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# LCA Operational Policy

## Pituitary and Pituitary-Related Tumours

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## 1 Introduction

This operational policy should be read in conjunction with the LCA Brain/CNS Cancer Clinical Guidelines.

### 1.1 Improving outcomes for people with brain and other central nervous system tumours

The guidance on cancer services for people with brain and other central nervous system tumours (CNS tumours) was published in 2006 and gives “advice on the service requirements for patients with CNS tumours”. Pituitary tumours represent approximately 15% of all CNS tumours and both presentation and management differ from the more common CNS tumours. Briefly, patients with pituitary tumours present with symptoms due to local pressure from the pituitary tumour on the optic pathways, through hormone imbalance or as an incidental finding. Management of pituitary tumours frequently involves surgical involvement although the long-term care is almost invariably delivered within endocrinology departments; for this reason a pituitary-specific multidisciplinary team (MDT) is both recommended and appropriate. Pituitary tumours are included within the CNS tumour guidance and are recognised as having specific requirements, with a pituitary-specific MDT working in parallel with but separately from a neuroscience brain tumour MDT.

Although from a strict pathological perspective, pituitary tumours and many other CNS tumours are rarely cancers, *Improving Outcomes for People with Brain and other CNS Tumours*<sup>1</sup>, published by the National Institute for Health and Care Excellence (NICE) in 2006, makes it clear that the concepts of benign and malignant “lack validity when applied in this clinical setting” (p.8). Furthermore, “it is the opinion of the Guidance Development Group that all intrinsic CNS tumours (grade 1–4) should be reported under the cancer waiting times standards” (p.9). The guidance includes malignant glioma, but also low-grade glioma, acoustic neuroma, optic glioma, meningioma and pituitary tumours, which have an entire chapter.

The measures that were used for the CNS (and pituitary) peer review process are included in a separate 2012 document: National Cancer Peer Review Programme.

Manual for Cancer Services: Brain and CNS Measures Version 1.2 [www.mycancertreatment.nhs.uk/wp-content/themes/mct/uploads/2012/09/resources\\_measures\\_Brain\\_and\\_CNS\\_Measures\\_July2011.pdf](http://www.mycancertreatment.nhs.uk/wp-content/themes/mct/uploads/2012/09/resources_measures_Brain_and_CNS_Measures_July2011.pdf).

In April 2013, an updated set of measures were published which will be relevant to future peer review processes. [www.mycancertreatment.nhs.uk/wp-content/themes/mct/uploads/2012/09/resources\\_measures\\_Brain\\_April2013.pdf](http://www.mycancertreatment.nhs.uk/wp-content/themes/mct/uploads/2012/09/resources_measures_Brain_April2013.pdf).

For this reason, the same structures, timelines and governance should apply to pituitary tumours as to any other cancer category.

The guidance on CNS tumours in general and pituitary specifically describes a model including a regional neuroscience pituitary MDT within a neuroscience (i.e. neurosurgical) centre, serving the LCA. It is also recognises that the delivery of sub-specialist services will depend on local circumstances and highlights the additional importance of involvement from more local endocrinology teams in the follow-up and long-term management of pituitary patients.

