Guy's and St Thomas' NHS Foundation Trust | King's College Hospital NHS Foundation Trust | Lewisham and Greenwich NHS Trust

King's College Hospital NHS Foundation Trust

NEURO-ONCOLOGY MULTIDISCIPLINARY TEAM

ANNUAL REPORT (Jan 2018 – Dec 2018)

This annual report has been agreed by:

MDT lead Prof Ashkan
Date 27/03/19

Trust lead clinician Dr Edmunds
Date 27/03/19

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1. Introduction

1.1 Achievements

2018 has been a successful year for the Neuro-oncology despite the challenging financial times we face. We have increasing numbers of patients living longer with improved quality of life. Our service was strongly represented at the British Neuro-oncology society meeting in July 2018 with a number or oral and poster presentations. A bi-monthly neuro-oncology research meeting has been established with presentations from a variety of multi-disciplinary team members at each meeting. We have increased the number of Clinical Nurse Specialists within the team to help meet the demands of the service and continue to develop what we can offer to patients and their relatives. In collaboration with the Brain Tumour Charity we have established a site specific Health and well-being event focusing on living well for patients and carers. This runs bi-monthly and is enjoying increasing popularity. The clinical Trial portfolio continues to expand. Prof Ashkan, the lead for the service, was voted UK Clinician of the Year as nominated by the Brain Tumour Charity. He was also selected as the neurosurgeon on the Tessa Jowell Brain Cancer Mission New Roads for Patients.

The brain tumour support group has adapted in response to patient feedback to offer a dedicated new diagnosis support group every quarter. The attendance for this has been consistently high with both patients and their carer's with positive feedback. The Support group continues to run monthly.

2018 saw the introduction of a dedicated multi-disciplinary Low Grade Glioma clinic. Patients have reviewed this service with high regard and satisfaction. The clinic benefits from the presence of the neuro-psychologist, neurologist with a specialist neuro-oncology interest, neurosurgeons who are expert in awake craniotomies using TMS and DTI imaging to plan these operations. The clinic is co-ordinated by the dedicated Low Grade Glioma Clinical Nurse Specialist who is the first post of this kind funded by the Brain Tumour Charity in the U.K..

An extended weekly neuro-oncology theatre list has been agreed upon and implemented for 2019.

1.2 Challenges

Capacity is the main challenge we face. The outpatient clinics and theatre list space are where the biggest challenges lie. As you will see from the data, the clinics are very busy, the outpatient clinic itself does not have the space for the neuro-oncology clinic to run as effectively as it could. The environment for patients waiting to be seen is not in keeping with the quality service provision in all other areas. Due to theatre closures over the summer of 2018 the list capacity was significantly reduced despite alternative arrangements due to the trust investing in modernisation of the Neuro theatres with upgraded laminar flow air change systems. The complexity of the operations has continually increased, this requires theatre lists to adapt with this and recognise that where it was previously possible for there to be up to three cases on a theatre list, now an awake craniotomy using intra-operative monitoring could require a whole days list.

The CNS work force face an increasing administrative work load without provision to tackle this. The nurse-led initiatives were established on low numbers of patients, the services have been successful and are chargeable however the administrative workload that comes with the clinics were not factored in to the standard operating procedure plan. We have attempted to bid for funding to meet this challenge but in 2018 were not successful.

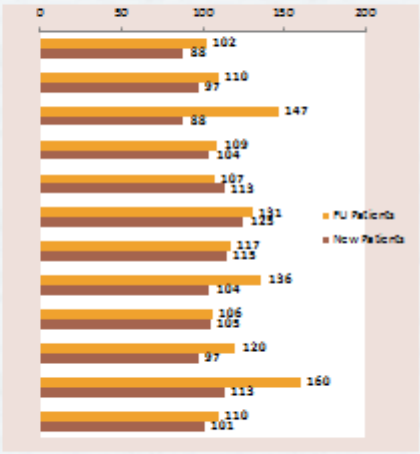
Integrating the eHNA in to the service is challenging, We have used paper HNA's in 2018 which will no longer be recognised in the data metrics. There are practical challenges including wifi access as well as the environmental challenges where patients might consider completing the assessment. The space to then complete the care plans with the patient has remained challenging in 2018. We are looking to our work programme for 2019 to devise innovative ways of working to integrate the eHNA in to our service.

2. Workload of MDT

2.1 Number of cases discussed

Patients Discussed in Neuro-oncology MDTs
Jan- Dec 2018

Date of First MDT	FU Patients	New Patients	Grand Total
Jan	102	88	190
Feb	110	97	207
Mar	147	88	235
Apr	109	104	213
May	107	113	220
Jun	131	125	256
Jul	117	115	232
Aug	136	104	240
Sep	106	105	211
Oct	120	97	217
Nov	160	113	273
Dec	110	101	211
Grand Total	1455	1250	2705



- Average per month=225, Median per month=219

Patients Discussed In MDTs -Comparison
April 2012 – Dec 2018

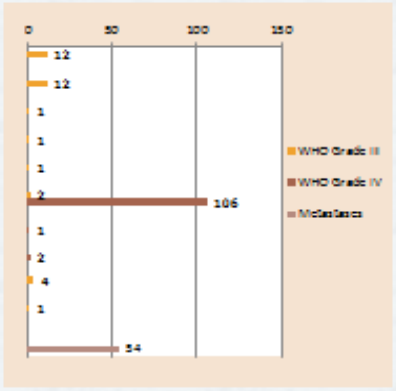
Year	FU Patients	New Patients	Grand Total
2012-2013	664	1294	1958
2013-2014	678	925	1603
2014-2015	849	978	1827
2015-2016	1012	1010	2022
2016-2017	1062	1100	2162
2017-2018	1338	1174	2512
April 2018 - Dec 2018	1096	977	2073
Grand Total	6699	7458	14157

Year	TOT New Patients Discussed	%of New Patients Trend
2012-2013	1958	66% (= 1294)
2013-2014	1603	58% (= 925)
2014-2015	1827	54% (= 978)
2015-2016	2022	50% (= 1010)
2016-2017	2162	51%(= 1100)
2017-2018	2512	47% (= 1174)
April 2018 - Dec 2018	2073	47%(= 977)

2.2 Number of new cancers diagnosed

Number of New Cancer Diagnosis WHO Grade III & IV
Brain tumours and Metastases Diagnosis
Jan- Dec 2018

Confirmed Diagnosis (type)	2018			Total for 2018
	WHO Grade III	WHO Grade IV	Metastases	
Anaplastic Astrocytoma	12			12
Anaplastic Oligodendroglioma	12			12
Astrocytoma	1			1
Atypical Meningioma	1			1
Ependymoma	1			1
Glioblastoma Multiforme	2	106		108
Glioma		1		1
Medulloblastoma		2		2
Oligodendroglioma	4			4
Pineal Tumour	1			1
Metastases			54	54
Grand Total	34	109	54	197



