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Introduction

Patients with head and neck cancer require high levels of specialist complex care from surgeons, oncologists, clinical nurse specialists, speech and language therapists, dietitians, oral surgeons, restorative dentists and specialist palliative care physicians. They also require input from specialist pathologists and radiologists right from the pre-treatment assessment to the point where rehabilitation is complete and beyond.

The LCA Head and Neck/Thyroid Cancer Clinical Guidelines combine the best aspects from the guidelines produced by the previous north west London, south west London and south east London cancer networks, and have been updated to reflect changes and developments in practice. The Manual for Cancer Services: Head and Neck measures (NHS England, 2014) was also taken into consideration.

These guidelines have been developed with input from specialists within the LCA Head and Neck Pathway Group. All members of this pathway group have had the opportunity to review the guidelines, and their comments have been taken into consideration. The aim of this document is to ensure that patients seen in any of the hospitals in the LCA are referred in a timely manner to an appropriate multidisciplinary team (MDT), and that their investigation, treatment, rehabilitation and continuing care through to survivorship or palliation is of the highest standard. It also seeks to reduce any variation or inequality of care within the LCA.

All Trusts are expected to be able to provide the standard of care detailed in these guidelines. To ensure that they continue to reflect best practice, the guidelines will be reviewed annually, in line with guidance from the National Institute for Health and Care Excellence and other national and international guidance, as well as significant new research publications.

It is important to mention that clinical research into head and neck cancer is an increasing area of activity in the UK and is led by the National Cancer Research Institute (NCRI) Head & Neck Cancer Clinical Studies Group. There are several national trials that are approved and run by this group, and most current units in the LCA contribute to these. The research entry from each unit has been highlighted and the plan is to increase the number of entries year on year.

It should also be noted that treatment for patients from the age of 16 to their 25th birthday should be in line with national guidance regarding the management of teenagers and young adults with cancer. Patients from the age of 16 to the end of their 18th year should be treated in a principal treatment centre.

Teenagers and young adults from the age of 19 to their 25th birthday will follow the adult pathway but should be offered choice of treatment in a teenage and young adult (TYA) designated hospital or at the principal treatment centre. Teenagers and young adults in this age group should be treated either in the principal treatment centre or a designated hospital (see Chapter 12).

For guidance on imaging, please refer to the Royal College of Radiologists’ Recommendations for cross-sectional imaging in cancer management, second edition.¹

Please note that these guidelines are complemented by exemplary pathway documents for upper aerodigestive tract (UAT) and thyroid cancers, and should be read in conjunction with those (see Appendix 10 and 11).

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1 www.rcr.ac.uk/docs/radiology/pdf/BFCR(14)2_1_Imaging.pdf
Executive Summary

The London Cancer Alliance (LCA) Head and Neck/Thyroid Cancer Clinical Guidelines have been developed in agreement with clinicians across the LCA. They combine evidence-based and best-practice recommendations, with the aim of ensuring that there are equitable, high-quality services across the LCA. The guidelines are multidisciplinary and cover early diagnosis, imaging, pathology, surgery, oncology, rehabilitation and survivorship.

Chapter 1 addresses reducing the time to diagnosis of primary head and neck tumours. It outlines urgent referral criteria for upper aerodigestive tract (UAT) and thyroid tumours. Chapter 2 deals with pathology services for head and neck, the preparation of specimens and biobanking.

Chapters 3–5 set out the multidisciplinary team (MDT) structure in line with peer review requirements, describe general principles and points of inter-professional communication, and outline the role of the key worker.

The patient information section in Chapter 6 provides a list of key areas to be discussed with each patient.

Chapter 7 deals with the importance of robust data collection and participation in clinical audits for the LCA provider Trusts.

Chapter 8 on surgery and oncology sets out key generic principles for treating head and neck tumours.

Rehabilitation and survivorship of head and neck cancer patients is outlined in Chapter 9, which details the ongoing care for patients living with their condition during and beyond treatment.

Palliative and supporting care are presented in Chapter 10, and improving patient experience is outlined in Chapter 11.

Chapter 12 provides information for managing paediatric, teenage and young adult patients.

Some of the recommendations in these guidelines will be challenging to implement, but as the role of the LCA is to ensure that world-class quality of care is delivered to its patients with cancer, it is anticipated that provider organisations within the LCA will use these guidelines as a tool to support change improvement. During the coming months, the clinicians will develop standards and measures against which organisations can be assessed.
1 Early Diagnosis

There is evidence that patients with head and neck cancer attend their GP or general dental practitioner (GDP) a number of times with symptoms related to their cancer before onward referral.

The Cancer Reform Strategy (2007)\(^1\) contains a number of key elements:

1. A 14-day standard from urgent GP referral to assessment in clinic (by a designated head and neck clinician at a local hospital that provides such services) or to a rapid-access neck lump assessment clinic.
   See Box 1 below for criteria.

2. A 31-day standard from diagnosis to treatment (including for recurrent disease).

3. A 62-day standard from GP referral to the start of treatment.

The Department of Health applies compliance targets to these standards that vary and may be updated (e.g. in 2011, the target is 96% for the 31-day first treatment standard, 96% for subsequent surgery, 94% for subsequent radiotherapy and 98% for the subsequent drugs standard; under the 62-day urgent GP referral to 1st treatment standard, the target is 85%).

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**Box 1: Head and neck cancer – urgent referral guidelines (England)**

- Hoarseness persisting for more than 6 weeks
- Ulceration of oral mucosa persisting for more than 3 weeks
- Oral swellings persisting for more than 3 weeks
- All red or red and white patches of the oral mucosa
- Dysphagia persisting for more than 3 weeks
- Unilateral nasal obstruction, particularly when associated with purulent discharge
- Unexplained tooth mobility not associated with periodontal disease
- Unresolving neck masses persisting for more than 3 weeks
- Cranial neuropathies
- Orbital masses

The level of suspicion is further increased if the patient is a heavy smoker or heavy alcohol drinker and is aged over 45 years and male. Other forms of tobacco use and/or chewing betel (areca nut) should also arouse suspicion.

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**Box 2: Thyroid cancer – urgent referral guidelines**

Patients with thyroid lump AND:

- Age >65
- Previous radiotherapy/family history
- Stridor
- Cervical lymphadenopathy
- Voice change
The LCA Head and Neck Pathway Group is developing new two week wait (2ww) referral forms to encourage more effective and prompt referrals to dedicated neck lump and 2ww clinics. It has been the view of the group that these clinics should be centralised in hospitals that provide expert cytology and radiology, and that have clinicians with interest and expertise in head and neck cancer. Until such time as referral forms for the whole of the LCA are available, the existing cancer network forms should be used (see Appendix 1).

Patients with suspected head and neck cancer should be seen at local hospitals by designated clinicians within a rapid assessment clinic. Designated head and neck surgeons, haematologists, histopathologists/cytologists and radiologists should cooperate to ensure that an appropriate diagnostic work-up is provided for patients with neck lumps. Patients found to have (or suspected of having) cancer should be referred without delay to the appropriate multidisciplinary team (MDT). There should be pre-booking systems for appointments at results clinics, where each patient with a diagnosis of cancer would be seen by a senior member of the MDT that deals with that type of cancer, and where support would be available from a clinical nurse specialist. The GP should be informed within 24 hours of diagnosis.

The LCA Head and Neck Pathway Group will be discussing ways to educate GPs and GDPs to ensure increasingly relevant and prompt referrals of patients with high-risk symptoms.

2 Pathology

The purpose of this document is to recommend ‘best-practice’ protocols to standardise the handling, gross description, sampling and histological reporting of head and neck biopsies and resection specimens and of thyroid resection specimens within cellular pathology departments across the LCA.

The dissection and reporting of all head and neck resection specimens should be appropriately supervised by a consultant pathologist with a specialist interest in head and neck pathology. All specialist head and neck histopathologists are expected to participate in the UK National Head and Neck Histopathology External Quality Assessment (EQA) scheme.

All malignant neoplasms and difficult cases should be discussed at a head and neck upper aerodigestive tract (UAT) or thyroid cancer multidisciplinary team (MDT) meeting. Head and neck and thyroid cancer cases should be reported in accordance with Royal College of Pathologists (RCPath) guidelines, and variations from the method should be recorded.

Minimum datasets have been agreed and are available on the RCPath website. Synoptic reports may be issued using minimum dataset-derived templates that are available for tumours at all the recognised subsites (see the web address below), or the template may accompany the free-text written report. The template reports are preferred by surgeons and oncologists, as they facilitate information capture for local, regional and national cancer databases.

www.rcpath.org/publications-media/publications/datasets/datasets-TP.htm

2.1 Preparation of specimens before dissection

Mucosal biopsies for excision of discrete lesions other than small biopsies should be orientated and digital photography considered. These biopsies usually require inking of the margins, and relevant blocks may be processed with a request for serial sections or levels, depending on local laboratory protocols. Small biopsies should be processed with a request for serials or levels and special stains for organisms, where appropriate.

Larger resection specimens should be orientated by the surgeon, usually by sutures and pinned to cork or card. The surgeon should indicate surgically critical margins; a good way of achieving this is to have a clinical diagram or digital photograph accompanying the specimen.

Laboratory photography (and sometimes faxes) of the specimen is recommended, where possible, to record the nature of the disease and the sites from which tissue blocks have been selected. The photograph may be printed for use as a photomap, and the digital images then presented at the head and neck oncology MDT meeting. Surgical margins should be painted with Indian ink or other tissue dye to facilitate the later microscopic identification of the proximity of pathology to the margin, unless the margin is cohesive and readily identified.

2.2 Notes on specimen site-specific considerations and block selection

2.2.1 Oral cavity and oropharynx

In general, these specimens may be assessed by cutting the specimen with a large knife into 5mm slices to demonstrate both the relationship of the tumour to mucosal resection margins and the maximum depth of
invasion by the tumour. Specimens from the central and lateral parts of the mouth are usually cut in the coronal plane, while specimens from the anterior mouth should be sliced in the sagittal plane. If the tumour is close to bone, the specimen may have to be decalcified with soft tissue in situ.

To check for human papillomavirus (HPV) infection, P16 immunostaining should be performed on sections from oropharyngeal squamous cell cancer, as recommended in the RCPath guidelines. Emerging research suggests that ideally the tumour tissue should also be tested for HPV 16/18 using polymerase chain reaction (PCR). In situ hybridisation testing for HPV family 16 DNA can be used, but it is less reliable than PCR. If the P16 antibody is not available in the referring Trust, spare sections or the block should accompany the positive biopsy, so that the test can be done at a hub hospital.

2.2.2 Salivary glands

A separate RCPath dataset for the handling of malignant neoplasms of the salivary gland was published in November 2013. The dataset proforma is included at the end of the document, and is available at: www.rcpath.org/Resources/RCPath/Migrated%20Resources/Documents/G/G115_SalivaryDataset_Nov13.pdf

Specimen handling and block selection

The exposed margin of the excised tissue should be marked with Indian ink or a suitable pigment before the tissue is serially sliced. If a major nerve has been resected, the proximal and distal margins should be indicated by the surgeon, thus facilitating accurate assessment of any perineural or intraneural invasion.

Blocks to be taken should include the following:

- Representative blocks of tumour (at least one per 10mm of tissue diameter), to include normal tissue and the relationship between the tumour and the nearest resection margin.
- For smaller tumours (<30mm), it is often appropriate to block the entire tumour; for larger tumours, macroscopically different areas should be sampled, particularly at the edge of the tumour.
- Lymph nodes within the gland or in peri-glandular soft tissue.
- Blocks from designated resection margins of nerves.

Neck dissection specimens associated with salivary neoplasms are handled as described below in section 2.6.

2.2.3 Larynx and hypopharynx

Total laryngectomy specimens require fixation in formalin for at least 24 hours. The hyoid bone may be dissected off and the specimens then decalcified in formic acid for 48 hours. More rapid decalcification (overnight) is possible using a stronger decalcification solution with a hydrochloric acid base or 5% nitric acid, but this compromises tissue morphology and impairs immunostaining. Tumour tissue should be sampled if possible before immersion of the resection specimen into decalcification fluid.

Block selection

5mm thick horizontal slices provide optimal demonstration of the relationship between the tumour and the laryngeal cartilages. For supraglottic carcinomas, blocks should include the relationship between the carcinoma and the anterior (submucosal) resection margin at the base of the tongue; blocks taken in the sagittal plane are more appropriate to demonstrate this feature. The description should include the subsite of origin of carcinoma, and the extent of involvement of laryngeal cartilages and extra-laryngeal tissues. Large blocks of selected laryngeal slices are usually taken to demonstrate site and facilitate measurement of the tumour and margins.
2.2.4 Paranasal sinuses and maxillectomy specimens

These are complex specimens that require careful orientation and labelling by the surgeon, if the pathologist is to provide accurate information. Whenever appropriate, the surgeon should assist the pathologist in the dissection of the intact specimen, to ensure that critical margins are orientated and submitted for histological examination. For partly disrupted specimens, it may sometimes be necessary for surgically critical margins to be sent as separate specimens to the laboratory.

2.3 General selection of blocks for histology

- Tumour – at least one block per 10mm diameter of tumour, including one selected to demonstrate the maximum depth of invasion; whole tumour if less than 10mm.
- Blocks of defined mucosal and soft tissue margins (e.g. epiglottis, trachea in larynx).
- Non-neoplastic mucosa.
- Bone surgical margins (if applicable).
- Bone or cartilage (larynx, nose), if grossly involved by tumour.
- Thyroid, if present in laryngectomy.
- Tracheostomy site.
- Nerves and vessels within and exiting the specimen, if appropriate.

2.4 Important data to be recorded at dissection

2.4.1 Site(s) and side(s) of the carcinoma(s)

For carcinomas that involve more than one site, the principal site of involvement should be recorded and coded; this may not be the site of origin. If required, the involvement of associated sites can be noted to help in later data analysis. Sites and subsites should be recorded according to the Union for International Cancer Control (UICC) nomenclature.

2.4.2 Type of resection specimen

The type of resection specimen should be recorded, for example, total or partial glossectomy, laryngectomy.

2.4.3 Pathological data

Maximum diameter of tumour (in millimetres) – the macroscopic diameter should be used unless the histological extent is greater than macroscopically apparent, in which case the microscopic dimension is used. As for other tissues (e.g. breast), measurements are made pragmatically, acknowledging distortion of tissues by fixation and processing.

Maximum depth of invasion (millimetres) below the luminal aspect of surface; if the tumour has ulcerated then the reconstructed surface should be used. The aim should be to provide a best estimate of tumour depth; for large carcinomas, this may be an approximation. A more detailed comment on the nature of the tissues invaded (mucosa, muscle, etc.) should be made in the ‘Comments’ sections.
**Figure 1: Descriptors of the size of the primary carcinoma**

Notes: (A) a nodular carcinoma; (B) an ulcerated carcinoma.

Depth of invasion refers to the depth of greatest spread in presumed continuity below the top of the adjacent mucosa. For both nodular and ulcerated tumours, the line of the original mucosal surface is reconstructed to determine the true thickness.

Source: Royal College of Pathologists guidelines.

### 2.5 Thyroid resection specimens

The specimen will usually be described as total (or near-total) thyroidectomy; right or left lobectomy; hemithyroidectomy (including isthmus); or isthmusectomy. It should be noted whether the thyroid capsule appears intact on receipt (excluding the intrathyroidal margin on lobectomy specimens).

The specimen should be weighed, measured and described grossly, particularly if there are any unusual features. In thyroidectomy specimens, measurements of each lobe and isthmus (plus pyramidal lobe, if present) should be noted where possible. The surface should be inked. The specimen should then be sliced (usually transversely) at intervals no thicker than a tissue block, and the cut surfaces of all the slices should be inspected.

The appearance and location(s) of the lesion(s) should be noted. The inclusion of a diagram or photograph in the records with annotation of block selection is best practice. It is important to record the greatest dimension of the lesion (or of the largest lesion, if multiple), as this defines the pT status. If this is <20mm, the macroscopic size should be confirmed or adjusted by the microscopic measurement of size. The presence of macroscopically apparent direct extension beyond the thyroid, which is prognostic, should be recorded (including which anatomical structures are invaded), to inform the pT3/4 staging. Clearances from the thyroid capsule and relevant resection margins should be measured and noted. The site and number of any possible parathyroid glands should be noted, and they should be sampled if present.

The number and site of lymph nodes submitted or identified in the main specimen should be recorded, and all the nodes should be sampled. Central/Level VI lymph nodes are often submitted with known papillary carcinoma or other specimens resected for malignancy.

#### 2.5.1 Block selection

The number of blocks taken will vary according to the tumour type. Tumour type may be known or suspected from any pre-operative cytology, enabling appropriate block-taking when the specimen is initially dissected. Alternatively, the specimen may require extra blocks to be taken after the initial histological diagnosis has been made. The use of mega blocks may be considered to show resection margin relationships to large lesions, and they may show the entire circumference of the capsule of such lesions in one section.
2.5.2  **Core data items for all malignant thyroid tumours**

- Type of malignancy.
- Whether a carcinoma is a single lesion or multifocal.
- Maximum dimension of carcinoma (largest if multifocal).
- Closest distance to surgical resection margin.
- Extension into extrathyroidal tissues, which should be identified, and whether the extension is macroscopic or microscopic.
- Number of foci of any lymphatic/vascular invasion.
- Site and number of lymph nodes sampled and number of those involved.
- SNOMED codes, in a version approved by the local cancer registry (TNM 7 recommended).

