King's College Hospital NHS
NHS Foundation Trust

Guidance on Cancer service:
Brain and other CNS tumours (Pituitary)

Operational Policy for the Care of patients
with pituitary and pituitary related tumours

South East London Cancer Network
Kent and Medway Cancer Network

OPERATIONAL POLICY 2011

June 2011

Agreed By:

…….. **Date:**

Lead Clinician Simon Aylwin

(Integrated) Cancer Centre

Operational Policy for the Care of patients with pituitary and pituitary-related tumours

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1. Introduction

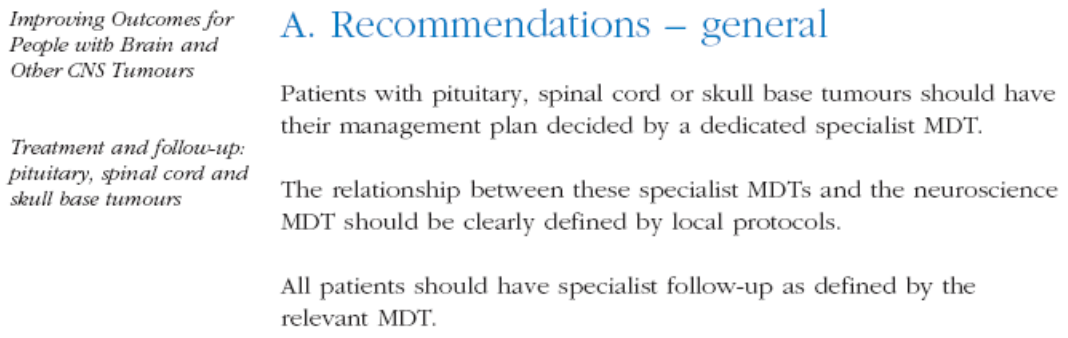
1.1. Improving outcomes for people with brain and other CNS tumours.

The Guidance on cancer services for people with brain and other CNS tumours (or '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 and for this reason a pituitary specific 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, the Brain and other CNS tumour IOG published 2006 makes it clear that the concept of benign and malignant 'lacks validity when applied in this clinical setting' (p8). 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' (p9). The IOG includes malignant glioma, but also low grade glioma, acoustic neuroma, optic glioma, meningioma, etc and pituitary tumours, which have an entire chapter.
http://www.nice.org.uk/nicemedia/pdf/CSG_brain_manual.pdf
http://www.cancer.nhs.uk/rehabilitation/documents/Gateway_11008_DEC_rehab_20081117.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 one or more regional cancer networks. It is also recognised 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.



Improving Outcomes for People with Brain and Other CNS Tumours

Treatment and follow-up: pituitary, spinal cord and skull base tumours

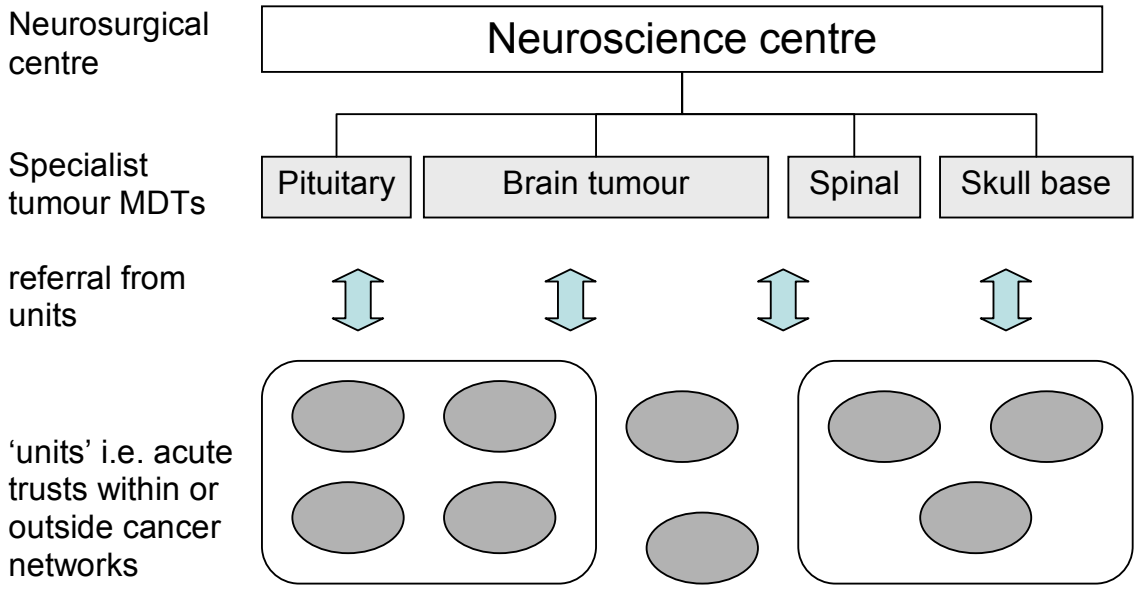
A. Recommendations – general

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.

Improving outcomes for patients with brain and other CNS tumours, NICE guidance of cancer services



The brain and other CNS tumours Improving outcomes 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 one or more cancer networks.

In practice, patients with pituitary tumours in 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.

This document outlines

- The scope, roles and responsibilities for a Pituitary-specific MDT and the operational framework for the MDT managing pituitary and pituitary-related tumours hosted by King's College Hospital (KCH), hereafter referred to as the 'Pituitary MDT'.
- The operational policy for paediatric patients, teenagers and young adults
- The referral process to the Pituitary MDT and the inter-relationship with endocrinologists from referring hospitals

1.2. Regional considerations

KCH provides specialist neurosurgery including pituitary tumour management principally to the South East London Cancer Network and Kent and Medway Cancer Network as well as other hospitals from neighbouring regions within Surrey and Sussex who refer their patients to KCH (total catchment area 3.8 million). The delivery of specialist care for pituitary tumours within the region is co-coordinated by the KCH Pituitary MDT and additional specialist care and follow-up is provided by endocrinologists in the referring hospitals. KCH is part of the Integrated Cancer Centre in partnership with Guy's and St Thomas' (GSTFT). Clinical oncology services for adults are provided by GSTFT for patients within SE London and by the Kent and Medway cancer centre in Maidstone.

'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 has a specific paediatric pathway, and involves an overlapping but distinct team. From 2008, adolescents and young adults (TYA) require involvement of the regional TYA cancer MDT although decision making remains with the site specific SELCN pituitary MDT at KCH for both paediatric and young adult practice. For these groups, clinical oncology is delivered from the Royal Marsden (Sutton).

1.3. Pituitary surgery and neuroscience at KCH

The regional neurosciences centre was established at KCH in 1995, and is supported by a purpose built endocrine investigation unit. Pituitary surgery is carried out by three neurosurgeons with subspecialty expertise in pituitary surgery, and supported by endocrinologists, neuroradiologists and neuropathology on site. Management of patients through the pathway is facilitated by a pathway co-ordinator and patients and families are supported by Clinical Nurse Specialists who are integral within the MDT.

The pituitary MDT operates in an environment has been specifically built for the running of multi-disciplinary meetings, with access to all patient data systems, on-line access to imaging from GSTFT, the latest information technology and the potential for video conferencing.

Our aim is to provide a bespoke package of care for patients with pituitary tumours, integrating the care delivered at KCH with aspects of patient management delivered by endocrinologists within the region. The diagnostic and treatment pathways are co-ordinated by the SELCN pituitary MDT can provide a complete package of care from the beginning of the patient pathway at diagnosis, through to surgical treatment, radiotherapy and to restoration of normal pituitary function. The extent to which pre-operative investigation and post operative management are delivered from KCH will depend on the individual referrer and patient requirements.

