

BRAIN & CNS PATHWAY BOARD

CONSTITUTION

JULY 2014

Date for Review: July 2015

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1. INTRODUCTION

2013/14 was a transitional year for cancer services in Greater Manchester and East Cheshire. The Greater Manchester and Cheshire Cancer Network ceased to exist in March 2013 when cancer networks nationally were amalgamated into strategic clinical networks as part of the NHS reorganisation. In Greater Manchester this coincided with the creation of Manchester Cancer, an integrated cancer system for Greater Manchester and East Cheshire.

Twenty Manchester Cancer Pathway Clinical Directors were appointed in late 2013 and took up their roles on 1st January 2014. They spent the first months in post forming their Pathway Boards, multi-professional clinical groups from across the region. These Pathway Boards are now formed and most had their first meeting in April/May of 2014.

As such, this is a transitional constitution document based on the legacy document. In July 2015 every Manchester Cancer Pathway Board will publish a full constitution alongside its annual report and work plan for the year ahead.

2. CONFIGURATION OF SERVICES

2.1 Manchester Cancer

Manchester Cancer covers a population just over 3.3 million.

North West Sector:

Wrightington Wigan and Leigh NHS Trust
Royal Bolton Hospital NHS Foundation Trust
Salford Royal NHS Foundation Trust

North East Sector:

Pennine Acute Hospitals NHS Trust (Bury, North Manchester, Oldham, Rochdale)
Central Manchester University Hospitals NHS Foundation Trust (incorporating Trafford Hospital)

South Sector:

Tameside Acute NHS Trust
Stockport Foundation NHS Trust
University Hospital of South Manchester NHS Foundation Trust
The Christie NHS Foundation Trust
East Cheshire NHS Trust

Brain and CNS patients from Mid Cheshire NHS Trust are referred to North Staffs Cancer Network; they do not fall within the jurisdiction of Manchester Cancer for this diagnostic group.

Some chemotherapy and clinical trials will continue to be delivered from Christie Hospital, although local chemotherapy is currently available at:

- Wigan
- Bolton
- Oldham
- East Cheshire
- Mid Cheshire

2.2 BRAIN & CNS NETWORK CONFIGURATION (14-1C-101k)

The agreed Neuroscience Centre is at Salford Royal NHS Foundation Trust.

The following NSMDTs will be hosted by Salford:

- Neuroscience brain & CNS MDT incorporating Specialist Spinal Cord MDT
- Specialist Pituitary MDT
- Specialist Skull Base MDT

The following NSMDT will be hosted by Christie Hospital NHS Foundation Trust

- Neuro-Oncology Supportive Care (Cancer Network) MDT – providing non-surgical / supportive care / rehabilitation aspects of patient care

There is one agreed stand-alone ‘Cancer Network’ Brain & CNS MDT (CNMDT), hosted by The Christie NHS Foundation Trust.

The following Neuroscience MDTs will be associated with the CNMDT:

- Neuroscience brain & CNS MDT incorporating Specialist Primary Spinal Cord MDT
- Specialist Pituitary MDT
- Specialist Skull Base MDT

The neuroscience centre is hosted by Salford Royal NHS Foundation Trust and the following NSMDTs are associated

- Neuroscience brain & CNS incorporating Specialist Primary Spinal Cord MDT
- Specialist Pituitary MDT
- Specialist Skull Base MDT

The 4 NSMDTs and the CNMDT will also link to the Brain & CNS CSG

Table 2: Neuro-Science teams

Team	Location	Lead Clinician
Neuroscience Centre	Salford Royal NHS Foundation Trust	Miss Tina Karabatsou
Neuroscience Brain & CNS MDT, with specialist Primary Spinal Cord MDT	Salford Royal NHS Foundation Trust	Miss Tina Karabatsou
Specialist Pituitary MDT	Salford Royal NHS Foundation Trust	Dr Tara Kearney
Specialist Skull Base MDT	Salford Royal NHS Foundation Trust	Mr Scott Rutherford
Neuro-Oncology Supportive Care (Cancer Network) Brain & CNS MDT	Christie Hospital NHS Foundation Trust	Dr Catherine McBain

2.3 LOCATION OF MULTIDISCIPLINARY SPECIALIST CLINICS (14-1C-102k)

Multi-disciplinary new patient neuro-oncology (including primary spinal tumour) clinics are held weekly at Salford Royal NHS Foundation Trust on Thursday mornings.

Skull Base tumour joint neuro-surgical and ENT clinics are held twice monthly at Salford Royal NHS Foundation Trust, on Tuesday mornings and Thursday afternoons. Now that stereotactic radiosurgery treatment has started at SRFT there is a joint clinical oncology / surgical / ENT clinic.

2.4 OPERATIONAL POLICY FOR NEURO-REHABILITATION CLINICS (14-1C-115k)

Neuro-rehabilitation facilities are hosted in the community at Christie Hospitals and Salford Royal NHS Foundation Trust

The operational policy can be found at Appendix 3.

3. PATHWAY BOARD TERMS OF REFERENCE (14-1C-104k)

The Manchester Cancer Brain & CNS Pathway Board is a multi-professional group chaired by Dr Catherine McBain, who is a Consultant Clinical Oncologist at The Christie Hospital NHS Foundation Trust

These terms of reference have been agreed by Dr Catherine McBain, Pathway Clinical Director for Brain Cancer, and Mr David Shackley, Medical Director of Manchester Cancer. The terms of reference will be subject to future review.

The Pathway Board

The Brain Cancer Pathway Board is a cancer care specific board with responsibility to improve cancer outcomes and patient experience for local people across Greater Manchester and areas of Cheshire (a catchment population of 3.2 million). This area is synonymous with the old Greater Manchester and Cheshire Cancer Network area.

The Pathway Board is led by a Pathway Clinical Director and is formed of a multidisciplinary team of clinicians and other staff from all of hospital trusts that are involved in the delivery of BRAIN cancer care in Greater Manchester. The Pathway Board also has membership and active participation from primary care and patients representatives.

The Brain Cancer Pathway Board reports into and is ultimately governed and held to account by the Manchester Cancer Provider Board.

Manchester Cancer Provider Board

The Manchester Cancer Provider Board is responsible for the service and clinical delivery arm of Manchester Cancer, Greater Manchester's integrated cancer system. Manchester Cancer has two other arms: research and education (see appendix for the structure of Manchester Cancer).

The Provider Board is independently chaired and consists of the Chief Executive Officers of the ten acute hospital trusts in the Greater Manchester area:

- Bolton NHS Foundation Trust
- Central Manchester University Hospitals NHS Foundation Trust
- East Cheshire NHS Trust
- Pennine Acute NHS Trust
- Salford Royal NHS Foundation Trust
- Stockport NHS Foundation Trust
- Tameside Hospital NHS Foundation Trust
- The Christie NHS Foundation Trust
- University Hospital of South Manchester NHS Foundation Trust;
- Wrightington, Wigan and Leigh NHS Foundation Trust;

The Provider Board regularly invites representatives of commissioners, the Strategic Clinical Network, and Manchester Cancer to its meetings.

Purpose of the Pathway Board

The purpose of the Pathway Board is to improve cancer care for patients on the Greater Manchester Brain cancer pathway. Specifically, the Pathway Board aims to save more lives, put patients at the centre of care, and improve patient experience. The Board will represent the interests of local people with cancer, respecting their wider needs and concerns. It is the primary source of clinical opinion on this pathway for the Manchester Cancer Provider Board and Greater Manchester's cancer commissioners.

The Pathway Board will gain a robust understanding of the key opportunities to improve outcomes and experience by gathering and reviewing intelligence about the BRAIN cancer pathway. It will ensure that objectives are set, with a supporting work programme that drives improvements in clinical care and patient experience.

The Pathway Board will also promote equality of access, choice and quality of care for all patients within Greater Manchester, irrespective of their individual circumstances. The Board will also work with cancer commissioners to provide expert opinion on the design of any commissioning pathways, metrics and specifications.

Role of the Pathway Board

The role of the Brain Cancer Pathway Board is to:

Represent the Manchester Cancer professional and patient community for Brain cancer.

Identify specific opportunities for improving outcomes and patient experience and convert these into agreed objectives and a prioritised programme of work.

Gain approval from Greater Manchester's cancer commissioners and the Manchester Cancer Provider Board for the programme of work and provide regular reporting on progress.

Design and implement new services for patients where these progress the objectives of commissioners and Manchester Cancer, can be resourced, and have been shown to provide improvements in outcomes that matter to patients.

Ensure that diagnosis and treatment guidelines are agreed and followed by all teams in provider trusts, and are annually reviewed.

Ensure that all providers working within the pathway collect the pathway dataset measures to a high standard of data quality and that this data is shared transparently amongst the Pathway Board and beyond.

Promote and develop research and innovation in the pathway, and have agreed objectives in this area.

Monitor performance and improvements in outcomes and patient experience via a pathway scorecard, understanding variation to identify areas for action.

Escalate any clinical concerns through provider trusts.

Highlight any key issues that cannot be resolved within the Pathway Board itself to the Medical Director of Manchester Cancer for assistance.

Ensure that decisions, work programmes, and scorecards involve clearly demonstrable patient participation.

Share best practices with other Pathway Boards within Manchester Cancer.

Contribute to cross-cutting initiatives (e.g. work streams in living with and beyond cancer and early diagnosis).

Discuss opportunities for improved education and training related to the pathway and implement new educational initiatives.

Develop an annual report of outcomes and patient experience, including an overview of progress, difficulties, peer review data and all relevant key documentation. This report will be published in July of each year and will be the key document for circulation to the Provider Board. A template for this report is available so that all Pathway Boards complete the report in a similar manner.

Membership principles

All member organisations of Manchester Cancer will have at least one representative on the Pathway Board unless they do not wish to be represented.

Provider trusts not part of Manchester Cancer can be represented on the Pathway Board if they have links to the Greater Manchester brain cancer pathway.

All specialties and professions involved in the delivery of the pathway will be represented.

The Board will have at least one patient or carer representative within its membership

One professional member of the Pathway Board will act as a Patient Advocate, offering support to the patient and carer representative(s).

