

**Greater Manchester  
Cancer Services**  
part of **Manchester Cancer**

**MINUTES**

**Living with and Beyond Cancer Pathway Board  
The Christie Trust HQ Room 6  
The Christie Hospital  
23<sup>rd</sup> March 2014**

Abbrev.

LW&BC : Living With and Beyond Cancer  
NCSI : National Cancer Survivorship Initiative

**Action Log:**

<b>Action</b>	<b>Owner</b>	<b>Date agreed</b>	<b>Status</b>
Review Terms of Reference	WM / ALL	25/03/2014	In Progress
Members of the group to consider how best to engage with users and bring ideas to the next meeting	WM / ALL	25/03/2014	In Progress
Members should indicate their availability for future meetings	WM / ALL	25/03/2014	Completed
Members of the group to consider how we might go about undertaking a mapping exercise of resources currently available to patients that are part of the recovery model.	WM / ALL	25/03/2014	In Progress
A draft programme of work for the group to consider at the next meeting	WM / ALL	25/03/2014	Email suggestions and comments to WM
Invite to members to put forward other venues for future meetings	ALL	25/03/2014	Email suggestions and comments to WM

## 1. Welcome and Apologies:

### Attendees:

Wendy Makin	LW&BC Pathway Director	Manchester Cancer
Ben Heyworth	Survivorship Manager	The Christie
Debbie Smith	Macmillan Info Manager	UHSM
Julie Pieczarka	Macmillan Info Manager	Mid Cheshire Hospital Trust
Valerie Goode	Nurse Clinician (lymphoma)	Manchester The Christie
Karen Livingstone	Clinical Specialist	UHSM
Ayse Gurpinar-Morgan	Clinical Psychologist	Bolton Hospital Trust
Kath Pantelides	Rehabilitation Manager	The Christie
Claire Higham	Consultant endocrinologist	The Christie
Felicity Keeling	Macmillan Info Manager	PAT
Abbas Chittalia	Consultant Clinical Oncologist (breast and lung cancer)	The Christie/Stockport NHS FT
Pat Jones	Lead Cancer Nurse	CMHT
Jo Keogh	Associate Director	PAT
Pauline West	Macmillan H&W Manager	Trafford General Hospital
Teresa Karren	Macmillan Development Manager	Macmillan cancer Support
Julie Orford		UHSM
Janet Parkinson	Macmillan Info Manager	East Cheshire Hospital Trust

### Apologies:

Ian Ainscough (SRFT) , Karen Buckley (East Cheshire)

## **2. An Introduction to Manchester Cancer “Setting the Scene”**

WM gave a brief overview of Manchester Cancer and explained that the LW&BC pathway group would be a cross-cutting group with a remit to promote the integration of survivorship into mainstream practice across all disease groups.

## **3. LWBC pathway Board constitution and responsibilities**

The MC provider board will hold us to account and will require an annual action plan from all provider boards by July 2014 on the proposed work and education programme.

Our work will support those who are living with cancer as a long term condition as well as those who remain free of cancer; we will work closely with the palliative care group in relation to those with on-going illness. As a cross cutting group, one of our responsibilities will be to influence and support the efforts of the disease specific pathways to understand, adopt and embed the principles of cancer survivorship.

Manchester cancer has a generic template for terms of reference. WM had amended as a first draft for the LWBC Board which was tabled at the meeting. Comments are invited and we will formally approve next meeting.

The responsibilities of individual LWBC representative include regular attendance at pathway board meetings (a target of 5/6 each year); active participation in the work including sharing of ideas and good practice, and to ensure that the 'survivorship agenda' is understood and adopted locally.

Membership will be reviewed after 6 months. WM felt that we already have a good balance of experience and knowledge across the area but we may identify others who should be co-opted in time. We will be seeking primary care and input from user representatives. User Involvement is an important part of each pathway board, as illustrated by the stakeholder panels used during the recruitment of the director roles.

We will liaise with the palliative care group as we recognise that in the independent sector, hospices and others provide support to patients and cares; how we ensure this representation for both will be under discussion.

Comments:

The group was asked to think through how the Board could fully utilise and include our user representatives. A board member will be invited to take on the role of supporting user

representatives. There will be a range of ways through which users can be involved e.g. via a reference group, via technology. The group agreed that this was an important consideration and we should also consider if user involvement should be time limited (KP).

