

Actions of the meeting held on  
Thursday 17 November 2011, 10:00

Yorkshire Cancer Network

St Gemma's Hospice, Moortown, Leeds, LS17 6QD

## Present:

Natalie Geddes	Calderdale and Huddersfield NHS Foundation Trust
Jane Mielniczek	Macmillan Cancer Support
Francesca Pendino	Mid Yorkshire Hospitals NHS Trust
Peter Allen	User Partnership Group
Marion Allinson (Co-Chair)	
Mitzi Blennerhassett	
Hugh Butcher (Co-Chair)	
Lesley Conti	
Sue Cooke	
Moira Dailey	
Rodney Dailey	
Jean Gallagher	
Anthony Hall	
Anne Jarvis	
John Marshall	
Edward McGowan	
Jeanette Newman	
Alan Rawson	
Patricia Thorpe	
Jane Archer	York Teaching Hospital NHS Foundation Trust
Francesca Evans	Yorkshire Cancer Network
Emma Jehan	
Colin Sloane	
June Toovey	

## Apologies

Christine Allmark, Pamela Brewis, Robert Brewis, Kenneth Corcoran, Robert De La Warr, Vicki James, Margaret Jennings, Helen Jones, Amanda Procter, Alan & Dorothy Smith, Louise Wem, Pamela Whitaker

1. Welcome, Introduction & Apologies			
Log No	Action	Lead(s)	Deadline
13	Hugh Butcher welcomed the Group and introduced 3 new members: <ul style="list-style-type: none"><li>• Anne Jarvis, Service User;</li><li>• Jeanette Newman, Service User;</li><li>• Jane Mielniczek, Macmillan Involvement Facilitator.</li></ul> To add new members to the Group membership.	E Jehan	01/12/2011

<b>2. Any Other Business - Urgent Items</b>			
Log No	Action	Lead(s)	Deadline
14	<p>Marion Allinson raised the issue of car parking at a recent visit to St. James's; the Bexley Wing multi storey car park was closed and staff members did not know where to direct people. It was agreed that this could be very distressing for patients and visitors.</p> <p>Jean Gallagher reported a problem with disabled parking at Bradford, following feedback she has had a very positive response from their Chief Executive and Estates department.</p> <p>It was agreed that Colin Sloane will feed back the Groups concerns to Angie Craig, Lead Cancer Manager at LTHT and the Estates department.</p>	C Sloane	01/12/2011
<b>3. Action Log from the last meeting</b>			
Log No	Action	Lead(s)	Deadline
15	The action log from the last meeting was agreed as an accurate record.	N/A	N/A
<b>4. Matters arising</b>			
Log No	Action	Lead(s)	Deadline
16	<p>► Standard Letters</p> <p>Colin Sloane gave the Group a brief overview of this issue; several members of the Group have raised concerns with Trust standard/template letters containing misleading or contradictory information being sent to patients. The Patient Information Steering Group had been leading on this work, however following recent changes to that Groups focus, the User Partnership Group were asked if they could take this forward.</p> <p>Jane Archer advised the Group that each Trust has specific ways of dealing with complaints regarding standard letters and it may be the place of Local Partnership Groups to deal with these issues.</p> <p>Following discussion it was agreed that Colin Sloane would put a paper together to look at the best way to take information related issues forward and report back to the Group at the next meeting. The Local Information Leads were asked to clarify their Trusts process for producing and reviewing standard letters.</p> <p>To update the Group at the next meeting.</p>	C Sloane	01/12/2011
17	To feedback to Colin Sloane, standard letter processes for each Trust.	Local Information Leads	01/12/2011
18	<p>► Links to the Yorkshire Cancer Research Network</p> <p>Colin Sloane informed the Group that Carol Sleigh plans to attend alternate meetings to update the Group on the work of the Research Network.</p> <p>To contact Colin Sloane if interested in joining the YCRN User Group.</p>	All	Ongoing