The Board will have named leads for:

- Early diagnosis
- Pathology
- Radiology
- Surgery
- Oncology
- Specialist nursing
- Living with and beyond cancer ('survivorship')
- Research
- Data collection (clinical outcomes/experience and research input).

It is possible for an individual to hold more than one of these posts. The Pathway Clinical Director is responsible for their fair appointment and holding them to account.

These named leads will link with wider Manchester Cancer Boards for these areas where they exist.

All members will be expected to attend regular meetings of the Pathway Board to ensure consistency of discussions and decision-making (meeting dates for the whole year will be set annually to allow members to make arrangements for their attendance).

A register of attendance will be kept: members should aim to attend at least 5 of the 6 meetings annually and an individual's membership of the Pathway Board will be reviewed in the event of frequent non-attendance.

Each member will have a named deputy who will attend on the rare occasions that the member of the Board cannot.

Frequency of meetings

The Brain Cancer Pathway Board will meet every two months.

Quorum

Quorum will be the Pathway Clinical Director plus five members of the Pathway Board or their named deputies.

Communication and engagement

Accurate representative minutes will be taken at all meetings and these will be circulated and then validated at the next meeting of the Board.

All minutes, circulated papers and associated data outputs will be archived and stored by the Pathway Clinical Director and relevant Pathway Manager.

The Pathway Board will design, organise and host at least one open meeting per year for the wider clinical community and local people. This meeting or meetings will include:

- An annual engagement event to account for its progress against its work programme objectives and to obtain input and feedback from the local professional community
- An annual educational event for wider pathway professionals and interested others to allow new developments and learning to be disseminated across the system

Representatives from all sections of the Manchester Cancer professional body will be invited to these events, as well as patient and public representatives and voluntary sector partners.

An annual report will be created and circulated to the Medical Director of the Manchester Cancer Provider Board by 31st July of each calendar year.

The agendas, minutes and work programmes of the Pathway Board, as well as copies of papers from educational and engagement events, will be made available to all in an open and transparent manner through the Manchester Cancer website once this has been developed.

Administrative support

Administrative support will be provided by the relevant Pathway Manager with the support of the Manchester Cancer core team. Over the course of a year, an average of one day per week administrative support will be provided.

4. MEMBERSHIP OF THE PATHWAY BOARD (14-1C-103k)

The Manchester Cancer Brain and CNS Pathway Board covers the following tumour groups and MDTs:

- Neuroscience brain & CNS MDT incorporating Specialist Spinal Cord MDT
- Specialist Pituitary MDT
- Specialist Skull Base MDT
- Neuro-Oncology Supportive Care (Cancer Network) MDT

The membership of the Brain & CNS Pathway Board is listed in table 1.

Table 1: Named Brain & CNS Pathway Board Members and agreed roles

Name	Profession/Speciality	Trust
Dr Catherine McBain	Pathway Director Consultant Clinical Oncologist	The Christie
Julie Emerson	SALT	The Christie
Sara Robinson	OT	The Christie
Elizabeth Molloy	CNS	The Christie
Dr Anna Tran	Consultant Oncologist	The Christie
Peter Selby	Consultant	CMFT
Dr Moe Sein	Consultant	East Cheshire
Miss K Karabatsou	Consultant Neurosurgeon/Lead for Neuro-oncology	SRFT
Mr Scott Rutherford	Consultant neurosurgeon/Lead for Skull Base	SRFT
Dr T Kearney	Consultant Endocrinologist/Lead for Pituitary MDT	SRFT
Sarah Cundliffe	Neuro/Oncology Specialist Nurse	SRFT
Alison Gilston-Hope	Neuro/Oncology Specilailist Nurse	SRFT
Andrea Wadeson	Base of Skull Specialist Nurse	SRFT
Dr K Dizayee	Consultant Physician	Stockport
Dr Chris Douglass	Consultant Neurologist	Tameside
Dr Samantha Kay	Palliative Care Consultant	UHSM
Dr Sophie Harrison	Palliative Care Consultant	UHSM
Dr A Ismail	Consultant Radiologist	WWL

5. NETWORK AGREED CLINICAL GUIDELINES (14-1C-107k)

The clinical guidelines for the diagnosis, management and treatment of brain and CNS tumours were reviewed by Dr Catherine McBain on 16 July 2013.

The Pathway Board has only been in place since spring 2014 and has not yet had the opportunity to review its clinical guidelines and patient pathways. As such, the guidelines created by the previous cancer network group have been adopted until such time as they can be reviewed and updated in the coming year.

All of the relevant documentation remains on the legacy website of the old cancer network www.gmccn.nhs.uk and will be migrated to the Manchester Cancer website over the coming months www.manchestercancer.org.

A full list of active current guidelines and their renewal dates will be produced for the updated constitution of July 2015.

6. NETWORK BRAIN & CNS TUMOUR PATIENT PATHWAYS - Adults (14-1C-109k-14-1C-112k)

6.1 The Presentation Pathway

Brain tumours are comparatively uncommon, but a brain tumour features in the list of differential diagnoses of patients presenting with a wide range of symptoms. While there are many other causes for symptoms, brain imaging is the pivotal investigation and there should be a low threshold for arranging imaging in all cases of unexplained neurological symptoms.

Any clinician who sees any patient in whom a brain tumour is a possibility, or who is in receipt of a “2week wait” referral for a suspected brain tumour patient, must arrange imaging to confirm or refute the diagnosis before onward referral to tertiary services. MR imaging is the gold standard, not CT (see Diagnostic Pathway 11-1C-106k below)

Patients may present to their GP or to A&E. Urgency of imaging and subsequent onward referral will depend on the clinical scenario, but broadly falls into 3 groups:

1) Acute: New onset and / or rapidly progressive neurological symptoms including, but not exclusively:

- Motor weakness
- Speech disturbance
- New-onset seizures
- Personality change
- Confusion
- Headaches, especially if progressive and / or associated with vomiting or visual disturbance
- Visual deterioration
- Deteriorating level of consciousness

These patients require urgent assessment. They may present either to their GP who should refer to the medical on-call team or by direct presentation to A&E. They require urgent brain imaging (MR if possible, CT initially if acutely unwell) and if a new primary tumour is demonstrated, urgent referral to SRFT, usually via the neuro-surgical on-call service. Examples include malignant gliomas, obstructing cerebellar tumours causing hydrocephalus or any tumour causing raised intracranial pressure or mass effect.

2) Symptomatic but medically stable. Examples include:

- Hearing loss
- Visual disturbance
- Cranial nerve palsies
- Endocrine disturbance
- Other subtle neurological symptoms

These patients present to their GP who may arrange outpatient imaging themselves or refer to outpatient services at the local Trust eg ENT, ophthalmology, neurology, general medicine, endocrinology for assessment and imaging investigations.

Following imaging confirmation, these patients can be referred directly to the relevant sub-specialised SRFT MDT lead clinician or to the MDT itself, or to subspecialist services locally eg skull-

base specialised ENT surgeons. Examples include non-malignant tumours including vestibular schwannomas, pituitary adenomas, low grade gliomas or meningiomas

3) Tumours diagnosed as incidental findings on brain imaging performed for a different indication.

It is comparatively common to identify small, asymptomatic tumours, especially meningiomas, on imaging performed for other reasons eg investigations for TIA or CVA. Not all of these cases require onward referral, but in cases where there is any doubt whatsoever, they can be referred to neurology or neurosurgery for advice. *Incidentally identified gliomas should be referred in line with acute pathways.*

Brain metastases

Presenting symptoms of patients with brain metastases may fall into any of the 3 above groups. Most brain mets patients should be re-referred to their treating oncologist in the first instance who will assess whether involvement of neuro-surgical services is warranted. The exceptions are patients with no previous cancer diagnosis, or patients with a brain solitary lesion, where referral to the neuro-surgical on-call is indicated to confirm the diagnosis.

Onward referral pathways for each of the 4 tumour groups (primary brain or spine, base of skull, pituitary, cerebral metastases) are detailed below.

6.2 The Diagnostic Pathway

Diagnosis and onward referral of all brain tumours is made on the basis of brain imaging. SRFT is a tertiary referral centre which does not accept referrals without an imaging diagnosis *and* access to the scans. No other laboratory tests are necessary for initial diagnosis (although blood tests may support the need for MR imaging in suspected pituitary tumours). The need for any other laboratory tests eg CSF sampling, serum gonadotrophins, will be advised following MDT discussion.

MR imaging is required to enable the specialist MDTs to adequately assess all cases. Unless the patient is medically unstable and requires emergency transfer to SRFT, the patient is extremely frail and unlikely to be a candidate for active treatment, or MR imaging is contra-indicated or against the patient's wishes, an MR brain scan should be acquired in all patients either as the primary investigation or if a new primary tumour is identified on CT scan.

Waiting for MDT discussion to confirm that an MR brain scan is required introduces unnecessary delays.

6.2.1 Network Imaging Guidelines

MR scans should be performed pre and post intravenous contrast. For gliomas, MR imaging should be performed in line with the GMCCN Network Imaging Guidelines, see below, currently being reviewed by the Brain & CNS Pathway Board.

The imaging sequences of the whole head in patients with primary brain tumours are as follows:

- Axial T2
- Coronal FLAIR
- Axial T1
- Diffusion-weighted imaging
- Post-Gadolinium axial & coronal T1

These sequences should be implemented for all hemispheric tumours, both supra- and infratentorially.

Other sequences eg for pituitary tumours or vestibular schwannomas are as per local radiology advice.

Routine staging CT scan of thorax / abdomen / pelvis is *not indicated* in patients with primary brain tumours, which do not metastasise. However, a CT body is required in patients with brain lesions thought to be metastases, particularly if they have no previous cancer diagnosis (a primary or other mets will be demonstrated in > 50% of cases). This should be arranged urgently, without waiting for MDT advice to do so.

6.2.2 Network Neuro-Pathology Guidelines

Histopathological / histochemical investigations are undertaken at the specialist centre (SRFT) if the MDT recommends, and the patient agrees to, neuro-surgical intervention.