<sup>1</sup> <http://www.nice.org.uk/nicemedia/live/10905/28963/28963.pdf>

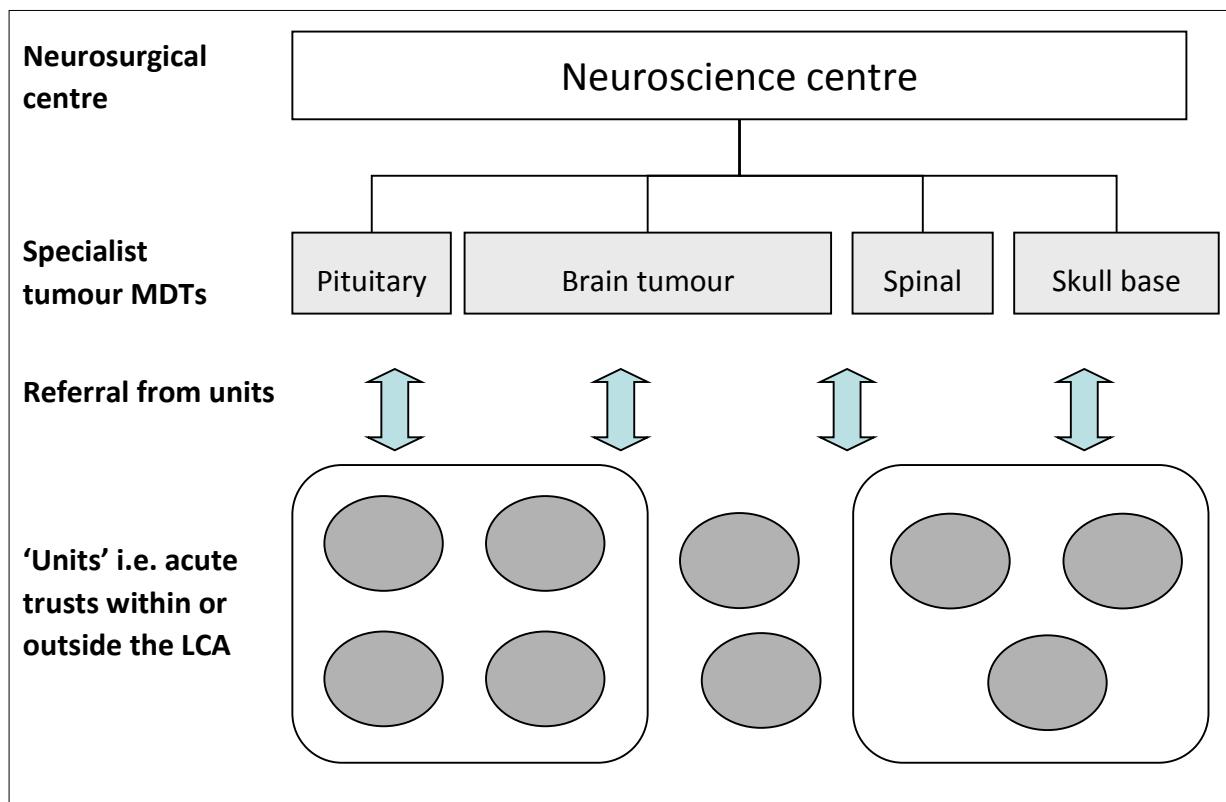
### Recommendations – general

Patients with pituitary, spinal cord or skull base tumours should have their management plan decided by a dedicated specialist MDT.

The relationship between these specialist MDTs and the neuroscience MDT should be clearly defined by local protocols.

All patients should have specialist follow-up as defined by the relevant MDT.

**Figure 1.1: Communication and information flow between specialist MDTs (including pituitary) within a neurosurgical centre and referring centres**



Source: NICE (2006), *Improving Outcomes for People with Brain and Other CNS Tumours*, p.80.

The NICE guidance describes a model where a specialist pituitary MDT within a neuroscience (i.e. neurosurgical) centre receives referrals from and communicates with acute Trusts or ‘units’ within the LCA

In practice, patients with pituitary tumours for whom surgery or radiotherapy might be considered are referred to a specialist pituitary MDT, whereas longer term and adjuvant medical treatment may be delivered by either the specialist centre and/or the local referring acute Trust.

These guidelines outline:

- the scope, roles and responsibilities for a pituitary-specific MDT and the operational framework for the MDT managing pituitary and pituitary-related tumours
- the operational policy for paediatric patients, teenagers and young adults
- the referral process to the pituitary MDT and the interrelationship with endocrinologists from referring hospitals.

## 1.2 Regional considerations

Pituitary and pituitary-related tumours include craniopharyngioma, and other parasellar tumours including meningiomas and cystic lesions that are considered likely to compromise pituitary function. In paediatric practice, craniopharyngiomas predominate. The pituitary MDT should have a specific paediatric pathway which involves an overlapping but distinct team. From 2008, teenagers and young adults (TYA) require the involvement of the regional TYA cancer MDT although decision making remains with the site-specific neurosciences MDT (pituitary) for both paediatric and young adult practice. For these groups, clinical oncology is delivered from The Royal Marsden (Sutton site).

# 2 Multidisciplinary Team Structure, Governance and Responsibilities

“All patients should benefit from assessment by the specialist membership of the pituitary MDT.” Core membership of the pituitary multidisciplinary team (MDT) should reflect that specified in the National Institute for Health and Care Excellence (NICE) guidance.

## 2.1 Responsibility of the MDT

The responsibilities of a neuroscience MDT (p.35, Table 7), centre MDT (p.38, Table 9) and pituitary MDT (p.75, Table 12) are outlined in the NICE guidance. The additional duties (in italics) reflect the fact that the guidance is concentrated on the management of tumours and underplays the importance of endocrine evaluation.

The following reflect the formal duties of a pituitary MDT.

- Confirm diagnosis for optimal management.
- Develop management plans at first presentation.
- Nominate the responsible clinician and/or key worker.
- Identify the individual responsible for the next stage of the management plan.
- Inform the referring team of the management plan.
- Liaise with the local endocrine team at the earliest opportunity.
- Ensure that there are appropriate and timely clinical and biochemical assessments pre- and post-operatively, either locally or at the centre of care.
- Establish pre-operative endocrine control where appropriate.
- Arrange admission for neurosurgical procedure.
- Review patients with recurrent/persistent disease.
- Implement the non-surgical aspects of the management plan.
- Develop MDT protocols for follow-up.
- Act as an educational resource.
- Organise regular site-specific meetings to review pathways.
- Develop evidence-based protocols.
- Manage a database.

- Audit clinical practice.
- Facilitate entry to clinical trials.

## 2.2 Responsibilities of the pituitary lead clinician

The principal responsibilities of the lead clinician are to ensure high-quality services and appropriate clinical management for patients with a pituitary tumour in line with the objectives laid out in the NICE Guidance on cancer services: Improving Outcomes for People with Brain and Other CNS Tumours (2006), hereafter referred to as NICE Brain and CNS IOG 2006

That is:

- To ensure that designated specialists work effectively together in teams such that decisions regarding all aspects of diagnosis, treatment and care of individual patients and decisions regarding the team's operational policies are multidisciplinary decisions.
- To ensure that care is given according to recognised guidelines (including guidelines for onward referrals) with appropriate information being collected to inform clinical decision making and to support clinical governance/audit.
- To ensure that mechanisms are in place to support entry of eligible patients into clinical trials, subject to patients giving fully informed consent.

## 2.3 Neuro-Oncology Disease Site Group (NDSG) meetings

The lead clinician and service improvement lead (coordinator) report to the neurosciences Neuro-Oncology Disease Site Group (NDSG) and attend regular meetings.