2.5.3  **Non-core data items**

- Detailed tumour subtypes, beyond the core data, may be recorded.
- Incidental microscopic conditions in the background thyroid should be recorded:
  1. To account for macroscopically described lesions that have prompted block-taking
  2. When they may have affected the clinical impression of tumour extent (e.g. benign, background nodules)
  3. When they may have clinical implications for the aftercare of the patient (e.g. thyroiditis).

2.6  **Neck dissections**

Several types of neck dissection may be received.

**Radical and modified radical (functional) dissection:** a radical neck dissection includes removal of cervical lymph nodes (Levels I–V), sternocleidomastoid muscle, internal jugular vein, and spinal accessory nerve and the submandibular salivary gland, while in a functional dissection, the sternocleidomastoid muscle, internal jugular vein, or the spinal accessory nerve may not be removed.

**Selective neck dissection:** involves removal of the nodal group(s) considered to be the most likely site for metastasis, preserving one or more nodal groups that are routinely removed in a radical dissection.

**Extended neck dissection:** when additional lymph node groups or non-lymphatic structures are removed.

There are seven anatomical groups (levels) of lymph nodes:

- Level I: nodes of the submandibular and submental (IA) triangles.
- Levels II, III and IV: nodes of the upper, middle and lower jugular chain. These nodes lie deep in the upper, middle and lower thirds of the sternocleidomastoid muscle, respectively. The point at which the omohyoid muscle crosses deep to the sternocleidomastoid muscle is a useful landmark separating Levels III and IV. Level IV extends from the omohyoid muscle to the clavicle.
- Level V: nodes of the posterior triangle, behind the posterior border of the sternocleidomastoid muscle.
- Level VI: nodes of the anterior compartment, around the midline visceral structures of the neck from the hyoid bone to the suprasternal notch.
- Level VII: nodes of the anterior compartment, below the suprasternal notch.
Parotid and periparotid lymph nodes lie lateral to the sternocleidomastoid or at its anterior edge, rather than in the deep chain.

Imaging studies may subclassify node Levels I, II and V. If separate groups are submitted, e.g. IIA and IIB, this should be noted in the pathology report. Since radiotherapy fields may be influenced by the presence of disease in specific nodal groups (e.g. Level IA or IIB), surgeons and pathologists should aspire to the most accurate differentiation and assessment of the nodal groups.

2.6.1 Preparation of the neck dissection specimen before sampling

The aim is optimal accuracy in lymph node retrieval from different levels in the neck. The surgeon may separate the node groups in theatre, and this is the preferred method in several specialist centres. The superior margin of each group may be marked with a suture. Each group may be placed in formalin in a separately labelled container. Nodes in addition to the main groups, e.g. parapharyngeal nodes, should be sent as separate specimens.

If an intact neck dissection specimen is sent it should be orientated by the surgeon and pinned or sutured to card or other suitable material. The surgeon should indicate surgically critical margins and identify the general territories of node groups by placing markers such as sutures at the centre of each anatomical group or by an accompanying clinical diagram. Intact functional neck dissection specimens should be photographed to record the nature of the disease and may provide a map to record the sites from which tissue blocks are selected. Surgically important margins should be marked with Indian ink or an appropriate dye.

2.6.2 Notes on neck dissection block selection

Lymph nodes may be dissected free, with a minimal amount of surrounding fat, unless extranodal spread is suspected, in which case tissue blocks required may include involved nodes with adjacent structures such as vessels and nerves. Tissue from the neck dissection should be divided into its separate anatomical levels and all embedded to assess all nodes in each level. Blocks are carefully recorded to avoid double-counting larger nodes that are present in more than one block. Note that large nodes containing obvious metastatic carcinoma only need to be sampled to identify any extracapsular spread. Larger nodes should be bisected or sliced. If there is obvious metastatic tumour, the half/slice with the more extensive tumour should be processed, together with the perinodal tissues to show the extent of extracapsular spread. One hematoxylin and eosin (H&E) stained section from each block is usually sufficient for routine assessment. The diameter of the largest metastasis should be recorded.

In the intact neck dissection specimens, the component structures should be identified by, for instance, the submandibular salivary gland; the sternocleidomastoid muscle; the omohyoid muscle; the external jugular vein; the spinal accessory nerve; and the tail of the parotid gland. Extended neck dissections may include skin or other structures such as the stylohyoid and digastric muscles. From the deep aspect, identify the internal jugular vein. Lymph nodes are identified by inspection and palpation around the vein and around the submandibular gland and adipose tissue of the anterior and posterior triangles, and are assigned to the appropriate anatomical level (this should be indicated by surgical markers).

A radical neck dissection yields an average of 25 nodes (range 10–30) in the absence of previous chemotherapy or irradiation, although on occasion 50–100 nodes may be identified. This examination would be expected to include, as a minimum, all palpable nodes greater than 3mm in diameter.
Other blocks for histology may include: submandibular gland, jugular vein, cranial nerves and sternocleidomastoid muscle if involved by tumour.

2.7 Frozen sections

The initial diagnosis of malignancy will usually be made before definitive surgery is performed. Intra-operative frozen section diagnosis of the nature of a neoplasm may be required. The assessment of the presence or absence of carcinoma at surgical resection margins is the most common indication for intra-operative frozen section diagnosis. The surgeon selects the tissue for frozen section diagnosis, bearing in mind that it is not usually possible to section material more than 10mm in diameter. Larger pieces of mucosa may be sent especially in plastic reconstruction cases, which may be orientated by suture. These should be inked and sampled with care to examine the true surgical margin.

The report on the frozen section specimen should form part of the final diagnostic report on the case.

2.8 Fine needle aspiration cytology (FNAC) biopsy of thyroid/neck lumps

Generally, only thyroid nodules and persistent lymph nodes >1cm should be evaluated by FNAC, since they have a greater potential to be clinically significant cancers. Occasionally, there may be nodules <1cm that require evaluation because of suspicious ultrasound findings, associated lymphadenopathy, a history of head and neck irradiation, or a history of thyroid cancer in one or more first-degree relatives.

In the presence of a suspicious thyroid nodule, assessment of lateral neck and central neck lymph nodes (more limited due to the presence of the thyroid) must be performed. Detection of abnormal lymph nodes should lead to fine needle aspiration of the lymph nodes. Needle aspiration biopsy is the most accurate method of investigation. Its accuracy is improved by ultrasound guidance. Ultrasonography can also add useful information and can improve accuracy.

Aspirates may be taken by physicians, surgeons, radiologists or pathologists. Palpable masses may be aspirated without image guidance. The results obtained are improved by immediate assessment of adequacy, either by a cytopathologist or a suitably trained biomedical scientist. In this case, the time spent in hospital sites remote from the laboratory should be recognised.

Specimens may be submitted either as directly prepared slides or in a liquid medium. Samples received in liquid should be prepared by the cytospin method, or by techniques appropriate for liquid-based cytology.

Where immediate assessment of adequacy is required, direct air-dried smears should be prepared and stained with a Romanowsky method. For directly prepared slides, all the material should be stained. For liquid specimens, representative samples may be used. Ideally, both Papanicolaou and Romanowsky methods should be employed. H&E staining offers no benefits over Papanicolaou staining and should not be used.

Further investigations are only rarely required but may include immunocytochemistry or flow cytometry. Where immediate assessment is performed, appropriate material for further investigations should be collected based on initial microscopic interpretation.

The report must include a text report. In addition, classification according to the RCPath guidance on reporting of thyroid cytology should be included.
2.9 Quality control

All cancer cases and other selected specimens should be discussed at a specialist head and neck MDT meeting.

2.10 Tissue banking

Several centres across the LCA are accruing tumour tissue, saliva and blood with the appropriate consent from patients with head and neck cancer. This is achieved via established tissue banks in those centres (two websites are referenced below). Standardised tissue accrual across the LCA is to be promoted and encouraged, as this will enable collaborative research and facilitate clinical trials in head and neck cancer.

http://biosampledirectory.ncri.org.uk/collections/90
www1.imperial.ac.uk/tissuebank/

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1 www.rcpath.org/publications-media/publications/datasets/thyroid-cancer.htm
3 www.rcpath.org/publications-media/publications/datasets/thyroid-cancer.htm
4 www.rcpath.org/Resources/RCPath/Migrated%20Resources/Documents/G/g086tpexfoliativecytologyfnacytology.pdf
3 Multidisciplinary Team Membership and Function

The National Institute for Health and Care Excellence’s Improving Outcomes Guidance (IOG) document\(^1\) as well as peer review processes have been in place for a number of years. The composition of head and neck multidisciplinary teams (MDTs) is well laid out nationally, and the pathway group recommends that all Trusts adhere to these guidelines.

All patients with head and neck tumours should be referred to the head and neck MDT for discussion. The head and neck MDT should meet weekly. Patients will be reviewed at the MDT meeting at initial diagnosis and if recurrent tumours are suspected.

There is a single named lead clinician for the MDT, who is a core team member and has responsibilities agreed by the lead clinician of the host Trust. The lead clinician is responsible for chairing the weekly meeting or for agreeing a rotating chair.

The MDT meets on a weekly basis (as a minimum) and discusses all patients with suspected head and neck tumours who are formally referred via the MDT coordinator. A minimum dataset for all patients discussed will be agreed in 2014 by the LCA Head and Neck Pathway Group.

The core members of the MDT include:

- surgeons: each MDT should include three or more designated surgeons, who are likely to be ear, nose and throat (ENT), maxillofacial, or plastic surgeons. It is important that each MDT should include, or have access to, surgeons who are proficient in reconstruction, including microvascular techniques. Each surgeon in the MDT should normally dedicate half of his or her time to head and neck cancer
- clinical oncologists: each MDT should, if possible, include two clinical oncologists, one of whom should always be present at meetings
- a restorative dentist
- pathologists with expertise in both histopathology and cytopathology, who participate in external quality assurance (EQA) schemes
- a radiologist
- clinical nurse specialists (CNSs)
- a speech and language therapist
- senior nursing staff from the head and neck ward
- a palliative care specialist (doctor or nurse), who should work with specialist palliative care services in the community
- a dietitian
- a team secretary to provide clerical support for the MDT, record all decisions made by the team and communicate appropriate information promptly to all those (such as GPs) who may require it
- a data manager to ensure that the MDT has all the relevant details for each meeting, to record details of care plans, and to ensure that data are available for other purposes, such as clinical audit
- an MDT coordinator, who should take responsibility for organising MDT meetings (see below). The coordinator may also take the role of team secretary and/or data manager, but should not be a CNS, since this is not an appropriate use of the CNS’s skills or time.
Within the MDT there is a nominated member responsible for users’ and carers’ issues and information, and a nominated member responsible for ensuring that recruitment into clinical trials and other well-designed studies is integrated into the function of the MDT.

All patients who are discussed should have recent relevant imaging. Details of staging investigations that have been undertaken should be supplied to the MDT coordinator to assist appropriate treatment planning.

During the meeting, the pathology for every patient who has undergone surgery should be discussed. In some cases, additional molecular testing may be requested and the results should be brought back to a subsequent meeting for discussion once the result has been formally agreed.

Clinicians will consider the potential entry of each patient into a clinical trial.

The MDT is also an important forum for establishing the specific needs of a patient. These needs include input from hospital or community specialist palliative care, inpatient therapies, ongoing rehabilitation needs and community therapies. It also provides an opportunity to identify psychological, social and spiritual needs that need ongoing management.

An agreed minimum dataset should be formally recorded during the MDT to reflect clinical workload, accurate patient numbers and a breakdown of tumour types.

A member of the team has responsibility for ensuring that the GP is informed of the MDT’s decision within 24 hours of the meeting, preferably after the decision has been communicated to the patient.

Most patients will be seen in an MDT clinic to discuss the outcome of the meeting and to agree the proposed treatment plan. This clinic should have surgeons skilled in both resection and reconstruction, oncologists, speech and language therapists, dietitians and CNSs. Oral surgeons and restorative dentists should be available in co-located clinics for same-day consultation.

All members of the team who have contact with patients at this point on the pathway should have formal training in advanced communication skills.

It is recommended that resection surgeons spend at least 75% of their time on head and neck cancer. Reconstructive surgeons should undertake at least 25 free flaps per year and should be experienced in a variety of soft tissue and bony flaps. There must be 24 hour/7 days a week emergency cover for potential flap complications.

1 www.nice.org.uk/guidance/csghn
4 Inter-Professional Communication

4.1 General principles

Communication needs to be timely and concise.

The fax-back route/electronic means should be used for urgent communications (meaning those that need to be with the GP within 24 hours) and should be followed up with a telephone call to confirm receipt.

Communications at key points along the patient journey must include:

- what the patient has been told
- who told the patient
- who was there with the patient (e.g. named partner/friend)
- what written/other information was offered
- next steps – when the patient is being seen or treatment started
- actions for the GP – for information only or suggesting specific GP actions (including information for Macmillan or district nursing colleagues)
- named key worker in secondary/tertiary care and any planned changes in key worker
- intent of treatment (curative/palliative)
- any additional information required from the GP (e.g. co-morbidities status)
- summary of medication and alterations to medication
- contact details for further information/discussion
- specialist assessment and intervention summary (e.g. allied health professional (AHP) input)
- treatment plan summary, when created and when amended
- written correspondence to be copied to all appropriate team members who have actions to be undertaken.

4.2 Key communication points

- Diagnosis.
- Multidisciplinary team discussions.
- Clinic appointment reviews.
- Treatment reviews.
- Decision points for changes in care planning.
- Decision point for end-of-life care planning.

The LCA Survivorship Group has recommended the adoption of the National Cancer Survivorship Initiative (NCSI) Treatment Summary. A copy of this document can be found at Appendix 6.

It is recommended that all LCA providers refer to the Improving Outcomes Guidance for MDT set-up details.
5 Clinical Nurse Specialist/Key Worker

The LCA has produced a key worker policy document (see Appendix 3), which should be read in conjunction with this guidance.

All patients seen within the LCA with a diagnosis of a head or neck tumour will be given the name and contact details of a key worker. The key worker will often be a clinical nurse specialist (CNS), but may also be a speech and language therapist, dietitian or prosthetist, where appropriate. It is the responsibility of this key worker to refer on to a new key worker when:

- a patient’s care and follow-up is taken over by another hospital
- a patient’s care is handed over to a community or hospital specialist palliative care team.

All multidisciplinary teams (MDTs) should have one or more trained head and neck cancer CNS to see patients before and after diagnosis, to provide continuing support, and to facilitate communication between the secondary and tertiary care teams (including the MDT), the patient’s GP, the community team and the patient. Patients may have joint key workers (one in the treating Trust and one in the community).

The CNS may act as a key worker, and should be involved in all ‘breaking bad news’ discussions.

The head and neck CNS is involved in all aspects of the disease journey, from diagnosis to end-of-life care, in both outpatient and inpatient settings. The CNS has a pivotal role in the MDT, ensuring that appropriate professionals are involved and working across boundaries in an effort to provide seamless care and support for patients and carers.

The head and neck CNS will play a key role in the following aspects of care:

- the delivery of holistic care
- coordination of care across sectors
- onward referrals to local services
- nurse-led outpatient care
- information giving
- holistic needs assessment
- communicating significant news
- pain control and symptom management in close collaboration with specialist palliative care
- carer support and assessment
- referral for benefits and financial advice
- end-of-life choices.
6 Patient Information

Every patient and family/carer must receive information about their condition in an appropriate format. Verbal and written information should be provided in a way that is clearly understood by patients and free of jargon. It may need to be sourced in the patient’s native language (if English is not their first language) and be delivered with the intervention of an interpreter. In some cases (but not in the communication of bad news), LanguageLine may be a useful tool, as it is widely available within NHS Trusts. Audio and videotaped formats will also be considered. The information should cover:

- description of the disease
- management of the disease
- diagnostic procedures
- treatment options and their effects (including potential adverse effects); any discussion of predicted outcome with patients should take account of their requirements and requests around this information
- drugs and other treatments
- self-management and care
- dietary and nutrition information
- contact details of the patient’s allocated key worker
- support organisations or internet resources recommended by the clinical team.

Information must be given in the most accessible format, based on the patient’s cognitive/communication needs. All patients should have the opportunity to have a relative/carer with them when information is being communicated.

The National Cancer Action Team introduced information prescriptions (IPs) across the country to provide standardised, personalised information for patients and their carers. This is a national resource accessed via the NHS Choices website. If IPs are not available, patients should be provided with (or signposted to) local sources of support, as well as information on cancer charities such as Macmillan Cancer Support. The pathway group will consider standardising written information across the LCA in 2014.
7 Data Collection

Data collection is important to assure and continuously improve standards of care delivered, as well as to provide high-quality clinical databases that serve a number of additional functions. Clinical data repositories enable clinical audit and evaluative research, and facilitate service planning. Furthermore they are a means of supporting informed patient choice of care.

The Data for Head and Neck Oncologists (DaHNO) system provides a continuous electronic comparative audit of the management of head and neck cancer. National head and neck cancer audit allows outcome assessment and provides a tool to improve standards of care, identifying areas of good and weak practice. A number of key areas in head and neck cancer impact on the incidence and outcomes of the disease and form areas for audit:

- prevention
- early presentation
- timely referral from ‘diagnostic’ to ‘therapy’ team
- management by multi-professional specialist teams
- consistent standards and patterns of treatment
- timely access to care.

LCA clinicians will contribute to comparative audit as an essential part of their role and the management of head and neck cancer.

Head and neck cancer audit will continue to be a priority for the LCA, to promote clinical governance and provide assurance to patients and carers of the quality of services provided.

