

## Meeting of the PCA Brain and CNS SSG

Thursday 14<sup>th</sup> November 2019 (10:30-12:30)

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 Paul Fewings

Consultant Neurosurgeon, University Hospitals Plymouth

# Reference DRAFT Notes

- 1.0Welcome and Introductions
- 1.2 Please refer to the separate record of attendance via the SWCN website.
- 1.3 The group considered the minutes of the meeting held on Thursday 16th May 2019.

## 2.0 Matters Arising

- 2.1 (Ref: 2.1.1) ED explained that there is a list of GP contacts but these are difficult to obtain from the CCG as the list is frequently changing.
- 2.1.1 PF explained that when a consultant refers a patient, the MDT outcome to the referring consultant is returned but not to the patients GP. In order to send the outcome the MDT Coordinator is required to search for patients GP details. This is challenging where a patient is not from Plymouth. Routinely this is not happening but the team feels that patients GPs should be notified.
- Plymouth has recently updated their SCR system and are exploring the
   possibility of generating an MDT letter to ensure GPs are receiving outcomes. This would not solve the problem for other trusts and may mean that when these patients are referred they will need entry onto the registry.
- ACTION: ED will go back and try to get access to a contact list. She
   2.1.3 confirmed that this would be the practice manager's address and not addresses for individual GPs. She will also explore getting the contacts from the FIT labs.
- 2.1.4 ACTION: JM to ensure that patients referred to MDT that are not Plymouth patients, are imputed onto the SCR system.



- 22 (Ref: 2.2) Website work is still in progress. Staff changes have meant that Vicky Edwards has taken the lead, but she has made clear that it is not a priority. Helen has completed all the work and the leaflets are ready to go.
- 2.3 (Ref: 2.3) The MDT is generally overrunning but this is accepted and running between 8:30-10:30. Exeter Neurologists attend the medical school on a Thursday and would join the MDT but room issues prevent this.
- 2.4 PF recently attended a meeting on MDT efficiency but feels that the current MDT is running well and it is relatively small in comparison to other tumour sites.

#### 3.0 **Patient Pathways**

- 3.1 Final Drafts of pathways are completed and requiring sign off.
- 3.2 ACTION: once signed off BK to upload final pathways onto the SWCN website in order for clinicians to access.
- 3.3 Kate Sheen (Rehabilitation Physio) is mapping a rehab pathway.

#### 4.0 Early Diagnosis of Brain Tumours

- 4.1 (Ref: 3.0) The teams are still looking into running a GP evening to provide education on recognising early symptoms of brain tumours and are hoping to take this forward in the new year.
- 4.2 PF has asked each member to note any late diagnosed patients at MDT in order to audit. Registrars need to be aware as an on call referral will mean that they will be first to pick up these patients.
- 4.3 The group accepted that in order to find tumours earlier, more people need scanning, which is not practical with current resources v the potential pick up rate.
- 4.4 TB explained that by definition, late diagnosed patients present symptoms late, which adds to the difficulty. TB would like to look at providing regional teaching sessions, to guide clinicians.
- 4.4.1 **ACTION:** TB to look at taking this forward.
- 4.5 The group identified that behavioural or psychiatric changes can be a missed symptom. Where a patient presents with such symptoms it can be very easy to follow the mental health route.

#### 5.0 **CNS Service Update**

- 5.1 The CNS team is 0.6 hours down for the foreseeable.
- 5.2 The team are no longer attending Cornwall as they have handed back the oncology services to the new Brain CNS Wendy Dryer.



- 5.3 An advert for a Band 4 support worker role is going out and someone should be in post before Christmas.
- 5.4 LD is currently piloting HWBC in Exeter. Patient surveys have now been sent and results are due back.

#### 6.0 **Physio Update**

7.0

8.0

- 6.1 Kate Sheen has been given an extra year of funding for her oncology pilot.
- 6.2 KS is working closely with St Luke's Hospice to help them understand the role of AHP's and rehab.
- 6.3 KS is beginning to collate data for the year. Feedback has been subjective but demonstrates a difference made to patient's quality of life.

#### Update from the Brain Tumour Support

- Rosemary welcomes Julie to the group who has taken over David as therepresentative in Cornwall.
- H&WB Events are on hold until there is a new band 4 support worker in place.

#### MDT Referral Process – Refer a Patient

- 8.1 The team have identified that often they are capturing sub-optimal
  information on referrals with the onus on the referrer to provide the information on databases.
- 8.2 The group worked through an example on refer a patient (www.referapatient.org) and discussed its implementation into their current systems.
- 8..3 Cancer Services Admin fear that an additional system alongside multiple systems already in place could mean that work would be duplicated. The group agreed that this system would work extremely well for on call and better for referring back to centres/clinicians but it is something that they cannot adopt now.
- 8.4 JM explained that they would continue to look at generated MDT letters from SCR to provide uniformity in the systems as multiple systems and to avoid errors.
- 8.5 JM and team are exploring the possibility of a shared drive containing all MDT outcomes that all clinicians can access.

#### 9.0 **AOB**

9.1 PF welcomed Titus Berei as the new MDT Lead and SSG chair. The group thanked Paul for chairing the group for the last few years.



9.2 ACTION: BK to liaise with TB and LD about the next meeting date due in May.

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