

Actions of the meeting held on  
**Wednesday 12 December 2007, 11:00**

Yorkshire Cancer Network

YCRN Conference Room 1, Ida Nurses Home, Cookridge Hospital

**Present:**

Reva Underwood	Bradford Cancer Support Centre
Marion Allinson (Chair)	User Partnership Group
Christine Allmark	
Hugh Butcher (Chair)	
Sue Cooke	
Rodney & Moira Dailey	
Sandra Parish	
Alan Rawson	
John Revely	
Diana Robinson	
Alan & Dorothy Smith	
Fiona Stephenson	Yorkshire Cancer Network
Georgina Thomson	
June Toovey	

**Apologies**

Mitzi Blennerhassett, Joan Lesley Conti, Vicki James, Margaret Jennings, Susan Keir, Aline Nowell, Keith Nowell, Jan Richardson, Jan Roberts, Sally Scales, David Shreeve, Colin Sloane, Pamela Whitaker

1. Welcome, Introduction & Apologies			
Log No	Action	Lead(s)	Deadline
73	<p>The group were informed that Aline &amp; Keith Nowell would temporarily be taking a break from membership of the group.</p> <p>Also the group were told that Brian Atkins has retired from the group.</p> <p>Hugh Butcher agreed to write to Brian, on behalf of the UPG, warmly thanking him for his sterling work on User Support and Involvement.</p>	H Butcher	N/A
3. Any Other Business - Urgent Items			
Log No	Action	Lead(s)	Deadline
74	<p>► Macmillan Mobile Information Unit</p> <p>June Toovey informed the group that the Macmillan Mobile Information Unit will be in the Network region for three weeks in September. This will be from 8th-28th September 2008. As three people need to be present on the unit at all times, volunteers are needed to help staff it. Service users and carers have been asked to volunteer. Professionals have also been asked but will be limited in the time that they can spare, but there will be at least one professional present at all times. Volunteers can offer as much or as little time as they would like and training will be given. The most appropriate venue within each locality, for the unit, is still being determined at present but as soon as this is decided a timetable can be drawn up of where it will be.</p> <p>To update at the next meeting when dates and venues will be available.</p> <p>To inform the Local User Partnership Groups about this and ask them for volunteers.</p>	P Atha	Review at Next Meeting

<b>3. Any Other Business - Urgent Items</b>			
Log No	Action	Lead(s)	Deadline
75	<p>► Cancer Reform Strategy</p> <p>June Toovey tabled to the group copies of the executive summary which includes a section on 'What the Cancer Reform Strategy means for patients' and the chapter titled 'Living with and beyond cancer'.</p> <p>The group were informed that this was a key paper that would set the priorities for cancer services in the foreseeable future. It was worthy of detailed study.</p> <p>To circulate hard copies of these two chapters to the group.</p>	P Atha	04/01/2008
76	Philip Melling to put a link to the Cancer Reform Strategy on the YCN website.	P Melling	31/12/2007
77	<p>► Mitzi Blennerhassett's Email</p> <p>A few months ago Mitzi Blennerhassett circulated an email about chemotherapy.</p> <p>Hugh Butcher to ask Mitzi Blennerhassett if she will lead on this item at the next meeting.</p> <p>To discuss at the next meeting and resend the email with the agenda.</p>	H Butcher/P Atha	Next Meeting
78	June Toovey to check if Mitzi Blennerhassett's suggestions are in the supportive care pathway.	J Toovey	01/01/2008
<b>4. Matters arising</b>			
Log No	Action	Lead(s)	Deadline
79	The minutes from the last meeting held on Wednesday 26th September were agreed as accurate.		N/A
<b>4.1. Web Content Manager Post</b>			
Log No	Action	Lead(s)	Deadline
80	June Toovey informed the group that Nazeem Mungur has been appointed to the Web Content Manager Post and will start on Monday 7th January. His job will be to develop a Website for Patient Information and it will be linked to the YCN Website. The group were informed that a similar position was created in Manchester 2 years ago and their Website has now gone live, <a href="http://www.gmccn.nhs.uk">www.gmccn.nhs.uk</a> .		N/A
<b>4.2. Location of meetings</b>			
Log No	Action	Lead(s)	Deadline
81	<p>The group discussed the possible venue for the meetings in 2008. The two options were:</p> <ul style="list-style-type: none"> <li>•Bexley Wing, St James's Institute of Oncology</li> <li>•St Michaels Hospice, Harrogate</li> </ul> <p>To circulate a form to the group explaining the venue choices and how they can be reached. The group to then send their choices back to the YCN by Wednesday 2nd January 2008.</p>	G Thomson	02/01/2008

