

Living with and Beyond Pathway Board – Minutes of Meeting

15th September 2015 3-5pm

Seminar room 8, Education Centre, University Hospitals South Manchester Foundation Trust

| Attendance | Representation |
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| Wendy Makin | Director/consultant Christie |
| Hodan Noor | Manchester Cancer - Pathway Manager |
| Sue Taylor | Patient representative |
| Lindsey Wilby | Manchester Cancer - Macmillan Project Manager - Living with and Beyond Cancer |
| Rachel McMillan | St Ann's Hospice and Neil Cliffe Centre representative |
| Victoria Cooper | Associate Macmillan Development Manager |
| Pat Jones | Lead Cancer Nurse, CMFT |
| Kathy Pantelides | AHP/Rehab manager Christie |
| Karen Livingstone | Physiotherapist breast/lymphedema UHSM |
| Jennifer Bagchi | SRFT Cancer HOW programme coordinator |
| Ann-Marie Kelly | Patient Information Manager WWL |
| Debbie Smith | Macmillan info and support manager, UHSM |
| Janet Parkinson | Macmillan info and support manager, East Cheshire |
| Claire Rehan | Clinical Psychologist, Bolton FT |
| Beverley Gail Meenan | Macmillan Lead Nurse for Cancer and Palliative Care, SFT |
| Jonathan Tubellross | Manchester Cancer - Macmillan User Involvement Manager |
| Claire Higham | Consultant endocrinologist, Christie |
| Zoe Nichd | Macmillan Quality Improvement Facilitator, Pennine Acute |
| Debbie Ashforth | Macmillan Transformation Programme Lead LW&BC Pennine Acute |
| Jo Farrington | SCN |
| Apologies | |
| Ian Ainscough | Macmillan info and support manager, SRFT |
| Julie Pieczarka | Macmillan info and support manager, Mid Cheshire |
| Abbas Chittalia | Consultant oncologist (breast and lung)- Christie and Stepping Hill |
| Karen Buckley | Lead cancer nurse manager, East Cheshire |
| Vanessa Hickson | Keyworker, Tameside |
| Julie Orford | Lead Macmillan Nurse, UHSM |
| Felicity Keeling | Macmillan Information and Support Service Manager, PAT |
| Sue Summerfield | Macmillan info and support manager, Bolton FT |
| Ben Heyworth | Survivorship project manager Christie |
| Liane Harris | GP, Cancer Lead Bury CCG |
| Brain Hixson | Patient representative |

In attendance:

Julie Foster Macmillan information support Libraries

Claire Moran Macmillan information support Libraries

| Agenda Item | Action |
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| 1. Apologies noted Apologies have been noted | |
| 2. Welcome and Introduction WPM welcomed new members from Pennine, SCN and Manchester Cancer User Involvement. | |
| 3. Accuracy of minutes from the last meeting Accepted as true reflection of the last meeting | |
| <p>4. Matters arising</p> <ul style="list-style-type: none"> - Health and Wellbeing Clinic cost models – 121 community projects in Bolton, Moving forward breast support events run 4 times a year at UHSM and CMFT (head and neck and colorectal) will share their costings. HN requested members who have had HWC in their areas to complete the template before the next meeting. - Health and Wellbeing clinic guidance – No further feedback was received from members. - Health and Wellbeing FAQ – No further feedback was received from members - WPM advised JT to share items to discuss on the agenda and new patient reps who wish to observe a board meeting are welcomed. - WPM proposed to amalgamate the document to support organisation to support the implementation and provide consistency and identify potential pitfalls. LW to include in the later in the year audit on what the costings are in running HWC. JF shared potentially to include life style changes to reduce recurrence for example dietary and the importance of secondary prevention. - Discussion about evidence WPM commented that there is evidence that cancer survivors are at higher risk of new cancers and other comorbidities so that it is important to promote diet and exercise goals to reduce risk. Life style message will be included in the guidance notes. | <p>Relevant to members who have had HWC to complete the template provided and send to HN. HN to amalgamate the FAQ and Guidance for circulation to Board members and Trust Leads for feedback.</p> <p>HN to share JF graphic on secondary prevention on food and nutrition.</p> |
| <p>5. Cancer Strategy 2015-2020</p> <p>WPM invited comments on the asked members on the new cancer strategy and the position paper from SCN. The role of the SCN is to support the strategy by influencing the commissioning agenda and will support the questions and developments of the tariff and how this will be resourced.</p> <p>Members’ feedback has been that the concept of LWBC, although the subject of a section in the strategy, this is deemed to be very new to many professionals although key people have been working on the recovery package within organisations. The strategy has been a great benefit to champions to raise the profile of survivorship. as a result of the strategy majority of boards are discussing and engagement on the living with agenda.</p> <p>Commissioning is a key to ensure the effectiveness of the strategy, from a patient perspective there is a concern on how this is shared and implemented in the community and primary care level as the supportive self-management will not be effective without this.</p> <p>In Manchester, The MCIP project has been delivering a large part of the agenda on living with and beyond cancer and a major LWBC education event for primary and community care is taking place in early November. WPM also noted that there was interest from GPs in other areas to include this in their cancer education programme. November. All credit to Macmillan for being the driving force including patient and carer voice.</p> | <p>HN to arrange meeting with WPM and Rehab Lead</p> <p>HN to share the SCN positioning paper</p> <p>JF will send the prevalence data to HN</p> |