- Number of WHO III&IV Diagnosis =143,
- 97% were operated (138 cases, Biopsy cases included)
- Number of Met Diagnosed 54, 96% cases treated per surgery (=52 cases), 2 cases were biopsies

COSD/ Brain Tumours WHO Grade III& IV managed by age group
Jan 2017 – Dec 2018

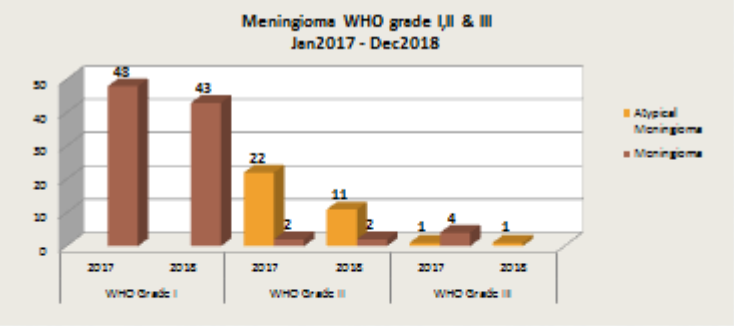
Surgery Date	Age Range	WHO Grade III		Tot surg proc (Grde III)	WHO Grade IV		Tot surg proc (Grde IV)	Grand Total
		Surgical procedures			Surgical procedures			
		Female	Male		Female	Male		
2017	16-20		1	1		2	2	3
	21-30	5		5	6	7	13	18
	31-40	8	8	16	2	3	5	21
	41-50	2	7	9	9	6	15	24
	51-60	1	5	6	21	28	49	55
	61-70	2	2	4	13	37	50	54
	71-80		3	3	5	22	27	30
	81<					1	1	1
2017 Total		18	26	44	56	106	162	206
2018	16-20		1	1				1
	21-30	2	4	6	7	4	11	17
	31-40	3	11	14	3	3	6	20
	41-50	2	5	7	6	9	15	22
	51-60	2	5	7	13	26	39	46
	61-70	2	3	5	18	26	44	49
	71-80	1	2	3	4	11	15	18
	81<				1	1	2	2
2018 Total		12	31	43	52	80	132	175
Grand Total		30	57	87	108	186	294	381

COSD/ Metastases Cases Managed by age Group Jan2017- Dec2018

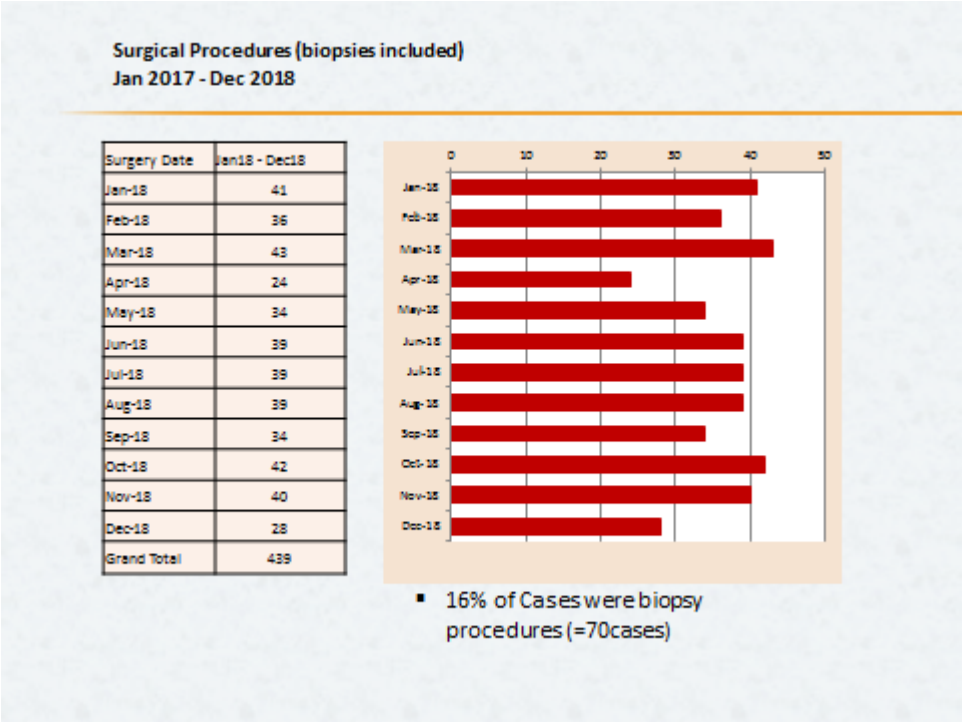
Surgery Date	Age Range	Surgical procedures		Grand Total
		Female	Male	
2017	30-40	10	1	11
	41-50	8	2	10
	51-60	18	11	29
	61-70	10	10	20
	71-80	2	6	8
Total (2017)		48	30	78
2018	30-40	3		3
	41-50	13	2	15
	51-60	12	5	17
	61-70	12	9	21
	71-80	2	6	8
Total (2018)		42	22	64
Grand Total		**90**	**52**	**142**

Meningioma - Confirmed diagnosis WHO Grade I, II &III Jan2017 – Dec2018

Confirmed Diagnosis (type)	WHO Grade I		WHO Grade II		WHO Grade III		Grand Total
	2017	2018	2017	2018	2017	2018	
Atypical Meningioma			22	11	1	1	35
Meningioma	43	43	2	2	4		94
Grand Total	43	43	24	13	5	1	134



2.3 Activity statistics: outpatient & surgical (where applicable)



Clinic numbers have continued to increase as evidence in Appendix 2 Please see work plan to address capacity concerns.

3. Data Collection & Audit

Data is collected and sent to the National Cancer Registry. The quarterly standards data for survivorship are sent to the Cancer Leads within the Trust to cross check and submit.

Data is submitted to the National Brain Registry.

The Trust does not currently have a generic data collection system but will be introducing Somerset from early 2019.