Each multidisciplinary team (MDT) will facilitate all of its professionals to contribute to the audit process in head and neck cancer, and ensure adequate administrative support is available to achieve this.
8 Surgical and Oncological Guidelines

8.1 Generic

Radiotherapy and surgery are the two most frequently used therapeutic modalities in head and neck cancer. For early stage tumours in many sites, surgical excision or radiotherapy have similar cure rates but have different side effect profiles. Radiotherapy traditionally offered higher rates of organ preservation; for some cancers where function is important, it is the treatment of choice. For example, radiotherapy allows preservation of natural speech and swallowing in carcinomas of the larynx and tongue base. At other sites (e.g. carcinoma of the oral cavity), surgical excision alone may be curative and can be associated with a very satisfactory functional outcome. The choice of treatment modality therefore depends on individual factors, including patient preference. It is important to ensure that the patient is involved in all decisions about treatment. The multidisciplinary team (MDT) meeting might suggest a best treatment option, but this and alternatives will always be discussed with the patient.

For advanced squamous cell carcinoma of the head and neck, single modality treatment (either surgery or radiotherapy alone) is associated with poor outcomes. For these tumours, the combined use of surgery and post-operative radiotherapy, or use of combined chemotherapy and radiation schedules, frequently offers the highest chance of achieving cure. In recent years, radiotherapy has benefited from advances in cancer imaging, treatment-planning computer software and developments in radiation-delivery technology. It is now one of the most technology-driven branches of medicine. Typically, head and neck cancer patients will have radiation therapy based on state-of-the-art imaging technology, including CT, MRI, PET or other imaging techniques. Optimisation of treatment planning is performed on high-speed computer software, which intelligently selects the most appropriate beam directions and shapes. Treatment is delivered by computer-driven linear accelerators with sub-millimetre accuracy, allowing radiation to be focused on the tumour-bearing tissues and minimising radiation to normal tissue structures.

Intensity-modulated radiation therapy (IMRT) is a new form of radiation therapy that allows better control of radiation dose delivery in the head and neck. In a randomised trial performed in the UK, IMRT has been shown to reduce radiation-induced xerostomia (the main long-term side effect of standard radiotherapy) from 75% to 39% \((p=0.004)\) at 12 months following treatment. A similar result has been demonstrated for patients with nasopharyngeal cancer. In a large meta-analysis of 93 trials and over 17,000 patients, concomitant chemotherapy (given during radiotherapy) was shown to improve loco-regional control rates and was associated with a 6.5% increase in survival \((p<0.0001)\). The benefits were largely confined to chemotherapy given during radiotherapy, rather than the adjuvant or neo-adjuvant setting. In addition, combining chemotherapy with radiation improves the rates of organ conservation. Cisplatin chemotherapy schedules are the most effective.

More recently, the administration of cetuximab (an anti-epidermal growth factor receptor antibody) concurrently with radiotherapy was shown to increase overall survival and loco-regional control in this setting. This was the first demonstration of activity of a biologically targeted therapy in cancer treatment. In the post-operative setting, two randomised controlled trials have demonstrated that the concomitant use of cisplatin during radiation increases tumour control and overall survival in high-risk patients with positive resection margins or extracapsular lymph node spread.
While concomitant chemotherapy has a proven role in improving outcomes for head and neck cancer, the role of neo-adjuvant chemotherapy remains controversial. Two recent studies suggested that the use of docetaxel, cisplatin and 5-fluorouracil prior to definitive radiotherapy improves survival. The use of non-standard radiotherapy/chemoradiation schedules in these trials has led to uncertainty as to the benefits of this approach when standard chemoradiation is prescribed.

**Recommendations**

Surgery and radiotherapy are the key modalities in the treatment of head and neck cancer.

Conformal radiotherapy planning and chemoradiation techniques should be available in all treatment centres.

IMRT has been shown to reduce long-term xerostomia and should be offered to all appropriate patients.

### 8.2 Tumour-specific pathways

A recently published multidisciplinary management guidelines document\(^1\) provides a consensus opinion on the management of head and neck cancer, based on the experience of UK-based international experts and current evidence in the medical literature. It is robust and evidence based, while being concise and pragmatic. Many clinicians currently working within the LCA contributed, and two were on the editorial team. All centres are advised to refer to these guidelines for the management of patients within the LCA.

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\(^1\) [https://entuk.org/head_neck/h_n_publication](https://entuk.org/head_neck/h_n_publication)
Rehabilitation and Survivorship

Rehabilitation should aim to improve cancer and treatment-related side effects, as well as the patient’s perception of these. Rehabilitation of speech, swallowing and the oral function, and psychological wellbeing are important.

Rehabilitation teams will include nurses, speech therapists, dietitians, physiotherapists, restorative dentists and psychologists. Much of this rehabilitation should be available locally, as well as in the cancer centres. Close liaison between the two is vital.

Access to rehabilitation services should be offered to patients at all stages of the pathway – from assessment and pre-treatment, through the treatment pathway and beyond. It is important that these services remain available beyond the normal oncological follow-up of patients.

The LCA Survivorship Group has recommended the adoption of an holistic needs assessment (HNA) tool (see Appendix 5) based on a distress thermometer and concerns checklist. The LCA has decided to measure its use within 31 days of diagnosis and within 6 weeks of primary treatment of head and neck cancer patients. All patients should be provided with an HNA as part of their initial information pack, so that they are given the choice of whether or not to complete it. The care plan developed following completion of an HNA must be shared with appropriate health and social care professionals after consent from the patient (or carer if acting in the patient’s best interests).
Table 1: Symptoms that could generate referral from survivorship monitoring

<table>
<thead>
<tr>
<th>Symptom/sign</th>
<th>Referrals/assessments/interventions to be considered</th>
</tr>
</thead>
</table>
| Shoulder/accessory nerve problem | Referral to physiotherapy  
Referral to specialist shoulder unit  
Referral back to MDT                                                                |
| Problems with speech             | Referral to speech and language therapist (SLT)  
Laryngectomy patients should maintain lifelong links with local head and neck SLT services |
| Dysphagia                        | Referral to SLT/referral to dietician  
Assessment by SLT  
Assess weight loss  
Dietary modification and dietary advice  
Referral back to MDT                                                                 |
| Trismus                          | Referral to SLT  
Dietary advice  
Referral back to MDT                                                                 |
| Dental problems/ORN              | Referral back to specialist MDT                                                                                      |
| Dry mouth                        | Artificial saliva  
Carry water bottle                                                                                                     |
| Excessive fatigue                | Referral to occupational therapy/physiotherapy for fatigue-management strategies  
Support for family and carers  
Training in management strategies                                                                 |
| Weight changes                   | Consider if steroid related and reduce/increase dose if clinically indicated  
Referral to dietician  
If weight loss related to nausea and vomiting, consider anti-emetics  
If weight gain, consider reducing dietary intake |
| Raised blood sugars              | Referral to diabetic nurse specialist/GP  
Start medication if appropriate  
Monitor blood sugars regularly  
Encourage low sugar diet  
Referral to dietician for dietary advice                                                                 |
| Constipation                     | Regular laxatives  
Encourage oral fluid intake  
Referral to dietician                                                                                                 |
| Anxiety/depression               | Non-pharmacological techniques: counselling, cognitive behaviour therapy, psychologist  
Antidepressant  
Consider psychiatric referral if depression unresponsive to treatment or if suicide risk identified |
10 Palliative Care

10.1 Definition

The World Health Organization (WHO) has defined palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.

It continues that palliative care “is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications”. This philosophy is endorsed in the NHS Cancer Plan and Improving Supportive and Palliative Care for Adults with Cancer.

The General Medical Council guidance Treatment and care towards the end of life: good practice in decision making states that “it is now widely agreed that high-quality treatment and care towards the end of life includes palliative care that focuses on managing pain and other distressing symptoms; providing psychological, social and spiritual support to patients; and supporting those close to the patient. However, it is not always recognised that palliative care can be provided at any stage in the progression of a patient’s illness, not only in the last few days of their life.”

Palliative care of the patient should be provided by both the general teams and specialist palliative care providers, as and when required, in accordance with the National Institute for Health and Care Excellence (NICE) guidance Improving Supportive and Palliative Care for Adults with Cancer.

10.2 Who provides palliative care?

Palliative care is provided by two distinct categories of health and social care professionals:

• those providing the day-to-day care to patients and carers, whether in their homes or in hospitals
• those who specialise in palliative care (consultants in palliative medicine and clinical nurse specialists in palliative care, for example).

Those providing day-to-day or other specialist care should be able to:

• assess the care needs of each patient and their family across the domains of physical, psychological, social spiritual and information needs
• meet those needs within the limits of their knowledge, skills and competence in palliative care
• know when to seek advice from, or refer to, specialist palliative care services.

(National Council for Palliative Care website)

10.3 Consideration of palliative care needs

There are key points in a patient’s illness when their palliative care needs should be specifically considered.

These key points include:

• pre-diagnosis if advanced disease is suspected
• diagnosis
The management of difficult-to-control symptoms involves adequate assessment, appropriate treatment, and adequate re-assessment (i.e. review of the efficacy and tolerability of the treatment).

Specific concern in some head and neck patients approaching end of life are airway compromise and carotid bleeding. Those potential life-ending events should be explicitly discussed with the patient and family (where appropriate) and specific measures and plans put in place.

Depending on the severity or complexity of symptoms, this may prompt referral to the relevant multiprofessional specialist palliative care services.

Within the LCA, specialist palliative care teams offer a consultative service, for all patients, based on physical, psychological, social, emotional or spiritual symptoms or needs, irrespective of diagnosis. Services are available within Trusts, hospices and community settings.

10.4 Referral

Guidance from the LCA Palliative Care Group, regarding referral to specialist palliative care services, advises the following:

1. The patient has active, progressive advanced disease, a limited prognosis, and the focus of care is on quality of life, for example:
   - Potentially fatal conditions where treatment has changed from curative to palliative intent, e.g. cancer, multiple co-morbidities where curative treatment is no longer possible
   - Complex symptom control issues during treatment
   - Treatment available to prolong life but prognosis is uncertain, e.g. advanced chronic obstructive pulmonary disease, advanced heart failure
   - Palliative treatment from the outset with no cure available, e.g. motor neurone disease, multiple systems atrophy, advanced dementia.

2. The patient has unresolved complex needs that cannot be met by the team responsible for the patient’s care. These needs may be physical, psychological, social and/or spiritual. Examples may include complicated symptoms, difficult family situations, or ethical issues, regarding treatment decisions.

If in any doubt, please contact the specialist palliative care team available in all LCA Trusts.

Referral can be made by an appropriate healthcare professional, with the consent of the patient, where the patient has capacity for this consent.
All patients should have contact with a specialist nurse (usually their key worker) from referral into secondary care. Specialist palliative care input should be available, when required, both at the multidisciplinary team meetings and at the initial consultation.

Patients who may benefit from specialist palliative care services should be identified, the referral discussed with the patient and carers, and then referral made as soon as possible.

The specialist palliative care team within each Trust is available for advice about symptom management.

It is also important to consider whether, if it has not been done already, referral should be made to the relevant community specialist palliative care service for ongoing support of the patient at home, following diagnosis in the outpatient department or hospital discharge. Again, the hospital specialist palliative care team can advise.

10.5 Management

LCA specialist palliative care teams have adopted the nationally available Palliative Care Adult Network Guidelines available at: http://book.pallcare.info/

2 www.nice.org.uk/guidance/csgsp
3 www.gmc-uk.org/static/documents/content/Treatment_and_care_towards_the_end_of_life_-_English_0414.pdf
4 www.nice.org.uk/guidance/csgsp
5 www.ncpc.org.uk/palliative-care-explained
11 Patient Experience/Satisfaction

“Patient experience is only as good as the weakest point in the patient pathway.”

Cancer services should be patient centred and should respond to patient and carer feedback. Excellent communication between professionals and patients is particularly important to improve patient satisfaction.

Positive patient experience is central to meeting the holistic care needs of the head and neck patient and their family/carers. All head and neck services should conduct an annual patient experience exercise. Services could consider gaining feedback on the patient experience using patient focus and support groups, one-to-one interviews and patient stories.

Key themes to explore include the patient pathway from first contact with the service through to onward referral, as appropriate. These should include:

- pre-diagnosis
- diagnosis
- surgical
- oncology
- key worker
- rehabilitation
- community support
- supportive and palliative care.

All health and social care staff working with patients, families and carers need communication skills training. The National Institute for Health and Care Excellence (NICE) guidelines identify four levels of communication training. There is evidence that all staff involved benefit from level 1 training, and this can impact on the patients’ experience (for example, the Sage and Thyme model for assisting people in distress).

All services should ensure that they provide the following:

- a local mechanism for collecting information from patients on every aspect of the patient pathway
- a mechanism for reviewing and reflecting any information regarding the patient experience from local and/or national data
- evidence of responding to feedback from patients on their experience.

---

1 NHS (2010), A Model of Care for Cancer Services, Clinical paper.
4 Moore PM, Wilkinson SSM and Rivera Mercado S (2004), Communication skills training for health care professionals working with cancer patients, their families and/or carers, Cochrane Database of Systematic Reviews 2: CD003751
12 Treatment of Teenagers and Young Adults

The Improving Outcomes in Children and Young People with Cancer (NICE, 2005) and the subsequent Manual for Cancer Services: Teenage and Young Adults Measures (Department of Health, 2013) recommend that patients aged 16–18 are managed at a principal treatment centre (PTC) for teenager and young adult (TYA) cancers and that those aged 19–24 are given the choice of being managed at a PTC or TYA designated hospital.

- The PTC for TYA for South Thames is The Royal Marsden (Surrey site).
- The PTC for North Thames (including North West London) is University College London Hospitals.

All patients within this age range, regardless of place of care, should be referred to the TYA multidisciplinary team (MDT) at the relevant PTC. Referral to the MDT should be made using the TYA referral form (see below) which can be found on the London Cancer Alliance (LCA) website: [www.londoncanceralliance.nhs.uk/media/68982/TYA%20MDT%20proforma%20March%202014.doc](http://www.londoncanceralliance.nhs.uk/media/68982/TYA%20MDT%20proforma%20March%202014.doc).

Discussion at the TYA MDT is in addition to the site-specific MDT (SSMDT); key functions of the TYA MDT are to agree the treatment plan of the SSMDT, ensure cancer registration and provide a psychosocial care plan. Members of the SSMDT or TYA service at the PTC or TYA designated hospitals are invited to attend the TYA MDT either remotely or in person.

**South Thames PTC contacts**

<table>
<thead>
<tr>
<th>The Royal Marsden NHS Foundation Trust</th>
<th>Lead Clinician – Dr Julia Chisholm <a href="mailto:julia.chisholm@rmh.nhs.uk">julia.chisholm@rmh.nhs.uk</a></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>TCT Nurse Consultant for Adolescents and Young Adults – Louise Soanes <a href="mailto:lsoanes@nhs.net">lsoanes@nhs.net</a></td>
</tr>
</tbody>
</table>

**London Cancer Alliance TYA designated centre contacts allied to The Royal Marsden PTC**

<table>
<thead>
<tr>
<th>Joint Centre (Guy’s and St Thomas’ NHS Foundation Trust/King’s College Hospital NHS Foundation Trust)</th>
<th>Guy’s and St Thomas’</th>
<th>Lead Clinician – Dr Robert Carr <a href="mailto:Robert.carr@gstt.nhs.uk">Robert.carr@gstt.nhs.uk</a></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Lead Nurse – Gavin Maynard-Wyatt <a href="mailto:Gavin.maynard-wyatt@gstt.nhs.uk">Gavin.maynard-wyatt@gstt.nhs.uk</a></td>
<td></td>
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</tbody>
</table>

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<tr>
<th>Joint Centre (Guy’s and St Thomas’ NHS Foundation Trust/ King’s College Hospital NHS Foundation Trust)</th>
<th>King’s College Hospital</th>
<th>Lead Clinician – Dr Donal McLornan <a href="mailto:donal.mclornan@nhs.net">donal.mclornan@nhs.net</a></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Lead Nurse – Gavin Maynard-Wyatt <a href="mailto:Gavin.maynard-wyatt@gstt.nhs.uk">Gavin.maynard-wyatt@gstt.nhs.uk</a></td>
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<table>
<thead>
<tr>
<th>St George’s Healthcare NHS Trust</th>
<th>St George’s Hospital</th>
<th>Lead Clinician – Dr Jens Samol <a href="mailto:jens.samol@stgeorges.nhs.uk">jens.samol@stgeorges.nhs.uk</a></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Lead Nurse – Linda Shephard <a href="mailto:Linda.shephard@stgeorges.nhs.uk">Linda.shephard@stgeorges.nhs.uk</a></td>
<td></td>
</tr>
</tbody>
</table>
North Thames PTC contacts

| University College London Hospitals | Lead Clinician – Dr Rachael Hough Rachael.hough@uclh.nhs.uk | TCT Nurse Consultant for Teenagers and Young Adults – Wendy King wendy.king@uclh.nhs.uk |

London Cancer Alliance TYA designated centre contacts allied to University College London Hospitals PTC

| Chelsea and Westminster Hospital NHS Foundation Trust | Chelsea and Westminster (HIV and skin only) | Lead Clinician – Dr Mark Bower (interim) Mark.Bower@chelwest.nhs.uk | Lead Nurse – Kate Shaw (interim) Kate.Shaw@chelwest.nhs.uk |
| Imperial College Healthcare NHS Trust | Charing Cross | Lead Clinician – Dr Josu de la Fuente (deputy) j.delafuente@imperial.ac.uk | Lead Nurse – Sinead Cope sinead.cope@imperial.nhs.uk |
| East and North Hertfordshire NHS Trust | Mount Vernon Cancer Centre | Lead Clinician – Dr Gordon Rustin grustin@nhs.net | Lead Nurse – Laura Miles laura.miles@nhs.net |
Appendix 1: Urgent Suspected Head and Neck Cancer Referral Forms

South West London Referral Form

SOUTH WEST LONDON CANCER NETWORK  Suspected Head and Neck Cancers Referral Form  (NICE 2006)

Urgent Referrals Criteria
(Please tick category)

HN 1 Any patient with persistent symptoms or signs related to the oral cavity, which does not resolve within
• weeks should be referred urgently – unless clearly benign.