## 2.4 Weekly specialist pituitary MDT meeting

*"The neuroscience MDT should meet at weekly intervals to review all new patients and advise on the initial management of their disease in accordance with national Cancer Waiting Times standards."*

NICE Brain and CNS IOG 2006  
[\(<http://www.nice.org.uk/nicemedia/live/10905/28963.pdf>\)](http://www.nice.org.uk/nicemedia/live/10905/28963.pdf)

The pituitary MDT meets weekly to ensure that all patients are discussed promptly following referral. All core members or their arranged cover attend each meeting. There should be an agreed pathway for discussion of paediatric/teenager and young adult cases at least every two weeks.

## 2.5 Attendance at MDT meetings

Core members or their arranged cover should attend at least two-thirds of the MDT meetings each year. Core members must attend at least a half of all MDT meetings each year in person. Attendance at the meetings is recorded by the MDT coordinator and is reviewed by the lead clinician on an annual basis.

## 2.6 Operational policy annual review meeting

The MDT meets weekly to review the operational policy and patient pathways. This meeting is usually chaired by the lead clinician. Any changes made to the operational policy will be discussed in this meeting.

## 2.7 Patients who should be referred to the pituitary MDT

The following patients should be referred to the pituitary MDT **as soon as the diagnosis is made** for management planning:

- all patients with confirmed pituitary mass lesions >1cm, including macroadenomas (secreting or non-functioning), cystic, mixed or indeterminate lesions, including prolactin-secreting macroadenomas
- all patients with suprasellar and hypothalamic lesions including craniopharyngioma
- patients with confirmed Cushing's disease, acromegaly or thyroid stimulating hormone (TSH) hypersecretion and prolactin macroadenoma
- patients with prolactin microadenoma who are refractory or intolerant of dopamine agonist treatment in whom surgery is considered
- patients with recurrent or persistent hormone excess states that may require radiotherapy, long-term medical treatment or end organ surgery
- patients with radiological evidence of tumour recurrence.

Patients who may also be referred for discussion:

- patients with clinical and biochemical evidence of anterior pituitary dysfunction without definable tumour mass: inflammatory, genetic or idiopathic
- patients with hyperprolactinaemia and either a confirmed microadenoma (tumour <1cm) or normal magnetic resonance imaging (MRI), prior to medical treatment.

**It is important to note, however, that any pituitary case for which a referring clinician would like guidance for further management should be discussed at the pituitary MDT.**

# 3 Communication and Patient Support

## 3.1 Communication with GPs and referring consultants

After first discussion at a multidisciplinary team (MDT) meeting, notification by summary is sent to the GP. When treatment is agreed with the patient (decision to treat), either in the outpatient clinic or on the ward following the MDT decision, the GP will be notified by letter. A diagnosis of 'cancer' is rarely relevant to a patient with a pituitary tumour. Most patients are relieved to understand that the tumours are not cancer. However, patients are still highly anxious about the diagnosis of an intracranial tumour and, as well as counselling, communication with primary care is essential. (Also, initial contact with a key worker is essential as patients like to feel there is someone they can access easily who can guide them through the pathway as outlined by the MDT.)

## 3.2 Key worker

At the first MDT patient-management discussion, a key worker is identified who may already have had contact with the patient. The key worker serves as the patient's advocate and liaison with the MDT as well as with extended community teams.

The key worker, in conjunction with the patient, the MDT and other appropriate services including primary care and community palliative care, facilitates access to appropriate services and information, promoting continuity along the patient pathway.

If a more appropriate person is identified as a key worker at any point in the patient's journey, this will be discussed with and agreed by the patient and the new key worker and recorded in the patient's notes. At all stages the key worker will have the most up-to-date and relevant information concerning the patient. It is their responsibility to hand this information over to any subsequent key worker.

### 3.3 Principal clinician

Each patient will have a principal clinician assigned at the first MDT meeting discussion. Often this will be one of the consultants to whom that patient was referred. However, the majority of patients who have not yet seen an endocrine specialist will be assigned a clinician at the first discussion. All principal clinicians involved in the management of the patient during their pathways will be part of the core MDT membership.

### 3.4 Communication with patients and families, and copying letters

Both endocrinology medical staff and the pituitary clinical nurse specialist are the main points of contact for all patients and families.

**Relevant information is available to all patients at each point in their care pathway. Written and verbal information is available from the clinical nurse specialist.**

### 3.5 The role of the clinical nurse specialists

The pituitary clinical nurse specialist role includes:

- acting as or allocating a key worker for all patients under the care of the MDT or seen in the pituitary service
- educating, supporting and counselling patients, providing relevant written information as appropriate
- contributing to the MDT discussion and patient assessment/care planning decisions of the team
- leading on patients' and carers' communication issues for the MDT and preparing and providing written information
- working with the coordinator to facilitate the pathway of the patients referred to the pituitary MDT meeting, ensuring where clinically appropriate that delays are avoided
- working with the clinical staff in preparing the cases for presentation at the MDT meeting
- ensuring that patients are able to access members of the MDT for support and advice as appropriate
- developing nurse-led services as agreed by the MDT, in particular for hormone replacement, medical treatment of pituitary tumours and tumour surveillance
- developing nurse-led services for dynamic pituitary function testing
- referring cases to the MDT meeting for discussion where recurrence is diagnosed during surveillance
- contributing to the management of the service
- contributing to the Trust-wide development of cancer services as requested and working as a member of the cancer nurses forum

- taking responsibility for ensuring that other team members have had appropriate communication skills training
- providing teaching and educational input to relevant courses and providing expert nursing advice and support to other health professionals in the area of pituitary disease
- ensuring that there is effective written and verbal communication between the MDT, referring Trusts, GPs and specialist centres
- working with the Trust's cancer data team, supporting the collection of cancer data and being involved in clinical audit
- leading on the patient satisfaction survey (see [section 3.6](#))
- being involved in research and in clinical audit in the area of pituitary disease.
- ensuring that the results of the patient's holistic needs assessment are taken into account in decision making.