Clinical Audit Report: Transcranial Magnetic Stimulation – Patient Reported Experience Measure

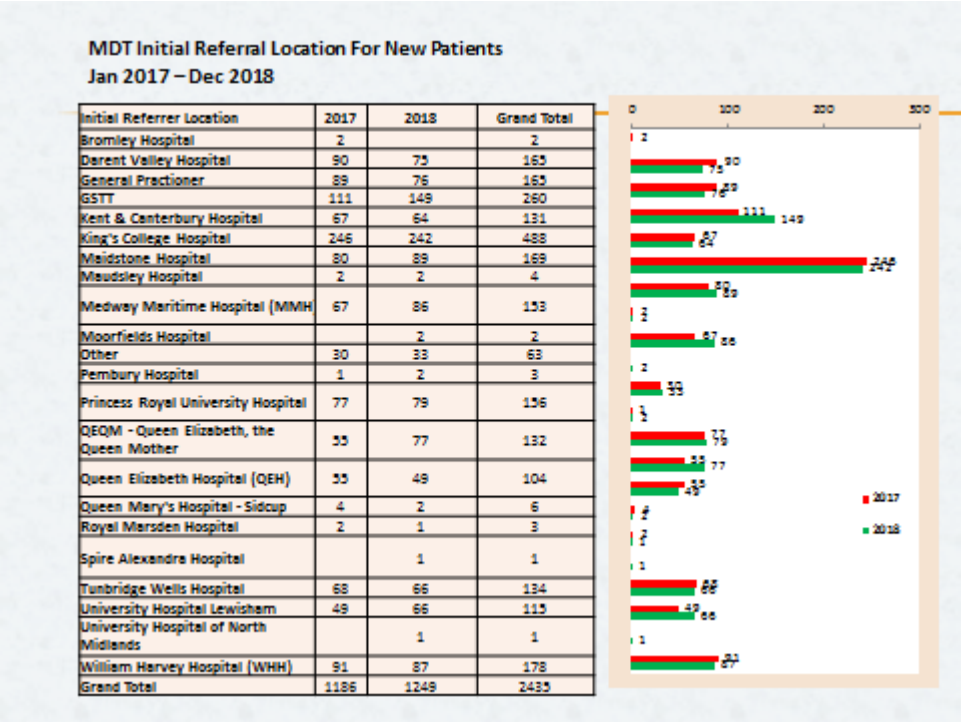
4. Cancer waiting times performance

Commitment	Operational Standard	Total	Breaches	Target achieved
Two week wait standard	93%	306	22	92.8%
62 day standard (urgent GP referral to treatment)	85%	2	0	100.0%
31 day standard (Decision to treat to first definitive treatment)	96%	146	8	94.5%

31 day subsequent treatment (Decision to treat to subsequent treatment)		39	1	97.4%

There were no transfers in or out to neuro-oncology, for patients on a 62 day pathway/two week wait referrals.

4 External referral patterns - *For tertiary services only*



MDT Initial Referral Location For New Patients
Jan 2017 – Dec 2018

Initial Referrer Location	2017	2018	Grand Total
Bromley Hospital	2		2
Darent Valley Hospital	90	75	165
General Practioner	89	76	165
GSTT	111	149	260
Kent & Canterbury Hospital	67	64	131
King's College Hospital	246	242	488
Maidstone Hospital	80	89	169
Maudsley Hospital	2	2	4
Medway Maritime Hospital (MMH	67	86	153
Moorfields Hospital		2	2
Other	30	33	63
Pembury Hospital	1	2	3
Princess Royal University Hospital	77	79	156
QEQM - Queen Elizabeth, the Queen Mother	55	77	132
Queen Elizabeth Hospital (QEH)	55	49	104
Queen Mary's Hospital - Sidcup	4	2	6
Royal Marsden Hospital	2	1	3
Spire Alexandra Hospital		1	1
Tunbridge Wells Hospital	68	66	134
University Hospital Lewisham	49	66	115
University Hospital of North Midlands		1	1
William Harvey Hospital (WHH)	91	87	178
Grand Total	1186	1249	2435

5 Attendance

5.1 Team attendance at MDT meetings

Our record keeping for the MDT attendance has not been as accurate as we would wish. We have put a plan in place for this to improve for 2019/20. Our MDT is video linked across four sites and the sign in sheet has not accurately captured professional's attendance. The neuro-oncology MDT runs additional meetings on weeks of a bank holiday to ensure that there are 52 meetings per year. In the instance of a bank holiday a smaller cohort of core members is present with an oncologist from Guys who comes to Kings for the meeting if there is not video linking facilities available. In 2019 there were 52 MDT meetings held.

5.2 Quorate attendance

In 2019 all meetings were quorate for the core team members and there was not a case where a decision could not be reached due to a member missing.

5.3 Attendance at SEL ACN Tumour Group meetings

There is currently not an SEL ACN group for neuro-oncology. It is anticipated that a South East London group will be established but has not yet been formed.

5.4 Attendance at KCH Cancer Committee

The neuro-oncology attendance at the Cancer Committee has been three times in the last year.

6 MDT operational meetings

6.1 Completion of MDM quality compliance self-assessment on March 27th 2019

Indicator Name	Indicator Code	Response	Indicator Description
There is a MDT for brain and other rare CNS tumours	B13/S/A/NS-16-001	Yes	Descriptor There should be a single named lead clinician for the MDT who should then be a core team member. The lead clinician of the MDT should have agreed the responsibilities of the position with the lead clinician of the host trust. The core team members for brain and rare CNS tumours should include: - two neurosurgeon - neurologist - neuro radiologist - two neuropathologist - clinical oncologist - clinical nurse specialist - clinical neuropsychologist - neuro-rehabilitation AHP liaison - specialist palliative care healthcare professionals - person responsible for user/carer issues - person responsible for clinical trials - MDT co-ordinator Notes The role of lead clinician of the MDT should not itself imply chronological seniority, superior experience or superior clinical ability. Where a medical specialty is referred to, the core team member should be a consultant. The cover for this member need not be a consultant. Where a medical skill rather than a specialty is referred to, this may be provided by one or more of the core members or by a career grade non-consultant medical staff member. All consultants responsible for the delivery of any of the main treatment modalities should be a core member of the MDT. The role of the imaging specialist can be met by a group of named specialists provided each meets the required workload. The role of the histopathologist can be met by a group of named histopathologists provided each meets workload and EQA requirements

Indicator Name	Indicator Code	Response	Indicator Description
There is a weekly MDT meeting for brain and other rare CNS tumours for treatment planning	B13/S/A/NS-16-002	Yes	Descriptor The MDT should have treatment planning meetings scheduled every week unless the meeting falls on a public holiday. The attendance at each individual scheduled treatment planning meeting should constitute a quorum, for 95% or more, of the meetings: - neurosurgeon - neurologist - neuro radiologist - neuropathologist - clinical oncologist - clinical nurse specialist - clinical neuropsychologist - neuro-rehabilitation AHP liaison - specialist palliative care healthcare professional Notes The % should be calculated over the last complete calendar year prior to the assessment. The members counting towards the quorum should be drawn from the list of named core members or their named cover as specified in the core membership measures and are therefore subject to the definition of acceptable core members or their cover. This measure does not imply any policy for what to do when an MDT meeting is not quorate. This is left to the MDT members' discretion.
There are clinical guidelines for brain and other rare CNS tumours in place	B13/S/A/NS-16-003	Yes	Descriptor There should be agreed clinical guidelines for brain and other rare CNS tumours, i.e. how a given patient should be clinically managed, usually at the level of which modalities of imaging and pathology investigation and which modalities of treatment are indicated, rather than detailed regimens or techniques. The clinical guidelines should include the management of : - cerebral metastases - protocol for emergency surgical interventions in patients with a CNS tumour, for intra-CNS problems caused by the tumour or its treatment. Notes Clinical guidelines should reflect national guidelines
Surgical core MDT members have 50% of their direct clinical care programmed activities for brain and other rare CNS tumours.	B13/S/A/NS-16-004	Yes	Descriptor Each surgical core MDT member should have 50% of their direct clinical care programmed activities (DCCPAs) specified for work related to and including relevant elective surgery and the management of patients with brain and other rare CNS tumours, including attendance at the MDT. Notes None