HN 2 Patients with unexplained red and white patches (including suspected lichen planus) of the oral mucosa
• Painful or
• Swollen or
• Bleeding

HN 3 Unexplained oral ulceration or mass of 3 weeks duration or more need urgent referral.

HN 4 Hoarseness of more than 3 weeks (with normal chest x-ray)

HN 5 Persistent, unexplained parotid or submandibular gland swellings

HN 6 Persistent, unexplained sore or painful throat

HN 7 Unilateral head or neck pain for more than 4 weeks

HN 8 Thyroid swelling with any of the following
• Solitary nodule increasing in size
• History of neck radiation
• Family History of an endocrine tumour
• Unexplained hoarseness or voice changes
• Cervical lymphadenopathy
• Pre-pubertal patients
• Patients aged 65+

Patient Awareness Questions
1. Has the patient been made aware of the nature of their referral? Yes  No
2. Has the patient been supplied with supportive information about the Urgent Suspected Cancer referral process? Yes  No
3. Have you asked the patient if they will be available to attend an appointment within the next two weeks? Yes  No
4. Has the patient indicated to you that they would be available to attend an appointment within the next two weeks? Yes  No

Date of GP decision to refer:
No of pages faxed:

GP DETAILS

GP Name & Initials:
Address:
Telephone No:
Fax No:

Post Code:

GP Practice Code:

PATIENT DETAILS

Last Name:
Address:
Daytime Tel or Mobile:
Date of Birth:
Interpreter required? Y  N
Gender:  M  F

Address:

Language:
Ethnicity:

Hospital No:

NHS No:

COMMENTS/OTHER REASONS FOR URGENT REFERRAL

Patient Awareness Questions:

SOUTH WEST LONDON CANCER NETWORK

How to make urgent referrals for suspected head and neck cancers

Please FAX/EMAIL this form to the Cancer Office at the relevant hospital, with or without an accompanying letter. Emails MUST be sent from a NHS.net address. Please ensure that the referral reaches the hospital within 24 hours of the GPs decision to refer date.
South East London Referral Form – Thyroid

SOUTH EAST LONDON CANCER NETWORK
Thyroid Urgent Suspected Cancer Referral

Please tick the box of the hospital clinic you are referring to and fax this form to the relevant Urgent Referral Team within 24 hours. Guidelines are on the reverse side.

- Princess Royal
  Fax: 01689 863187
  Tel: 01689 865676
- Queen Elizabeth
  Fax: 020 8836 4035
  Tel: 020 8836 5964/5
- Guy’s & St Thomas’
  Fax: 020 7188 0923
  Tel: 020 7188 0902
- King’s College
  Fax: 020 3299 1515
  Tel: 020 3299 1516
- Lewisham
  Fax: 020 8333 3451
  Tel: 020 8333 3450
- Queen Mary’s
  Fax: 020 8308 9264
  Tel: 020 8308 3230

SECTION 1 – PATIENT INFORMATION. PLEASE COMPLETE IN BLOCK CAPITALS.

<table>
<thead>
<tr>
<th>SURNAME</th>
<th>Patient visited this hospital before? Y / N</th>
</tr>
</thead>
<tbody>
<tr>
<td>FIRST NAME</td>
<td>NHS Number</td>
</tr>
<tr>
<td>Gender</td>
<td>M / F</td>
</tr>
<tr>
<td>Address</td>
<td>Post Code</td>
</tr>
<tr>
<td>Interpreter required? Y / N</td>
<td>Transport required? Y / N</td>
</tr>
<tr>
<td>Daytime Telephone</td>
<td>Home Telephone (if different) / Mobile No.</td>
</tr>
</tbody>
</table>

SECTION 2 – PRACTICE INFORMATION. USE PRACTICE STAMP IF AVAILABLE.

<table>
<thead>
<tr>
<th>Referring GP</th>
<th>Date of referral</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practice Address</td>
<td>Telephone</td>
</tr>
<tr>
<td>Post Code</td>
<td>Fax</td>
</tr>
</tbody>
</table>

SECTION 3 – CLINICAL INFORMATION. PLEASE TICK THE RELEVANT BOXES.

Symptoms & History
- A thyroid nodule associated with any of the following...
  - Solitary / dominant nodule increasing by >1cm in last 3 - 6 months
  - Firm / immobile nodule
  - Unexplained hoarseness or voice changes
  - Cervical lymphadenopathy
  - Other (please specify)
- History of neck irradiation
- Family history of endocrine tumour or MEN
- Previous diagnosis / family history of thyroid cancer
- Very young (pre-pubertal) patient
- Patient aged 65 years and older

Additional information - Attach patient computer record summary if available. Continue on separate sheet if required.
SOUTH EAST LONDON CANCER NETWORK
Information to support Thyroid referrals

Refer urgently patients with:

- A thyroid nodule associated with any of the following:
  - A solitary or dominant nodule increasing by more than 1cm in the last 3 – 6 months.
  - A firm or immobile nodule.
  - Unexplained hoarseness or voice changes.
  - Cervical lymphadenopathy.
  - A history of neck irradiation.
  - A family history of an endocrine tumour or Multiple Endocrine Neoplasia (MEN).
  - Previous diagnosis / family history of thyroid cancer.
  - Very young (pre-pubertal) patient.
  - Patient aged 65 years and older.

Use this proforma to refer urgently (2 Week Wait)

Refer immediately (acute admission) patients:

- A thyroid swelling rapidly increasing over days or weeks.
- With recent onset of tracheal compression including stridor due to thyroid swelling.

Phone the Thyroid / ENT team at your local hospital to arrange admission

Patient information and support:

Consider the information and support needs of patients and the people who care for them while they are waiting for the referral appointment. Resources for GPs to use are available from the Cancer Network on 020 7188 7090, or visit our website www.selcn.nhs.uk.

Approved by the South East London Cancer Network in November 2006.
For comments or additional copies contact the Network on Tel 020 7188 7090 / Fax 020 7188 7120, or visit our website: www.selcn.nhs.uk.
North West London Referral Form – Head and Neck

**URGENT SUSPECTED HEAD and NECK CANCER REFERAL FORM**

**PLEASE ENSURE THAT THIS FORM IS ATTACHED TO YOUR CHOOSE AND BOOK REFERRAL**

Consultant/Hospital to which patient is being referred:

<table>
<thead>
<tr>
<th>Patient details</th>
<th>GP / GDP Details (please circle)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS No</td>
<td>Dr:</td>
</tr>
<tr>
<td>Surname:</td>
<td>Address:</td>
</tr>
<tr>
<td>First Name:</td>
<td>Tel:</td>
</tr>
<tr>
<td>Age / D.O.B:</td>
<td>Fax:</td>
</tr>
<tr>
<td>Address:</td>
<td>Email:</td>
</tr>
<tr>
<td>Postcode:</td>
<td>Date of decision to refer:</td>
</tr>
<tr>
<td>Tel day:</td>
<td>Tel evening/mobile:</td>
</tr>
<tr>
<td>Signature:</td>
<td></td>
</tr>
</tbody>
</table>

**Details of Patient’s GP** *(for General Dental Practitioner Referrals):*

<table>
<thead>
<tr>
<th>Dr:</th>
<th>Address:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tel:</td>
<td></td>
</tr>
</tbody>
</table>

- Have you told the patient that you suspect Head and Neck cancer? **Y / N**
- Have you given the patient the 2WW information leaflet **Y / N**
- Have you told the patient they will be seen within 2 weeks? **Y / N**
- Has the patient had a previous diagnosis of cancer? **Y / N** *(Specify if known)*
- Has the patient previously visited this hospital? **Y / N**
- Hospital number *(if known)*: **                      **
- First language: **                      **
- Interpreter required? **Y / N**

**Symptoms and Clinical Findings**

For suspected thyroid cancer, please use specific Thyroid 2ww form

**CANCER AREA SUSPECTED** *(please tick as appropriate)*

<table>
<thead>
<tr>
<th>Oral Cavity</th>
<th>Larynx</th>
<th>Pharynx</th>
<th>Salivary Gland</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sinus</td>
<td>Lip</td>
<td>Nose</td>
<td></td>
</tr>
</tbody>
</table>

**RISK FACTORS**

| Smoker | Ex-smoker | Chews Tobacco / Paan / Betel | * Alcohol units consumed per week | 

<table>
<thead>
<tr>
<th>Lump in neck &gt; 3 weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hoarseness (refer smokers immediately, otherwise refer if for more than 4 weeks with normal CXR)</td>
</tr>
<tr>
<td>Otalgia / sore throat (&gt; 3 weeks, no other cause)</td>
</tr>
<tr>
<td>Ulcer/mass in oral cavity (no other cause)</td>
</tr>
<tr>
<td>Dysphagia</td>
</tr>
<tr>
<td>Red and/or white patches on oral mucosa (especially if plus Pain, Bleeding, Swelling)</td>
</tr>
<tr>
<td>Unexplained tooth mobility &gt; 3 weeks</td>
</tr>
</tbody>
</table>

**STRIDOR – Refer immediately**

**P.T.O.**

---

Please ensure this form is received in the Trust within 24 hours of GP or Dental decision to refer

Latest version of the form is available at [www.nwcn.nhs.uk](http://www.nwcn.nhs.uk)

Version 3.8
### Additional Clinical Information:
Include any investigations arranged or results obtained, and any other information you think relevant

* Alcohol units per drink:
  The NHS recommends men should not regularly drink more than 3-4 units a day and women should not regularly drink more than 2-3 units a day. ‘Regularly’ in this context means drinking at this sort of level every day or most days of the week. Please refer to [http://www.nhs.uk/tools/pages/nhsalcoholtracker.aspx](http://www.nhs.uk/tools/pages/nhsalcoholtracker.aspx) to calculate number of units in various alcoholic drinks.

<table>
<thead>
<tr>
<th>North West London Hospitals NHS Trust</th>
<th>Ealing Hospital NHS Trust</th>
<th>Imperial College Healthcare NHS Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fax: 020 8235 4188</td>
<td>Fax: 020 8967 5005</td>
<td>Fax: 020 3312 1580</td>
</tr>
<tr>
<td>Tel: 020 8235 4293</td>
<td>Tel: 020 8967 5000, x 3921</td>
<td>Tel: 020 3312 1527</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hillingdon Hospital NHS Trust</td>
<td>West Middlesex University Hospital NHS Trust</td>
<td>The Royal Marsden NHS Foundation Trust</td>
</tr>
<tr>
<td>2WW fax line : 01895 279807</td>
<td>Fax: 020 8321 5157</td>
<td>Fax: 020 8661 3149</td>
</tr>
<tr>
<td>(Maxillofacial)</td>
<td>Tel: 020 8321 6776</td>
<td>Tel: 0800 731 2325</td>
</tr>
<tr>
<td>Alternante Fax: 01895 279538</td>
<td></td>
<td>Email: <a href="mailto:rmh-tr.referrals@nhs.net">rmh-tr.referrals@nhs.net</a></td>
</tr>
<tr>
<td>Tel: 01895 279256</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(ENT)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alternante Fax: 01895 279408</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tel: 01895 279715</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please ensure this form is received in the Trust within 24 hours of GP or Dental decision to refer.

Latest version of the form is available at [www.nwlcn.nhs.uk](http://www.nwlcn.nhs.uk)

Version 3.8
### URGENT SUSPECTED THYROID CANCER REFERRAL FORM

Please ensure that this form is attached to your choose and book referral

<table>
<thead>
<tr>
<th>Hospital to which patient is being referred:</th>
</tr>
</thead>
</table>

#### Patient details

<table>
<thead>
<tr>
<th>NHS No:</th>
<th>Dr:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surname:</td>
<td>Address:</td>
</tr>
<tr>
<td>First Name:</td>
<td></td>
</tr>
<tr>
<td>Age / D.O.B:</td>
<td>Tel:</td>
</tr>
<tr>
<td>Address:</td>
<td>Fax:</td>
</tr>
<tr>
<td>Postcode:</td>
<td>Email:</td>
</tr>
<tr>
<td>Tel day:</td>
<td></td>
</tr>
<tr>
<td>Tel eve:</td>
<td>Date of decision to refer:</td>
</tr>
</tbody>
</table>

#### GP Details

| Have you informed the patient that you suspect thyroid cancer? | Y / N |
| Have you given the patient the 2WW information leaflet | Y / N |
| Have you told the patient they will be seen within 2 weeks? | Y / N |
| Has the patient had a previous diagnosis of cancer? | Y / N (Specify if known) |
| Has the patient previously visited this hospital? | Y / N |
| Hospital number (if known): | |
| First language: | |
| Interpreter required? | Y / N |

#### Symptoms and Clinical Findings

- [ ] Solitary / dominant nodule increasing by >1cm in last 3 - 6 months
- [ ] Firm / immobile nodule
- [ ] Unexplained hoarseness or voice changes
- [ ] Cervical lymphadenopathy
- [ ] Other (please specify)
- [ ] History of neck irradiation
- [ ] Family history of endocrine tumour or MEN
- [ ] Previous diagnosis / family history of thyroid cancer
- [ ] Very young (pre-pubertal) patient
- [ ] Patient aged 65 years and older

#### Additional Information: Include any investigations arranged or results obtained and any other information you think is relevant.

Continue on a separate sheet if necessary ensuring patient details and referring doctor's name are on additional sheets.

Please ensure this form is received in the Trust within 24 hours of GP decision to refer

Latest version of the form is available at www.nwlcn.nhs.uk

version 1.4
Information to support Thyroid referrals

Refer patients urgently with:

- A thyroid nodule associated with any of the following:
  - A solitary or dominant nodule increasing by more than 1cm in the last 3 – 6 months.
  - A firm or immobile nodule.
  - Unexplained hoarseness or voice changes.
  - Cervical lymphadenopathy.
  - A history of neck irradiation.
  - A family history of an endocrine tumour or Multiple Endocrine Neoplasia (MEN).
  - Previous diagnosis / family history of thyroid cancer.
  - Patients under 18 years must be seen at St Mary’s only.
  - Patient aged 65 years and older.

Refer immediately (acute admission) patients:

- A thyroid swelling rapidly increasing over days or weeks.
- With recent onset of tracheal compression including stridor due to thyroid swelling.

Phone the Thyroid team at your local hospital to arrange admission

<table>
<thead>
<tr>
<th>North West London Hospitals NHS Trust</th>
<th>Imperial College Healthcare NHS Trust</th>
<th>Chelsea and Westminster NHS Foundation Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fax: 020 8235 4189</td>
<td>Fax: 020 3312 1580</td>
<td>Fax: 020 3315 8814</td>
</tr>
<tr>
<td>Tel: 020 8235 4200</td>
<td>Tel: 020 3312 1527</td>
<td>Tel: 020 3315 2027</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ealing Hospital NHS Trust</th>
<th>Hillingdon Hospital NHS Trust</th>
<th>West Middlesex University Hospital NHS Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fax: 020 8967 5005</td>
<td>2WW dedicated fax line: 01895 279807</td>
<td>Fax: 020 8321 5157</td>
</tr>
<tr>
<td>Tel: 020 8967 5000, x3921</td>
<td>Alternate Fax: 01895 279408</td>
<td>Tel: 020 8321 6776</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The Royal Marsden NHS Foundation Trust</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Fax: 020 8661 3149</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tel: 0800 731 2325</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Email: <a href="mailto:rmh-tr.referrals@nhs.net">rmh-tr.referrals@nhs.net</a></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please ensure this form is received in the Trust within 24 hours of GP decision to refer
Latest version of the form is available at [www.nwlcn.nhs.uk](http://www.nwlcn.nhs.uk)
version 1.4
Appendix 2: NCSI Treatment Summary

Dear Dr X

Re: Add in patient name, address, date of birth and record number

Your patient has now completed their initial treatment for cancer and a summary of their diagnosis, treatment and on-going management plan are outlined below. The patient has a copy of this summary.

<table>
<thead>
<tr>
<th>Diagnosis:</th>
<th>Date of Diagnosis:</th>
<th>Organ/Staging</th>
<th>Local/Distant</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Summary of Treatment and relevant dates:

<table>
<thead>
<tr>
<th>Treatment Aim:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Possible treatment toxicities and / or late effects:

<table>
<thead>
<tr>
<th>Advice entry onto primary care palliative or supportive care register</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes / No</td>
</tr>
</tbody>
</table>

DS 1500 application completed

<table>
<thead>
<tr>
<th>Prescription Charge exemption arranged</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes/No</td>
</tr>
</tbody>
</table>

Alert Symptoms that require referral back to specialist team:

<table>
<thead>
<tr>
<th>Contacts for re referrals or queries:</th>
</tr>
</thead>
<tbody>
<tr>
<td>In Hours:</td>
</tr>
<tr>
<td>Out of hours:</td>
</tr>
</tbody>
</table>

Other service referrals made: (delete as nec)

<table>
<thead>
<tr>
<th>District Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>AHP</td>
</tr>
<tr>
<td>Social Worker</td>
</tr>
<tr>
<td>Dietician</td>
</tr>
<tr>
<td>Clinical Nurse Specialist</td>
</tr>
<tr>
<td>Psychologist</td>
</tr>
<tr>
<td>Benefits/Advice Service</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

Secondary Care Ongoing Management Plan: (tests, appointments etc)

Required GP actions in addition to GP Cancer Care Review (e.g. ongoing medication, osteoporosis and cardiac screening)

Summary of information given to the patient about their cancer and future progress:

Additional information including issues relating to lifestyle and support needs:

Completing Doctor:  
Signature:  
Date:  

40
### GP READ CODES FOR COMMON CANCERS (For GP Use only). Other codes available if required. (Note: System codes are case sensitive so always ensure codes are transcribed exactly as below).