While a histological diagnosis is sought if possible in the majority of patients, histological diagnosis is not mandatory for diagnosis. The risks and benefits of attempted neurosurgical intervention to obtain histology are weighed up during MDT discussion; in many cases the risks are not felt to be justified. Imaging diagnoses in this patient group are accurate and are an accepted substitute for histological diagnosis.

All neuro-surgery is undertaken at the neuro-surgical centre at SRFT. All specimens are analysed at SRFT, which is the regional diagnostic centre for adult neuro-pathology for Manchester Cancer, by 2 sub-specialised consultant neuro-pathologists (Dr Daniel Duplessis and Dr Piyali Pal). Biopsies / histology are reported in line with best practice in this field.

Intra- and extra-axial CNS and pituitary tumours are reported in line with applicable datasets for those respective tumour groups as published by the Royal College of Pathologists (3rd Edition, April 2011). Reporting includes immuno-histochemical and cytogenetics-based biomarkers, performed either in-house or out-sourced locally. Immuno-histochemical diagnostic and prognostic markers including IDH-1 are performed at SRFT; molecular diagnostics including 1p19q analysis is performed at the regional cytogenetics laboratory at The Christie NHS FT. Electron-microscopy is undertaken at SRFT.

There is an informal North West Neuro-pathology group including a 3 monthly joint meeting with Liverpool and Preston to present and review difficult cases, and to facilitate the provision of second opinions. In very difficult / controversial cases, there is also the facility to refer to international experts (via procedures which comply with human tissue act legislation).

There is no requirement for any other clinician or clinical team to undertake histological investigations in this patient group (the only exception being cases of brain metastases from cancer of unknown primary site, which are managed in line with the CUP IOG, when biopsy of accessible extra-cranial sites may be recommended).

6.3 Red-flagging of diagnostic imaging suggestive of new primary CNS tumours:

Referral of patients to the relevant NSMDT within 2 working days within receipt of imaging report:

It has been agreed with the Network Crosscutting radiology group and with the Network cancer managers group that all brain scans showing a new diagnosis of a suspected malignant brain tumour will flag the case to the Cancer Services Team in their acute trust, in line with the “red-flag” policy for management of unsuspected cancers at other sites in the body. This covers new diagnoses of primary potentially malignant tumours only eg primary gliomas, ependymomas, primary CNS lymphomas, meningiomas causing significant oedema or mass effect, solitary metastases or metastases in patients with no known cancer diagnosis. It does not include benign disease eg pituitary tumours, vestibular schwannomas (acoustic neuromas) or incidentally detected meningiomas. Further clarification can be sought from the local trust Imaging Group representative.

Cancer services refer onwards to the MDT co-ordinator at SRFT. However, the purpose of this is to provide a safety-net so that patients cannot “get lost” if abnormal imaging results are not picked up; **it will not result in anyone contacting the patient and does not replace the clinical referral pathways described below.**

Management of patients with suspected recurrence

All patients with primary brain and spinal tumours, pituitary and skull base tumours remain under long-term follow-up by members of the relevant MDT. Any cases of suspected recurrence should therefore be discussed with treating clinician in the first instance to advise on appropriate investigation and management. Patients with known tumours who are admitted with tumour-related symptoms eg seizures do not necessarily need to go through the diagnostic and acute referral pathways again.

If the patient is medically unstable eg deteriorating level of consciousness or signs of raised intracranial pressure, advice can be sought from the neuro-surgical on-call team **BUT** consideration needs to be given to the stage of the patient’s illness eg the terminal phases of malignant gliomas. The patient’s treating clinician or their team, or if the on-call clinical oncology registrar at The Christie, should be contacted if in any doubt.

Onward referral to site specialised MDTs following imaging diagnosis.

Following imaging diagnosis, patients should be referred on as follows:

1) Primary Brain / Primary spinal cord tumours

- i) Acute: New onset and / or rapidly progressive neurological symptoms.

Diagnostic examples include (but are not exclusively): malignant gliomas, obstructing cerebellar tumours causing hydrocephalus, any tumour causing oedema or mass effect, multiple brain lesions consistent with metastatic disease in a patient with no previous cancer diagnosis.

The diagnosing clinician, or a member of their team, should telephone the neuro-surgical on call registrar at SRFT via SRFT switchboard, providing details of patient demographics, clinical history and location of scans. This service is available 24/7. The on-call team will review the images and if immediate transfer for urgent neuro-surgical intervention is indicated, will arrange this. (Emergency transfer is indicated in only a minority of patients). Advice may also be given regarding additional investigations and immediate management eg commencement of dexamethasone. This referral also acts as referral to the neuro-oncology MDT (the on-call service automatically flag it to the MDT) which takes place every Tuesday morning. Deadline for accepting

acute referrals is 9am Tuesday morning and there is no cap on the MDT agenda size so all cases will be discussed. MDT co-ordinator Diane Jones/Diane Horrocks Tel: 0161 206 1378, Fax: 0161 206 0899.

ii) Symptomatic but medically stable

Examples include tumours diagnosed via out-patient presentation and imaging eg low grade gliomas, symptomatic meningiomas, ependymomas.

The diagnosing clinician (GP or hospital doctor) should refer patients by faxed letter to Miss Konstantina Karabatsou, neuro-oncology lead neurosurgeon at SRFT under the 62 or 31 day cancer pathway. She will triage the referral and arrange MDT discussion and clinic review as appropriate. Her secretary, Angela can be contacted on: Tel 0161 206 8338, Fax: 0161 206 4606.

iii) Tumours diagnosed as incidental findings

Examples include meningiomas, benign lesions eg pineal cysts, other lesions of uncertain significance, many of which do not require intervention.

The diagnosing clinician (GP or hospital doctor) should refer these patients by faxed letter to one of the neuro-oncology neuro-surgeons (Miss K Karabatsou, Mr John Leach, Mr Ajit Sofat, Mr James Leggate, Mr Kanna Gnanalingham) at SRFT. They will triage the referral and arrange MDT discussion, clinic review or provide reassurance as appropriate. Referrals should be faxed to: Fax: 0161 206 4606.

2) Brain metastases

A selected subgroup of patients with brain metastases may benefit from neuro-surgical intervention or stereotactic radiosurgery. This is defined as patients with:

Solitary or < 4 cerebral metastases, all < 4cm

AND who are of good performance status (KP > 70, ie independent and self-caring)

AND who have systemically controlled / radically treatable disease.

Routine referral of all patients with brain mets to neuro-oncology services is therefore NOT indicated. For most patients, the decision about whether to refer on to the neuro-surgical MDT is best made by the patient's treating oncologist following discussion with the patient and assessment of the above factors.

However, direct referral to the neuro-surgical service is indicated for:

- Patients of previously good performance status presenting with a posterior fossa lesion causing hydrocephalus or deteriorating consciousness
- Patients with any number of lesions but no known cancer diagnosis (to exclude other diagnoses eg abscesses)
- Patients with a solitary lesion *confirmed on MR imaging* (with or without mass effect) where other differentials eg second primary tumours may be possible

These referrals should be made via the SRFT neuro-surgical on-call via SRFT switchboard. If in doubt, it is better to seek advice from the neuro-surgical on-call team.

3) Base of Skull Tumours

The majority of skull base tumours are slow-growing and benign or low grade, most commonly meningiomas or vestibular schwannomas; even rare malignant tumours at this site generally behave

indolently. Most patients present via OP clinics, emergency neuro-surgical intervention is very rarely required.

i) Medically unstable patients (rapidly progressive neurological symptoms esp signs of hydrocephalus and / or falling Glasgow Coma Score): Referral via SRFT neuro-surgical on-call.

ii) Symptomatic but medically stable patients eg hearing loss, dizziness, cranial nerve palsies, diplopia.

Referral pathway will depend upon diagnosing clinician eg

- Local ENT surgeons will initially refer on to one of the 2 base-of-skull specialist ENT surgeons (Mr Simon Lloyd and Mr Simon Freeman at SRFT / CMHC) who form part of the core skull base MDT
- Local ophthalmologists will refer to specialist oculoplastic ophthalmic surgeons (Mr Brian Leatherbarrow at The Royal Eye Hospital) who is part of the skull base MDT extended membership.
- General physicians / neurologists or GPs should refer directly in writing to Mr Andy King or Mr Scott Rutherford, base of skull neuro-surgeons at SRFT, who will arrange MDT discussion.

iii) Asymptomatic: Tumours identified as an incidental finding during brain imaging performed for another reason eg small meningiomas, asymptomatic acoustic neuromas.

The diagnosing clinician should write directly to Prof King or Mr Rutherford at SRFT (letters addressed to the general neuro-surgical pool will be triaged to them). They will arrange for the case to be reviewed at the MDT as appropriate.

The Base of Skull MDT meets on alternate Friday mornings; co-ordinator is Stuart Whitehead on mobile 07891 066161 or pager 07623 617445

4) Pituitary Tumours

Patients with suspected pituitary tumours are initially referred to an endocrinologist at their local acute trust who will arrange blood tests and MR imaging. The SRFT specialist pituitary endocrinology team (Dr Tara Kearney / Dr Anise Mukerjee) also accept GP direct referrals, which is particularly appropriate if the patient has clinically obvious pituitary disease eg acromegaly and the GP has already arranged MR imaging.

If a pituitary tumour is diagnosed, the endocrinologist will arrange for the case to be discussed at the specialist pituitary MDT. Many acute trust endocrinologists attend this meeting in person. If they do not, they refer the case on to SRFT or to one of the larger local units whose clinicians do attend the MDT (eg CMHC or PANTS).

It is extremely uncommon for patients with pituitary tumours to require emergency neurosurgical intervention (there is approximately 1 case of pituitary apoplexy per year in Greater Manchester). If there is concern about acute deterioration (particularly rapidly progressive visual disturbance, radiological diagnosis of pituitary apoplexy or symptoms of raised intracranial pressure) the on-call neuro-surgical team at SRFT should be contacted.

The pituitary MDT meets on the second Thursday of the month. Co-ordinator is Diane Horrocks Tel 0161 206 0080, Fax: 0161 206 0899.