### 3.6 Patient experience and written information

As stated earlier in this document, the clinical nurse specialists are responsible for maintaining relevant and up-to-date patient information for pituitary disease/tumours. Their role is to support the patient and their carers throughout the pathway of care. The clinical nurse specialist will provide information to patients in outpatient departments and by telephone consultation as well as during inpatient stay.

The clinical nurse specialist should undertake a number of initiatives to involve patients and carers and to gather feedback on their experiences of pituitary care. These initiatives may include:

- patient feedback surveys
- focus groups
- carer feedback to staff.

## 4 Composition of the Multidisciplinary Team and Supporting Services

### 4.1 Pituitary neurosurgery

Neurosurgeons who perform pituitary surgery on each site undertake a substantial volume of pituitary work and operate through trans-sphenoidal route and by craniotomy where indicated and utilise endoscopic-assisted techniques. All inpatients are under joint management with the endocrinology team. Established evidence-based protocols are followed for peri-operative hydrocortisone replacement and for management of diabetes insipidus.

24-hour cover for emergencies is provided within the context of the neurosurgical rota, and emergency pituitary patients will almost invariably be transferred to one of the recognised pituitary surgeons the day following admission. In exceptional circumstances, intervention will be undertaken by the on-call neurosurgical team.

This is likely to occur only with:

- immediate life-threatening pituitary apoplexy with obtundation
- severe acute visual deterioration in pituitary apoplexy

- progressive raised intracranial pressure.

In these exceptional circumstances, patients may require pituitary debulking or ventriculoperitoneal shunting. Patients should also be referred on to a member of the core team the following the day for further management. In an emergency, if there is no neurosurgical member of the core team available due to leave, then consideration should be given to referral to another centre where pituitary specialist neurosurgery can be offered.

## 4.2 Endocrinology

Pituitary patients referred from general practice or from other specialty teams (ophthalmology, neurology) will almost invariably be seen by a member of the endocrinology team. Tertiary referrals from outside hospitals will be initially discussed in the pituitary multidisciplinary team (MDT) meeting where an endocrine consultant will be identified if there is none specified. If the referral comes from an endocrinologist at a referring unit, then the initial appointment may be with the endocrine team or the patient may be seen directly in a combined pituitary clinic.

The endocrinology team maintains a specialist daycare facility (Programmed Investigation Unit) that performs baseline pituitary function testing and dynamic testing where required, and provides an environment for the multidisciplinary pre-assessment of patients prior to neurosurgical intervention. Patients will have baseline biochemical pre-operative assessment in all cases and dynamic function testing with functioning pituitary tumours. Dynamic tests can be performed at the centre or may have been performed at referring hospitals.

All pituitary inpatients are jointly managed between the dedicated pituitary neurosurgeons and the endocrine team. The endocrine consultants offer rotational input with consultant cover for leave. Inpatients will also be jointly managed with one of the endocrine or pituitary clinical nurse specialists.

## 4.3 Clinical oncology

Fractionated radiotherapy is required in a significant proportion of pituitary tumours in the event of visible post-operative tumour remnant or persistent biochemical disease, or with radiological or biochemical recurrence. Decision to treat with fractionated radiotherapy is made at the MDT. Single dose radiotherapy (e.g. Gamma Knife) is limited to only a few centres in London, but, where appropriate following MDT discussion, patients may be referred to the nearest centre providing this treatment.

## 4.4 Radiology

There should always be a neuroradiologist with a sub-specialty interest in pituitary and hypothalamic disease available both for the MDT meeting and for urgent enquiries. Computerised tomography (CT) and magnetic resonance imaging (MRI) will be routinely available for patients with known or suspected pituitary tumours.

Petrosal venous sampling used in the diagnosis of Cushing's disease (ACTH secreting pituitary adenoma) is available by an interventional radiologist at each centre.

## 4.5 Neuropathology

Diagnosis of pituitary adenomas is based both on pre-operative biochemical and post-operative histology. A neuropathologist should report diagnostic histological assessment for patients with pituitary or para-

pituitary disease at the MDT. A recently proposed grading system Ki-67: [1% (Bouin-Hollande fixative) or >3% (formalin fixative)], mitoses: [2/10 High Power field (HPF)], p53: positive [10 strongly positive nuclei/10 HPF] for invasive pituitary tumours may be helpful.<sup>2</sup> All post-operative histopathology findings should be discussed at the MDT, since in those patients with increased risk of recurrence, there should be discussion and documentation of surveillance plans. Neuropathology at each centre should be part of the external quality assessment.

#### 4.6 Clinical biochemistry

Although most patients will be referred with biochemical data, all patients have endocrine testing prior to pituitary surgery. Close liaison should be maintained with the biochemistry department through a named consultant biochemist.

#### 4.7 Pharmacy

All specialist drugs used by the endocrinology team have written shared care protocols for communication with general practice and are included in the joint formulary. Close links between the pharmacy lead and division business managers ensure that all drug usage outside of tariff is accounted for, especially for somatostatin analogues, growth hormone (GH) receptor antagonists and recombinant human GH.

#### 4.8 Palliative care and medical oncology

Palliative care is required for true pituitary cancer in exceptionally rare circumstances. Where palliative care is required, patients should have input from a centre's palliative care service, which will be well positioned to identify a local team if relevant. Use of cytotoxic chemotherapy for patients with pituitary tumours is unusual, but when this is indicated, treatment will be discussed with and supported by the clinical oncology team. In the rare diagnosis of pituitary germ cell tumours (germinoma), patients are referred to the supra-regional service at The Royal Marsden.

