Manchester Cancer

Brain & CNS Pathway Board

Annual Report 2013/14

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Version 1.4

1.Executive summary

Brain and CNS cancer surgery is based at Salford Royal Foundation Trust with robust and strong links with the oncology service at the Christie NHS Foundation Trust. There are four associated MDTs, all of whom have seen a rise in the number of cases discussed over the last three years.

Other Trusts have clear well established procedures and guidelines for referral into the service and this is further supported by an electronic referral process.

The service continues to develop and innovate. In recent years this included the development of the Christies at Salford radiotherapy centre and the use of stereotactic radio surgery. This service also has seen a rise in its activity, with a doubling in cases treated between 2012/13 and 2013/14.

Therefore this is a stable, well run and mature service with a strong ethos of team working.

The pathway board is largely drawn from the members of the old Greater Manchester and Cheshire NSSG and benefits from having the continuity of the same chair person. There are however gaps in the membership.

Namely there is no GP or patient representative and Pennine Acute NHS Trust is still the only associated Trust still to nominate a representative. The board will hope to address all of these deficits in this coming year.

Because of the nature of brain cancer there is little scope for developing early detection and prevention strategies. However the board will look to support, through its education programme, primary care colleagues in symptom recognition and understanding of brain and CNS cancer.

The board faces a number of challenges in its first year. Firstly it is to agree the outcome measures or outputs that will be used to assess and monitor the patient and carer experience along the whole pathway. This will be addressed as part of this year's action plan.

As part of this it is also planning to support patients and carers better in living with and beyond their disease by deploying a patient hand help record. This will also be part of the work pan for the coming year.

Lastly it will also review all guidelines as part of what will be the on-going quality assurance of the pathway. This will be a key function of the pathway board and one that it looks forward to undertaking.

The board has only been in existence since the 6th May 2014 and has just met twice. The full potential of the members is still to be realised but progress has been made even in this short time. The board sees this report as transitional one and looks forward to developing the pathway in the next twelve months and beyond.

In the coming year the board has set 5 objectives and these are –

- Optimise data collection to generate outcome measures

- Introduction of 5ALA-guided resection into routine practice of suitable patients with high grade gliomas
- Maintain IOG compliance of MDTs
- Introduction of MGMT testing for high grade gliomas
- Introduction of patient-held records

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 annual report. It outlines the current configuration of services, the progress in forming the Pathway Board, the data on outcomes and experience that the Board took into account when setting its objectives, and what those objectives are for 2014/15 and beyond. In July 2015 every Manchester Cancer Pathway Board will publish a full annual report, outlining the work of its first full year and its progress against those objectives.

This annual report is designed to:

- Provide a summary of the work programme, outcomes and progress of the Board – alongside the minutes of its meetings, its action plan and its scorecard, it is the key document for the Board.
- Provide an overview to the hospital trust CEOs and other interested parties about the current situation across Manchester Cancer in this particular cancer area
- Meet the requirements of the National Cancer Peer Review Programme
- Be openly published on the external facing website.

2. General overview

The Specialist Neuroscience Multi-disciplinary Team members are expected to operate according to the standards laid out in the following documents;

Improving Outcomes Guidance in Brain and CNS tumours, NICE 2006
Manual of Cancer Service Standards, Brain and CNS measures, April 2012
Guidelines for the Management of Brain and CNS tumours, 2010 – GMCCN

Nationally Brain tumours represent 1% of all cancers diagnosed yet 3% of all deaths. Of these deaths 71% will be under the age of 75 years, compared to 47% for all cancers.

Further, 58% of adults diagnosed with bran cancer die within a year compared to 5% for breast cancer and 35% for leukaemia and 7% for prostate cancer.

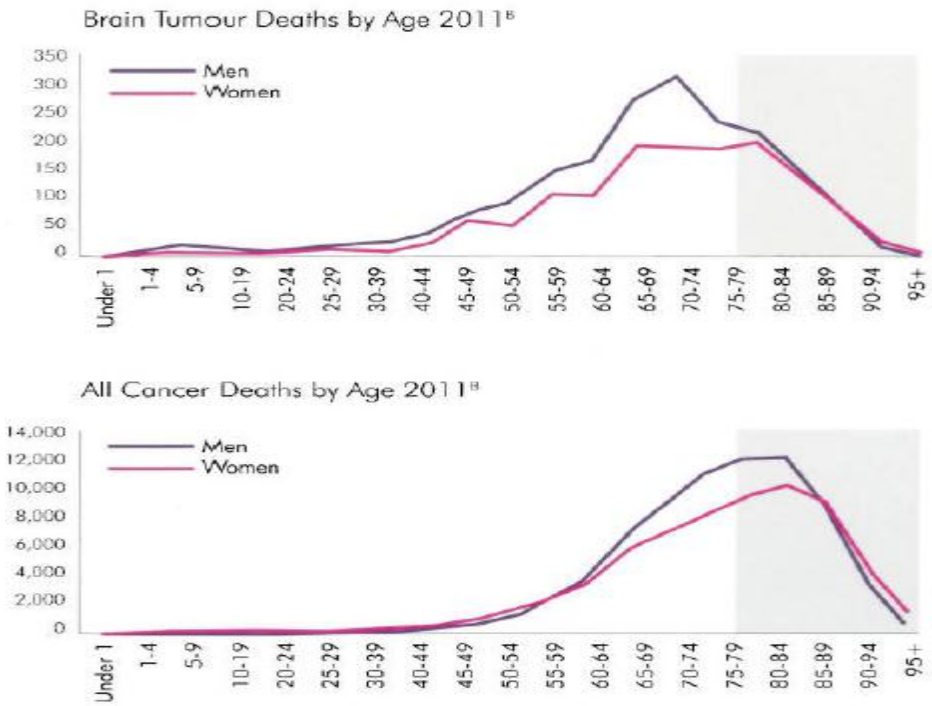
There is considerable regional variation in incidence, ranging from 108 per million in London to 139 per million in the North-west of England. This makes the North-west the 4th highest region with 9 more per million than the national average.

In terms of diagnosis in 2011 the North-west was the second highest in terms of number of brain tumours diagnosed with 568 cases.

New Brain tumours diagnosed by region	Total	Male	Female	Total per 1M people	Male per 1m people	Female per 1M people
South west	487	265	222	145	84	61
Yorkshire & the Humber	434	240	194	142	82	60
East midlands	398	223	175	140	83	57
North west	568	325	243	139	83	56
North east	203	112	91	136	77	59
West midlands	403	237	166	127	76	51
South east	654	381	273	123	75	48
East	437	240	197	123	70	53
London	430	242	188	108	64	44
England	4014	2265	1749	130	77	53

Table 1 – Brain tumours diagnosed in England 2011

Regionally and nationally there is also variation between genders in the number of cases diagnosed. In the north-west 83 males per million people are diagnosed compare with 56 females per million.



Graph 1 Brain tumour research report on national research funding – July 2013

3. Background to the pathway.

The Brain & CNS Site Specific Group (NSSG) was in existence supported by Greater Manchester and Cheshire Cancer Network. Due to the reconfigurations of Networks' nationally the former NSSG was dissolved and a Brain & CNS Pathway board was formed.

The purpose of the board is to ensure that services for patients with suspected or diagnosed brain & CNS cancer are being delivered in accordance with NICE Improving Outcomes Guidance and peer review cancer quality measures, as well as further developing the standards of care for those patients in a post treatment phase of the pathway.

In principal, the basis of the pathway board is the same as the old NSSG, with members drawn from referring acute trusts and the four constituent MDTs, as well as the clinical support services involved in cancer management along the entire patient care pathway.

The old NSSG functioned very well and made the pathway as efficient as possible, with well-constructed guidelines and referral processes. The new pathway board will benefit from this experience as the majority of the pathway board made up of previous members of the NSSG and the pathway director, Dr McBain was also the previous group's chair.