2. MDT Structure, governance and responsibilities

"All patients should benefit from assessment by the specialist membership of the pituitary MDT"

For a decade or more, patients with pituitary tumours requiring resection or radiotherapy have been seen in a multidisciplinary 'combined pituitary clinic' (CPC) with radiological review meeting prior to the clinic itself. The KCH Pituitary MDT weekly meeting (Pituitary MDM) was formally initiated in May 2007 after a 6 month consultation process in response to the growing activity and prompted by the publication of the CNS tumour Improving Outcomes Guidance. Core team members or their cover attend the MDM on a weekly basis and MDT attendance is recorded. The MDM has identified representation at the Tumour Working Group (TWG or NSSG).

Core membership of the pituitary MDT reflects the IOG (p76 table 13). In addition, representatives from other hospitals regularly attend the pituitary MDM.

2.1. Responsibility of the MDT

The responsibilities of a neuroscience MDT (p35 table 7) cancer network MDT (p38 table 9) and pituitary MDT (p75 table 12) are outlined in the IOG. The bullet points below represent the synthesis of these responsibilities since a 'cancer network' MDT outside of the neurosciences centre does not exist as an entity within the management of pituitary tumours. The additional duties (in italics) reflect the fact that the IOG is orientated to the management of tumour and underplays the importance of endocrine evaluation. In our opinion these should be a core to any future national guideline.

The following reflects the formal duties for a multi-disciplinary pituitary team

- Confirm diagnosis for optimal management
- Develop management plans at first presentation
- Nominate responsible clinician and/or key worker
- Identify individual responsible for next stage of management plan
- Inform the referring team of the management plan
- *Liaise with local endocrine team at the earliest opportunity*
- *Ensure appropriate and timely clinical and biochemical assessment pre- and post operatively either locally or at the centre*
- *Establish preoperative endocrine control where appropriate*
- *Arrange admission for neurosurgical procedure*
- Review patients with recurrent/persistent disease
- Implement 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 pituitary Lead Clinician

10-2K-101	Single Named Lead Clinician with Agreed Responsibilities
Compliance	*Named lead clinician for the MDT agreed by the lead clinician of the host trust.The written responsibilities agreed by the lead clinician of the MDT and lead clinician of the host trust.*
Notes	There should be a single named lead clinician for the MDT who should then be a core team member.

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 as laid out in the Manual of Cancer Service Standards.

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.

(Manual of Cancer Standards 2004)

2.3. KCH Pituitary MDT Core Team Members definition

10-2K-102	Core Team Membership
Compliance	*The name of each core team member with their role, agreed by the lead clinician of the MDT* *The job plans of the relevant specialists.* *The documentation of completion of a course of training in microvascular surgery by one of the core surgical members.*
Notes	The MDT should provide the names of the core team members for named roles in the team relevant to the group of tumours it deals with. **1.**The core team common to all NSMDTs should include: • a neuroradiologist; • two neuropathologist**s**. • a clinical oncologist; • a nurse**,** who should be put forward for review against the MDT nurse measures in this section; • a MDT coordinator**/**secretary; • a NHS- employed member of the core or extended team should be nominated as having specific responsibility for users' and carers' issues and information; • a member of the core team should be nominated as the person responsible for ensuring that recruitment into clinical trials and other well designed studies is integrated into the function of the MDT. In addition, the following should be included: **3.** For a NSMDT declared as dealing with pituitary tumours: a neurosurgeon with a practice in pituitary surgery or ENT surgeon with a practice in pituitary surgery; • an endocrinologist with a practice in pituitary disorders.
10-2K-103	Extended Team Membership
Compliance	*The name of each extended team member with their role, agreed by the lead clinician of the MDT.*
Notes	For a NSMDT declared as dealing with pituitary tumours: • an ophthalmologist with a practice in visual disturbance due to CNS malignancy; • an AHP agreed as having responsibility for liaison with rehabilitation services.
10-2K-106	Cover Arrangements for Core Members
Compliance	*The written arrangements agreed by the lead clinician of the MDT.*
Notes	The MDT should agree cover arrangements for each core member. *Core members should arrange cover only from within the discipline of the core member type as listed in measure*

2.4. KCH Pituitary MDT Core Team Members (adult)

name	position	hospital	cover
Specialist pituitary neurosurgeons			
Mr Nick Thomas	Consultant Neurosurgeon	KCH	Mr Sinan Barazi
Mr Peter Bullock	Consultant Neurosurgeon	KCH	Mr Sinan Barazi
Mr Sinan Barazi	Consultant Neurosurgeon	KCH	Mr Nick Thomas
Specialist Endocrinologists			
Dr Simon Aylwin (MDT lead)	Consultant Endocrinologist	KCH	Prof McGregor
Prof Alan McGregor	Consultant Endocrinologist	KCH	Dr Simon Aylwin
Dr Jackie Gilbert	Consultant Endocrinologist	KCH	Dr Simon Aylwin
tbc	Consultant Endocrinologist	GSTFT	tbc
Dr John Miell	Consultant Endocrinologist	Lewisham	Endocrine SpR
Neuroradiologists			
Dr Tim Hampton	Consultant Neuroradiologist	KCH	Dr Naomi Sibtain
Neuropathologists			
Dr Istvan Bodi	Consultant Neuropathologist	KCH	Dr Al-Sarraj
Dr Andrew King	Consultant Neuropathologist	KCH	Dr Al-Sarraj
Clinical Oncologists			
Dr David Landau	Consultant Clinical Oncologist	GSTFT	Dr Ron Beaney tbc
Clinical Biochemistry			
Mr Roy Sherwood	Consultant Biochemist	KCH	Ms Hagosa Abraha
Clinical Nurse specialists			
Ms Patsy Coskeran	Pituitary nurse specialist	KCH	Ms Nadia Gordon
Ms Nadia Gordon	Pituitary nurse specialist	KCH	Ms Patsy Coskeran
Co-coordinator			
Ms Julia Palasinska	Pituitary coordinator	KCH	Ms Maria Campbell
Extended team members			
Mr Paul RiordanEva	Consultant Ophthalmologist	KCH	
tbc	Allied Health professional for rehab liaison		
Dr Pauline Kane	Consultant Radiologist (petrosal sinus sampling)	KCH	
Mr Sefton Bentley	Investigation unit manager	KCH	

2.5. KCH Pituitary MDT Core Team Members (paediatric, teenage and young adult)

Specialist pituitary surgeons			
Mr. Nick Thomas	Consultant Neurosurgeon	KCH	Mr Chris Chandler
Specialist Endocrinologists			
Dr Simon Aylwin (MDM lead)	Consultant Endocrinologist	KCH	Dr Buchanan
Dr Charles Buchanan	Consultant Paediatric Endocrinologist	KCH	Dr Aylwin
Neuroradiologists			
Dr Tim Hampton	Consultant Neuroradiologist	KCH	Dr Naomi Sibtain
Neuropathologists			
Dr Andrew King	Consultant Neuropathologist	KCH	Dr Al-Sarraj
Clinical Oncologists			
Dr Frank Saran	Consultant Clinical Oncologist	RMH	
Clinical Nurse specialists			
Ms Kate Davies	Paediatric endocrine CNS	KCH	Ms Nadia Gordon
Co-coordinator			
Ms Julia Palasinska	Endocrine pathway coordinator	KCH	Maria Campbell

2.6. NDSG meetings

The lead clinician and service improvement lead (co-ordinator) report to the Neurosciences NSDG and attends regular meetings.

10-2K-104	MDT Attendance at NDSG Meetings
Compliance	*The attendance record(s) of the NDSG(s).*
Notes	The NSMDT should send a core team member as a representative to at least two thirds of the meetings of the NDSGs associated with the NSMDTs which the team under review, relates to.

2.7. Weekly Specialist Pituitary MDT meeting

10-2K-105	Patient Management Planning Meeting
Compliance	*Attendance records of the meetings.* *Written procedure agreed by the lead clinician of the MDT.* *Where relevant, the frequency of meeting, agreed by the Chair of the NDSG.*
Notes	*Note: NSMDTs dealing only with the specialised tumour groups (pituitary, skull base and spine) should meet at agreed frequencies, and each MDT comply with the rest of this measure.*

"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."