6.4 TREATMENT PATHWAYS

Treatment pathway depends on the outcome of the discussion at the neuroscience, skull base or pituitary MDT. All patients are discussed both pre and post-operatively, unless surgery had to be performed as an emergency before MDT discussion was possible (see emergency surgery policy section P22).

All surgery is performed at SRFT; radiotherapy is delivered at The Christie or The [Christie@Salford](#) satellite unit; all chemotherapy is dispensed from (if tablets) or delivered at (if intravenous) The Christie.

Primary Brain or Spinal Tumours

Following discussion at the neuro-oncology MDT, patients with may be managed with neuro-surgery, radiotherapy, chemotherapy, best supportive care or active surveillance. In the majority of cases, the treating clinician is present in the neuro-oncology MDT and prompt arrangements for clinic review are made. In other cases, onward referral to other teams is arranged as detailed below.

Patients may be seen by:

Neuro-oncology neuro-surgeon if surgery is being offered or active surveillance suggested. Neuro-surgical policy is that patients who are being offered surgery should be seen in clinic within 1 week of MDT discussion and operated on within 2 weeks.

Neuro-oncologist if the patient has already undergone surgery and further treatment with radiotherapy and / or chemotherapy is being recommended, or where patients are not felt to be surgical candidates but there are oncological management options eg palliative radiotherapy. Patients are seen within 1 week of MDT discussion.

Local Palliative Care Specialist Team if patient is not well enough to come to clinic or is not a candidate for active treatment, it is recommended that best supportive care is delivered via the local teams.

Referral to local PCST is made by telephone by one of the MDT clinical nurse specialists or a member of the palliative care team who was present at the MDT discussion. The formal neuro-oncology MDT minutes are also forwarded, and the neuro-oncology team remain available for ongoing telephone advice.

TYA MDT / TYA clinic - patient \leq 24 years of age.

Patients are seen within a week of the neuroscience MDT by Dr Rao Gattamaneni who is a core member of both MDTs and will arrange for the case to be discussed at the TYA MDT. Cross-cover in this aspect is provided by Dr Martin McCabe.

Lymphoma MDT – if diagnosis of primary CNS lymphoma has been histologically confirmed, patients will be nominated for discussion at the GMCCN Lymphoma MDT (at The Christie every Friday pm) via the NSMDT minutes, which will be forwarded to the Lymphoma team (Prof John Radford, Dr Kim Linton) with additional personal communication by one of the neuro-oncologists. Patients who are is potentially suitable for intensive chemotherapy or clinical trial entry will be seen in the Lymphoma new patient clinic (Wednesday pms); patients not well enough for chemotherapy will be seen in the neuro-oncology clinic by the neuro-oncology team to discuss radiotherapy or palliative care. Patients are managed in line with the national CNS Lymphoma Management Guidelines.

All new primary brain and spinal tumours patients are nominated for discussion at the Network MDT by core members of that MDT who attend both meetings eg the CNSs or AHPs.

Cases are re-discussed in the neuro-science MDT and Network MDT at key points in their patient journey eg at relapse or if symptoms change. They are nominated for re-discussion by their treating clinician, keyworker or AHP.

Cerebral metastases:

There are 3 subgroups of brain metastases patients for whom referral to the neuroscience MDT is appropriate (as outlined above),

1) Good prognosis patients who may benefit from surgical resection or stereotactic radiosurgery.

This group is defined as:

- Patients with solitary or less than 4 cerebral metastases, all measuring ≤ 4 cm
- AND who are of good performance status (KP ≥ 70 ie independent and self-caring)
- AND who have systemically controlled disease

2) Patients with hydrocephalus or critically raised intracranial pressure, particularly from an obstructing cerebellar tumour

3) Patients with cancer of unknown primary site with no disease elsewhere in the body where neuro-surgical biopsy at be considered to obtain a histological diagnosis.

All patients with brain metastases are managed in close collaboration with their treating site-specialised oncologists.

A stereotactic radiosurgery service for Manchester Cancer at SRFT will become operational in December 2011, meaning that patients will no longer have to travel to the National Gamma Knife Centre at Sheffield. Specialist multidisciplinary clinic will be held in The Christie at Salford satellite unit; stereo-tactic radiosurgery will be planned and delivered there on an outpatient basis.

There are 4 possible outcomes for patients referred to the MDT for indication 1 above (≤ 4 small mets in fit patients with systemically controlled cancer)

i) Suitable for neuro-surgical intervention: patients will be seen by a neuro-oncology neuro-surgeon

ii) Suitable for stereotactic radiosurgery (SRS): Patients will be seen in the specialist SRS clinic at SRFT by a neuro-oncologist

iii) Suitable for either SRS or surgery: Patients will be seen jointly by a neuro-oncologist and a neuro-surgeon in the SRS clinic at SRFT to discuss the pros and cons of each approach

iv) Not suitable for either SRS or surgery: Referral back to treating oncologist via MDT minutes for consideration of palliative whole brain radiotherapy or best supportive care

Patients referred to the neuro-science MDT who are to be offered surgery for brain metastases causing raised ICP or hydrocephalus or for biopsy of CUP will be seen by a neuro-surgeon. In cases of obstructing hydrocephalus they may be transferred as an emergency.

Base of Skull Tumour Patients

Skull base patients will be seen in an out-patient clinic by a core member or the skull base MDT team to discuss active surveillance, surgery or radiotherapy, as per MDT advice. All treatment and follow-

up is supervised by an MDT core member. Patients with supportive care or rehabilitation needs are referred on to the Cancer Network MDT, with liaison via their key worker.

Pituitary tumour patients

Pituitary tumour patients will be seen in a specialist clinic by an endocrinologist or surgeon associated with the pituitary MDT to discuss the recommended medical or surgical management, or active surveillance. If radiotherapy is being recommended, they are referred on to a clinical oncologist associated with the pituitary MDT. Patients are referred on to the Cancer Network MDT as required, at the discretion of treating clinicians and clinical nurse specialists.

6.5 FOLLOW UP PATHWAY

Patients with primary brain and spinal cord tumours remain under long-term follow-up by the site-specialist MDT teams. Patients with primary brain and spinal cord tumours who have received radiotherapy or chemotherapy are never discharged. Almost all follow-up occurs in specialist clinics at The Christie or SRFT; some pituitary patients may be followed up by endocrinologists at local acute Trusts working in conjunction with the specialist pituitary MDT.

Frequency of visits and imaging follow-up is diagnosis-dependent; this is detailed in the GMCCN CNS Management policy documents.

Management of recurrence

At the time of recurrence, cases may be referred back to the appropriate site-specialised MDT by their treating clinician. Criteria for re-discussion at specialist MDT includes the potential for further active treatment with neuro-surgery, radiotherapy or alternatives, or for clarification / sub-specialist review of imaging findings. Patients are not routinely required to be re-referred to the MDT for a change in medical management eg endocrinological therapy or chemotherapy regime.

Patients whose recurrence is accompanied by a change in their symptoms are referred back to the Network MDT by their treating clinician or key-worker. If referral to a local SPCMDT is appropriate, it will be made via the Network MDT (which includes SPC members) unless the patient is profoundly unwell and requires end of life care in which case the direct referral to the local SPC MDT can be made by members of the treating team, key worker or other involved health professionals following discussion of the case with the patient's treating clinician or their cross-cover. Late effects of treatment will be considered within the Cancer Network MDT; there is no specific late effects MDT for patients with brain & CNS tumours.

In cases of confirmed or suspected disease recurrence patients, the patient's treating consultant should be contacted directly in the first instance via their secretaries. They will advise re bringing forward the patients clinic appointment, indications for and nature of additional imaging and arrange re-discussion at the specialist MDT in line in line with the guidance above.

7. NETWORK COMMUNICATION FRAMEWORK (14-1C-113K)

The communication framework is as laid out in the IOG document. Detailed descriptions of the enactment of these policies are detailed in the operational policies of the 3 site-specific MDTs, but in summary, MDT minutes are typed and faxed or posted to referring clinicians, GP and other relevant bodies eg SPC or Network MDT within 1 working day of MDT discussion. In cases where information needs to be conveyed more urgently, the relevant clinical nurse specialist will telephone the treating acute trust team to convey the MDT opinion.

To ensure that minutes reach the case-notes of in-patients at referring hospitals whose treating clinician may have changed since the referral was made (eg if patient moved from MAU to a ward), and to ensure that referring hospitals' cancer services teams are aware of brain tumour cases diagnosed, MDT minutes are sent by secure email to cancer services teams in each hospital within 24 hours of MDT. A pathway whereby they print off the minutes and convey the outcome to the treating clinician within 1 working day has been agreed and was introduced in 2012. It remains under review but appears to be improving speed communication.

The policy for communications between providers of care for brain & CNS tumours is described below:

- Patients with an initial imaging diagnosis of a CNS tumour should have been logged on to a dataset of the NSMDT within one week of the date of the image report
- A clinical summary from the clinician in charge of the patient at the time of the imaging diagnosis should have been received by the NSMDT within 2 working days of the date of the imaging report
- A written summary of the proposed management plan be sent out from the NSMDT within one working day of the MDT meeting to the referring clinician, the CNMDT and the GP
- The patient or their carers are informed of the diagnosis within one working day for inpatients and 5 working days for outpatients of the NSMDT meeting at which it is confirmed
- The patient or their carers are informed of the management plan by the NSMDT within one working day for inpatients and 5 working days for outpatients of the NSMDT meeting at which it is decided
- A referral for relevant patients is sent to the rehabilitation or palliative care service within one working day of the decision being made
- A referral of relevant patients for management by a member of the CNMDT is sent within 2 days of discharge from neurosurgical care
- Patients or their carers are informed of the identity and role of their key worker within one working day for inpatients and 5 working days for outpatients of the NSMDT meeting
- A referral back to the neuroscience MDT for further management of possible recurrence is sent from the multidisciplinary specialist clinic within one working day of the decision

8. PROTOCOL FOR EMERGENCY SURGICAL INTERVENTIONS (14-1C-114K)

The area-wide protocol for emergency surgical interventions in patients with a CNS tumour, for intra-CNS problems caused by the tumour or its treatment is described below:

All emergency intervention is at SRFT. Cases referred to the neuro-surgical on-call service who are felt to require emergency neurosurgical intervention due to critically raised intracranial pressure, rapidly progressive neurological symptoms and / or deteriorating level of consciousness will be transferred to SRFT as an emergency and managed at the discretion of the neuro-surgical on-call

team. In these circumstances it is accepted that brain tumour patients may be operated upon by surgeons other than core MDT. The aim of surgery is to stabilize the patient. The case is always discussed at the next MDT to determine next steps in management.