<table>
<thead>
<tr>
<th>System 1</th>
<th>(5 digit codes)</th>
<th>All other systems</th>
<th>Version 3 five byte codes (October 2010 release)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis:</strong></td>
<td></td>
<td><strong>Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Lung Malignant Tumour</td>
<td>XaOKG</td>
<td>Malignant neoplasm of bronchus or lung</td>
<td>B22z.</td>
</tr>
<tr>
<td>Carcinoma of Prostate</td>
<td>X78y6</td>
<td>Malignant neoplasm of prostate</td>
<td>B46..</td>
</tr>
<tr>
<td>Malignant tumour of rectum</td>
<td>XE1vW</td>
<td>Malignant neoplasm of Rectum</td>
<td>B141.</td>
</tr>
<tr>
<td>Bowel Intestine</td>
<td>X78gK</td>
<td>Malignant neoplasm of Colon</td>
<td>B13..</td>
</tr>
<tr>
<td>Large Bowel</td>
<td>X78gN</td>
<td>Malignant neoplasm of female breast</td>
<td>B34..</td>
</tr>
<tr>
<td>Female Malignant Neoplasia</td>
<td>B34..</td>
<td>Malignant neoplasm of male breast</td>
<td>B35..</td>
</tr>
<tr>
<td>Male Malignant Neoplasia</td>
<td>B35..</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Histology/Staging/Grade:</strong></td>
<td><strong>Histology/Staging/Grade:</strong></td>
<td><strong>Histology/Staging/Grade:</strong></td>
<td></td>
</tr>
<tr>
<td>Tumour grade</td>
<td>X7A6m</td>
<td>Tumour staging</td>
<td>4M..</td>
</tr>
<tr>
<td>Dukes/Gleason tumour stage</td>
<td>XaOLF</td>
<td>Gleason grading of prostate Ca</td>
<td>4M0..</td>
</tr>
<tr>
<td>Recurrent tumour</td>
<td>XaOR3</td>
<td>Recurrence of tumour</td>
<td>4M6..</td>
</tr>
<tr>
<td>Local Tumour Spread</td>
<td>X7818</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mets from 1°</td>
<td>XaFr.</td>
<td>Metastatic NOS</td>
<td>B13.</td>
</tr>
<tr>
<td><strong>Treatment:</strong></td>
<td><strong>Treatment:</strong></td>
<td><strong>Treatment:</strong></td>
<td></td>
</tr>
<tr>
<td>Palliative Radiotherapy</td>
<td>5149.</td>
<td>Radiotherapy tumour palliation</td>
<td>5149.</td>
</tr>
<tr>
<td>Curative Radiotherapy</td>
<td>XalpH</td>
<td>Radiotherapy</td>
<td>7M371</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>x71bL</td>
<td>Chemotherapy</td>
<td>8BAD.</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>Xa851</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Treatment Aim:</strong></td>
<td><strong>Treatment Aim:</strong></td>
<td><strong>Treatment Aim:</strong></td>
<td></td>
</tr>
<tr>
<td>Curative procedure</td>
<td>Xallm</td>
<td>Curative treatment</td>
<td>8BJ0.</td>
</tr>
<tr>
<td>Palliative procedure</td>
<td>Xail3</td>
<td>Palliative treatment</td>
<td>8BJ1.</td>
</tr>
<tr>
<td><strong>Treatment toxicities/late effects:</strong></td>
<td><strong>Ongoing Management Plan:</strong></td>
<td><strong>Ongoing Management Plan:</strong></td>
<td></td>
</tr>
<tr>
<td>Osteoporotic #</td>
<td>Xa1TO</td>
<td>At risk of osteoporosis</td>
<td>1409.</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>XaELC</td>
<td>Osteoporosis</td>
<td>N330.</td>
</tr>
<tr>
<td>Infection</td>
<td>Xa9ua</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ongoing Management Plan:</strong></td>
<td><strong>Ongoing Management Plan:</strong></td>
<td><strong>Ongoing Management Plan:</strong></td>
<td></td>
</tr>
<tr>
<td>Follow up arranged (&lt;1yr)</td>
<td>8H8..</td>
<td>Follow up arranged</td>
<td>8H8..</td>
</tr>
<tr>
<td>Follow up arranged (&gt;1yr)</td>
<td>XaL..</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No FU</td>
<td>8HA1.</td>
<td>No follow up arranged</td>
<td>8HA..</td>
</tr>
<tr>
<td>Referral PRN</td>
<td>8HAZ.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Referrals made to other services:</strong></td>
<td><strong>Referrals made to other services:</strong></td>
<td><strong>Referrals made to other services:</strong></td>
<td></td>
</tr>
<tr>
<td>District Nurse</td>
<td>Xa8sn</td>
<td>Refer to District Nurse</td>
<td>8H72.</td>
</tr>
<tr>
<td>Social Worker</td>
<td>Xa8sr</td>
<td>Refer to Social Worker</td>
<td>8H75.</td>
</tr>
<tr>
<td>Nurse Specialist</td>
<td>XaAgq</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SALT</td>
<td>XaBT6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Actions required by the GP</td>
<td>Actions required by the GP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------</td>
<td>-----------------------------------</td>
<td></td>
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</tr>
<tr>
<td>Tumour marker monitoring</td>
<td>PSA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSA</td>
<td>Osteoporosis monitoring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Osteoporosis monitoring</td>
<td>Referral for specialist opinion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral for specialist opinion</td>
<td>Advised to apply for free</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advised to apply for free prescriptions</td>
<td>Tumour marker monitoring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tumour marker monitoring</td>
<td>PSA</td>
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<td></td>
</tr>
<tr>
<td>PSA</td>
<td>Osteoporosis monitoring</td>
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</tr>
<tr>
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<td>Referral for specialist opinion</td>
<td></td>
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</tr>
<tr>
<td>Referral for specialist opinion</td>
<td>Advised to apply for free</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advised to apply for free prescriptions</td>
<td>Tumour marker monitoring</td>
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<tr>
<td>Carers details</td>
<td>Carer details</td>
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Appendix 3: LCA Key Worker Policy

Definition
A key worker is a person who, with the patient’s consent and agreement, takes a key role in coordinating the patient’s care and promoting continuity, ensuring the patient knows who to access for information and advice in relation to their cancer diagnosis. In addition, the key worker will facilitate patients making informed decisions about their treatment.

The implementation of the key worker role is a requirement of the National Cancer Peer Review Programme and detailed in the Manual for Cancer Services, originally published by the National Cancer Action Team (NCAT), and related site-specific Improving Outcomes Guidance, issued by the National Institute for Health and Care Excellence (NICE).

Principles and responsibilities

Designation
1. The key worker is a named clinical member of the site-specific multidisciplinary team (MDT), and acts as the point of contact between the patient and MDT.
2. The key worker is a healthcare professional.
3. The key worker is assigned by the core clinical nurse specialist of an MDT, agreed by the MDT and recorded within the patient record and multidisciplinary meeting proforma.
4. The name of the key worker, designation and contact details will also be recorded in the patient handheld record (PHR), if used, and included in all correspondence and in the patient medical records. All entries in the medical notes will comply with the NHS Litigation Authority standards.

Access
5. All cancer patients will be made aware of their allocated key worker, but have the right to ask for an alternative if they prefer. This will usually happen at diagnosis.
6. The key worker will provide a contact number to all the patients for whom they act as the key worker.

Multi-professional communication
7. If a more appropriate person is identified as a key worker at a point in the patient’s pathway, this will be discussed and agreed by the patient and the new key worker, and recorded in the patient’s notes. This situation is most likely to arise with referral to the specialist palliative care team. In such cases the specialist palliative care clinical nurse specialist will check if a key worker has already been identified for the patient by the relevant tumour MDT. The specialist palliative care clinical nurse specialist will then negotiate and document care responsibilities in the patient’s notes.
8. The key worker may change as patients pass through various stages of the care trajectory or when care is transferred to a different Trust. It is the responsibility of the key worker to hand over to the next one, to document this in the patient’s notes and to keep the patient informed.
9. The key worker will lead on patient communication issues and coordination of the pathway for patients referred to the team.

10. The key worker will ensure that the patient pathway is coordinated and that all relevant information is transferred to the appropriate professionals as the patient moves across care boundaries, e.g. on admission to and discharge from institutions, when care is transferred between teams.

11. The key worker has responsibility for ensuring holistic needs assessments (HNAs) are recorded/documentated in patient records.

**Patient communication and support**

12. Where possible, the key worker will be available to support the patient on diagnosis to signpost and provide them with information and contacts for the MDT, national information and support services, self-help groups and associated site-specific support.

13. If the key worker is not available at the time of diagnosis, the person who is providing support at the time will ensure that the patient is aware of the key worker role and provide the relevant contact details.

14. The key worker will be accessible to the patient as a constant point of contact, handing over to colleagues when unavailable and making sure that the patient has clear information about alternative contacts and cover arrangements.

15. The key worker will provide information, care and support throughout the patient journey **regardless of the patient’s condition**, liaising between health professionals to ensure continuity of care and a seamless service.

**Data/audit**

16. The key worker will contribute to the audit of the key worker role in their organisation.

**Annex A**

**NCAT peer review standard**

There should be an operational policy whereby a single named key worker for the patient’s care at a given time is identified by the MDT members for each individual patient and the name and contact number of the current key worker is recorded in the patient’s case notes. The responsibility for ensuring that the key worker is identified should be that of the nurse MDT member(s).

The above policy should have been implemented for patients who came under the MDT’s care after publication of these measures and who are under their care at the time of the peer review visit.

**Notes**

- According to the NICE supportive and palliative care guidance, a key worker is a person who, with the patient’s consent and agreement, takes a key role in coordinating the patient’s care and promoting continuity, e.g. ensuring that the patient knows who to access for information and advice. This is not intended to have the same connotation as the key worker in social work.

- It may be necessary to agree a single key worker across both a cancer site-specific MDT and the specialist palliative care MDT for certain patients.
Appendix 4: Competencies for Key Worker Role

• Work as an integral member of the multidisciplinary team (MDT) to ensure continuity of patient care.
• Initiate and participate in case conferences with all professionals involved in the delivery of patient care.
• Communicate and coordinate information to patients and carers, evaluating their levels of understanding and utilising a range of skills/techniques to overcome any communication difficulties.
• Demonstrate ability to verbally summarise patient information to facilitate understanding.
• Act as an advocate for the patient.
• Act as a communication resource and coordinator for other members of the MDT in the care of the key worker’s patient caseload.
• In conjunction with the MDT, provide patients with comprehensive information on the options available to them for treatment and care. Utilise their specialist knowledge and skills regarding disclosure of information.
• Coordinate the onward referral of patient and/or family members to appropriate clinical or support services.
• Ensure accurate follow-up documentation is maintained, including any changes in the named key worker.
• Utilise support strategies and interventions available to care for patients with complex needs, for example patients exhibiting denial/anger following a cancer diagnosis, adverse reactions to alteration in body image or reaching end of life.
• Demonstrate knowledge of holistic care relating to areas across the patient journey such as screening, curative and palliative treatment, spiritual care, aspects of nutrition and pharmacology, rehabilitation, discharge and collaborative working.
• Initiate appropriate referral or access to sources of specialist support for those experiencing, for example, sexual difficulties as a result of their illness or treatment.
• Utilise all forms of patient information to enable the patient to have a better understanding of their diagnosis and treatment plan. This will include the use of specific resources for patient/carers from minority groups.
• Facilitate the development of teaching and learning skills used to educate patients and other personnel.
• Contribute to the monitoring, audit and evaluation of adherence to policy/procedures/guidelines and standards of practice, initiating changes where appropriate to improve delivery of care to patients/carers within the MDT.
• Demonstrate ability to recognise abnormal grief reactions and refer on to appropriate agencies and healthcare professionals.
• Demonstrate a comprehensive knowledge of the assessment, care, management support, training education and information requirements for patients and carers across the care pathway for the particular speciality area.
• Assess and provide support that is appropriate to the context and sensitive to meet the patient/carer and/or family’s needs, facilitating access to additional support from other healthcare professionals or agencies as applicable and with the agreement of the patient and/or carer.
• Understand the ethical issues relating to treatment in advanced disease.
• Have sufficient knowledge and links with national/local support groups and be able to provide/record information relating to these groups to guide and advise patients.

• Provide information, education and relevant telephone contacts to patients and carers regarding the procedures and management of the side effects of treatment associated with the client group encountered in their practice.

• Be aware of local contact arrangements in the event of patients experiencing unwanted side effects.

• Demonstrate knowledge to prepare, inform and educate patients/carers for survivorship and, where applicable, primary care personnel regarding any associated care requirements, symptom management and contact details on discharge.

• Participate in inter-professional/inter-agency evaluation and audit to effect change for the continued improvement of the quality of care and service for patients.
Appendix 5: LCA Holistic Needs Assessment Tool

London Holistic Needs Assessment

For each item below, please tick yes or no if they have been a concern for you during the last week, including today. Please also tick discuss if you wish to speak about it with your health professional.

Choose not to complete the assessment today by ticking this box ☐

For health professional use:

Date:

Date of diagnosis:

Diagnosis:

Pathway point:

For patient use:

Name:

Hospital/ NHS number:

Date:

Date of diagnosis:

Date:

Date of diagnosis:

Date:

For patient use:

Other actions/outcomes e.g. additional information given, health promotion, smoking cessation, ‘My actions’:

Preferred name:

Hospital/NHS number:

Care Plan

During my holistic needs assessment, these issues were identified and discussed:

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Other actions/outcomes e.g. additional information given, health promotion, smoking cessation, ‘My actions’:

Signed (patient):

Signed (healthcare professional):

For health professional use:

Date of diagnosis:

Signed:

Follow-up plan:
Appendix 6: Cancer Survivorship Guidelines

As cancer treatments become more effective, more people are living with and beyond cancer with specific needs as a direct result of the cancer and its treatment. The consequences of cancer treatment are dependent on multiple factors and affect each person differently. Consequences may be physical (e.g. cardiovascular conditions, impact on fertility, bone health and gastro-intestinal); emotional and psychological (e.g. anxiety, self-confidence and depression); social; spiritual; or cognitive. They can have an impact on every aspect of a person and on their family’s lives, from the ability to work, through to the ability to have a family or to participate in social activities. It is widely acknowledged that cancer survivors have a multitude of unmet needs following treatment, with a majority still having some needs 6 months later. Good survivorship care enables the person to live as full and active a life as possible.

Survivorship can be defined as:

“cover[ing] the physical, psychological and economic issues of cancer, from diagnosis until end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get healthcare and follow-up treatment, late effects of treatment, second cancer and quality of life. Family members, friends and caregivers are also part of the survivorship experiences.”

National Cancer Institute, Dictionary of Cancer Terms, definition of ‘survivorship’ (www.cancer.gov/dictionary?CdrID=445089)

The National Cancer Survivorship Initiative (NCSI) vision document (DH 2010) mandated five shifts in care for individuals completing cancer treatment. NCSI advocates cancer being treated as a chronic illness, with patients empowered and supported to take an active role in their care. Improving Outcomes: a Strategy for Cancer (DH 2011) states that people living with and beyond a cancer diagnosis should have their full needs addressed to prevent long-term disability, enabling them to live a full, active, good quality life for as long as possible. Work within the NCSI has to date focused on survivorship from the end of treatment, but its report, Living With and Beyond Cancer: Taking Action to Improve Outcomes (DH 2013), acknowledges that survivorship care from the point of diagnosis is also vital. It challenges services to develop further and focuses on five new areas:

- information and support from diagnosis
- promoting recovery
- sustaining recovery
- managing consequences
- supporting people with active and advanced disease.

The importance of good survivorship care is well known: those who have unmet needs are 20% more likely to visit their GP and twice as likely to attend A&E than their healthy counterparts. They are more likely to be unemployed and many report economic hardship. Much has been achieved both nationally and locally to address this agenda. It is essential that in the LCA our patients have access to high-quality, equitable survivorship services on a par with the best in the country. We will continue to build on the successes to date.
The Consequences of Cancer and its Treatment (CCaT) collaborative group (a Macmillan Community of Interest) produced a ‘10 Top Tips’ guidance document for patients. These cover the key components of good survivorship care, and the LCA expects services to address these areas. The following nine points for professionals are based on the CCaT’s work.

1 Discuss a person’s needs.

The holistic needs assessment (HNA) has been shown to be effective in identifying a person’s areas of concern. It can take many forms and the LCA has developed its own tool, based on the concerns checklist and distress thermometer. The tool allows patients to specify what is of most concern to them, and so directs subsequent discussion and intervention to addressing these needs. It has scope to cover physical, emotional, spiritual, finance and welfare, and practical concerns. It is anticipated that as the HNA becomes embedded within the pathway, patients will start to ask for an HNA and professionals need to be able to respond to this.

**Recommendation:** Every patient should be offered an HNA at key pathway points, including at diagnosis and end of treatment, and whenever a person requests one.