#### 4.9 Role of MDT coordinator

An MDT coordinator supports each MDT meeting. The coordinator ensures that all patients requiring discussion are added to the meeting agenda, that all necessary diagnostic information (scans, reports etc.) is available, that the management plan agreed at the meeting is recorded and that cancer waiting times data is collected. The MDT coordinator may be a clinical nurse specialist or non-clinical administrator working closely with the clinical nurse specialist, supporting the exchange of information between the specialist team and referring units. Referring units are able to access the MDT coordinator directly to ensure that patients are discussed at the specialist MDT without delay. Requests and the organisation of diagnostic information are coordinated through this role.

<sup>2</sup> Trouillas J et al. (2013), A new prognostic clinicopathological classification of pituitary adenomas: a multicentric case-control study of 410 patients with 8 years post-operative follow-up, *Acta Neuropathologica* 126(1):123–125.

## 5 Diagnosis, Diagnostic and Treatment Pathways

See [Appendix 1](#) for flow charts describing presentation, diagnosis, treatment and follow-up pathways.

### 5.1 Patient management planning decision

Patients may be discussed in the pituitary multidisciplinary team (MDT) meeting at the following stages:

- **At diagnosis:** within 2 weeks of referral to review initial information and plan clinical biochemical and other assessments. At this stage the patient may or may not have been clinically assessed.
- **Pre-surgery:** complete information including biochemical data, clinical assessment and visual fields. This step may be unnecessary if all data are available at diagnosis above.
- **Early post-operative ‘histology’:** following surgery where indicated to review histology and immediate peri-operative endocrine results and magnetic resonance imaging (MRI) results (performed within 48 hours of surgery) where applicable.
- **At 3 months post-operative:** to review post-operative pituitary function testing and MRI. At this stage patients will either exit the pathway or will be referred for additional therapy.
- **Pituitary review:** to review efficacy of non-surgical intervention.
- **Recurrence:** if there is radiological or endocrine suspicion of relapse during surveillance.

### 5.2 Structure of the MDT meeting

The lead clinician is the chair of the MDT meeting and has responsibility for making sure that the meeting runs efficiently and that the appropriate conclusions of each case are summarised so that they can be recorded by the clinical staff and/or MDT coordinator.

Cases are presented by the endocrine team or the pituitary clinical nurse specialist. Case presentation will include name, age, presenting symptoms, findings on examination and all pre-operative endocrine investigations. Radiology and pathology are presented by the appropriate members of the team. All cases should be prepared using a standardised proforma to ensure that all relevant information is available before discussion. The outcomes of the meeting should be clearly recorded to form the basis of the written communication to the patient, the referrer and the GP. Outcomes of MDT discussions should also be recorded on a cancer registry database where possible (e.g. Somerset), to facilitate future data collection regarding MDT activity and performance.

### 5.3 Operational function of the MDT meeting: diagnostic pathway

For the majority of patients, the time of diagnosis of a pituitary tumour is the date of the radiological diagnosis by MRI. In a minority, a biochemical or endocrine diagnosis is made first. The MDT takes the MRI as the point where the diagnostic pathway begins.

Objectives of the diagnostic pathway within the weekly MDT meeting are as follows:

- Review new patients referred with pituitary tumours within the LCA, ensuring rapid and equal access.
- Decide on the appropriateness of further investigations and urgent endocrine evaluation required in order to formulate a management plan.
- Arrange emergency surgical admission where appropriate (unusual).

- Ensure proper documentation of all decisions in clinical notes, in the electronic record and on the electronic database.
- Review the results of additional investigations or assessments.
- Assess the need for surgical treatment.
- Arrange for the patient to see one of the core members within 31 days of referral (ideally with a pituitary MRI) to discuss management plans.
- Ensure that decisions made are communicated to GPs, referring consultants and local endocrinologists.

The diagnostic pathway is completed when a decision to treat (DTT) – surgical or non-surgical – is taken with the patient.

#### 5.4 Treatment pathway

Once a DTT is taken, the treatment pathway is initiated.

- For patients requiring neurosurgery, an admission date is provided as soon as possible, ideally within 31 days from the DTT.
- A pre-assessment will be arranged with the patient
- The patient's GP is informed by letter at the earliest opportunity.

Where medical treatment is advocated, this will normally be commenced immediately, although it may be that the patient is initiated as a booked daycase, e.g. with injectable somatostatin analogue therapy. In those patients treated with temozolomide chemotherapy, consent will be taken and the treatment initiated as a daycare.

During the inpatient stay, patients are jointly managed by neurosurgical and endocrine teams according to defined protocols.

#### 5.5 Follow-up pathway

Following MDT meeting discussion of patient management at approximately 3 months following surgery, many patients will be appropriately discharged for follow-up by referring clinicians or local hospitals.

Before then the MDT will:

- discuss post-operative patients to correlate radiology, endocrine findings and histology to formulate a final diagnosis
- provide a detailed early post-operative summary to referrers and the local endocrinologist
- arrange post-operative biochemical and radiological assessment either local to the patient or at the pituitary MDT centre
- decide on the need for non-operative further tumour management (i.e. medical adjuvant therapy or radiotherapy)
- determine the management of patients with persistent or recurrent tumour or endocrine dysfunction
- ensure feedback to referrers regarding the appropriateness of referral in line with agreed guidelines.

