

**Actions of the meeting held on
Monday 11 May 2009, 10:00**

Yorkshire Cancer Network

St Gemma's Hospice

Present:

Mrs C Allmark	Leeds Teaching Hospitals NHS Trust
Mrs J Garrud	
Ms V James	
Ms J Sharp	
Ms M Allinson	User Partnership Group
Mrs P Brewis	
Mr R Brewis	
Mr H Butcher	
Mrs S Cooke	
Mr A Hall	
Mrs S Keir	
Mr A Rawson	
Mrs J Stead	
Mr P Mayor	York Hospitals NHS Foundation Trust
Mrs J Archer (Chair)	Yorkshire Cancer Network
Mr C Sloane (Chair)	
Mrs J Toovey	

Apologies

Mrs M Coleman, Mrs C Downes, Ms T Hiley, Mrs M Jennings, Ms J Roberts, Mr P Sale, Ms S Smith, Ms F Stephenson, Mrs L Wem, Mrs C Wheelhouse, Mrs L Wood

1. UI/PI Leads Only 10.00-10.30			
Log No	Action	Lead(s)	Deadline
1	<p>This part of the meeting did not go ahead due to the large amount of apologies received.</p> <p>It was agreed that in future this section will follow the Information Leads only part of the meeting. Future timings will be 10.30am to 12.00 Main meeting 12.00 to 12.30pm Information leads only 12.30pm to 1.00pm UI/PI Leads only</p> <p>Amend future agendas and timings to suit.</p>	Jehan, E	Next Meeting
2. Welcome, Introduction & Apologies			
Log No	Action	Lead(s)	Deadline
2	Colin welcomed all to the meeting and a round of introductions were made.	N/A	N/A
3. Action Log from the last meeting			
Log No	Action	Lead(s)	Deadline
3	The Action Log from the last meeting was accepted as a true record.	N/A	N/A

4. Matters arising			
Log No	Action	Lead(s)	Deadline
4	There were no matters arising that were not already on today's agenda	N/A	N/A
5. YCN Patient Information & Support Website - update			
Log No	Action	Lead(s)	Deadline
5	<p>Colin gave a brief update about the YCN Cancer Information and Support Website. The website project has been on hold for some time now due to long term sickness leave internally in the YCN.</p> <p>Although not completely resolved we are now in a position to begin to move forward with the project again. In the short term Colin Sloane will be working 1 day per week as project manager and will re-establish links with JamKit the website developers in order to push forward the website the delivery of the website content management system. The excellent work that this group has been involved in already will still go forward to inform the design, look and feel of the website.</p> <p>This group will continue to be the steering group for the project and Colin will give regular updates and will be asking for the groups involvement as the website develops.</p> <p>Colin to give regular updates to the group.</p>	Sloane, C	Ongoing
6. Information Workshop feedback			
Log No	Action	Lead(s)	Deadline
6	<p>Jane tabled a report from the information workshop held on the 23rd March 2009. Jane reported that the workshop had gone very well and evaluated positively. The report has been widely circulated. June asked if there had been any discussion at the workshop around the sustainability of the network information agenda for information resources. It was agreed that this could be a topic for discussion at a future workshop or within this group.</p> <p>Future discussion about sustainability of network process for the development of cancer information resources.</p>	Archer, J	06/08/2009

7. Network Patient Information Resources			
Log No	Action	Lead(s)	Deadline
7	<p>Jane gave an update of where we are with the current information resources going through the network process at the moment.</p> <p>1.Bone Marrow Aspiration and Biopsy •Now withdrawn - decided to use Macmillan/cancerbacup booklet</p> <p>2.Information About Your Skin Tunnelled Catheter • In progress</p> <p>3.Information Following Treatment for Patients with Early Breast Cancer •In progress - possible change to title</p> <p>4.Information for patients diagnosed with skin cancer • In progress</p> <p>5.Introducing Radiotherapy in Early Breast Cancer • In progress</p> <p>6.Lung Cancer : Managing Your Symptoms</p> <p>7.Lung Cancer and Smoking</p> <p>8.Lung Cancer Clinical Trials</p> <p>9.Lung Investigations • all the above completed and available.</p> <p>10.Managing nutrition when eating and swallowing is difficult • In progress</p> <p>11.Operations for Lung Cancer</p> <p>12.Sentinel Lymph Node Biopsy</p> <p>13.Small Cell Lung Cancer • all the above completed and available.</p> <p>14.Surgery for Cervical Cancer - Radical Hysterectomy</p> <p>15.Surgery for Cervical Cancer (Trachelectomy) - information for patients</p> <p>16.Surgery for Endometrial Cancer</p> <p>17.Surgery for Ovarian Cancer</p> <p>18.The Leeds Cancer Centre Gynaecology Cancer Services</p> <p>19.Ward 28 - Gynae Cancer Surgical Ward • All the above are in progress</p> <p>20.What is a Neck Dissection? • In progress</p> <p>21.When Your Treatment Is Completed •In progress</p> <p>22. Prescriptions exemption information • In progress</p> <p>Jane will keep the group updated at future meetings. Some of the group members were interested in the lung information 'When your treatment is completed' feeling this is something that all cancer sites should be offering, they asked if they could see a copy. Jane agreed to bring some along to the next meeting.</p> <p>Jane to bring copies of the 'When your treatment is completed' Lung information to the next meeting.</p> <p>Colin, Jane, Sue and Tony to have a draft booklet ready by the 26th June to submit to the Editorial panel All will report back to the next meeting.</p>	Archer, J	06/08/2009

