

Date of Meeting 23<sup>rd</sup> September 2016  
 Time of meeting 12:00 – 13:30  
 Venue Meeting room 10 - 2nd floor - SRFT Mayo

**Apologies:**

Andrea Wadeson Rebecca Price

The minutes of the last meeting were reviewed and approved.

**1. Macmillan Living With And Beyond Cancer Survivorship Grants**

**a. Brain Metastases Educational Day**

Discussion summary	8 <sup>th</sup> July Brain Metastases Educational Day took place. Feedback given showed the day was very successful. Link to the video from the event : <a href="https://www.youtube.com/channel/UCKI2c4tjYpyQnCCXc97MDSQ">https://www.youtube.com/channel/UCKI2c4tjYpyQnCCXc97MDSQ</a> A second education day has been organised for Thursday 11 <sup>th</sup> May 2017.
Conclusion	Hester Benson to leave the project team at the end of October following final submission of project findings report.
Actions and responsibility	No actions taken following discussion.

**b. Holistic needs assessment in primary CNS tumours and design of health and well-being event**

Discussion summary	HB informed the group of the findings from collation of the results of the HNA's completed by patients. Results from the first HNA the patients completed showed common themes were across the board. Patients stated the main issues they were experiencing were Acute Fatigue, Worry/anxiety/fear of reoccurrence, Transport and driving issues, issues with appearance, mobility and depression. Results from the 2 <sup>nd</sup> HNA established patients experiences had only slightly differed in the six weeks since the first HNA was completed siting the same issues as being the most troublesome. However, Appetite, fatigue, nausea and loss of taste scored highly in the list of issues patients were struggling with at this stage.
Conclusion	Leaflets and small discussion groups were both things patients felt would be a great

	<p>help to them whilst undergoing treatment.</p> <p>From these findings, the team have organised a support group / patient engagement day for up to 30 people, due to take place on, Sunday 13<sup>th</sup> December 9:30am – 4pm to help patients to interact with others undergoing similar treatment and gain further information around managements of their diagnosis on a day to day basis through leaflets or from linking up with others who may be coping with the same issues. Success of this day will be evaluated and possibly replicated upon review of feedback.</p> <p>As fatigue has been identified as a prevalent issue experienced by patients, the team have been approached by a team in Edinburgh to collaborate efforts in setting up a to Randomised trial to test an interventions to combat fatigue. Health coaching, Information booklets or A patient activation interview prior to health coaching would be given to the patients taken part to see which method is most effective. This has yet to be finalised due to funding being sought.</p>
Actions and responsibility	No actions taken following discussion.

## 2. Patient Engagement Group

Discussion summary	<p>Update on the formation of the Brain and CNS small community was given to say they have met twice since the last BPEG.</p> <p>Once to support Hester to support her in her projects and another time to discuss the Blue books project.</p> <p>Thanks given to those sending through details of those wanting to join the community. 13 people are part of this group currently.</p>
Conclusion	Good feedback was given for the user involvement training session Catherine attended.
Actions and responsibility	No actions taken following discussion.

## 3. Peer Review Reports 2015-16: Internal validation issues and workplan goals relating to this group

Discussion summary	For information - Peer review report due in November 2016.
Conclusion	Feedback to be given once report reviewed
Actions and responsibility	To be discussed at next meeting.

## 4. Patient held records – blue book project

Discussion summary	LF collated comments from small community. Consensus was the group felt the books were fantastic and that they would help in management of their treatment in a great way.  Staff promotion of blue books is vital to success.
Conclusion	Promotion of use the books to be increased. Books to be given out at the Christie to patients on a trial basis to extend the pilot. Review of content will then take place.
Actions and responsibility	No actions taken following discussion.

**5. Any other business**

Date and time of next meeting – **27<sup>th</sup> January 2017, 11.00 – 12.30hrs**  
**Seminar Room B - Hope building, SRFT**