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| <p>Rehab capacity to deliver the LWBC aspirations is a concern. HN noted that she and WPM will be meeting with the AHP group lead to discuss..</p> <p>JF shared the focus the emphasis is for the SCN community and primary care alongside influencing commissioners. Improving communication between primary and secondary care. JF is working on collating prevalence data approx. over 90 thousand living in greater Manchester with a cancer diagnoses to understand the scale and impact these improvements can make.</p> <p>The summit showcase the patient voice was heard and the outcome of engaging patients is very apparent in the last few months.</p> | |
| <p>6. Annual plan – roles and responsibilities</p> <p>WPM introduced the work plan and welcomed volunteers from the Borad to become involved in any of these important projects:</p> <ul style="list-style-type: none"> • Patient experience of life after treatment: Pilot questionnaire to be developed; probably test in breast colorectal and prostate , capturing experience from 12 months and further out from treatment. It would make sense to adopt tested methodology. WPM noted that this had been proposed as a measure in the national strategy.– <p>Public Health England is doing road shows which is a group who could/know survey and SF36 JF going to the meeting and will see if she can make any useful contacts to help with this.</p> <ul style="list-style-type: none"> • Support for those who are in the ‘Living With’ category: development of models of care plans and HWBE that work well for this group; and to explore what could be adopted from LTC (see also below item 7)and feasibility of a buddy system. Consequences of treatment: for agreed specific COT, baseline mapping and pathways and proposals to develop further 2016-17 – ST was keen to ensure that this this would include late effects from radiotherapy as well as other treatment modalities. <p>WPM noted that education has not been listed on this plan as there are three key large events and pathway boards are now linking in with this board in their development of education. JF hoped that this would promote the engagement of primary and community teams with the recovery package implementation.</p> <p>Manchester University will be reporting on the impact of the primary care cancer education programme which could be used as a basis to develop an education strategy.</p> | <p>Members to email HN their area of interest to support the work programme.</p> |
| <p>7. Macmillan Community Outreach service overview-</p> <p>a) TA presentation was received from the he Macmillan Information and support service hosted by the Libraries in Manchester covering Manchester City based in Gorton and the other in Wythenshawe.</p> <p>The service is advertised in the libraries and recently linking to GP education events. The service has developed a directory of cancer support services in Manchester and will share with HN and information managers.</p> | <p>HN to share presentation with the minutes.</p> |

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| <p>The hospital Macmillan service promotes the library information service to provide future support in the community</p> | |
| <p>8. Lymphoedema WPM informed the Board that</p> <p>9. previous reviews of the lymphedema services highlighted gaps in provision and recruitment of staff and this remains an issue. Following discussions with the lead CCG for cancer (Adrian Hackney) and</p> <p>T TP the Associate Director at Manchester Cancer a proposal has been developed to raise the issue has again been raised with the Greater Manchester Commission Board. Further assessment and possible solutions have been requested and this work is being commissioner led by Coral Higgins and Sue Sykes. This needs to go further than simply provision of lymphoedema services and start with how people are recognised and triaged within primary care. The work will consider pathways within primary/community care, specialist pathways, patient education and generic referrals for swelling of limbs.</p> <p>Further detail to follow in the coming months. KL recently did a workforce analysis which highlighted Manchester had 12.7WTE in December 2012 and since August 2015 the staff total 4.2WTE.</p> | |
| <p>10. Innovation fund update</p> <p>LW updated members on the progress of innovation project there has been delays in the recruitment of workforce for half of the projects who will now share preliminary findings in June next year rather than the full report.</p> <p>There are two at risk Lung Cancer project faces a recruitment delay due to a freeze on recruitment by the organisation, there is also the Head and Neck cancer who are currently struggling to get a backfill cover for specialist speech therapist due to the skills set needed. The OG has only recruitment one patient for their structures exercise programme but further report should show an increase.</p> <p>WPM commented that we are making efforts to engage with those Boards which do not have a project running; for example haematology, skin and HPB.</p> | |
| <p>11. Locality progress update</p> <p>12. This is important for us to map and build upon LWBC service developments so all members of the Board are asked to help with information on activities within their organisation/locality.</p> <p>HN received 4 returns on the locality progress in response to the cancer strategy, outstanding members to feedback.</p> | <p>Members to send locality progress to HN</p> |
| <p>13. Future meeting matrix – HN requested members to complete the matrix before the end of the meeting all future dates will be published at the next meeting in November.</p> | |
| <p>14. Any other business</p> <p>-Any issues faced by Teenagers and Young adults?</p> <p>Dr Leahy, Director of the TYA Board is seeking any information on issues faced by young people living with and beyond cancer. Transition to adult services and transition between services has been highlighted as an area to work on. Steve Ball at Manchester Children is very keen in developing a transition agenda and (XXXX) Paediatric Oncologist at MRI. HN to share the contacts with ML.</p> <p>The support from the TYA works effectively; JT shared the development of TYA event to</p> | <p>JL will share feedback</p> |

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| <p>identify needs and ideas of young people and will feedback at the next meeting. Proposal the TYA board education could include LW&BC.</p> <p>- Trust Leads Meeting</p> <p>HN presented at the Trust leads meeting; the feedback has been that all organisations would like further guidance on the Health and wellbeing clinics and the current recovery package activity within their own locals.</p> <p>HN informed members that an audit will be going out later in the year to provide an accurate activity of the recovery package and the HWC guidance will also be disseminated for feedback.</p> <p>- Any Trusts hosting HWC are reminded to consider inviting hospice representatives to provide information about services they offer. JT has shared information material and posters to share with patients.</p> | |
| <p>15. Meeting dates for 2015/15</p> <p>10th November – Seminar Room 9 & 10 Level 2 Mayo building, Salford Royal FT</p> <p>27th Jan – Seminar Room 1, Mayo</p> <p>24th March - Seminar 7 - UHSM Education Centre</p> <p>23rd June – Seminar Room B – Hope Building, SRFT</p> <p>19th October – Seminar Room B – Hope Building, SRFT</p> | |