The Pituitary MDT meets weekly to ensure all patients are discussed within days of referral and is held on Wednesday morning at 1100 in The Belgrave MDM Seminar Room Ground floor, King's College Hospital. All core members or their cover attend each meeting. Once a month (first wed of each calendar month) the pituitary MDM includes the paediatric/TYA cases.

Within the IOG a distinction is made between the neuroscience specialist MDT and the cancer network MDT. KCH serves two networks and effectively provides the role for both specialist and CN MDT, liaising with referring clinicians and local endocrinologists directly rather than through an intermediary cancer network MDT

2.8. Attendance at MDT meetings:

10-2K-107	Core Members Attendance
Compliance	*Attendance record of the MDT.* *Note:The intention is that core members of the team should be personally committed to it, reflected in their personal attendance at a substantial proportion of meetings, not relying instead on their cover arrangements. Reviewers should use their judgment on this matter and should highlight in their report where this commitmentis lacking.*
Notes	Core members or their arranged cover (see measure should attend at least two thirds of the number of meetings.

Core members or their arranged cover should attend at least 66% 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 co-coordinator and is reviewed by the lead clinician on an annual basis.

2.9. Operational Policy Annual Review Meeting

10-2K-108	Operational Policy Meeting
Compliance	*The minutes of at least one meeting agreed by the lead clinician of the MDT to illustrate the recording of at least some operational policies.*
Notes	Besides the regular meetings to discuss individual patients the team should meet at least annually to discuss, review, agree and record at least some operational policies

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

2.10. Patients that should be referred to the pituitary MDT

10-2K-109	Policy for Patients to be Discussed by the MDT
Compliance	*The operational policy agreed by the lead clinician of the MDT.*
Notes	There should be an operational policy for the team which specifies that all new cancer patients will be reviewed by the NSMDT at least: • post initial radiological diagnosis, pre-, potential histological confirmation; • post histological confirmation pre-, potential definitive surgical procedure; • post definitive surgical procedure, pre-, potential adjuvant treatment; • any other times as are agreed in the area-wide patient pathways. *Notes:As stated in the Cancer Reform Strategy, the care of all patients should be formally reviewed by an MDT.*

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

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

Patients that may also be referred for discussion

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

3. Communication and patient support

3.1. Communication with GPs and referring Consultants.

10-2K-110	Informing the GP of the Diagnosis
Compliance	*The policy agreed by the lead clinician of the MDT.* *The results of the audit.*
Notes	The MDT should have agreed a policy whereby after a patient is given a diagnosis of cancer, the patient's GP is informed of the diagnosis by the end of the following working day. The MDT should have completed an audit against this policy of the timeliness of notification to GPs of the diagnosis of cancer.

After first discussion at an MDM, notification by summary is sent to the GP by the end of the following working day. 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(within 48 hours). 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 was Keyowrker is essential as patients likes to feel there I someone who they can assess easily who can guide them through the pathway as outlined by the MDT)

3.2. Key worker

10-2K-111	Key Worker Policy
Compliance	*The written policy agreed by the lead clinician of the MDT.* *Reviewers should spot check some relevant patients' case notes.*
Notes	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 for each individual patient and the name and contact number of the current key worker is recorded in the patient's case notes.

At the first MDM patient management discussion a key worker is identified who may already have had contact with the patient (contact is normally made within the first 24 hours once referral is received). The key worker will almost always be a CNS. The Keywoker serves as the patients advocate and liason with the MDT as well as with extended community teams.

The Key worker, in conjunction with the patients, MDT and other appropriate services, including primary care and community palliative care, ensures access to appropriate service 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 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. Principle clinician

10-2K-112	Principal Clinician Policy
Compliance	*The written policy agreed by the lead clinician of the MDT.* *Reviewers should spot check some relevant patients' case notes.* *The reviewers should enquire as to the working practice of the team with regard to this policy.*
Notes	There should be an operational policy for the MDT whereby: • at each stage of the patient's pathway, a single named principal clinician for that patient is identified; • the name of the patient's current principal clinician is recorded in the casenotes; • the nature of the role and the name of each current principal clinician, is communicated to the patient.

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

3.4. Communication with Patients and Families & Copying letters

10-2K-117	Patients' Permanent Consultation Record
Compliance	*The reviewers should enquire of the working practice of the team and see anonymised examples of records given to patients. Note:It is recommended that they are available in languages and formats understandable by patients, including local ethnic minorities and people with disabilities. This may necessitate the provision of visual and audio material.*
Notes	The MDT should be offering patients the opportunity of apermanent record or summary of at least a consultation with the patient and the doctor when the following are discussed: • Diagnosis • Treatment options and plan • Relevant follow up (discharge) arrangements

Both endocrinology medical staff and the Pituitary CNS are the main points of contact for all patients and families. The Clinical Nurse Specialist/s are available via pager, Monday to Friday. (Patient Swith concerns are advise to call in at set times via the telephone consulatation clinic which the nurse specialist runs). All patients receive copies of the MDM summaries and any other correspondence, this policy has been in place from January 2005. The summaries produced after the MDM discussions are comprehensive in nature to ensure that patients are able to have access to all the facts in their case.

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

3.5. The Role of the Clinical Nurse Specialists

10-2K-113	Attendance at the National Advanced Communications Skills Training
Compliance	*Written confirmation of the MDT members who have attended the National advanced communications skills training programme*
Notes	At least those core members of the team who have direct clinical contact with patients should have attended the national advanced communications skills training.
10-2K-114	Specialist Training for Core Nurse Member
Compliance	*Confirmation of successful completion of the course.*
Notes	The MDT should have at least one core nurse member who should have successfully completed a programme of study in their specialist area of nursing practice, which has been accredited for at least 20 credits at 1st degree level.
10-2K-115	List of Responsibilities for Core Nurse Members
Compliance	*The list of responsibilities, agreed by the lead clinician of the MDT and the core nurse member(s).*
Notes	The MDT should have agreed a list of responsibilities with each of the core nurse members of the team, which includes the following: • Contributing to the multidisciplinary discussion and patient assessment/care planning decision of the team at their regular meetings; • Providing expert nursing advice and support to other health professionals in the nurse's specialist area of practice; • Involvement in clinical audit; • Leading on patient and carers' communication issues and co-ordination of the patient pathway for patients referred to the team - acting as the key worker or responsible for nominating the key worker for the patient's dealings with the team.
10-2K-116	List of Additional Responsibilities for Core Nurse Member
Compliance	*The list of responsibilities agreed by the lead clinician of the MDT and the relevant core nurse member(s).*
Notes	The MDT should have agreed a list of responsibilities with at least one of the core nurse members of the team, which in addition to the items listed in measure ….includes: • Contributing to the management of the service • Utilising research in the nurse's specialist area of practice..
10-2K-126	Specialist Clinic Attendance by Core Nurse MDT Members
Compliance	*The named members and their timetables agreed by the lead clinician of the MDT and the relevant line manager of the nurses' employing trust(s).*
Notes	Each specialist nurse MDT core member should have time specified for attendance at a multidisciplinary specialist clinic as agreed and defined in the relevant measures for the network board and the trusts

In the SELCN Pituitary MDT, The Pituitary Clinical Nurse Specialist role includes:

- To be the key worker and first point of contact for all patients under the care of the MDT.
- To educate support and counsel patients providing relevant written information as appropriate.
- To lead on patient and carer's communication issues for the MDT and to prepare and provide written information.
- To work with the co-ordinator to facilitate the pathway of the patients referred to the Pituitary MDM, ensuring where clinically appropriate that delays are avoided.
- To work with the clinical staff in preparing the cases for presentation at the MDT meeting.
- To ensure that patients are able to access members of the MDT for support and advice as appropriate.
- To develop nurse led services as agreed by the MDT in particular for hormone replacement and tumour surveillance
- To refer cases to the MDM for discussion where recurrence is diagnosed during surveillance
- To contribute to the Trust wide development of cancer services as requested and work as a member of the Cancer Nurses Forum.
- To take responsibility for ensuring that other team members have had appropriate communication skills training

- To provide teaching and educational input to relevant courses and provide expert nursing advice and support to other health professionals in the area of pituitary disease.
- To ensure effective written communication and verbal communication between the MDT, referring Trusts, GPs and specialist centres.
- To work with the Trust Cancer Data Team supporting the collection of cancer data and involve in clinical audit
- To lead on the patient satisfaction survey (see below)
- To be involved in research in the area of pituitary disease

3.6. Patient experience and written information

10-2K-118	Patients' Experience Exercise
Compliance	*The results (complete or in progress) of the exercise.*
Notes	The MDT should have undertaken or be undertaking an exercise during the previous two years prior to the review to obtain feedback on patients experience of the services offered. The exercise should at least ascertain whether patients were: • offered a key worker; • offered the MDT's information for patients and carers (written or otherwise) • offered the opportunity of a permanent record or summary of a consultation at which their treatment options were discussed; • given the name of their principle clinician and an explanation of the role of principle clinician.
10-2K-119	Outcome of Patients' Experience Exercise
Compliance	*The results of the exercise. A report of the action taken.*
Notes	Exercises in measure 10-2K-119 having been completed during the previous two years should have been presented and discussed at an MDT meeting and the team should have implemented at least one action point arising from the exercise.
10-2K-120	Provision of Patient Written Information
Compliance	*The written (visual and audio if used - see note below) material.* *Notes: It is recommended that it is available in languages and formats understandable by patients including local ethnic minorities and people with disabilities. This may necessitate the provision of visual and audio material. For the purpose of self assessment, the team should confirm the written information which is routinely offered to patients.*
Notes	The MDT should provide patients and carers with written material which includes: • information specific to the MDT about local provision of the services offering the treatment for brain and CNS malignancies; • information about patient involvement groups and patient selfhelp groups; • information about the services offering psychological, social and spiritual/cultural support, if available; • information specific to brain and CNS malignancies about the diseases and their treatment options (including names and functions/roles of the team members treating them).

As described earlier in this document the Clinical Nurse Specialists are responsible for maintaining relevant and up to date patient information for Pituitary disease/tumours. The CNS's role is to support the patient and their carers throughout the pathway of care. The CNS will provide information to patients in outpatients, by telephone consultation as well as during inpatient stay and are accessible via the hospital paging service. At present there is no out of hours service.

We undertake a number of initiatives to involve patients and carers and gather feedback on their experiences of Pituitary care at King's. These initiatives have included:

- On line patient survey
- Focused groups
- Carer feedback to staff
- A patient diary with patients recording their admission journeys

We are piloting a storybook for patients to complete during and after their pathway to be used in discussion with us.

4. Composition of the MDT and supporting services

4.1. Pituitary Neurosurgery

10-2K-122	50% Specified Surgical Programmed Activities
Compliance	*The named members and their job plans agreed by the lead clinician of the MDT and the relevant clinical directors of the surgeons' employing trust(s).*
Notes	Each surgical core MDT member should have 50% of their direct clinical care programmed activities specified for the management of neuro-oncology patients. This should include time specified for attendance at a multidisciplinary specialist clinic as agreed and defined in the relevant measures for the network board and the trusts

10-2K-124	Specified Surgical Programmed Activities- Applicable to NSMDTs dealing with pituitary tumours
Compliance	*The named members and their job plans agreed by the lead clinician of the MDT and the relevant clinical directors of the surgeons' employing trust(s).*
Notes	Each surgical core MDT member should have specified DCC Pas for attendance at a multidisciplinary specialist clinic as agreed and defined in the relevant measures for the network board and the trusts

Surgery for Pituitary tumours within SE London and Kent & Medway CNs is carried out on the Kings College Hospital site. There are twelve neurosurgeons on the King's Denmark Hill site of whom Mr Nick Thomas, Mr Peter Bullock and Mr Sinan Barazi are recognised members of the adult pituitary MDT. Both surgeons undertake a substantial volume of pituitary work and operate through trans-sphenoidal route and by craniotomy where indicated and utilise endoscopic-assisted techniques which have been used at KCH since 2008. There are two neurosurgical wards at KCH and 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 ventriculo peritoneal 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

King's has three full time endocrinologists with sub-speciality expertise in pituitary endocrinology (Prof McGregor HEFCE funded, Dr Aylwin and Dr Gilbert NHS) supported by specialist registrars and CNSs. Patients referred from general practice or from other speciality teams within KCH (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 MDM 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 but more frequently patients may be seen directly by a neurosurgeon in the Combined Pituitary Clinic. All patients will be assessed and clerked by an endocrine team member prior to their admission unless this is considered an emergency.

The endocrinology team maintains a specialist daycase facility (programmed investigation unit PIU) that performs baseline pituitary function testing and dynamic testing where required, and provides an environment for the multi-disciplinary pre-assessment of patients prior to neurosurgical intervention. Patients will have baseline biochemical preoperative

assessment in all cases and dynamic function testing with functioning pituitary tumours. Dynamic tests can be performed at KCH 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 CNSs.

4.3. Clinical Oncology

10-2K-125	Specialist Clinic Attendance by Core Oncologist MDT Members
Compliance	*The named members and their job plans agreed by the lead clinician of the MDT and the relevant clinical directors of the oncologists' employing trust(s).*
Notes	Each oncologist MDT core member should have specified DCC PAs for attendance at a multidisciplinary specialist clinic as agreed and defined in the relevant measures for the network board and the trusts

Fractionated radiotherapy is required in a significant proportion of pituitary tumours in the event of visible postoperative tumour remnant or biochemical persistent disease, or with radiological or biochemical recurrence. Adult patients requiring radiotherapy are seen in a dedicated combined pituitary clinic that runs on a monthly basis (third Monday, 2pm) by the clinical oncologist Dr David Landau. There is no radiotherapy apparatus on site at King's College Hospital and radiotherapy is provided at GSTFT or at Maidstone under Dr Gill Sadler. Single dose radiotherapy (e.g. gamma knife) is not available but where appropriate patients are referred elsewhere.

4.4. Radiology

10-2K-127	50%Specified Radiological Programmed Activities
Compliance	*The named members and their job plans agreed by the lead clinician of the MDT and the relevant clinical directors of the neuroradiologists' employing trust(s).*
Notes	Each neuroradiologist MDT core member should have 50% of their direct clinical care programmed activities specified for the practice of neuroradiology.

CT & MRI are provided within the neuroradiology department at KCH. There are six consultant neuroradiologists at KCH site providing both diagnostic and therapeutic interventional procedures. Emergency cover is provided on a 24-hour basis. Dr Hampton is the neuro-radiologist for the MDT with Dr Sibtain as cover for the MDM. Dr Connor provides neuroradiology during the combined pituitary clinic. Therefore, there will always be a neuroradiologist with a subspecialty interest in pituitary and hypothalamic disease available both for the MDM and for urgent enquiries. The waiting times for patients with known or suspected pituitary tumours are very short and MRI and CT are routinely available within a 2 week time frame and within 24 hours for urgent cases.

Petrosal venous sampling used in the diagnosis of Cushing's disease (ACTH secreting pituitary adenoma) is performed by Dr Pauline Kane in general radiology.

4.5. Neuropathology

Diagnosis of pituitary adenomas is based both on preoperative biochemical and post-operative histology. Dr Andrew King is the nominated MDT core member although all four specialist neuropathologists at KCH are involved in the diagnostic histological assessment for patients with pituitary or para-pituitary disease. This provides the opportunity for team discussions for challenging cases and internal quality control process. Neuropathology at KCH takes part in the EQA and is recognised as a centre of excellence and the neuropathologists involved are considered as world authorities in pituitary disease.

