GMCA GREATER MANCHESTER COMBINED AUTHORITY

NHS in Greater Manchester

Greater Manchester Cancer

Brain and CNS Pathway Board

Patient Experience Group Meeting (BPEG)
Minutes and Actions

Meeting time and date: Friday 12 July 2019 11:15-12:45

Venue: Seminar Room 8, Mayo Building, Salford Royal Foundation Trust.

Members in attendance			
Name	**Role**	**Organisation**	**Attendance 2019/20**
Catherine McBain	Chair/ Consultant Clinical Oncologist	The Christie NHS Foundation Trust	2/2
Fiona Lewis	Pathway Manager	GM Cancer	2/2
Julie Emerson	Specialist AHP	The Christie NHS Foundation Trust/ Salford Royal NHS Foundation Trust	2/2
Liz Molloy	Neuro Onc CNS	The Christie NHS Foundation Trust	2/1
Karen Farrow	User Representative	Macmillan User Involvement	2/1
James Turner	Macmillan User Facilitator	The Christie NHS Foundation Trust	2/1
Mike Clinton	Macmillan RP Manager	Salford Royal NHS Foundation Trust	2/1
Sarah Cundliffe	Neuro Oncologist CNS	Salford Royal NHS Foundation Trust	2/2
Helen Entwistle	Skull Base CNS	Salford Royal NHS Foundation Trust	2/1
Alison Gilston-Hope	Neuro Oncologist CNS	Salford Royal NHS Foundation Trust	2/1
Maryam Bagheri	Macmillan Recovery Package RN	Salford Royal NHS Foundation Trust	2/2
Andrea Wadeson	Skull Base CNS	Salford Royal NHS Foundation Trust	2/1
Fiona Cains	Pituitary/Brain CNS	Salford Royal NHS Foundation Trust	2/1
Sara Robson	Specialist AHP	The Christie NHS Foundation Trust/ Salford Royal NHS Foundation Trust	2/2
Samantha Wong	Clinical Psychologist	Salford Royal NHS Foundation Trust	1/1

Apologies		
Name	**Role**	**Organisation**
Alison Armstrong	GMC Programme Lead	GMC
Tina Karabatsou	Neuro Surgeon	SRFT
Liz Molloy	Neuro Onc CNS	The Christie NHS Foundation Trust
Karen Farrow	User Representative	Macmillan User Involvement
James Turner	Macmillan User Facilitator	The Christie NHS Foundation Trust
Mike Clinton	Macmillan RP Manager	Salford Royal NHS Foundation Trust
Sheetal Jash	User Involvement	
Lisa Herman	User Involvement	
Karen Farrow	User Involvement	
Mark Hodson	User Involvement	

Andrea Wadeson	Skull Base CNS	Salford Royal NHS Foundation Trust

1. Welcome and Apologies	
Discussion summary	Members of the board were welcomed, introductions were made and apologies were noted.
Actions and responsibility	

2. Minutes of the last meeting	
Discussion summary	Minutes of the last meeting were discussed and agreed as a true record.
Actions and responsibility	FL to load to Greater Manchester website

3. Implementation of the Recovery package	
Discussion summary	**HNA** SRFT - MB provided an overview of the EHNA at SRFT. Numbers - • 66% of EHNA has been completed with another • 10% pending. • 9% had expired, not got back to us re: concerns • 15% of patients declined (this includes patients with confusion where it would be difficult to complete and having to mark as declined). The system is expected to be updated to reflect this group. An analysis on the 99 EHNA assessments completed since 01/06/19 (aimed to be patient led but are still being completed via paper as there is no funding for an IPad to enable this). Split of gender: 48 females, 51 males Age of respondents broken down: • 71+ - 17% • 61- 70 - 21% - most concerns, more co morbidities, more financial worries • 51-60 - 23% - main proportion of respondents • 31 - 40 - 16% - high number of concerns vs number of respondents, possibly due to working age, financial worries • 21- 30 - 8% • 17-20 - 4% Data showing where on pathway patients are completing EHNA before the target - Day 31 of diagnosis: • 61% at initial diagnosis • 19% during treatment - showing we are capturing patients along the way. • 4% at end of treatment • 3% transitioning at palliative stage • 0% Follow up

- 0% Pre-hab
- 8% at Recurrence

HNA's are mainly captured on the ward.

Main top 10 patient concerns captured include:

- Worry, fear and anxiety is the main theme
- Moving around and walking
- Pain and discomfort post-operative, tiredness and exhaustion
- Constipation
- Jobs and Money (finances particularly in the younger age bracket and area

Main information needs are: mainly at diagnosis, Exercise and activity. The majority are getting the information they needed

There are gender differences in the type of concerns expressed.
Cognitive impairment, hearing loss, in pain, unsure of patient capacity. MB will visit the ward to individually assess if the patient can be offered a HNA and will revisit again to assess the patient at a later date. HNA may not be suitable for every patient, probably geared more towards the breast patient.

MB still feels there are people being missed, for example patients attending for biopsies. MC is collecting the full data though he wouldn't know if there are missing any unless he compares with the number of patients going for surgery.

It was interesting that this sample is reflective of the demographic and the incidence of the tumour group.

SW was interested in the results of the screened out due to cognitive problems and would like to see how this can identify the psychological needs to inform and expand the service.

