

Living with and Beyond Pathway Board – Minutes of Meeting

27th of January 2015 3-5pm

Seminar Room 2, Mayo building, Salford Royal FT

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

In Attendance:

Damion Aston , LW&BC Programme Manager, Bury CCG

Robin Muir, Consultant Psychologist, Bolton Foundation Trust

Agenda Item	Action
<p>1. Apologies noted Apologies have been noted</p>	
<p>2. Welcome and Introduction Welcome to Kathy McGuirk from the SCN, Robin Muir Consultant Psychologist from Bolton representing Claire Rehan, and Damion Aston LW&BC Programme Manager Bury CCG</p>	
<p>3. Minutes from the last meeting : Correction spelling of name - Liz Islam Plan B project Manager. All other information has been accepted as true reflection of the last meeting.</p>	
<p>4. Matters arising</p> <ul style="list-style-type: none"> - Health and Wellbeing Clinic cost models HN updated members she has only receive the Christie cost analysis so far. IA will send the SRFT report to HN and PJ will send the return from CMFT. LW will make contact through the innovation fund with UHSM to report on approximate cost analysis of their health and wellbeing clinics. - Scoping buddy system and care plan (Aintree) HN has made contact but unfortunately they were unable to attend this meeting, however there is an opportunity for board members to visit Aintree and HN can facilitate that relationship. BH informed the group that ST would be interested in that visit to Aintree and should be included in the introductions. - Late effects questionnaire 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 has been sent to all pathway boards to complete. Only one return received so far; HN sent a reminder to Pathway Managers to chase consensus update from tumour boards. WPM informed the Board about a Macmillan pilot project of a 'virtual MDT', starting later this year. This will be hosted in Manchester at Christie but referrals will come from across England. These will be invited in relation to patients who have had pelvic tumours, bone marrow transplants and those treated in childhood. The objective is to bring a panel of experts on later consequences of treatment to review anonymised clinical information including imaging, and then to put forward suggestions and recommendation on next steps to managing the late effects. The expectation is a two week return of a collated response to the referrer; it will up to referrers on the extent to which they act upon the advice. Cancer leads and Medical Directors will be approached to help recruitment to a bank of experts. 	<p>HN to draft cost model report for March meeting if SRFT, CMFT and UHSM is received.</p> <p>HN to facilitate a meeting with Aintree and LW&BC members.</p>
<p>5. Strategic Clinical Network : points from Kathy McGuirk KM updated members on the restructure of the SCN which has now been formalised. From the 1st April 2016 Greater Manchester and East Cheshire SCN will be aligned with the Academic Health Science Network. The South Cumbria and Lancashire SCN will link with Merseyside. She described a pilot project in Lancashire with a focus to support cancer patients in</p>	

<u>Questionnaire methodology</u>		
Rules	Sub-factor	Comments
Use of open and closed questions	<ul style="list-style-type: none"> - Depends upon topic - Depends upon Stage of Journey 	The group concluded this is largely dependent on the goals of the survey, topic and stage of cancer experience.
Information page	<ul style="list-style-type: none"> - Explaining the questionnaire - How long it will take - Option of not disclosing information/completing questionnaire - Data protection/not shared by third parties/how the information will be used - Only necessary personal information 	The use of an information page was important to ensure participants are aware of key messages. The group advised an honest, informative information page will improve completion and response rates.
Assistance and Accessibility	<p>Explain options to help fill in the survey</p> <p>Options for other languages</p>	A clear explanation of where assistance can be found is required. Options for other languages should be offered and available.
Electronic and Paper copy		Ability to access the survey in different forms would improve uptake and accessibility
Use of plain English		Questions need to make use of plain English language.
Medical jargon to be explained in footnote or link		Where medical terms are used, these must be explained via a footnote, glossary, or hyperlink, to ensure participants are able to understand all terms and words.
No acronyms		Acronyms should be avoided

Living with and Beyond Cancer Questionnaire – Suggested Themes

Suggested Theme	Why this theme is important...	
Emotional and Psychological Support	<ul style="list-style-type: none"> • Are ALL emotional and psychological needs assessed and met? • Different psychological needs are incurred over time. • Different accessibility to support amongst patients— Support groups/meet-ups, family and friends, psychological support services. • Impacts upon relationships. • Acceptance of what has happened. • Is there capacity to get all issues addressed? • Holistic approach to the individual as a whole. 	
Late Effects Consequences of treatment	<ul style="list-style-type: none"> • Managing symptoms and physical needs. • Disability. • Sexual function and relationships. • Access to rehabilitation and occupational therapy. • Have all health needs been assessed at 12months? 	
Fear/Uncertainty of the future Planning for the future	<ul style="list-style-type: none"> • Fear of reoccurrence. • ‘Getting back on track’ <ul style="list-style-type: none"> ○ Career/Employment ○ ‘new life’ ○ Well informed ○ Do’s and Don’ts of ‘new life’ • Potential for an individualised plan at 12 months post treatment. 	
Financial and employment	<ul style="list-style-type: none"> • Ability to carry on former employment/study 	

