Manchester Cancer

Brain and CNS Cancer Pathway Board

Annual Report 2014/15

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Version 1.4

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 (3 distinct neuro-oncology sub-specialities at SRFT, 1 supportive care at Christie), all of whom are represented on the pathway board.

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

The Christie at Salford radiotherapy centre with the use of stereotactic radio surgery is now well developed and established. The activity volumes for this service are in appendix 1.

The board is able to confirm that the service underpinning this pathway is stable, well run and mature with a strong ethos of team working across all the professions. It complies with the 2006 NICE Improving Outcomes Guidance for brain and spinal tumours.

In the course of the first year of Manchester Cancer, the board reflected on how it was functioning within the confines of the prescribed structure. It felt that because of the unique nature of the service and the disease, having a pathway board based solely on organisational representation (with a majority of board members not directly involved in treating brain tumour patients) meant that the board did not benefit from the range of available expertise and experience required.

To address this and increase the amount of relevant clinical input, the board decided to restructure itself. As a consequence the Pathway Board is now supported by two sub-groups that drive the agenda forward. The first sub-group is the Strategic Management Group, (SMG) which comprises clinicians directly involved with the delivery of the service. It is clinically focussed, with a responsibility to manage the clinical outcome and research objectives.

The patient experience and standardisation of service objectives are managed by the Patient Experience Group (PEG). There is a broader and developing membership to this group and it is where the patient representation is expected to sit.

The Pathway Board (PB) remains in place and is the body responsible for the overall governance of the pathway and delivery of the Manchester Cancer objectives. It is drawn from referring Trusts, representatives of the 4 brain and CNS MDTs, the 2 subgroups and allied health professionals. This is where GP representation is expected to sit. There are 8 meetings per year (3 SMG, 3 PEG, 2 PB).

Increasing the contribution of the staff involved in managing the pathway, within a network structure, was the biggest challenge the board faced in its first year. However, the revised structure is becoming increasingly established, is demonstrating improved engagement with staff of all disciplines and backgrounds, and is beginning to deliver on the Board's objectives.

In the 2014/15 annual report it set 5 objectives, 4 of which were delivered.in full, one delivered in part. These were

- Introduction of 5ALA-guided resection into routine practice for suitable patients with high grade gliomas
- Maintenance of IOG compliance of MDTs
- Introduction of patient-held records
- Optimisation of data collection to generate outcome measures

The one objective which remains outstanding is the introduction of MGMT testing for high grade gliomas. Progress towards this has been made, and it is now technically and logistically feasible; the only remaining barrier to realising it is funding agreement
The Board wishes to prominently highlight to readers that this test is now routine in every other major centre in the UK, and in many smaller units. It is vital in selecting patients, particularly those over 70, for chemotherapy and is a critical prognostic marker in younger patients with grade 4 gliomas. The situation of being unable to deliver this testing, which is central to the optimisation of patient care, is becoming increasingly indefensible. The cost is £150 per sample for 150 patients per year.

Because of the nature of brain cancer, there is little scope for developing early detection and prevention strategies. In addition, evidence that early detection improves outcomes is lacking, although earlier detection does reduce acute presentation. However, the board will look to support primary care colleagues in symptom recognition and earlier referral for investigation through its education programme.

The board has successfully supported two bids to the Macmillan Cancer Living With and Beyond Cancer fund. Both of these bids will monitor the patient and carer experience along the pathway following treatment and, by better understanding the needs of patients and carers during this phase of the disease, aim to improve experience and survivorship. One bid focuses on patients with primary brain tumours, the other on patients with secondary (metastatic) brain tumours (further summary information is set out in Appendix 2).

The work of these two projects will be within this year's action plan.

The pathway board and its subgroups will also review all of the 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.

Over the course of the forthcoming year the board has set the following objectives –

1. Continue to pursue, possibly via a business case, the routine introduction of MGMT testing in Manchester
2. Fully revise and extend clinical guidelines to include standardised imaging follow-up policies
3. Introduce banking of brain tumour tissue
4. Successfully deliver both Macmillan funded projects supporting patients in living with and beyond their disease

5. The board will work with primary care commissioners and secondary care providers to develop a response to the recommendations for Brain & CNS cancer made in the NICE guidance “Suspected cancer: recognition and referral”.