The Christie - JE provided an overview of HNA at The Christie. There is a mixture of online and face to face which is offered to everyone

Numbers -
There were 78 patients registered, 6 patients pending. Out of the 72 completed (35 have completed) representing 49%. The team are getting together to see how to improve update though these patients are coming in every day and getting a lot of support or in need of more information. Patients in SRFT are inpatients with more time vs patients in clinic on a Friday PM.

Information requests:
10 out of 35 asked about complimentary therapy and diet and nutrition,
9 asked about making a will
7 asked about Health and Wellbeing and managing symptoms
6 asked about sun protection

	Conclusions drawn Main concerns captured include and seem to be more physical symptoms: 19 expressed concerns about fatigue, 17 expressed concerns about concentration and uncertainty 16 expressed concerns about sleeping difficulties 13 expressed concerns about the future 12 expressed concerns about fear and anxiety 12 expressed concerns about constipation 11 expressed concerns about moving around walking, 11 expressed concerns about sadness and depression 10 expressed concerns about vision 10 expressed concerns about children **Addressing Identified Needs -** CMcB thanked MB and JE for the presentation provided. There was a discussion around what and how the information was dealt with. MB dealt with at word level, felt that to be able to quantify the worry that patients have and the opportunity to explore the details behind the worry helped the patients, utilising family and friends, and signposting patients to their CNS. Anxiety is a massive term and exploring their concerns It was felt that may have helped with more appropriate referrals to psychological services. Any moderate to severe worries were referred to psychological services though it may be refused at the time, it is reassuring to the patient that this was available. The CNS's have level 2 training to carry out psychological psychometric testing, though it has hardly got to a stage where a referral was needed urgently Concluding that on the whole needs being met , reassuring for patients that staff have time to listen Physical / mobility input - No issues really identified, HNA is helping patients to manage expectations and utilising OT and physiotherapy intervention The patient satisfaction survey has yet to be analysed. **Progressive patients** JE informed the group that progressive patients are seen in MDT (Wed and Friday) with capacity to do them. There is some difficulty is tracing these patients. MB will keep patients informed if not dealt with at ward level. Discussion of previous research that there is enough data to analyse which has influenced some of the National HNA documentation which was moulded slightly towards neuro need (mobility, swallowing and liaison) because of the work we had done previously Options of Ipad or paper were offered to patients with the majority preferring paper, as some perceive a massive questionnaire and tend to be out off by this. Another comment that the HNA was supposed to be patient led though a family member is sometimes there. MB tends to see patients on their own and feel that patients can be

	more honest. It was agreed that there was plenty of research opportunities for the future arising from these pieces of work. **Treatment Summaries** This needs to be on the next agenda for an update as MC has developed treatment summaries into a new format. **Health and Wellbeing Events vs Patient Information Day** A Health and Wellbeing event held by Skull base team at Marriott Piccadilly was well successful and well attended by patients and had to increase capacity on the day. Awaiting event feedback. This was Simon Lloyd funded - this was a one off event. Next events - a low grade glioma event being organised by TK. A discussion around a different format, different talk but definitely need another one with a generic event also being considered which may be more suitable for the low grade gliomas however, it was agreed that the CNS group are unique group as patients have particular needs. The metastatic breast also run their own events.
Actions and responsibility	Continue with HNA metrics being collated as described. MB to share presentation to SW

4. Psychological Provision	
Discussion summary	SW gave an update on the clinical psychology department informing the group there would be better provision from September and updated the current position of the waiting list for al tumours. **Referrals** - • Helen and Russel triage the referrals and will notify SW if these need to be expedited. • CMcB asked if there were referral criteria's and appropriateness of patients referred. SW agreed to take this away. She informed the group that there was a cognitive test pre and post op and that a follow up protocol exists. **Capacity** - • In terms of assessing for capacity, this can be done by any clinician and doesn't have to be a neurologist unless there is a concern. • Concerns are usually raised by OT to be able to judge a patients capacity to go home or not. It was also important not to assess too early after treatment. **Future psychology provision -** • Discussed closer working with PMcD and understanding how we can link into the work in the psychology pathway board
Actions and responsibility	SW to work up referral criteria and follow up protocol FL to invite Padraig McDonnell to the next meeting - Action closed PMcD confirmed

5. Acute Oncology Nurse Study Afternoon	
Discussion summary	A study event has bene organised for the 15th July with AON attendance and representation from nearly all Trusts.

Actions and responsibility	To note

6. GM Cancer Innovation Fund	
Discussion summary	CMcB informed members of a joint bid with Dr David Woolf and Bernie Delayhoyde for a bid for funding towards a 12 month pilot of a novel, rapid-access, combined neuro-oncology and pulmonary oncology clinic for patients presenting with brain metastases from a previously-unsuspected synchronous lung primary. This has been submitted for consideration.
Actions and responsibility	To note, update will be provided at the next meeting.

7. BPEG membership; group functioning	
Discussion summary	CMcB to meet with Jane Cronin and Paula Daley with regards involving more user representation in the group.
Actions and responsibility	FL to organise meeting for September.

8. AOB	
Discussion summary	Stephen Kennedy to be invited to the next meeting on 18th October.
Actions and responsibility	

12. Date and time of the next meeting	
Discussion summary	Next meeting 18th October in Meeting Room 8 in the Mayo Building, SRFT.
Actions and responsibility	