

**Actions of the meeting held on
Friday 12 September 2008, 10:00**

Yorkshire Cancer Network

St Gemma's Hospice

Present:

Mrs H Hey	Bradford Teaching Hospitals NHS Foundation Trust
Mrs C Allmark	Leeds Teaching Hospitals NHS Trust
Ms S Morgan	
Ms S Smith	
Mrs M Coleman	Mid Yorkshire Hospitals NHS Trust
Ms M Allinson	User Partnership Group
Mr H Butcher	
Mrs S Cooke	
Mr A Rawson	
Mr P Sale	
Mr P Mayor	York Hospitals NHS Foundation Trust
Mrs J Archer (Chair)	Yorkshire Cancer Network
Mr C Sloane (Chair)	
Mrs J Toovey	

Apologies

Ms M Jennings

1. UI/PI Leads Only 10.00-10.30			
Log No	Action	Lead(s)	Deadline
34	<p>This session was cancelled as only one UI/PI Lead was present (Maggie Coleman). Helen Hey raised concern about the level of commitment and suggested this needs 'chasing up'. It was proposed that June Toovey should raise the issue with the Lead Nurses.</p> <p>Colin Sloane, Jane Archer and June Toovey to discuss and June Toovey is to approach the Lead Nurses.</p>	C Sloane/J Archer & J Toovey	Next meeting
2. Welcome and Apologies			
Log No	Action	Lead(s)	Deadline
35	<p>The meeting opened with a chairs welcome, followed by introductions from all members.</p> <p>It was noted that Margaret Coleman prefers to be called Maggie.</p>	N/A	N/A

3. Action Log from the last meeting			
Log No	Action	Lead(s)	Deadline
36	<p>Paul Mayor informed members that the statement initially recorded outlining Suzanne Curry's post at York was incorrect. Paul Mayor had previously informed Colin Sloane about this and an amendment had been made. Paul Mayor informed the group that York were fully committed to the patient information agenda and that the [information lead] role was under review and that there was no funding issue associated with this role. Therefore, it was hoped they would resume a full service as soon as possible.</p> <p>Hugh Butcher noted that the action log stated that the Terms of Reference had been revised following comments at the last meeting. He requested that a copy of these agreed Terms of Reference which were distributed with the action log from this meeting.</p> <p>Clair Irving to send the revised Terms of Reference to all group members with the action log.</p>	C Irving	26/09/2008
5. Website Project - presentation (report to follow prior to meeting)			
Log No	Action	Lead(s)	Deadline
37	<p>June Toovey outlined Nazeem Mungur's (web content manager) ongoing sick leave. Colin Sloane presented the website consultation findings and conclusions. A report was circulated to the group members prior to the meeting. Copies are available to those who did not attend.</p> <p>Colin Sloane's presentation and report to be circulated with the action log for this meeting.</p>	C Irving	26/09/2008
38	<p>Hugh Butcher asked if it was possible to isolate details of how many respondents were Service Users and how many were Health Professionals. Colin Sloane estimated from the number he issued that approx 75% were Health Professionals and approx 25% were Service Users. Hugh Butcher felt it might be useful to differentiate between comments and words chosen in order to bear this in mind when planning the content for the website.</p> <p>Colin Sloane to seek out this information and report back at the next meeting.</p>	C Sloane	Next Meeting

5. Website Project - presentation (report to follow prior to meeting)			
Log No	Action	Lead(s)	Deadline
39	<p>June Toovey outlined the purpose of the YCN Patient Information & Support Website and how it is expected it to fit in with the existing YCN site.</p> <p>Discussion points raised can be summarised as follows; bear in mind the age and category of audience/user the website might appeal to. Careful use of language and colour schemes would help make it more user friendly, how we might best address the needs of those who are dyslexic and non English readers/speakers should be considered. It was reiterated that these are all valuable issues to discuss but more so when the group starts to unpick the issues relating to building the actual content; the next phase of the project.</p> <p>At the close of Colin Sloane's presentation, steering group members were asked to consider a few points in preparation for the next steps of the project with Jamkit, the Content Management System (CMS) design company. These were as follows;</p> <p>Q 7 What adjectives are used to describe your organisation (in this case website)</p> <p>(as per Colin Sloane's presentation slide) add reassuring</p> <p>In order of preference:-</p> <p>1 welcoming 2 patient focussed 3 accessible 4 caring 5 reliable</p> <p>The rest of the words being used to enhance this.</p> <p>Q 9 Websites that we LIKE</p> <p>Helen Hey supplied three - Pancreatic Cancer UK, CancerHelp UK, Cancer Research UK (CRUK) Breast Cancer Care, Lymphoma Association, NHS Direct, Cancerbackup,</p> <p>Q 8 Websites we DO NOT LIKE</p> <p>Several members mentioned Macmillan Cancer Support (since their re-branding). It was generally felt to be very wordy and too corporate in style, not easy to read, too many logo's, too many capital letters and often associated with fundraising.</p> <p>Any suggestions of websites we like or any other suggestions, please forward to Colin Sloane via email before 30th September 2008</p>	All	30/09/2008
40	June Toovey to insert information about dyslexia/browsealoud software/crossbow education etc.	J Toovey	Next Meeting
41	Members to consider for a future meeting, which iconic images represent Yorkshire to them and which would look good as part of the banner for the YCN patient information and support website.	All	Next Meeting
42	Anyone with local images that they would like to include in the YCN website should contact Colin Sloane with details of their Trusts image bank lead/location.	All	Next Meeting