Indicator Name	Indicator Code	Response	Indicator Description
There are agreed patient pathways in place for brain and other rare CNS tumours	B13/S/A/NS-16-005	Yes	Descriptor There should be patient pathways, i.e. the named services, hospitals and MDTs which a patient should be referred to according to named indications, during their investigation, treatment, psychological and social support, rehabilitation and follow up. The pathways should include the relevant contact points for the services, hospitals and MDTs. The pathway should include the following specifications: - that all diagnostic imaging suggestive of primary tumours should be referred to the MDT within 2 working days; - the indications for referral for biopsy; - that the treatment planning decision for initial management and for the initial management of at least the first recurrence, should be made only after discussion at the MDT; - when a MDT refers patients to a RNSMDT as part of the patient pathway, it should be the RNSMDT which the professionals in charge of the patient's non surgical treatment and rehabilitation are members of; - what the roles are, in the follow up process, of the multidisciplinary specialist clinics. - that any patient with metastatic carcinoma of unknown origin should be referred on for discussion by the carcinoma of unknown primary MDT - arrangements between the lymphoma MDT and the NSMDT for the management of primary central nervous system lymphoma (PCNSL) - the brain and other rare CNS tumours pathways for TYAs, including initial management, follow up on completion of first line treatment and cases involving NHS specialised services. Notes None
The MDT meets the minimum workload	B13/S/A/NS-17-001	Yes	Descriptor The MDT should receive at least 100 newly diagnosed cases of intracerebral tumours for discussion per year. Notes This is calculated as the average over two years prior to the review/assessment.

Palliative care does not currently attend the MDT unless they need to discuss a particular case. They liaise via the Neuro-oncology CNS's who ensure their view/care plan is represented.
The Neuropsychologist attends the dedicated Low Grade glioma MDT where her expertise is required for all patients. She is available to attend main the neuro-oncology MDT on a Friday if required.

7 Learning and development

CNS learning and development: Mind and Body Clinical Skills Course 24th September 2018; The Brain Tumour Charity Nurse and Allied Health Professional Conference - 19th Sept;
British Neuro-oncology Society conference 4-6th July 2018;
Bridges Training: An introduction to supporting self-management in rehabilitation; St Christopher's Hospice: Foundations in cognitive behavioural therapy (CBT) for physical healthcare professionals (working in long term or life limiting conditions and at the end of life).
Advanced history taking and assessment for nurses at UWL May 2018.
There is access to Advanced communication skills training for members of the MDT.
Team presented at KHP neuroscience nursing conference realising the potential of neuroscience nursing in June 2018.
CNS team have access to clinical supervision on a monthly basis.

8 Patient and carer feedback and involvement

8.1 NCPES results

- There were 12 responses identified as relating to Neuro-oncology in the 2017 NCPES.
- Within the comments received there were 10 (62.5%) positive comments and 6 (37.5%) negative ones. Some patients had both positive and negative aspects to their care.
  Issues:
- Outpatients: Waiting times, over crowding, communication.
- Communication from referrers and following their care at Kings
- Post-treatment isolation
- Access to CNS's – not neuro specific
- Psychological support services – delays in appointment times.
- My Care plans
  Focused areas for neuro-oncology:
- Ringing bed manager day before operation very stressful.
- First operation set 24/1/17 cancelled on the day. Second appointment 31/1/17 cancelled on the day
- My infection could have been caught earlier
- The only thing I can fault is the waiting time to see a consultant on a clinic day. Very rarely do you see the consultant at the specified time of your appointment
  Focused areas identified as skull base:
- "The information that I was originally given about my skull biopsy was completely misleading and incorrect."
- Communication between the staff and the patient is reported as being confusing and significant information given.
- Only one comment received.
  Solutions:

- **Outpatients**: Two stream meeting planned to try to look at improving the current situation by moving back the clinic start time to 2:45 so that it allows for the pre-clinic MDT to finish at 2:30, aiming to allow the clinic to start on time. Re-draft the clinic letter to explain the likely delays in appointments and set expectation.

- Secondly to look at the re-planning of outpatients. Aiming to use all of suite 5 for neuro-oncology to have enough clinic rooms for clinicians to see patients. This would enable patients to all have a seat in clinic and help the clinic to keep to time and cope with the current capacity issues.

- **Communication:** To offer 'road shows' with the up to date operational policy to referrers in Kent and GP's. This would ensure a smoother process for patients as the referrer would know what to expect. We have had two recent incidents of patients coming to clinic expecting a brain biopsy to be performed in the clinic. This is a direct result from miscommunication with the referrer and was not on their MDT discussion.
- Communication following onward referral from Kings was felt to be poor. It isn't clear from the survey how this needs to be improved from the Kings side of care. We will therefore conduct a scoping exercise from patients with metastases following their return to their local team. This is felt to be the most likely cohort of patients affected by onward referral as it is outside the direct team. We will then use this information to look at ways to improve their pathway when leaving Kings.

- **Post-treatment isolation**: A comment stating the patient felt isolated once treatment was completed and scared of what was going on that they couldn't see.
- It is not clear if this was a Neuro patient however we know our patients can feel this way on completion of their initial treatment.
- We have already got a monthly support group in place with a quarterly newly diagnosed support group.
- We have created a site specific Living well programme that runs every two months and focuses on the key areas identified in a wide scale patient experience exercise carried out by the Brain Tumour Charity.
- We are applying for funding to release some capacity of the Lead CNS to offer 1:2:1 sessions with patients post-diagnosis and treatment offering psychological support with neurocognitive rehabilitation exercises.

- **Access to CNS's:** Not site specific but a nationwide concern.
- A new cns started on the 19th November WTE.
- We have submitted a bid for secretarial support after looking at the proportion of time spent on administrative support. This would improve access to CNS's by increasing accessibility
- Our voicemails are regularly updated to reflect where we are that week and when the patients can expect a call back.
- We are updating our CNS leaflet to offer a clear explanation of what we can do for patients and their carers and our role. We will also look at how we can improve the signposting to the CNS team for referrers who require clinical advice.
- We will carry out our own patient experience work to look at whether this is a problem currently and find out more information.
- We will introduce the brain specific KCH patient experience survey.

