

Actions of the meeting held on  
Wednesday 26 September 2007, 11:00

Yorkshire Cancer Network

YCRN Conference Room 1, Ida Nurses Home, Cookridge Hospital

**Present:**

Ms M Jalloh	
Ms J Harrison	Airedale NHS Trust
Ms V James	Leeds Teaching Hospitals NHS Trust
Mrs S Scales	
Ms E Aspinall	St Gemma's Hospice
Mrs J Hustwit	
Ms M Allinson (Chair)	User Partnership Group
Mrs J Conti	
Mrs S Cooke	
Mrs A Nowell	
Mr K Nowell	
Mr A Rawson	
Ms J Roberts	
Mrs D Robinson	
Mr P Sale	
Mr C Sloane	
Miss P Atha	Yorkshire Cancer Network
Mr P Melling	
Ms F Stephenson	
Mrs J Toovey	

**1. Apologies**

Mr B Atkins, Mrs M Blennerhassett, Mr H Butcher, Mr & Mrs R Dailey, Mrs S Keir, Mrs P Oates, Mr J Revely, Miss R Rider, Mrs L Russell, Mr D Shreeve, Ms S Smith, Mrs K Smith, Ms R Underwood, Mrs P Whitaker

1. Welcome, Introduction & Apologies			
Log No	Action	Lead(s)	Deadline
35	Members were informed of the resignations from Pat Oates, Ruth Rider, David Howe and Fred Walker. Each was thanked for their individual contributions during their time with the Group. Pat Oates and Ruth Rider have agreed to remain on the editorial panel and would like to continue to receive minutes.  To send a letter of thanks for their contributions.	J Toovey	31/10/2007
2. Chair's Remarks			
Log No	Action	Lead(s)	Deadline
36	Marion Allinson referred to the End of Life Event scheduled on 19th October and suggested the time allocated on the programme for discussion be increased. She enquired as to whether the programme had been circulated to all members of the User Partnership Group.  Fiona Stephenson to look into extending discussion time and to speak with Sophie Thornborow regarding the programme distribution.	F Stephenson	03/10/2007

<b>2. Chair's Remarks</b>			
Log No	Action	Lead(s)	Deadline
37	Following the visit to the Hull Oncology Centre, Marion Allinson wrote to David Fox regarding holistic care at the New Oncology Wing (NOW) and has received a response indicating he would speak with colleagues and feedback.  To keep the group informed.	M Allinson	12/12/2007
38	YCN Macmillan Web Content Manager - Interviews took place on 17th September and a candidate has been offer the post subject to pre-recruitment checks.  To announce appointment once start date is finalised.	P Atha	31/10/2007
39	Marion Allinson referred to Prime Minister's remarks where he announced that Breast Cancer screening will be increased by 8 years and Colon Cancer screening will be extended to people in their 70's.  To keep up to date on progress.	All	Ongoing
<b>3. Any Other Business - Urgent Items</b>			
Log No	Action	Lead(s)	Deadline
40	June Toovey announced that the Yorkshire Cancer Network aim to move to 21 Wetherby Road on the Harrogate District Hospital site early-mid January 2008. Facilities for Network Group meetings are still being explored. The Group asked the Network to consider a central location for meetings.  Fiona Stephenson agreed to liaise with members regarding meeting locations as this work progresses.	F Stephenson	12/12/2007
41	Jane Garrud, Medical Illustrator has asked the YCN if any members would like to be on their INFOP Group (the Leeds Trust patient information review panel).  Any interested volunteers to contact Pauline Atha who will forward details to Jane Garrud.	All / P Atha	31/10/2007
42	Colinne Sheard, Network Support Officer for the User Partnership Group leaves on 3rd October. Pauline Atha will be the group's interim contact. This post is currently going through the recruitment process and the group will be kept informed.  Due to current staffing levels, members were asked to keep contact to a minimum where possible during reduced staffing levels.	All	Review 12/12/2007
43	To notify the Group of the contact details for the new Network Support Officer once appointment has been made.	P Atha	30/11/2007
<b>4. Minutes of last meeting</b>			
Log No	Action	Lead(s)	Deadline
44	Agreed as true record.		N/A