<p>issues</p>	<ul style="list-style-type: none"> • Benefit advice: <ul style="list-style-type: none"> ○ Where to get help ○ Complexity of the 'system' ○ Continual changes to the financial system 	
<p>Organisational issues</p>	<p>Participants reported having strong feelings regarding their organisational experience of the health service, after treatment:</p> <ul style="list-style-type: none"> • Multiple sources of information – not all the information is the same • Service delivery failure issues • Competency/training of staff • Mistakes/errors during experience • Multiple service providers – patients having to relay information to various sources 	
<p>Entitlements (Disability)</p>	<ul style="list-style-type: none"> • Not all people are aware of disability entitlements. • Difficulty in society understanding cancer as a disability. • More formal/wider recognition of cancer as a disability. 	
<p>Carer's issue</p>	<p>Participants felt the questionnaire should also focus on the needs of and experience of those who are the patient carer's.</p>	
<p>Additional Theme</p>	<p>Participants felt it is important to include an additional theme/question for respondents to include information they wish to disclose not captured by the questionnaire.</p>	
<p>Members thanked JT and the focus group for the work that has been undertaken. WPM noted that the national cancer strategy published last year proposed a new metric for experience of life after cancer. She had asked John Herring (SCN) to find out how far this had progressed and if so was there potential for development and testing in MC. MK also highlighted building on the Equality Act; a new guidance from July 2016 will strengthen expectations about communication and access to information..</p>		<p>MK/JH (SCN) to brief WPM.</p> <p>KM to share the link on the access to information guidance.</p>
<p>Objective 3a) Strategies to promote increased adoption and use of care plans</p> <p>Leads: Pat Jones, Ben Heyworth, Sue Taylor, Sue Summerfield, Lindsey Wilby.</p>		

<p>BH and PJ will develop an action plan to share at the next meeting. KM will research existing national models of services using care plans.</p> <p>WPM suggested that we should aim to produce something useful for the tumour pathway boards. The objective for members is to develop guidance on the models available and to explore the potentials, barriers and opportunities similar to the Health and Wellbeing Events guidance paper.</p> <p>There was discussion on the opportunity of cancer care reviews in primary care, and how this can inform care plans and what are the opportunities and challenges. LW has the MCIP care plans and LH other information; she is also exploring within Bury CCG the benefits of having a generic model of care plans for Long Term Conditions and cancer might fit with this.</p> <p>Objective 4 Living with Cancer recommendations</p> <p>Potential of buddy systems for peer support:</p> <p>JT reported that a further focus group in February was planning to consider the need scope the needs and the areas to cover regarding buddy systems and to explore whether formal or informal models are best. It was felt there should be consideration of what was to be expected of a buddy (competencies) and if a formal system, that resources would be needed. KM has explored from a national perspective, telephone support in mental health service which uses formal and informal methods. KM had encountered a model in HIV that used paid volunteer patients (at band 5) who have access to records, who do holistic needs assessment for newly diagnosed patients with HIV.</p> <p>Different stages require different support and such it is important to highlight the stages and the structures needed in implementing buddy system. WPM proposed that members should enquire within their organisations, especially services outside cancer who have developed buddy systems, and report back next time></p> <p>- Development of a ‘coping with uncertainty’ approach with patients and carers</p> <p>Leads: WPM, R McM, JT/user input.</p> <p>The aim would be to develop a simple approach that could be promoted among professionals in routine contacts with patients, particularly at completion of treatment. and adopted easily to reduce some of the anxieties about this universally experienced difficulty. Simply recognising that most people experience is important. The Christie psycho-oncology team have developed a brief intervention for patients. RM suggested possibly the clinician should start the conversations on “from experience we know you will be thinking... or feeling ...” and they have the opportunity to come back if the</p>	<p>BH and PJ to develop an action plan to move forward care plan objective and report meeting.</p> <p>HN to share the MCIP and Vision care plans with BH and PJ.</p> <p>Manchester User involvement to feedback on the progress of focus group at the next meeting.</p> <p>All LWBC members to find out about local adoption of buddy systems</p>
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<p>patient needs support in dealing with uncertainty. We might be able to come up with some top tips around this for patients and staff.</p> <p>HN mentioned the value of health coaching skills, motivational interview techniques also enable clinicians to be more effective. KM to share contacts with LH on motivational interview training.</p> <p>WPM hopes that the psycho-oncology team will support the development of an approach and to consider there are specific resources needed to promote. LH updated IAPT service option in Bury the team are not going to support this because their focus is not cancer and they also asked for funding. LH proposed they need to access 'talk cancer' training.</p> <p>HN to write poster "you said we did" to feedback on the outcome of all the focus group engagement activity in the past year.</p>	<p>KM to share contacts with LH on motivational interview training</p>
<p>7. Manchester Cancer Vanguard</p> <p>The proposal for a Cancer vanguard initiative was developed through Manchester Cancer Provider Board, The Christie and Trafford CCG (as lead cancer commissioner). This was fully supported and submitted (http://gmcancervanguard.org/documents/) and was announced as being successful in September 2015. Approval of the vanguard was dependent on the GM team working in partnership with 2 similar scale applications covering all of Greater London, and this has now been formally agreed.</p> <p>There is now a single national cancer vanguard to explore new models of delivering care to cancer patients: the London partners are The Royal Marsden NHS Foundation Trust and University College Hospitals London NHS Foundation Trust (UCLH), who lead South London and North London collaborations respectively. Since the GM proposal covers 3 million people, the vanguard provides additional scale taking the total combined population to over 10 million residents. The national vanguard approach provides opportunities to share learning and expertise in piloting changes to the cancer healthcare system, but still allows for GM to develop a local approach to transformation.</p> <p>The vanguard provides Greater Manchester with the opportunity to radically restructure both the commissioning and provision of cancer care across the entire patient pathway in order to realise fundamental improvements in clinical outcomes and patient experience and to also secure long term financial and clinical sustainability. This work will form a key transformational work stream in the Devolution Manchester programme and will complement the new organisational forms and functions currently being considered.</p> <p>The cancer vanguard is a two year programme and includes Living with and</p>	

