

Present:

Rosemary Oldridge	
Cheryl Downes	Leeds Teaching Hospitals NHS Trust
Francesca Pendino	Mid Yorkshire Hospitals NHS Trust
Marion Allinson (Chair)	User Partnership Group
Christine Allmark	
Mitzi Blennerhassett	
Hugh Butcher (Chair)	
Madge Parker	
Alan Rawson	
Jan Roberts	
Peter Sale	
Alan & Dorothy Smith	
Pamela Whitaker	
Clair Irving	Yorkshire Cancer Network
Colin Sloane	
Fiona Stephenson	
June Toovey	

Apologies

Pat Akerman, Veronica Allinson, Jane Archer, Maggie Clough, Joan Lesley Conti, Sue Cooke, Rodney Dailey, Christine Holman, Doreen Horton, Margaret Jennings, Susan Keir, Pat Marsden, Diana Robinson, Sally Scales, Trish Thornton, Reva Underwood, David Woodhall

1. Welcome, Introduction & Apologies			
Log No	Action	Lead(s)	Deadline
24	<p>Hugh Butcher welcomed the group and round the table introductions were made.</p> <p>Hugh Butcher reminded the group that the new way of working agreed at the last Away Day was now being implemented. The User Partnership Group now had a more strategic role, with the responsibility for implementing its decisions being delegated to Sub Groups. The success of these changes will be reviewed in one year's time</p>	N/A	N/A
2. Any Other Business - Urgent Items			
Log No	Action	Lead(s)	Deadline
25	Colin Sloane informed the group that following his successful bid to Macmillan, the User Partnership group have been awarded an annual grant of £9000.	N/A	N/A
26	<p>The group held a discussion on the issue of transport to the meeting. Some members offered to provide this for those who are having difficulties.</p> <p>Members who are having difficulty attending meetings due to transport issues are to contact Colin Sloane (01423 555786 or colin.sloane@ycn.nhs.uk) who will endeavour to resolve these.</p>	All	Next meeting

2. Any Other Business - Urgent Items			
Log No	Action	Lead(s)	Deadline
27	Alan Smith requested that name cards are brought along to the meetings. Clair Irving to ensure this happens.	C Irving	Next Meeting
4. Matters arising			
Log No	Action	Lead(s)	Deadline
28	<p>▶ Radiotherapy Behind The Scenes Tour</p> <p>Colin Sloane informed the group that he has offered dates in October 2008 to the Radiotherapy department, Bexley Wing, Leeds however he is still awaiting a response.</p> <p>The group discussed the timing of the tours and requested that Colin Sloane try to put the start time back to 18.30 or 19.00 if possible to allow for travelling time.</p> <p>Everyone was encouraged to attend.</p> <p>Colin Sloane to request a later start time and to inform the group once dates have been secured.</p>	C Sloane	Next Meeting
29	Colin Sloane informed the group that the Royal opening of the Bexley Wing, Leeds was a successful and enjoyable day out. Members Sue Cook, Sue Keir, Trish Thornton and Rachel Dixey attended along with Colin Sloane.	N/A	N/A
4.1 Item 7 Log 14 confidentiality statement NSSG/NCCG Handbook			
Log No	Action	Lead(s)	Deadline
30	<p>Colin Sloane tabled the Confidentiality Agreement document and encouraged the group to offer any suggestions for improvements. Following some discussion, four suggestions emerged:-</p> <ol style="list-style-type: none"> 1. Alan Smith suggested that if the group are asked to be mindful of the importance of confidentiality and code of conduct at the beginning of each meeting, signing a formal document may not be necessary. 2. Francesca Pendino suggested considering adding any underpinning legislation to the existing document. 3. Jeanette Roberts suggested working with the document on a trial basis to see how it goes. 4. Peter Sale suggested that a clause be added around speaking to the press. <p>The group agreed to work with the existing document, making some changes to include a piece about the press and to include a statement to allow any members with a specific issue which they feel ought to be discussed outside of the group, the option to bring the matter to other members for group a decision to be made.</p> <p>Colin Sloane to make the relevant changes to the Confidentiality Agreement and circulate to the group.</p>	C Sloane	31/10/2008
31	<p>Members discussed whether Health Professionals as well as Service Users should be asked to sign the document. The group were unsure if this will already be covered by their professional contracts.</p> <p>Fiona Stephenson suggested that the Confidentiality Agreement and Code of Conduct policy could be added to the Terms of Reference, adding in any legal references if appropriate.</p> <p>Fiona Stephenson agreed to develop the Terms of Reference accordingly.</p>	F Stephenson	31/10/2008