1 Introduction – the Pathway Board and its vision

This is the annual report of the Manchester Cancer Brain and CNS cancer Pathway Board for 2014/15. 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.

This annual report outlines how the Pathway Board has contributed in 2014/15 to the achievement of Manchester Cancer's four overarching objectives:

- Improving outcomes, with a focus on survival
- Improving patient experience
- Increasing research and clinical innovation
- Delivering compliant and high quality services

1.1. Vision

The board has this year benefitted from increasing the amount of relevant clinical expertise made available to the decision making process. It has also created two more appropriate forums where the objectives of Manchester Cancer can be better managed, within the governance structure of the Pathway Board.

Because of the nature of the disease there is little opportunity for early detection or preventative actions that can be taken. Therefore the focus of the board will be on supporting innovation, quality assurance of the pathway and enhancing the experience of those living with and beyond their cancer.

As an example of this the board will work with primary care commissioners and secondary care providers to develop a response to the recommendations for Brain & CNS cancer made in the NICE guidance "Suspected cancer: recognition and referral".

The board will also 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.

1.2. Membership

The Pathway board membership is as follows -

Brain & CNS		
Trust	**Nominee**	**Profession/ specialty**
Christie	Dr Catherine McBain	Chair
Bolton	Dr Arun Kallat	Cons Elderly Care Physician
Christie	Julie Emerson	Neuro-oncology AHP
	Sara Robson	Neuro-oncology AHP
	Elizabeth Molloy	Neuro-oncology Clinical Nurse Specialist
	Dr Anna Tran	Consultant Oncologist
CMFT	Prof Peter Selby	Consultant
East Cheshire	Dr Moe Sein	Consultant
Pennine	TBC	
SRFT	Miss K Karabatsou	Cons Neurosurgeon/Lead for Neuro-oncology
	Mr S Rutherford	Cons Neurosurgeon/Lead for Skull Base
	Dr T Kearney	Cons Endocrinologist/Lead for Pituitary MDT
	Cundliffe Sarah	Neuro/Oncology Clinical Nurse Specialist
	Alison Gilston-Hope	Neuro/Oncology Specialist Nurse
	Andrea Wadeson	Base of Skull Clinical Nurse Specialist
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
Salford CCG	Dr Steven Elliot	GP representative

1.3. Meetings

The pathway board met three times in 2014 and has met within the new structure once in 2015. Both the strategic management group (SMG) and the patient experience groups (PEG) have met twice since their constitution in January 2015.

The board has asked that the SMG and the PEG meet three times per year. The Pathway Board will then meet twice a year to co-ordinate the reporting of the board objectives to Manchester Cancer.

Below are the dates of the pathway board meetings and the links to the board minutes;

25th April 2014
http://manchestercancer.org/wp-content/uploads/2014/09/Brain-CNS-Cancer-Pathway-Board-Meeting-Minutes.pdf
1st July 2014
http://manchestercancer.org/wp-content/uploads/2014/09/Brain-CNS-Cancer-Pathway-Board-Meeting-Minutes1.pdf
3rd October 2014
http://manchestercancer.org/wp-content/uploads/2014/09/Brain-CNS-Cancer-Pathway-Board-Meeting-Minutes2.pdf
21st April 2015
http://manchestercancer.org/wp-content/uploads/2014/09/Brain-CNS-Cancer-Pathway-Board-Meeting-Minutes-DRAFT-VERSION.pdf

The board attendances for these meetings are contained within appendix 3.

The board has in 2015 welcomed GP representation from Salford CCG and has identified potential patient/carer representatives. Their inclusion will be managed by the Macmillan patient involvement team on behalf of the board.

There remains no representation from Pennine Acute NHS Hospitals Trust. This is a persistent problem and was raised in the 2014/15 report. There have been discussions with the lead cancer manager at Pennine and these discussions have been on-going into the new structure.