#### 5.6 The regional referral base

The referral base for neuro-oncology for the London Cancer Alliance encompasses a population of around 10 million. However, the catchment for its pituitary services is significantly greater; King's College Hospital

serves a large geographical area including the established catchment area of South East London and Kent and Medway and parts of Surrey. Imperial College Healthcare NHS Trust serves North West London, South West London and parts of Surrey. St George's Healthcare NHS Trust serves South West London, Surrey, West Sussex and Hampshire.

## 5.7 Relationship of the pituitary MDT to referring hospitals

The success of the implementation of the *Improving Outcomes for People with Brain and Other CNS Tumours* guidance is dependent on the relationship between the referring hospital and the pituitary MDT, and the availability and accessibility of its expertise. The MDT is open to the referring units on all occasions that it meets. Clinicians may regularly attend from referring centres, either in person or by video-link. The lead clinician is responsible for at least annual discussion with the clinicians (principally endocrinologists and ophthalmologists) from the referring hospitals. The relationship between endocrinologists from referring units is complex and the involvement and responsibility of the referring hospital in pre-operative diagnostic evaluation and post-operative management may be very significant.

Where patients are identified as having secreting tumours requiring specialist investigation, referring teams are advised to refer patients to the specialist MDT earlier rather than later even if further diagnostic evaluation is proposed, to avoid unnecessary delay and to ensure that treatment deadlines are met. Complex dynamic investigations may be undertaken at the referring unit if this can be achieved in a timely manner, but the option of having dynamic tests and/or imaging at the pituitary MDT centre should be available to all clinicians referring patients to the pituitary MDT. Following initial referral and discussion, it is recognised that some patients will be referred back to the referring endocrinologist without neurosurgical involvement.

All patients with pituitary tumours who are to be referred for neurosurgical treatment should be discussed at the specialist pituitary MDT.

## 5.8 Pituitary MDT and catchment population

Pituitary tumours are based on their size and defined as 'micro-' (<10mm) or 'macro-' (>10mm). The requirement for surgical treatment of the tumour depends both on size and also on the presence of hormone hypersecretion. Prolactin-secreting adenomas seldom require surgical intervention and are managed medically. Non-functioning macroadenomas and the majority of other secreting microadenomas require surgical treatment. Small non-functioning tumours are typically monitored. Craniopharyngiomas and other cystic lesions are also included within the registry since their management is surgical.

Determining the incidence of pituitary tumours is challenging since the largest proportion of tumours that present clinically are prolactin-secreting microadenomas which are treated medically, and for which inclusion in a registry would be unusual outside a clinical study. Other tumours which may also be treated medically or managed conservatively are unlikely to be registered. Surgical series are more likely to be more accurate even if they only include a proportion of the total patients with pituitary adenomas. The quoted incidence rate within the National Cancer Intelligence Network (1995–2000) is 1.66 per 100,000 but this almost certainly represents an underestimate; a more recent study from Belgium measured a prevalence of one case of pituitary adenoma per 1,064 individuals.

## 6 Waiting times, Audit, Service Development and Clinical Trials

### 6.1 Decision to treat (DTT)

When the patient agrees a surgical treatment plan with the neurosurgeon, the date is recorded as DTT.

### 6.2 Cancer waiting times

In accordance with national requirements, a pituitary multidisciplinary team (MDT) centre should monitor cancer waiting times. This must be done for patients who are referred directly from primary care but also for tertiary patients to ensure that patients are managed expediently.

Since the majority of patients are referred from secondary care and are not on a 2 week wait referral, the initial target of first appointment and DTT does not apply. For brain tumours, and by extension for pituitary tumours, the date of diagnosis is usually taken as the date of the diagnostic magnetic resonance imaging (MRI). For patients with hormone excess states (high growth hormone, cortisol or TSHoma), the diagnosis will be taken as the diagnostic blood test.

Current cancer waiting times targets suggest that these patients should receive definitive treatment within 31 days of DTT. Notably, cancer waiting times do not currently apply to pituitary tumours, since these are rarely malignant. Nevertheless, it is recommended practice that, where possible, patients receive definitive treatment within 31 days from DTT.

### 6.3 Pituitary data collection

It is anticipated that data collection will occur across the whole of the London Cancer Alliance catchment and will include patients referred from elsewhere in the region.

### 6.4 Participation in local and regional audit

The lead clinician or nominated deputy should aim to attend at least two-thirds of the relevant tumour board meetings. In addition, the general manager of neurosciences attends these meetings.

### 6.5 Patient satisfaction survey

The MDT will agree on an annual patient satisfaction survey. The MDT will review the results of this survey and agree actions arising at the next annual meeting. Monitoring of action points will be the responsibility of the service improvement lead.

### 6.6 Service improvement lead

One member of the MDT – likely to be the MDT coordinator or clinical nurse specialist – is nominated as the person responsible for ensuring that service improvement is integrated into the functioning of the MDT. The core team of the MDT should complete and periodically update a process map covering the key stages of the patient's pathway from the receipt of the referral to the point of referral on for medical evaluation, surgical treatment, post-operative evaluation and to adjuvant therapy if required. Audit of the process of the pathway will be conducted each 12 months, and summary points identified. A report including an action plan will be prepared and produced by the MDT to cover service improvements, including addressing patient waiting times, and any necessary changes to the process map. The report will be prepared by the service improvement lead and lead clinician.

The network service improvement lead will discuss priorities in the report and action plan with the lead for service improvement and agree implementation arrangements. Data before and after implementation of the highest priority item in the action plan will be collected and compared.

