

Living with and Beyond Pathway Board – Minutes of Meeting

24th March 2016 3-5pm

Seminar Room 7, Education and Research Centre,
University Hospital of South Manchester NHS Foundation Trust

Attendance	Representation
Wendy Makin	Director/consultant Christie
Ben Heyworth	Survivorship project manager Christie
Lindsey Wilby	Macmillan Project Manager, Living with and Beyond Cancer, Manchester Cancer
Kathy Pantelides	AHP/Rehab manager Christie
Brian Hixson	Patient representative
Beverley Gail Meenan	Macmillan Lead Nurse for Cancer and Palliative Care, SFT
Kathy McGuirk	SCN Quality Improvement Manager
Debbie Ashforth	Macmillan Transformation Programme Lead LW&BC Pennine Acute
Janet Parkinson	Macmillan info and support manager, East Cheshire
Victoria Cooper	Associate Macmillan Development Manager
Ann-Marie Kelly	Patient Information Manager WWL
Sue Taylor	Patient representative
Vanessa Hickson	Specialist Breast Cancer Nurse, Tameside
Michelle Leach	User Involvement Manager, Manchester Cancer
Damian Aston	LW&BC Programme Manager, Bury CCG
Sinead Collins	Centre Head, Maggie's
Pat Jones	Lead Cancer Nurse, CMFT
Apologies	
Debbie Smith	Macmillan info and support manager, UHSM
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
Felicity Keeling	Macmillan Information and Support Service Manager, PAT
Margaret Hayes	Macmillan CNS, Stockport
Karen Livingstone	Physiotherapist breast/lymphedema, UHSM
Rachel McMillan	St Ann's Hospice and Neil Cliffe Centre representative
Ian Ainscough	Macmillan info and support manager, SRFT
Claire Rehan	Clinical Psychologist, Bolton FT
Sue Summerfield	Macmillan info and support manager, Bolton FT
Claire Higham	Consultant endocrinologist, Christie
Liane Harris	GP, Cancer Lead Bury CCG
Alison McCarthy	Lead Cancer nurse, PAT

Agenda Item	Action
<p>1. Apologies noted Apologies have been noted</p>	
<p>2. Welcome and Introduction Welcome to Kathy McGuirk from the SCN, Damian Aston from Bury CCG, and Sinead Collins from Maggie's. Welcome back to Vanessa Hickson from Tameside.</p>	
<p>3. Minutes from the last meeting The minutes were accepted as a true reflection of the last meeting. Actions from the minutes have either been completed or are covered on today's agenda.</p>	
<p>4. Matters arising</p> <ul style="list-style-type: none"> - <i>Health and Wellbeing Clinic cost models</i> A couple more examples of costs for health and wellbeing clinics were sent to Hodan following the previous meeting, but not enough to perform any sort of analysis. We await the publication of the national commissioning model for the Recovery Package. - <i>Late effects questionnaire</i> The mapping exercise is currently underway for all tumour pathways to identify the important specific as well as commonly encountered late effects relevant to their patient groups and treatments, and to describe what is needed in terms of monitoring. We are also asking who patients with specific problems might be referred to; the intention is to build up intelligence on access to expertise to manage these. A survey was sent to all pathway boards to complete, and we are still encouraging response to this questionnaire. Only Brain/CNS and skin have been received so far, but we are expecting responses from the colorectal and breast pathway boards shortly. - <i>SCN national patient conference</i> A survey is now available online where interested parties can submit ideas for what the national patient conference should cover and how it should be structured, so KM will share the link to that. 	<p>Board members to continue to submit examples of costs of running HWB events</p> <p>KM to share link to conference planning questionnaire</p>
<p>5. Proposal to include community representative on Pathway Board In response to an email from Tracy Kelly, it was proposed that a representative from community services be added to the membership of this Board. The proposal was supported by the Board.</p> <p>It was noted that in general, it is preferable for members from the same organisation to take turns in attending or deputise for each other, rather than constantly increasing the Board's membership.</p>	<p>WPM will inform Tracy Kelly that the proposal was supported.</p>
<p>6. Strategic Clinical Network : update from Kathy McGuirk KM updated members on the progress of the NHS England guidance on implementing the 2015 cancer strategy. It was originally expected to be published by Christmas 2015, but is now anticipated in June 2016.</p>	
<p>7. Annual plan – roles and responsibilities /progress update and action planning</p>	

