

# Manchester Cancer

## Brain & CNS patient experience group minutes

**Date of Meeting** 15<sup>th</sup> January 2016  
**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
Hester Benson		
Nicola Martin		

### In attendance

Rebecca Price – Manchester Cancer      Lucie Francis – 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

Agreed as an accurate record.

#### 1. Format of the BPEG / aims of future meetings

The board discussed the current format of the BPEG meetings, Core members and possible change in frequency. It was agreed that the group would meet formally twice a year. The same group will meet at to attend **\*\*\*Catherine to insert details of the 3 meetings, months and meeting titles.\*\*\***

#### 2. Supportive care MDT / BPEG Programme update

HB explained the premise of the project which is to undertake a Holistic needs assessment (HNA) with every patient diagnosed with tumours of any grade, managed through any part of the brain and CNS service. The purpose is to gain an overview, quantifying the magnitude of needs of different types and assess how this varies with patient group and diagnosis. This work is including all patients diagnosed from 1/1/16 until 30/6/10 and is well underway. The results will be used to develop our survivorship programme including information packages and health and well-being events.

She went onto explain the premise of the second LWBC project which is to support non-neuro-oncology health care professionals involved in managing and supporting patients with brain metastases. The number of patients developing brain metastases is increasing; the treatment they receive increasingly includes combinations of surgery, stereotactic radiosurgery and whole-brain radiotherapy and more patients are living for longer. Their

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care remains predominantly with their site-specialised teams e.g. breast, lung or community teams who often do not feel well-equipped to assess, manage or support neurological problems and can be unsure who and when to refer on. This work is beginning by undertaking a detailed questionnaire survey to gauge educational needs and then use that information to develop an educational programme, aimed initially at staff but potentially extending to patients, to address that.

### iii) Improving links with pituitary team

b) Patient satisfaction

c) Audit

d) Research

### 3. Cancer Network MDT Peer review

### 4. Patient involvement - Proposed future plan

LF expressed her ambitions for the board for the upcoming year in regards to User involvement. She went on to explain that she had been in contact with a number of PaBC and was currently reviewing their suitability for the board or other outside projects. LF has agreed to work with JE and Liz Molloy to redesign the patient information leaflets and possibly create more hand outs for the CNS's to use to better inform patients.

5. **AOB**

7. **Time & date of next meetings**

**Board - 03<sup>rd</sup> May 2016 1:30PM SRFT**

**SMG - 19<sup>th</sup> April 2016 - 8am SRFT**

**BPEG – 17<sup>th</sup> June 2016 – 11am SRFT**