NHS

Peninsula Cancer Alliance

Meeting of the PCA Brain and CNS SSG

Thursday 22nd November 2018 (11:00-13:00)

Future Inns Hotel, Plymouth

FREEDOM OF INFORMATION

This group will observe the requirements of the Freedom of Information Act (2000) which allows a general right of access to recorded information including minutes of meetings, subject to specific exemptions. No one present today had any objections to their names being distributed in the minutes.

Chair: Paul Fewings
Consultant Neurosurgeon, University Hospitals Plymouth NHS Trust

Reference	DRAFT Notes
1.0	**Welcome and Introductions**
1.1	Please refer to separate record of attendance via this link.
1.2	The minutes of the meeting held on 10th May 2018 were considered;
1.3	**Matters Arising**
1.3.1	***Ref 2.7*** **(MDT Submissions)** PF has discussed MDT submission cut off times with radiology. Late submissions will be accepted; this is the right thing to do for the patient. It has been agreed that the MDT Coordinator and/or relevant Radiologist will be informed of all late submissions in order to allow relevant preparatory work to be undertaken prior to the MDTM.
1.3.2	***Ref 4.0*** **(SRS Cover)** It is acknowledged that there is no SRS cover when LL is on annual leave; however, this has not caused any detrimental impact to patients and/or the overall patient pathway.
1.3.3	***Refs 6.3 (MDT Outcomes)*** *GPs* do not automatically receive MDT outcomes, and there is a time lag from a patient being referred to the MDT and the patient being seen in clinic. This causes difficulties for GPs when patients seek advice and/or express their concern/anxieties during the intervening period as GPs' may not have any knowledge of the discussions/plan.
1.3.3.1	PF has discussed this with the Lead Cancer Nurse (SD) and it has been acknowledged that a lack of administrative capacity is the causative factor.
1.3.3.2	At present, all MDT outcomes are reported back to the referring clinician. The MDT coordinator is then tasked with identifying the email address of the patient's GP in order to forward communications. Difficulties often arise in establishing the correct email address.
1.3.3.3	It is acknowledged that patients are referred to the MDT via a number of settings so the solution needs to accommodate all possible entry points.

1.3.3.4 ED suggested that SJD (qFIT Project Manager) may be able to share a list of GP contact details for all surgeries in the Peninsula.

1.3.3.5 **Action**: NK to contact SJD and request this information to be shared with the MDT Coordinator at UHP.

1.3.3.6 **Action**: PF to discuss administrative barriers further with SD.

2.0 SSG Matters/Updates

2.1 Brain and CNS SSG Constitution

2.1.1 LD and NK to update the existing draft which will then be sent out to the group for comments.

2.2 Peninsula Brain and CNS Service Website update

2.2.1 The team is working towards the provision of a stand-alone website where information about the Brain and CNS service, as well as an information hub for patients can be facilitated. SM advised that he is awaiting an update on progress from the UHP IT department. Estimate costs of hosting and updating the portal have been obtained and are very reasonable.

2.2.2 The CNSs have prepared content and it is hoped that the website will be up and running within the next 6 months. An update will be provided at the next meeting.

3.0 MDTs

3.1 NK provided a short update to the group on the current NHSE MDT pilot project led by Professor Martin Gore. For further information, please follow this link to a short presentation.

3.2 MDT Streamlining-discussion

3.2.1 The group were of the view that the MDT at Derriford (DH) is efficient and that the suggested reforms are not particularly relevant to their patient cohorts.

3.2.2 PF was of the view that the validated MDT tool (as presented by Dr Tayana Soukup at a recent Pan-Peninsula MDT event) would not be particularly helpful as the data set would not adequately reflect the quality of decision making for some of the disease processes.

3.2.3 Overall, the running of the MDT is going very well and attendance has increased since last year. Dr McCormack has previously voiced concern that clinicians who are not visible on the screen, may be inadvertently left out of discussions.

3.2.4 Neurologists in Exeter have expressed their desire to attend the MDT, however, the timing and location is not ideal. If Exeter patients could be discussed at the beginning they would be able to come. PF suggested that Exeter patients could be discussed at 08:45.

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3.2.5. **Action**: LD to propose this and if in agreement, this could be trialled to see if attendance improves.

3.2.6 The MDTM is frequently overrunning; the room booking needs to be extended until at least 10:30.

Action: Megan Stacey (UHP MDT Co-ordinator to action this request).

3.2.7 MDT outcomes are usually available in 24 hrs for inpatients and 5 working days for outpatients. MDT coordinators undertake live typing during the meeting and this is helping to speed up the process.

4.0 Clinical Guidelines

4.1 NICE Guidance (NG 99): *"Brain tumours (primary) and brain metastases in adults (July 2018)"*

4.1.2 Follow-up scanning for incidental findings of meningioma's that could be potentially high grade or dural base metastases would usually be undertaken at 3 months, followed by yearly surveillance.

4.1.3 NG99 scanning recommendations for incidental meningioma's are at 1 year and 5 years. There is however no evidence base for this recommendation.

4.1.4 **Action**: PF will ask one of the SpRs to undertake a retrospective audit looking at the last 5 years of data for surveillance patients to ascertain how many patients went on to have SRS/interventions within 5 years.

4.1.5 The SSG have agreed that NG99 guidance for surveillance imaging of incidental meningioma's will not be followed. This decision will be reviewed once audit data has been collected, analysed and presented.

4.2 **Patient Pathways**

4.1 PF will follow-up on the outstanding patient pathways;

- Acoustic pathway
- Pituitary pathway (follow-up information needs updating)
- Unknown primary pathway
- Lymphoma pathway

4.1.1 **Actions**:

PF to action the above.

JF to document a rehab pathway.

NK/LD to circulate the pathways for final comments when ready.