The NSSG had a work plan and service delivery programme to cover the period 2013 – 2016 and this has been adopted for delivery by the pathway board.

4. Configuration of services

There are four Multi-Disciplinary Teams (MDTs): three (neuro-oncology and primary spine, base of skull and pituitary) are based at Salford Royal NHS Foundation Trust as this is the regional Neurosciences provider. The fourth, the supportive care network MDT, is based at the Christie NHS Foundation Trust.

The purpose of the MDTs

- To provide safe and effective advice
- To offer services that are up-to-date, based on the best available evidence and compliant with NICE IOG guidelines
- To constantly review their practice
- To ensure best communication levels between its members and referring clinicians
- To ensure that the personal development of its members is supported and maximized

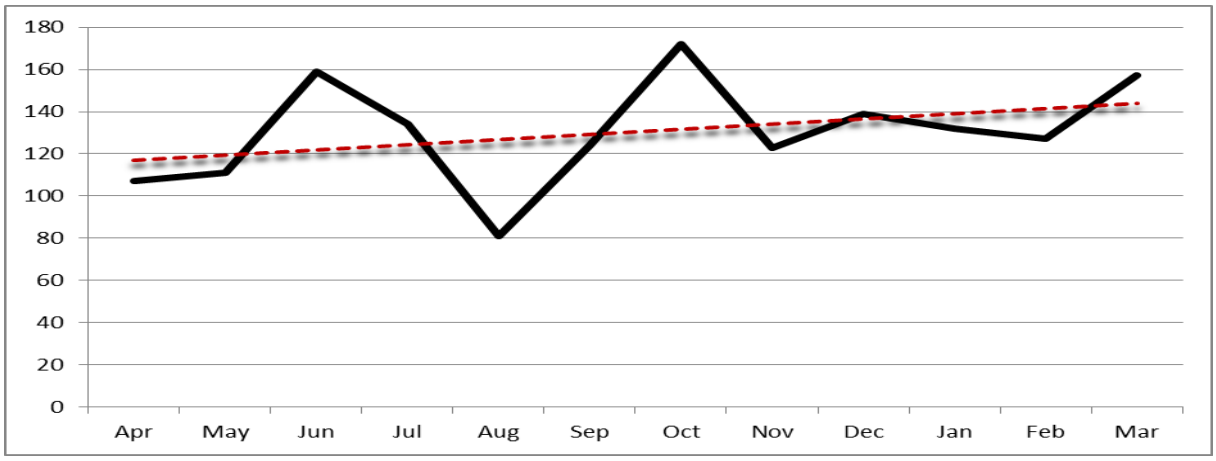
4.1 Neuro-oncology MDT

The Neuro-oncology MDT at Salford Royal NHS Foundation Trust (SRFT) was initially established in 2004, and over time there has been a considerable increase in the numbers of referrals to the MDT due to the complexity of brain and spinal tumours.

All primary brain and spinal tumour cases across what was recognised as the Greater Manchester and Cheshire Cancer Network footprint are referred to the Neuro oncology MDT, many as acute referrals initially referred to the neuro-surgical on-call service.
Patients with cerebral metastases (and other indicated pathologies) are also referred if they are for consideration of neurosurgical intervention or for Stereotactic Radiosurgery (SRS).

Those patients who have undergone previous surgery or oncological treatments for brain or spinal tumours in the past may also be discussed if there is a need to review follow up scans or if there has been a clinical deterioration and an entire MDT opinion is required.

On average the agenda for the MDT now routinely comprises between forty-five and sixty-five patients per week, representing a quadrupling of the MDT work in recent years. Since the opening of the SRS facility within The Christie at Salford in December 2011, the numbers of referrals have increased and further increases are anticipated.



Neuro oncology MDT- Total Number of cases discussed by month April 2013 – Mar 2014

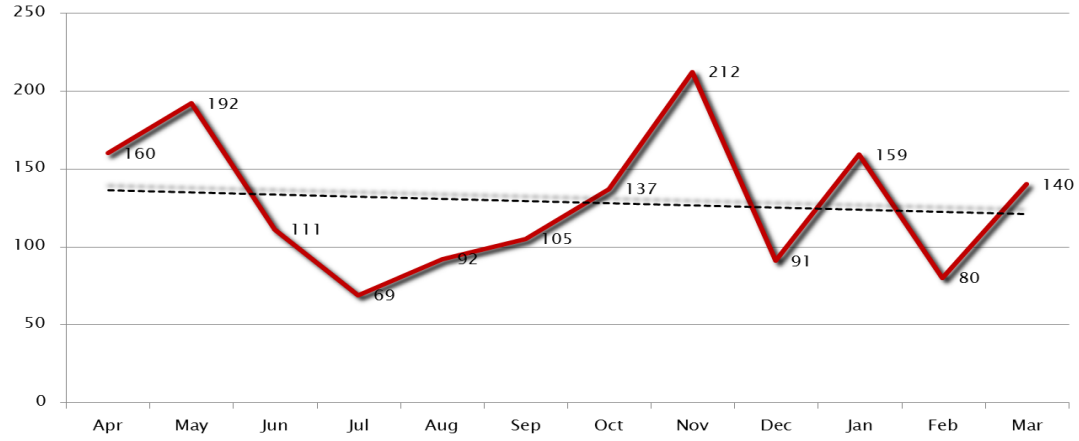
4.2 Base of Skull MDT

This MDT includes neuro-surgeons, ENT and ophthalmic surgeons who work together to provide multi-disciplinary management of patients with tumours arising at the base of the skull. It receives referrals from the local neuroscience unit (30 Neurologists and 19 Neurosurgeons based at SRFT), from a variety of clinicians and specialties across the Greater Manchester region, as well as from a wider referral base across the UK and from abroad based on their longstanding reputation.

In addition, imaging findings are often complex and images performed outside SRFT may not have been reported by a specialist neuro-radiologist. Review of these external radiological diagnosis by the skull base neuro-radiologists forms an important role of the MDT. The volume of cases, the range of referral sources and the complexity of some of the patients presents unique operational challenges.

Because of the nature of the disease skull base patients are seldom discharged, which leaves an ever increasing group of patients requiring on-going multidisciplinary management. The agenda

now routinely comprises up to 120 cases per fortnight, representing a steady number in MDT workload.



Base of skull MDT- Total Number of cases discussed by month April 2013 – Mar 201

4.3 Pituitary MDT

The Pituitary Tumour MDT was established pre-2002 to facilitate discussion of pituitary cases across the region and although the vast majority of cases have benign pathology, the service falls within the Brain and CNS IOG.

The Pituitary surgical service in Manchester is one of the busiest in the country serving a population of approximately 3.5 million adults and 5 million children. Pituitary surgery is undertaken at both Salford Royal Hospital (adults) and Royal Manchester Children's hospitals (RMCH).

As a consequence over the last few years the numbers of cases discussed has increased and the proceedings of the MDT have been formalised. In 2013/14 the MDT discussed 328 cases and the number of cases that went to surgery has over the 5 years from 2009 until 2013 increased from 61 to 104.