2. Summary of delivery against 2014/15 plan

No	Objective	Alignment with Provider Board objectives	Tasks	By	Status Green = achieved Amber = partially achieved Red = not achieved
1	Optimise data collection to generate outcome measures	Objective no 1			
2	Introduction of 5ALA-guided resection into routine practice of suitable patients with high grade gliomas	Objective no 1			
3	Maintain IOG compliance of MDTs	Objective no 4			
4	Introduction of MGMT testing for high grade gliomas	Objective no 1	Organisational and logistic aspects completed; only remaining barrier is funding.		
5	Introduction of patient-held records	Objective no 3			

3. Improving outcomes, with a focus on survival

3.1. Information

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.

Within Greater Manchester, clinical outcomes measures are collated from two main sources:

1) Information on surgical outcomes, including operated numbers, post-op complication rates and 30-day mortality and readmission rates are supplied to and collated by Dr Foster and the Society of British Neurosurgeons. This data is now available for all UK centres, although it has not yet been fully released into the public domain

2) Information for patients referred onwards to The Christie for radiotherapy and/or chemotherapy is collated via the Christie Clinical Outcomes Unit. The first report will be published on the Christie website and further interrogation of this data will be undertaken. This data can be directly compared to national outcomes via publications from the NCIN. Some example comparators are given below.

This objective from the 2013/14 was successfully delivered and the Brain & CNS board is one of the first boards to produce this level of outcome data. This aspect of the Pathway Board's work will be expanded in the coming year. The outcome report can be found on the following link – http://www.christie.nhs.uk/our-standards/clinical-outcomes/the-christie-outcomes/cancer-specific-reports.aspx

There are presently no national clinical lines of enquiry in the brain tumour population.

3.2. Progress

As outlined above, the work undertaken this year to develop the infrastructure to support and develop routine data collection is now beginning to bear the expected results.

3.3. Challenges

The main remaining gaps are that full long-term survival data is not yet available on patients not referred to Christie i.e. those with low-grade or benign tumours who do not require non-surgical treatment.

However, the 5-year survival of this group is likely to be 100% (if their disease progressed, they would be referred to Christie and therefore captured). In due course, this information will be

accessible via the NCIN, but due to the indolent or benign nature of these tumours, the Board does not deem this to be a priority area.

The second gap in recording outcomes is the survival in those patients of very poor prognosis and performance status whose case is discussed at the Neuro-oncology MDT but who are referred directly to community palliative care. Many palliative patients, who opt for only symptom control (without active treatment), *are* seen in the neuro-oncology clinics and their data is captured. The missing data is from the subgroup of patient not well enough to come to clinic and generally very near the end of their lives. Work is on-going to capture survival data in these patients as well via the NCIN and possibly The Christie COU.

Improving survival in malignant brain tumours is a major international challenge; there is no 'quick-fix'. There is still a dearth of active treatment options and of high-quality clinical trials. The Board have made progress in this area by significantly improving the quality of surgery via the routine introduction of post-operative imaging, leading to re-resection of some sub-total resections, and with the use of 5-ALA guided resections.

We plan to improve our outcomes further by ensuring that management of older patients is optimised and MGMT testing is vital for this. The support we need is funding agreement to introduce routine testing.

4. Improving patient experience

4.1. Information

In the 2014 national patient experience survey only 42 responses were collected therefore it is difficult to draw any conclusions that would allow targeted actions to be planned.

The Brain & CNS cancer treatments are almost all delivered at two organisations, Salford Royal and the Christie. The Christie NHSFT conducts a 200 patient survey every month which includes all patients from all modalities and specialties.

A patient satisfaction survey to assess the entire Pituitary patient journey was devised and distributed during 2012 - 2013. This will be repeated by the Endocrinology Specialist Nurses in 2015 for any patients who have undergone Pituitary surgery and the results of this survey will be utilised when reassessing the Pituitary service as a whole.

The endocrine service have also asked several patients to give their perspective through 'patients' stories' and have used these as learning tools within the MDT. Several patients have personal web pages where they have documented their medical progress, from the diagnosis of their tumour through to the treatment and subsequent on-going care. These are widely available and reflect well upon the services provided by the MDT.

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 with a response rate of 61%.