<b>5.1. Colorectal &amp; Urology Representation</b>			
Log No	Action	Lead(s)	Deadline
45	<p>A request for user representation on the Colorectal and Urology Groups has not been sent. It was agreed that it would be helpful to have a document outlining what representation on an NSSG involves.</p> <p>To form part of Hugh Butcher and Lorraine Hunt's work.</p>	H Butcher / L Hunt	12/12/2007
<b>5.2. NOW visit feedback &amp; naming</b>			
Log No	Action	Lead(s)	Deadline
46	<p>Diana Robinson gave positive feedback on the recent visit to the New Oncology Wing. It was reported that Hugh Butcher met with David Fox to put forward comments received at the last meeting from members regarding the naming of the Wing. A meeting took place in Leeds on Tuesday 25th September but no announcement has yet been made.</p> <p>June Toovey to inform the Group of the new name once announced.</p>	J Toovey	12/12/2007
47	<p>Alan Rawson enquired about the utilisation of radiotherapy machines.</p> <p>Vicky James to monitor this through the Leeds Group and Sally Scales to keep group informed accordingly.</p>	Vicky James / Sally Scales	Review 2008
<b>5.3. Resuscitation Policy for People with Cancer Update</b>			
Log No	Action	Lead(s)	Deadline
48	<p>Fiona Stephenson reported that the End of Life DNAR event scheduled for Friday 19th October was progressing and subsequent to the meeting a report will be produced and circulated. Keith Nowell requested that the same process be carried out with North Yorkshire.</p> <p>It was noted that the Out of Hours form was to be (marginally) amended after discussion with some representatives from the UPG.</p> <p>Fiona Stephenson to raise this with the Chair of the Palliative Care Group.</p> <p>Fiona Stephenson to check the Out of Hours form has been amended with the Chair.</p>	F Stephenson	17/12/2007
<b>5.4. Dissemination of information</b>			
Log No	Action	Lead(s)	Deadline
49	To be carried forward for the new User Involvement Facilitator to address.	User Involvement Facilitator	Review 12/12/2007

<b>6. Update re User Facilitator post</b>			
Log No	Action	Lead(s)	Deadline
<b>50</b>	<p>The post is pending Board approval to go to external advert via NHS Jobs (<a href="http://www.jobs.nhs.uk">www.jobs.nhs.uk</a>). The revised job description resubmitted to the NHS Agenda for Change team achieved Band 5 status. June Toovey outlined the AfC banding structure and process. Discussion followed where some members raised concerns over the salary for the post. An in-depth discussion followed.</p> <p>It was noted that Marion Allinson and Hugh Butcher were both involved in the interview and selection process. If the calibre of applicants falls short and an appointment not made, the Group could revisit the job description and consider compiling a proposal to the Board.</p> <p>To circulate a copy of the job description and person specification to the Group for information.</p>	P Atha	10/10/2007
<b>7. Work programme 'Think' papers feedback</b>			
Log No	Action	Lead(s)	Deadline
<b>51</b>	The group discussed the papers circulated with the agenda and agreed a way forward on each Think Paper presented, as detailed:		
<b>7.1. Aims/Objectives A1 &amp; A2 - June Toovey &amp; David Howe</b>			
Log No	Action	Lead(s)	Deadline
<b>52</b>	<p>► A1 June Toovey gave a brief outline of the paper and asked the group for comments. Following discussion it was agreed to form a sub-group to produce the audit tool (utilising the current communication audit tool) for the purpose of carrying out survey's within the MDTs, through the NSSG's.</p> <p>This will also be raised in a forthcoming meeting with the User Involvement and Patient Information Leads.</p> <p>It was proposed that the outcome of the audit be taken to the NSSG which in turn can be feed back to the User Group, but the responsibility lies with the MDT to take action on the outcomes of the audit.</p> <p>Volunteers interested in joining sub-group to send their names to Pauline Atha.</p> <p>Sally Scales and Jan Roberts put their names forward.</p>	All	12/12/2007
<b>53</b>	To arrange a sub-group to take this work forward.	J Toovey / P Atha	12/12/2007
<b>54</b>	<p>► A2 June Toovey gave a brief outline of the paper, outlining the importance of service users on NSSGs and how this work links into the work Hugh Butcher has completed in relation to developing training, support and mentoring for service users on NSSGs.</p> <p>To produce a table listing Network Groups, the service user representative(s) and the User Involvement and Patient Information Lead and circulate to members for reference.</p>	P Atha	12/12/2007
<b>55</b>	Anyone interested in representing user involvement in any Network Groups to contact June Toovey.	All	Ongoing