4.4 Supportive Care Cancer Network MDT

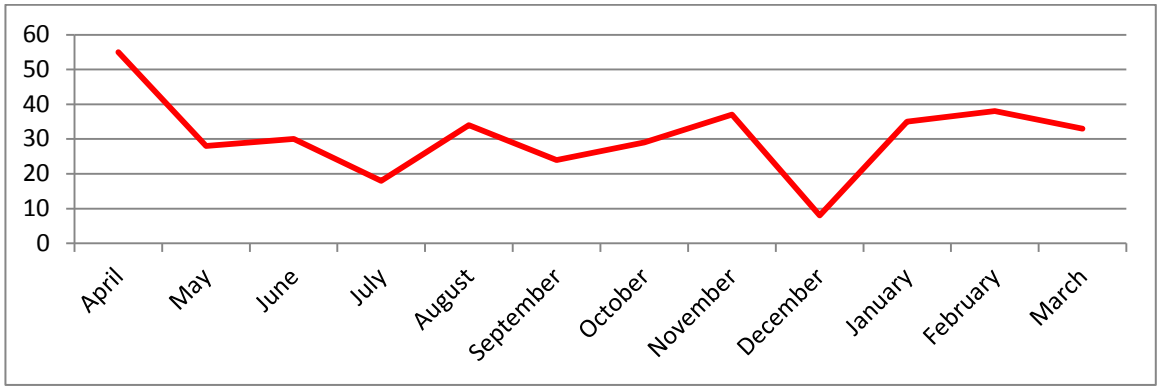
The Supportive Care Cancer Network MDT was established in January 2012 when it became necessary to separate the NS (Neuro science) MDT and the Cancer Network MDT due to time restraints at the combined meeting.

It is a multi- professional group serving the population of 3.2 million across what was recognised as the Greater Manchester and Cheshire Cancer Network footprint and is now well established.

The MDT is made up of core members who are all involved in the management of patients with primary brain and central nervous system primary tumour including primary cerebral lymphoma, skull base and pituitary tumour.

A fortnightly meeting is held to oversee the on-going delivery of the non-surgical aspects of the patient's treatment plan, such as specialist nursing care, neuro-rehabilitation, neuropsychology

and palliative care at the time of diagnosis and other key points in their cancer journey, in line with the recommendations within the IOG p24. Patient information has been reviewed in line with the Patient Information Prescription and a folder of information is given to patients early in their diagnosis.



Supported care MDT- Total Number of cases discussed by month April 2013 – Mar 2014

5. Clinical guidelines

The Pathway Board has only been in place since its first meeting on the 6th May 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 has been migrated from the old cancer network website and can now be found at - http://www.gmccn.nhs.uk/hp/Groups/NetworkSiteSpecificGroupsNSSGs/BrainCNS/DocumentsInformation/GMCCNClinicalGuidelines

A full list of active current guidelines and their renewal dates will be produced for the next annual report of July 2015.

6. Clinical information and outcomes

1. Surgery performed

Type of Operations	Number of patients
Craniotomy	294
Brain Biopsy	43
Other Brain Surgeries (Shunt insertion etc.)	5
Spinal Tumour Removal/biopsy	84
Total	426

Neuro-oncology Surgery performed 2013/14 – NO peer review documentation

Neuro-oncology 28-day Mortality 2013/14

In this period there were 336 cranial surgeries with 1.4% 28-day mortality in total and only 0.9% mortality as inpatient.

In-patient deaths

1. GBM- post-operative hematoma
2. Meningioma-died 11th day postop; PE
3. Respiratory failure post lymphoma biopsy 13th day post-op

Deaths post discharge

4. GBM died day 26 postop-well at discharge.
5. Met; Disease progression-died 17th day postop shunt op at peripheral hospital

2. Base of skull surgery performed 2013 14

Intervention	Number
Carcinoma	2
Chondrosarcoma	1
Epidermoid/Dermoid	5
Facial Schwannoma	1
Glomus jugulare	1
Inflammatory lesion (granuloma)	1
Meningioma	29
Trigeminal Schwannoma	3
Vertigo/Meniere's disease	1
Other tumour	1
Chiari malformation	3

Cochlear Schwannoma	1
Neurovascular compression syndrome	42
Vestibular Schwannoma	55
Other tumour	1
Grand Total	**147**

3. **Stereotactic Radiosurgery undertaken**

YEAR	TOTAL PATIENTS	ISOCENTRES	METASTASES	ACOUSTICS	MENINGIOMAS
2011/12	10	12	10	0	0
2012/13	45	59	37	7	1
2013/14	94	132	61	31	2
2014/15	32	59	25	6	1

Number of patients treated by SRS 2011/12 – 2014/15

7. Patient experience

Assessing the patient experience was discussed at the July board meeting. It was agreed that a full review of the patient experience surveys was required to identify possible areas of concern and this will be tabled at the next board meeting.

Because of the length and complexity of the pathway the board felt that having a patient survey taken at only one point on the pathway could mean that it was less than informative and be difficult to identify any particular underlying reasons for unfavourable feedback.

In the national Cancer patient experience survey 2012-2013 for Salford Royal NHS Foundation Trust a total 340 patients from Salford Royal were eligible to participate in the survey. Of these, 203 completed the questionnaires and posted them back to the Trust.
Of the 203, 18 patients were diagnosed with a tumour or cancer of the brain and central nervous system.

On reviewing the published results, there were no responses to the following sections for the Brain & CNS patient group:

- Seeing your GP
- Diagnostics tests
- Finding out what was wrong with you
- Deciding the best treatment for you
- Clinical Nurse Specialist
- Support for all people with cancer
- Cancer Research
- Operations

- Hospital doctors
- Ward nurses
- Hospital care and nurses
- Information given to you before you left hospital and home support
- Hospital Care as day/out patient
- Care from GP
- Overall NHS care

However in accordance with the requirements of the NICE Improving Outcomes Guidance for patients with brain and other CNS tumours, the Salford Skull Base service developed and distributed a disease specific patient questionnaire in order to provide detailed and constructive feedback that can be used to shape the service provided to patients. 100 questionnaires were distributed to a random selection of patients who had been diagnosed with a skull base tumour.

Results
The response rate was 61%. 47.2% were female and 52.8% were male; which is a similar response rate to the national cancer survey.
Overall, the feedback was very positive. Some examples include:
• 89% of patients were satisfied or very satisfied with the length of their appointment.
• 86% of patients felt that investigations were explained to them.
• 78% of patients felt that the diagnosis was discussed in a sensitive manner.
• 97% of patients were given the name of the Clinical Nurse Specialist.
• 92% of patients were given the contact details of the Clinical Nurse Specialist.
• 97% of patients felt that the risks and side effects were explained to them.
• 97% of patients felt that there operation was explained to them.
• 92% of patients felt that they understood the answers given to questions posed.
• 92% of patients felt that the Clinical Nurse Specialist listened carefully to their concerns.
• 95% of patients had confidence in the Doctor's treating them.
• 97% of patients felt they were treated with dignity and respect most if the time.

Some areas where we could improve include:
• 25% of patients felt they did not receive their results in a timely manner.
• 50% of patients remember receiving patient information in a leaflet format.
• 20% of patients found it difficult to contact the Clinical Nurse Specialist at times.
• 61% of patients felt they were not given the details of appropriate support groups.

In response to the areas which require improvement the MDT devised an action plan to address each area of concern.

The board will review how patient feedback is gathered at the next meeting and agree a patient experience survey and reporting process.

