

Actions of the meeting held on  
Tuesday 20 May 2008, 10:00

Yorkshire Cancer Network

St Gemma's Hospice

**Present:**

Ms J Harrison	Airedale NHS Trust
Mrs R Underwood	Bradford Cancer Support Centre
Mrs H Hey	Bradford Teaching Hospitals NHS Foundation Trust
Mrs V Allinson	Calderdale and Huddersfield NHS Foundation Trust
Ms M Jennings	Harrogate and District NHS Foundation Trust
Ms C Downes	Leeds Teaching Hospitals NHS Trust
Ms S Smith	
Ms M Allinson	User Partnership Group
Mrs C Allmark	
Mrs S Keir	
Mr A Rawson	
Ms J Roberts	
Mr P Sale	
Ms M Clough	York Hospitals NHS Foundation Trust
Mr C Sloane (Chair)	Yorkshire Cancer Network
Ms F Stephenson	
Mrs J Toovey	

**Apologies**

Mr H Butcher, Mrs S Cooke, Mrs L Priestley

1. Welcome, Introduction & Apologies			
Log No	Action	Lead(s)	Deadline
1	June Toovey informed members that this group is an amalgamation of the User Involvement/Patient Information Leads (UI/Pis), the YCN User Partnership Information Sub Group and the Locality Information Leads Group (LILs). Historically these groups have met individually and there has been some cross over in the content of their respective agendas and work plans. It seemed therefore, sensible to amalgamate the 3 groups and bring them together into one group. There will be an opportunity for the User Involvement/Patient Information Leads to discuss issues relating to their User Involvement role at the start of each meeting and for the Locality Information leads at the end of the meetings and members from both of these groups present at the meeting agreed that would be useful.		N/A
2. User Involvement Leads			
Log No	Action	Lead(s)	Deadline
2	<p>► Terms of Reference and Work Plan</p> <p>The UI/PI Leads role description was tabled for comments and the following recommendations were made:-</p> <p>1.Tenure to be 2 years minimum with the option to continue if the Lead wishes to.</p> <p>2. Bullet point 2 under Key Duties, change to: Help to develop and integrate Patient Information Pathways into the work of the Network Site Specific Groups (NSSGs).</p> <p>Colin Sloane to make changes to the Role Description.</p>	C Sloane	08/07/2008

<b>2. User Involvement Leads</b>			
Log No	Action	Lead(s)	Deadline
3	<p>► NSSG Induction pack</p> <p>Colin Sloane explained that a suggestion from the recent NSSG Training day was to have an induction pack for patient/carer reps on the NSSGs to include information about training and support available, the work plan, terms of reference, annual report and a jargon buster including some general acronyms and some tailored to each of the cancer sites. Colin Sloane agreed to draft one together and distribute for comment to members of this group and to the wider membership of the main user partnership group. Final draft to be tabled for approval at the next main UPG meeting on the 10th June 2008.</p> <p>Colin Sloane to draft the NSSG Induction pack together and distribute by 23rd May 2008.</p>	C Sloane	23/05/2008
4	Members to feedback any comments by 3rd June 2008.	All	03/06/2008
5	Colin Sloane to table for approval at the main UPG meeting 10th June 2008.	C Sloane	10/06/2008
<b>3. Information</b>			
Log No	Action	Lead(s)	Deadline
6	<p>► Terms of Reference</p> <p>A draft terms of reference document was tabled at the meeting. The group suggested that the references to User Involvement should be taken out as the focus of this group is patient information. It was agreed that the User Involvement Facilitator and the Information and Support Manager should jointly chair the group for 6 Months and then explore the options for future chairing of the meetings. It was agreed that the frequency of meetings should be 4 per year with the option for further meetings as and when required.</p> <p>Colin Sloane to make changes to TOR and send out to group members for comment.</p>	C Sloane	13/06/2008
7	Colin Sloane to table the final draft at the next meeting for approval/adoption.	C Sloane	08/07/2008
8	<p>► Work Plan</p> <p>The group agreed that a work plan should be drafted together in line with the Network Information Strategy and sent out to group members for comment. The work of the Editorial panel should be incorporated into this. The work plan also needs a strong focus on how to ensure information pathways are developed alongside clinical pathways and how that might be measured. The work plan also needs to reflect equality and diversity issues relating to cancer information.</p> <p>June Toovey, Colin Sloane and Fiona Stephenson to draft a work plan and send out to group members for comment.</p>	J Toovey/C Sloane & F Stephenson	08/07/2008
9	<p>► Links to the Main UPG and others</p> <p>The information sub group will be the main source of advice to the Network Supportive and Palliative Care Steering Group. The group will also have a link to the Main UPG and will from time to time table reports and consults with the Main UPG membership as well as other Network groups.</p>		N/A

<b>3. Information</b>			
Log No	Action	Lead(s)	Deadline
10	<p>► Information Website Project</p> <p>Colin Sloane and June Toovey explained the project and asked if the Information Sub group would be happy to be the reference group for the project. The group agreed. Nazeem Mungur (YCN Macmillan Web Content Manager) will present at the next meeting of this group (8th July 2008). He will show some examples of information and support websites developed by other Networks and is also putting together a short questionnaire to obtain feedback. Nazeem will circulate an e-mail with links to the existing website along with the feedback questionnaire. It was agreed that this can be circulated wider to other health professional colleagues and across the User Involvement group in the localities etc. However, the feedback needs to be structured and therefore needs to be done by using the questionnaire.</p> <p>Nazeem to formulate questions and distribute with links to example websites.</p>	N Mungar	08/07/2008
<b>5. Locality Information Leads</b>			
Log No	Action	Lead(s)	Deadline
11	<p>► Macmillan Mobile Unit</p> <p>LILs discussed how the project had progressed and information was shared regarding the project. June Toovey to meet with Pam Ramaswamy from Macmillan on 23rd May 2008 to get an update on the project.</p> <p>To update the group at the next meeting.</p>	J Toovey	08/07/2008
12	To put the Macmillan mobile unit on the agenda of the next information sub group meeting.	C Murray	08/07/2008
13	<p>► Data bases and data collection</p> <p>Sadie Smith reported difficulties using the Macmillan Data base for information centres. The group agreed to continue to use their individual data collection systems until the problems with the Macmillan data base had been rectified</p> <p>The group asked how the information being sent to the network was being used.</p> <p>June Toovey to investigate and report back.</p>	J Toovey	08/07/2008
14	<p>► Terms of Reference and Work Plan</p> <p>The LILs group discussed the purpose of their meeting and agreed it would be used as an informal opportunity for the local information centre managers to network and share information. It was agreed that an action log would not be required to be taken for the meeting and the group would provide reports into the information sub group as required.</p>		N/A
<b>6. Any Other Business</b>			
Log No	Action	Lead(s)	Deadline
15	June Toovey informed the group that Jane Archer (Patient Information & Support Manager) and Nazeem Mungur (YCN Macmillan Web Content Manager) are currently on sick leave.		N/A

**Date of Next Meeting(s)**

Tuesday 8th July 2008 10:00 am  
St Gemma's Hospice