4.6. Clinical Biochemistry

KCH has a well established endocrine laboratory with almost all hormone assays performed on site. KCH is a supra-regional service which takes part in national quality control programmes. A number of service improvements have recently been established to ensure that comprehensive baseline assessment is carried out on all pituitary patients pre-operatively, included prolactin measurements after dilution and precipitation of prolactin complexes. This is particularly important to identify patients with large tumours (prolactin macroadenomas) that can nonetheless be managed by medical treatment. Although most patients will be referred with biochemical data, all patients have endocrine testing prior to pituitary surgery. Close liaison is maintained with the biochemistry department through a named principal 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 pharmacy lead and division business managers ensure that all drug usage outside of tariff is accounted for, especially for somatostatin analogues, 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, there is a well established Palliative Care Service at King's who will be well positioned to identify a local team. 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 Co-ordinator

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

4.10. Other Clinical Support Services

King's College Hospital provides an interpretation service as listed below

1. Onsite Spanish and Italian Interpreting and Translation
2. Interpreters for pre-booked face to face consultations
3. Telephone interpreting for urgent situations when it isn't possible to pre-book an interpreter to come on site (24 hours a day)
4. Translators for the deaf and hard of hearing RNID/RAD interpreters

Pre-booking is required and the service is accessible via either the CNS or MDT member.

5. Diagnosis, diagnostic and treatment pathways

5.1. Patient management planning decision

10-2K-121	Patient Management Planning Decision
Compliance	*Anonymised examples of the record of a meeting and individual anonymised treatment plans.* The core MDT at their regular meetings should agree and record individual patient's management plans. A record should be made of the plan. The record should include: • the identity of patients discussed; • the stage in the patient's pathway at which the MDT discussion is taking place (e.g. for illustration; provisionally diagnosed pre-biopsy, post-biopsy pre-definitive surgery, post-op pre-adjuvant treatment, recurrence); • the diagnosis; • the multidisciplinary management decision relevant to that stage in the pathway; i.e. to which modalities of treatment and/or supportive and palliative care or rehabilitation, they are to be referred for consideration.
Notes	

Patients are discussed in the pituitary MDM at the following stages:

I **At diagnosis**: within 2 week of referral to review initial information and plan clinical biochemical and other assessment. At this stage the patient may or may not have been clinically assessed.

II **Pre-surgery**: complete information including biochemical data, clinical assessment and visual fields. This step may be unnecessary if all data are available at (I) above

III **Early Post operative 'histology'**: following surgery where indicated to review histology and immediate perioperative endocrine results

IV **3 months post operative:** to review post operative dynamic testing and MRI. At this stage patients will either exit the pathway or will be referred for additional therapy

V **Pituitary review:** to review efficacy of non-surgical intervention

VI **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 co-ordinator.

Cases are presented by the Endocrine team or the Pituitary CNS. Case presentation will include name, age, presenting symptoms, findings on examination and all pre-op endocrine investigations. Radiology and pathology is presented by appropriate members of the team. All cases are prepared within the EPR database so that there is an immediate and accessible document.

On each occasion, a detailed summary is prepared prior to the meeting on the electronic record. The outcomes of the meeting are then added in real time to the summary which is then committed and saved. This forms the written communication to patient, referrer and GP

5.3. Clinical guidelines

10-2K-128 Compliance Notes	Clinical Guidelines *The guidelines agreed by the chair of the NDSG and the lead clinician of the MDT.* The MDT should agree the area-wide clinical guidelines.

Insert guidelines used

5.4. Operational function of the MDM: diagnostic pathway

10-2K-129	The Diagnostic Pathway
Compliance	*The pathway agreed by the chair of the NDSG and the lead clinician of the MDT.*
Notes	The MDT should agree its role in the area-wide diagnostic pathway and add any locally relevant content including named hospital services.

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 MDM

- Review new patients referred with pituitary tumours within the network, 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 and on EPR
- Review 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 MRI) to discuss management plans.
- Ensure decisions made are communicated to General Practitioners, 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.

5.5. Treatment Pathway

10-2K-130	The Treatment Pathway
Compliance	*The pathway agreed by the chair of the NDSG and the lead clinician of the MDT.*
Notes	The MDT should agree its role in the area-wide treatment pathway and add any locally relevant content including named MDTs and services.

Once a DTT is taken the treatment pathway is initiated.

1. The CNS in the combined pituitary clinic is informed of the DTT.
2. Neurosurgeon enters details onto the EPR admissions system and provides a date where possible
3. GP is informed by letter at earliest opportunity
4. **Neurosurgical admissions manager will ensure that the patient is admitted within 31 days from DTT**
5. Neurosurgical admissions will arrange preadmission to be carried out by the endocrine CNS, the endocrine team and the neuro-anaesthetist where necessary

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

Since most patients for surgery will have had preassessment investigations at the time of initial diagnosis, there should be few additional steps. Operative preassessment is carried out by the pituitary CNSs and/or endocrine junior staff, with anaesthetic review occurring on the same day wherever possible.

An integrated pathway document is under preparation for the admission. During the inpatient stay the patients are jointly managed by neurosurgical and endocrine teams according to defined protocols.

5.6. Follow-up Pathway

10-2K-131	The Follow Up Pathway
Compliance	*The pathway agreed by the chair of the NDSG and the lead clinician of the MDT*.
Notes	The MDT should agree its role in the area-wide follow up pathway and add any locally relevant content including named MDTs.

- 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 KCH
- Decide on the need for non-operative further tumour management (i.e. medical adjuvant therapy or radiotherapy)
- Determine 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

After the completion of the initial 3 months after surgical treatment many patients will be appropriately discharged for follow up by referring clinicians or local hospitals

5.7. The regional referral base

10-2K-132	The Communication Framework
Compliance	The framework agreed by the chair of the NDSG and the lead clinician of the MDT.
Notes	The MDT should agree its role in the area-wide communication framework and add any locally relevant content including named MDTs and multidisciplinary clinics.

King's is the referral centre for Neuro-oncology for the South East London Cancer Network (SELCN) with a population of 1.5 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. In addition, certain selected patients typically those with complex conditions within neighbouring catchment areas may also be referred from Surrey and Sussex as tertiary referrals.

South East London Cancer Network (and SHA)		
	RJZ KING'S COLLEGE HOSPITAL NHS TRUST	5LF LEWISHAM PCT
	RG3 BROMLEY HOSPITALS NHS TRUST	5LD LAMBETH PCT
	RG2 QUEEN ELIZABETH HOSPITAL NHS TRUST	5A8 GREENWICH PCT
	RGZ QUEEN MARY'S SIDCUP NHS TRUST	5LE SOUTHWARK PCT
	RJ2 THE LEWISHAM HOSPITAL NHS TRUST	5A7 BROMLEY PCT
	RJ1 GUY'S AND ST THOMAS' NHS TRUST	TAK BEXLEY CARE TRUST
Kent and Medway		
	RWF MAIDSTONE AND TUNBRIDGE WELLS NHS TRUST	5LP SHEPWAY PCT
	RVV EAST KENT HOSPITALS NHS TRUST	5L4 SWALE PCT
	RPA MEDWAY NHS TRUST	5L2 MAIDSTONE WEALD PCT
	RXC EAST SUSSEX HOSPITALS NHS TRUST	5L3 MEDWAY PCT
	RN7 DARTFORD AND GRAVESHAM NHS TRUST	5CM DARTFORD, GRAVESHAM AND SWANLEY PCT
		5FF SOUTH WEST KENT PCT
		5LL ASHFORD PCT
		5LM CANTERBURY AND COASTAL PCT
		5LN EAST KENT COASTAL PCT
		5FJ HASTINGS AND ST LEONARDS PCT
		5LT SUSSEX DOWNS AND WEALD PCT
		5FH BEXHILL AND ROTHER PCT
Surrey, West Sussex and Hampshire		
	RDU FRIMLEY PARK HOSPITAL NHS TRUST	