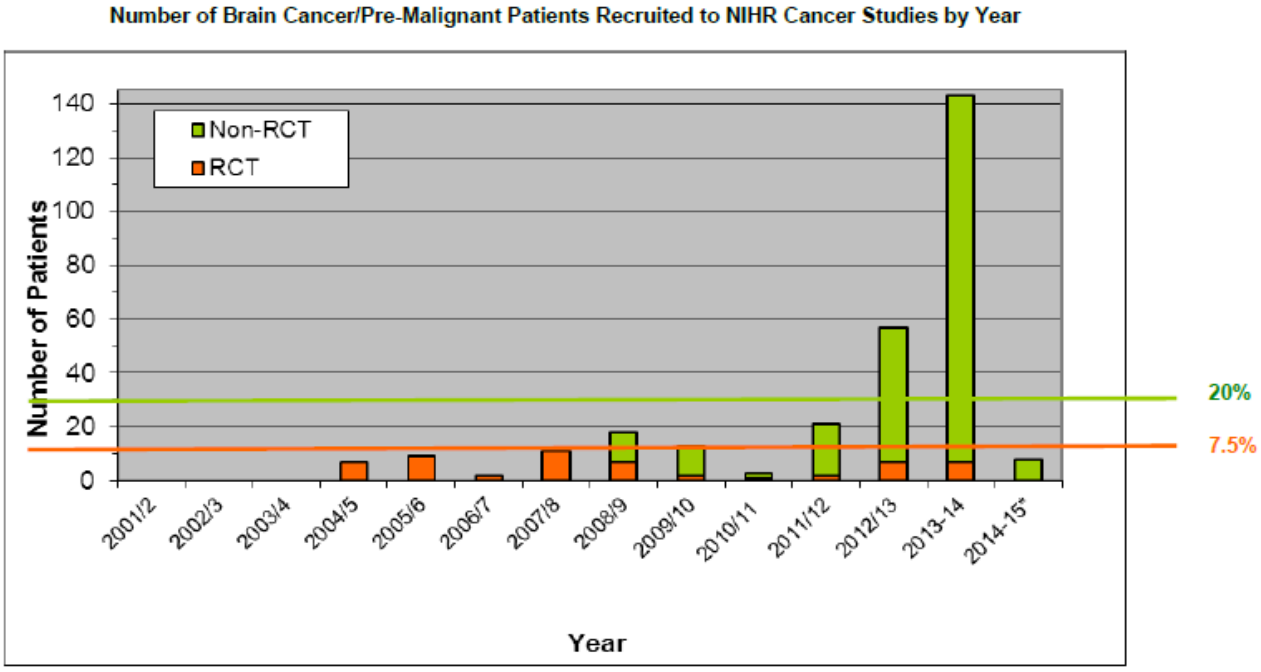
The pathway board would also welcome a close working relationship with the Living with and Beyond Cancer pathway board and is keen to be part of part of the process that will address the assessment and care planning of patients living with and beyond cancer. The board will take forward any recommendations from the Living with and Beyond Cancer pathway board and ensure improvements are made.

8. Research and clinical trials

Data on recruitment to clinical trials is reviewed at all pathway board meeting and the position at the July pathway board is below.

In 2013/14 7 brain cancer/pre-malignant patients were recruited to randomised control trials (RCT) and 136 such patients were recruited into non RCTs. This meant that nationally the Greater Manchester CLRN was the best recruiter into brain cancer clinical trials.

The target for 2014/15 is 11 and 30 respectively. So far 2 RCT recruits have been recruited and 6 for non RCTs.



The clinical trials portfolio offered to patients in Manchester is one of the widest in the country, encompassing industry-sponsored trials as well as NCRN adopted studies. However, the portfolio is smaller than for many other disease groups, and many studies open to only very limited numbers of patients, representing the unique challenges of conducting research in this area

The Christie/ Salford Brain & CNS trials portfolio is nationally highly competitive, with all possible studies open. Many studies are opened at a small number of centres nationally and The Christie is consistently within this subgroup. In addition the group is recruiting into/ in set up for industry sponsored studies and will push for inclusion of these studies into the NIHR portfolio.

Where targets have not been reached, this has been due to lack of availability of places in competitively recruiting studies or due to early closure of trials. . Brain and CNS tumours are a CRUK priority area and the Pathway Board will continue to do all it can to further research recruitment. The group is highly committed to CNS research and will ensure that all potentially eligible patients are offered study entry.

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8.1 Published research in peer-reviewed literature in the past year:

- Tang IP, Freeman SR, Rutherford SA, King AT, Ramsden RT, Lloyd SK.
  Surgical Outcomes in Cystic Vestibular Schwannoma versus Solid Vestibular Schwannoma.
  Otol Neurotol. 2014 May 16.
- Tang IP, Freeman SR, Kontorinis G, Tang MY, Rutherford SA, King AT, Lloyd SK.
  Geniculate neuralgia: a systematic review. J Laryngol Otol. 2014 May 13:1-6.
- Kontorinis G, Freeman SR, Potter G, Rutherford SA, Siripurapu R, King AT, Lloyd SK.
  Management of cerebellopontine angle lipomas: need for long-term radiologic surveillance?
  Otol Neurotol. 2014 Jun;35(5):e163-8.
- Mahtani S, Glynn F, Mawman DJ, O'Driscoll MP, Green K, Bruce I, Freeman SR, Lloyd SK.
  Outcomes of Cochlear Reimplantation in Adults.
  Otol Neurotol. 2014 Mar 17.
- Freeman SR, Stivaros SM, Ramsden RT, O'Driscoll MP, Nichani JR, Bruce IA, Green KM, Henderson LA, Rutherford SA, King AT, Lloyd SK.
  The management of cochlear nerve deficiency.
  Cochlear Implants Int. 2013 Nov;14 Suppl 4:S27-31
- Lloyd SK, Glynn FJ, Rutherford SA, King AT, Mawman DJ, O'Driscoll MP, Evans DG, Ramsden RT, Freeman SR.
  Ipsilateral cochlear implantation after cochlear nerve preserving vestibular schwannoma surgery in patients with neurofibromatosis type 2.
  Otol Neurotol. 2014 Jan;35(1):43-51.
- Tysome JR, Axon PR, Donnelly NP, Evans DG, Ferner RE, O'Connor AF, Freeman SR, Gleeson M, Halliday D, Harris F, Jiang D, Kerr R, King A, Knight RD, Lloyd SK, Macfarlane R, Mannion R, Mawman D, O'Driscoll M, Parry A, Ramsden J, Ramsden R, Rutherford SA, Saeed SR, Thomas N, Vanat ZH.
  English consensus protocol evaluating candidacy for auditory brainstem and cochlear implantation in neurofibromatosis type 2. Otol Neurotol. 2013 Dec;34(9):1743-7.
- Lloyd SK.
  Sudden sensorineural hearing loss: early diagnosis improves outcome.
  Br J Gen Pract. 2013 Aug;6(613):e592-4.
- Lloyd SK, Evans DG.
  Neurofibromatosis type 2 (NF2): diagnosis and management.
  Handb Clin Neurol. 2013;115:957-67.
- Moffat DA, Lloyd SK, Macfarlane R, Mannion R, King A, Rutherford S, Axon PR, Donnelly N, Freeman S, Tysome JR, Evans DG, Ramsden RT.
  Outcome of translabryinthine surgery for vestibular schwannoma in neurofibromatosis type 2.
  Br J Neurosurg. 2013 Aug;27(4):446-53.
- Ammori MB, King AT, Siripurapu R, Herwadkar AV, Rutherford SA.
  Factors Influencing Decision-making and Outcome in the Surgical Management of Trigeminal Neuralgia.
  J Neurol Surg B Skull Base. 2013 Apr;74(2):75-81.