The Neuro-oncology specialist nurses have devised, and are in the process of distributing, a patient satisfaction questionnaire for Neuro-oncology patients; findings will be discussed at the Patient Experience Group and any necessary actions agreed and monitored. These results will be presented in next year's annual report.

The SRS service regularly monitors patient satisfaction. Findings of the last study in 2013-14 revealed high levels of satisfaction with no major causes for concern.

4.2. Progress

Therefore the Board are confident, in the absence of the National patient experience survey that the service continues to draw feedback from their patients. This underlines the commitment of the Board and services to improve the patient experience and collect local data as well.

These local surveys will be undertaken within 2015 and reported to the board as soon as the results are available.

4.3. Challenges

The Board feel confident that patient feedback will continue to support service delivery. They feel that by the nature of being a two centre service and the experience of the MDT staff in undertaking such surveys that this challenge will continue to be met.

5. Increasing research and innovative practice

5.1. Information

Over 2014/15 the number of Brain & CNS cancer patients recruited into trials when is as follows –

Internal Christie Number	Trial name (sponsor)	Phase	Tumour type	Date opened	Recruitment End	Target recruitment	Number recruited
10_Dog11_13	**BR14**/ 26053-22054 (EORTC)	III	Non-co-deleted Anaplastic Glioma	Jul-10	Apr-15	35	24
11_Dog11_18	**OPARATIC** (Cancer Research UK)	I	Relapsed Glioblastoma	Nov-11	New cohort open	14	2
12_Dog11_20	**NBT** (ICR)	Observational	Glioma	Dec-12	Feb-15	150	152
13_Dog11_23	**SATIVEX** (GW Pharma Ltd)	Ib - II	Recurrent Glioblastoma	Jan-14	Sep-15	4	4
13_Dog11_21	**MO28347** (Roche Pharma Ltd)	IIIb	Glioblastoma	Jan-14	Aug-18	6	6
13_Dog11_22	**TAVAREC** 26091 (EORTC)	II	Recurrent grade II and grade III non-codeleted gliomas	Jan-14	Apr-15	5	1
14_Dog11_27	**EORTC 26101**	III	Recurrent GBM	Aug-14	October 14	5	2
14_Dog11_26	**Checkmate 143**	III	Recurrent glioblastoma multiforme	October 2014	April 2015	3	3
13_Dog11_24	**HCQ**	III	GBM in patients > 70 or PS > 2	October 2014		6	1

Table 1 - Clinical trials portfolio

There are also a number of NCRN Portfolio trials that are either in set-up or under discussion, these are –

Internal Christie Number	Trial name (sponsor)	Trial title	Phase	Tumour type	Date opened	Target recruitment
14_Dog11_29	**HIPPO** (Cancer Research UK)	A randomised phase II trial of Hippocampal Sparing versus Conventional Whole Brain Radiotherapy after surgical resection or radiosurgery in favourable prognosis patients with 1-4 brain metastases	II	Brain metastases treated with surgery or SRS	June 2015	14
	CAM BMT	Cambridge Brain Mets Trial 1: A proof of principle phase 1b/randomised phase II study of afatinib penetration into cerebral metastases for patients undergoing neurosurgical resection, both with and without prior, low-dose, targeted radiotherapy	Ib/II	Brain metastases	July 2015	Approx. 4
12_Dog11_20	**ROAM (EORTC)**	Randomized controlled trial of the addition of radiotherapy following resection of grade 2 meningioma	III	Atypical (grade 2) meningioma, post-op	Nov 2015	Approx 6
	VIMPAT (UCB Pharma)	A randomised controlled trial to assess the efficacy and toxicity of the use of prophylactic lacosimide in patients with newly diagnosed high grade glioma	III	Newly-diagnosed grade 3 and 4 gliomas	TBC	Approx 10

Table 2 NCRN Portfolio trials that are either in set-up or under discussion

Lastly there are two trials not in the NCN portfolio but for which NCRN portfolio adoption has been applied for -