## 6.7 Roles and responsibilities of service improvement lead

- To work with the lead clinician and MDT members to identify key service improvement priorities relating to the agreed clinical care pathway.
- To undertake mapping exercises which meet the criteria for peer review annually.
- To oversee the production of a pathway map and action plan for service improvement which addresses patient waiting times, identifies risk areas and supports coordination of care.
- To promote service improvement within the MDT, encouraging colleagues to support and participate in service improvement activities.

## 6.8 Participation in approved clinical trials

Where applicable, patients will be invited to participate in clinical trials. This will be discussed during clinic visits but the possibility might be identified at the MDT meeting.

# 7 Referral to the Multidisciplinary Team

## 7.1 Referral to the MDT (internal or external)

Referrers have access to and may engage any member of the core team. Contact details of all core members, particularly those of the MDT coordinator, should be available to all referring clinicians. Referrals are all directed to the pituitary MDT coordinator. Where possible, relevant biochemical investigation results should be included on the MDT referral proforma. However, to avoid delays for patient discussion and hence the decision to treat (DTT), any outstanding pituitary function testing can be planned at the pituitary MDT centre, particularly if planning for those investigations is complex at the referring hospital. Ideally, pituitary imaging from other centres should be transferred via the Image Exchange Portal (IEP) for upload at the pituitary MDT centre prior to the MDT meeting.

As a rule, all new patients are discussed at the next MDT meeting.

### 7.1.1 Advice only

For some patients it may not be necessary to be seen at the specialist centre as there may be no need for surgery. The details of such patients and the proposed treatment plan will still be stored electronically (ideally using a cancer registry database) under a patient number. Referrers are welcome to attend meetings. Video-conferencing will be helpful for contact with distant hospitals.

## 7.2 Referral details

### 7.2.1 Clinical data

Clinical data may or may not be complete. As a minimum it should indicate the presenting and any other associated symptoms and any important co-morbidities. Clinical details of ophthalmic symptoms are essential.

### **7.2.2 Biochemical data**

Any patient with a pituitary tumour should have a prolactin measurement at the earliest opportunity. Referral can be made either prior to or with endocrine evaluation. Any missing endocrine tests will be arranged by the pituitary MDT centre.

The full pituitary order set includes:

- TFT (fT4, fT3 and TSH)
- prolactin (and prolactin after dilution if relevant, depending on type of prolactin assay)
- random GH, IGF-1
- cortisol (0900 preferred)
- FSH/LH, oestradiol (female) or testosterone (male), SHBG.

### **7.2.3 Imaging**

For referrals outside the pituitary MDT centre, radiology should be sent in advance of the meeting, via IEP, to allow the neuroradiologist to review the imaging prior to the MDT meeting.

### **7.2.4 Ophthalmic assessment**

Where available, acuities and formal perimetry should be included in the referral or, alternatively, a clinical assessment of visual fields.

## **7.3 Inclusion in the MDT meeting**

Where possible, proformas or letters including the details outlined above should be sent to the pituitary MDT coordinator 48 hours before the meeting to allow sufficient time for the neuroradiologist to review the imaging prior to the meeting. However, any emergency patients can be included at the last minute. It is the responsibility of the MDT coordinator to ensure that the relevant radiology is available. Generally, patients should be discussed at the next meeting following receipt of their referral.

The agreed management plan for each patient should be clearly documented. It is recommended that this management plan is recorded electronically, and where possible on a cancer registry database. This documentation should be uploaded within 48 hours of discussion. In addition, copies are sent (via post and by email) to referrers, the GP and to relevant personnel. On each occasion where a patient is reviewed a second or subsequent time by the MDT, a new record outlining the agreed management plan at that time will be generated and treated as above.

## **7.4 Urgent/emergency referrals**

Urgent admission may be required in the following circumstances:

- rapidly progressive visual disturbance
- clinical or radiological diagnosis of pituitary apoplexy
- evidence of raised intracranial pressure.

For urgent transfer/admission requests, we recommend contacting the endocrinologist and the neurosurgical core team member via the hospital switchboard to arrange transfer or admission. In a rare out-of-hours emergency (see [section 4.1](#)), the on-call neurosurgical team can be contacted through switchboard.

In urgent and emergency circumstances, clinical decisions may need to be made outside the MDT meetings. In such cases, the consultant in charge of the patient will initiate or refer for treatment without delay and the management plan will be presented at the next MDT meeting.

## 7.5 Direct referral from GP

Once pituitary disease is suspected, GPs can refer patients to their local hospital but may refer directly to the specialist centre. Examples where it would be appropriate to refer directly before radiological evidence would include:

- bitemporal visual field defect detected by GP or high street optician
- clinical or biochemical features of hypopituitarism
- elevated prolactin
- strong clinical and biochemical suspicion of acromegaly or cortisol excess.

In these circumstances the endocrine consultants will arrange either an MDT review or clinic appointment. Patients with visual field defect should be referred as 2 week wait but this will not materially affect their pathway.

GPs should always request a prolactin and ideally a full baseline biochemical assessment (see [section 4.2](#)) if they suspect pituitary disease and the patient should be referred to the endocrine department or to the pituitary service. The unit may opt to investigate and stage the tumour depending on their level of interest. However, in cases of potentially resectable tumours, long delays should be avoided in order to comply with the cancer waiting times.

## 7.6 Referrals from ophthalmology and neurology

Patients with mass effect – typically visual field defects or headache as the primary symptom – will often be diagnosed with a pituitary tumour without any available biochemical details or endocrine clinical information. Waiting for an extensive biochemical work-up should not delay referral to the MDT, particularly in those patients referred by non-endocrinologists. However, the single most useful biochemical marker is a serum prolactin which will identify patients who may be treated medically even with a large pituitary tumour and associated significant visual field defect. Therefore, this should be obtained if at all possible.

