

Manchester Cancer

Brain & CNS patient experience group minutes

Date of Meeting 27th February 2015
Time of meeting 10.45hrs – 11.45hrs
Venue Seminar room 8, Mayo building, SRFT

In attendance

Dr Catherine McBain - Chair

Julie Emerson

Helen

Sara Robson

Andrea Wadeson

Elizabeth Molloy

Sarah Cundliffe

James Leighton – Manchester Cancer

2. Introduction, background, format & Purpose of meetings

Dr McBain chaired the meeting and welcomed all to the inaugural meeting. She informed the group how this meeting would help address the overall agenda of the pathway board and the wider agenda of Manchester Cancer.

2. Examples of improving patient experience in practice:

a) Blue book project

Julie Emerson provided the group with an update on the progress of the project to roll out the patient held record (Blue book).

She informed the group on how the document was developed, what it contained and the level of patient involvement that took place. It was first used for high risk patients in October 14 and so far 44 books had been given out.

Since December there has been a process of patient staff engagement to remind those involved on the purpose and usefulness of the book. Julie also outlined a recent audit that was undertaken. This involved 19 patients and reported that –

- 2 patients of the 19 did not recall getting the books (they are given out at time of diagnosis)
- 7 patients reported that Christie staff had asked for it
- 1 reported that it was asked for at another site
- 5 said they had not used it
- With regard to the information contained within, none felt that there was any missing information
- Overall most patients found it to be useful

Feedback and issues raised by the audit –

- Patients felt the book would be better to be given out pre-surgery
- The seizure diary was felt by patients to be very useful
- There was a mixed response to the “My record “section which allowed the patient to reflect on their disease
- Some of the younger patients preferred to keep information electronically rather than on paper

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Next steps for the Blue book

Develop a version for the low-grade patients.

Funding is via charity donation and this could be issue in the future.

Undertake more feedback in 6 months' time.

JE then confirmed that whilst the service found it to be useful, it's use now needed to be embedded with patients. She suggested during 2 week follow-up calls and radiotherapy sessions, staff should ask to see the blue book as a way of reinforcing its significance.

The group then had a discussion on which other patient types this could be distributed to. AW suggested seeking the views of meningioma and base of skull patients on its use in their care. CMcB suggested that following the discussion it would be useful to set out the actions suggested as a plan for taking this initiative forward.

Action - JE and AW agreed to set out criteria for selecting other patient groups for a wider roll out

b) Piloting a holistic assessment tool in the clinic

Sarah Cundliffe (SC) provided a presentation of her Masters dissertation on the use of a holistic assessment tool in an out-patient clinic. She outlined that primary brain tumour patients underwent a range of psychological states once diagnosed and that there was no measurement undertaken of the affect to the patient of the change in emotional status.

Her research was to assess how acceptable and feasible the health needs assessment tool would be to staff and patients. The assessment comprised a distress thermometer, a quality of life assessment tool and a brain tumour specific questionnaire all of which are in extensive use in clinical trials currently.

The patients selected were 40 diagnosed gliomas patients selected and introduced the questionnaire at the pre-op and post-op stages as well as two-week telephone follow-up.

Feedback and issues raised by the audit

- 97% of patients reported that they found it useful to complete the questionnaire
- 53% reported that it encouraged them to talk more about their emotional state
- 66% felt that it help them address unreported problems

She also reported that there was a similar level of feedback on the acceptance of the tool from nursing staff. Her dissertation concluded that it was useful and acceptable to patients and staff.

She reported that currently it is not given out to all patients post –operatively. That the nursing staff makes a judgement on which patient would benefit from its use. There followed a discussion on how best to select patients and target the use of the tool.

3. **Update on survivorship grants**

CMcB provided an update on the two applications to the Macmillan innovation fund for living with and beyond cancer projects.

JL confirmed the timescales for deciding the successful bids.

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4. Patient satisfaction surveys -results and future plans

This was deferred until the next meeting.

5. Work plan and goals for the group

The group felt that this was a useful meeting and a good way of supporting the cancer agenda. They agreed to meet 3 times per year and that the next meeting would be in June 19th.

There was also a discussion on membership of the group and suggested that there should be patient representation included in this group. Other nominated members were the specialist radiographer and the treatment review team at Christie and Salford, the Salford acute oncology specialist nursing team and the epilepsy nursing team.

Action – CmcB agreed to invite a nominated patient representative to the next meeting.

Action – JL to contact those nominated and invite to the next meeting.

6. AOB

There was no other business

7. Time & date of next meeting

19th June 2015 10.45 – 11.45 Seminar room 8, Mayo Building, SRFT

11th December 2015