



Northern Cancer Alliance Head and Neck Stratified Follow Up Clinical Review and Surveillance Guidelines

Developed and endorsed by the Head and Neck Cancer Pathway Group March 2024

| Title: | | NCA Head and Neck Stratified Follow Up Clinical Review and Surveillance Guidelines | | | | |
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INTRODUCTION

This document provides regional guidelines to complement existing National Institute for Health and Care Excellence (NICE) and NCA tumour specific guidance. This guideline does not override the individual responsibility of healthcare professionals in making decisions appropriate to the circumstances of the individual patient.

It is not anticipated that the guidelines will cover all clinical situations in all patients, but where unusual circumstances exist, it is expected that such treatments would be discussed in the appropriate MDT.

The guidelines will be reviewed on an annual basis. Where new treatments are introduced between revisions they will be added as an addendum to the current guideline.

Personalised Stratified Follow-Up (PSFU) offers a more effective approach to after-care than traditional medical models of follow-up which has the potential to reduce costs and improve patient satisfaction. Evidence for this model is based on the work undertaken by the National Cancer Survivorship Initiative in 2011. This aligns with the national strategy for implementation of Patient-Initiated Follow-Up (PIFU) pathways and reducing the amount of face-to-face clinical appointments.

Patients with a head and neck cancer of head and neck origin will be considered for PSFU assuming they meet the inclusion criteria below.

STRATIFIED FOLLOW-UP

Stratified follow-up can lead to a reduction of routine face-to-face appointments in a patient's pathway. Following treatment, aftercare is discussed with the patient and the appropriate pathway assigned. Patients may move between pathways as their needs change.

The pathways are as follows:

Supported self-management (PIFU): Patient led follow-up where the individual receives support and interventions to empower them to self-manage their health outside of a hospital setting. They receive surveillance tests but do not have routine clinic appointments (face-to-face or telephone with a member of their clinical team).

Hospital led face-to-face or telephone follow up: Clinician led follow up where the individual will receive surveillance tests as per the clinical guidelines. Clinic appointments are scheduled as required and can be face to face or telephone consultations, and with a Doctor or Nurse Specialist.

This arrangement should be reviewed regularly. Local arrangements as to where follow-up takes place should be considered i.e. following adjuvant radiotherapy people are referred-back to their surgical team for follow-up which can continue following implementation of these guidelines. Individual choice should also be offered as to where this takes place i.e. local hospital or centre.

The length of time between follow-up appointments should be personalised in-line with the risk stratification of the individual patient (including how activated and able they are to self-manage).

Patients suitable for stratified follow up should be offered a 1:1 appointment with a Cancer Nurse Specialist (CNS) at the end of their primary treatment to explain what their follow up care plan will be, to ensure the patient knows how to contact the service if there are any

concerns or symptoms in between surveillance testing. This could be done at the same time as the end of treatment summary and review of the holistic needs assessment (HNA).

A process must be in-place for rapid re-entry of patients to the specialist cancer service as required.

Supportive/end of life care services: Clinician led with palliative care input as required, when no further treatment options are available, attending hospital appointments is potentially difficult for people. Transfer of care to the G.P. and palliative care services should be discussed and the G.P. made aware of this discussion. Community palliative care teams should be involved with the consent of the individual.

PATIENT SELECTION CRITERIA FOR STRATIFIED FOLLOW UP

Inclusion Criteria:

- Biopsy proven Head and Neck Squamous Cell Carcinoma
- Treatment completed and currently on either surveillance or Best Supportive Care pathway
- Self managing dietary needs
- Stable airway
- Any other patient deemed suitable following a clinical decision making process

Exclusion criteria:

- Under 18 years at diagnosis
- Patients on clinical trials where the protocol requires clinical review
- Patients whose holistic needs assessment suggests that they are not yet ready to selfmanage their aftercare
- Patients with an airway that is at high risk of deterioration for whom active intervention is appropriate
- Patients on active management of nutritional intake where early intervention may be needed (e.g. recurrent strictures/ high likelihood of successful decannulation of PEG)
- Patients who are deemed unlikely to represent with new or recurrent symptoms based on previously observed behaviours and non-engagement.

The option of PSFU should be available for all individuals who are clinically deemed suitable based on the above. However this pathway is not suitable for everybody, and some may continue to need hospital-based aftercare.

Any individual participating in a clinical trial should be followed-up as per trial protocol.

Following the multidisciplinary meeting (MDT) individuals should be reviewed and made aware of their future follow-up management plan. Decisions regarding stratified follow-up can be discussed in the MDT but are only confirmed when a discussion has taken place with individuals. The chosen pathway is then documented in the medical notes and should be communicated to the G.P, preferably via the treatment summary. Regardless of follow-up pathway all individuals should be offered a treatment summary and holistic needs assessment with their CNS or community service if available.

