

Brain and CNS Patient experience meeting minutes

Date of Meeting 17th June 2016
Time of meeting 11.00hrs – 12.30hrs
Venue Seminar Room 6, Mayo Building, SRFT

- 1. Welcome, Introduction and apologies** Catherine McBain
Apologies - Joe Morrison
- 2. Minutes of last meeting** Rebecca Price
Accepted
- 3. Patient Engagement Group** Lucie Francis
Update on the formation of the Brain and CNS small community / Discussion of the role of and support for patient and carer reps

LF circulated a document to outline some of the work her and her team had been doing thus far.

A small community had been formed and met 2 times to date.

1st meeting Catherine and Julie attended to brief the small community on what to expect from the board.

2nd meeting was to nominate a patient rep to attend the pathway board.

The idea behind this is for said patient rep to attend all meetings on behalf of the small community and act as a link between the board and the patient group, giving feedback from both sides.

Lucie explained this was a new and innovative way of using patient involvement to help to contribute to the work of the board. The board thanked the patient reps for their time and continued commitment to the board.

The board discussed the issue of the best way to engage with patients in clinic to inform them of the patient group and the work they are doing. Patient information leaflets had already been created by Lucie, Julie and Li but felt the uptake of this was fairly poor. The group agreed that it would still be advantageous to push on with circulating these leaflets to patients in follow up clinics rather than those undergoing active treatment or having been given a new diagnosis.

The board also discussed the creation of a clinical terminology 'jargon buster' which the board agreed to help work with Lucie the patient reps to devise.

User involvement awareness session 7/7/16 or 20/9/16: attendees?

LF to find out who can attend this and get back to CMB to inform the board. CMB has registered to attend on 20/9/16.

4. Macmillan Living With And Beyond Cancer Survivorship Grants

- i) Holistic needs assessment in primary CNS tumours and design of health and well-being event

Hester Benson (HB) explained the rationale behind the project. The project is currently in the last month of data collection of the 6 month collection timeframe.

Julie Emerson (JE) explained that the survey takes on average between 20-40 minutes to complete for patients in clinic. The board's nursing members explained that they had recognised there was a need for this to be completed with a nurse present as this would help with ensuring the form was fully explained and the patient felt supported whilst answering each question. The Patient reps felt that they would be happy to

complete this independently, but with the support of a nurse nearby for reassurance, eg in a clinic waiting room.

The aim of the data collection is to better inform the board of areas of need to address at the patient health and wellbeing event as well as ascertaining the areas of greatest need for different patient groups and considering how these might be assessed and addressed in the future, after this project ends. There was a short discussion about the health and well-being event, such as location, content, date to hold the event, length of the event itself, which Hester will continue with the small community.

Hester posed the option of the Maggie's centre being a viable option for location; patient reps concurred. Feedback from the patient reps showed that familiarity of locations key, this will help with patients planning of journey time eliminating the stress of finding the venue also.

The next steps for this project were briefly discussed as it was identified that a practical way forward should be agreed on whether to continue collecting this data post the close of this project.

Overview including formal title, potential publication plans and possible adoption into routine practice were discussed and agreed to be finalised at a later date. HB agreed to attend a Patient small community meeting to gain feedback on what patients feel the direction of this project should take.

ii) Brain metastases education project

Update of results so far - Hester Benson (HB) explained the rationale behind the project. Questionnaire was sent out to clinical staff aimed around identifying educational needs or gaps in learning that they felt they would benefit from having addressed. .

Following on from this on 8th July 2016, a free Brain Metastases Educational Day will be held at The Christie, specifically aimed at addressing the areas of greatest educational need identified in the survey results. More than 100 people have so far registered for this event.

Plans for project continuation will be discussed at a later date due to limited time in the meeting.

5. Peer Review Reports 2015-16: Internal validation issues and work plan goals relating to this group

JE, SC and AW briefly talked the board through the work plans of the Network, Neuro-oncology and skull base MDTs respectively for the next 12 months, as well as any relevant internal validation reports for the last 12 months.

MDT attendance appeared to be one of the areas that was lacking in completeness.

AW highlighted the concern highlighted in the Skull Base MDT peer review report which was that as she was the only nurse running this service and this presented problems if ever she was on leave with continuity of service not being upheld.

6. Manchester Cancer Annual Report and 2016-17 work plan

Catherine McBain

CMB informed the board that as she had now received the groups MDT peer review reports she would begin to incorporate these into the Manchester cancer annual report.

The Report and annual plan will be available on the Manchester Cancer website in July 2016.

7. Patient held records – blue book project

Julie Emerson

JE explained the rationale around introducing 'blue books' into routine Brain and CNS care.

The books are intended to be given to each patient for them to hold a record of their care plan and treatment undergone throughout their care journey. Not unlike those given to expectant mothers when

*under the care of maternity services, the aim of the books is to keep every patient informed on their care plans and their diagnosis by recording key information within the book itself.
Patient feedback was positive as they felt that this would be a useful and informative document that may help with clarifying part of the patients care to others should they need to do so. Eg if the patient needed to provide key information regarding their care to the emergency services.*

The group agreed it would be advantageous to take this idea to the small community group to gain greater feedback on how to develop this.

8. AOB

none

9. Date and time of next meeting

September 23rd 2016 - 11:00 – 12:30 – Seminar room 10 – Mayo building.(srft)

January 27th 2017 11:00 – 12:30 – room to be booked (srft)