Helbrow J, Bertaglia V, Blackhall F, Faivre-Finn C, Whitfield G. Management of Brain Metastases in Small Cell Lung Cancer- Does Stereotactic Radiosurgery have a part to play? *(Submitted April 2014 as a Brief Report to the Journal of Thoracic Oncology).*

- Whitfield GA, Price P, Price GJ, Moore CJ. Machine assisted delineation or automated segmentation of radiotherapy volumes – are we going in the right direction ? British Journal of Radiology 2013; 86(1021):20110718. doi: 10.1259/bjr.20110718.
- Helbrow J, McBain C, Gattamaneni R, Tran A, McCarthy C, Edwards R, Redikin J, Handley J, O'Hara C, Kennedy J, Mills S, Soh C, Leggate J, Whitfield G. Stereotactic Radiosurgery for Brain Metastases at The Christie at Salford Royal Hospital: Our Two-Year Experience. *(Oral poster presentation, British Neuro-oncology Society Meeting, Liverpool 9-11 July 2014).*
- Phase 1 study of anti-PlGF monoclonal antibody (mAb) RO5323441 (RO) and anti-VEGF mab bevacizumab (BV) in patients with recurrent glioblastoma (GBM). Lassen UN, Chinot OL, McBain CA, Sorensen M, Larsen VA, Barrie M, Roth P, Krieter O, Wang K, Habben K, Tessier J, Lahr A, Whiley M, Weller M J Clin Oncol 2013;31:suppl; abstr 2092

- Briggs S, Wilson B, Benson S, Hope A, Karabatsou T, Whitfield G, Gattamaneni R, Tran A, McBain C. Management of Glioblastoma Multiforme in the Elderly: Variations in treatment pathways. *(Poster presented at British Neuro-oncology Society Meeting, Durham 10-12 July 2013).*
- Chow D, McCarthy C, Handley J, McBain C, Tran A, Leggate J, Gattamaneni R, Whitfield G. Audit of Stereotactic Radiosurgery for Brain Metastases at The Christie at Salford Royal Hospital. *(Poster and oral presentation at Royal College of Radiologists' Audit Competition 2013*
- O'Connor JPB, Tofts PS, Miles KA, Parkes LM, Thompson G, Jackson A. Dynamic contrast-enhanced imaging techniques: CT and MRI. BJR 2012: 84; S112-S120.

9. Innovation in clinical practice

9.1 Joint surgery and oncology clinics in the base of skull service

9.2 Joint working with epileptologists

The neuro-oncology clinical nurse specialists, epilepsy nurse specialists and neuro-oncology specialist AHPS have set up a working group to discuss management of brain tumour patients with epilepsy. This has developed shared documentation, referral pathways and educational support.

This ensures compliance with NICE Epilepsy Guidelines and optimises the management of epilepsy in brain tumour patients. This has the support and involvement of neuro-oncologists, neuro-surgeons and neurologists from the Greater Manchester area.

9.3 Neuro-oncology AHOS involvement in the network MDT

The Specialist Allied Health Professional (AHP) posts for brain and CNS tumour rehabilitation were developed to meet the requirements of the Improving Outcomes Guidance (2006). The importance of rehabilitation and the challenges of delivering it had been recognised in the IOG and the need for AHPs as core members of the team was identified.

Greater Manchester & Cheshire Network specialist commissioners in conjunction with The Christie NHS Foundation Trust and Salford Royal Hospital NHS Foundation Trust agreed 2 posts to improve rehabilitation for patients with a primary brain or CNS tumour including spinal, skull base, pituitary

and primary cerebral lymphoma. Other networks funded full AHP teams (speech & language therapist, occupational therapist, physiotherapist and dietician) who delivered the care.

The appointed AHPs developed an innovative model of working; the first in the country. The purpose of the AHPs is to

a) Identify patients with rehabilitation needs; provide specialist advice to them and to act as an advocate for patients who cannot access services

b) To develop and implement best practice rehabilitation pathways

c) To develop the local AHP workforce through formal and informal education

d) To develop rehabilitation services in conjunction with local providers and commissioners.

In the period April 2013 to March 2014 204 referrals for rehabilitation were received and actioned.

Key achievements of this model of working:

The establishment of this role across the network of Trusts. AHPs in the acute and community services working in neuro-rehab, palliative care and general rehab are aware of the service and liaison occurs routinely to share information about changes to treatment plans and the effects of treatment on the patient's rehabilitation.

The patient and carer focus group are to develop a patient held document to be piloted in September 2014 thus providing a tangible improvement in the patient's experience and safety.

The AHPs have been invited to speak to Neuro-oncology AHPs in London and at the British Society of Rehabilitation Medicine in Bristol in October 2014 due to interest in this model of working.

Contributing to the local neuro sciences network review to ensure this patient group are included within plans for service development and their needs are considered when changes to neuro rehabilitation provision are made

9.3 Patient held document (PHD)

The use of a PHD for patients with a high grade primary brain tumour was investigated as a way of improving patient experience. This patient group receive care across a number of health and social care boundaries and communication can be a challenge.

A survey of staff opinions and patient focus groups found that staff and patients were positive about the use of a PHD and the document was developed with input from patients, carers and staff. The plan is to implement the PHD in the autumn as a pilot project. It will be offered to new patients at diagnosis.

The potential benefits are improved ownership of information and self-management by patients and carers, improved safety, communication and a better patient experience.

Other new developments within the service are the implementation of a low grade gliomas service and the roll out of a web based referral system to all Trusts.

10. The Pathway Board

Formation of the Board
The principle of Manchester Cancer Pathway Boards is that they should be professionally and institutionally representative, yet small and manageable in size. To help Pathway Clinical Directors form institutionally representative Boards the Manchester Cancer central team sought nominations from trusts for their representative(s) on 16 of the 20 Pathway Boards. Nominations were not sought for Children's, Sarcoma, Palliative Care and Early Diagnosis as alternative arrangements were necessary in these areas.

For each Pathway Board trusts were asked to provide up to three nominations from a range of professions from which the trust representative(s) could be chosen. The team asked that nominations included a brief statement of the individual's suitability for membership of the relevant Pathway Board.

Nominations were passed to Pathway Clinical Directors who took them into account when forming their Boards. Trusts were informed during this process that Directors would not be obliged to accept all trust nominations but that, if a Pathway Clinical Director wished to appoint a trust representative that had not been nominated by their organisation, this would be discussed with the Trust Cancer Clinical Lead.

The board agreed the terms of reference at its first meeting on 6th May and these can be found in appendix 1.

10.1 Membership

The board is comprised of the members as listed in the table below.

Pennine Acute NHS Trust does not have a representative as yet. This is as a result of their nomination leaving the Trust before the board was formed. Also the previous member at the GMCCN meetings had retired. Work is on-going with Pennine Acute to identify an appropriate representative.

Also the GP and patient representative are still to be nominated. Both of these nominations will be co-ordinated through Manchester cancer.

Trust	Nominee	Profession/ specialty
Bolton	Arun Kallat	Cons Elderly Care Physician
Christie	Julie Emerson	SALT
	Sara Robson	OT
	Elizabeth Molloy	CNS
	Dr Anna Tran	Consultant Oncologist
CMFT	Peter Selby	Consultant

East Cheshire	Dr Moe Sein	Consultant
Pennine	TBC	
SRFT	K Karabatsou	Cons Neurosurgeon/Lead for Neurooncology
	S Rutherford	Cons Neurosurgeon/Lead for Skull Base
	T Kearney	Cons Endocrinologist/Lead for Pituitary MDT
	Cundliffe Sarah	Neuro/Oncology Specialist Nurse
	Alison Gilston-Hope	Neuro/Oncology Specialist Nurse
	Andrea Wadeson	Base of skull specialist nurse
Stockport	Dr K Dizayee	Consultant Physician
Tameside	Dr Chris Douglass	Consultant Neurologist
UHSM	Dr Samantha Kay	Palliative Care Consultant
	Dr Sophie Harrison	Palliative Care Consultant
WWL	Dr A Ismail	Consultant Radiologist

10.2 Meetings

The board has met twice and has one more meeting scheduled for this calendar year. The minutes for the May and July boards are in appendix 3.

The meeting attendance record is recorded within appendix 2.

11. Progress and challenges to date

Although the board has only met twice it has made good progress in re-establishing itself following a hiatus since the demise of the Greater Manchester and Cheshire NSSG. The group is experienced and there is good inter-dependencies across the full range of brain and CNS cancer.

The one biggest challenge remains in finding a suitable time slot to allow the full board to meet. Also Pennine acute are still to nominate a board representative, meaning that the north-east sector is not reaping the benefit of participating.