In the absence of critically raised intracranial pressure, rapidly progressive neurological symptoms and / or deteriorating level of consciousness, any issues with patients on treatment should be directed back to treating team at Christie. The on-call team at Christie can be contacted 24/7.

9. AREA LEAD FOR NEURO-REHABILITATION (14-1C-106K)

- The named lead for neuro-rehabilitation for Manchester Cancer is Mrs Julie Emerson
- Mrs Emerson is a specialist AHP with recognized specialist clinical skills in oncology and neurological rehabilitation, band 8, level 4 practitioner
- One session per week is allocated to the area lead role
- A description of the role and list of responsibilities for the role, agreed by Dr Catherine McBain and Mrs Julie Emerson is shown below

Area Rehabilitation Lead Role

The area lead for neuro-rehabilitation should be a member of the NDSG with a responsibility for overseeing and signposting access to appropriate acute, specialist inpatient neurological/spinal rehabilitation and community neuro-rehabilitation services for patients with brain and CNS tumours.

Area Rehabilitation Lead Responsibilities

- Attend the NDSG as representative for AHP services.
- Identify the need for service provision for patients with brain and CNS tumours with functional deficits resulting from their disease or side effects of its treatment
- Ensure appropriate clinical intervention through appropriate and effective rehabilitation and management programmes for patients with CNS tumours throughout their treatment pathway across the network.
- Act as a resource and signpost access to local neurological, spinal and general rehabilitation inpatient, community and voluntary sector (hospice) services.
- Guide liaison with acute, specialist inpatient neurological/spinal rehabilitation and community services to influence provision and commissioning of rehabilitation services for patients with CNS tumours.
- **NB:** this role will not be able to direct the provision and criteria of these services which are decided and commissioned locally.
- Assist the Regional Cancer Network AHP Lead in the implementation of National Cancer and Palliative
- Care Rehabilitation Pathways 8 for patients with CNS tumours.
- Assist the Regional Cancer Network AHP Lead to ensure compliance with the Peer Review Rehabilitation
- Assist the Regional Cancer Network AHP Lead to co-ordinate education training and research; to improve knowledge and skills in oncology throughout the network and to improve service provision for patients with CNS tumours across the network.

The Operational Policy for Neuro-rehabilitation Facilities is reproduced in appendix 3.

10. CHEMOTHERAPY TREATMENT ALGORITHMS (14-1C-108k)

Chemotherapy algorithms are included within the Clinical Guidelines document. The following link takes the reader to the current chemotherapy algorithms used by Christie oncologists.

<http://nww.christie.nhs.uk/documents/default.aspx?Category=Y&Category1=1>

11. TEENAGERS & YOUNG ADULTS (TYA) PATHWAYS

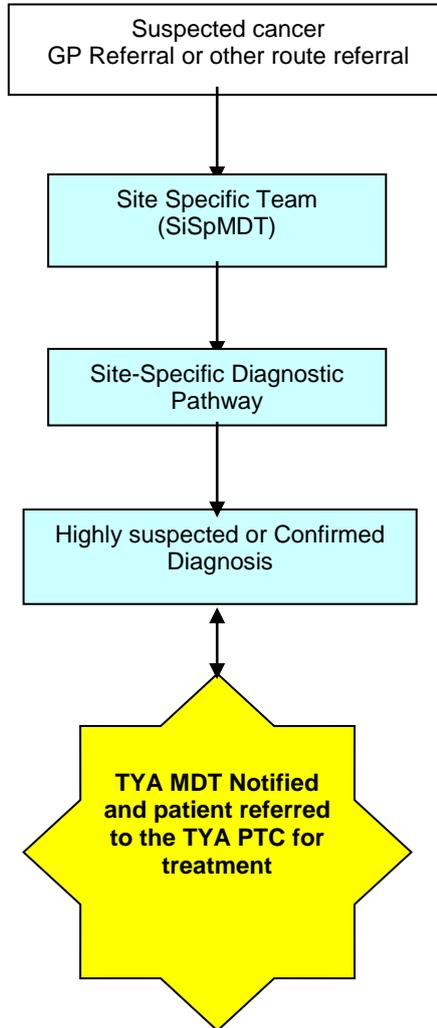
11.1 Pathway for Initial Management

All treatment in patients under 16 takes place at Royal Manchester Children's Hospital (RMCH) under supervision of paediatric neuro-oncology teams and is out with the remit of this group.

Patients aged 16-24 (mainly 18-24, under 18 very rarely) are referred to the SRFT neuro-oncology teams. They are managed in line with agreed TYA MDT pathways outlined above, and all are referred to TYA MDT at RMCH so that patients have access to specialist support services. All radiotherapy and chemotherapy in patients under 24 is delivered via the Young Oncology Unit (YOU) at Christie within the TYA framework.

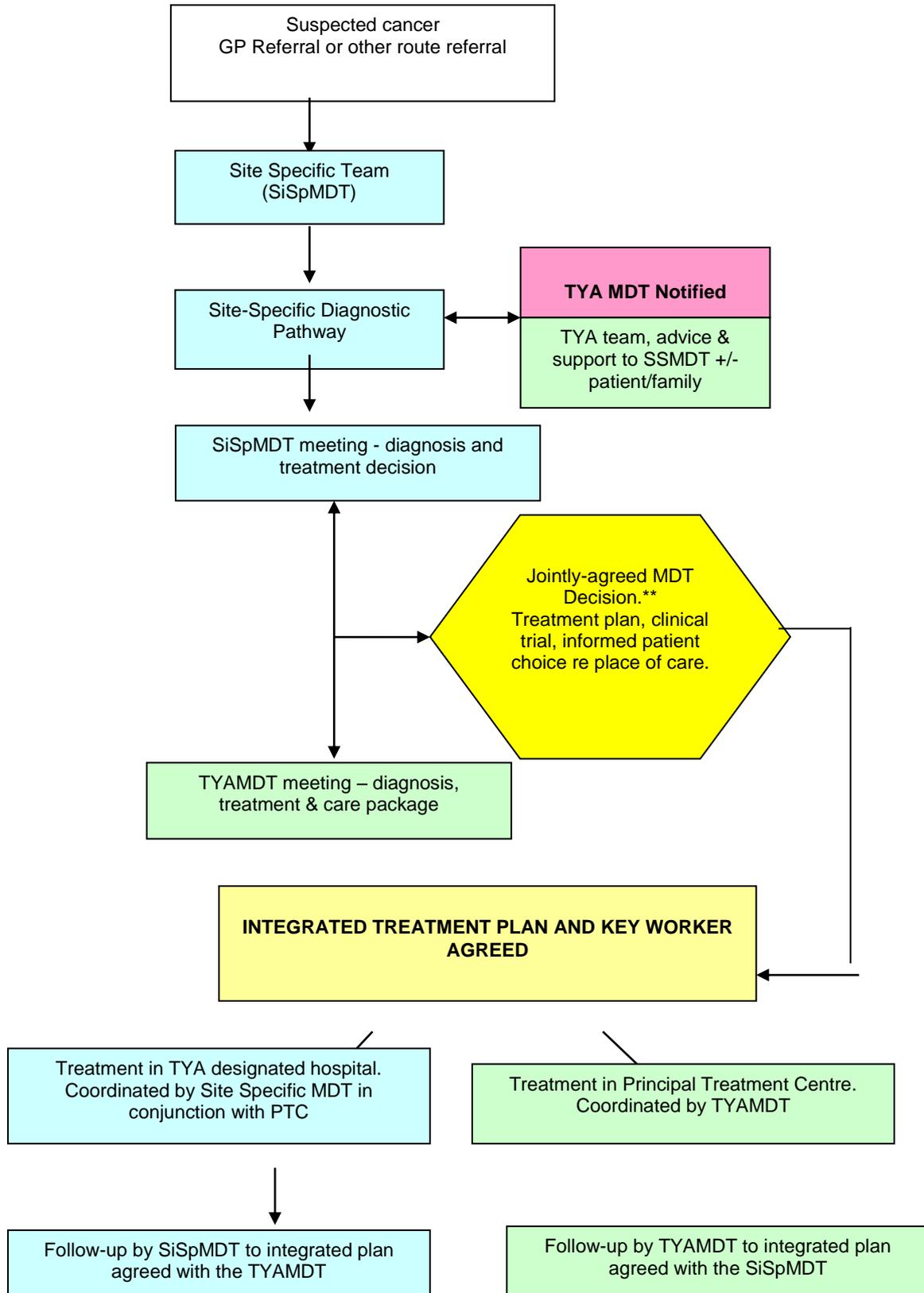
The TYACN Pathways for Initial Management

TEENAGE AND YOUNG ADULT PATHWAY 16-18 YEARS INCLUSIVE
(Designated and Non Designated TYA Hospitals)



