

## Living with and Beyond Pathway Board – Minutes of Meeting

15<sup>th</sup> September 2014

Location: Education Centre, The Christie

Time: 3 to 5pm

<b>Attendance</b>	<b>Representation</b>
Wendy Makin	Director/consultant Christie
Kathy Pantelides	AHP/Rehab manager Christie
Ben Heyworth	Survivorship project manager Christie
Claire Rehan	Clinical Psychologist, Bolton FT
Alison Grunshaw	CMFT attended on behalf of Pat Jones
Pauline West	Macmillan info and support manager, Trafford
Janet Parkinson	Macmillan info and support manager, East Cheshire
Beverley Gail Meenan	Macmillan Lead Nurse for Cancer and Palliative Care, SFT
Lindsey Wilby	Manchester Cancer - Macmillan Project Manager - Living with and Beyond Cancer
Felicity Keeling	Macmillan Information and Support Service Manager, PAT
Karen Livingstone	Physiotherapist breast/lymphedema UHSM
Ann-Marie Kelly	Patient Information Manager WWL
Julie Atkin-Ward	Macmillan Development Manager
Liane Harris	GP, Cancer Lead Bury CCG
Rachel Mcmillan	St Ann's Hospice and Neil Cliffe Centre representative
Sue Taylor	Patient representative
Julie Orford	Lead Macmillan Nurse, UHSM
Hodan Noor	Manchester Cancer - Pathway Manager
<b>Apologies</b>	
Brain Hixson	Patient representative
Julie Pieczarka	Macmillan info and support manager, Mid Cheshire
Debbie Smith	Macmillan info and support manager, UHSM
Ian Ainscough	Macmillan info and support manager, SRFT
Claire Higham	Consultant endocrinologist –Christie and Stepping Hill
Val Goode	Nurse clinician, Lymphoma team, Christie
Abbas Chittalia	Consultant oncologist (breast and lung)- Christie and Stepping Hill
Karen Buckley	Lead cancer nurse manager, East Cheshire
Jo Keogh	Strategic cancer lead, PAT
Vanessa Hickson	Keyworker, Tameside

Agenda Item	Action																				
1. Apologies as above																					
2. Welcome and Introduction WPM welcomed Lindsey Wilby, Macmillan Project Manager for Living With and Beyond Cancer who is one of the Manchester Cancer team.																					
3. Minutes from the last meeting Minutes accepted as true reflection of the last meeting, amend job title error listed against Julie Atkin-Ward.																					
4. Action log review The log was reviewed and amended to reflect the discussions of the meeting																					
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5. Update from Manchester Cancer  <ul style="list-style-type: none"> <li>- The involvement of people affected by cancer – WPM informed members the paper describes the different aspects of patient and carer involvement members are requested to share any feedback and reflect this when focusing on the work plan.</li> <li>- Manchester Cancer and joint working of School of Oncology- Briefing will be shared at the next meeting.</li> <li>- Synopsis of Manchester Cancer Pathway Board Annual plans – feedback on the annual plans identified several groups identified survivorship e.g. Breast, Colorectal have initiated cancer survivorship baseline surveys; Head and Neck mentioned service development before, during and post treatment including working with palliative care; Sarcoma also specified the work of engaging with survivorship. WPM highlighted this is an encouraging start for pathway boards . Our responsibility is to support the tumour pathways in the many and varied challenges of survivorship agenda, including utilising the innovation fund to implement or test change in their respective clinical areas.</li> </ul>																					
6. Work programme action log  <p><b><i>Engagement with Manchester Cancer pathway boards and beyond/Education event</i></b></p> <p>Aim is to promote the concept of survivorship/LWBC by developing a communication strategy and glossary of terms to enable shared understanding of our vision, and for consistency when interacting with pathway boards. An educational event that will raise awareness across all pathways is planned for <b>November 25 2014</b>. The proposal is to host jointly with Palliative and end of life care board; this was debated as time is limited,; WPM explained that this was proposed in view of the significant overlap in the ‘living with’ group; both Boards need to organise a meeting to convey a clear message of their purpose and engage with the tumour groups, and there will be better attendance if this is expected for one event rather than two. RMcM felt strongly that this made</p>																					

sense, as there is a continuum. The members agreed there is a benefit to incorporate palliative care to address the whole living with and beyond pathway of care.

The invitations will go to pathway boards and CCG leads however members of both Boards are welcome to attend if they are able to do so (please let Hodan know) .

The group discussed ideas in relation to the content and format of the education:

- Setting the scene of survivorship/living with/palliative care
- Consider invited speakers
- 'Market stalls' – wider information available before meeting and at break
- Pre- event questionnaire or a quiz which can be re-run post the event to assess shift in knowledge.
- Information on 'where we are now' from baseline surveys etc
- Patient stories positive or negative via. Videos or face2face (treating illness and wellness)- possibly from contacts who attend Neil Cliffe and Trafford Health and Wellbeing Centres.
- Promote the recovery package and other key tools that will improve outcomes and experience
- A compilation by posters/video clips about what different professionals are doing now
- Promote the role of champions and the expectations of the other pathway boards
- Prompts to reflection for staff to incorporate as part of their learning and development
- CPD points for attending

LW will develop further with members who have expressed interest to support.