5. YCN High level supportive care pathway			
Log No	Action	Lead(s)	Deadline
32	<p>June Toovey gave a presentation to the group on the Supportive Care Pathway, highlighting the importance of this being incorporated into each site specific clinical pathway over the next few years.</p> <p>The group were informed that this has been ratified by the YCN Network Board in May 2008, endorsing the four key elements to be incorporated within all YCN pathways. These four elements are Single Contact with the assigned Key Worker, Holistic Assessment, Key Discussion Point with patients and Patient Information. June Toovey discussed how these elements may be audited, the benefits for patients and summarised any planned further work.</p> <p>June Toovey agreed that the Supportive Care pathway document could be circulated amongst local user groups in order to influence local hospitals to start using it.</p> <p>Clair Irving to circulate the presentation with the action log.</p>	C Irving	26/09/2008
6. Reports from New Sub Groups			
Log No	Action	Lead(s)	Deadline
33	<p>Colin Sloane reminded members that the Sub Groups are not closed groups and welcomed anyone interested in joining to contact him.</p> <p>Members to contact Colin Sloane (01423 555786 or colin.sloane@ycn.nhs.uk) if they are interested in becoming a member of any of the Sub Groups.</p>	All	Ongoing
6.1 Implementation Group			
Log No	Action	Lead(s)	Deadline
34	<p>Colin Sloane informed the group that the YCN User Partnership Implementation Sub Group met on the 15th September 2008. Membership includes Colin Sloane, Hugh Butcher, Marion Allinson, Christine Allmark, June Toovey, Fiona Stephenson, Sue Cooke and Margaret Wharton.</p> <p>The group intend to meet every month to focus on steering the work of the main User Partnership group along with that of the Sub Groups, ensuring that work streams are progressed in order to achieve the aims of the work plan. Currently, the group's Terms of Reference are being amended.</p> <p>Marion Allinson reminded the group of the feedback proforma for those members wanting to add an item to the agenda or those who sit on NSSGs and have come across an issue they feel would be beneficial to be brought to the main group. This needs to be passed to Colin Sloane for this to be taken through the implementation group.</p> <p>Colin Sloane to keep the group updated at the next meeting.</p>	C Sloane	Next Meeting
6.2 Patient Experience Sub Group			
Log No	Action	Lead(s)	Deadline
35	<p>Colin Sloane informed the group that the first meeting was held on the 14th July 2008 during which members were split into two groups to focus on what it is Service Users/Health Professionals want from a survey and when surveys should be carried out. Results from both groups were very similar.</p> <p>The group were informed that a smaller working group may be put together to draft a questionnaire. Currently, Colin Sloane is looking to recruit a 'Champion Consultant' for support and to drive this work forward.</p> <p>Colin Sloane to keep the group updated on this work.</p>	C Sloane	Next Meeting

6. Reports from New Sub Groups			
6.3 Patient Information Steering Group			
Log No	Action	Lead(s)	Deadline
36	<p>Colin Sloane reported that the main focus of this group is the Patient Information Website. At the last meeting on the 8th July 2008, the group were asked to look at three existing websites from the questionnaire to ascertain how easy/difficult it was to navigate around the sites to locate specific information. Following this Colin Sloane put together a consultation which was widely circulated for comment. All the results have now been collated for Colin Sloane to present to the next meeting due to be held on 12th September 2008.</p> <p>Colin Sloane to keep the group updated on this work.</p>	C Sloane	Next Meeting
6.4 Recruitment / Training and Support Sub Group			
Log No	Action	Lead(s)	Deadline
37	<p>Colin Sloane informed the group that this Sub Group are yet to meet. The first meeting date has been scheduled for 6th October 2008. The focus of this group will be developing CancerVoices and NSSG training, looking at current and new ways of recruitment and developing further materials to encourage others to get involved.</p> <p>Colin Sloane to keep the group updated on this work.</p>	C Sloane	Next Meeting
7. Monitoring and Recording the Impact of User Involvement (A6 work plan)			
Log No	Action	Lead(s)	Deadline
38	<p>Hugh Butcher tabled the 'Think Paper' on aim B6. 'Design and establish a system for monitoring, recording and reviewing progress towards implementing the work plan.' He suggested that a small sub group be put together in order to progress this work, possibly half a dozen members to meet three times with the purpose of reporting back to the main group with solid proposals which are implementable.</p> <p>Hugh Butcher asked for volunteers. The following members agreed they would like to get involved:-</p> <p>Colin Sloane, Hugh Butcher, Pam Whittaker, Peter Sale and Fiona Stephenson</p> <p>Airedale has been decided to be the venue of these meetings.</p> <p>Since the sub group require one more member, anyone who is interested in getting involved is to contact Colin Sloane (01423 5557886 or colin.sloane@ycn.nhs.uk).</p>	All	26/09/2008
39	Clair Irving to organise possible meeting dates.	C Irving	26/09/2008