TEENAGE AND YOUNG ADULT PATHWAY 19-24 YEARS

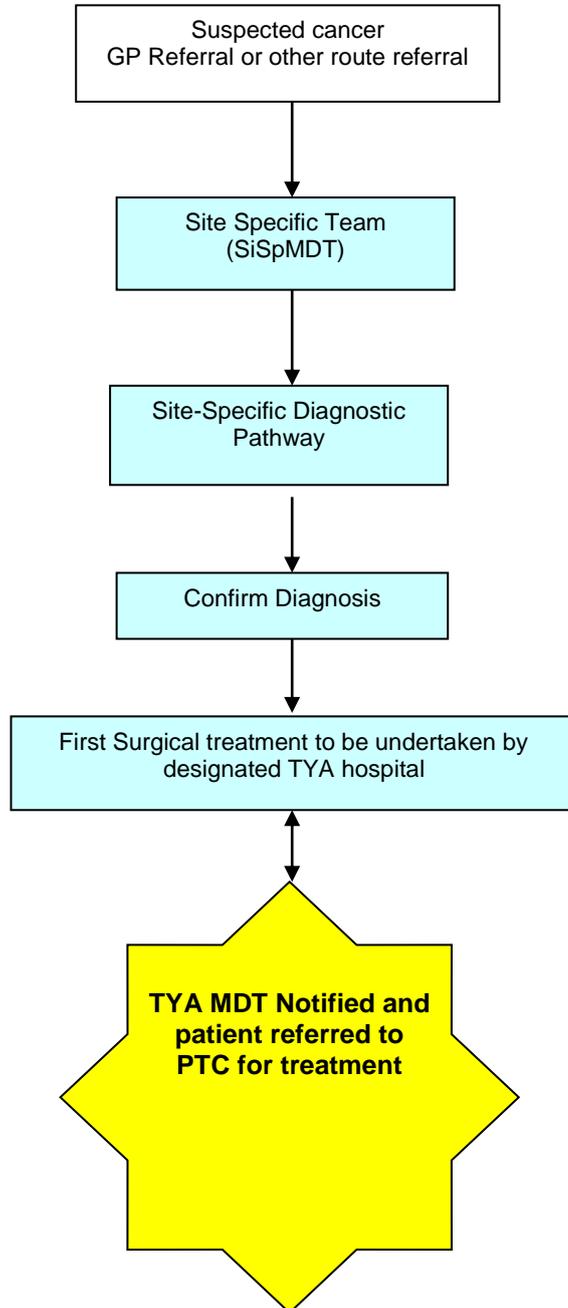
Designated TYA Hospitals



** Jointly agreed MDT decision should not delay the start of urgent treatment

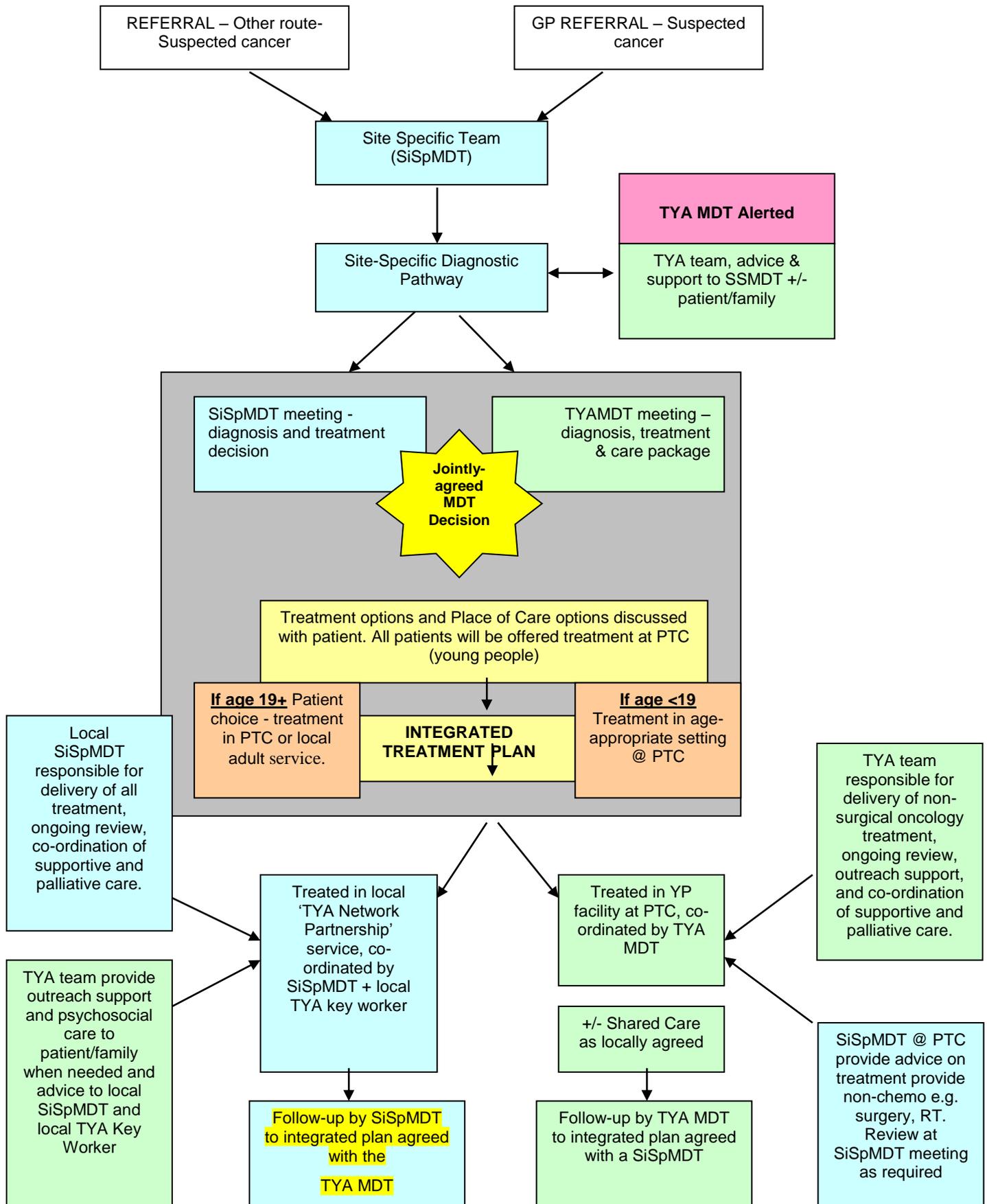
TEENAGE AND YOUNG ADULT PATHWAY 19-24 YEARS.

Non Designated TYA Hospitals



11.2 Pathway for Follow Up on Completion of First Line of Treatment

All TYA patients remain under long term follow up in MDT clinics at YOU in line with TYA Improving Outcomes Guidance. Patient aged 16-24yrs Referred to a Site-specific MDT that is NOT based at a Principal Treatment Centre (Young People)



Appendix 1: NOTIFICATION OF NEWLY-DIAGNOSED PRIMARY BRAIN AND SPINAL TUMOURS TO THE SALFORD NEURO-ONCOLOGY MDT

The Cancer Network groups would like to extend the systems already in place for flagging previously unsuspected cancers to their hospital cancer services to include newly diagnosed primary brain and spinal tumours.

This system aims to ensure that all patients with newly-diagnosed brain or spinal tumours have been referred to the neuro-oncology team at Salford. **It does not replace the clinical pathway where the radiology report is returned to the treating clinician, who contacts the neuro-surgical on-call. It will exist in parallel to this, to provide a safety net to ensure that no newly diagnosed tumour is overlooked.**

We ask that any radiologist reporting a brain scan which shows an apparent, previously undiagnosed, primary brain or spinal tumour call an alert in line with their local practice, forwarding patient demographic and diagnostic details to Cancer Services in their hospital.

This applies only to:

Newly identified tumours in patients with no previous brain tumour or cancer diagnosis. This will include high grade gliomas, low grade gliomas, clinically significant meningiomas, primary cerebral lymphomas, cerebral tumours of unknown type, primary spinal tumours e.g. ependymomas.

It does not apply to:

Re-scans of patients known to have brain tumours
Brain metastases in patients already known to have cancer

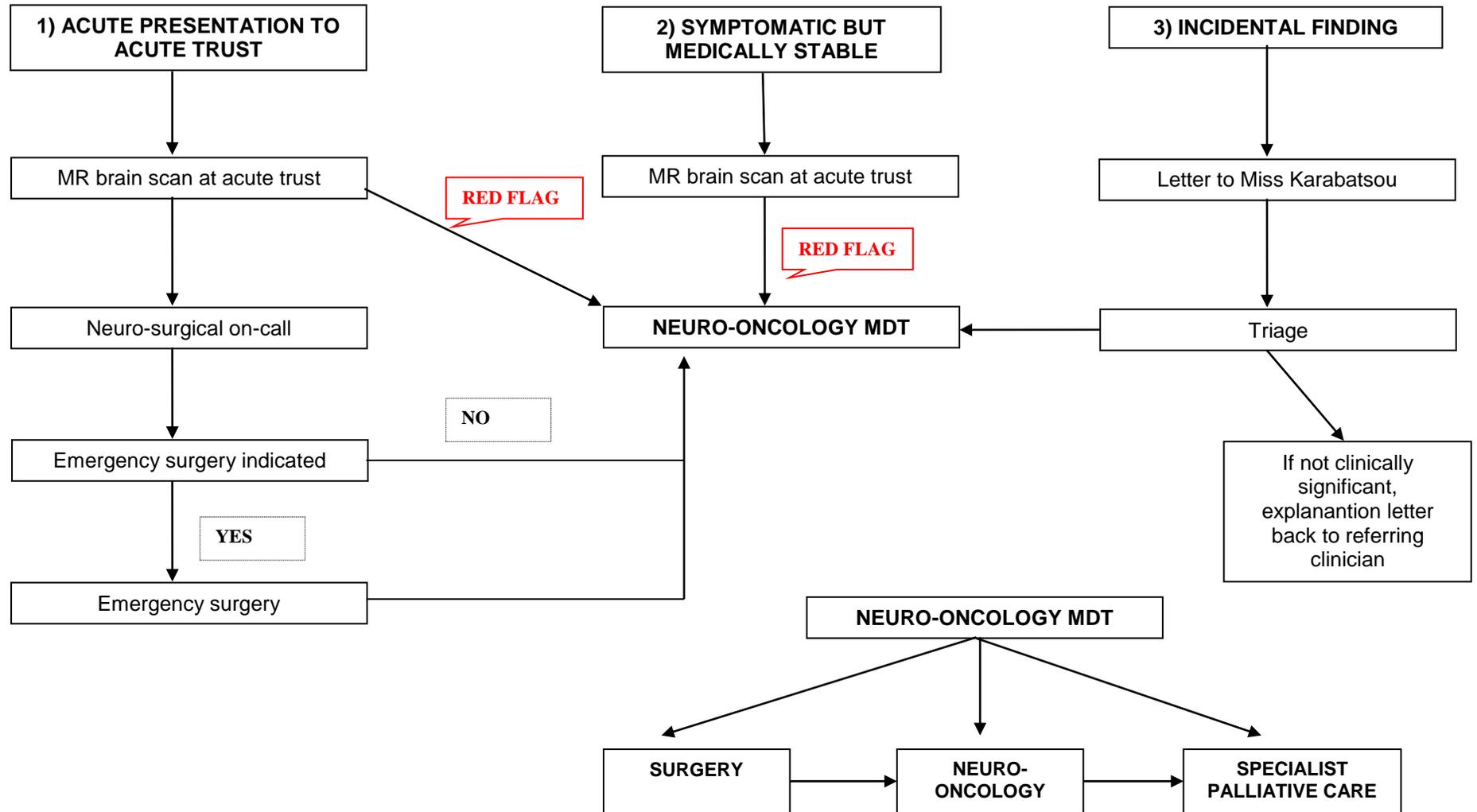
The numbers of these patients are small, typically 0 – 2 per hospital per week, and we aim for this system to be pragmatic and not onerous. However, it is important and is being introduced to ensure that all of these patients are being optimally managed and do not “fall through the net”.