5.8. Relationship of the Pituitary MDT to referring hospitals

The success of the implementation of the Improving Outcomes Guidance is dependant on the relationship between the referring hospital and the SELCN Pituitary MDT, and the availability and accessibility of its expertise. The MDM is open to the referring units on all occasions that it meets. Clinicians regularly attend from referring centres. 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 and is complex and the involvement and responsibility of the referring hospital in the pre-operative diagnostic evaluation and the post-operative management may be very significant. There is however only one specialist team for the network and therefore the unit teams are responsible for ensuring that all patients with a diagnosis of pituitary tumour are referred to the specialist MDT at KCH. 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 investigation 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 KCH is available to all members of the SE London and Kent & Medway Cancer Networks. Following initial referral and discussion, it is recognised that some patients will be referred back to the referring endocrinologist without neurosurgical involvement, but all patients in section X.X must be referred, documented and form part of overall network audit arrangements.

Within the South East Thames Integrated Cancer Centre surgical resection for pituitary tumours and the immediate post-operative care is only performed at King's College Hospital. All patients with pituitary tumours that are to be referred for neurosurgical treatment should be discussed at the specialist pituitary MDT.

5.9. Pituitary MDT and Catchment Population

10-2K-138	MDT Workload
Compliance	*The number of cases, averaged over the two years prior to the peer review visit or self assessment.*
Notes	The MDT should discuss at least 100 cases per year of primary intracerebral malignancy, newly presenting to the MDT for the first time

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 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 that are treated medically, and for which inclusion in a registry would be unusual outside of a clinical study. Other tumours 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 centre (1995-2000) is 1.66 per 100 000 but this almost certainly represents an underestimate and a true figure is closer to 3/100 000 for all surgically treated pituitary tumours would be likely from the literature. If we consider the typical pituitary tumour requiring neurosurgery (a non-functioning pituitary adenoma or NFPA) the incidence is quoted as 1.85/100 000. Based on the incidence, our activity approximates to a catchment of just over 3 million, approximately the potential pituitary resection workload for SE London, Kent and East Sussex.

5.10. Pituitary referrals and procedures undertaken by the King's MDT.

The table shows the total number of patients referred to the pituitary MDT and discussed in the MDM. Since mid-2007 all new referrals to the pituitary multidisciplinary team have been included in the pituitary MDM database. These patients are mostly tertiary referrals from endocrinologists, ophthalmologists or neurologists. Many but not all subsequently undergo surgery. Other patients discussed in the pituitary MDM will either be follow-up discussions or patients with recurrent disease.

5.11. Pituitary MDT activity 1997-2010

	2007	2008	2009	2010
Total MDM referrals (new and follow up)		552	466	605
MDM new patients referred		115	118	187
Pituitary surgical procedures	85	102	110	102
Neuropathology specimens registered	84	87	81	

5.12. Data on specimens received by the neuropathology department 1997-2009

All specimens registered since 1997 are held in a departmental database including the name, DOB, and the nature of the specimen (pituitary biopsy, brain biopsy, cytospin, bone biopsy or other) and diagnostic code. The following are included:

- Pituitary biopsy (any pathology)
- Craniopharyngioma
- Other cysts where these were associated with known or suspected pituitary dysfunction

The most common diagnostic codes are adenoma- (unspecified), craniopharyngioma and normal. Many normal specimens are from patients with cortisol excess. Data for total samples are shown in the figure. Note, approx 50 patients had more than one procedure. Most suprasellar meningiomas have been omitted.

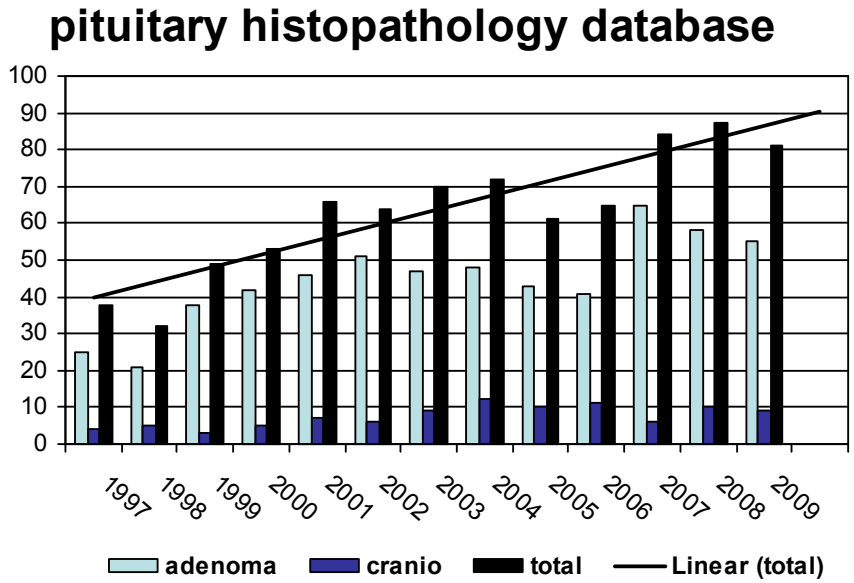
Aggregating the patients indicates that betweeen 1997-2009 there were:

- 560 pituitary adenomas
- 93 craniopharyngiomas and 19 cysts
- 26 normal pituitary
- 22 inflammatory/infective process
- 13 infarcted, necrotic or haemorragic

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	
adenoma	25	21	38	42	46	51	47	48	43	41	65	58	55	
cranio	4	5	3	5	7	6	9	12	10	11	6	10	9	
total	38	32	49	53	66	64	70	72	61	65	84	87	81	

Note: 'total' is not expected to represent the sum of the most common conditions

The total procedures and two of the more common diagnoses are shown above and illustrated in the figure below; detailed analysis is included in appendix 3.



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, Kings College Hospitals monitors cancer waiting times. This must be done for patients who are referred directly from primary care but also for tertiary patients where Kings must work with referring hospitals to ensure that patients do not breach waiting times.

Since the majority of patients are referred from secondary care and were not on a two 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 MRI. For patients with hormone excess states (high GH, cortisol or TSHoma), the diagnosis will be taken as the diagnostic blood test.

The KCH pituitary MDT audit the time from diagonstic test (typically MRI scan) to the DTT. All patients should receive surgery within 31 days of the DTT. (see appendix 2)

6.3. Pituitary Database and Minimum dataset

10-2K-133	Data collection
Compliance	*Anonymised examples of the recorded data for individual patients.* *Note: For the purpose of self assessment, the team should confirm that they started to record the MDS*
Notes	The MDT should be recording its agreed part of the brain and CNS malignancy MDS, according to the area data collection specification, in an electronically retrievable form.

King's is in the process of developing a database that supports the pituitary service. It will be designed for use by Consultants and Clinical Nurse Specialists to store patient summary clinical and pathway information, for audit/information reporting, for tracking patients through the system and monitoring the progress of the patients along the pathway. Detailed clinical information on each patient is stored in that patient's electronic (EPR) record.

6.4. Participation in local and regional audit

10-2K-134	Agreed Participation in Area Audit
Compliance	*The project agreed by the lead clinician of the MDT and the Chair of the NDSG.*
Notes	The MDT should agree to participate in the area audit project agreed by the NDSG. *Notes: Additional projects may be agreed and funded.*
10-2K-135	Annually Review or Present Results from Participation in Area Audit
Compliance	*Written confirmation of review of progress of audit sufficient to show compliance with the measure.* *Note: Compliance with this measure automatically confers compliance with the previous measure.*
Notes	The MDT should annually review the progress of the project or present the results of the completed network audit project to the NDSG for discussion at one of their meetings. *Notes: For MDTs which have previously been peer reviewed the project should have been completed since that previous review.*

The lead clinician or his nominated deputy attends at least two thirds of the South East London Tumour Board meetings. In addition, the General Manager of Neurosciences attends these meetings. The records of attendance will be kept by the Network Site Specific Group.