<b>7.2. Aims/Ojectives A3 - Fiona Stephenson, Jan Roberts, Diana Robinson</b>			
Log No	Action	Lead(s)	Deadline
56	<p>Fiona Stephenson gave a brief outline the paper and proposed next steps to form a sub-group to define the questions for commissioners (ie. what users want to know about commissioning and how users can influence the process). To then meet with Lead team to discuss in more detail prior to meeting with a Commissioner from a PCT.</p> <p>Fiona Stephenson requested 4-5 volunteers to form the sub-group to take this work forward and anyone interested to contact Pauline Atha.</p> <p>Jan Roberts and Diana Robinson put their names forward.</p>	All	12/12/2007
57	To arrange a sub-group meeting to define the questions for commissioners and feedback to the main group prior to meeting the YCN Lead team.	F Stephenson / P Atha	12/12/2007
<b>7.3. Aims/Objectives A4 - Marion Allinson, Sue Cooke, Keith &amp; Aline Nowell</b>			
Log No	Action	Lead(s)	Deadline
58	<p>Marion Allinson reported that they had met with June Toovey prior to this meeting to discuss the Supportive &amp; Palliative Care Guidance to gain a better understanding and to explore how users can be involved in the implementation of the guidance. They are now in a better position to produce a "Think Paper" to circulate to the group.</p> <p>To produce a "Think Paper" for circulation to the group early in the new year.</p>	M Allinson / K Nowell / A Nowell / S Cooke	January 2008
<b>7.4. Aims/Objectives A6 - Hugh Butcher &amp; Lorraine Hunt</b>			
Log No	Action	Lead(s)	Deadline
59	<p>The "Think Paper" was briefly discussed in Hugh Butcher's absence and praised for its comprehensiveness. However it was highlighted that only 4 responses were received to the questionnaire circulated to current user representatives on NSSGs. It was agreed to re-circulate to those who had not returned the form since this was circulated in the holiday season.</p> <p>To send out the questionnaire to users on NSSGs who had not responded, extend the completion deadline and send responses to Hugh Butcher.</p>	P Atha	10/10/2007
<b>7.5. Aims/Objectives B1 &amp; B2 - Peter Sale</b>			
Log No	Action	Lead(s)	Deadline
60	<p>Peter Sale read his paper to the group regarding the new government legislation regarding the establishment of Local Involvement Networks (LINKs). He proposed that User Partnership Group members should become involved in their local hospital's patient-carer panel to develop stronger links.</p> <p>He stated he would be attending a Bradford/Airedale meeting on 22 October and will feedback at the next meeting.</p> <p>Members were asked to research what is happening in their own patch and report back to the group at the next meeting.</p>	All	12/12/2007
61	Members were encouraged to join local LINKs groups.	All	12/12/2007
62	To circulate Peter Sale's paper with the minutes.	P Atha	10/10/2007

### 7.6. Aims/Objectives B3 (Including Links Event report) - Colin Sloane

Log No	Action	Lead(s)	Deadline
63	<p>Colin Sloane gave an overview of his paper regarding developing stronger links with the seven local User Partnership Groups and sharing work plans and information between the groups. He reminded members of the facility of being able to upload terms of reference, agendas, minutes and work programmes on to the YCN website (www.ycn.nhs.uk).</p> <p>All documentation for uploading onto the YCN website should be done by emailing these to Philip Melling (philip.melling@leedsth.nhs.uk).</p> <p>Members to arrange for this documentation to be submitted to Philip Melling on an on-going basis.</p>	All	On-going
64	<p>The group discussed the information displayed on the YCN website and minor amendments were made. It was agreed that instead of naming the chair of the local user partnership group, the user facilitator's name and email address be displayed and links to their website also be included.</p> <p>To make proposed amendments.</p>	P Melling	26/09/2007
65	<p>To re-establish links with local user partnership group chairs once the new facilitator is in post.</p>	User Involvement Facilitator	12/12/2007