Please forward the following details to cancer services who will contact the neuro-oncology MDT directly. **This action will not result in anyone contacting the patient.**

Patient name.....
Date of Birth.....
NHS Number.....
Date of scan.....
Location of scan.....
Diagnosing radiologist.....
Referring clinician.....

To cancer services: Please fax this sheet to Diane Jones, Neuro-oncology MDT co-ordinator at SRFT, Tel: 0161 206 1378, Fax: 0161 206 0899. The MDT will feed back directly to the treating clinician, with a copy to cancer services for local records

Appendix 2: Referral Pathways



Appendix 3: Operational Policy for Neuro-rehabilitation Facilities (14-1C-115k)

Title: Operational Policy for Brain and CNS Tumour Rehabilitation



Purpose: To provide staff with guidance on the operating principles and processes associated with the Brain and CNS tumour rehabilitation Specialist AHP service.

Document Application: Greater Manchester and Cheshire Cancer Network (GMCCN) wide

Responsibilities for implementation: Julie Emerson and Sara Robson, Specialist AHPs. Liz Jordan, Line Manager

Date Issued: May 2012

Review Date: May 2014

Author: Julie Emerson and Sara Robson, Specialist AHPs, Brain and CNS tumour Rehabilitation.

Consultation Process: GMCCN

References (if applicable): Department of Health (2001) The NHS Cancer Plan, National Pathway for Brain and CNS tumours 2009, Manchester Cancer, NICE Improving outcomes for people with brain and CNS tumours 2006, NICE Improving Supportive and Palliative Care for Adults with Cancer 2004

Associated policies/documents: Christie and SRHFT

Clinical supervision

Lone worker

Consent

Health and safety

Risk assessment and management

Data protection

Intranet Category for Location:

Policies & Guidelines – Organisational Practice, Clinical services; AHP specialist brain and CNS tumour rehabilitation service operational policy

Abbreviations:

AHP – Allied Health Profession

OT – Occupational Therapy

Approved by: Risk Committee

Date:

CONTENTS

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1	Introduction	3
2	Location of Specialist AHP brain and CNS tumour rehabilitation service	3
3	Purpose	3
4	Management and leadership	4
5	Patient pathway assumptions	4
6	Access criteria	4
7	Admission process	4
8	Admission and Discharge Activity	5
9	Performance indicators	5
10	Service continuity	5

Appendices

Appendix A: Patient pathway

Appendix B: Standard referral form

Appendix C: Brain & CNS Tumour Rehab Pathway

1. Introduction

- a) The Specialist AHP brain and CNS tumour rehabilitation posts were funded by GMCCN and are hosted by The Christie NHS Foundation Trust. The Specialist AHPs are responsible for leading and co-ordinating a network wide rehabilitation service for adults with brain and CNS tumour. This is a new service.

2. Location

- a) The service is based at The Christie and Salford Royal.
- b) The service is available from 8.00am to 4.00pm 5 days per week with flexible working dependant on the needs of the service.
- c) The contact details are:- 07827 955 047 or 07827 955 048

3. Purpose

The required outcomes from this service are:

- To coordinate the rehabilitation of adults with brain and CNS tumour across the Manchester Cancer footprint.
- To refer on to local services in a timely manner providing information about the urgency / non-urgency of the referral to support prioritisation locally.
- To promote delivery of an efficient, high quality and timely intervention for patients transferred to rehabilitation services across the network which supports rehabilitation, reduces inappropriate hospital admission and facilitates preferred place of care.
- To use expert clinical reasoning and knowledge to support colleagues in other rehabilitation teams to implement high quality evidence based clinical practice
- To be an expert resource for AHP rehabilitation in brain and CNS tumour.
- To promote learning in this specialist area across the network by supporting the development of education and clinical skills opportunities.
- To contribute to and report on the audit of the service
- To develop the service in line with the Manchester Cancer and commissioner requirements / vision for brain and CNS tumour rehabilitation service across the footprint.
- To provide a service to meet national guidelines and best practice and local and national pathways of care.
- To signpost patients, carers and professionals to the appropriate services.

4. Management & Leadership

- a) The Specialist AHPs are managerially led by the Rehabilitation Unit Manager at The Christie.
- b) The Specialist AHPs report professionally to the occupational therapy lead at SRHFT and the speech & language lead at The Christie Hospital NHS Trust.
- c) Clinical supervision will take place in line with the trust Clinical supervision policy.
- d) The Specialist AHPs report to Manchester Cancer for the strategic development of the service.
- e) To work collaboratively with and report regularly to consultants and specialist nurses about the service and developments.

5. Patient Pathway Assumptions: Brain and CNS tumour rehabilitation

- a) Each patient will have been referred to the MDT at SRFT and have a confirmed diagnosis of primary brain and/or CNS tumour.
- b) The patient will have identified rehabilitation needs.
- c) The Specialist AHPs will liaise with therapists at the specialist treatment centers and identify patients for rehabilitation post treatment and ensure patients are transferred to local services.

- e) Specialist AHPs will be involved in highly specialist joint assessments and rehabilitation care planning.

6. Access Criteria for Specialist AHP brain and CNS service.

- a) All patients will have a primary brain or CNS tumour or a brain / CNS tumour with an unknown primary.
- b) All patients will have rehabilitation needs.
- c) All patients will be under the care of Consultant Neuro Clinical Oncologists, Consultant Neuro radiologists or Consultant Neuro Surgeons at The Christie and /or SRFT.
- d) All patients will be under the care of the MDT at The Christie or SRFT specialist centers.
- e) Patients aged 16 to 24 will have access to adult services if not currently known to the young oncology service, where the adult service best meets the patients needs.

7. Admission Process – refer to appendix 1 patient pathway

- a) All patients will be referred by a member of the MDT, identified by the Specialist AHP, by a local AHP or by self referral.
- b) A standard referral form with personal and clinical details will be completed. See appendix 2
- c) Patients will be seen on acute wards and in specialist MDT out patient clinics at SRFT, and The Christie. Patients may be seen at district general hospitals or in community at the request of the local therapist where a highly specialist opinion is required.

8. Admission & Discharge Activity

- a) Rehabilitation needs are to be co-ordinated by the Specialist AHP brain and CNS service.
- b) Data is to be recorded on the appropriate data collection system. Medway at The Christie and iSoft or Medway at SRFT.
- c) When a patient is transferred to another rehabilitation service, the appropriate referral information must be sent by post or faxed to a safe-haven fax. Patient information should not be emailed between organisations.
- d) If the patient is discharged from the service e.g. at the patient's request or at the end of life, the local therapists will be informed verbally or in writing, as appropriate.

9. Performance Indicators

It is imperative that we are able to monitor the performance of this development, via key performance indicators. These are monitored within Manchester Cancer???. They are described below.

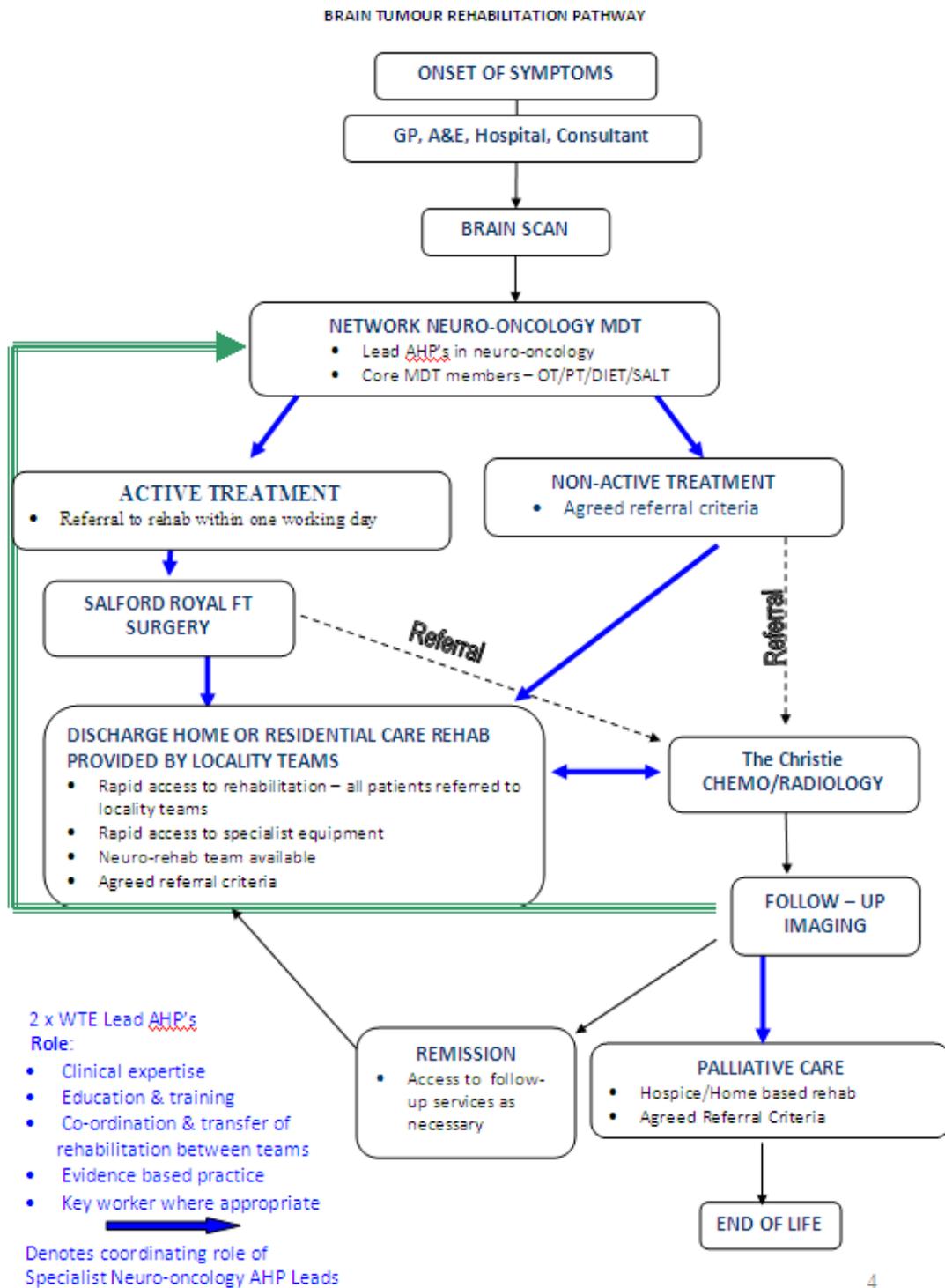
Key Performance Indicators (KPI)

