Peninsula Cancer Alliance

Meeting of the PCA Brain and CNS SSG

Thursday 16th May 2019 (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.

Stand in Chair: Mr Samiul Muquit
Consultant Neurosurgeon, University Hospitals Plymouth

Reference	DRAFT Notes
1.0	**Welcome and Introductions**
1.2	Please refer to separate record of attendance via this link.
1.3	The minutes of the meeting held on Thursday 22nd November 2018 were considered.
2.0	**Matters Arising**
2.1	(Ref: 1.3.3) the group discussed the need for information to be disseminated to GPs in a timely matter.
2.1.1	ACTION: PCA to contact the CCG's to see if there are any definitive contact lists for GPs (i.e. not just the practice manager addresses)
2.2	(Ref: 2.2) Work is still in progress concerning the website.
2.2.1	ACTION: LD and colleagues to chase up on this
2.3	(Ref: 3.2) The plan was for the Exeter neurologists to attend the MDT at the beginning of the list but this could not be facilitated. Fiona Minear will return to post on the 3rd June and it is hoped that her schedule could work around this.
2.4	(Ref :3.2.6) MDT meetings are no longer overrunning as the meeting time has been extended.
2.5	Patient Pathways An update was given on the patient pathways (Ref: 4.2) • Pituitary pathway requires updating. SM to action. • Unknown primary/ Lymphoma ACTION: LD and PF to work on this

- Acoustic pathway
  ACTION : Tracey Mason (skull Base Nurse) to follow up

2.6 (Ref:4.1.1)JF informed the group that work is underway on the rehab pathway. Kate Sheen (physiotherapist is now in post and there is a variety of patient pathways. The team are working on ensuring that the pathways are more robust.

3.0 **Early Diagnosis of Brain Tumours**

3.1 The team are looking at running a GP to provide information on how to recognise early symptoms/ signs of possible tumour diagnosis.

3.2 The team agreed that it would be helpful to audit late diagnosis in order to identify where there are opportunities to identify signs/ symptom earlier. It is not uncommon in skull base tumours for patients to have a significant wait until they are referred for a scan. The delay has been identified in primary care, before the GP has referred the patient into hospital.

3.2.1 ACTION: SM to find out what audit support/ funds are available to make this work.

4.0 **CNS Service update**

4.1 LD provided the group with an update on the CNS service.

4.2 The full team is now back, with job shares for Torbay, Cornwall and Plymouth. LD is currently heading up the Exeter and North Devon team.

4.3 Cornwall is looking into funding a full time CNS Neuro/CUP with the hope that this post will be filled in the autumn, Macmillan funded for 3 years. Local CNS team will need to look at how this will work alongside the current service.

4.4 Taunton patients are currently being referred to Exeter for oncological treatment, however they are not supported by the CNS service due to lack of capacity/ funding. This is being addressed by the Exeter service.

4.4.1 ACTION: UHP MDT to liaise with Anne McCormack at Exeter to review possible options.

4.5 End of treatment Summaries are a generic proforma that will be used to explain the treatments received by patients and inform re potential side effects/toxicities of oncology treatments to GPs. It will also inform GPs on how to re access services should they need to. Note oncology patients are not discharged.

5.0 **Physiotherapy Pilot**

5.1 JF provided the group with an update

5.2 The service (offered to patients with high-grade tumours) seems to be going really well. Kate has picked up 14 patients (a mixture of referrals and patients

in the acute setting). There have been 33 “face to face” contacts. Audit data has also been collected pre and post the new service being set up.

5.3 Educational work with collaborating service providers (e.g. hospices) is required to ensure that patients with malignancies on a palliative care pathway are provided appropriate rehab to improve quality of life and ensure that teams are working collaboratively to maximise patient outcome.

5.4 Kate is helping patients to get home quicker, with the right package of support in place; it has already been recognised that it would be helpful to have an occupational therapist to further enhance this service.

6.0 **Update from the Brain Tumour Support**

6.1 Rosemary Wormington and David Haq provided the group with an update on their charity work.

6.2 A recent H&WB event took place in Truro organised by the BTS charity. The purpose of the event was to ensure that patients have information about accessing services in their area. Over 40 people attended the 4-hour session, which had a broad range of organisations in attendance. The event was support by the CNS team, which was beneficial.

6.2.1 Future events are planned for Plymouth and Exeter

6.3 A patient and family event was also hosted in March with 150 attendees made up of clinicians/ patients/families. The event was very holistic with a lot of support and educational content provided.

7.0 **Research and Audit**

7.1 Jason (SpR) is working on an audit project looking at incidental meningioma’s.

7.2 The time from surgery to the first MRI has been previously audited but this is being repeated.

7.3 David Hilton is looking at DNA tumour cells.

7.4 Recruitment for the MOT study is suboptimal as not enough patients are being identified and consented to join it, this has been due to changes in the consent team.

8.0 **AOB**

8.1 Date of next meeting to be confirmed.

8.1.1 ACTION: PCA to liaise with LD and PF regarding the next meeting date.

-END-

.