<b>5. LINKS Event Report</b>			
Log No	Action	Lead(s)	Deadline
19	<p>The 2011 YCN LINKS Event Report was tabled. Colin Sloane apologised for his absence on the day and thanked members of the Group, in particular June Toovey and Marion Allinson, for ensuring the event went ahead successfully.</p> <p>The report contains a short list of recommendations for the User Partnership Group to consider and include in the Work Programme.</p> <p>Marion Allinson informed the Group that 2 clear themes arose; 1) the need to work more closely with Locality Groups, and; 2) the need to collect current patient experiences.</p> <p>To include the recommendations into the Groups Work Programme.</p>	C Sloane	01/12/2011
20	<p>Colin Sloane tabled an updated list of LINKS contacts and encouraged members of the Group to get involved with their local Group.</p> <p>To circulate the list with the action log.</p>	E Jehan	01/12/2011
21	<p>Francesca Pendino queried whether there were plans to share the YCN LINKS Event Report with the Network Board to demonstrate the work undertaken by the Group and its relationship with the locality groups.</p> <p>It was agreed that the Co-Chairs will include the YCN LINKS Report in their annual report to the Board.</p> <p>To add an User Involvement update to a future Board agenda.</p>	C Sloane	Ongoing
<b>6. Equality &amp; Diversity Project - update</b>			
Log No	Action	Lead(s)	Deadline
22	<p>for the benefit of new Group members Colin Sloane gave a brief overview of the project. Following a successful bid to Macmillan for funding for a 2 Equality &amp; Diversity Project Workers the Network advertised for a Learning Disabilities (LD) Outreach Worker and a Black &amp; Minority Ethnic (BME) Outreach Worker. The LD post was appointed to however the BME post was not.</p> <p>The first meeting of the Equality &amp; Diversity Steering Group took place in September and was well attended. It was agreed to have a sub group for each arm of the project (LD &amp; BME), the main group will meet as and when required.</p>	N/A	N/A

<b>6. Equality &amp; Diversity Project - update</b>			
Log No	Action	Lead(s)	Deadline
23	<p>► Learning Disabilities</p> <p>Francesca Evans (LD Project Worker) has been in post for several months focussing on the needs of cancer patients with Learning Disabilities. An interim progress report will be available in March/April 2012.</p> <p>Francesca has developed a questionnaire and recently undertook her first interview with a cancer patient and her carer. A further 3 potential interviewees have been identified and work is on-going to identify more.</p> <p>Work is also underway with the Bradford Palliative Care team who have put in a bid to Macmillan for funding for a LD project.</p> <p>Sue Cooke informed the Group that Breast Cancer Care have undertaken a project and developed literature specifically for patients with learning disabilities. Francesca agreed to meet with Sue to discuss this further. Further information can be found on the Breast Cancer Care website (<a href="http://www2.breastcancercare.org.uk/publications/breast-health/your-breasts-your-health-supporting-people-learning-disabilities-bcc163">http://www2.breastcancercare.org.uk/publications/breast-health/your-breasts-your-health-supporting-people-learning-disabilities-bcc163</a>)</p> <p>The next meeting of this Group is on Friday 2nd December at the Shine Centre in Leeds.</p> <p>To update the Group at the next meeting.</p>	F Evans	28/02/2012
24	<p>► BME Groups</p> <p>The second post, to focus on the needs of cancer patients from BME (Black &amp; Minority Ethnic) Groups, was not appointed to. Hannah Hurley is leading on this work and the funding for the post has been used to commission INVOLVE; an external organisation with experience working with BME Groups across the region, to take specific projects forward.</p> <p>The project will focus on working with South Asian groups however it is anticipated the once complete the User Partnership Group will consider how to work with other BME Groups across the region.</p> <p>The next meeting of this Group is on Wednesday 23rd November at the Womens Activity Centre in Halifax.</p> <p>To update the Group at the next meeting.</p>	H Hurley / C Sloane	28/02/2012
<b>7. Peer Review Self Assessment Report &amp; Feedback</b>			
Log No	Action	Lead(s)	Deadline
25	<p>Colin Sloane updated the Group following the recent Peer Review and Self Assessment of the Group.</p> <p>The Group scored 100% at Self Assessment however scored 92% at Internal Validation, failing on one measure; lack of a Lead Clinician as a member of the Group. Only 2 other Networks scored as highly.</p> <p>The next step will be to continue to develop the Work Programme.</p>	N/A	N/A