12. Vision and objectives

The board has benefitted from the legacy of the excellent work undertaken by the previous Greater Manchester and Cheshire NSSG. As a result of which the pathway is well managed with clear referral protocols and mechanisms for patients to be reviewed, assessed and treated

This is coupled with the fact that the nature of the disease means that there is little scope for early detection and preventative measures to be deployed.

Also the service is based on one site with good robust links to the Christie NHS foundation Trust. As a consequence the agenda of this board will be unlike the agendas of other pathway boards.

So the board sees its focus being on supporting innovation, quality assurance of the pathway and enhancing the experience of those living with and beyond their cancer. Therefore the board will deepen its knowledge base and understanding of the whole pathway and put in place actions were the patient outcomes, survival rates and experience can be improved and enhanced.

Appendix 1 – Pathway Board Terms of Reference

Brain & CNS Pathway Board

Terms of Reference

These terms of reference were agreed on -2014 by ,–Dr Catherine McBain Pathway Clinical Director for Brain Cancer, and Mr David Shackley, Medical Director of Greater Manchester Cancer Services, on behalf of the Greater Manchester Cancer Services Provider Board. The terms of reference will be subject to future review.

1. The Pathway Board

1.1. 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.

1.2. 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 tumour care in Greater Manchester. The Pathway Board also has membership and active participation from primary care and patients representatives.

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

2. Greater Manchester Cancer Services Provider Board

2.1. The Greater Manchester Cancer Services 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).

2.2. 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;

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

3. Purpose of the Pathway Board

3.1. 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 Greater Manchester Cancer Services Provider Board and Greater Manchester's cancer commissioners.

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

3.3. 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.

4. Role of the Pathway Board

The role of the Brain Cancer Pathway Board is to:

4.1. Represent the Greater Manchester Cancer Services professional and patient community for Brain and primary spinal tumours.

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

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

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

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

4.6. 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.

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

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

4.9. Escalate any clinical concerns through provider trusts.

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

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

4.12. Share best practices with other Pathway Boards within Greater Manchester Cancer Services.

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

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

4.15. 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.

5. Membership principles

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

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

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

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

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

5.6. 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).

5.7. 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.

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

5.9. 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).

5.10. 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.

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

6. Frequency of meetings

6.1. The Brain Cancer Pathway Board will meet every two months.

7. Quorum

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

8. Communication and engagement

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

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

8.3. 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

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

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

8.6. 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 Greater Manchester Cancer Services website once this has been developed.

9. Administrative support

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

11 Appendix 2 – Pathway Board meeting attendance

Brain & CNS				
NAME	**ROLE**	**TRUST**	**06/05/2014**	**01/07/2014**
Arun Kallat	Cons Elderly Care Physician	Bolton	Apologies	Apologies
Julie Emerson	SALT	Christie	Attended	Attended
Sara Robson	OT		Attended	Apologies
Elizabeth Molloy	CNS		Attended	Attended
Dr A Tran	Consultant		Attended	Attended
Peter Selby	Consultant	CMFT	Aplogies	Apologies
Dr Moe Sein	Consultant	East Cheshire	Attended	Attended
TBC		Pennine		
K Karabatsou	Cons Neurosurgeon/ Lead for Neuro-oncology	SRFT	Attended	Apologies
S Rutherford	Cons Neurosurgeon/ Lead for Skull Base		Attended	Apologies
T Kearney	Cons Endocrinologist/ Lead for Pituitary MDT		Apologies	Apologies
Andrea Wadeson	CNS		Attended	Attended
Sarah Cundliffe	CNS			Attended
Alison Gilston-Hope	CNS		Attended	Attended
Dr K Dizayee	Consultant Physician	Stockport	Apologies	Apologies
Dr C Douglass	Consultant Neurologist	Tameside	Apologies	Attended
Dr Samantha Kay	Palliative Care Consultant	UHSM	Attended	
Dr Sophie Harrison	Palliative Care Consultant			Attended
Dr A Ismail	Consultant Radiologist	WWL	Apologies	Apologies

12 Appendix 3 – Pathway Board minutes to 31st July 2014

Brain & CNS CANCER PATHWAY BOARD MEETING

MINUTES

DATE: 25/04/2014

Member's attending:

Dr McBain (Chair)	**Christie**	**Dr Sam Kay**	**UHSM**
Julie Emerson	**Christie**	**Andrea Wadseon**	**Salford**
Sara Robson	**Christie**	**Alison Gilston-Hope**	**Salford**
Elizabeth Molloy	**Christie**	**Dr Tran**	**Christie**
Dr Sein	**East Cheshire**		
Miss Karabatsou	**Salford**		
Mr Rutherford	**Salford**		

Apologies

Dr Kallat	**Bolton**	**Dr Douglass**	**Tameside**
Prof Selby	**CMFT**	**Dr Kearney**	**Salford**
Dr Ismail	**WWL**	**Dr Dizayee**	**Stockport**

In attendance J Leighton Manchester cancer

- **Introductions and apologies**

Dr McBain (CMB) welcomed all to the meeting and noted the apologies received.

- **Introduction to Manchester cancer**

CMB outlined the purpose of the pathway board and clarified the only role of members is in reviewing the whole pathway as a stakeholder in improving the outcomes for patients. She stressed that the priority would be to create and maintain an efficient and effective pathway.

- **Board member introductions**

The board members present introduced themselves to the meeting. James Leighton (JL) explained that there would be a patient representative on the board; however their participation would occur after an engagement event to be held in conjunction with Macmillan cancer.

This engagement event is now confirmed to take place on 23rd June. The board asked that they invite identified carers or patients who know the brain/CNS pathway to this event. JL to discuss.
Action – JL to discuss patient invitations with event organisers

There was further discussion on GP representation and Manchester cancer will lead on this.

- **Discussion of board objectives**

A review of the previous GMCCN work schedule (2012-2016) took place. This was to begin the action planning for the pathway board. In a round table discussion there were a number of outline objectives discussed -

- Improved data collection
- Development of pathway board work plan
- Design and deployment of services that will meet the needs of the patients
- Identify opportunities for change
- Maintain the guidelines for brain and CNS cancer

There was a consensus formed that the level of intelligence currently available is something that should be built upon to allow for proper analysis of the pathway. Potential sources of new information that could be used is new data on presentation rates and live audit data from the British base of skull society

There was discussion on the use of the Christie database as a vehicle to gather such data. This was considered as an option and CMB agreed to meet with Dr Livesey form the Christie to review.
Action – CMB to meet with Dr Livesey and review the Christie database and report back to next board meeting.

- **Board roles**

In view of the large number of apologies this was deferred until the next meeting.

CMB raised the issue of engagement with the survivorship agenda. There was a lack of clarity on how brain/CNS cancer would be represented on the living with and beyond cancer pathway board. As a consequence JL agreed to progress this within Manchester cancer.
JL – to discuss with Manchester cancer

- **Future meetings**

JL agreed to circulate a meeting date scheduler to help establish the best day and session on which to hold the meeting. It was agreed that all meetings would be held at Salford Royal.

The next meeting is scheduled for the afternoon of July 1st and this will remain. It is planned to hold one more subsequent meeting in this calendar year, with the number of future meetings decided by the board action plan.
Action - JL to send out to all board members

- **Educational event**

Board members were asked to consider holding an educational event on brain and CNS cancer as part of their work plan. Members agreed to consider both the topic of the meeting and the target audience. This is to be discussed at the next board meeting.
Action - JL to put on agenda of next board meeting.