	Trial name sponsor	Trial title	Phase	IMP	Tumour type	Date opened	Target recruitment	Number recruited
14_Dog11_28	TSPO	Investigation of the utility of the novel PET tracer TSPO in the identification of brain metastases	1	None – imaging study	Brain metastases patients prior to SRS	Mar 2015	25	1
	Glioma imaging study	Translocator Protein Expression in Transformin g Gliomas		Imaging study	patients with low grade glioma – (with concerns for higher grade transformation)	Jan 2015		2

Table 3 Other Clinical Trials – non-NCN portfolio / portfolio adoption applied for

The Brain & CNS trials portfolio is nationally highly competitive, with great effort made by Salford and the Christie to open all possible studies. Many trials of novel agents e.g. Checkmate-143, Sativex, TAMIGA are open at only a small number of centres nationally and the Christie is consistently within this subgroup.

Important achievements this year are the opening of the Checkmate 143 Nivolumab study, where The Christie is the UK lead site (Dr McBain is UK Chief Investigator) and the advancement of the HIPPO study, an NCRN-adopted multi-centre RCT written by and initiated by which Dr Whitfield (member of the Brain & CNS SMG), who is the chief investigator.

Both Dr McBain and Dr Whitfield sit on the NCRN Brain Clinical Subgroup making them well-placed to pro-actively manage Manchester's trials portfolio. Dr McBain also sits on the CSG Novel Agents Subcommittee.

The service is highly committed to CNS research and all potentially eligible patients are offered study entry.

5.2. Progress

Recruitment to both the NIHR portfolio of trials and non NIHR trials in 2014/15 are reported above.

5.3. Challenges

The four MDTs are very active in clinical research at a local level and regularly present and publish research. Some studies require very challenging streamlining of patient pathways to meet tight study timelines, and the entire MDT functions cohesively to deliver this. Where recruitment targets have not been met, there have been clear reasons e.g. trial closed early (EORTC 26101) or cohort slots less available than anticipated (OPARATIC), or recruitment difficulties which have proved common to all investigating sites (TAVAREC).

There are no national trials specific to skull base surgery that the MDT is able to recruit to. However the skull base MDT members do play a prominent role in the British Skull Base Society (including Professor King as past president and Mr Rutherford as council member) and thereby continue to act as a major influence in any future national research initiatives.

Recruitment relies not just on offering and conducting trials, but on having trials to offer. The MDTs and the board will do all they can to engage with Sponsors to ensure that all possible industry-sponsored and NCRN portfolio studies are available to Manchester and Salford patients, and that all patients are considered for trial entry.

Delivering complaint and high quality services

5.4. Information

All primary brain and spinal tumour cases across what was recognised as the Manchester Cancer 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). On average the agenda for the MDT now routinely comprises between forty-five and sixty-five patients per week and the time required for MDT has increased over the past 5 years from 3 hours to 5 hours. The MDT is still attempting to deliver this in one session, but this requires review.

The Base of Skull 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.

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.

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.

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 tumours.

5.5. Progress

The board has had a successful year and has achieved most of its objectives from the 2013/14 report. In terms of service development it has started to use a patient held record and is now starting to interrogate service led outcome data.

The guidelines and service manuals will be revised this year. Until this is complete the existing pathway and supporting documents are now located on the Manchester Cancer website and can be found on the links below.

Guidelines
http://manchestercancer.org/wp-content/uploads/2014/09/CNS_Management_policy_July_2013_v_51.pdf

Management guidance for acute trusts
http://manchestercancer.org/wpcontent/uploads/2014/09/Referral_pathways_for_acute_trusts_with_Christie_logo1.pdf

Referral pathways - *http://manchestercancer.org/wpcontent/uploads/2014/09/Brain_tumour_referral_pathways1.pdf*

At this point in time the board has no plans for educational events as it is waiting for the cancer education strategy to be developed by Manchester Cancer. Once this strategy has been agreed the board will support and contribute to all Brain and CNS cancer education as required.

5.6. Challenges

One of the main challenges to the service is that the referrals to the MDT continue to increase. Please see table 1 below. This puts a strain on the MDT members in delivering the workload within the time resource available. The MDT and service leads will explore if a second MDT meeting needs to be set up and will test what are the costs and benefits of delivering this.