- **Support services:** Psychological support services – There is a long waiting time for RDCIS
- There are also waiting times for psychological support via Palliative care services.
- We have been utilising the services in the community via the CSI reducing waiting times. KCH bid for psychological support services has been successful now waiting for the new posts to begin.

- Financial support – patients have been utilising the service at Guys with a short waiting time but this is not always easy to access depending on where the patient lives.
- We have a list of services from the CSI which we will make patients aware of more routinely and include on their care plan.

- **My Care Plans:** Patients reported not having care plans as a Trust wide response.
- Following HNA completion a care plan is formulated, this is translated in to the clinic letter. This may not be clear to the patient, therefore improved sign posting is required.
- Care plans following End of Treatment are more clearly defined, these are copied to patients and GP's following the HNA discussion.
- Label care plans as their own entity and ensure they are discussed with the patient.
- The HNA care plan will be available on epr so automatically uploaded increasing the uptake of this tool as it will be time saving.
- Following successful recruitment of admin support to neuro-oncology cns team the number of patients completing the HNA will increase and consequently the My Care plan figures will improve in keeping with our work plan.
- Skull base and pituitary services will be using the HNA for patients with severe consequences of treatment.

- **Positives**: "I feel I have been treated very well and with compassion"
- "From the very beginning and continuing treatment it has been outstanding!"
- "The operation at Kings College London was wonderful. My recovery was swift, very informative on any questions raised, honest, with the ups and downs."
- "Clinical neurology nurse Jess was very helpful."
- "Mr Vergani did his best and he was a good communicator."

- **Actions:** Introduce the Trust Brain KCH survey for future patient experience work.
- CNS team currently enrolled on advanced assessment skills training, CBT foundation skills, Advanced communication skills, psychological level 2 training. We will look to get all cns's through the ANP pathway at the appropriate time. BNOS 2019 to be held in London, CNS Lead to be on the organising committee.
- CNS team presented four abstracts led by CNS's at BNOS 2018 all related to patient experience and how the CNS's have improved the patient pathway nurse-led initiatives. CNS's to begin work on quality of life patient experience before January 2019 ready for BNOS 2019.

8.2 Local surveys

Patients attending the Living Well events are surveyed prior to leaving, giving a 100% response rate. These are the comments from the latest workshop in November 2018 where the focus was on psychological support:
100% of attendees valued having access to the Brain Tumour Charity representative.
100% of attendees would recommend this event to family and friends if needed.

Additional comments:
"Good information given, great to have time to talk and focus on information services"
"Friendly relaxing atmosphere and very informative"
"Very informative and useful, very interested in doing fundraising schemes to help support others"
"Thank you for the opportunity to be a person and not an illness"
"I found this session very good. It is nice that you can speak with people"
"Very helpful to know that support is available to both patients and carers"
"All presentations useful and provided a great deal of information's. It's good to know that support is available if needed and to know that you are not alone"
"Could have done with this support a few years ago"

This year we have surveyed patients anonymously on their use of alternative therapies including Cannabinoids. This was chosen for an oral poster presentation at BNOS 2018.

8.3 Delivery of LWBC agenda

The Neuro-oncology CNS team deliver a number of nurse-led services. The histology results are all given by the neuro-oncology cns's trained in advanced communication skills. This clinic also ensures that 100% of patients meet their CNS at diagnosis. The clinic is ran from the cancer information centre where the patient is greeted by a volunteer and able to wait in a calm, relaxing environment with a drink provided for them. Following their results they are able to obtain any written information needed and are aware of the centres existence for future needs. The clinic is registered on pims and the CNS's book their patients in. There is currently not admin support for this. The clinic generates a letter and onward referral as well as scan bookings and HNA. There is no admin support for these tasks, the nurses write their own letters, book the follow up appointments and any other referrals i.e palliative care. In 2018 the e-HNA was not completed in this clinic due to resource constraints and practical considerations like working WIFI.

There is a daily telephone clinic booked on to pims for the neuro-oncology CNS team. This aims to prevent unnecessary admissions, GP appointments and offers a supportive space for patients and their relatives to discuss any burning issues. The clinic is also used for medications management and ensuring communication between teams for complex patients. If there was admin support in place it would be possible them to book in the people with completed eHNA's for the care plan to be discussed and formulated.

There is an outpatient neuro-oncology clinic three times a month at Kings College Hospital. One of these focuses on Teenage and young adults. The Neuro-oncology CNS's prepare the pre-clinic MDT meeting and carry out all outcomes from this clinic. There is no allocated clinic room for the neuro-oncology CNS's who at present stand in the corridor co-ordinating the clinic. There is not the space in this clinic to carry out the eHNA assessment though it would be one of the desirable times to use the tool.

There is a weekly oncology clinic at Guys Cancer Centre which the neuro-oncology cns's attend and review patients within, Here they are allocated a clinic room. The CNS's review on-treat patients having chemotherapy and see the patient on radiotherapy for their mid-treat review and EOT. These clinic appointments generate a clinic letter which are hand typed by the CNS. There is no admin support available for this. When the practical requirements are in place it will be possible to extend time slots to carry out eHNA's in this clinic.

The neuro-oncology CNS's are not currently running holistic support clinics. It is in the work plan for 2019 to change this. For the majority of brain tumour patients self-management of their disease is unrealistic. However it is possible to reduce appointments through the use of skype and effective assessment at key points.

Treatment summaries are in use but they are currently produced on an individual basis opposed to a set proforma. They are completed by the CNS's and are used to advise the GP on what to monitor for example blood sugar monitoring for patients on steroids, side effects of the radiotherapy and triggers to contact the Hospital team.

There is a site specific Health and Wellbeing event ran every two months in Neuro-oncology
from set up in 2018. This is a nurse-led initiative with MDT support. There is a monthly support group for patients and carers as well as a quarterly support group for newly diagnosed patients.