5. Website Project - presentation (report to follow prior to meeting)			
Log No	Action	Lead(s)	Deadline
43	<p>► The Next Steps</p> <p>The Jamkit questionnaire will be completed by Colin Sloane based upon this meeting's discussions and following receipt of this, will develop and subsequently provide three 'design concepts'.</p> <p>YCN will also request estimates/quotes from Jamkit relating to additional specifications and discuss the possibility of additional features (MP3/Browsealoud/ translation etc).</p> <p>Marion Allinson noted the Psychology Sub Group proposal to develop a leaflet to inform Service Users about the Holistic Assessment process.</p> <p>To keep the group updated on the progress of this.</p>	C Sloane	Next Meeting
6. National Information Prescriptions			
Log No	Action	Lead(s)	Deadline
44	<p>Jane Archer reported that a number of information prescription (20) pilots have been undertaken in a variety of settings and a for a range of long term conditions (these include heart, diabetes & cancer).</p> <p>Expected delivery date for implementing this is early 2009. For more information and to view developed versions see http://www.nationalcancerpathways.org.uk.</p> <p>Clair Irving to distribute the National pathways/prescriptions website address with the action log.</p>	C Irving	26/09/2008
7. Update on information pathways			
Log No	Action	Lead(s)	Deadline
45	<p>Jane Archer outlined the national agenda to produce network information pathways for all site specific groups. Each cancer type within the main headings well need to have a patient information pathway. For example gynaecology will have pathways for endometrial, ovarian, cervical, vulval and vaginal. These will be based upon the national and local versions and will reflect the information resources that should be offered to all patients for that cancer type.</p> <p>National pathways developed already are as follows; breast, gynae, bowel, prostate. Currently being disseminated for comment is lung.</p> <p>The network is undergoing a period of development with these pathways and they are being integrated into the clinical timed pathways to ensure that they are an integral part of patient care.</p> <p>Jane Archer is to speak with National Cancer Action Team (NCAT) Lead prior to next meeting and feedback on expectations etc at the next meeting.</p>	J Archer	Next Meeting

9. Any Other Business			
Log No	Action	Lead(s)	Deadline
46	<p>► Managing the Stress of Cancer Booklet</p> <p>Marion Allinson proposed that the network develop the afore mentioned resource for use across the Network. Bradford already produce it and Airedale are about to.</p> <p>A discussion followed about its current use and the professional view on which patients it is most suitable for. It was agreed that before any decisions were made about its development, the Steering Group members should have a copy to read so that discussion at the next meeting would be more informed. It was also proposed that it would be raised at the Psychosocial Sub Group that the members of that group do the same. Suggestion that the resource is produced in a professional manner in CD format with the written version perhaps broken down into smaller sections, perhaps printed sheets. This is just a suggestion and much more dialogue needs to occur prior to this.</p> <p>Once initial discussions have taken place, an author will be approached about developing it.</p> <p>Colin Sloane to ensure all Information Steering Group members get a copy of the booklet.</p>	C Sloane	Next Meeting
47	<p>June Toovey & Colin Sloane are to ensure that this is brought up at the Psychosocial Group meeting for discussion, with an example of the resource.</p>	J Toovey & C Sloane	20/11/2008
48	<p>► Macmillan 'Home but not Alone' – research project</p> <p>Christine Allmark is the User/Research Lead for this project and outlined that the study is underway and focus groups are currently being organised with head and neck patients which is the 'listening phase' of the study.</p> <p>Members to contact Christine Allmark for more information about this initiative.</p>	All	Ongoing
49	<p>► CRUK Consumer Group</p> <p>Christine Allmark is a member and will feed back to this group regularly.</p> <p>Christine Allmark to update the group at the next meeting.</p>	C Allmark	Next Meeting
10. Date and time of next meeting			
Log No	Action	Lead(s)	Deadline
50	<p>Group members happy with St Gemmas as a venue for the meetings</p> <p>Dates for the next meeting to be circulated by Colin Sloane.</p>	C Sloane	31/10/2008

11. Locality Information Leads Only 12.00-12.30			
11.1 Information in alternative formats - pilot project			
Log No	Action	Lead(s)	Deadline
51	<p>Sadie Smith & Reva Underwood were thanked for the time and effort they had given in looking at the resources available for Colorectal Cancer patients (and their carers) in Non-English and non-written formats. Sadie Smith discussed the process undertaken and the findings. It was agreed that it would be useful to replicate this exercise across all of the cancer sites but to hold off until the picture with National Information Pathways becomes clearer.</p> <p>Colin Sloane noted that feedback about this item is useful for the whole group hear, as it relates directly to the work plan of the group. It was agreed that feedback relating to the work plan will be part of the main meeting agenda in the future.</p> <p>Report to be sent out with Action Log.</p>	C Irving	26/09/2008
52	Details of the readspeak/text to talk & talk to text software available to be circulated with the Action Log.	C Irvng	26/09/2008
53	Feedback relating to the work plan will be part of the main meeting agenda in the future.	C Sloane	Ongoing

Date of Next Meeting(s)

Monday 3rd November 2008 10:00 am
Seminar Room, Martin House Hospice