

**Actions of the meeting held on
Tuesday 10 June 2008, 10:30**

Yorkshire Cancer Network

Lecture Room, Cookridge Suite, Level 7, Bexley Wing, St James's University Hospital

Present:

Reva Underwood	Bradford Cancer Support Centre
Suzanne Vaughan	Lancaster University
Sally Scales	Leeds Teaching Hospitals NHS Trust
Marion Allinson (Chair)	User Partnership Group
Christine Allmark	
Moira Dailey	
Rodney Dailey	
Sue Farr	
Christine Holman	
Madge Parker	
Alan Rawson	
Jan Roberts	
Alan & Dorothy Smith	
Trish Thornton	
Marlene Holland	Yorkshire Cancer Network
Angela Millett	
Clair Murray	
Colin Sloane	

Apologies

Jane Archer, Mitzi Blennerhassett, Hugh Butcher, Maggie Clough, Joan Lesley Conti, Cheryl Downes, Janet Harrison, Vicki James, Margaret Jennings, Susan Keir, Francesca Pendino, John Revely, Diana Robinson, Fiona Stephenson, June Toovey, Pamela Whitaker

2. Any Other Business - Urgent Items			
Log No	Action	Lead(s)	Deadline
1	Sally Scales informed members that the Bexley Wing is to be officially opened by a member of the royal family in the afternoon of the 17th July 2008. The guest list is to include two service users/carers of this group. Clair Murray to write to service users/carers of the group to request that anyone who is interested in attending the official opening respond to register their interest before 27th June 2008.	C Murray	20/06/2008
2	Service users/Carers to register their interest by 27th June 2008.	Service Users/Carers	27/06/2008
3	Colin Sloane to randomly select two Service Users/Carers to attend the official opening of the Bexley Wing and write to them confirming the final arrangements.	C Sloane	27/06/2008
3. Action Log from the last meeting			
Log No	Action	Lead(s)	Deadline
4	The action log was agreed to be a true record of the last meeting. Rosemary Oldridge and Madge Parker did not receive the last action log. Clair Murray to check Rosemary Oldridge and Madge Parker's email and postal addresses.	C Murray	27/06/2008

User Partnership Group : Actions of the meeting held on Tuesday 10th June 2008 10:30 am

4. Matters arising			
Log No	Action	Lead(s)	Deadline
5	The group commented that the air conditioning in the Lecture Room, Cookridge Conference Suite, SJUH makes it very difficult to hear and so it was suggested that a microphone is used at the next meeting when the venue of subsequent meetings will be discussed. To discuss an alternative venue at the next meeting.	All	09/09/2008
5. YCN UPG Away Day feedback			
Log No	Action	Lead(s)	Deadline
6			
5.1. Overview of the Day			
Log No	Action	Lead(s)	Deadline
7	Colin Sloane and Marion Allinson informed the group that the Away Day was a success and proved to be a productive and valuable experience.		N/A
5.2. Morning Workshop feedback (A1,A2 and A6 on work plan)			
Log No	Action	Lead(s)	Deadline
8	Colin Sloane shared the Away Day report with the group, talked through the topics discussed from the work plan at the away day and highlighted the suggestions which were put forward during the workshops. These suggestions are to be taken forward by the sub groups.		N/A
5.3. Afternoon Workshop recommendations			
Log No	Action	Lead(s)	Deadline
9	Colin Sloane talked through the recommendations from the Away Day document with the group. Future plans for the main UPG group are to meet four times a year with one of those meetings being an Away Day to review progress. An Implementation group is to be formed, meeting once a month to push the work plan forward and is to include co chairs of the main UPG and sub groups and two other members from the main UPG. There are also plans to set up a Recruitment, Training & Support sub group and a Patient Experience Survey sub group to begin with to drive forward specific areas of the work plan. Other sub groups are to be formed as and when the work programme dictates. These recommendations were accepted by the group. Clair Murray to circulate an expression of interest form to all members of the group.	C Murray	20/06/2008
10	Members of the group to return their expression of interest forms back to clair.murray@ycn.nhs.uk or to call Clair Murray on 01423 555688 to register their interest by 30th June 2008.	All	30/06/2008