9 Research

MEMBRAIN project: Management Evaluation of Metastases in the Brain
J Jung, J Tailor, E Dalton, LJ Glancz, J Roach, R Zakaria, S Lammy, A Chari, E Edlmann, K Budohoski, LJ Livermore, K Yu, MD Jenkinson, P Brennan, L Brazil, C Bunce, K Ashkan*, F Vergani*on behalf of the BNTRC

Functional Considerations in Surgical Approaches to High Grade Lesions in the Insula
J Lavrador

10 Clinical trials

Proposed Neuro Oncology Studies								
Trial	**Full Title**	**Study Status**	**PI**	**Comm / Non Comm**	**Research meeting**	**Potential Open Date**	**Intended Target No**	**Comments**
Reo-Glio	ReoGlio: A dose-finding study of the safety and tolerability of intravenous reovirus (REOLYSIN®) plus granulocyte-macrophage colony-stimulating factor (GM-CSF) in combination with standard of care chemoradiotherapy (CTRT) /adjuvant chemotherapy for Glioblastoma Multiforme (GBM)	Proposed	Lucy Brazil	Non-commercial	To be re-discussed once esclation part of trial opens (if selected as site)	Autumn-2017	TBC	Trial not currently seeking to open more sites to the escalation phase but would like to collect feasibility of sites which may open to the expansion phase (approx. Autumn 2017). A.Reid@leeds.ac.uk e-mailed for up-date 02/10/2017) LB to contact trial for further up-date (18/12/2017)
STELLAR	This is a randomized, open-label, multicenter, active-controlled study to evaluate the efficacy and safety of eflornithine with lomustine compared to lomustine alone in patients with anaplastic astrocytoma (AA) whose tumors have progressed or recurred following external beam radiation therapy (EBRT) and temozolomide chemotherapy	Proposed	Lucy Brazil	Non-commercial	29/10/2018	TBC	TBC	Preparing submission for national approvals

Trial	Full Title	Study Status	PI	Comm / Non Comm	Research meeting	Potential Open Date	Intended Target No	Comments
CANC 40528	An open label dose escalation study to estimate maximum tolerated dose (MTD), identify dose-limiting toxicities (DLTs) and study pharmacokinetics following a single dose of intracerebrally administered temozolomide-based SI-053, in adult patients with newly diagnosed glioblastoma.	Proposed	Keyoumars Ashkan	Non-commercial	07/12/2018	TBC	TBC	
BRIOCHE	BRIOChe study: Brain Re-Irradiation Or Chemotherapy.A Phase II trial of re-irradiation or chemotherapy for recurrent glioblastoma	Proposed	Omar Al-Salihi	Non-commercial	07/12/2018	TBC	TBC	Early stages of setup - to be run by RT team

Neuro Oncology Studies in Set Up

Trial	Full Title	Study Status	PI	Comm / Non Comm	Date discussed	Potential Open Date	Intended Target No	Comments
EORTC 26081 CODEL	Phase 3 Intergroup Study of Radiotherapy versus Temozolamide versus Radiotherapy with Concomitant and Adjuvant Temozolomide for patients with Newly Diagnosed Anaplastic Oligodendroglioma or Anaplastic Mixed Glioma with Chromosomal co-deletions of 1p and 19q	Proposed	Lucy Brazil	Non-commercial	To be re-discussed - if confirmed selected as site	Dec-16	TBC	**SUSPENDED AT PRESENT- Update from MF: Sponsor not ready to send documents.** Trial has been suspended due to mature data from a previous study that showed PCV gave a huge survival advantage, therefore standard arm has changed, protocol amendment for this pending. LB is CI for UK. From EORTC meeting in Brussels in Jan - aiming to re-open this in EU by Autumn 2015. Protocol still being finalised. Study likely to open early 2017. Now 2018 E-mailed for up-date 02/10/2017 LB to contact trial for further up-date (18/12/2017) - may need to be resubmitted to REC Awaiting for up-date (18/05/2018)

Trial	Full Title	Study Status	PI	Comm / Non Comm	Date discussed	Potential Open Date	Intended Target No	Comments
EORTC 1709	A phase III trial of marizomib in combination with standard temozolomide-based radiochemotherapy versus standard temozolomide-based radiochemotherapy alone in patients with newly diagnosed glioblastoma	Proposed	Lucy Brazil	Non-commercial	18/12/2017	?	TBC	Approved - feasibliity completed - selected. Setup underway - issue with Marizomib pharmacy preparation time. All local approvals completed. To be seens as 1-stop. Ideally on Wednesdays as greater capacity in pharmacy then. Pharmacy pro-forma to be completed. SIV booked for 17/12/2018
Abbvie F16-249	A Study of Radiologically Evident Treatment Effects in Subjects with Glioblastoma Multiforme (GBM)	Proposed	Lucy Brazil	Commercial	18/12/2017		TBC	No up-date - focusing on 'eye tox' study first
IPI-GLIO	A Phase II, Open Label, Randomised Study of Ipilimumab with Temozolomide versus Temozolomide alone after surgery and chemoradiotherapy in patients with recently diagnosed glioblastoma	Propsed	Lucy Brazil	Non-commercial	13/07/2018	End of 2018	TBC	Issue with pharmacy accountability resolved, setup nearing completion, aiming to open in January 2019
M16-534	Phase 3b Study for Management of Ocular Side Effects in Subjects with EGFR-Amplified Glioblastoma Receiving Depatuxizumab Mafodotin (ABT-414)	Proposed	Lucy Brazil	Commerical	29/10/2018	Jan-19	TBC	Contracts currently being agreed. Meeting held with Mr Lim to discuss plan / selection of products to be used for different arms (27/12/2018). Training visitsfor Ophthamology to be arranged ASAP - aim to open January 2019

Declined/not setup Neuro Oncology Studies								
Trial	**Full Title**	**Study Status**	**PI**	**Comm / Non Comm**	**Date discussed**	**Potential Open Date**	**Intended Target No**	**Comments**
GSAM Project (EORTC)	Stability of Actionable Mutations in Glioblastomas- Is a second surgical resection/biopsy required for personalized medicine of recurrent glioblastoma patients?	Declined	Lucy Brazil	Non-commercial		Jun-16		MF: cannot open at Kings/ Guys. LB received path contract. Trial not setup - recorded as such - 21/09/2017
CANC 31689	A Global Multicenter Study of Nivolumab in Subjects with Refractory Malignancies with Microsatellite Instability High and Mismatch Repair Deficiency.	Declined	Lucy Brazil	commercial				Kings CNS . Spomsored by BMS. LB to do expression of interest. ? Early phase to do trial. Trial not setup - recorded as such - 21/09/2017
EORTC 1553	SPECTA: Screening Cancer Patients for Efficient Clinical Trial Access	Declined	TBC	Non-commercial	18/12/2017		?	Declined - LB to discuss if KCH can run trial
CA209848	A Randomized, Open-Label, Phase 2 Study of Nivolumab in Combination with Ipilimumab or Nivolumab Monotherapy in Participants with Advanced or Metastatic Solid Tumors of High Tumor Mutational Burden (TMB-H)	Proposed	Lucy Brazil	Comm	13/07/2018	TBC	TBC	No Neuro Cohort, therefore feasiblility not completed