6.5. Patient Satisfaction Survey

The MDT will agree on an annual patient satisfaction survey (first completed Sept 2009). The MDT will review the results of this survey and agree actions arising at their next annual meeting. The CNS in the pituitary service is responsible for collating data and will be reporting to the MDT. Monitoring of action points will be the responsibility of Service Improvement Lead.

6.6. Service Improvement Lead

One member of the MDM- likely to be the MDT co-coordinator or CNS- is nominated as the person responsible for ensuring that service improvement is integrated into the functioning of the MDM. The core team of the MDM should complete and periodically update a process map covering the key stages of their 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 & Responsibilities of Service improvement lead

- To work with the lead clinician and MDT members to identify key service improvement priorities relating to the agreed network 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 co-ordination 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

10-2K-136	MDT Response to the NDSG's Approved List of Clinical Trials
Compliance	*The response including remedial action agreed by the lead clinician of the MDT and Chair of the NDSG.*
Notes	The MDT should produce a written response annually to theNDSG's approved list of trials and other well designed studies, which fulfils the following: • for each clinical trial and other well designed study the MDT should agree to enter patients or state the reasons why it will not be able to; • the remedial action arising from the MDT's recruitment results, agreed with the NDSG.
10-2K-137	Remedial Action from Trial Recruitment Results
Compliance	*The reviewers should enquire as to the implementation of the recommended actions*.
Notes	The remedial action arising from the MDT's recruitment results, agreed with the NDSG should have been carried out.

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 MDM.

6.9. Recent studies

Principal (site) Investigator. A study to evaluate treatment with a combination of Pegvisomant plus Sandostatin LAR, Pegvisomant (alone) and Sandostatin (alone) in patients with acromegaly (LREC 03-644) *completed*

Principal (site) Investigator. A study to compare the efficacy and safety of pegvisomant to that of sandostatin LAR depot in patients with acromegaly (LREC 03-643) *completed*

A randomised, open-labeled, multicentre study comparing the efficacy and safety of medical treatment with Sandostatin LAR with that of surgical therapy in newly diagnosed acromegalic patients with microadenomas or macroadenomas (LREC 02-196) *completed*

Non-commercial studies

Multi centre study of cabergoline alone and in combination with pegvisomant in the management of active acromegaly REC 06/Q1407/52 ***active***

Cardiac and skeletal energy metabolism in abnormal growth hormone states REC 06/Q0401/53 ***active***

Add more studies here

7. Referral to the MDT

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 are made available to all referring clinicians (SE London and Kent and Medway Cancer Network). Referrals are all directed via the endocrine secretarial offices to the pituitary MDM co-coordinator. Referrals may be either addressed to the neurosurgeons or endocrinologists but in either case will be forwarded to the endocrine office. Referrals may be sent by fax but post is preferred in addition to avoid loss of detail on biochemical results. MRIs need to be sent by CD since image link lacks sufficient detail.

Pituitary Service Fax Number 020 3299 3570
Email: Julia.palasinska@nhs .net (tbc)

By post:

Department of Endocrinology or Neurosurgery
King's College Hospital
Denmark Hill
London SE5 9RS

New patients will all be given a hospital number so that summaries and correspondence can be entered onto EPR and imaging archived into PACS. Referrals will be vetted by the lead clinician or cover or the consultant to whom the referral is addressed. If the consultant is on annual leave or is not available for 48 hours the letter should be screened by the designated cover. This allows for inclusion on the MDT whilst an appointment is arranged. If none is specified a consultant will be allocated at the first MDM. In some circumstances it may be more expedient to see the patient first and then arrange the MDM review subsequently. *As a rule, all new patients are discussed at the next MDT meeting.*

Most new patients will be seen either in the multidisciplinary 'combined' pituitary clinic, as a daycase assessment or in general endocrine clinics.

'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 on EPR under a patient number. Referrers are welcome to attend meetings. Video-conferencing is available for contact with distant hospitals.

7.2. Referral details

The KCH MDT welcomes any referral with full or incomplete data. Our approach is to assume responsibility for any patient referred and we can arrange to complete the clinical, biochemical and radiological assessment. We do not wish patients to be unnecessarily delayed to ensure all investigations are available. All investigations that are collected should be made available.

Imaging:
Radiology should be sent on a disc rather than hard copy. These can then be incorporated into PACS, viewed and discussed at the MDM for specialist opinion. Reports of outside imaging will be recorded on EPR.

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. Where available, endocrine results should ideally be in the form of laboratory print out or as a minimum should include units and reference range for hormone data. Any missing endocrine tests will be arranged.

The full pituitary order set includes:
TFT (fT4, fT3 and TSH)
prolactin and prolactin after dilution
random GH
IGF-1
cortisol (0900 preferred)
FSH/ LH
Estradiol (female) or testosterone (male)
SHBG

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.

Ophthalmic assessment
Where available formal perimetry should be included in the referral or otherwise a clinical assessment of visual fields. Goldman perimetry is preferred, with visual acuities.

7.3. Inclusion in the MDM

All patients to be discussed must be nominated to the MDT co-ordinator by 5pm Monday for the complete list to be circulated for the Wednesday meeting; in an emergency patients can be included at the last minute. It is the responsibility of the MDM coordinator to ensure that the relevant radiology is available. Generally there is no waiting time and patients are discussed at the next meeting following receipt of their referral.

The agreed management plan for each patient is documented using the standard letter template during the meeting on the Pituitary MDM letter. Summary letter and outcomes will be available on EPR by 5pm Wednesday. In addition, paper copies are sent to referrers, the GP and to patients in accordance with King's guidelines. On each occasion where a patient is reviewed a second or subsequent time by the MDT a new letter 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 *both* contacting the Endocrinologist/Neuro-surgical core team member via King's switchboard *and* faxing a referral to the pituitary co-ordinator o 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 of 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 MDM.

7.5. Direct referral from GP

Once pituitary disease is suspected GP's 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 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 full baseline biochemical assessment (see section 4.2 above) 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 potentially resectable patients 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. It is an over-riding principle of the KCH pituitary MDT that patients can be referred as soon as the diagnosis is made, without requiring complete data. However, the single most useful biochemical marker is a serum prolactin which will identify patients that may be treated medically even with significant visual field defect, and this should be obtained if at all possible.

Details of the agreed referral guidelines from ophthalmology and neurology are included in appendix 1.

7.7. Referrals from South East London Cancer Network and Kent and Medway Cancer Network diagnostic teams

Endocrinologists, neurologists and ophthalmologists are the most frequent specialists to diagnose a pituitary tumour.

The following patients should be referred to the multi-disciplinary meeting for discussion on further management. *(copied from section 2.9)*
The following patients should be referred to the pituitary MDT **as soon as the diagnosis is made** for management planning.

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

Patients that may also be referred for discussion

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

7.8. Referral of paediatric patients

Pituitary tumours are rare in paediatric practice but concern will be extreme when these are diagnosed. Children with growth failure or endocrine disturbance will typically be referred to the paediatric endocrinologist. If pituitary tumours are diagnosed by paediatricians in other units then the referral should be both to Dr Charles Buchanan and to the pituitary office to be certain that no delay occurs. These patients will be discussed at the monthly paediatric and TYA pituitary MDM, although they will usually be reviewed at the first available MDM.

Emergency presentation with raised intracranial pressure out of hours will 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.

7.9. Interface with Neuro-oncology MDM

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 MDM should be referred to the Specialist Pituitary MDM. In certain patients, for example with parasellar meningioma, discussion in both meetings may be required.