### ***Baseline mapping of Recovery Package and survivorship engagement***

The agreed mapping tool (based upon that developed by the colorectal group) has been disseminated, closing date of the mapping on the 21<sup>st</sup> of October. The tool is to map all elements of the recovery package to gain an understanding of current state of adoption of different elements by pathway and by Trust.

WPM reported on the post treatment summary/information audit of Christie patients. This is on-going and 60 electronic patient records have been audited to date, based upon a random selection of those whose treatment plan was with curative intent 9-12 months earlier, across all disease groups. There has been a significant proportion found to be ineligible for the audit because of change in the disease status, usually requiring on going treatment, so these were excluded. To date nearly 40 had been completed and the plan is to continue with additional numbers. The headlines are that a formal summary template has not been used, but some teams who are generating recognisable end of treatment letters which are very positive examples. However the letters do not appear routinely to be copied to the patients. It is also apparent that a number of letters are directed to the referring consultant and copied to the GP, and this changes the focus and does not prompt actions for primary care. All of this will be valuable information to discuss with the tumour pathways.

The point was made that those 'Living with' also need a summary of some sort – something to consider.

<p><b>Macmillan Innovation Fund</b></p> <p>The Project Manager will be leading on the plan to work with pathway boards; and to develop criteria and application process for pathway boards. LW presented the paper on the management processes, criteria and timescale for disseminating the innovation fund. This was supported by Board members. The timescale is tight so information will be circulated next month and a further opportunity to discuss the fund will be at the education event in November- bids will need to be submitted by the end of December.</p> <p>BH has developed a transformational map as a visual means of capturing current survivorship activities in Greater Manchester- which are growing. Copies were shared at the Board. It was suggested that this could be circulated with the application details for reference to stimulate more ideas.</p> <p><b>Development of a patient/carer/ public involvement strategy</b></p> <p>Aim is to engage with the Manchester Cancer overarching user engagement strategy, but to us to identify and implement a range of opportunities for others to engage with LWBC work.</p> <p>The following suggestions and comments were put forward:</p> <ul style="list-style-type: none"> <li>○ Develop good practice engagement models that can be shared across all organisations</li> <li>○ Note many patients prefer to work on local projects, in their local areas</li> <li>○ There are a wide range of opportunities from co-creating service improvements, buddying schemes, raising awareness at public/community events</li> </ul> <p>Develop a store of patient stories to be used at Pathway Boards and other meetings.</p> <ul style="list-style-type: none"> <li>○ Potential to utilise the national patient survey as the bench mark for measuring improvement of experience.</li> </ul> <p>Agreed action: Pathway Board Members to identify the key themes to promote patients and to identify if there are any existing groups in their areas/organisations, who these might be accessed. To bring back to next Board for discussion when we will agree priority actions.</p> <p><b>Exploration of the needs of those 'Living with' cancer</b></p> <p>To ensure that the aims of cancer survivorship as described in objectives 1 to 4 also meet the needs of those 'Living with Cancer' as well as those free from cancer. It has been agreed Palliative Care Pathway Board that a joint a working group between each would consider the needs for patients living with the cancer or the effects of treatment.</p> <p>WPM tabled the draft ToR for the Living with Cancer Task Group that has been produced after discussion between the two pathway directors. It is to be a time-limited, exploratory piece of work that will report conclusions to both Boards by march 2015 and actions that receive approval will be part of the next years' action plan. LH suggested that it would be valuable to invite a GP and possibly a care of the elderly specialist to support this group.</p> <p>HN to share the ToR at the Palliative Care Board for agreement and nominations. She will convene the task group following this.</p>	
<p>7. Board member updates</p> <p>Unfortunately not enough time for a round table discussion- please bring any local updates to share next time: how are you promoting LWBC in your respective organisation? What are the difficulties, what works well? Any new developments?</p>	

## Manchester Cancer

<p>8. A.O.B.</p> <ul style="list-style-type: none"> <li>○ SCN representative will attend the next meeting and will report on a CCG mapping exercise in relation their plans re LWBC and the recovery model in local strategies.</li> <li>○ Lymphedema services: WPM commented that the current availability (and lack of access) is being reviewed along with psychological support, as part of the pan Manchester Macmillan Cancer Improvement Programme (MCIP). We may be able to build on this with what is known about provision in wider Greater Manchester and Cheshire – it was agreed that this is an important issue for many LWBC patients</li> <li>○ South Sector Living with and Beyond Cancer event: South Manchester, Stockport Tameside and Macclesfield rolling out the recovery package.</li> <li>○ Conference in Liverpool: CR will share the learning from ‘informed Decision Making in Cancer Patients’ specifically focused on psychological approaches.</li> <li>○ Christie hosting 20<sup>th</sup> November Men’s health and wellbeing event (run x2 back to back) starting 12noon until 7pm</li> </ul>	
<p>9. Date of next meeting</p> <p><b>21<sup>st</sup> November 3-5pm Trafford Health and Wellbeing Centre M41 5SN</b></p> <p><b>(NB Education event , afternoon of 25 November 2014, Education Centre, Wythenshawe Hospital)</b></p> <p><b>20<sup>th</sup> January 2014, 3-5pm, Trafford Health and Wellbeing Centre</b></p>	