Neuro Oncology Studies Open to Recruitment									
Trial	**Full Title**	**PI**	**Comm / Non Comm**	**Target No.**	**Date discussed**	**Total No. Consent**	**Total No. Rand/ Reg**	**Year to Date (Apr 2018 - Mar 2019**	**Comments**
ROAM	Patients with atypical menigioma and randomising them between immediate RT and delayed RT	K Ashkan				6	6	3	
PRAM	Patterns of tumour recurrance	K Ashkan				16			Imaging study run at King's
PARADIGM	OlaPArib And RADiotherapy In newly-diagnosed GlioblastoMa: Short-course radiotherapy plus olaparib for newly diagnosed glioblastoma in patients unsuitable for radical chemoradiation: a randomised phase II clinical trial preceded by a lead-in phase I dose escalation study.	Lucy Brazil	Non-Comm			8	5	4	

Trial	Full Title	PI	Comm / Non Comm	Target No.	Date discussed	Total No. Consent	Total No. Rand/ Reg	Year to Date (Apr 2018 - Mar 2019	Comments
Abbvie Intellance 1	A Randomized, Placebo Controlled Phase 3 Study of ABT-414 with Concurrent Chemoradiation and Adjuvant Temozolomide in Subjects with Newly Diagnosed Glioblastoma (GBM) with Epidermal Growth Factor	Lucy Brazil	Commercial			12 (pre-screen) 5	5	0	Now closed to recruitment (closed early as trial opened additional sites which increased screening activity).
Sativex - new	Survival Outcomes and Interventions Pre and Post Treatment during the GWCA1208 Trial	Proposed	Lucy Brazil	Commercial	18/12/2017	7	7	7	Approved. PSV 18/12/2017. Trial in setup - hoping to open in April-2018 (delayed). Setup now underway
Fatigue	Measuring cognitive processing in chronic fatigue syndrome and other long term conditions (LTCs)	Proposed	Alicia Hughes	Non-commercial	07/12/2018				Being run at King's - opted not to also open at Guy's

Neuro Oncology Studies Closed to Recruitment					
Trial	**Full Title**	**PI**	**Comm / Non Comm**	**Total No. Recruited**	**Comments**
ACT IV	An International, Randomized, Double-Blind, Controlled Study of Rindopepimut/GM-CSF with Adjuvant Temozolomide in Patients with Newly Diagnosed, Surgically Resected, EGFRvIII-positive Glioblastoma	Ron Beaney	Commercial	1	Closed to recruitment Sept 2014. 1 patient, now discontinued treatment. To archive trial?
EORTC 26101	Phase III trial exploring the combination of bevacizumab and lomustine in patients with first recurrence of a glioblastoma	Lucy Brazil	Non-commercial	3	Closed end of Nov. 1 patient on follow up. Bevacizumab found no survival benefit
GALA 5	Feasibility of 5-ALA and Carmustine wafers for Glioblastoma (GALA-5). An Evaluation of the Tolerability and Feasibility of combining 5-Amino-Levulinic Acid (5-ALA) with Carmustine Wafers (Gliadel) in the Surgical Management of Primary Glioblastoma	Prof Ashkan	UNK	13	Not run by OHCT - KCH study. Patients on follow up.
NBT	National Brain Tumour Study - Identification of low penetrance alleles for GLIOMAS through genome-wide association analyses using SNPs	Lucy Brazil	Non-commercial	163	Recruitment now suspended pending further funding.
Sativex (GWCA1208)	A two part study to assess the tolerability, safety and pharmacodynamics of Sativex in combination with dose-intense Temozolomide in patients with recurrent glioblastoma	Lucy Brazil	Commercial	7	Closed to recruitment all patients on survival follow up.
AbbVie	ABT 414 alone or ABT 414 plus temozolomide versus lomustine or temozolomide for recurrent glioblastoma: a randomized phase II study ofthe EORTC Brain Tumor Group	Lucy Brazil	commercial	5	3 patients on treatment. 2 has just come off treatment.

Trial	Full Title	PI	Comm / Non Comm	Total No. Recruited	Comments
BR14	Phase III trial on Concurrent and Adjuvant Temozolomide chemotherapy in non-1p/19q deleted anaplastic glioma. The CATNON Intergroup trial.	Lucy Brazil	Non-commercial	6	Patient on follow up. No additional patients on chemo
HCQ	A randomised phase 2 trial investigating the additional benefit of hydroxychloroquine (HCQ) to years and older with high grade gliomas (HGG)	Lucy Brazil	Non-commercial	11	Translational addition still in negotiation - awaiting sponsor advice on getting Paraformaldehyde PFA
DCVax	A Phase III clinical trial evaluating DCVax®-L, autologous dendritic cells pulsed with tumour lysate antigen for the treatment of glioblastoma multiform.	Prof Ashkan	Commercial	30	KCH Study- not managed by OHCT. Closed to recruitment, analysing data. Stavros from KCH not permitted to pass on recruitment info by sponsor. May open anytime soon. Recruitment suspended for a year.
STING ICT-07	A Phase III randomized double-blind, controlled study of ICT-107 with maintenance temozolomide (TMZ) in newly diagnosed glioblastoma following resection and concomitant TMZ chemoradiotherapy	Ron Beaney	Commercial	0	Funding for trial withdrawn, therefore trial never setup
EORTC 1320	Trabectin for recurrent Grade II or Grade III meningioma - a randomised phase II study of the EORTC Brain Tumour Group	Ron Beaney	Non-commercial	4	Trial now closed. Interim safet analysis showed IMP arm to be insufficiently effective with a large number of side effects
GALA BID		Prof Ashkan	Non-commercial	20	Done at Kings. Surgical Intervention Contact person: Lauren Perkin at Kings.Now closed
HIPPO	A Randomized 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	Dr Brazil	Non-commercial		UCL sponsored. To be run by RT team, agreed by breast research meeting. CORRD- Up for discussion. Will open as soon as appropriate patient identified