7.10. Intrahospital Referrals :

Internal referrals should be discussed in the next MDM meeting.

All patients admitted to King's College Hospital with a suspected or confirmed diagnosis of pituitary disease/tumours should be referred for discussion at the Specialist MDM, and if in patients their care should always be transferred to either the neurosurgical or endocrine core members.

8. Appendices

8.1. Appendix 1 Recommended procedure for referral by ophthalmologists of pituitary and other suprasellar tumours

Specialist care for pituitary tumours at King's College Hospital is co-ordinated on behalf of the South East London and Kent and Medway Cancer Networks by the KCH Pituitary Multi-Disciplinary Team (MDT), primarily via the weekly (Wednesday morning) Pituitary Multi-Disciplinary Meeting (MDM), after which urgent day case endocrine assessment and then urgent or elective admission are arranged if surgical intervention is considered appropriate.

1 All patients with confirmed pituitary mass lesions (>1cm), or suprasellar or hypothalamic lesions including presumed craniopharyngiomas and meningiomas, should be referred to the Pituitary MDT.

2 Referrals may be sent by fax, but additionally by post is preferred to avoid loss of detail of biochemical results. Referrals can either be to specific clinicians or to 'consultant endocrinologist' or 'pituitary neurosurgeon'.

Pituitary Service Fax Number: 020 3299 3790

By post: Pituitary MDM Co-ordinator
Department of Endocrinology
King's College Hospital
Denmark Hill
London SE5 9RS

Radiology should be sent on a CD.

3 Every patient with a pituitary tumour should have a prolactin measurement as soon as possible. **Any endocrine results should be in the form of laboratory print out or as a minimum should include units and reference range. The result can be chased by the KCH MDT if we know where a test is requested, and should not delay referral.**

4 Details of onset and progression of visual symptoms are essential. Visual acuities and results of perimetry, preferably Goldmann visual fields, should be included with the referral.

5 Emergency 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 emergency transfer/admission requests, please contact the Endocrinology and Neuro-Surgery on-call team via King's switchboard (020 3299 9000) and fax a referral to the Pituitary MDM Co-ordinator.

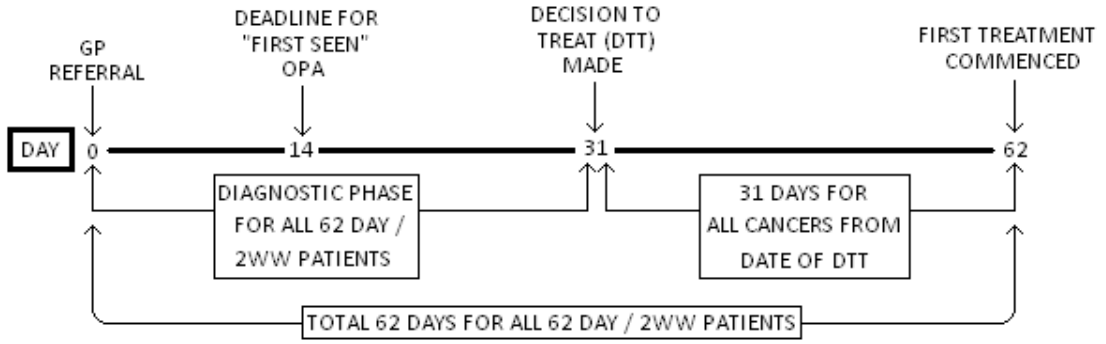
6 It may be desirable to refer the patient for endocrine assessment to a local endocrinologist *in parallel*, and to notify the KCH pituitary MDT of the named consultant to ensure continuity and communication. This should not however delay KCH referral.

8.2. Appendix 2 Waiting times summary

CANCER TARGETS INFORMATION

62 DAY / TWO WEEK WAIT (2WW) CANCER TARGETS

Two week wait targets are unusual for pituitary tumours since the majority do not come from primary care. 2WW patients are those patients who are referred *from their GP* with a suspected and previously undiagnosed cancer. We must either exclude a diagnosis of cancer, or treat the cancer, within 62 days of the referral. The diagnosis and treatment pathway must conform to certain time conditions, as shown:



Example:

Patient is referred on October 1st. They must have their "first seen" OPA before October 15th, and their ultimate target for all diagnosis and treatment to be completed is 62 days from date of referral, i.e. December 2nd. From whenever their Decision To Treat is made, they will have 31 days to be treated, but for Two Week Wait patients this must remain within the ultimate 62 day target, i.e. if diagnosis is delayed and a decision is finally made on November 23rdh, treatment must still occur by December 2nd.

N.B. Adjustments are no longer officially allowed under the 2ww rules, except after a Decision To Treat has been made.

31 DAY CANCER TARGETS

31 Day patients are 'cancer' patients who are not referred urgently by the GP, and whose pathway starts once they have made a decision to treat. This scenario is more typical pf pituitary patients. These can include subsequent treatments (e.g. repeat surgery or radiotherapy), and recurrent treatments. Certain adjustments can be taken, as a Decision To Treat has been made.

8.3. Apppendix 1 Detailed summary of pituitary procedures

Pituitary summary

Detailed breakdown of the pathology diagnostic coding. Most samples were entered as pituitary biopsy. Where the entry was as brain biopsy, patients are included if they were craniopharyngiomas. Patients with Rathke's cleft and other sella cysts do not have a separate code and are included under cyst NOS.

Aggregating the patients is possible, and indicates that there were:

- 560 pituitary adenomas
- 93 craniopharyngiomas and 19 cysts
- 26 normal pituitary
- 22 inflammatory/infective process
- 13 infarcted, necrotic or haemorragic

Count of refdiagn.descr	year													
refdiagn.descr	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Grand Total
Adenoma, NOS	25	21	38	42	46	49	41	44	39	39	62	58	34	538
Craniopharyngioma	4	5	3	5	7	6	9	12	10	11	6	10	5	93
Normal tissue, NOS	2		1	1	3		5	2	3	3	2	3	1	26
Morphological description only	3	2		1		2		2				5	4	19
Cyst, NOS	1		1		2	1	2		2		2	5	2	18
Prolactinoma						2	2	1	2	1	2			10
Acidophil adenoma							3	3	2	1			1	10
Morphological abnormality, NOS				1	1	1		1		2	1	1		8
Inflammation, NOS		1	1		1		1		1		2			7
Necrosis, NOS		1			1		2	2						6
Carcinoma, metastatic, NOS					1		1	1		2				5
Meningioma, NOS		2								3				5
Inflammation, chronic, NOS			2		1				1		1			5
Haemorrhage, NOS	1			1	1	1								4
Abscess, NOS							1				1	1		3
Lymphocytic infiltrate, NOS							1			1		1		3
Inflammation, acute, NOS										1	1		1	3
Morphology not applicable					1	1								2
Infarcts, NOS	1		1											2
Inadequate for diagnosis											1	1		2
Metastatic tumour			2											2
Carcinoma, NOS						1		1						2

table cont.

Count of refdiagn.descr	year													
refdiagn.descr	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Grand Total
Tumour, NOS											1			1
Lymphoma, NOS												1		1
Meningioma, malignant									1					1
Haematoma, NOS								1						1
Meningioma, transitional							1							1
Gangliocytic paraganglioma													1	1
Astrocytoma, NOS												1		1
Adenoid squamous cell carcinoma	1													1
Epidermoid cyst				1										1
Morphology unknown					1									1
Chromophobe adenoma							1							1
Neoplasm, benign				1										1
Normal position, NOS								1						1
Adenocarcinoma in situ, NOS								1						1
Plasma cell, myeloma											1			1
Adhesive arachnoiditis										1				1
Schwannoma, NOS													1	1
Tuberculosis, NOS											1			1
Grand Total	38	32	49	53	66	64	70	72	61	65	84	87	50	791