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5.0 **Audit**

5.1.1 In addition to the suggested surveillance scanning audit (ref 4.1.4), LL proposed an audit looking at meningioma SRS; atypical vs grade 1.

5.2 RW (Charity Representative) highlighted that waiting times for scans (for patients on surveillance) are very long; this can cause great anxiety for patients. There is a need to identify if there are any avoidable reasons for the delays.

6.0 **Peer Review**

6.1 DH hold monthly M&M meetings, patients for discussion usually arise from trauma, not cancer diagnoses. If a cancer patient is discussed at the M&M, this will be flagged to LD and TM to document.

6.1.1 The hospital has a robust self-assessment process in place.

7.0 **Research Update**:

7.1 DH relayed apologies from Oliver Hanemann.

7.2 The team remains active in research participation and support the medical school which is funded as a National centre of excellence for brain tumours. Support is also given to Brain UK and cases are also submitted to National studies.

7.3 The MOT study suffered a set-back due to a lack of consenting, however, the study is about to re-start.

7.4 It is hoped that a link on the proposed new website will enable information about research to be shared more easily.

7.5 The 100,000 genomes project comes to an end in December 18. As of October 2018, genomic testing for the South West is being undertaken by the SW regional hub (based in Bristol); there is also a new test directory.

7.5.1 Availability of whole genome sequencing will initially be for sarcoma, paeds and haematology.

8.0 ***Brain Tumour Support***

8.1 David Haq provided the group with valuable insight as to his role at Brain Tumour Support and the type of help that can be provided by the charity.

8.2 Firstly, David wished to express thanks on behalf of the patients he has met who have voiced their gratitude for the care they have received from the Peninsula neuro-oncology staff.

8.3 Referrals usually come from the CNS team, with a few self-referrals. Initial contact is typically by made by telephone, followed by a face to face meeting to better understand the situation of the patient/family.

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8.4 Patients are often anxious and family members frequently described feeling useless, with limited coping strategies. Examples of difficulties that commonly present include relationship problems/family dysfunction, difficulties adapting to a loss of career/change in routine, and a decline in mental health.

8.5 David's post is jointly funded by Macmillan and Brain Tumour Support. The charity provides direct support to patients and their families throughout their journey. There are 3 support groups in Devon; Plymouth, Truro and Exeter.

8.6 LD expressed thanks on behalf of the team for the great work that David does to support the CNS team and patients in the community.

9.0 Service Delivery

9.1 ***Staffing***

9.1.1 The CNS team at DH is currently down 1 CNS (0.6 WTE) due to sickness absence. LD continues to provide support to patients in Exeter, however it is becoming increasingly challenging to manage the work load. Requests for support from the Peninsula Trusts have previously been made.

9.1.2 Exeter clinicians have noticed an unusual number of oncology referrals from Bristol, due to a shortage of Consultant Oncologists in Bristol.

9.1.3 Concerns were raised about the waiting times for patients to see an Oncologist at RCH (only 1 new patient appointment/week). PF emphasised the need for a triage process for booking patients and to ensure the matter is placed on the risk register.

9.1.4 A support worker has joined the team at DH to help with health needs assessments. The neurosurgical ward also had a new band 7 nurse with a 2nd band 7 due to join the team shortly and the ward will also see an increase in the number of band 6 nurses.

9.2 ***Gliolan***

- LD is looking at the process of how unused Gliolan product is returned to Pharmacy for re-issue.
- LD has requested that Gliolan is added to the surgical list.
- Coding needs to be clarified to ensure that payments are received.
- Ward staff require training on the administration of the product LD coordinating this training with pharmacy and CNS team.
- Patient information leaflet has been drafted

9.3 ***IT***

LL has encountered challenges arising from new IT software not interacting efficiently with the servers. Whilst this has resulted in an increase in time spent on planning treatment, it has not adversely affected patient care.

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9.4 **2ww referral forms**

9.4.1 ED asked for clarification as to the referral process for patients with radiological evidence of a brain tumour following a GP requested MRI scan.

9.4.2 PF advised that the radiology report includes a link which activates an email to the MDT coordinator, who then sends a referral form out to the GP.

9.4.3 ED suggested that the Devon CCGs could host the referral form for all Devon GPs via the online formulary.

Addendum:

9.4.4 LL sent email clarification of the 2ww referral process:

1. An incidental finding of a tumour on a scan performed at the request of the GP: the report contains the email address and other contact details for cancer services. It is up to the GP to action this. Radiology does not alert cancer services. We would usually ask our secretaries to alert the GP surgery to the unexpected finding on the report. They can then use ICE to make a referral to cancer services (and tick a box to say they have already had a scan so that another MRI request isn't generated).

2. If the GP makes a 2WW referral from ICE this automatically makes a referral to cancer services on the requisite form (via an email) and generates an MRI request. Cancer services then track the referral and the report. If the report shows a tumour it goes on the next MDT as it has already been referred.

10.0 **Service Updates**

10.1 ***Derriford***

10.1.1 A skull base nurse has been in place for the last 6 months and CNS led clinics started last week (for grade 1 acoustic neuroma patients). The service will continue to develop.

10.2 JF: funding has been secured for a physiotherapy pilot project and interviews for this post commence next week. The focus will be on shortening the inpatient stay for high grade glioma patients by bridging the gap in services between primary and secondary care. It is hoped that a more timely discharge home will increase quality of life for patients.

11.0 **AOB**

11.1 LD: would like to host an educational evening on high grade tumours for GPs/professionals. Further details to follow in due course.

11.2 Discussions about SCR have been pended over to next meeting.

13.0 **Date of Next Meeting**

13.1 *Thursday 16th May 2019 (10:30-13:00), details to be circulated in due course.*

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