2 Provide a treatment summary and care plan

A treatment summary provides a summary of the cancer treatments received by the end of first treatment, planned follow-ups (including mechanisms for these) and signs and symptoms of which to be aware. Their aim is to provide information not only to the patient, but also to the GP about possible consequences of cancer and its treatment, signs of recurrence and other important information.

A care plan is generated as a result of an HNA and is the agreed plan between the patient and healthcare professional about how the identified areas of concern will be addressed. This may cover provision of information (e.g. through an information prescription), onward referral for specialist assessment and intervention (e.g. breathlessness management), or things which the patient themselves can do (e.g. contact their HR department about graduated return to work options).

**Recommendation:** An end of treatment consultation should be offered to every patient. This should include an end of treatment HNA and associated written care plan, and should also include the discussion and provision of a comprehensive treatment summary.

3 Provide a main contact

Several pieces of UK-wide work have shown the necessity of a key contact, or key worker, not least the national Cancer Patient Experience Survey. It is now agreed that both patients and GPs (and other healthcare professionals) benefit from having a named person to contact if they need help or advice about issues related to the consequences of cancer and its treatment.

**Recommendation:** The treatment summary should include the details of a key worker in addition to details of who to contact out of hours. This should be sent to the GP, the patient and any others whom the patient identifies as necessary.
4 Identify post-treatment symptoms

As discussed above, cancer and its treatments can have far-reaching consequences and people with associated unmet needs are more likely to access healthcare services than their healthy counterparts. Providing information on likely post-treatment symptoms (e.g. neuropathic pain following thoracic surgery or peripheral neuropathy following chemotherapy), and how these can be managed or avoided, allows people to seek the right help from the right people at the right time.

**Recommendation:** Information on anticipated or possible consequences of cancer treatment and what to do if they occur should be routinely provided to all patients. This should be done from the time of discussion of treatment onwards, with the information clearly reiterated during the end of treatment consultation.

5 Provide support about day-to-day concerns

Life changes following a cancer diagnosis. It is recognised that people need help and support to find a ‘new normal’. This may cover any one of a multitude of aspects, from work and education, through to financial worries and needing help with caring responsibilities. Help should be offered at all key points in the pathway, but may be of particular relevance at the end of treatment and may well be highlighted in the HNA. There are various options for written information provision (e.g. Macmillan Cancer Support information leaflets and information prescriptions) as well as some specialist services (e.g. Citizens Advice). Reports published by the NCSI, available on the NCSI website, may be of use to professionals.

**Recommendation:** Patients should be routinely asked about whether they need support with day-to-day issues and referrals made to specialist services when necessary.

6 Talk about how you feel

Having a cancer diagnosis has an emotional impact, and at the end of treatment people experience a wide range of emotions. Sometimes, these can be dealt with by the person alone or with support from the key worker and others, but some people will need referral to psychological support services. This may be true not only for patients but their family and carers too.

**Recommendation:** Use an HNA to identify emotional concerns. Further screening tools (e.g. the Hospital Anxiety and Depression Scale) should be considered, with subsequent referrals made as necessary.

7 Healthy lifestyle

There is a growing body of evidence which supports the adoption of a healthy lifestyle for those who have had a cancer diagnosis.

**Recommendation:** Patients are provided with dietary advice, based on the WCRF recommendations, at the end of treatment with referral to specialist dietitians as needed.
Physical activity

There has been a dramatic rise in the amount of high-quality published research on the role of exercise in cancer in recent years. Physical activity results in improvement in quality of life, fitness and function and symptoms related to cancer and its treatments. It reduces cancer recurrence, incidence of second cancers and reduces both all-cause and cancer-specific mortality.

There is wide consensus that cancer survivors should exercise to the same level as the general population for health benefits. Research suggests that a combination of cardiovascular and muscular strength training has additional benefits over and above undertaking only one type of exercise.

**Recommendations:** Patients should be encouraged to maintain or increase their level of physical activity both during and after treatment in line with national guidance. They should be referred for specialist assessment by a physiotherapist as necessary.

Patients should also be offered access to a health promotion event, such as a health and well-being clinic, at the end of treatment.

8 Self-managed follow-up

There is a move towards increased self-management and follow-up closer to home. This has clear benefits to patients, including reduced anxiety in the lead-up to routine appointments and less interference in their day-to-day life caused by travelling to hospitals. In addition, research has shown that recurrence is more likely to be detected by the patient themselves between appointments, rather than at the outpatient appointment. By reducing unnecessary appointments, Trusts are able to see new patients more quickly and spend more time with more complex patients.

For self-management to be effective, patients need to be given the right information about the signs and symptoms of recurrence and clear pathways to follow if they have concerns. They should also be guaranteed a fast, explicit route to re-access services if necessary. A telephone helpline is suggested, which should be staffed by senior, experienced staff.

**Recommendation:** In addition to the use of treatment summaries (as described above), services should investigate the feasibility of rolling out self-managed/patient-led follow-up.

9 Encourage survivors to share their experience

Sharing the experience of living with and beyond cancer can be beneficial to the patients themselves, their carers and others who have a cancer experience. Providing feedback on their experience, and volunteering and participation in research can all have a positive impact on the patient.

**Recommendation:** Patients should be offered information about local support groups and where they can access further information on sharing their experiences.

To summarise, these guidelines set out how to best address survivorship care, based on best available evidence, current national policy and guidance and in response to work such as the national Cancer Patient Experience Survey.
## Appendix 7: Teenagers and Young Adults: Referral to Multidisciplinary Team Proforma

External referrals to The Royal Marsden TYA MDT: please complete section A and provide copies of site-specific MDT outcome sheet and original pathology report. We are unable to register patient on the TYAC database without this information.

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| Family / social circumstances: | |
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| Education / work: | |
|-------------------| |
|                   | |

| Psychosocial issues: | |
|---------------------| |
|                     | |

| Site-specific MDT treatment plan accepted by TYA MDT?: | |
|--------------------------------------------------------| |
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Appendix 8: LCA Specialist Palliative Care Referral Form

Specialist Palliative Care (SPC) Community and SPC Inpatient Unit Referral Form

Specialist Palliative Care Community Teams & Inpatient Units across South & West London

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<tbody>
<tr>
<td>Bostall Hill, Abbey Wood SE2 0GB</td>
<td>Lewisham High Street SE13 6LH</td>
<td>Lawrie Park Rd, London SE26 6DZ</td>
</tr>
<tr>
<td>Home care:</td>
<td>Tel: 020 8333 3017 Fax: 020 8333 3270</td>
<td>Home care:</td>
</tr>
<tr>
<td>Tel: 020 83205837 Fax: 020 83205839</td>
<td></td>
<td>Tel: 020 8776 5656 Fax: 020 87765798</td>
</tr>
<tr>
<td>Admissions:</td>
<td></td>
<td>Admissions:</td>
</tr>
<tr>
<td>Tel: 020 83122244 Fax: 020 83124344</td>
<td></td>
<td>Tel: 020 87684582 Fax: 020 88659505</td>
</tr>
</tbody>
</table>

Guy’s & St Thomas’ Community Team: Guy’s Hospital, Great Maze Pond SE1 9RT
Tel: 020 71884754 Fax: 020 71884748

Meadow House Hospice
Southall UB1 3HW
Tel: 020 89675179 Fax: 020 89675756

Michael Sobell House
Northwood, Middlesex HA6 2RN
Tel:01923 844531 Fax: 01923 844565

For further information and advice on these services, please visit the Help the Hospices service directory at: http://www.helpinhospices.org.uk/about-hospice-care/find-a-hospice/uk-hospice-and-palliative-care-services/ and enter the postcode provided above.

Every LCA hospital has a Specialist Palliative Care team; if your patient is a hospital inpatient, please contact the team, via the relevant hospital switchboard.

Fax Message

From:                    To:                      
Fax No:                  Date:                   
No. of pages (incl cover sheet): 
Additional Information

Confidentiality: The content of this fax and attached documents are confidential and intended for the use of the addressee designated above. If you are not the addressee, you are hereby notified that you may not disclose, reproduce or otherwise disseminate or make use of this information for yourself or any third party. If you have received this in error, please notify us on the telephone number given above.

PLEASE SEND COPIES OF RECENT CLINICAL CORRESPONDENCE WITH THIS FORM – including recent clinic letters, blood tests and most recent imaging
NB. INSUFFICIENT INFORMATION MAY DELAY PATIENT ASSESSMENT

PATIENT NAME ................................................................. NHS No: .........................................................

LCA Palliative Care Group Revised April 2014

53
### Referral Form for SPC Community and Inpatient Units (2/3)

#### Essential Patient Details

<table>
<thead>
<tr>
<th>Surname</th>
<th>Male/Female</th>
<th>Age</th>
<th>Patient consent to palliative care involvement?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes ☐ No ☐</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>First Name</th>
<th>DoB</th>
<th>Is GP aware of referral?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Yes ☐ No ☐</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Address</th>
<th>Marital Status</th>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>NHS number</th>
<th>Hospital No.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Primary diagnosis(es)

- [ ]

#### Communication

- Fluent in English? Yes ☐ No ☐ (If ‘no’ proceed with remaining questions)
- First Language, if not English:
- Would interpreter be helpful to patient and Palliative Care staff? Yes ☐ No ☐
- Other barriers to communication / registered disabilities:

#### Next of Kin/Patient Representatives

<table>
<thead>
<tr>
<th>Name</th>
<th>Address</th>
<th>Telephone</th>
<th>Fax</th>
<th>Relationship to patient</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social Services</th>
<th>Name</th>
<th>Telephone</th>
<th>Fax/email</th>
<th>CCG:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Main Carer (if different from above)

<table>
<thead>
<tr>
<th>Name</th>
<th>Address</th>
<th>Telephone</th>
<th>Fax</th>
<th>Relationship to patient</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Continuing care assessment completed:</th>
<th>Yes/No</th>
<th>Continuing care funding agreed:</th>
<th>Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Reason for Referral

- Pain/symptom control
- Emotional/psychological support
- Social/financial
- Assessment for hospice admission
- Carer support
- Other reason (please give details below):

#### Service requested

- Home assessment and support
- Hospital assessment
- Day Care
- Outpatient service
- Admission (circle)
- Respite / symptom control / terminal care
- Hospice at Home

#### The patient is currently

- At Home
- In Hospital [see over]
- Other e.g. Nursing Home
- Please specify
- Does patient live alone? Yes ☐ No ☐

#### Any access issues (e.g. key safe):

- MRSA Status
  - Positive ☐
  - Negative ☐
  - Not known ☐

- Any other communicable infection:

#### Special device in situ

- Yes ☐ No ☐

If yes, give details (e.g. trachea / PEG / ICD / NIPPV):

#### Referrer’s Name (please print)

#### Contact number:

#### Bleep no:

#### IS REFERRAL URGENT (assess within 2 working days)?

- Yes ☐ No ☐

If URGENT, please phone us for immediate advice
Referral Form for SPC Community and Inpatient Units

<table>
<thead>
<tr>
<th>In-Patient details</th>
<th>Patient Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>NHS No:</td>
</tr>
<tr>
<td>Ward</td>
<td>Direct Ward Ext.</td>
</tr>
<tr>
<td>Key worker</td>
<td>Date of discharge (if known)</td>
</tr>
<tr>
<td>Consultant</td>
<td>Is Palliative Care team involved? Yes ☐ No ☐</td>
</tr>
</tbody>
</table>

Brief History of diagnosis(es) and Key treatments

<table>
<thead>
<tr>
<th>Date</th>
<th>Progression of disease and investigations/treatment</th>
<th>Consultant and hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Current palliative care problems

1.  
2.  
3.  
4.  
5.  
6.  

Patient Mobility:  Bariatric Nursing required? Yes ☐ No ☐ 

Any other comments/information (including preferences expressed about care or other psychosocial or spiritual issues)

Referrer’s expectation of current treatment (please circle) symptom control / life prolonging / curative  

<table>
<thead>
<tr>
<th>Prognosis:</th>
<th>In your opinion, is the patient</th>
<th>Stable? Yes ☐ No ☐</th>
<th>Unstable? Yes ☐ No ☐</th>
<th>Deteriorating? Yes ☐ No ☐</th>
<th>Dying? Yes ☐ No ☐</th>
<th>Is death anticipated within: Months ☐ Weeks ☐ Days ☐</th>
</tr>
</thead>
</table>

Patient on Coordinate My Care? Yes ☐ No ☐ Unknown ☐ If not please give reason... 

On the GSF register? Yes ☐ No ☐ Unknown ☐ 

DNACPR in place? Yes ☐ No ☐ 

Past Medical and Psychiatric History  Current Medication

<table>
<thead>
<tr>
<th>Past Medical and Psychiatric History</th>
<th>Current Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Known Drug Sensitivities/Allergies:</th>
<th>Yes ☐ No ☐</th>
</tr>
</thead>
<tbody>
<tr>
<td>Details:</td>
<td></td>
</tr>
</tbody>
</table>

Insight: Has patient been told diagnosis? Yes ☐ No ☐ 
Is the carer aware of patient’s diagnosis? Yes ☐ No ☐ 
Does patient discuss the illness freely Yes ☐ No ☐ 

Please ensure patients are aware information will be held on computer according to the Data Protection Act.

Referrer’s signature: Name: (please print) 
Job title: Contact number: Bleep no: 
Surgery or Hospital: Date: 

LCA Palliative Care Group Revised April 2014
Appendix 9: Histopathology Datasets for Head and Neck Cancers

Dataset for primary oral cavity carcinoma (page 1)

<table>
<thead>
<tr>
<th>Surname</th>
<th>Forenames</th>
<th>Date of birth</th>
<th>Sex</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>Hospital no</td>
<td>NHS/CHI no.</td>
<td></td>
</tr>
<tr>
<td>Date of receipt</td>
<td>Date of reporting</td>
<td>Report no.</td>
<td></td>
</tr>
</tbody>
</table>

Pathologist

<table>
<thead>
<tr>
<th>Clinical Data:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of specimen</td>
</tr>
<tr>
<td>Resection</td>
</tr>
<tr>
<td>Clinical TNM stage</td>
</tr>
<tr>
<td>New primary</td>
</tr>
<tr>
<td>Previous radiotherapy</td>
</tr>
<tr>
<td>Previous chemotherapy</td>
</tr>
<tr>
<td>Primary tumour</td>
</tr>
<tr>
<td>Right</td>
</tr>
<tr>
<td>Histological type</td>
</tr>
<tr>
<td>Papillary</td>
</tr>
<tr>
<td>Other malignancy (specify):</td>
</tr>
<tr>
<td>Differentiation</td>
</tr>
<tr>
<td>Invasive front</td>
</tr>
<tr>
<td>Maximum diameter</td>
</tr>
<tr>
<td>Maximum depth of invasion</td>
</tr>
<tr>
<td>Distance from invasive tumour to mucosal margin</td>
</tr>
<tr>
<td>Deep margin</td>
</tr>
<tr>
<td>Vascular invasion</td>
</tr>
<tr>
<td>Nerve invasion</td>
</tr>
<tr>
<td>Bone/cartilage invasion</td>
</tr>
<tr>
<td>If present: Erosive</td>
</tr>
<tr>
<td>Severe dysplasia:</td>
</tr>
</tbody>
</table>

Comments/Additional Information
Dataset for primary oral cavity carcinoma (page 2)

<table>
<thead>
<tr>
<th>Surname</th>
<th>Forenames</th>
<th>Date of birth</th>
<th>Sex</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>Hospital no.</td>
<td>NHS/CHI no.</td>
<td></td>
</tr>
<tr>
<td>Date of receipt</td>
<td>Date of reporting</td>
<td>Report no.</td>
<td></td>
</tr>
<tr>
<td>Pathologist</td>
<td>Surgeon</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Summary of Pathological Data

<table>
<thead>
<tr>
<th>Tumour site</th>
<th>Tumour type</th>
<th>pTNM stage</th>
<th>SNOMED codes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>pT... pN...</td>
<td>T... M...</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>T... M...</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Resection of primary tumour</th>
<th>Clear</th>
<th>Close</th>
<th>Involved</th>
</tr>
</thead>
</table>

Signature: .................................................. Date: ....../....../......
Dataset for primary oropharyngeal carcinoma (page 1)

Surname ……………….. Forenames …………….. Date of birth ……./……./…… Sex ……
Hospital ……………….. Hospital no. ……………….. NHS/CHI no. ………………..
Date of receipt ……./……./…… Date of reporting ……./……./…… Report no. ………………..
Pathologist ……………… Surgeon …………………

**Clinical Data**

**Type of specimen**
- Incisional/endoscopic biopsy □
- Excisional biopsy □

<table>
<thead>
<tr>
<th>Resection</th>
<th>Yes □</th>
<th>No □</th>
<th>If yes: Partial □</th>
<th>Total □</th>
</tr>
</thead>
</table>

Clinical TNM stage………..
- T…..
- N…..
- M…..

<table>
<thead>
<tr>
<th>New primary</th>
<th>□</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Recurrence</th>
<th>□</th>
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<table>
<thead>
<tr>
<th>Not known</th>
<th>□</th>
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</thead>
</table>

<table>
<thead>
<tr>
<th>Previous radiotherapy</th>
<th>Yes □</th>
<th>No □</th>
<th>Not known □</th>
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</thead>
</table>

<table>
<thead>
<tr>
<th>Previous chemotherapy</th>
<th>Yes □</th>
<th>No □</th>
<th>Not known □</th>
</tr>
</thead>
</table>

**Primary tumour**

Site……………..
- Oropharynx,…
- Subsite(s)………………………..

