Meeting of the *London Cancer* Brain and Spine pathway board

Date: Monday 10th June 2019, 14.00-15.30pm

Venue: Cancer Day 1, Queen's Hospital, Rom Valley Way, Romford, Essex, RM7 0AG

Chair: Edward McKintosh

1. Welcome and introductions and minutes from last meeting

- EM welcomed the group and introductions were made. A new patient representative, Gill Cuffaro was welcomed to the board
- Previous minutes signed off as true record.

2. Brain tumouR Information and Analysis Network (BRIAN) Database

- Due to unforeseen circumstances Shona from the Brain Tumour Charity was unable to attend the board.
- PS gave a short explanation of the BRIAN database. Patients can enter their treatment, tumour types, experiences, side-effects, decisions etc. This will give patients and clinicians a better understanding of the symptoms associated with treatments.
- Patients volunteer to share their data.
- There will be a public launch in September so the Brain Tumour Charity should be re-invited to present at that month's board.

ACTION – SE to arrange Brain Tumour Charity Presentation at the next board.

3. Reconfiguration

- EM informed members that NHS London have requested that Barts/BHRUT attend a meeting tomorrow re their proposed reconfiguration. Clinicians were not invited to this meeting (although will be to future meetings), instead Mark Johnson will represent Barts.
- The proposed plan is still to move all malignant craniotomies to Queen's Hospital. In the proposal, biopsies as a day case may subsequently be centralised at the Royal London Hospital as a unified day case biopsy pathway.
- Cost neutrality is an important consideration and movement of complex spine surgery from Romford to the Royal London is being considered, to balance the flow of cranial surgery towards Romford.
- In the proposal, meningiomas will be at managed at Queen's Hospital, Romford. There is no plan to change skull base/pituitary.
- EM acknowledged that the proposal is dependent on Barts/BHRUT surgeons and CNS being offered the infrastructure to work across both sites, i.e. to access patient records, book tests etc.
- Currently there are 5 CNS' across both hospitals. LT challenged whether this was sufficient. LT also queried whether patients will be assigned different CNS' across both hospitals and if so whether this would offer optimal patient experience? EM stated that the plan would be for patients to seen pre-op at Royal London,

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have surgery at Queen's Romford and then back at Royal London with results/follow up. Other than the single admission for surgery, there would be no changes in current clinic attendances.

- LT asked what the realistic timescale was for full implementation of the plan? EM thought the bulk could be complete in 1or 2 years. Achievement of the full vision for integration would be more like 5 years.
- It was noted that gateway 4 was due for completion in summer 2016. This is well overdue however it is unclear if any reconfiguration would need to restart at gateway 1 and whether the documents for the original reconfiguration were still relevant.
- Barts and BHRUT are to be invited to present plans to the August Collaborative board.

ACTION:

- EM to share an update from the NHSE meeting when he has spoken with from Barts senior management.
- EM to share slides that document proposal when appropriate.

4. MDT Audit

- LT, KG and EM confirmed that their respective Trusts are due to begin the 'live' MDT audit this week.
- In 5 weeks' time completed forms should be sent to SE who will analyse and present data in September.
- SE to send Trust specific results back to MDT leads for review and comment. Permission will then be requested to share further.

ACTION:

- Audits to be returned to SE in 5 weeks (with 4 weeks' worth of MDT data).

5. 2nd October Patient's Event

- The agenda for the 2nd October is now nearly finalised. Dr Mark Barrington, the chair of the psychosocial ERG, has recommended Dr Ronan Burke from NHNN to speak on anxiety and fear. The board agreed to go ahead with the invitation to Dr Burke.
- It was agreed that the sexual concerns talk should not be incorporated with a talk on fertility. Sexual concerns are a greater unmet need, fertility is covered in oncology outpatient appointments for those in whom it is relevant.
- In order to ensure that the speakers offer practical advice they should be asked to include a slide on key takeaway points.
- We are almost ready to release event communications. Those members that are on Twitter are asked to retweet publicity for the event.
- Charities will be invited to the event and asked to publicise via their comms channels.
- SE will update the poster will and send to Hospitals to put up in clinic.

ACTION:

- SE to send updated poster electronically and hard copies in the post.

6. NHNN/Queen's Hospital Pathology Service

- CO'R confirmed that the issue of BHRUT operating a suboptimal telepathology service with NHNN has been escalated via the Trust rick register.
- A new server is to be installed next week that should mean Queen's hospital's system can support telepathology.
- SB's opinion on the new effect of new server to be sought.
- NHNN still offering intraoperative diagnosis to BHRUT

ACTION

SE to request SB's opinion on the functioning of the new telepathology service

7. Community AHP Directory

- Patients commonly report a gap in support when they move into the community after hospital discharge. The board should consider how we can support patients to access services and help make clinicians aware of what is available.
- Obstacles to access discussed. Some rehab services will only see patients who have a prospect of recovery, others restrict access to low grade patients as they not clear if their diagnosis 'counts' as a cancer. LT suggested that patients could challenge these practices as discriminatory.
- GC noted that there are many local services run by charities and voluntary groups that arrange activities such as walks for patients and carers that whilst not directly related to treatment can be beneficial. Capturing these services should be included in any mapping.
- SC gave an update on the collaborative's work in this area. A company has been commissioned to map all the rehab services available in acute, community, palliative and hospice setting in London. Recommendations will be made for each London STP as to the rehab service gaps.
- A national database of services is being developed for AHPs and lead CNS'. Instructions for referring into community services will also be offered. The alliances have committed to updating the database.
- Barts have an Acute Neuro-rehab facility in place, applicable for those with cord compression and high grade gliomas. The facility was financed by Macmillan for 2 years, it has shown very positive outcomes for patients and can demonstrate significant savings. Therefore it is anticipated that Barts will continue funding when Macmillan support expires.