<b>4.3. Admin support for the group</b>			
Log No	Action	Lead(s)	Deadline
82	The group were informed that a new Network Support Officer has been appointed who will temporarily support the group until Helen Ryan returns from Maternity leave. Her name is Clair Murray and she will be starting on Wednesday 2nd January 2008.		N/A
<b>4.4. Name for the New Oncology Wing</b>			
Log No	Action	Lead(s)	Deadline
83	The New Oncology Wing has been named the Bexley Wing, St James's Institute of Oncology.		N/A
<b>4.5. User Involvement Facilitator Post</b>			
Log No	Action	Lead(s)	Deadline
84	Colin Sloane has been appointed for the User Involvement Facilitator Post to replace Martin Child. He will be starting on Wednesday 2nd January 2008.		N/A
<b>4.6. Process for Claiming Expenses</b>			
Log No	Action	Lead(s)	Deadline
85	To defer to the next meeting.	P Atha	Next Meeting
<b>4.7. Computer disposal policy</b>			
Log No	Action	Lead(s)	Deadline
86	<p>The group were informed that the Trust no longer allow recycling of old computers that are not being used. This is because in the past people have gone to the Trust if they are having problems with the computer and expect them to fix it and there were concerns regarding insurance cover.</p> <p>On a related issue, Sue Cooke informed the group that if you are an employee of the NHS you are entitled to get a substantial discount off the Microsoft Office Package, however if you are a volunteer you are not entitled to this discount. The group thought that this was unfair and would like to try change the policy.</p> <p>Hugh Butcher to pursue both matters with the Network Business Manager.</p>	H Butcher	Next Meeting
87	<p>To change this agenda item to 'Communication Policy'.</p> <p>To review at the next meeting.</p>	P Atha	Next Meeting

<b>5.1. A1: Broadening methods for collecting service user feedback</b>			
Log No	Action	Lead(s)	Deadline
88	<p>June Toovey explained to the group that there was nothing to report on this yet as the new User Involvement Facilitator would be taking responsibility for progressing this aspect of the UPG Work Plan.</p> <p>Several members of the group volunteered to help with this in the meeting. These volunteers were Hugh Butcher, Marion Allinson, Christine Allmark and Alan Rawson.</p> <p>Any other group members wishing to volunteer to contact June Toovey, <a href="mailto:june.toovey@leedsth.nhs.uk">june.toovey@leedsth.nhs.uk</a>.</p>	C Sloane	Ongoing
<b>5.2. A2 &amp; A6: Service user involvement on Network Groups - training and support; draft role description for service users on NSSGs</b>			
Log No	Action	Lead(s)	Deadline
89	<p>The group thanked all those that contributed information that was used to help write the two papers circulated to the group.</p> <p>Hugh Butcher presented the recommendations in his paper which were:</p> <ul style="list-style-type: none"> <li>•Training &amp; Induction Programme, Welcome Pack</li> <li>•Mentor/Buddy system</li> <li>•Make meetings more user friendly e.g. begin with a round of introductions, use of name plates etc.</li> <li>•Action-Learning Sets, to share and develop good practice</li> <li>•Half-Day Workshop for UPG members on NSSG's, to finalise above actions</li> </ul> <p>The group agreed the first four recommendations be implemented, with the fifth one to be implemented as soon as possible.</p> <p>It was recommended that these recommendations be pursued by Colin Sloane on taking up the post as User Involvement Facilitator.</p>	C Sloane	Next Meeting
90	<p>Fiona Stephenson presented the Person Specification for users on NSSG's.</p> <p>The group endorsed the Person Specification written by Fiona Stephenson.</p> <p>To circulate the Person Specification to all group members and to the NSSG User Involvement &amp; Patient Information leads.</p>	G Thomson	31/12/2007
91	<p>June Toovey supported the points about changes to Network group processes and reminded the group that this would be a long process to change culture and understanding of the NSSG's.</p> <p>Members felt that Users don't always have an 'equal voice' in the NSSG meetings which is very disheartening.</p> <p>June Toovey informed the group that Macmillan run training courses. These include a module called 'Being a Service User'. The Network are currently enquiring into what these training courses would involve and the cost.</p>		N/A
<b>5.3. A3: Engage with and gain an understanding of the commissioning process</b>			
Log No	Action	Lead(s)	Deadline
92	To defer to the next meeting.		Next Meeting

<b>5.4. A4: Influence the implementation of the Supportive &amp; Palliative Care Guidance</b>			
Log No	Action	Lead(s)	Deadline
93	<p>Marion Allinson gave an update and informed the group that the Supportive and Palliative care guidance must be implemented by December 2008. There are currently two members of the group involved in this.</p> <p>June Toovey told the group that the Supportive Pathway Workshop was held on 6th December 2007. Key points that were identified included continuity of care (key contact), Holistic assessment with appropriate care planning and delivery, patient information being at appropriate points in the pathway and key discussions with patients.</p> <p>The Palliative Care Pathway Workshop is being held on 17th December 2007.</p> <p>The group felt they would like to be involved with this piece of work.</p> <p>To circulate the palliative care pathway, when drawn up, to the UPG for comments.</p> <p>To update at the next meeting.</p>	J Toovey	Review at Next Meeting
<b>5.5. B1 &amp; B2: Developing stronger links with the wider PPI agenda</b>			
Log No	Action	Lead(s)	Deadline
94	To defer to the next meeting.	P Atha	Next Meeting
<b>5.6. B3: Develop stronger links with local user groups</b>			
Log No	Action	Lead(s)	Deadline
95	To defer to the next meeting.	P Atha	Next Meeting
<b>6. Do Not Attempt Resuscitation Event report</b>			
Log No	Action	Lead(s)	Deadline
96	<p>June Toovey informed the group that the event was a great success. It was well attended on the day and the feedback has been very positive. Any other issues in the future will hopefully use this event as a model due to its success.</p> <p>The group thanked all those that helped and attended the event.</p>		N/A
<b>7. YCN Management Board report</b>			
Log No	Action	Lead(s)	Deadline
97	To defer to the next meeting.	P Atha	Next Meeting

### Date of Next Meeting(s)

Monday 18th February 2008 11:00 am  
 Cookridge Suite Conference Room, Level 7, Bexley Wing, St James's University Hospital