<b>7. Peer Review Self Assessment Report &amp; Feedback</b>			
<b>7.1 Membership Review</b>			
Log No	Action	Lead(s)	Deadline
26	<p>The large Group membership was raised at the recent Internal Validation, the Peer Review team suggested a membership review and highlighted that there is need to involve new and different members in work streams.</p> <p>To undertake a Group membership review.</p>	C Sloane	Ongoing
<b>7.2 Executive Group</b>			
Log No	Action	Lead(s)	Deadline
27	<p>The Peer Review Team suggested the formation of an Executive Group to progress specific areas of work. The Group will initially meet on a monthly basis and Colin Sloane asked for expressions of interest.</p> <p>It was also suggested that the Exec Group will look at succession planning as Hugh Butcher and Marion Allinson have been in the roles of Co-Chairs for 5/6 years now.</p> <p>To contact Colin Sloane if interested in being a member of the Exec Group.</p>	All	01/12/2011
<b>8. YCN UPG Forward Plan</b>			
Log No	Action	Lead(s)	Deadline
28	<p>Discussion took place regarding future work for the Group.</p> <p>Work will continue to ensure each NSSG have Service Users on the membership.</p> <p>Current work stream priorities for the Network are:</p> <ul style="list-style-type: none"> <li>• AEDI Project (Awareness and Early Diagnosis Initiative), a public awareness campaign; Be Clear On Cancer, focussing on bowel cancer is planned. John Marshall has agreed to be part of this work.</li> <li>• Survivorship Project; key work streams have been agreed and are being taken forward by the Survivorship Group. The Network Service Improvement Facilitators are working with the NSSGs to progress individual projects.</li> <li>• End of Life Care; a meeting is planned to look at how the User Partnership Group can be involved in the End of Life Care work.</li> </ul> <p>To update the Group on the progress of projects as necessary.</p>	C Sloane	Ongoing
29	<p>Colin Sloane informed the Group that he will continue to support local User Partnership Groups.</p> <p>To contact Colin Sloane if support is needed for local Groups.</p>	All	Ongoing
<b>9. AOB</b>			
Log No	Action	Lead(s)	Deadline
30	<p>Colin Sloane tabled an update on Strategic Health Authorities (SHAs) and Clinical Commissioning Groups (CCGs) and advised the Group that changes are occurring continually.</p> <p>To circulate the update with the action log.</p>	E Jehan	01/12/2011

<b>9. AOB</b>			
Log No	Action	Lead(s)	Deadline
31	<p>Sue Cooke informed the Group that LTHT have asked her to compile a list of the patient feedback received from the New Perspectives courses run at the Robert Ogden Centre. Feedback includes general comments, complaints, areas for improvement and so on and Sue is currently grouping the feedback into themes and identifying which hospital the comments relate to.</p> <p>Permission from the patients has been received to share this feedback.</p> <p>To send the feedback to Colin Sloane.</p>	S Cooke	Ongoing
32	<p>Mitzi Blennerhassett brought a number of websites and articles to the Groups attention.</p> <p>To circulate the information with the action log.</p>	E Jehan	01/12/2011

**Date of Next Meeting(s)**

Tuesday 28th February 2012 10:00am  
 St Gemma's Hospice, Moortown, Leeds, LS17 6QD

Thursday 29th March 2012 10:00am  
 St Gemma's Hospice, Moortown, Leeds, LS17 6QD [EVENT]

Wednesday 27th June 2012 10:00am  
 St Gemma's Hospice, Moortown, Leeds, LS17 6QD

Thursday 27th September 2012 10:00am  
 St Gemma's Hospice, Moortown, Leeds, LS17 6QD [EVENT]

Tuesday 13th November 2012 10:00am  
 St Gemma's Hospice, Moortown, Leeds, LS17 6QD