Year	Number of Patients	% Operated (including biopsy)
2013/14	1545	28% (= 426)
2014/15	1780	27% (= 478)

Table 4 – Number of MDT discussions per year

Another significant challenge is the deployment of MGMT testing. This test is vital in selecting patients, particularly those over 70, for chemotherapy and is a critical prognostic marker in younger patients with grade 4 gliomas.

Currently this is not provided within Greater Manchester which puts the conurbation at variance with accepted practice nationally. The Board wishes to prominently highlight that this test is now routine in every other major centre in the UK, and in many smaller units.

Progress towards this objective has been made, and it is now technically and logistically feasible. The only remaining barrier to realising it is the funding agreement. The cost is £150 per sample for 150 patients per year and being unable to deliver this testing is becoming increasingly indefensible.

The board hopes to work with the relevant stakeholders to address this anomaly and provide parity for our patients with the rest of the country.

The board are also mindful that there is a national review of stereotactic radiosurgery (SRS) provision currently being undertaken. The board awaits the output from this review and it will respond accordingly. It intends to work with providers, commissioners and user groups to minimise the impact and ensure that a high quality service remains in place.

As previously outlined the Board has restructured and has started to manage the Brain & CNS cancer agenda in a more inclusive and integrated fashion. Therefore in its first year the board has resolved its first challenge and will now benefit from this work.

The board remain confident that with the wider participation and streamlined delegation of responsibilities it will be in a position to better overcome any difficulties it might face over the coming months.

6. Objectives for 2015/16

The board have set five objectives for this year and these are –

1. Continue to pursue, possibly via a business case, the routine introduction of MGMT testing in Manchester
2. Fully revise and extend clinical guidelines to include standardised imaging follow-up policies
3. Introduce banking of brain tumour tissue
4. Manage the successful delivery of the two Macmillan funded Living With and Beyond projects
5. Construct a response to the recommendations for Brain & CNS cancer made in the NICE guidance “Suspected cancer: recognition and referral”.

The work of the board will not be limited to just these objectives. As the year unfolds new challenges and opportunities will be identified, for example the national stereotactic radiosurgery review.

The board feel that as a high quality, dedicated, functioning group they are adaptable and capable of accepting and addressing all possibilities to deliver the objectives of Manchester Cancer.

Appendix 1 – Stereotactic Radiotherapy Service activity

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	83	136	58	17	7

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

7. Appendix 2 – Summary of the Macmillan living with and beyond cancer projects

Patients with brain and CNS tumours are a highly diverse group of people with varied diagnoses, prognoses, symptoms, ages and cultures. Treatment regimens are therefore also very varied and can range from active surveillance via scans to surgery, radiotherapy and chemotherapy interventions.

Due to the nature of this group of tumours, the needs of our patients differ depending on the location, grade and histology of the tumour. Frequently-encountered issues for patients living with and beyond treatment for brain tumours include speech and communication difficulties, mobility problems, short-term memory loss and cognitive dysfunction, personality change and epilepsy, in addition to the other difficulties common to the other cancer types.

The pathway board was successful in a bid to the Macmillan Living With and Beyond Cancer fund for two projects. These projects to address the identified unmet needs of two patient groups in living with and beyond their treatment:

i. Patients with primary brain tumours who have completed active treatment but who continue to have disabilities and survivorship challenges.

ii. Patients with brain metastases from any primary site who have been successfully treated with neurosurgery or stereotactic radiosurgery (SRS)

The first project is to introduce a living with and beyond programme for patients with primary Brain and CNS tumours, and provide effective and successful health and well-being events in the future. There is presently no survivorship programme for this patient group. It is felt that to be able to do this most effectively and with the best possible outcomes, we first need to identify a true picture of our patients' needs and determine the optimal method of assessing, recording and addressing those needs.

While valuable, the current range of health needs assessment tools do not provide enough detail on these specific neurological symptom domains to allow a proper evaluation of the needs of our patients and how we might address those via health and well-being events. This project will address this and will identify and use the most appropriate tool.

