

Manchester Cancer

Brain & CNS patient experience group minutes

Date of Meeting 19th June 2015
Time of meeting 10.45hrs – 11.45hrs
Venue Meeting room2, Mayo building, SRFT

Members present

Dr Catherine McBain (Chair)	Julie Emerson	Alison Gilston-Hope
Sara Robson	Elizabeth Molloy	Sarah Cundliffe
Nicola Martin		

Apologies

Andrea Wadeson	Dr Gemma Walls	Charlotte Stackhouse
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In attendance

James Leighton – Manchester Cancer Michelle Leach – Manchester Cancer

Welcome, introductions and apologies

Dr McBain (CMcB) welcomed all to the meeting and noted the apologies received.

Minutes for the last meeting and matters arising

These were adopted as an accurate record of the meeting and the matters arising were –

(i) Blue book project

Julie Emerson (JE) provided the group with an update on the progress of the project to roll out the patient held record (Blue book). She confirmed that a shared drive had been set up on the Salford system which will be used to record the names of patients that receive the patient held record.

CMcB confirmed that the record is currently being piloted with high grade disease patients but will now be made available to all grades of the disease. The intention was to have the 200 records distributed evenly between the patients having high and low grade disease.

There followed a discussion on how the patient held record was being used and received by patients and staff. JL agreed to contact the pathway manager for the acute oncology board about promoting its use.

Action – JL to send an information sheet to the Acute Oncology pathway board

Patient involvement and support in practice

Michelle Leach(ML), the nominated user involvement manager for the Brain board outlined her role and how her work would complement and support the work of the board and PEG. She explained that the work of the user involvement team will be to develop a network of service users and widen the type of patients that are currently being recruited to the pathway boards.

ML asked that if any board members identified a potential user that they send her the details of the users and she will undertake the follow up conversation.

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CMcB mentioned that there was a patient support group in existence and that she felt it would be good to build a relationship with this group. She agreed to pass the contact details onto ML.

Action – CMcB to send Sue Wigglesworth contact details to ML

3. Peer review feedback and issues raised

The group discussed the completion of the recent round of peer review self-assessment. CMcB confirmed that largely it had been a positive experience. However she raised the issue that again the reviewers did not recognise the pathway board as a suitable network group. JL agreed to discuss this with Manchester Cancer and the reviewing team.

Action – JL to reinforce the status of the Pathway board as the network group for the purposes of peer review.

Action – CMcB and JE agreed to send the peer review reports to JL for the annual report

4. Patient satisfaction surveys -results and future plans

JL confirmed that there would be no national patient satisfaction survey undertaken this year. Therefore any assessment would be done at a local level. Sarah Cundliffe (SC) confirmed that a local survey had been drafted and was ready to be sent out as soon as a number of logistical issues were addressed.

5. 2015/16 Work plan and goals for the group

The group felt that the living with and beyond innovation group would form the bulk of the work for the coming year. However CMcB asked that the work programmes following peer review was collated and brought to the next group.

Action – JL to collate work programme from each MDT and table at the next PEG meeting for review

Patient concerns thermometer was now available on the CWP system at the Christie and this was now available to be used. This was felt to be a resource for the group as the data can now be interrogated.

Liz Molloy (LM) discussed an issue raised at the network MDT and the support for patients with high grade tumours with young families. The meeting felt that the available support for these patients and their families was not known. As a consequence Dr Walls (GW) agreed to scope out the available support for the group and report back at a future meeting.

ML informed the group that there may be a Macmillan on-line portal based at UHSM that could signpost patients to available support. She agreed to follow this up on behalf of the group.

Action – GW to identify the available support for high grade tumour patients with young families

Action – ML to investigate the on-line portal based at UHSM

6. AOB

- Update on survivorship grants

JE and Sara Robson (SR) provided an update on both of the successful bids. They confirmed that the project manager post had been approved for recruitment and could now go to advert. This will be progressed over the next few weeks. JL agreed to post on the Manchester Cancer website.

Action - JL to post recruitment advert on Manchester Cancer website

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7. Time & date of next meetings

Board 22nd September 2015

SMG 17th November 2015

PEG - 11th December 2015