- **Any other business**

There was no other business discussed

- **Date & Venues for Future Meetings**

The next meeting of the board will be on **Tuesday 1st July 1.30pm**,**Seminar room 6 Mayo building, SRFT**

Brain & CNS CANCER PATHWAY BOARD MEETING

MINUTES

DATE: 01/07/2014

Member's attending:

Dr McBain (Chair)	**Christie**	**Dr Harrison**	**UHSM**
Julie Emerson	**AHP, Christie**	**Andrea Wadeson**	**Skull Base CNS, SRFT**
Alison Gilston-Hope	**SRFT**	**Elizabeth Molloy**	**Christie**
Dr Tran	**Christie**	**Dr Sein**	**East Cheshire**
Sarah Cundliffe	**SRFT**	**Dr Douglass**	**Tameside / SRFT**

Apologies

Dr Kallat	**Bolton**	**Prof Selby**	**CMFT**
Dr Kearney	**SRFT**	**Dr Ismail**	**WWL**
Dr Dizayee	**Stockport**	**Miss Karabatsou**	**SRFT**
Mr Rutherford	**SRFT**	**Sara Robson**	**Christie**

In attendance

J Leighton	**Manchester cancer**

- **Introductions and apologies**

Dr McBain (CMB) welcomed all to the meeting and noted the apologies received.

- **Minutes of the last meeting**

Dr Tran was added to the attendance and Dr Harrison was removed from the list of apologies as her attendance is shared with Dr Kay.

Some other typos were corrected and the minutes accepted as a record of the meeting.

- **Board roles**

CMB outlined the purpose of the board and how the Manchester cancer boards have been constituted.

Andrea Wadeson (AW) raised an issue with regard to peer review, and what appeared to be some confusion, on how the board and the previously established NDSG group relate. CMB confirmed that the board essentially replaces the NDSG as there were no plans to hold both the NDSG and pathway board meetings. This would be fed back to the relevant cancer manager.
Action - JL to discuss with the cancer manager at SRFT and send out the relevant Manchester cancer briefing note.

There was further discussion on GP and patient representation. CMB outlined the recent patient representative event and that Manchester cancer would lead on this. However some board members had identified certain GPs as potential board members. This will be followed up by CMB
Action – CMB to review nominated GP representatives.

CMB then went onto discuss the difficulty in scheduling of the pathway board to ensure nominated representation. After a recent poll there was no session identified as an ideal time for the group to meet.

- **Proposed clinical outcome measures**

CMB outlined the board outlined the objectives set for pathway boards by Manchester cancer. However she explained that the brain pathway is not comparable to other pathways as there is no structural change required and because of the work successfully undertaken by the previous network group.

One thing that the board did feel should be undertaken is the generation of outcome measures to demonstrate year on year improvement. CMB then tabled a list of proposed outcomes measures for the board to review. These were –

1. **Overall tumour numbers and % by grade**
    a. Important demographic but not a metric that reflects the quality of care.
2. **% of high grade tumours presenting as emergencies to A&E**
    a) This is complicated by the onset of symptoms (FAST test +ve and within 4 hrs) the pts would attend a recognised stroke centre (SRFT, SHH, Fairfield). Therefore pick up from these centres will increase.
    b) The complexities of managing cancer pts picked up on a stroke pathway across the primary/secondary care boundary and across greater Manchester.
    c) The fact that % of cases presenting to A&E does not reflect quality of care or early detection rates as it does for some other cancer types
3. **% of cases operated on as an emergency**
    a. Routinely collected by the neuroscience MDT (Miss Karabatsou (TK)). **CMB to discuss with TK**.
4. **% of cases operated on by a non neuro-oncology core surgeon**
    a. Should be measured for the board. **CMB to discuss with TK**.
5. **% of high grade gliomas operated on within 2 weeks of MDT**
    a. Current internal target **CMB to discuss with TK**.
6. **Survival – 2 year survival of GBM pts treated with chemo-RT**
    a. Difficult for neuro pts. In this category of GBM grade 4 pts with chemo/RT 2 year survival is accessible and reproducible and therefore more appropriate.
7. **1 year survival**
    a. See 6
8. **% of GBM pts who receive active treatment? Who are operated on? Who have complex resections?**
    a. See 6
9. **Patient satisfaction**
    a. Difficult because of small numbers and accessing suitable pts. Should use the last 100 pts with the information generated by the SRFT audit department. Agreed as an annual measure for the board and looking for a broad measure for pts diagnosed 6-9 months ago.
10. **% of patients who had research discussed with them?**
    a. Difficult to gather as it would be a retrospective measure which may prove difficult to confirm.
11. **Research recruitment figures**
    a. Agreed to report - but needs to be all trials and not just NCRN trials
12. **Treatment toxicity**
    a. Hard to collect
13. **% discussed at network MDT/ reviewed by neuro AHP/ who had holistic needs assessment completed.**

a. Looking for a measure for the more holistic aspects of the service. To review outside of the board meeting.

14. **30 day mortality – post-surgery and post-chemotherapy**
    a. Agreed to report
15. **% on gold standard framework**
    a. Not thought to be a measure of care as the GP puts the pt on the framework. To review alternative potential measures outside of the board meeting.
16. **1 year survival of brain mets pts treated with SRS**
    a. Agreed to measure
17. **Vestibular schwannoma outcomes?**
    a. AW to review alternative potential measures outside of the board meeting. (? Function)
18. **Pituitary measure**
    a. To review alternative potential measures outside of the board meeting.
19. **2 week wait referrals**
    a. Dr Douglass (CD) reported low pick up rates form GP requested CT scans
    b. Agreed to report

During discussion other possible measures proposed were

GP requested scanning rates and pick up rates.

This is currently provided in Macclesfield and Tameside. Not every area in GM has GP requesting scans. The board agreed that this is more likely to be an audit rather than an outcome measure.

- **Annual report**

CMB outlined the board annual report process and timescales. The report would be drawing from the peer review reports and assessments. CMB asked the relevant leads to send the most up to date documentation to JL.

Action – speciality leads to send peer review documentation to pathway manager.

- **Research and audit**

The board noted the paper form the NIHR on current clinical trials participation. The board noted that there was no national ranking as expressed in previous reports. JL to discuss this with NIHR.

Action – JL to obtain a national ranking for clinical trial recruitment.

- **Data**

CMB outlined the data input system currently used with the Christie and the potential usefulness this could have for future analysis of activity. She also outlined the existing databases in base of skull and within the neurosciences group.

- **Educational event**

This is to remain a standing item on the agenda and kept under review by the board.

- **Any other business**

Dr Sein confirmed that there was now remote electronic access for referrals to the MDT. Dr Douglass to check if this was also available at Tameside.

Dr Harrison raised the issue of UHSM having visibility that their patients have been discussed at the relevant MDT. This will be kept under review by both organisations.

CMB informed the board that the Radiology support at the MDT has been reduced as a participating Radiologist has left the Trust. This may have an impact on the quality of Radiology input at the MDT and will be kept under review.

- **Date & Venues for Future Meetings**

The next meeting of the board is scheduled to be on the 7th October; however Tuesday afternoon remains a difficult session for all to attend. CMB asked that the board is polled about re-arranging this date to one of the following dates –

- 30th September 13.30 – 15.30
- 3rd October 13.00 - 15.00
- 3rd October 14.00 – 16.00

Following a poll of Board members I can confirm that the next meeting of the pathway board will be held on **Friday 3rd October 13.00 – 15.00hrs**. The venue will remain at SRFT.