MINIMUM FOLLOW-UP SCHEDULE

Following the end of treatment there will be:

- A review of the Holistic Needs Assessment (HNA)
- A comprehensive information booklet be given to the patient which advises them of their planned follow up, access back into the service and support services available
- Completion of the End of Treatment summary clearly stating the method of follow up and sent to the patient and their GP

- Information supplied regarding health and wellbeing
- · Confirmation of booking of planned investigations and how results will be received

A minimum follow-up schedule should be agreed and communicated between the specialist team, primary care and the patient. The follow-up schedule may be conducted in the form of telephone clinics or virtual clinics in-place of conventional face-to-face clinics for patients.

Suggested surveillance schedule and format:

| Investigation /Year | 0 – 1 | 1 – 2 | 2 -3 | 3 – 4 | 4 – 5 |
|---|------------|--|--|--------------------------------------|--------------------------------------|
| Face-to-Face outpatient appointment | 4-6 weekly | 8-10 weekly | 3-4 monthly | 6 monthly | 6 monthly |
| Telephone appointment (if appropriate) | | Alternating with F2F 8-10 weekly | Alternating with F2F 3-4 monthly | Alternating with F2F 6 monthly | Alternating with F2F 6 monthly |
| PIFU | | | If meets criteria | | |

Suggested surveillance schedule:

Best supportive care patient management is very individual and would be as agreed between the patient and their clinical team.

See appendix 1 for further information including when the HNA and treatment summaries should be completed.

For patients whose treatment is palliative, consideration should be given to discharging them back to the care of their GP.

SURVEILLANCE

All patients following initial treatment for Head and Neck cancer will be given information about self-care and surveillance. A list of symptoms that could be a cause for concern and a contact number for the Head and Neck CNS will be given as part of the information pack developed by Trusts and included in a patient's treatment summary.

Patients who contact any member of the specialist team with worrying symptoms will be seen by the appropriate team within two weeks (in line with 2 week wait) and if necessary, the case will be discussed at the MDT meeting.

A treatment summary should be sent to the GP and patient within 6 weeks following primary treatment - surgery, chemotherapy or radiotherapy. Follow up after surgery should focus on post-operative issues, promoting and sustaining recovery (including early detection and management of late effects) and future planning.

DISCHARGE FROM SERVICE

All patients on a PSFU pathway will be discharged back to the GPs care at **5 years** (unless they are palliative and may be discharged sooner) and will have to re-access the service via their GP. Written information will be given to the patient/GP on the patient's End of Treatment summary to advise them regarding this date.

Head and Neck Stratified Follow Up Summary



Treatment decision clinic for best supportive care

Best Supportive Care Pathway – end of treatment appointment:

- Review HNA and action if required (including information on access to support available)
- CNS to discuss PIFU and provide written information with contact details
- Complete End of Treatment Summary* confirming PIFU including information on H&N specific risks (airway, bleeding, aspiration etc.)

*End of Treatment Summary document sent to:

- Patient
- GP
- Hospital Clinical Team

Complete treatment response, suitable for surveillance – end of treatment appointment:

- Review HNA and action if required (including information on access to support available)
- Complete End of Treatment Summary* confirming plan for follow up:
 - Year 1 planned clinical led face-to-face follow up
 - At end of year 1, review HNA and action if required (including access to support available)
 - Consider alternating with telephone follow-up in year 2
- Year 2 planned clinical led follow up (telephone and/or face-to-face)
- At end of year 2, review HNA and action if required (including access to support available)

 Year 3 – if suitable for PIFU, CNS / Consultant to discuss PIFU with patient and provide written information with contact details

Or

 Continue with planned clinical led follow-up (telephone and/or face-toface)

5 years - discharge at the end of year 5 (if suitable / in-line with local guidelines)

APPENDIX

1.1 CLINICAL RESPONSIBILITIES AND ROLES

Stratification

The clinical team / consultant is responsible for identifying patients suitable for supported self-management. The decision should be made based on holistic needs assessment, clinical judgement and discussion with the patient, then recorded appropriately within the Trust clinical systems.

Stratified Follow up Consultation

The CNS will manage the stratified follow up consultation. They will ensure that the patient is provided with written information, a treatment summary has been completed and a copy has been sent/given to the patient and sent to the GP. A holistic needs assessment will also be carried out and action taken as necessary. All surveillance and scans should be in place and patients are aware of how results will be received.

Re- access to Services

Patients will receive verbal and written information about how to re access the service if they have a problem or concern at the consultation appointment with the CNS. Patients should contact their clinical team via telephone who will give them verbal advice or arrange a clinic appointment. Patients can also re-access the service via their GP.

