

Greater Manchester Cancer**Brain and CNS** Pathway Board**Pathway Board**
Minutes and Actions**Meeting time and date: 18 October 2019**

Venue: Seminar Room B Hope Building, SRFT

Name	Pathway Board Role	Organisation	Attendance 19/20
Dr Catherine McBain	Pathway Director	GM Cancer	3/3
Fiona Lewis	Pathway Manager	GM Cancer	3/3
Andrea Wadeson	Skull Base CNS	SRFT	3/2
Sarah Cundliffe	Neuro Onc CNS	SRFT	3/3
Fiona Cains	Neuro Onc & Pit surgery CNS	SRFT	3/2
Allison Gilston Hope	Neuro Onc CNS	SRFT	3/2
Maryam Bagheri	Macmillan SN for Neuro Onc & Brain mets	SRFT	3/3
Samantha Wong	Neuro Psychology	SRFT	2/2
Liz Molloy	Neuro Onc CNS	The Christie	3/2
James Turner	Macmillan QI facilitator	The Christie	3/2
Cath Comley	Commissioning Manager	Stockport CCG	1/1
Karen Farrow	User Involvement rep	GM Cancer	3/2
Sarah Robson	AHP in brain and CNS	SRFT	3/3

Guests in attendance

Name	Role	Organisation
William Jones	Chief Executive	Brain Trust Charity
Padraig McDonnell	Psychology Clinical Lead	GM Cancer
David Wright	TYA Clinical Lead	The Christie
Shannon Wesley	UI Facilitator	The Christie
Paula Daley	UI Team Leader	GM Cancer

Apologies

Name	Pathway Board Role	Organisation
Helen Entwistle	Skull base CNS	SRFT
Jane Cronin	User Involvement manager	GM Cancer
Julie Emerson		
Stephen Kennedy	Macmillan facilitator	
Karen Farrow	User Involvement rep	GM Cancer

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CMcB opened the meeting welcomed everyone to the meeting. Introductions were made around the room.

2. Minutes of last meeting

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Discussion summary	Minutes of the last meeting on 12 July were signed off as an accurate reflection from the meeting. Update of Actions: <ul style="list-style-type: none"> • All actions complete
Actions and responsibility	FL to add to Greater Manchester Cancer website - closed

3. Submission of HNA extract to GM Cancer conference

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Discussion summary	MB explained that she has submitted a poster abstract for submission for the conference from which she is awaiting to hear whether it has been accepted. There has been 76 submissions in total and space to display is minimal.
Actions and responsibility	To continue development of poster for submission.

4. Psychology provision

Discussion summary	<p>CMcB welcomed PD as she would like to address the psychological provision; the reason being two-fold :-</p> <ol style="list-style-type: none"> 1. To ensure we are addressing those needs (highlighted from the HNA) and 2. Whether we were using psychological support in the best way with the appropriate use of patient's time and resources. <p>PD had met with SW in preparation to this meeting, introduced himself as the clinical director for the Psychological support and Mental health pathway board and spoke to the attached slides.</p> <p> Brain-CNS presentation.pptx</p> <ul style="list-style-type: none"> • PD was aware that this group would already be aware of highly specialist access to neuro psychological and rehab services and wanted today to concentrate on explaining the other aspects of psychological care services and the psychological support and well-being pathway board which is heavily supported by service user voice to do this better and to push this agenda. The question is how we support this as we need to be pragmatic due to limited resources. • The HNA has highlighted the needs for psychological support. The top 5 commonly reported concerns in all the tumour groups are consistent with the HNA results undertaken by MB. • He explained that there are stepped care approaches (NICE) which describes the components of 4 stepped models, with integration with colleagues in mental health colleagues. (e.g. IAPS (Improved Access to Psychological Therapies) a government programme for primary health access for people living with LTC (i e with cancer presenting with anxiety and depression). The Christie does have a psycho oncology service, patients have to be a Christie patient; this is a great resource and a good model but do struggle with high demand and equity of access. He described the 4 stepped care levels as follows:- ○ Level 4 are highly specialist services.
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- Level 3 is the main service for discussion and the main group where these people are best placed to be seen possibly not at SRFT for example someone living further away in GM.
- Level 2 tend to be specialist roles – i.e. CNS with specialist communicators training with additional skills in problem solving and sign posting. 10% of cancer patients may need this level. There is a strong economic argument that earlier support leads to better patient compliance to treatment, reduction to escalate to higher levels of psychological support and less distress in the longer term but difficult to get the evidence for this.
- Level 1 is a three hour workshop for anyone in contact with a cancer patient such as hospital porters and admin staff.
- Psychological services directory in each GM locality is available through the GM website under pathway –
<https://gmcancerorguk.files.wordpress.com/2019/06/directory-of-services-gm-cancer-psychological-mental-health-apr-2019-v3.pdf>

SW spoke the attached slides and updated on the following at SRFT :

- Service provision
- Staff speciality, their roles and tumour speciality
- Waiting times - 1st Sept - 62 referrals (6 with more than 1 issue), endocrinology may need to wait a little longer on WL.
- Management of referrals and that the criteria list needs some further development. She explained that some of the referrals need an MDT approach.
- The following spreadsheet highlights the variation in provision and the IAP locations in the community.



neuropsychology Oct 19 CNRT
general overview d.p dashboard for referre



- SW will invite Selina Makin a newly appointed tumour specific clinical neuropsychologist to attend this meeting.
- The group discussed upskilling from level 2 to level 3 upon discussion from criteria categories and patient risk and spoke about the difficulty of managing level 2 patients who may need escalation to level3 with awareness of waiting list and managing that patient in the meantime.