8. MRI Head Referrals

- The collaborative held a recent GP education event, at which the board was invited to contribute.
- SE and SK put together two slides giving advice to GPs explaining the rationale behind, and process of, referring for direct access MRIs.
  A high number of patients are being referred via 2ww to neuro-oncology clinics when they would be better served in neurology clinics. This is an inefficient use of resources and the unnecessary transfer across departments leads to poor patient experience. If an MRI head is performed before referral the GP could send the patient to the most appropriate department.
- Uptake may be low as GPs are reluctant to take on managing the result of the scan, hence referral straight to hospital. Concern also raised that GPs will routinely send patients with abnormal scans straight to A&E. Clearly there is a need to educate GPs how to manage results.
- LT suggested that we want as many relevant patients to have an MRI or CT, this is the only way to achieve earlier diagnosis.
- All CCGs bar City and Hackney commission InHealth to provide direct access MRI Heads. Some CCGs also offer their GPs the opportunity to refer to hospitals.
- InHealth have shared their referral data per CCG. There are variations but this may be caused by CCGs offering the Trust route.

ACTION – SE to request GP requested MRI Head data from Trusts

9. Recovery Package Statistics

- As the living with and beyond cancer lead for the collaborative SC has the remit to facilitate the implementation of the recovery package. SC is working particularly closely with breast, prostate and colorectal teams to introduce stratified follow up pathways.
- Data circulated is collected by CNS' who send onto their Trust recovery package managers who review and send onto SC. SC sends onto the analytics team at RM Partners.
- In the circulated data, the denominator used in ascertaining achievement is the new cancer diagnosis reported in cancer waiting times. If more HNAs are being performed than the recorded new diagnosis it is possible to achieve higher than 100%.
- Members think that RM partners statistics are significantly incorrect. These show rates of 300% completion for some metrics and 0% for others, neither of which seem very likely. Members were asked to contact

their recovery package manager to discuss how they can improve data collection. At UCLH the contact is Avril Van Der Loo, at BHRUT it is Lucy Brookes, at Barts it is Nicholas Wong.

- It is hard to define end of treatment in terms of when holistic needs assessments should be complete, with the metrics not necessarily matching the timings of what patients actually need. SC suggests that if there is no obvious end point to choose a point at which the patient will not be having treatment for the next few months.
- SC may soon have data on all HNAs given, regardless of the time point of delivery. This will include the resulting actions/interventions. The group is particularly keen to see this data if it can be broken down by tumour type.

ACTION – Members to discuss how to improve recovery package data collection with recovery package managers

10.AOB

- Clinical oncologists are holding a meeting to update their guidelines next week. Andy Elsmore is updating surgical guidelines.

11.Next Meeting

- Wednesday 18th September 2019, 2-4pm in Radiotherapy Seminar Room, Radiotherapy Department, Basement King George V Building, Barts hospital

ACTION LOG

Action reference	Action	Owner	Date Due	Status
Nov05	SW/SE to check if PS can attend an MDT meeting	SE	June	
Jan 01	SE to invite a BRIAN representative to talk to the board on potential of the database	SE	June	
Jun01	SE to arrange Brain Tumour Charity Presentation at the next board.	SE	Sept	
Jun02	EM to share an update from the NHSE meeting when he has spoken with from Barts senior management.	EM	Aug	
Jun03	EM to share slides that document proposal when appropriate.	EM	Aug	
Jun04	MDT Audits to be returned to SE in 5 weeks (with 4 weeks' worth of MDT data).	SE	July	
Jun 05	SE to send updated poster electronically and hard copies in the post.	SE	June	
Jun 06	SE to request GP requested MRI Head data from Trusts	SE	Sept	
Jun 07	Members to discuss how to improve recovery package data collection with recovery package managers	All	Sept	

Attendees

Name	Initials	Trust/Organisation
Edward McKintosh	EM	*London Cancer*

Name	Initials	Trust/Organisation
Babar Vaqas	VB	BHRUT
Cass O'Reilly	CoR	BHRUT
Gil Cuffaro	GC	Patient/Carer Representative
Kim Grove	KG	BHRUT
Lewis Thorne	LT	NHNN
Philip Scard	PS	Patient Representative
Rachel Lewis	RL	Barts Health
Sharon Cavanagh	SC	UCLH Cancer Collaborative
Simon Evans	SE	*London Cancer*

Apologies

Name	Initials	Trust/Organisation
Jane Evanson	JE	NHNN
Maggie Fitzgerald	MF	Mount Vernon
Naomi Fersht	NF	NHNN
Louise Dulley	LD	BHRUT
Sebastian Brandner	SB	NHNN
Louise Platt	LP	NHNN
Johnathan Martin	JM	NHNN
Jon Melbourne	JM	NHNN