## **Background**

WM gave a brief overview of her professional background and the growing interest in cancer survivorship nationally. WM highlighted the RAGE women, who lived with severe late effects from radiotherapy given a number of years earlier, as being the catalyst for initiatives by Macmillan Cancer Support. This leads to recognition that treatments for cancer can have long term consequences which are generally not a result of poor care or techniques. The formation of the NCSI and the Visioning Document followed. Coupled with increasing clinician interest in the documentation of the late effects, this also reflected a growing patient voice saying that cancer survivorship should be given a higher priority. WM likened the situation to the development in palliative care that occurred during the 1980s.

Comments:

Survivorship is often talked about these days, but do professionals really have an understanding of the implications? How are we taking this forward? (SJ)

There is a growing expectation that Primary Care will also have to change, and support cancer patients closer to home. (TK)

Engaging with commissioners is very important as the agenda cuts across all aspects of the health economy. (JP)

Macmillan GPs are very keen to work on G.P Care reviews and can be very influential. (DS)

The other pathway leads have a responsibility to show that they are addressing survivorship principles in each of their pathways; to begin with our expectation might be, for example, adoption of the elements of the recovery package. Macmillan Cancer support have recognised the size of this task so our work will be supported by a part-time project manager and also a short term innovation fund which the other pathway can use to start implementation. LW&BC pathway board will have the task of reviewing their proposals and ensuring they will support and move the work forward. (WM)

#### **4. Videos: Continuity of Care and the Recovery Model**

The group viewed two video presentations around the continuity of care and the recovery model.

All of the films were produced by Macmillan and are now available on YouTube.

- **Electronic Holistic Needs Assessment:** <http://youtu.be/V9jwh6-9VZU>
- **Holistic Needs Assessment and Care Planning:** <http://youtu.be/q6PCBkfEks4>
- **Training for Holistic Needs Assessment and Care Planning:** <http://youtu.be/F6iQv4aJePA>
- **Recovery Package:** <http://www.youtube.com/watch?v=tBDo3XJG378>

#### **5. Current activities and next steps**

There was a round table discussion around next steps and the expectations of board members.

- Services already exist but it needs to come together. Patient education is the key: communication (AC)
- Engaging patients is really tough (KP)
- However, there have been some successes. The Hope Course is successful because patients recommend it to their peers. It was advertised on the back of toilet doors. (DS)
- However, there is evidence to suggest this is not consistent across the country. (KP)
- It's difficult to get the nursing teams to "think beyond their disease group" (JP)
- In East Cheshire, a walking group has been very successful in bringing together patients of different diagnoses as well as promoting activity (JP)
- We've grown our walking group out of the HOPE course. We found that some ladies were walking without wigs - a safe, confident environment. (DS)
- Some discrepancies exist within clinical follow up between disease groups e.g. gynaecology vs. GI around late effects. Pathways ( for monitoring/management of later effects) should be accessible by all at risk groups (CH)
- Patients are most receptive to change at the point of diagnosis. Also, the carers and family who might need support. (TK)

- The next generation will be more ready to question and ask for more than the current older patients. (JP)
- Signposting to existing services is very important. (TK)
- “Stepping Out” pilot: What people need out of treatment is very different to when they are receiving treatment. (PW , who gave a brief outline of the “stepping out” project)
- The Recovery Package is not just a replacement – we need to think more broadly and ensure we maintain a person-centred approach. (AGM)
- An obvious thing to get behind would be for elements of the recovery package to be embedded across all areas. We should look at a mapping exercise of existing resources and try and identify numbers of patients affected. (WM)
- Vital to get the consultants and GPs on board (KP)
- Risk stratification is not just medical but must include holistic need as well. (FK)
- We also need to maintain a consistency of language: highlight what exactly we mean by “survivorship” for example. (AGM)
- Inviting managers and gaining executive buy-in is vital (JO)

## **6. Agreed actions for Board members**

- To comment on draft terms of reference for signoff at the next meeting
- To develop a survivorship glossary for professionals and patients , such as a friendly translation of ‘ holistic needs assessment’ , ‘self-management’, recovery package etc.
- Ideas for how we might undertake a baseline mapping of existing resources and practice
- Contribute your views on priorities to include in our work programme

## **7. Future meetings**

These will be 2 monthly, with some variation on day of the week and venue: to be circulated shortly