

London Cancer Brain and Spine Pathway Board

Date: **Friday 5th October 2018, 09.30-11.00**

Venue: **West Meeting Room, 6th Floor Central, 250 Euston Road, NW1 2PG**

Chair: **Edward McKintosh, Pathway Director**

1. Welcome, Apologies and minutes of last meeting

- Members of the board were welcomed, introductions were made and apologies heard.
- The minutes of the last meeting were accepted as an accurate record of proceedings.

2. Stratified Follow Up

- Sharon Cavanagh Macmillan Integrated Cancer Lead gave an introduction to stratified follow.
- Stratified follow up enables a follow up pathway that is individualised to the patient. It requires empowering patients to manage their own care.
- Patients on stratified follow up either remain under the care of the MDT or are discharged to their GP who arrange follow up tests.
- Key elements that enable stratified follow up are education towards self-management, embedded recovery package and remote monitoring.
- Patients generally like stratified follow up as it limits return appointments in hospitals. Clinicians have capacity released.
- SC is looking to extend to rarer cancers having piloted stratified follow up in breast, colorectal and prostate.
- SC walked through the colorectal stratified follow pathway. Key milestones include patients' movement onto either face to face follow ups or supported self-management strata. In supported self-management clear processes for receiving test results are required. In the Colorectal example results are interpreted to patients by CNS'. Patients understand that there is a possibility they will receive results in person if there are significant findings.
- Systems have been piloted to ensure clinicians view reported scans, at the Whittington consultants are required to 'check-in' reports. It is hoped that stratified follow empowers patients' to chase their own scan results.
- The board feel acoustic neuroma and meningioma patients would benefit from this pathway, and would complement recent work such as new remote elements such as telephone clinics. However these patients would not be receiving the recovery package.
- The board acknowledged further work is required to embed the recovery package, in particular completion of HNA is low even accounting for acknowledged data collection issues. Indeed PS noted that he had not received a HNA since completing chemotherapy.

UCLH Cancer Collaborative brings together hospital trusts, GPs, health service commissioners, local authorities and patients across north and east London and west Essex.

- A working group will be established for implementing stratified follow up on a specific patient cohort. SC notes that she would be happy to chair.
- The working group should consider benign meningioma patients despite not being cancer the effect on patients is often no less devastating.
- Of relevance, 'my brain and me' to be added to the next agenda. Stratified follow up to be added as a standing item.

ACTION: Stratified Follow Up working group to be established.

3. Reconfiguration of Neuro-oncology Surgical Services

- EM confirmed that Barts and BHRUT wish to merge to serve the populations of North East London and West Essex. NHS London are considering the proposal.
- Prof Kathy Pritchard-Jones has confirmed that she wishes the Bart and BHRUT MDTs to amalgamate before Christmas.
- Service merger plans are at an early stage, EM will share with the board when appropriate.

4. Clinical Trials

- Sophie Morris, Senior Project Manager - MDT Improvement at the UCLH Cancer Collaborative explained that the genesis of the MDT improvement coaches lies in the MDT Improvement Report authored by Prof Muntzer Mughal and Jacob Goodman. This report contains some key recommendations around having clearly defined MDT roles (e.g. data lead) and a recruitment programme in place for MDT leads.
- 12 coaches comprising 4 CNS and 8 Consultants have been recruited. These coaches will go into 12 MDTs to act as a catalyst for change.
- In terms of baseline data SM recommends pragmatic and consistent methods such as extraction from existing MDT proformas.
- The programme is funded until March 2019, SM is hoping for funding to continue beyond this date.
- In our patch NHNN, Queen's in Romford, Barts Health all have MDTs. It is likely Mount Vernon also host an MDT.
- It was noted that an external view may see potential for change that someone deeply embedded in an MDT may miss.
- SM stressed that the role of the coach is to help MDTs identify what they want to change rather than direct the change.
- The unification of Barts/BRHUT MDTs is still at an early stage so are not yet in a place where coaching may be worthwhile. However EM is to let SM know in a few months if/when Barts/BHRUT are ready.
- The coaching is available from early November therefore board members were encouraged to get back in touch with SM ASAP if they are interested.

ACTION:

SM to contact Jeremy Rees and Paul Mullholland re whether UCLH wish to join the MDT improvement programme.

EM to send SE summary slide for further circulation

5. Patient Engagement Event

- Members were encouraged to attend the event. There are opportunities to meet patients' charities and our speakers.
- Members were also asked to encourage patients to attend. Similarly they should circulate the flyer to their MDTs.

6. Trials

- EM is considering approaching charities to fund a trials website which would easily allow patients and clinicians to look up available trials.
- SE suggested that the board view Dr Wai Keong's (a haematologist at UCLH) trials link website as an example of what can be achieved.

7. BRIAN Website

- Philip Scard introduced the BRIAN database, established by the Brains Trust.
- It enables patients to input symptoms and quality of life data related to treatments/trials they are currently on.
- The data is anonymous. This also means which hospital the patient is being treated at is not included.
- The board agreed this could be a very valuable tool for research and understanding patient experience. PS felt it may help patients understand when their tumours are likely to transform and the effectiveness of each treatment.
- EM will discuss the database further with the Brains Trust it may be something that should be routinely highlighted to patients.

8. AOB

- The board wish to have a further meeting before the end of the year. The date was set as 27th November 2-4. We would like to have a board at Queen's Romford. LD volunteered to help find a venue.

9. Next Meeting

- 27th November 2-4 venue tbc

TBC

Attendees

Name	Role	Trust/Organisation
Edward McKintosh	Chair & Neurosurgeon	Barts Health
Simon Evans	Project Manager	London Cancer
Phillip Scard	Patient Representative	
Sharon Cavanagh	Macmillan Integrated Care Programme Lead	UCLH CC
Jonathan Martin	Consultant in Palliative Medicine	UCLH
Louise Dulley	Oncologist	BHRUT

Name	Role	Trust/Organisation
Sophie Morris	Project Manager	UCLH CC
Kim Grove	CNS	BHRUT
Sebastien Brander	Pathologist	UCLH
Saloni Kapoor	GP	

Apologies

Name	Role	Trust/Organisation
Rachel Lewis	Oncologist	Barts Health
Louise Platt	AHP	UCLH
Naomi Fersht	Oncologist	UCLH