7. Monitoring and Recording the Impact of User Involvement (A6 work plan)			
7.1 Lancaster University/ Macmillan Research Project update			
Log No	Action	Lead(s)	Deadline
40	<p>Hugh Butcher reminded the group of the research that Suzanne Vaughan from Lancaster University is carrying out, assessing the effectiveness of user involvement by interviewing those who users are trying to influence.</p> <p>A meeting was held with Sue Hinder (Researcher) along with Colin Sloane, Marion Allinson and Hugh Butcher to identify eight target people to be interviewed to assess what effect user involvement is having on their practice. The following names have been given. Those prioritized for Sue Hinder, if only 4 are to be interviewed are asterisked :-</p> <ul style="list-style-type: none"> • Di Gilson - Consultant Clinical Oncologist ** • Georgina Haslam - PCT - GP Cancer Lead ** • Sally Scales - Lead Cancer Nurse • Ruth Hawkins - Deputy National Co coordinator, Cancer Peer Review Team ** • Jane Archer, YCN Patient Information Manager • June Toovey, YCN Nurse Director • Fiona Stephenson, YCN Project Manager • Rob Webster, YCN Board Chair ** • Barry Tinkler, YCN Lead Manager • Cath Miller - Director of Nursing • Maggie Clough - Upper GI Cancer Nurse Specialist <p>Hugh Butcher to keep the group updated on this work.</p>	H Butcher	Next Meeting
41	Colin Sloane to ask Phillip Melling to post the final generic NSSG handbook on the YCN webpage.	C Sloane	Next Meeting
8. Good News Stories			
Log No	Action	Lead(s)	Deadline
42	Colin Sloane congratulated the group on the successful influence they are having in practice and how opinions on the importance of user involvement are becoming much more positive. For example the Radiotherapy Department's (Bexley Wing, SJUH) first port of call when revising its booking procedures was to consult with users as they viewed their input as being extremely valuable.	N/A	N/A
8.1 NSSG/NCGG Handbook			
Log No	Action	Lead(s)	Deadline
43	<p>Colin Sloane informed the group that the NSSG handbook is now in its final format now that the confidentiality agreement has been added. The document has received some great feedback and plans have been made to share this with other networks. Colin Sloane has written a piece on this for the Cancer Action Team newsletter.</p> <p>Marion Allinson raised the question as to whether this document should be taken to the YCN Board for ratification.</p> <p>June Toovey advised that she would look into whether the NSSG handbook needs to be taken through the YCN Board and report back to Colin Sloane.</p>	J Toovey	Next Meeting

8. Good News Stories			
8.2 Increasing Involvement			
Log No	Action	Lead(s)	Deadline
44	<p>Colin Sloane informed the group that user involvement is increasing on NSSG groups, resulting in most groups now having user representation. The following members are in the process of joining:-</p> <p>Jan Roberts - Lung NSSG Madge Parker - Gynaecology NSSG Alan and Dorothy Smith - Upper GI NSSG Mitzi Blennerhassett - Palliative Care NSSG Tony Hall - Urology NSSG</p> <p>Colin Sloane to keep the group updated on the success of this recruitment.</p>	C Sloane	Next Meeting
9. Date and time of next meeting			
Log No	Action	Lead(s)	Deadline
45	<p>The group decided that the next meeting would be held at the beginning of January 2009.</p> <p>Colin Sloane to circulate the date and time of the next meeting.</p>	C Sloane	28/11/2008

Date of Next Meeting

To be scheduled