Appendix 4 – Pathway Board Annual Plan 2014/15

Brain &CNS Pathway Board Annual Plan 2014-15

Pathway Clinical Director:	Dr Catherine McBain
Pathway Board Members:	
Pathway Manager:	James Leighton
Date agreed by Pathway Board:	To be ratified at next pathway board
Date agreed by Medical Director:	To be confirmed
Review date:	

Summary of objectives

No	Objective	Alignment with Provider Board objectives
1	Optimise data collection to generate outcome measures	**Generation of robust outcome data including 1 year survival**
2	Introduction of 5ALA-guided resection into routine practice of suitable patients with high grade gliomas	**Improve 1 and 2 year survival** **Improve patient experience by offering best care**
3	Maintain IOG compliance of MDTs	**1 year survival** **Patient experience**
4	Introduction of MGMT testing for high grade gliomas	**1 year survival and patient experience (by ensuring patients receive the most appropriate treatment)** **Research and innovation**
5	Introduction of patient-held records	**To improve patient experience** **To develop innovation in clinical practice**

Objective 1: Optimise data collection to generate outcome data

Objective:	*To optimise data collection to allow the generation of meaningful outcome measures. Due to the disparate nature of the tumours encompassed by the CNS service, data and outcomes are collected in various MDT-specific local and national databases. We will scrutinise our data collection to enable the sustainable generation of outcome measures.*
Rationale:	*The Board wishes to be able to reliably generate meaningful annual outcome data, to facilitate national and international comparison, and year on year comparison of our own outcomes.* *This will ensure that the patient care delivered compares favourably with other centres and identify areas where care might be improved.*
By (date):	*31/3/15*
Board measure(s):	*The ability to generate outcome figures for 1 and 2 year survivals without additional task-specific audit* *>90% of new patients referred to Christie to have Web forms generated*
Risks to success:	*Time and other commitments of involved personnel eg MDT lead clinicians, MDT co-ordinators, data managers, doctors, clinical nurse specialists.* *Mitigation: Aim for an efficient, unified, sustainable approach*
Support required:	*Recognition and protection of the vital role of existing data managers.* *Reflection in job-planning and appraisal of the effort and commitment of MDT clinicians in generating this data*

Work programme

Action	**Resp.**	**By (date)**
Dr Livesy, head of Clinical Outcomes Unit, The Christie NHS FT to present to Pathway Board	CMB	3/10/14
Clinical Oncology consultants to ensure 100% of new patients seen are entered into the Christie web-portal	CMB/AT	3/10/14
Final list of outcome measures agreed	All	3/12/14
Full commencement of routine data collection	All	1/1/15
Audit of completeness of data collected	CMB / KK / TK / SR	31/3/15

Objective 2: Introduction of 5-ALA guided resection into routine practice

Objective:	*To make 5-ALA guided resection of malignant primary brain tumours standard of care for eligible patients.*
Rationale:	*There is randomised controlled trial evidence demonstrating that ingestion of the drug 5-ALA prior to surgery results in fluorescence of tumour tissue at time of surgery and that performing fluorescent-guided resection maximises resection rates and prolongs progression free survival. This technique has been standard of care for some time in other leading centres, but its introduction to SRFT has been subject to various delays. The Board feels that this technique is important in improving patient outcome and survival.*
By (date):	*1/12/14*
Board measure(s):	*1 and 2 year survival for GBM patients* *Aim for 80% of potentially suitable patients able to have 5-ALA guided resections*
Risks to success:	*Limited availability of 5ALA-agent – funding from SRFT may not be adequate to offer it to all eligible patients* *Technical problems in theatre / of operating microscope* *Mitigation: Careful patient selection and attention to detail in use of technology*
Support required:	*On-going review of numbers of patients suitable for 5ALA resection vs number of patients to whom it was possible to offer it. Funding presently agreed for only 25 cases per year; number of eligible cases could be double that.*

Work programme

Action	**Resp.**	**By (date)**
Final approval of 5-ALA use by SRFT	KK	30/7/14
Patient selection via MDT	Neuroscience MDT / core neurosurgeons	31/3/14
Audit of outcomes – –maximal safe tumour resection confirmed on post-op imaging; survival	KK	31/3/14 and ongoing
Review of training needs of all core neurosurgeons	KK	3/1/15
Review of number of eligible patients vs number undergoing 5ALA guided resection	CMB / KK	31/3/15

Objective 3: Maintain IOG compliance of MDTs

Objective:	*Maintain the previously-achieved IOG compliance of the Neuro-oncology, Base of Skull, Pituitary and Supportive Care MDTs.*
Rationale:	*Following their publication in 2006, full implementation of the IOGs was achieved via the cancer network and local N West Specialist Commissioners. However, this compliance is under threat due to loss of key personnel in neuro-radiology, increasing pressure of work on all individuals but particularly MDT co-ordinators and neuro-radiologists and general threats of funding cuts impacting on eg the distribution of minutes to Acute Trusts (pathways previously agreed and implemented via local cancer services teams no longer as universally robust due to cuts) .* *To lose IOG compliance would be a hugely retrograde step for patient care and The Board are concerned that radiology review is no longer included in neuro-oncology MDT minutes, and the timelines and consistency of minutes distribution are lapsing.*
By (date):	*31/12/14*
Board measure(s):	*Patient satisfaction* *1 and 2 year survival figures* *Continued >90% compliance with all aspects of IOGs, particularly timelines for distribution of minutes and MDT staffing.*
Risks to success:	*Withdrawal of funding for key staff* *Increased pressure of work on key staff meaning they are no longer able to fulfil their roles.* *Mitigation: Good communication and working relationships with relevant managers*
Support required:	*Recognition of the vital nature of this objective* *Protection of the CNS services from staffing cuts* *Sustainable SRFT Consultant Neuro-radiologist replacement post with MDT preparation and attendance properly recognised and scheduled in job plan.*

Work programme

Action	**Resp.**	**By (date)**
Agreement of new consultant radiologist job-plan	KK / SRFT	3/10/14
Appointment of core neuro-oncology neuro-radiologist replacement post	SRFT	1/2/15
Audit of adequacy of MDT minutes and distribution times	CMB / KK / All	31/3/15

Objective 4: Introduction of MGMT testing for Neuro-pathology reporting

Objective:	*Introduction of MGMT testing for high grade gliomas.*
Rationale:	*MGMT status is a vital marker of prognosis and chances of response to chemotherapy which we have not presently been able to offer. However, clinical trial evidence, particularly in the elderly, has emphasised that care not guided by this marker may be sub-standard.* *Introduction of this measure will help to improve outcomes and patient experience and ensure highest quality care.*
By (date):	*31/3/15*
Board measure(s):	*Testing of >90% of glioblastomas for MGMT methylation.* *> 90% of all tumour reports issued in line with minimum dataset requirements* *Patient satisfaction* *1 year survival*
Risks to success:	*Neuro-Pathology consultant staff time* *Funding*
Support required:	*Recognition of the vital nature of excellence in neuropathology with appropriate additional support of necessary* *Possible, funding for MGMT test*

Work programme

Action	**Resp.**	**By (date)**
Pilot study of in-house MGMT testing and comparison of results with MGMT status determined by central laboratories for clinical trials	D Duplessis	31/10/14
Determination of MGMT testing policy	CMB / KK / D Duplessis	31/11/14
Addressing of any funding issues	SRFT	1/1/15
Full implementation, including compliance with specimen turnaround time, in > 90% patients	D Duplessis	31/3/15

Objective 5: Introduction of patient-held records

Objective:	Introduction of a patient hand held document for patients with a high grade primary brain tumour.
Rationale:	This patient group receive care across a number of health and social care boundaries and communication can be a challenge. The patient hand held record document was developed with input from patients, carers and staff
By (date):	
Board measure(s):	Completion of the pilot and successful feedback from patients, carers and staff to allow full roll out.
Risks to success:	Change of work processes for key staff Mitigation: Good communication and working relationships with relevant managers
Support required:	

Work programme

Action	**Resp.**	**By (date)**
Determination of pilot study process and parameters	JE	Sept 13 to 14
Commencement of pilot study of patient hand held record	JE	Sept 2014
Interim review	JE	March 2015
Review at completion of pilot study	JE	Sept 2015
Full implementation and deployment to all diagnosed patients	JE	Autumn 2015