The second project is to use the funding to improve the care and experience of patients living with and beyond treatment for brain metastases from cancer of any primary site, particularly those patients who have been successfully treated with neurosurgery, radiotherapy or stereotactic radiosurgery (SRS), in any location in community, primary, secondary or tertiary care settings.

Brain metastases occur in 20-30% of all cancer patients, and are particularly prevalent in patients with primary breast, lung and renal cancers and melanoma. Historically, brain metastases developed late in the course of the disease and were a terminal or near-terminal event. However, improvements in systemic treatments e.g. chemotherapy and novel agents, and more pro-active treatment of brain metastases with surgery or radiosurgery mean that more patients are living

longer following treatment. This is a comparatively new and growing patient group and the board is keen to work towards improving their care and survivorship experience.

This project aims to facilitate the sharing of specialist neuro-oncology expertise in the management of areas such as epilepsy, steroids, neuro-cognitive dysfunction and optimisation of functioning in patients with residual neurological deficits, providing an educational resource and ensuring that all patients have access to the highest standards of specialist advice and care.

By improving understanding of the options for treating, managing or optimising function in the presence of neurological disability, referrals are more likely to be better directed and more targeted, leading to improved patient experience and improved utilisation of existing resources e.g. community rehab teams.

It would also ensure patients have access to specialist services e.g. specialist optometry clinics and epilepsy support services that more general cancer care professionals may be unaware of.

The funding will be used to support the recruitment of dedicated project management to take these bids to a successful conclusion. They will be completed within the timescales agreed with the funding and administrative bodies.

8. Appendix 3 – Meeting attendance

NAME	ROLE	TRUST	06/05/2014	01/07/2014	0/10/2014	21/04/2015
Arun Kallat	Cons Elderly Care Physician	Bolton	Apologies	Apologies	Apologies	Apologies
Dr catherine McBain	Consultant		✓	✓	✓	✓
Julie Emerson	SALT	Christie	✓	✓	✓	✓
Sara Robson	OT		✓	Apologies	✓	✓
Elizabeth Molloy	CNS		✓	✓	✓	✓
Dr A Tran	Consultant		✓	✓	✓	✓
Peter Selby	Consultant	CMFT	Aplogies	Apologies	✓	Apologies
Dr Moe Sein	Consultant	East Cheshire	✓	✓	✓	✓
TBC		Pennine				
K Karabatsou	Cons Neurosurgeon/ Lead for Neuro-oncology	SRFT	✓	Apologies	✓	✓
S Rutherford	Cons Neurosurgeon/ Lead for Skull Base		✓	Apologies	✓	Apologies
T Kearney	Cons Endocrinologist/ Lead for Pituitary MDT		Apologies	Apologies	Apologies	Apologies
Andrea Wadeson	CNS		✓	✓	✓	✓
Sarah Cundliffe	CNS		✓	✓	✓	Apologies
Alison Gilston-Hope	CNS		✓	✓	✓	✓
Dr K Dizayee	Consultant Physician	Stockport	Apologies	Apologies	Apologies	Apologies
Dr C Douglass	Consultant Neurologist	Tameside	Apologies	✓	✓	Apologies
Dr Samantha Kay	Palliative Care Consultant	UHSM	✓		Apologies	
Dr Sophie Harrison	Palliative Care Consultant			✓	Apologies	✓
Dr A Ismail	Consultant Radiologist	WWL	Apologies	Apologies	Apologies	Apologies
Dr Steve Elliot	GP	Salford CCG			Apologies	Apologies

9. Appendix 4 - Pathway Board Annual Plan 2015/16

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:	
Review date:	22nd September 2015

Summary of objectives

No	Objective	Alignment with Provider Board objectives
1	To develop the routine introduction of MGMT testing in Manchester	Objective no 1 – clinical outcomes & survival
2	Fully revise and extend the clinical guidelines to include standardised imaging follow-up policies	Objective no 1 – clinical outcomes & survival
3	Introduce banking of brain tumour tissue	Objective no 2 - Research
4	Manage the successful delivery of both Macmillan funded Living With and Beyond projects	Objectives no 1 & 3 – clinical outcomes & survival plus patient experience
5	The board will work with primary care commissioners and secondary care providers to develop a response to the recommendations for Brain & CNS cancer made in the NICE guidance "Suspected cancer: recognition and referral".	Objectives no 1 & 4 – clinical outcomes & survival plus standardisation of the service