Actions and responsibility

SW to share location of community provision - closed
AW, PMcD and SW to convene to develop a flow chart to access to services, where we refer patients more locally and building on the service availability on the website.
Training needs to add additional skills rom level 2 to level 3.

5. Interface between TYA and Adult**Discussion summary**

DW is the clinical director for TYA Pathway Board; he was joined by Dr G Whitfield and invited to the meeting to discuss the interface challenges between the TYA (16- 24 year old) and adult services and wanted to address where we can work more collaborative at Pathway board level or at operational level. The children attend SRFT for surgery and Christie for oncology treatment.

The issues highlighted were:-

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	<ul style="list-style-type: none"> The age of the patient at 16-17 years old entering which service upon initial presentation and then upon relapse. (e.g. those treated as children who survive into TYA age range and then relapse) Those diagnosed within range of TYA services and move into adult services – what happen when these relapse beyond the age of 25 years old (the TYA services are clear that they no longer belong to them (also the size of the TYA services to be able to support this group if the over 25's were accepted back). A conversation with the patient to make this clear would be difficult after completion of initial treatment. CMB added that there are additional challenges that the patient and family in the TYA services are so well looked after in comparison to the adult service. DW informed the group that there are some grey areas in the TYA pathway (e.g. where there is no significant break in treatment would continue in TYA care but for those with a break would move into adult services, which will mean an inequity of service. Some clarity and communication to patients with some additional support initially would help. There is inequity depending on which consultant they are under as some consultants hang on to the patients longer than others. The TYA services are so well supported don't tend to hear from them There are great challenges (missed key milestones both socially and developmentally and independent living and dependency on others is a huge challenge) for this age group; also this is a massively difficult disease area, with much long term side effects. <p>The group discussed thoughts and ideas around transition and concluded that we need to scope what is out there, what the needs are. Need to define at what transition is between the two services written on paper for patient support and expectation. From a user perspective, KF felt strongly that the worse feeling to be is feeling you don't belong. A user representative in this age group to be recruited.</p>
Actions and responsibility	Action - small group to work on this (CMcB, DW, AGH EM) DW will ascertain baseline figures and needs in the first instance.

6. Recovery package implementation

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Discussion summary	<p>HNA update from SRFT:-</p> <ul style="list-style-type: none"> MB informed the group that work has been continuing with patients on the ward, there has been Health and wellbeing event for all tumour groups. Mainly H&N patients, held at the Mayo, SRFT. Around 60 people attended with a presence from Citizens advice, support groups, HNA checklist. Patients were signposted to different services (market stalls) and given their clinic appointment to attend - each tumour group saw their CNS. Another low grade glioma event was discussed for 5th June , this is a functioning well group FC informed the group about a Pituitary session a few weeks ago was very successful PD – felt that large groups of patients in a speciality do work well and gave an example of a breast event and relationship and talked about relationship reliance William Jones from the Brain charity informed the group that funding for events overlaps with their charity objective and would support future events. Action - Will Jones CE Happy to share what other hospitals, could offer financial support. And could provide an update from London, Glasgow, Oxford, Berkshire. Events for caregivers works well they require a different agenda and networking. KF pointed out that most patients would not have a driving licence and rely heavily on their carers to attend.

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	<ul style="list-style-type: none"> JT updated the group on CCG funding. This was something that was agreed that an OPD to support this would attract a fee of £80 but was not sure how the conversation has moved on. Not massively attended for various reasons CMcB to WJ - Mixed grades - invite to events and asked for some advice – WJ from experience felt from experience that these work well as these dealt with difficult issues which are not covered in health and wellbeing events, these are conversations and support for issues which are not openly addressed. They have different needs to patients. The HWB doesn't capture their needs for those who are not living well and have a terminal illness. <p>Christie HNA update at The Christie :</p> <ul style="list-style-type: none"> JT updated that the average HNA completed per quarter is 1200 as a whole but not all tumour groups are using HNA. Paper and electronic format combined the biggest collection site in GM. The brain tumour group completed about 101 in this quarter. HNA OPD has been established though the uptake was been poor. A PM Friday clinic is not a good time, resulting in low numbers and DNA, try to capture when towards end of r/t. Could have another person an hour. Would need training EM informed the group that there is approximately a 50% uptake. Some just don't want to do it and very few like to do it online and didn't necessarily want a care plan. Patients felt better just talking through the HNA without needing something tangible to take away but reported feeling better. JT - talked about care coordinators what their needs are and splitting tumour groups and areas to develop a business case from this; however, PD expressed that for this group of patients with neuro complexity may not be for a B level expressing concerns. MB agreed that all patients needed some support, a background to neurological needs and skills to interpret their needs and it was agreed that training for B4 would need to include level 2 and know when to refer onwards. The group as a whole felt that this patient group would need a more skilled workforce and with finding ways of working, training and a close partnership team working may work. <p>Treatment Summaries – not discussed.</p>
Actions and responsibility	Action - Will Jones CE Happy to share what other hospitals, and offer financial support for holding events.

7. GM Cancer innovation fund

Discussion summary	No update available.
Actions and responsibility	

8. BPEG membership

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Discussion summary	JC has joined the group as user involvement manager, she will be recruiting more members as User involvement, and CMcB is seeking consultant involvement. Stephen Kennedy and Tina Karabatsou have been invited to this meeting but could not attend today.
Actions and responsibility	

9. AOB

Discussion summary	WJ reflected upon today's meeting and praised the work of the group. KF informed the group that she would be stepping down when more User Involvement members have been recruited; She was thanked profusely for the tremendous and valuable contributions she has made. Next Meeting 7 February 2020
Actions and responsibility	FL to send invite