beyond/supportive care and palliative care as part of the 6 work streams described below. The work streams will include commissioners, providers, professionals and people affected by cancer.



The workstream for Living with and beyond/supportive care and palliative care includes

- Major transformation of follow-up (breast, urology, colorectal). Culture change, learning from MCIP and NCSI.
- Goals of Care Initiative (GOCI) focus on people living with cancer and exploring how to support patients through the transition to match the aims of treatment from clinician perspective and bringing together with patients goals and priority of care. Shared with patients, palliative care, primary care which will support the advance care planning conversations.
- Enhanced decision making around cancer treatment at the later part of the pathway focus on people living with cancer.
- 7 day specialist palliative care services, prioritised by the MC palliative and end of life care pathway board and SCN. There is a need to develop new models and to address the workforce challenge. St Ann’s hospice need to link with the palliative board to engage with the project to ensure there is a link in the management of care.

8. Evaluating alternative models of patient follow-up in oncology clinics - Study Report

The report highlights interesting nurse led follow-up model members to read and feedback any thoughts.

9. User Involvement update

There is an opportunity to develop a small community of users in the future. BH commented that there needs to be clarity on the work to ensure the 6 meetings are utilised effectively. There is an ongoing recruitment drive working with MC user involvement team.

KM mentioned that the SCN are hosting another national conference for patients hosted in July, Manchester SCN are involved but the national team are organising. HN suggested this could be an opportunity to direct the agenda and highlight the key areas to cover from the work of Manchester Cancer. BH would like to see the showcasing of coproduction with patients as good examples in Manchester Cancer. KM said she will find out if the agenda has been set and

Members to email HN their thoughts on what should be included in the national conference to send to the Cancer

<p>if there is opportunity to influence.</p>	<p>Manager at SCN.</p>
<p>10. Innovation fund update Quarter reports are due to be completed will be reporting at the next meeting. The showcase event was originally going to be held in June however due to project start date there will be two events one in June and the next in October.</p>	
<p>11. A.O.B Spread the word! 'Changing prospects' conference 11 March 2016 (www.changingprospects.co.uk) – members to register through the website and send to members outside of Greater Manchester. HN to disseminate to the SCN members in Lancashire and South Cumbria any international members interested to join can also via video feed.</p> <p>HN will be changing jobs and working as the PET CT Scan Education Programme Manager for the School of Oncology from the 1st of March. A new Pathway Manager will be recruited to support the pathway work. WPM and all members said how much they had valued Hodan's input and support for LWBC and were very sorry to lose her.</p> <p>JT is also moving on to working as a project manager at ST Helen's emergency care the team are currently working on his replacement. Members thank JT for his tremendous contribution at a short period of time.</p> <p>Maggie's at Christie Centre Head has been invited to join the LWBC at our next meeting and will tell us about the role of this new development in Manchester.</p>	
<p>12. Meeting dates for 2015/15</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>	