<table>
<thead>
<tr>
<th>Right</th>
<th>□</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Left</th>
<th>□</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Midline</th>
<th>□</th>
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</thead>
</table>

**Histological type:** squamous cell carcinoma □

<table>
<thead>
<tr>
<th>Conventional</th>
<th>□</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Verrucous</th>
<th>□</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Papillary</th>
<th>□</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Acantholytic</th>
<th>□</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Other (specify)</th>
<th>□</th>
</tr>
</thead>
</table>

**Other malignancy (specify):…………………………………………..**

**Differentiation**
- Well □
- Moderate □
- Poor □

**Invasive front**
- cohesive □
- non-cohesive □

**Maximum diameter …………. (mm)**

**Maximum depth of invasion ……. (mm)**

<table>
<thead>
<tr>
<th>Distance from invasive tumour to mucosal margin ………….. (mm)</th>
<th>□</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>deep margin ………………… (mm)</th>
<th>□</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Vascular invasion</th>
<th>Yes □</th>
<th>No □</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Nerve invasion</th>
<th>Yes □</th>
<th>No □</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Bone/cartilage invasion</th>
<th>Yes □</th>
<th>No □</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>If present: Erosive □</th>
<th>Infiltrating □</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Carcinoma at margin:</th>
<th>Yes □</th>
<th>No □</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Severe dysplasia</th>
<th>Yes □</th>
<th>No □</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>If yes: Dysplasia at margin:</th>
<th>Yes □</th>
<th>No □</th>
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</table>

<table>
<thead>
<tr>
<th>HPV status:</th>
<th>Not known □</th>
<th>Negative □</th>
<th>Positive □</th>
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<table>
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<th>p16 testing</th>
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<table>
<thead>
<tr>
<th>Negative □</th>
<th>Positive □</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>ISH testing</th>
<th>□</th>
</tr>
</thead>
</table>

| Negative □ | Positive □ |
Dataset for primary oropharyngeal carcinoma (page 2)

Surname ………………………… Forenames ……………………… Date of birth ……./……./…… Sex ………
Hospital ………………………… Hospital no. ……………………… NHS/CHI no. …………………
Date of receipt ……./……./…… Date of reporting ……./……./…… Report no. …………………
Pathologist …………………… Surgeon ……………………

Comments/Additional Information

Summary of Pathological Data

Tumour site……………………………………
Tumour type…………………………………
pTNM stage pT….. pN…..
SNOMED codes
T……………… M………………
T……………… M………………

Resection of primary tumour Clear ☐ Close ☐ Involved ☐

Signature: …………………………………………………… Date: ……./……./……
Dataset for salivary carcinoma resections (page 1)

Surname…………………… Forenames…………………… Date of birth……/……/…… Sex……
Hospital…………………… Hospital no…………………… NHS/CHI no………………
Date of receipt……/……/…… Date of reporting……/……/…… Report no………………
Pathologist…………………… Surgeon……………………

Clinical Data

Site: Parotid ☐ Submandibular ☐ Sublingual ☐
Other site ☐ (Please specify)………………
Laterality: Left ☐ Right ☐
Type of specimen: Incisional ☐ Excisional ☐ Resection ☐
Histological type:…………………………
Histological grade (if appropriate)…………
Maximum diameter………………………(mm)
Extraglandular extension – macroscopic: Yes ☐ No ☐
Extraglandular extension – microscopic: Yes ☐ No ☐
If present, estimate distance (mm) ………
Perineural invasion Yes ☐ No ☐
Minimum excision margin…………………(mm)

Comments/Additional Information:

Summary of Pathological Data

Tumour site…………………………………..
Tumour type………………………………..
pTNM stage pT…… pN……
SNOMED codes
T……………… M………………
T……………… M………………
Resection of primary tumour Clear (>5 mm) ☐ Close (>1 mm) ☐ Involved ☐

Signature: …………………………… Date: ……/……/……
Dataset for primary laryngeal carcinoma (page 1)

<table>
<thead>
<tr>
<th>Surname</th>
<th>Forenames</th>
<th>Date of birth</th>
<th>Sex</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>Hospital no.</td>
<td>NHS/CHI no.</td>
<td></td>
</tr>
<tr>
<td>Date of receipt</td>
<td>Date of reporting</td>
<td>Report no.</td>
<td></td>
</tr>
<tr>
<td>Pathologist</td>
<td>Surgeon</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Clinical Data

<table>
<thead>
<tr>
<th><strong>Type of specimen</strong></th>
<th>Incisional biopsy</th>
<th>Excisional biopsy</th>
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</thead>
<tbody>
<tr>
<td>Resection</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>If yes, Partial</td>
<td>Total</td>
</tr>
</tbody>
</table>

**Clinical TNM stage:**

- T........
- N......
- M......

**New primary:**

- Possibility:
  - Recurrence
  - Not known

**Previous radiotherapy:**

- Yes
- No
- Not known

**Previous chemotherapy:**

- Yes
- No
- Not known

**Primary tumour:**

<table>
<thead>
<tr>
<th>Site</th>
<th>Larynx</th>
<th>Subsite(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right</td>
<td>Left</td>
<td>Midline</td>
</tr>
</tbody>
</table>

**Histological type:**

- Squamous cell carcinoma
- Conventional
- Verrucous
- Papillary
- Acantholytic
- Other (specify) ............

**Other malignancy (specify):**

<table>
<thead>
<tr>
<th>Well</th>
<th>Moderate</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Invasive front:**

- Cohesive
- Non-cohesive

**Maximum diameter:**

<table>
<thead>
<tr>
<th>mm</th>
</tr>
</thead>
</table>

**Deep tissue planes involved:**

- Paraglottic space
- Pre-epiglottic space

**Cartilage invasion**

- Yes
- No

**If present:**

- Inner table
- Full thickness

**Distance from invasive tumour to**

- Mucosal margin
- Deep margin

**Vascular invasion**

- Yes
- No

**Nerve invasion**

- Yes
- No

**Severe dysplasia**

- Yes
- No

**If yes:**

- Dysplasia at margin: Yes
- No

### Comments/Additional Information
Dataset for primary laryngeal carcinoma (page 2)

Surname …………………. Forenames …………………. Date of birth ……/……/……. Sex ……..

Hospital …………………. Hospital no. …………………. NHS/CHI no. ………………….

Date of receipt ……/……/……. Date of reporting ……/……/……. Report no. ………………….

Pathologist …………………. Surgeon ………………….

---

Summary of Pathological Data

Tumour site…………………………………….

Tumour type…………………………………….

pTNM stage pT….. pN………

SNOMED codes

T………………. M……………….

T………………. M……………….

Resection of primary tumour Clear ☐ Close ☐ Involved ☐

---

Signature: ………………………………………………. Date: ……/……/…..
Dataset for primary nasopharyngeal carcinoma

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63
# Dataset for primary hypopharyngeal carcinoma (page 1)

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<th>Surgeon</th>
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## Clinical Data

### Type of specimen
- Incisional/endooscopic biopsy
- Excisional biopsy

### Resection
- Yes
- No
- If yes, Partial
- Total

### Clinical TNM stage
- T
- N
- M

### New primary
- Yes
- No
- Not known

### Recurrence
- Yes
- No
- Not known

### Previous radiotherapy
- Yes
- No
- Not known

### Previous chemotherapy
- Yes
- No
- Not known

### Primary tumour
- Site
- Hypopharynx
- Subsite(s)

### Histological type: squamous cell carcinoma
- Conventional
- Verrucous
- Papillary
- Acantholytic
- Other (specify)

### Other malignancy (specify)

### Differentiation
- Well
- Moderate
- Poor

### Invasive front
- Cohesive
- Non-cohesive

### Maximum diameter
- (mm)

### Maximum depth of invasion
- (mm)

### Distance from invasive tumour to mucosal margin
- (mm)

### Deep margin
- (mm)

### Vascular invasion
- Yes
- No

### Nerve invasion
- Yes
- No

### Cartilage invasion
- Yes
- No

### Severe dysplasia
- Yes
- No
- If yes: Dysplasia at margin
- Yes
- No

### Comments/Additional Information

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Dataset for primary hypopharyngeal carcinoma (page 2)

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Date of receipt ....../....../......  Date of reporting ....../....../......  Report no. ..........................
Pathologist ..........................  Surgeon ..........................

Summary of Pathological Data

Tumour site........................................

Tumour type........................................

pTNM stage  \(pT\) ...... \(pN\)......

SNOMED codes

\(T\).............  \(M\).............

\(T\).............  \(M\).............

Resection of primary tumour  Clear \(\square\)  Close \(\square\)  Involved \(\square\)

Signature: ..................................................  Date: ....../....../......
Dataset for thyroid cancer histopathology (page 1)

Surname .......................... Forenames .......................... Date of birth ....../....../...... Sex ....
Hospital .......................... Hospital no. .......................... NHS no. ..........................
Date of receipt ....../....../...... Date of reporting ....../....../...... Report no. ..........................
Pathologist ........................ Surgeon ..........................

Clinical Data

Specimen type  Tick the least number of boxes that fully accounts for everything received
Thyroidectomy  Total □ Near total □ Not stated □
Hemithyroidectomy  Right □ Left □ Not stated □
Total □ Near total □ Isthmus □
Biopsy of thyroid □
Biopsy/resection of metastasis (define site) ..............................................................

Gross description of thyroid specimen
Location of carcinoma(s)  Right lobe □ Left lobe □ Isthmus □ Unknown □

Microscopic report

Papillary carcinoma

Single incidental microcarcinoma □ Multiple incidental microcarcinoma □ Classical PTC □
Variant: Encapsulated FVPTC □ Non-encapsulated FVPTC □ Other type (specify) ..................
For encapsulated FVPTC, no. of foci of capsular invasion ........ and number of foci of vascular invasion ........
Dataset for thyroid cancer histopathology (page 2)

Follicular carcinoma
Not Hürthle cell type □ or Hürthle cell (oncocytic) follicular carcinoma □

Minimally invasive (capsule only) □ Minimally invasive (angioinvasion) □ *(Select both types of invasion if both are seen)*

Widely invasive □

Number of foci of angioinvasion found for the follicular carcinoma .................

Medullary carcinoma □ Definite background C-cell hyperplasia □

For all above types

Minority poorly differentiated (not anaplastic) component Absent □ Present □

Poorly differentiated carcinoma □ *(Majority (> 50%) of tumour is poorly differentiated)*

Undifferentiated/anaplastic carcinoma □

Differentiated component identified (specify).................................

Mixed follicular/papillary and medullary carcinoma □

Surname ...................... Forenames ...................... Hospital no. ......................

For all tumour types

Confined to thyroid □

Unifocal □ Multifocal □

Size ............................... mm

Minimal extension beyond thyroid capsule into sternothyroid or perithyroidal soft tissues only, pT3 □

Microscopic extension beyond thyroid capsule into subcutaneous soft tissues, larynx, trachea, oesophagus or recurrent laryngeal nerve, pT4a □

Microscopic extension beyond thyroid capsule into prevertebral fascia, mediastinal vessels or encasement of carotid artery, pT4b □

Any macroscopic extension beyond thyroid capsule, pT4b □
Dataset for thyroid cancer histopathology (page 3)

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<th>Number of foci found</th>
<th>Uncertain □</th>
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<td>......</td>
<td>Number of lymph nodes positive</td>
<td>............</td>
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<tr>
<td>Site of lymph nodes involved</td>
<td>..................................................</td>
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<tr>
<td>Unilateral Level VI □</td>
<td>Any other group □</td>
<td>Unable to assess □</td>
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<td>Excision margins</td>
<td>Free of tumour □</td>
<td>Minimum distance ......mm</td>
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<tr>
<td>Tumour present on microscopy □</td>
<td>Tumour present macroscopically □</td>
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<td>Adjacent thyroid</td>
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<td>Normal □</td>
<td>Mild thyroiditis □</td>
<td>Severe thyroiditis □</td>
<td>Nodular goitre □</td>
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<tr>
<td>C-cell hyperplasia (medullary carcinoma only) Yes □</td>
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<td>Uncertain □</td>
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<td>Other (define) ......................</td>
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**Comments**

---

Parathyroids identified | Number ....... | Site(s) ...... | Pathology ..............................................
---|---|---|---|
| Stage | pT ......... | pN ......... | M1? □ | R ......... |

Signature ......................... | Date ....../....../...... | SNOMED code TB6 M ......................
Dataset for lymph node excision specimens (page 1)

Surname ……………………… Forenames ………………….. Date of birth ………/……/…… Sex ………

Hospital ……………………… Hospital no. ………………….. NHS/CHI no. ………………….

Date of receipt ………/……/…… Date of reporting ………/……/…… Report no. ………………….

Pathologist ……………………… Surgeon ……………………..

**Sentinel node(s)**

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<th>II B</th>
<th>III</th>
<th>IV</th>
<th>V</th>
<th>VI</th>
<th>other</th>
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<td>No. positive nodes</td>
<td>ECS present</td>
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**Right neck dissection**

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Dataset for lymph node excision specimens (page 2)

**Left neck dissection**

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<th>IIB</th>
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**Comments/Additional Information**

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**Summary of Pathological Data**

Tumour type

Tumour site

pTNM stage pN......

SNOMED codes T............. M.............

Signature: .......................... Date: ....../....../......
Appendix 10: Thyroid Exemplar Pathway

Introduction
Most thyroid malignancy is not aggressive: even if managed sub-optimally, 80% of patients will have excellent survival rates. However, serious lifelong complications can follow poor early treatment. This makes appropriate management through a specialist thyroid cancer multidisciplinary team (MDT) essential.

It is important to recognise that most thyroid nodules are benign. Also most Thy3 cytology is benign.

This document should be used/reviewed in conjunction with the thyroid exemplar pathway summary sheet (see Annex C) and the LCA Head and Neck/Thyroid Cancer Clinical Guidelines.

Cross-Pathway Themes

Prevention
- Differentiated thyroid cancer (papillary and follicular malignancy, representing most thyroid malignancy) cannot at present be predicted or prevented.
- Medullary thyroid cancer should prompt the search for the RET proto-oncogene and therefore the prevention of disease in their family.
- Rarely papillary thyroid cancer is familial.

Enhanced recovery programme
- All surgical patients should be considered for inclusion in a bespoke enhanced recovery programme.

Holistic needs assessment
- As a minimum, this should be completed at the time of diagnosis (within 4 weeks) and on completion of first definitive treatment (within 6 weeks). This should also be utilised, as required, at any point on the pathway.

GP communication
- Standardised templates to be used across the London Cancer Alliance (LCA) at key time points on the pathway. Minimum: initial consultation, diagnosis and treatment plan, multidisciplinary initial care plan, end of treatment summary.
- Standardised clinic letter format for follow-up appointments.

Patient information
- Timing of appropriate information is key. Suggest providing information prior to the two week wait (2ww) appointment detailing what to expect, and including details of the most common investigations, such as fine needle aspiration. Patients must be given information appropriate to the stage of their investigation (i.e. most patients with thyroid nodules will have benign disease and should not be disturbed by high risk of cancer; most patients with Thy3 will have benign disease diagnosed at surgery).
- Standardise minimum set of information provided to patients across the LCA at set points on the pathway.
Supportive care/psychological support services

- There are key opportunities from the start of the pathway to offer psychological support to patient/carers and their families and to address any financial concerns/social issues.

Thyroid dataset

- To be included in the pathway to ensure LCA-wide compliance with timely and comprehensive data submission.

Stages of the Thyroid Pathway

Referral source

- A&E
- GP
- General dental practitioner 2ww (see Appendix 1, Urgent Referral, though few thyroid cancers are diagnosed via this route)
- Internal referral, often from imaging
- Lump/bump/rapid access clinic
- Tertiary referrals
- Recurrences

Assessment and diagnosis

- Consultant clinic appointment.
- Investigation of thyroid function, performed before ultrasound.
- Investigation: ultrasound of nodule, thyroid and neck. There is a strong view that ultrasound should be performed in specialist centres. The LCA should work towards this goal. It is suggested that ultrasound experience should encompass 150 thyroid ultrasounds per annum.
- Investigation: fine needle aspiration cytology; fine needle aspiration should be ultrasound guided. Cytology, especially Thy3, must be discussed to ensure individual good care. The MDT must also audit Thy3 throughout its population catchment area.