## 7.7 Referral of paediatric patients

Pituitary tumours are rare in paediatric practice. Children with growth failure or endocrine disturbance will typically be referred to the paediatric endocrinologist. Mechanisms should be in place to discuss these patients, where necessary, at the specialist centre MDT meeting, with representation from the clinicians managing these patients.

Emergency presentation with raised intracranial pressure out-of-hours should be directed to the on-call neurosurgical team for immediate consideration of ventriculo-peritoneal shunting. These patients will be immediately referred on to the paediatric endocrinologist and designated paediatric neurosurgeons.

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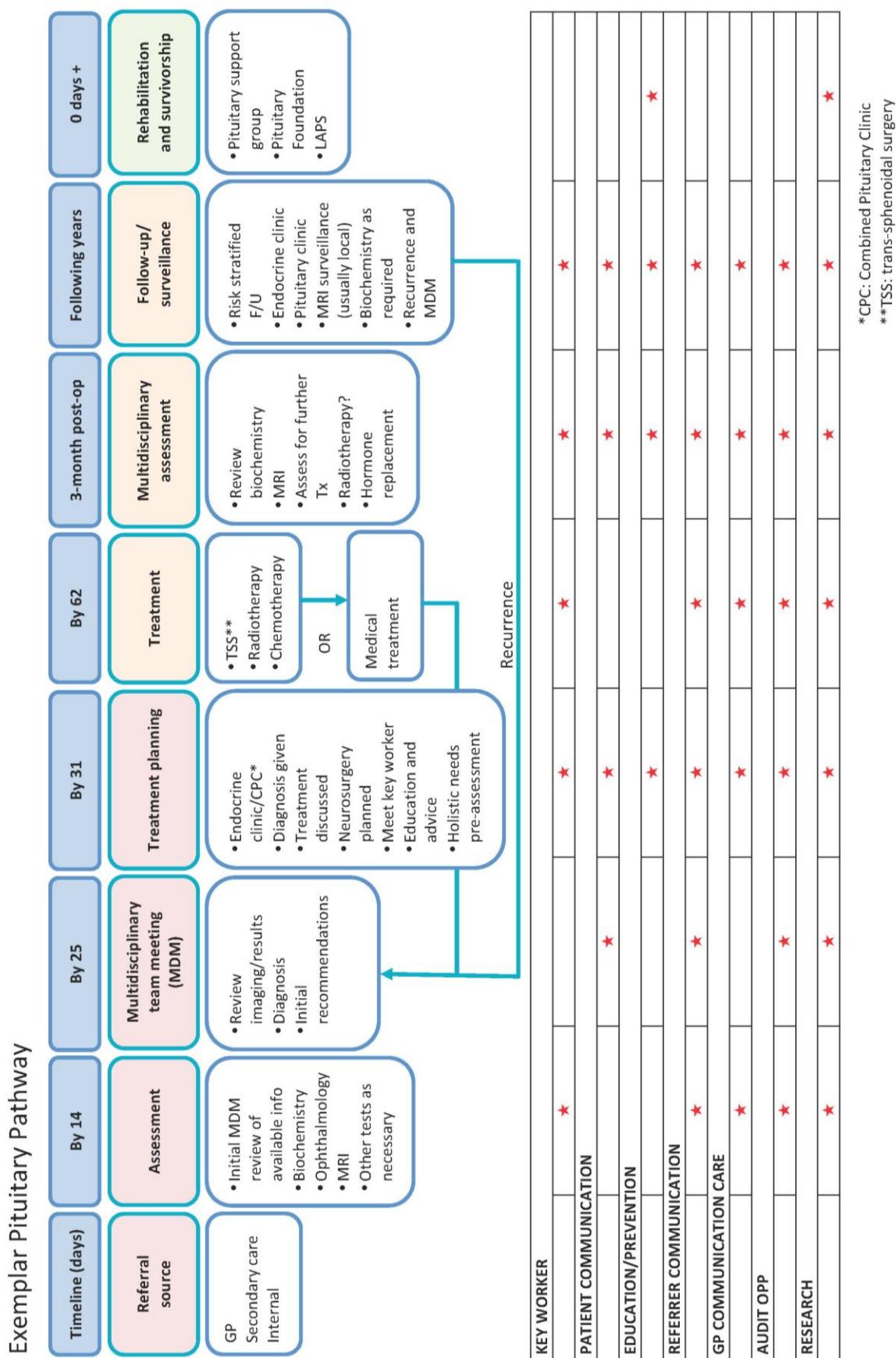
## **7.8 Interface with neuro-oncology MDT meeting**

Where the first presentation is with mass effect, patients may be initially referred to the brain tumour (neuro-oncology) MDT. Patients identified as having pituitary disease or tumours in the neuro-oncology MDT meeting should be referred to the pituitary MDT meeting. In certain patients, e.g. with parasellar meningioma, discussion in both meetings may be required.

## **7.9 Intra-hospital referrals**

Internal referrals should be discussed in the next MDT meeting.

## Appendix 1 Exemplar Pituitary Pathway



KEY WORKER	PATIENT COMMUNICATION	EDUCATION/PREVENTION	REFERRER COMMUNICATION	GP COMMUNICATION CARE	AUDIT OPP	RESEARCH
★	★	★	★	★	★	★
	★	★	★	★	★	★
		★	★	★	★	★
			★	★	★	★
				★	★	★
					★	★
						★

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