Objective 1:

Objective:	To develop the routine introduction of MGMT testing in Manchester
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 Improved patient satisfaction Improved 1 year survival rates
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)**
Develop a business case to support the introduction of this test	Service team	Nov 15
Gain approval from relevant trust service team		Dec 15
Full implementation, including compliance with specimen turnaround time, in > 90% patients		31/3/16

Objective 2:

Objective:	Fully revise and extend the clinical guidelines to include standardised imaging follow-up policies
Rationale:	The guidelines of the pathway are now due for revision and need to reflect any changes in practice, service provision and processes. In addition, growing pressure on radiology departments makes a formal review of follow-up imaging policies indicated and timely.
By (date):	November 15
Board measure(s):	Revised guidelines and management policy including new standardised imaging follow-up policies
Risks to success:	Time and other commitments of involved personnel Resources
Support required:	None identified

Work programme		
Action	**Resp.**	**By (date)**
Revision of guidelines and management policy	PD	Oct 15
Table at SMG meeting for approval	PM	Nov 15
Table for adoption at Pathway Board meting	PM	Jan 16

Objective 3:

Objective:	Introduce banking of brain tumour tissue
Rationale:	BRAIN UK is an MRC-funded initiative supported by the British Neuro-pathological Society which is cataloguing the diagnostic tissue holdings of UK neuropathology centres and making these extensive archives available to the research community for high quality neurological research. To date there is access to over 60,000 cases. These valuable tissue resources are derived from post mortem examinations and contain neurological conditions from a range of conditions including cancer as well as many normal cases which are useful as controls.
By (date):	January 2016
Board measure(s):	To direct and support the clinical teams in retrieving pathological material to contribute to the Brain bank
Risks to success:	The research ethical approval process and patient approval The commitment of clinical teams Possible additional resource required by Department of Pathology
Support required:	Support at executive level for organisational change process

Work programme

Action	**Resp.**	**By (date)**
SMG approval and commitment	CMcB	Nov 15
Identify potential resource implications	SMG	Nov 15
Service teams to agree process for retrieval, despatch and recording of sample	SRFT	Nov 15
Agree a process for patient consent	SRFT	Nov 15

Objective 4:

Objective:	Manage the successful delivery of both Macmillan funded Living With and Beyond projects
Rationale:	To successfully deliver the Macmillan funded Living With and Beyond projects so that the proposed outcomes are fully realised.
By (date):	March 2016
Board measure(s):	Agreed health needs assessment tool Learning tool available for clinical staff caring for patients with Brain Mets
Risks to success:	Failure to recruit project management support Time and other commitments of involved personnel Resources
Support required:	Support at executive level for organisational change process

Work programme

Action	**Resp.**	**By (date)**
Recruitment of project management resource	JE / SR	Aug 15
Commencement of Project	Project Man	Sep 15
Report to Pathway board	PD/PM	Mar 16

Objective 5:

Objective:	The board will work with primary care commissioners and secondary care providers to develop a response to the recommendations for Brain & CNS cancer made in the NICE guidance "Suspected cancer: recognition and referral".
Rationale:	This guidance has asked for direct access to MR scanning for primary care; the availability of direct access to this diagnostic tool to GPs is currently unknown. Equally the implication of this for providers also needs to be better understood.
By (date):	Dec 2015
Board measure(s):	Audit of direct access MR scanning Protocol written to support delivery of the guidance
Risks to success:	Time and other commitments of involved personnel Resources - available scanning and reporting capability Mitigation: Aim for an efficient, unified, sustainable approach.
Support required:	Support at executive level for organisational change process Increased support for neuro-oncology MDT which is likely to experience an increase in referrals of patients with incidental findings.

Work programme

Action	**Resp.**	**By (date)**
Audit the scanning departments on primary care access	PM	Q2
Liaise with commissioners to understand possible volumes	PD	Q2
Review at board	Board	Nov 15
Develop protocol to ensure correct patients access scanning	Board	Jan 16