<p>Objective 1a) Benchmarking metrics including ‘Life after treatment’ audit of patient experience and RP targets. Lead: WPM, JT, KP</p> <p>It was noted that recommendation 55 in the cancer strategy relates to the development of a patient experience tool, and that there has been some discussion about Manchester acting as a pilot site for the metric. WPM has passed the outcomes of Jonathan Turnbull-Ross’s patient focus group to the Macmillan/NHS England team who are working on this. They are committed to rolling it out until 2017. The Board agreed to suspend work on a Manchester Cancer-specific patient experience tool, at least until the outcome of the national work is available.</p>	
<p>Objective 1b) Tumour pathway audit of their agreed plans for EOT summary information (after curative treatment at least) and availability to patients , by March 2016</p> <p>WPM will chase pathways boards for this information, and develop an audit proposal.</p>	Action: WPM
<p>Objective 1c) Baseline recovery package assessment- further data collection from all acute trusts Dec 2015 lead to also include provision of financial/employment advice at each site</p> <p>LW presented the interim findings of the updated mapping exercise she had carried out across all Manchester Cancer Trusts. The intention was to establish which tumour site-specific teams within each Trust have implemented each of the elements of the Recovery Package. The response has been very variable, with some Trusts providing a single response for all tumour types, others providing an individual response for each tumour site, and others failing to respond at all. The data is not yet ready to be analysed because it is incomplete, and a failure to respond doesn’t necessarily mean that teams are not carrying out activities such as Holistic Needs Assessment.</p>	LW will continue to chase responses via the lead cancer nurses.
<p>Objective 2) Development of Manchester Cancer-wide guidance for Health and Wellbeing clinics</p> <p>Now this guidance has been published, KM will add it to the resources page of the SCN website.</p>	Action: KM
<p>Objective 3) Strategies to promote increased adoption and use of care plans</p> <p>BHe reported that a questionnaire has been created on the use of care plans, and that Martine Tempest-Mitchell is in the process of putting this into survey monkey for distribution. It has been designed for staff but it would be interesting to share it with patients too.</p> <p>We need to define what we mean by a care plan – it should provide a road map of what will happen next, and which services will be involved.</p> <p>KM gave an example of the care planning approach used as part of the House of Care model (used to manage Long Term Conditions): patients have all of their results sent to them, and are expected to not only attend a 20 minute-long care planning meeting, but to bring their own questions/agenda with them.</p>	BHe to distribute questionnaire KM to share report when it has been signed off
<p>Objective 4b) Exploring buddy systems</p> <p>KM stated that her research showed that buddying systems costs around £350 per patient for 10 sessions, including travel and training.</p>	

<p>KP reported that she hadn't had a response to her approaches to Aintree. VC highlighted Macmillan Solutions, a 12 week programme addressing 3 defined outcomes per patient...but acknowledged that this was designed to provide solutions to more practical problems.</p> <p>BHi stated that support groups, including online support groups and social media, can provide an informal buddying network. It was asked who supports the support groups? Macmillan Information Support professionals are tasked with keeping their local lists updated (and ML commented that User Involvement have tried to do the same), but it is an almost impossible task.</p> <p>Objective 4c) What can be applied/adapted from other long-term conditions? KM gave further details of the House of Care model that has been adopted in Leeds via a project called "The Year of Care" – the 3 CCGs were given one year to embed the model in practice. They would be happy to visit us to explain how they achieved this.</p> <p>DA stated that Bury is leading on the regional diabetes strategy, which has just been published. WPM said that all of these initiatives need to be connected, making reference to Professor Shahid Ali's presentation at the recent Changing Prospects conference on tools for monitoring patients remotely in primary care.</p> <p>Objective 4d) Development of a 'coping with uncertainty' approach with patients and carers WPM has discussed the development of a tool with Claire Baguley, Programme Manager for the Psychological Professions Network, and will set up another meeting shortly.</p>	<p>VC to find out what Macmillan's strategic approach is to keeping supported groups going, and keeping lists up to date.</p> <p>KM to share report when it has been signed off</p> <p>Action: WPM</p>
<p>8. Presentation by Sinead Collins, Centre Head at Maggie's</p> <p>SC gave a presentation about the new Maggie's centre at The Christie, which is opening shortly. The official opening is 26th April, followed by launch events for Christie staff on 3rd and 4th May.</p> <p>Maggie's provides free practical, emotional and social support to people with cancer and their family and friends, following the ideas about cancer care originally laid out by Maggie Keswick Jencks.</p> <p>Built in the grounds of NHS cancer hospitals, Maggie's Centres are places with professional staff on hand to offer the support people need.</p> <p>The Centres are places to find practical advice about benefits and eating well; places where qualified experts provide emotional support; places to meet other people; places where you can simply sit quietly with a cup of tea. You can talk to, and get advice from, a range of professional people. The Centres are staffed by Cancer Support Specialists, Benefits Advisors, Nutritionists and Psychologists who can support you in whichever way best suits your needs.</p> <p>The first Maggie's Centre opened in Edinburgh in 1996 and since then Maggie's has continued to grow, with 17 Centres at major NHS cancer hospitals in the UK, online and abroad.</p>	

<p>9. User Involvement update</p> <p>ML gave an update on the progress of the Manchester Cancer User Involvement team: their primary target was to engage a pool of 100 people affected by cancer by 31st March – they have 99 with a week to go! They are also on track to have at least one person affected by cancer on each of the fully-functioning Pathway Boards – currently they have representation of 15 out of 17.</p> <p>The team has worked with people affected by cancer to co-produce documentation on What is Macmillan, What is Manchester Cancer, and How You Can Get Involved. They are currently co-producing an awareness for professional session, with a target for all Pathway Directors to attend this in 2016-17.</p>	
<p>10. Innovation fund update</p> <p>a) Third quarterly reports</p> <p>LW highlighted the progress of some of the Innovation Fund projects; half are now reaching their conclusion and the main outcomes of these will be presented at an event in June, the details of which will be confirmed and shared with the Board in the next few weeks.</p> <p>b) PlanBe update</p> <p>BHe gave a demonstration of the purpose and functionality of the PlanBe interactive module, focussing on how users can select which areas of health and wellbeing they would like to focus on. He also explained the rating system that has been chosen for the strength of evidence available for each lifestyle choice or intervention. The Board was very supportive of this piece of work.</p>	
<p>11. Vanguard briefing: clinical transformation overview – and discussion re: how this will impact our 2016/17 work plan</p> <p>There was insufficient time to consider this item at this meeting, so it will be carried over for full discussion at the next meeting in June.</p>	
<p>12. Meeting dates for 2016</p> <p>23rd June – Seminar Room B – Hope Building, SRFT 19th October – Seminar Room B – Hope Building, SRFT</p>	