

Date of Meeting 12<sup>th</sup> January 2018  
 Time of meeting 11:00 – 12:30  
 Venue Meeting room 3 SRFT Mayo building

**Apologies:**

Mark Hodson	Sheetal Jash
Cliff Chen	Mel Atack
Anna Tran	Andrea Wadeson
Marie Buckley	Sarah Cundliffe

**Attendees**

Catherine McBain	Karen Farrow	Anne Keegan
Rebecca Price	Julie Emerson	Samantha Wong
Elizabeth Molly	Sara Robson	
Alison Gilson-Hope	Helen Entwistle	

The minutes of the last meeting were reviewed and approved.

**1. Recovery Package**

- a. Health and well-being events / Brain tumour support group

Discussion summary	<p>The team discussed the logistics of holding future health and wellbeing events for Brain and CNS patients across GM.</p> <p>The event scheduled to take place at the Christie on 25/11/17 unfortunately did not take place, due to poor uptake during preregistration. This was disappointing as the same registration method had been used for the previous successful event. Potential reasons were discussed along with a need to explore this further if planning future events.</p> <p>A G-H described plans for another event, at The Victoria and Albert hotel in Central Manchester on behalf of SRFT; 9:30-2:30 on 12/03/18 (date moved 18/03/18). This is being organized in conjunction with The Brain Tumour Charity who have agreed to some financial support.</p> <p>This event is currently open to all patients with a brain tumour; however this is to be discussed in detail between the clinical team as to how this will be advertised to patients given that this opens the event up to a wide cohort of patients.</p> <p>Both Anne and Karen, attending as patient representatives, agreed that it would be advantageous to be all inclusive when inviting patients as they felt that differentiating between grades of tumour is not necessary, given that most patients regardless of their grade of tumour experience similar core issues.</p> <p>Alison Gilson Hope briefly ran through the speakers arranged to give talks on the day and will circulate an agenda for the day closer to the event.</p> <p>Liz Malloy informed the group that the brain tumour patient support group is now up and running with the first meeting due to take place on the 5<sup>th</sup> February at the</p>
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	<p>Northern Tennis Club on Palatine Road. It is being facilitated by Brain Tumour Support and it has been agreed that the group is open to primary brain tumour patients and their carers but all brain tumour patients are welcomed should they feel they would like to attend.</p> <p>Liz circulated a flyer for all to review and asked for teams to begin promoting these events to all patients.</p> <p>The group acknowledged that location of the event may make it difficult for some patients to attend but have agreed to review the uptake of the event with this factor in mind.</p>
Conclusion	
Actions and responsibility	<p>Teams to promote the patient support group and the event on 12/03/18</p> <p><i>**NB These minutes reflect discussion in the meeting, but please see covering email regarding significant subsequent changes to the event planned for 12/3/18**</i></p>

b) On-going use of HNA's and further development

Discussion summary	<p>JE fed back to the group that she had completed an exercise in which she reviewed the number of HNA's conducted against the number of patients seen. 75 out of 305 patients seen had completed a HNA (23%). Reasons for this low-uptake were discussed. These were felt to include that patients accept an HNA form but do not return it, or that patients seem to perceive that their needs are being met.</p> <p>However, despite the low rate of HNA completion, only 11% of the 305 (31 patients) had NOT had conversations with the nursing / AHP teams regarding their needs (10/31 having been referred straight to community palliative care, 4/31 inpatients in other hospitals, some out of area referrals, some no information recorded). At this time, no changes to practice were suggested but the team will continue to proactively monitor matters.</p> <p>The Christie target that all patients should have undertaken a HNA by March 2018 was noted and highlighted that this deadline has been extended given that funding has yet to be sourced to resource this.</p> <p>The group discussed the complications of agreeing which template to use and what medium to collect this information (electronic vs paper).</p> <p>SRFT staff commented that they were not aware of any discussion of this issue within SRFT, although this may change with the appointment of a H&amp;WB co-ordinator for SRFT.</p>
Conclusion	<p>On-going discussion is needed by all to overcome the issues stated above and meet the aspiration of introducing HNA into routine care for all patients.</p>
Actions and responsibility	<p>The group have agreed to continue to trying to conduct as many HNA's as possible and review their position in the upcoming months.</p>

c) Implementing the recovery package: End of treatment summaries: views on letters to patients vs summaries

Discussion summary	<p>CMB discussed examples of end of treatment summaries she had reviewed from other tumour groups to inform the creation of a Brain and CNS EOTS. CMB also described the variation in approaches of different teams e.g. the lung team write directly to patients.</p> <p>The group discussed and evaluated the idea of whether to write the summaries directly to the patient and forward a copy to the GP, pros and cons were discussed. It was agreed that all felt writing to the patient, drawing on the models of the lung group, would be the best way to communicate this information. The group also agreed that end of treatment summaries should be generated after completion of each significant treatment episode, i.e. surgery, radiotherapy, chemotherapy.</p> <p>They discussed the idea of having proformas for each treatment summary to ensure that the same quality of information is given to all patients regardless of treating clinician.</p>
Conclusion	The group discussed at length multiple ways to communicate this information to patients and agreed to set up a smaller focus group to work on putting some draft examples together for all to review.
Actions and responsibility	Further discussion will take place at the next BPEG meeting following circulation of the draft summaries.