### 8. Process for Claiming Expenses

Log No	Action	Lead(s)	Deadline
66	<p>June Toovey referred to the Payment of Expenses Briefing Paper dated 24.07.07 produced by Martin Child at the last meeting and indicated that it was not a true record in that it stated passenger miles was payable at 2p per mile when that was not current policy.</p> <p>She referred to the revised briefing paper dated 26.09.07 circulated with the agenda and proposed the development of a Network Policy on the payment of expenses for services users, bearing in mind the budget available, provided by the Macmillan Grant which is for operating costs of the user partnership group.</p> <p>June Toovey asked if anyone would be interested in working with her to develop the policy.</p> <p>Keith Nowell referred to a national policy that could be used as a framework for the policy.</p> <p>Colin Sloane offered to be involved in the development of the policy.</p> <p>June Toovey and Colin Sloane to meet to produce a draft policy and take to the main group for discussion.</p>	J Toovey / C Sloane	12/12/2007
67	<p>An in-depth discussion followed on the funding available and the method of claiming (i.e. the need to submit receipts to support claims). It was stressed that the process complied with the LTHT policy and auditing requirements.</p> <p>It was proposed that this process be reviewed once the Network relocated to Harrogate and to also explore the possibility of reimbursement on the day of the meeting where possible.</p> <p>To review in early 2008.</p>	J Toovey / P Atha	Review 2008

<b>9. Electronic Communication &amp; Discussion</b>			
Log No	Action	Lead(s)	Deadline
68	<p>Philip Melling attended the meeting to present a possible solution to provide a platform for members to communicate electronically, easily and readily between meetings.</p> <p>He reported that a new email group had been set up: YCN-UPG@yahoogroups.com and this email would enable people to contact one another who have signed up to this group. Following discussion it was agreed that the originator of the initial email would be responsible for collating replies and feeding back to the main group.</p> <p>Philip Melling agreed to send out an email to all current members of the YCN UPG to invite to join the Yahoo email group which will give users the option to accept or decline membership.</p>	P Melling	12/12/2007
69	<p>Members requested an up to date membership list with contact details for circulation around the group.</p> <p>Pauline Atha agreed to produce a list of all members who had given their consent for details to be shared amongst the group.</p>	P Atha	12/12/2007
70	<p>Also raised was the issue of the length of the current meetings due to the extensive agenda and whether this required more frequent meetings, i.e. monthly or six-weekly instead of the current bi-monthly.</p> <p>It was agreed that the frequency of meetings be discussed once the new facilitator is in place and we allow 3hrs for the meetings and review once the YCN moves to Harrogate.</p>	J Toovey	Review 2008
71	<p>A detailed discussion followed, including how those who do not have access to a PC are excluded from such communications. Marion Allinson said she had made enquiries regarding decommissioned IT equipment and whether it could be made available to service users. Enquiries regarding the Trust's disposal policy had not been clarified, but would be followed up.</p> <p>To enquire about the Trust's disposal policy for IT equipment.</p>	P Atha	12/12/2007
72	<p>Keith Nowell requested that documents sent out for comment be circulated in Word format in order that the changes can be made directly into the document. In addition, any draft documents carry the version number for YCN produced documentation.</p> <p>It was agreed on the understanding that all changes made within the document are highlighted clearly, preferably with the "track changes" option available on Word, where all additions, deletions and comments are highlighted and version numbers on documents would be utilised.</p> <p>To ensure documents are circulated in Word format when circulated for comment and they carry appropriate version numbers.</p>	P Atha	On-going

### **Date of Next Meeting(s)**

Friday 12th October 2007 10:00 am  
YCRN Conference Room 1, Ida Nurses Home, Cookridge Hospital [EVENT]

Friday 19th October 2007 10:00 am  
YCRN Conference Room, Ida Nurses Home, Cookridge Hospital [EVENT]

Wednesday 12th December 2007 11:00 am  
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