Appendix 1: Clinic numbers

ALL APPOINTMENTS	Column Labels				
	2017/18	2018/19			Grand Total
Row Labels	Q4	Q1	Q2	Q3	
DH/GLIOMA01	**15**	**20**	**12**	**18**	**65**
GLIOMA CLINIC/TUE/AM - Low Grade Glioma Clinic 1st Tues AM FUP				**6**	**6**
GLIOMA CLINIC/TUE/AM - Low Grade Glioma Clinic 1st Tues AM FUP				6	6
GLIOMA CLINIC/TUE/AM - Low Grade Glioma Clinic every 1st Tues AM month	**15**	**20**	**12**		**47**
GLIOMA CLINIC/TUE/AM - Low Grade Glioma Clinic every 1st Tues AM month	15	20	12		47
GLIOMA/TUE/NEW1 - Low Grade Glioma Clinic 1st Tues AM NEW 1				**7**	**7**
GLIOMA/TUE/NEW1 - Low Grade Glioma Clinic 1st Tues AM NEW 1				7	7
GLIOMA/TUE/NEW2 - Low Grade Glioma Clinic 1st Tues AM NEW 2				**5**	**5**
GLIOMA/TUE/NEW2 - Low Grade Glioma Clinic 1st Tues AM NEW 2				5	5
DH/NEUROADOLESCENT				**92**	**92**
CON/ADOL/FUP/MONPM1 - Mr Chandler/Mr Bhangoo Adol FUP 1st Mon PM1				**79**	**79**
CON/ADOL/FUP/MONPM1 - Mr Chandler/Mr Bhangoo Adol FUP 1st Mon PM1				79	79
CON/ADOL/NEW/MONPM1 - Mr Chandler/Mr Bhangoo Adol NEW 1st Mon PM1				**11**	**11**
CON/ADOL/NEW/MONPM1 - Mr Chandler/Mr Bhangoo Adol NEW 1st Mon PM1				11	11
CON/ADOL/NEW/MONPM2 - Mr Chandler/Mr Bhangoo Adol NEW 1st Mon PM2				**2**	**2**
CON/ADOL/NEW/MONPM2 - Mr Chandler/Mr Bhangoo Adol NEW 1st Mon PM2				2	2
DH/NEURONCPREASS				**107**	**107**
CON/FUP/MONAM - Neuro-Onc Pre Assessment Clinic				**42**	**42**
CON/FUP/MONAM - Neuro-Onc Pre Assessment Clinic				42	42
CON/NEW/MONAM - Neuro-Onc Pre Assessment Clinic				**65**	**65**
CON/NEW/MONAM - Neuro-Onc Pre Assessment Clinic				65	65
DH/NEUROONC				**124**	**124**
CONS/FUP/MONPM1 - Mr Ashkan/ Mr Bhangoo Wk.4 Neuro Oncology Clinic				**103**	**103**
CONS/FUP/MONPM1 - Mr Ashkan/ Mr Bhangoo Wk.4 Neuro Oncology Clinic				103	103
CONS/NEW/MONPM1 - Mr Ashkan/ Mr Bhangoo Wk.4 Neuro Oncology Clinic				**9**	**9**
CONS/NEW/MONPM1 - Mr Ashkan/ Mr Bhangoo Wk.4 Neuro Oncology Clinic				9	9
CONS/NEW/MONPM2 - Mr Ashkan/ Mr Bhangoo Wk.4 Neuro Oncology Clinic				**6**	**6**
CONS/NEW/MONPM2 - Mr Ashkan/ Mr Bhangoo Wk.4 Neuro Oncology Clinic				6	6
CONS/NEW/MONPM3 - Mr Ashkan/ Mr Bhangoo Wk.4 Neuro Oncology Clinic				**5**	**5**
CONS/NEW/MONPM3 - Mr Ashkan/ Mr Bhangoo Wk.4 Neuro Oncology Clinic				5	5
CONS/NEW/MONPM4 - Mr Ashkan/ Mr Bhangoo Wk.4 Neuro Oncology Clinic				**1**	**1**
CONS/NEW/MONPM4 - Mr Ashkan/ Mr Bhangoo Wk.4 Neuro Oncology Clinic				1	1
DH/NEUROONC/MDT	**390**	**684**	**704**	**655**	**2433**
CC DH/NEUROONC/MDT - MDT ONCOLOGY	**28**				**28**
CC DH/NEUROONC/MDT - MDT ONCOLOGY	28				28
NEUROONC FUP - Neuro Oncol MDT FUP FRI	**210**	**347**	**381**	**366**	**1304**
NEUROONC FUP - Neuro Oncol MDT FUP FRI	210	347	381	366	1304
NEUROONC NEW - Neuro Oncol MDT NEW FRI	**152**	**337**	**323**	**289**	**1101**
NEUROONC NEW - Neuro Oncol MDT NEW FRI	152	337	323	289	1101
DH/NEUROONC/REG				**159**	**159**
REG/FUP/TUEPM1 - Neuro Oncology Clinic Gullan & Askan FUP Tues PM				**142**	**142**
REG/FUP/TUEPM1 - Neuro Oncology Clinic Gullan & Askan FUP Tues PM				142	142
REG/NEW/TUEPM1 - Neuro Oncology Clinic Gullan & Askan Tues PM 1				**15**	**15**
REG/NEW/TUEPM1 - Neuro Oncology Clinic Gullan & Askan Tues PM 1				15	15
REG/NEW/TUEPM2 - Neuro Oncology Clinic Gullan & Askan Tues PM 2				**2**	**2**
REG/NEW/TUEPM2 - Neuro Oncology Clinic Gullan & Askan Tues PM 2				2	2
DH/NEUROONCOLOGY		**13**	**13**	**18**	**44**
GF/FUP/NEUROONCOLOGY - Dr Finnerty FOLLOW UP Neuro Oncology Clinic 1st Tues AM		**10**	**8**	**15**	**33**
GF/FUP/NEUROONCOLOGY - Dr Finnerty FOLLOW UP Neuro Oncology Clinic 1st Tues AM		10	8	15	33
GF/NEW/NEUROONCOLOGY - Dr Finnerty NEW Neuro Oncology Clinic 1st Tues AM		**3**	**5**	**3**	**11**
GF/NEW/NEUROONCOLOGY - Dr Finnerty NEW Neuro Oncology Clinic 1st Tues AM		3	5	3	11
HURWITZ01	**62**	**73**	**76**	**71**	**282**
HURWITZ1 - Telephone Clinic	**62**	**73**	**76**	**71**	**282**
HURWITZ1 - Telephone Clinic	62	73	76	71	282
NLRC	**99**	**93**	**101**	**97**	**390**
NLRC1 - Nurse Led Results Clinic	**99**	**93**	**101**	**97**	**390**
NLRC1 - Nurse Led Results Clinic	99	93	101	97	390
WALFORD01	**504**	**553**	**515**	**596**	**2168**
WALFORD02 - Neuro Oncology Telephone Clinic	**107**	**84**	**95**	**131**	**417**
WALFORD02 - Neuro Oncology Telephone Clinic	107	84	95	131	417
WALFORD03 - Neuro Oncology Telephone Clinic	**132**	**147**	**136**	**118**	**533**
WALFORD03 - Neuro Oncology Telephone Clinic	132	147	136	118	533
WALFORD04 - Neuro Oncology Telephone Clinic	**103**	**130**	**129**	**154**	**516**
WALFORD04 - Neuro Oncology Telephone Clinic	103	130	129	154	516
WALFORD05 - Neuro Oncology Telephone Clinic	**68**	**82**	**60**	**100**	**310**
WALFORD05 - Neuro Oncology Telephone Clinic	68	82	60	100	310
WALFORD06 - Nurse led Telephone Clinic	**94**	**110**	**95**	**93**	**392**
WALFORD06 - Nurse led Telephone Clinic	94	110	95	93	392
Grand Total	**1070**	**1436**	**1421**	**1937**	**5864**