the next 5 years. You can contact your local CNS team directly on xxxxx if you have concerns in between appointments or wish to be seen sooner than your scheduled follow up.

Please do not hesitate to contact us on xxxxx if you have any questions or wish to discuss further.

**Letter template for existing patients available if required.*

Appendix 3 – Best Practice

The following table sets out a summary of best practice learning taken from discussions from hospitals that have transitioned to a localised nurse led follow up process outside of SWAG.

Summary of Learning
Keep patients under consultant follow up if there are any complex issues.
Ensure open lines of communication between the CNSs and consultants to troubleshoot throughout the follow up process.
Whilst transitioning from a consultant to nurse led process, the CNS team should sit in the relevant clinic for a while to gain confidence and ensure adequate time for Consultant support/reviews as needed.
Having a CNS in the consultation when consultant explains to the patient that they will be followed up in a nurse led clinic, really helps transfer of care and reassurance that if need to be seen by consultant again won't be long process for appointments.
During the transition from the patient seeing a consultant to the lung CNS, a referral letter should be sent from the consultant to the lung CNS stating discharge from consultant follow up. This avoids duplication of appointments.
Keep a database to track when patients are due to be seen next. Use this to check the patients due in clinic and request X rays and chase CT reports. Once complete the clinic coordinator can book the patients into clinic.
The consultant and lung CNS should have separate follow up clinics. This makes it easier to audit who has seen which patient.
Ensure you refer patients to their GP or physician if there is no surgical related issue. This avoids using follow up time to discuss unrelated issues.
Be clear to the patient that although they are being seen by a Lung CNS, the Respiratory team is a large team that discuss patients on a regular basis, so if a patient does have recurrence they understand the reason for referring back to a consultant led clinic.

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