- i) a specialist AHP will attend each weekly NSMDT
- ii) a specialist AHP will attend bi monthly supportive care cancer network MDT
- iii) the rehabilitation pathway will be audited at least every two years
- iv) the specialist AHPs will deliver at least one network wide study day a year.

10. Service continuity

- a) The Specialist AHPs will rota annual leave to provide cover for the service.
- b) Specialist AHPs will prepare for planned annual leave to cover essential work.

Appendix A



Appendix B Referral form to Specialist AHPs

Referral to Specialist AHP brain and CNS service																								
Name (or affix patient sticker)	DOB	NHS number																						
Address	GP	Location of patient now?																						
Tel NOK	Tel	going to?																						
Diagnosis: Tumour type:																								
Grade: I II III IV																								
Treatment plan e.g. surgery, radiotherapy, chemotherapy, future appointments etc																								
Prognosis:	Patient aware? Yes / no	Family aware? Yes / no																						
Date referred:	Date actioned (AHP:to complete)	Local PCT:																						
Functional status on: (date) _____																								
<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 60%;">Karnofsky Performance Scale (Please tick)</th> <th style="width: 40%;">Function on referral</th> </tr> </thead> <tbody> <tr> <td><input type="checkbox"/> 100 Normal; no complaints and no evidence of disease</td> <td><input type="checkbox"/> Motor weakness</td> </tr> <tr> <td><input type="checkbox"/> 90 Able to carry on normal activity with only minor symptoms</td> <td><input type="checkbox"/> Sensory changes</td> </tr> <tr> <td><input type="checkbox"/> 80 Normal activity with effort; some moderate symptoms from disease</td> <td><input type="checkbox"/> Mobility impaired</td> </tr> <tr> <td><input type="checkbox"/> 70 Cares for self but unable to carry on normal activities</td> <td><input type="checkbox"/> Communication altered</td> </tr> <tr> <td><input type="checkbox"/> 60 Cares for most needs but requires occasional assistance</td> <td><input type="checkbox"/> Swallowing impaired</td> </tr> <tr> <td><input type="checkbox"/> 50 Needs considerable assistance to carry out ADL; frequent medical care</td> <td><input type="checkbox"/> Visual / hearing impairment</td> </tr> <tr> <td><input type="checkbox"/> 40 Disabled; requires special assistance and care</td> <td><input type="checkbox"/> Emotional/behavioural change</td> </tr> <tr> <td><input type="checkbox"/> 30 Severely disabled; hospitalised but death not imminent</td> <td><input type="checkbox"/> Cognitive/ perceptual deficit</td> </tr> <tr> <td><input type="checkbox"/> 20 Very sick; requires active supportive treatment</td> <td><input type="checkbox"/> Weight loss</td> </tr> <tr> <td><input type="checkbox"/> 10 Moribund; death threatened or imminent.</td> <td><input type="checkbox"/> Seizures</td> </tr> </tbody> </table>			Karnofsky Performance Scale (Please tick)	Function on referral	<input type="checkbox"/> 100 Normal; no complaints and no evidence of disease	<input type="checkbox"/> Motor weakness	<input type="checkbox"/> 90 Able to carry on normal activity with only minor symptoms	<input type="checkbox"/> Sensory changes	<input type="checkbox"/> 80 Normal activity with effort; some moderate symptoms from disease	<input type="checkbox"/> Mobility impaired	<input type="checkbox"/> 70 Cares for self but unable to carry on normal activities	<input type="checkbox"/> Communication altered	<input type="checkbox"/> 60 Cares for most needs but requires occasional assistance	<input type="checkbox"/> Swallowing impaired	<input type="checkbox"/> 50 Needs considerable assistance to carry out ADL; frequent medical care	<input type="checkbox"/> Visual / hearing impairment	<input type="checkbox"/> 40 Disabled; requires special assistance and care	<input type="checkbox"/> Emotional/behavioural change	<input type="checkbox"/> 30 Severely disabled; hospitalised but death not imminent	<input type="checkbox"/> Cognitive/ perceptual deficit	<input type="checkbox"/> 20 Very sick; requires active supportive treatment	<input type="checkbox"/> Weight loss	<input type="checkbox"/> 10 Moribund; death threatened or imminent.	<input type="checkbox"/> Seizures
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<input type="checkbox"/> 10 Moribund; death threatened or imminent.	<input type="checkbox"/> Seizures																							
Reason for referral to specialist AHP: (what input is needed? assessment, maintenance, prevention, enabling, curative, improve, supportive, palliative)																								
Triage: Urgent 1-7 days Timely: 1 to 4 weeks Non urgent: more than 4 weeks																								
Mobility: independent with stick/frame wheelchair need assistance of 1 2 3 4																								
Managing stairs? Yes / No Don't need to use stairs																								
Managing personal care tasks? Yes / No Managing daily household tasks ? Yes / No																								
Eating and drinking well? Yes / No . Give details																								
Communicating effectively? Yes / No Give details																								
Any current community therapy and / or nursing input? District nurse Dietitian OT PT S<																								
Name:	Signature:	Date:																						
Designation:	Telephone number:																							

Appendix C: Brain & CNS Tumour Rehab Pathway

Brain & CNS Tumour Rehabilitation Pathway		
Stage in pathway	Role of Network AHPs	Role of Local AHPs
<p>NEURO SCIENCE MDT</p> <p>Brain scan discussed and treatment planned</p>	<p>NETWORK MDT</p> <p>Network AHP identifies rehab need.</p> <p>Refer to local AHPs if not for surgery and advise re: rehab needs and approach.</p>	<p>COMMUNITY OR ACUTE</p> <p>Deliver rehabilitation.</p> <p>Liaise with network AHP for advice / information</p>
<p>SURGERY SALFORD</p> <p>Surgical procedure</p>	<p>NETWORK AHP</p> <p>Involved when patient is transferred to other acute or community provider. Where discharge is complex. Where there is a delay in local service provision. To support local AHP service provider. Contacts patient on discharge to ensure equipment and services are in place.</p>	<p>SALFORD ROYAL ACUTE AHPs</p> <p>Screen carried out to assess rehab needs. Referral made to Salford acute services. Acute AHPs treat and refer to local rehab services on discharge. Network AHPs made aware of rehab needs on discharge.</p>
<p>Radiotherapy The Christie or The Christie at Salford</p> <p>Medical team review during treatment and identify rehab needs</p> <p>Refer on to network AHPs</p>	<p>NETWORK AHP</p> <p>Liaise with staff involved in delivering treatment. Assess rehab needs in XRT clinic or community, give advice, refer on, liaise with other AHP services.</p>	<p>COMMUNITY or ACUTE</p> <p>Christie AHPs treat if admitted during XRT and manage patient.</p> <p>Review radiographers / nurses identify rehab needs during treatment and refer on to specialist AHPs</p>
<p>CHEMOTHERAPY</p> <p>Medical team and research nurses identify rehab needs</p> <p>Refer on to specialist AHPs</p>	<p>NETWORK AHP</p> <p>Liaise with community AHPs pre / post clinic</p> <p>Assess for rehab needs</p> <p>Refer on to local services</p> <p>Deliver training</p> <p>Provide clinical support</p>	<p>COMMUNITY</p> <p>Liaise with specialist AHPs pre clinic with concerns, feedback</p>
<p>SURVIVORSHIP</p> <p>Christie Neuro-oncology team follow up in conjunction with GP and other specialists e.g. neurosurgeons, epileptologists etc</p>	<p>NETWORK AHP</p> <p>Liaise with community AHPs</p> <p>Assess for rehab needs jointly</p> <p>Refer on to local services</p> <p>Deliver training</p> <p>Provide clinical support</p>	<p>COMMUNITY</p> <p>Contact Specialist AHPs for specific rehab info regarding treatment side effects</p> <p>Support groups</p> <p>Treat specific rehab needs – goal related</p>
<p>END OF LIFE</p> <p>Medical team and community staff identify supportive care needs</p> <p>Refer on to specialist AHPs for advice and referral to local services</p>	<p>NETWORK AHP</p> <p>Liaise with community AHPs re specific queries</p> <p>Refer on to local services</p> <p>Provide clinical support</p>	<p>COMMUNITY</p> <p>Symptom and supportive care management locally</p> <p>Liaise with specialist AHPs re: specific supportive care queries</p>