7. Network Patient Information Resources			
Log No	Action	Lead(s)	Deadline
13	<p>Other information to be considered for Network wide use are: The 'Managing the Stress of Cancer' booklet This booklet was first developed by Dr James Brennan, Consultant Clinical Psychologist from Bristol. It was then adapted for the Bradford area by the Bradford Cancer User Partnership group, it has since also been adapted by the Airedale Cancer User Partnership group for use in Airedale. The Leeds User Partnership group have also expressed an interest in developing a version for Leeds. It would seem a sensible idea to develop the booklet for the whole of the YCN area.</p> <p>It was agreed that this would be a good idea. There has been some really positive feedback from cancer patients and carers and indeed the booklet was first brought to the Bradford user group by David Woodhall who was the Chair of the group at the time, David was a cancer patient who sadly passed away very suddenly last week, he had found the booklet extremely useful and was instrumental in driving the project forward with the Bradford UPG. Similar positive feedback has been collected throughout a number of consultation exercises in Bradford and Airedale.</p> <p>There has been some concern raised mainly from health professional colleagues about the booklet potentially being alarming to some patients. There are sections in the booklet that could potentially shock some patients/carers. However, members of this group felt that the benefits of the booklet to the many, far out weighs any negative impact.</p> <p>The booklet is on the agenda of the network psychosocial sub group on the 13th May and Colin will attend to give feedback from this meeting.</p> <p>Colin asked the group for volunteers to help to adapt the booklet for the network If the Psychosocial sub group support this idea. Sue Kier and Tony Hall kindly agreed to help. Colin, Jane, Sue and Tony agreed to have a draft ready for the next meeting of this group.</p>	Archer,J	06/08/2009
8. Information Prescriptions agenda			
Log No	Action	Lead(s)	Deadline
8	<p>Phase 2 of the National Information Prescriptions Pilots are underway and a newsletter has been produced by the national Cancer Action team with updates from the pilot sites. The newsletter will be distributed with this action log.</p> <p>A call for expressions of interest to join in with phase 2a has been received and the network are currently asking for interest from local trusts in the patch, Leeds have expressed some interest and Jane will be liaising with them over the coming weeks.</p> <p>Send out the Newsletter with the action log</p>	Jehan, E	next meeting

9. Progress on the YCN Patient Information Pathways			
Log No	Action	Lead(s)	Deadline
9	<p>Jane Archer gave an update on the network information pathways. There are now 8 pathways signed off and all others are on course to be completed by the end of May 2009.</p> <p>Jane Archer, Colin Sloane and June Toovey are beginning to look at putting together an implementation policy to ensure the pathways are used and embedded into the day to day practice across the network. Further progress will be reported at the next meeting.</p> <p>Agenda Item - Progress report on Pathways and Implementation policy to be reported at the next meeting</p>	Archer,J	next meeting
10. Editorial Panel			
Log No	Action	Lead(s)	Deadline
10	<p>There are a number of information materials currently going through the editorial panel process. The process seems to be working very well and the group has recently grown in terms of membership.</p>	Archer,J	N/A
11. Supportive and Palliative Care Implementation Update			
Log No	Action	Lead(s)	Deadline
11	<p>June Toovey explained a little about the implementation of the supportive and palliative care guidance for adults with cancer. Within the guidance there are 13 priority areas and the YCN are currently working on 10 of those as follows: Priorities/Tasks (major areas of the project)</p> <ul style="list-style-type: none"> ■1.Key worker implemented with policy and competencies for all stages of patient pathway ■2.Holistic assessment implementation documentation and sharing information ■3.Communicating significant news ■4.Implementation of the information strategy and action plan <ul style="list-style-type: none"> a.Generic information pathway and site specific information pathways b.Information prescriptions linked to information pathways and what happening wider across SHA for LTC c.Information web site development ■5.Specialist palliative care ■6.Psychological support ■7.Implementation of the User involvement strategy and action plan <ul style="list-style-type: none"> a.Education and support for service users to get more involved b.Recruitment of more service users including supporting policies for user involvement c.Linking all user groups across the YCN d.Patient survey of patient experience for use across all sites and MDTs in the YCN ■8.Supportive care and rehabilitation ■9.Palliative care strategy and needs assessment ■10.Bereavement <p>The implementation deadline has been set for December 2009. Jane Archer and Colin Sloane agreed to send out the full version of the Information Priorities from the guidance with this action log.</p> <p>Send detailed information about the information priorities from the S+P guidance with the action log</p>	Jehan, E	next meeting

12. Any Other Business			
Log No	Action	Lead(s)	Deadline
12	<p>Jane informed the group that they are still able to suggest venues for the siting of the Macmillan Mobile Cancer Information Unit. Suggestions to Helen Tuvey at Macmillan Tel: 01904 756406 Email: htuvey@macmillan.org.uk</p> <p>Marion reminded all those who are attending the LINKS event on the 19th May that filming will be in process throughout the day which will be contributing to the Network User Partnership groups recruitment DVD.</p> <p>Christine Allmark fed back from the user involvement in research open event which was held at the New Bexley Wing on Saturday 25th April. The day had been successful and 8 people had expressed an interest in the research user group.</p> <p>Hugh suggested and the group agreed to move the User Involvement/Patient Information Leads(UI/PI) slot to the end of the meeting. Future meetings will start at 10.30am for all members. Local Information Leads(LIL's) will have a 30min slot from 12.12.30pm and then If UI/PI Leads are able to attend we will have a slot for them at 12.30 to 1.00pm</p> <p>Future meetings to start 10.30 for all members with lunch at 12.00 12.00 to 12.30pm LIL's 12.30 to 1.00pm UI/PI Leads</p>	Jehan, E	next meeting

Date of Next Meeting(s)

Thursday 6th August 2009 10:00am
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