## **2. Patient Engagement Group / Brain and CNS Small Community**

Discussion summary	<p>Unfortunately Mel Attack was unable to attend today's meeting, however provided a written update following the Brain and CNS Small Community Focus Group discussing Psychological Support for family members and children and the creation of a support leaflet intended to signpost patients to any psychological support resources available.</p> <p>The impression was that the leaflet was simple and discreet. All members of the group agreed it was definitely what they had in mind when they started to discuss the idea of this.</p> <p>The following points were agreed for amendments:</p> <ol style="list-style-type: none"> <li>1. Have this as a tri fold leaflet to allow more information and larger font.</li> <li>2. Increase font size</li> <li>3. Most were happy with logo however copyright and gender neutral logo were discussed. Sammi will look into this.</li> <li>4. Put the first paragraph in clear bullets</li> <li>5. Put the title in larger/bolder print</li> <li>6. Add Macmillan information centres as a resource</li> <li>7. Add a one liner about the family days/events at Brain Tumour Charity and Brains trust</li> <li>8. Remove the word bereavement where possible out of the generic text</li> <li>9. Use some bright colour to make more appealing</li> </ol> <p>Sammi Wong tabled a printed example of the leaflets following amendments recommended from the small community.</p> <p>The group have asked for Sammi to add the new brain tumour support group details to the leaflet.</p>
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	<p>Sammi noted that the leaflet was not formatted how she had intended, so will circulate the final draft to the group electronically.</p> <p>Numbers of patients and carers presently involved in the Small Community were discussed; it was agreed that increasing the membership would be beneficial at this time.</p>
Conclusion	<p>The Small Community continues to function well and CMB expressed her thanks to the Small Community, the reps present and to Mel for stepping into Lucie's shoes while Lucie is off on maternity leave.</p> <p>The Small Community is a valuable resource and the Board look forward to continuing to work with them to develop the end of treatment summaries and further survivorship events.</p>
Actions and responsibility	<p>SW to make further minor amendments to the leaflet and circulate electronically to the group.</p> <p>Team (CMB / JE) to D/W Mel Atack re increasing small community patient numbers by re-advertising opportunities for involvement.</p>

### 3. Education

#### a) GATEWAYC

Discussion summary	<p>CMB explained the rationale behind the GATEWAYC, online GP education portal, being led by Dr Sarah Taylor (the GP lead for GM Cancer) and the Vanguard project teams. The primary issues being tackled are referral symptoms and what symptoms of concern GPs should be looking out for.</p> <p>CMB informed the group that a script has been written that covers Brain and CNS cancers, and filming for a segment for the for the brain and CNS module of the Gateway C project has now been completed.</p>
Conclusion	<p>The group were very supportive of this initiative</p>
Actions and responsibility	<p>CMB will continue to work with the GATEWAYC team to develop this project and feedback to the board regarding this. It is hoped it will be live within the first half of 2018.</p>

### 4. Research

#### a) Update on BT Life and other research proposals

Discussion summary	<p>BT Life is a randomised controlled trial comparing 3 different interventions to help brain tumour patients overcome post-treatment fatigue. It has been funded by the Brain Tumour Charity; Manchester is one of 3 centres (with Edinburgh and Glasgow). It is planned to open in summer of 2018.</p>
Conclusion /Actions	<p>CMB and SR to continue to work on this project and feedback at next meeting.</p>

#### b) Peer review and annual work plan

Discussion summary	The annual work plan has been previously circulated; there are no changes. The Network MDT is to undergo internal peer review in 2018; the month is yet to be agreed. JE is leading on preparing the documents Network MDT is currently technically noncompliant due to staffing issues, although this is not felt to be affecting the service.
Conclusion /Actions	JE and CMB to feedback at next meeting

**c) Any other business**

Discussion summary	None
Conclusion	
Actions and responsibility	

**Time and date of next meeting:**

**Friday 4<sup>th</sup> May 11am – 12.30pm – room to be finalised.**