Multidisciplinary team meeting

- Agree LCA-wide minimum data for case presentation at the MDT meeting.
- Agree referral criteria to the MDT meeting.
- Treatment plan recommended (including pre-op assessment, surgery).
- Communication to patient and GP.
- Thyroid dataset completed.
- Paediatric and young adult cases to be discussed at appropriate MDT (Great Ormond Street Hospital in north west London, The Royal Marsden in south London). Surgery to be carried out by surgeon(s) with thyroid cancer and paediatric expertise.
Diagnosis and treatment planning

- Diagnosis given to patient (in presence of clinical nurse specialist (CNS)/key worker)
- Treatment plan explained to patient (in presence of CNS/key worker)
- Pre-treatment assessment clinic appointment given to patient
- Children and teenage and young adults to be discussed at appropriate extra MDT meeting
- Holistic needs assessment (HNA) completed
- Enhanced recovery programme (ERP/ERAS) commenced
- Refer to specialist oncology speech and language therapist and dietitian, as required

Pre-treatment assessment

- To include general surgical assessment
- Information prescription
- Vocal cord assessment
- Thyroid dataset completed
- ERP/ERAS

Treatment

- Surgery:
  - Surgeon: to report data to British Association of Endocrine and Thyroid Surgeons (BAETS) national database
  - Admission on day of surgery as appropriate
  - Calcium investigation and plan
  - Start thyroxine
  - End of Treatment Summary completed on discharge (including detail regarding follow-up)

- Radioactive iodine ablation or treatment:
  - The LCA awaits British Thyroid Association (BTA) joint guidance on use of routine thyroid remnant ablation
  - Guidance to patient, including pregnancy and radiation protection advice
  - Recombinant thyroid-stimulating hormone (TSH) stimulated ablation, TSH withdrawal for therapy radioiodine
  - Follow-up

- Radiotherapy (rarely required):
  - Weekly review in on-treat clinic – CNS, dietitian, speech and language therapist and oncologist/on-treat support radiographer/nurse. (Some patients may benefit from twice weekly dietetic review)
  - Offer psychological support to patient/carers and their families and address any financial concerns/social issues
  - After-care and rehabilitation plan agreed with patient
  - End of Treatment Summary completed on discharge (including detail regarding follow-up)
• Systemic therapy and clinical trials:
  – Probable referral to The Royal Marsden

• Best supportive care:
  – Early referral to local support team and community specialist palliative care services with or without dual care
  – Access to allied health professionals (AHPs) for relevant rehabilitation or to CNS, as required
  – Offer psychological support to patient/carers and their families and address any financial concerns/social issues
  – Communication with GP using standard template

**Follow-up/surveillance**

• Risk-stratified follow-up to guide investigation and follow-up (see old TSH guidance, awaiting BTA 2014 guidance)
• Appropriate TSH (old TSH guidance – see Annex A)
• Mass follow-up, ultrasound
• Function follow-up Tg and Tg antibodies
• Appropriate calcium and active vitamin D for hypoparathyroid management
• Radionucleotide imaging, where appropriate
• Plan for pregnancy (e.g. thyroxine dose in pregnancy)
• Triggers for MDT discussion

**Rehabilitation**

• HNA completed
• Delivered by specialist AHPs/CNS/dental/prosthetics
• Access to audiology
• Offer psychological support to patient/carers and their families and address any financial concerns/social issues
• Gold standard: hub and spoke model (services based within the centre outreaching to satellite clinics/clinics closer to home)
• Utilise specialist head and neck local support teams to support this, as available
• Speech therapy, where appropriate
• Dietitian, where required

**Survivorship**

• Signpost to local support and information centres, e.g. the Butterfly Centre
• Butterfly thyroid cancer DVD
• Local meetings

**Children, Teenagers and Young Adults**

Please see Chapter 12 for information on children, teenagers and young adults, including how to make a referral, and contact information for the PTC and TYA designated centres in the LCA.
Annex A: Referrals for thyroid tumours

**Urgent referral**
- Enlarging thyroid lump (>1cm in 3–6 months)
- Firm/immobile mass
- Patient >64 or <18
- Previous neck irradiation
- Associated cervical lymphadenopathy
- Voice change
- Family history of thyroid cancer or relevant endocrine tumour

Through the whole LCA, only 7–12% of 2ww referrals transpire, after investigation, to have thyroid malignancy. The number of urgent referrals with thyroid cancer is unknown, but anecdotally equally low.

**Referral to thyroid MDT**
- New thyroid cancer Thy4 or Thy5
- Recurrent cancer
- Follicular and Thy3
- Inherited thyroid cancer syndrome
- All paediatric and young adult cases
- Tertiary referral with thyroid cancer

In order to assess the safety and efficiency of the whole MDT, Thy3 needs to be discussed at the MDT. This allows individual assessment and audit of the crucial Thy3 pathway.

**Referral to thyroid MDT minimum dataset**
- Patient demographics, name, age, GP, contact
- Patient’s complaint
- Source of referral
- Next outpatient appointment, date and place
- TSH
- Ultrasound appearance

**Referral timelines**
- GP referral time from referral to surgery for cancer – 62 days
- If consultant upgrade (e.g. after MDT discussion of cytology) then 31 days from that time. This represents the bulk of thyroid cancer work. Routine 28 days to MDT discussion allows this information to reach the patient by 31 days, and operation planned by 62 days
- Urgent referral seen in 2 weeks in clinic
Annex B: TSH Suppression in Differentiated Thyroid Cancer

Key:
- **High risk**
- High risk; disease free ATA 5-10 years
- High risk; disease free ETA 5-10 years
- Low risk, initial therapy
- Low risk, follow up

Pacini ETA consensus EJE 2006 154:787
Cooper ATA guidance Thyroid 2009 19(11);1167
Exemplar Thyroid Pathway

**Timeline (days)**
- By 14: Assessment and diagnosis
  - Referral source: A&E, GP Normal, GP 2ww, Internal, U/S service, Tertiary, Recurrence
  - Clinic, TSH, U/S FNA
- By 25: Multidisciplinary team meeting (MDM)
  - Minimum dataset, Management plan, Surgical list, Communication, Thyroid dataset
- By 35: Diagnosis and treatment planning
  - Diagnosis given, Treatment discussed, Holistic needs, Support services, ERP
- By 62: Treatment
  - Surgery, Vocal cord check, Calcium Rx, Database
- By 83: Multidisciplinary team meeting (MDM)
  - Minimum dataset, Risk stratification, Management plan, Radioactive iodine, Communication, Thyroid dataset, Prevention for family
- Ongoing: Follow-up/surveillance
  - Risk stratified follow up, Appropriate TSH, Mass, function assess, Biochemical assess, Pregnancy, Recurrence and MDT
- Ongoing: Rehabilitation and survivorship
  - Local meeting, Butterfly, Speech therapy

**Urgent referral Seen within 2 weeks**
- Enlarging thyroid lump
- Firm/immobile mass
- Patient >64 or <18
- Previous neck irradiation
- Associated cervical LN
- Voice change
- FH of thyroid cancer

**Referral to MDT**
- New thyroid cancer Thy4 or Thy5
- Recurrent cancer
- Follicular/equivocal Thy3
- Inherited thyroid cancer syndrome
- All paediatric cases
- Tertiary referral with thyroid

**Pathology guidelines**
- *Pathology guidelines*

**Imaging guidelines**
- *Imaging guidelines*

**Annex C: Thyroid Exemplar Pathway Diagram**

**RESEARCH**
- *RESEARCH*

**GP COMMUNICATION**
- *GP COMMUNICATION*

**PATIENT COMMUNICATION**
- *PATIENT COMMUNICATION*

**PATIENT INFORMATION**
- *PATIENT INFORMATION*

**SUPPORTIVE CARE**
- *SUPPORTIVE CARE*

**THYROID DATA**
- *THYROID DATA*
Appendix 11: Upper Aerodigestive Tract Exemplar Pathway

Introduction

Cancer of the upper aerodigestive tract (UAT) arises almost universally from the surface squamous cells and is most common in smokers. There are also smaller groups of rarer cancers (including those arising from salivary tissue) that demand particular expertise. Over 850 new head and neck cases are diagnosed in the London Cancer Alliance (LCA) each year. Outcomes vary widely, depending on site of origin and stage. Treatment is usually surgery or radiotherapy for early cancers, and a combination of both, often with the addition of chemotherapy, for advanced cancers. The delivery of both radiotherapy and surgery in this area is highly technical and specialised. The cancer itself and the associated treatment will often affect speech, swallowing, nutritional intake, breathing, dentition and cosmesis. It is vital, therefore, that each patient should have access to, and be managed proactively by, a specialist multidisciplinary team (MDT) to optimise functional outcomes and quality of life, and to minimise complications. Early diagnosis and prompt treatment lead to better outcomes. Following treatment, side effects can be life-long, and continuing input from appropriate professionals should be available throughout survivorship.

Cross-pathway themes

Prevention:

- GP/general dental practitioner (GDP) initiates smoking cessation intervention, with or without ETOH/lifestyle advice at time of referral.
- There are key opportunities to reinforce these messages at a number of points on the pathway: at initial consultation, time of diagnosis, pre-treatment assessment clinic, during treatment, post-treatment and subsequently at wellness days/education meetings, as part of the survivorship agenda.

Enhanced recovery programme (ERP/ERAS):

- All surgical patients should be considered for inclusion in a bespoke enhanced recovery programme.
- As a minimum, this should include early optimisation of patients, carbohydrate loading and standardised integrated care pathways.

Holistic needs assessment (HNA):

- As a minimum, this should be completed at time of diagnosis (within 4 weeks) and on completion of first definitive treatment (within 6 weeks). It should also be utilised, as required, at any point on the pathway.
- Liverpool Patient Concerns Inventory¹ may be adopted in place of HNA for head and neck. Guidance will be issued by the LCA in a due course.

GP communication:

- Standardised templates to be used across the LCA at key time points on the pathway. Minimum should include initial consultation, diagnosis and treatment plan, multidisciplinary initial care plan, end of treatment summary.
- Standardised clinic letter format for follow-up appointments.
- Outstanding action: seek GP input into content of minimum dataset for standardised templates.
Patient information:

- Timing of information is key. Suggest providing information prior to the two week wait (2ww) appointment detailing what to expect, and including details of the most common investigations, such as fine needle aspiration.
- Standardise minimum set of information provided to patients across the LCA at set points on the pathway.

Supportive care/psychological support services:

- There are key opportunities from the start of the pathway to offer psychological support to patient/carers and their families and to address any financial concerns/social issues.

Research:

- To be considered for all patients across the pathway.

Data for Head and Neck Oncologists (DAHNO):

- To be included in the pathway to ensure LCA-wide compliance with timely and comprehensive data submission.

Stages of the UAT Pathway

Referral source:

- A&E
- GP or GDP 2ww
- Internal referral
- Lump/bump/rapid access clinic
- Tertiary referrals
- Recurrences during surveillance
- Enhanced recovery programme commences as indicated

Assessment and diagnosis:

- Consultant clinic appointment.
- Investigation: imaging before biopsy, examination under anaesthetic and biopsy, or biopsy under local anaesthesia, cytology and photograph of lesion (see the Royal College of Radiologists’ *Recommendations for cross-sectional imaging in cancer management* (second edition) ‘Head and neck cancers’ and Chapter 2 of these guidelines).
- Smoking cessation intervention with or without ETOH/ lifestyle advice.
- Signposting to relevant allied health professionals (AHPs), as required, e.g. for assessment and management of dysphagia and/or associated nutritional impairments.
- Information on tissue banking given to patient.
Multidisciplinary team meeting:
- Agree LCA-wide minimum data for case presentation at the MDT meeting\(^2\).
- Each patient presented at the MDT meeting must have an allocated head and neck consultant prior to presentation.
- Treatment plan recommended (including detailing support services required, e.g. nutrition/gastroenterology/radiology, surgical voice restoration, dental with or without prosthetics, audiology, nuclear medicine, pre-operative assessment).
- At-risk patients discussed (including patients flagged for early AHP intervention at initial consultation).
- DAHNO dataset completed.
- Tissue banking discussed.
- Recruitment to clinical trials, as indicated.

Diagnosis and treatment planning:
- Diagnosis given to patient (in presence of clinical nurse specialist (CNS)/key worker).
- Treatment plan explained to patient (in presence of CNS/key worker).
- Patient informed of support services required, e.g. nutrition/gastroenterology/radiology, surgical voice restoration, dental (with or without prosthetics), audiology, nuclear medicine, pre-operative assessment.
- Multidisciplinary pre-treatment assessment clinic appointment given to patient.
- HNA completed.

Multidisciplinary pre-treatment assessment:
- To include CNS, dietitian, speech and language therapist (core); physiotherapist, occupational therapist (extended).
- Information prescription to be completed.
- Carbohydrate loading information and product provided for surgical patients.
- Patient recorded outcome measure completed.
- Initial multidisciplinary care plan agreed.
- Offer psychological support to patient/carers and their families and address any financial concerns/social issues.
- DAHNO dataset completed.
- ERP/ERAS.

Treatment

Radical:
- Surgery:
  - Admission on day of surgery as appropriate
  - Carbohydrate loading
  - ERP/ERAS
– Intensive AHP/CNS intervention during inpatient admission – utilising integrated care pathways as gold standard.
– Offer psychological support to patient/carers and their families, and address any financial concerns/social issues
– After-care and rehabilitation plan agreed with patient
– End of Treatment Summary completed on discharge (including detail on follow-up)

• Oncological:

Induction chemotherapy:
– Pre-chemotherapy discussion (nurse led)
– Access to acute oncology service
– Access to AHP/CNS during chemotherapy treatment

Intensity modulated radiotherapy (IMRT)/ChemoIMRT:
– Weekly review in on-treat clinic – CNS, dietitian, speech and language therapist and oncologist/on-treat support radiographer/nurse. (Some patients may benefit from twice weekly dietetic review)
– Offer psychological support to patient/carers and their families and address any financial concerns/social issues
– After-care and rehabilitation plan agreed with patient
– End of Treatment Summary completed on discharge (including detail regarding follow-up)

Palliative:

• Surgery:
  – Early referral to local support team and community specialist palliative care services
  – After-care/rehabilitation/supportive care plan agreed with patient
  – End of Treatment Summary completed on discharge (including detail regarding follow-up)

• Oncological:

Chemotherapy:
– Pre-chemotherapy discussion (nurse led)
– Access to acute oncology service.
– Access to AHP/CNS during chemotherapy treatment
– Offer psychological support to patient/carers and their families and address any financial concerns/social issues
– Early referral to local support team and community specialist palliative care services +/- dual care
– After-care/rehabilitation/supportive care plan agreed with patient
– End of Treatment Summary completed on discharge (including detail regarding follow-up)

Radiotherapy:
– Weekly review in on-treat clinic – CNS, dietitian, speech and language therapist and oncologist/on-treat support radiographer/nurse. (Some patients may benefit from twice weekly dietetic review)
– Offer psychological support to patient/carers and their families and address any financial concerns/social issues
– After-care and rehabilitation plan agreed with patient
– End of Treatment Summary completed on discharge (including detail regarding follow-up)

• Best supportive care:
  – Early referral to local support team and community specialist palliative care services +/- dual care
  – Access to AHP/CNS as required
  – Offer psychological support to patient/carers and their families and address any financial concerns/social issues
  – Communication with GP using standard template

**Follow-up/surveillance:**

• Post-treatment imaging and clinical follow-up
• Risk-stratified follow-up/traffic-light system/2-year sign-off sheet for further review with CNS only with strict criteria for referral back to consultant/repatriation to DGH/satellite specialist clinics
• MDT meeting to discuss all post-treatment PET-CT +/- suspected residual/recurrent disease
• Re-referral of patients diagnosed with osteoradionecrosis requiring surgical intervention to AHP/CNS team to access pre-treatment assessment clinic

**Rehabilitation:**

• HNA completed
• Delivered by specialist AHPs/CNS/dental/prosthetics
• Access to audiology
• Offer psychological support to patient/carers and their families and address any financial concerns/social issues
• Gold standard: hub and spoke model (services based within the centre reaching out to satellite clinics/clinics closer to home)
• Utilise specialist head and neck local support teams to support this, as available

**Survivorship:**

• Head and neck education course
• Wellness days (head and neck specific)
• Offer psychological support to patient/carers and their families and address any financial concerns/social issues

**Children, Teenagers and Young Adults**

Please see Chapter 12 for information on children, teenagers and young adults, including how to make a referral and contact information for the PTC and TYA designated centres in the LCA.

1 [www.headandneckcancer.co.uk/For+professionals/Quality+of+Life+(QOL)/Patient+Concerns+Inventory.aspx](http://www.headandneckcancer.co.uk/For+professionals/Quality+of+Life+(QOL)/Patient+Concerns+Inventory.aspx)
Exemplar UAT Pathway

Timeline (days)

By 14
- Referral source
- Assessment and diagnosis
  - A&E
  - GP or GDP 2 weeks wait
  - Internal Referral Lump/Bump/Rapid Access Clinic
  - Tertiary Referrals
  - Recurrences during surveillance
  - Consultant Clinic Appointment
  - Investigations
  - Smoking cessation intervention +/- ETOH/lifestyle advice
  - Signposting to relevant head and neck specialist allied health professionals as required.
  - Signposting to dental
  - Imaging
  - Pathology
  - Tissue bank information form given to patient
- Multidisciplinary team meeting (MDM)
  - Complete LCA wide minimum dataset for case presentation at the MDM.
  - All cases to have allocated head and neck consultant prior to presentation
  - Treatment plan recommended
  - At risk patients discussed
  - Signposting to relevant Allied Health Professionals as required.
  - Signposting to dental
- Diagnosis and treatment planning
  - Diagnosis given to patient
  - Treatment plan explained
  - Patient informed of support services required
  - Pre-Treatment Assessment Clinic appointment provided
- Multidisciplinary pre-treatment assessment
  - To include AHP/CNS team
  - Information prescription
  - Patient reported outcome measure recorded
  - Multidisciplinary care plan agreed
  - Initiate psychological support
- Treatment
  - Radical – surgery/ oncological
  - Palliative – surgery/ oncological
  - Best supportive care
  - Acute Oncology Service

Initial within 14 days
- Follow-up/ surveillance
  - Post-treatment imaging and clinical follow up
  - Risk stratified follow-up
  - Multidisciplinary Meeting: to discuss all post treatment imaging +/- suspected residual/ recurrent disease or consequences of treatment.
- Rehabilitation and survivorship
  - Delivered by head and neck specialist allied health professionals and clinical nurse specialists using hub and spoke model/ local support teams
  - Audiology
  - Dental
  - Psychological/ social/ financial support
  - Head and neck specific wellness day workshops
  - Head and neck specific education courses

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<th>PATIENT INFORMATION</th>
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LCA HEAD AND NECK/THYROID CANCER CLINICAL GUIDELINES