6. YCN Service Improvement - Future Pathways in cancer			
Log No	Action	Lead(s)	Deadline
11	<p>Marlene Holland and Angela Millett gave a presentation to the group on the structure of the YCN Service Improvement team and an insight into pathway development, highlighting the importance of user involvement.</p> <p>Clair Murray to circulate the presentation to the group with the action log.</p>	C Murray	27/06/2008
7. NSSG Training day report (A2 and A6 on work plan)			
Log No	Action	Lead(s)	Deadline
12	<p>Colin Sloane tabled the NSSG/NCCG Training Day report from the 9th May 2008. The group were informed that there are plans to continue to run these sessions following the success of the pilot course. Following discussions from the training day, Colin Sloane produced a draft User Involvement NSSG handbook which was shared with the group.</p> <p>Members to send any comments or suggestions on the User Involvement NSSG/NCCG handbook to clair.murray@ycn.nhs.uk before the 27th June 2008.</p>	All	27/06/2008
13	Colin Sloane to finalise the User Involvement NSSG/NCCG handbook for circulation to the group before the 9th September 2008.	09/06/2008	09/09/2008
14	<p>The group discussed the issues surrounding confidentiality agreements for members who regularly attend NSSG/NCCG meetings.</p> <p>Colin Sloane agreed to seek advice on this issue and draft a confidentially clause for NSSG/NCCG representatives to sign if this is appropriate.</p>	C Sloane	09/09/2008
8. Timely and appropriate communication between Primary and Secondary care			
Log No	Action	Lead(s)	Deadline
15	<p>Colin Sloane tabled the reply received from the Patient Safety Agency stating that they are aware of the issues raised, however to resolve these they require a National IT solution in place.</p> <p>YCN Service Improvement team are to continue considering these issues during pathway development work.</p>	YCN Service Improvement Team	Ongoing
9. Final Expenses Policy (for agreement)			
Log No	Action	Lead(s)	Deadline
16	<p>Colin Sloane tabled the final expenses policy to the group which was agreed as a final version.</p> <p>Clair Murray to post the final expenses policy on the YCN website.</p>	C Murray	30/06/2008
10. Research project - 'Impact of user involvement'			
Log No	Action	Lead(s)	Deadline
17	<p>Suzanne Vaughan from The Institute for Health Research informed the group of a study currently underway at Lancaster University - 'Measuring and demonstrating the impact of user involvement on health and social care services for cancer in the UK'. The study is a joint project between Lancaster University and Macmillan Cancer Support. Suzanne Vaughan asked if the UPG would support this research. The group agreed to share good practice/successes.</p> <p>Members to become involved in this work as and when necessary.</p>	All	Ongoing

11. Information Steering Group Feedback			
Log No	Action	Lead(s)	Deadline
18	Colin Sloane tabled the action log from the last Information Steering Group meeting.		N/A
12. Good News Stories			
Log No	Action	Lead(s)	Deadline
19			
12.1. Cancer pathways			
Log No	Action	Lead(s)	Deadline
20	Colin Sloane celebrated the important influences group members have had on pathway development work.		N/A
12.2. Spinal Cord Compression			
Log No	Action	Lead(s)	Deadline
21	Colin Sloane informed the group that Keith Nowell received a letter from the National Collaborating Centre for Cancer thanking him for his helpful feedback on patient's experiences of metastatic spinal cord compression and to ask permission to use some of his quotes in the final guidelines.		N/A
12.3. Nothing Personal			
Log No	Action	Lead(s)	Deadline
22	Colin Sloane and Marion Allinson informed the group that Mitzi Blennerhassett has recently had her book 'Nothing Personal' published. The group were encouraged to read this remarkable book. The YCN has two copies should anyone wish to borrow one or alternatively this will be available at libraries in the near future, ISBN number 978-1-84619-010-0. Marion Allinson suggested that Mitzi Blennerhassett contact Radio Four's women's hour to share her experience.		N/A
13. Management Board report and Network Chairs meeting			
Log No	Action	Lead(s)	Deadline
23	<p>Marion Allinson gave members an overview of the Management Board Report, highlighting the broad aim of the YCN which in essence is to ease the burden of those with cancer and to improve outcomes. To strive to have fully functional NSSGs which will have direct reporting responsibility to the Board. The Board to support Chairs of the Network Groups in helping achieve this.</p> <p>At the April Management Board meeting the supportive pathway and the four key elements identified as important for patient experience were agreed and signed off by the board. These key elements are to feature in every site specific pathway. The group requested that June Toovey is asked to attend the next meeting to present this information.</p> <p>Clair Murray to ask June Toovey to present the supportive pathway to the group at the next meeting.</p>	C Murray	09/09/2008

Date of Next Meeting(s)

Tuesday 9th September 2008 12:30 pm

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