

Actions of the meeting held on
Thursday 18 February 2010, 10:00

Yorkshire Cancer Network

St Gemma's Hospice, Moortown, Leeds, LS17 6QD

Present:

Mr K Sohanpal	Airedale NHS Trust
Mrs R Underwood	Bradford Cancer Support Centre
Mrs C Allmark	Leeds Teaching Hospitals NHS Trust
Mrs J Garrud	
Mr T Mansell	
Ms J Sharp	
Mr D Thomas	
Mrs M Coleman	Mid Yorkshire Hospitals NHS Trust
Ms H Lancaster	
Ms M Allinson	User Partnership Group
Mrs P Brewis	
Mr R Brewis	
Mrs S Cooke	
Mr A Hall	
S Keir	
Mr E McGowan	
Mrs J Archer (Chair)	Yorkshire Cancer Network
Miss E Jehan	
Mr C Sloane (Chair)	

Apologies

Mrs V Allinson, Mr H Butcher, Ms C Deeks, Mr A Henry, Ms T Hiley, Dr M Matthews, P Mayor, Ms J Roberts, Mrs J Stead, Mrs J Toovey, Mrs L Wem, Mrs L Wood

1. Welcome and Apologies			
Log No	Action	Lead(s)	Deadline
40	Colin Sloane welcome the Group and round table introductions were made. The Group welcomed new member David Thomas; Children's Oncology Macmillan CNS at St. James's and Paediatric User Involvement & Patient Information Lead, who attended with Anne McDonnell from Newcastle Hospitals who is shadowing David for a few days. To add David Thomas to the Group membership.	E Jehan	04.03.2010
2. Action Log from the last meeting			
Log No	Action	Lead(s)	Deadline
41	The Action Log from the last meeting was agreed as an accurate record.	N/A	N/A

3. Macmillan Mobile Information Unit Schedule 2010			
Log No	Action	Lead(s)	Deadline
42	<p>Jane Archer informed the Group that dates have been set for 'Beryl'; the Macmillan Mobile Information Unit to visit the YCN in 2010:</p> <ul style="list-style-type: none"> • 29th March - 1st April • 9th - 12th August • 18th - 21st October <p>A document was tabled to allow members of the Group to make suggestions for sites/locations for the Unit to visit.</p> <p>To circulate Macmillan Mobile Information Unit location suggestions document to the Group.</p>	E Jehan	04.03.2010
43	<p>Jane Archer informed the Group that hard copies of the 2009 Annual Report and 2010 'Beryl's News' were available.</p> <p>To circulate the 2009 Annual Report and 2010 'Beryl's News' to the Group with the Action Log.</p>	E Jehan	04.03.2010
4. YCN Patient & Support Website - update			
Log No	Action	Lead(s)	Deadline
44	<p>Colin Sloane gave a short demonstration of the YCN Patient Information & Support Website. The site is not currently live but can be viewed at http://ycn.jamkit.com. Members of the Group were invited to view the website and feedback comments/suggestions using the feedback link.</p> <p>The Group were informed that the Web Content Administrator post has gone to advert, this will be a part time (3 day) post managed by Colin Sloane, it is hoped that when this post is in place work will progress quickly.</p> <p>To update the Group at the next meeting.</p>	C Sloane	11.05.2010
5. YCN Information Pathways including 'All Cancers' pathway review			
Log No	Action	Lead(s)	Deadline
45	<p>Jane Archer reminded the Group that she will shortly be undertaking a review of the Generic Patient Information Pathway and requested members of the Group interested in reviewing this information contact her.</p> <p>The Site Specific Information Pathways will be reviewed in Spring/Summer.</p> <p>Interested members of the Group to contact Jane Archer via email: jane.archer@ycn.nhs.uk or phone: 01423 555785</p>	All	Ongoing
46	To set up a meeting at St. Gemma's in March.	E Jehan	04.03.2010
6. Resources in development			
Log No	Action	Lead(s)	Deadline
47	Jane Archer thanked members of the Group involved in the YCN Editorial Panel for all their work over the past months as a higher than usual level of patient information resources have been out for review.	N/A	N/A

6. Resources in development			
6.1 Informing Patients about the 2 week wait - urgent referral system			
Log No	Action	Lead(s)	Deadline
48	<p>Jane Archer reported that changes have been made to this resource following it being sent to the Editorial Panel for review. The Group agreed do a final review of the amended resource prior to it being sent to the Primary Care Group for their input.</p> <p>The Group discussed the title and agreed on Jane Garrud's suggestion of; 'An Urgent Referral To Hospital - Why Me?'</p> <p>Jane Archer will be working with the YCN Primary Care Group to look at how best to implement this resource.</p> <p>The Group discussed the implications of having the YCN logo on the front of the resource as not all patients who receive it will receive a cancer diagnosis. Maggie Coleman suggested that many patients may find this distressing if the GP has not explained the referral.</p> <p>To change the title of the resource.</p>	J Archer	04.02.2010
49	To circulate the 2nd draft to the Group for comments by Friday 12th March.	E Jehan	04.03.2010
50	To circulate the 2nd draft of the resource to the Primary Care Group for comments.	E Jehan	04.03.2010
6.2 Free Prescriptions for Cancer Patients			
Log No	Action	Lead(s)	Deadline
51	<p>Jane Archer informed the Group that she has made changes to the resources following it being sent to the Editorial Panel for review.</p> <p>The Group agreed to do a final review of the resource prior to it being sent to Medical Illustrations for printing. Jane Archer asked members of the Group to pay particular attention to the accuracy of the section on refunds.</p> <p>To circulate the final draft to the Group for comments by Friday 12th March.</p>	E Jehan	04.03.2010
6.3 Holistic Needs Assessment			
Log No	Action	Lead(s)	Deadline
52	<p>Jane Archer informed the Group that June Toovey has made significant changes to the first draft of the resource, the second draft has been circulated to a small group of Service Users and Health Care Professionals prior to circulation to the Editorial Panel.</p> <p>To circulate to members of the Group for comments by Friday 12th March.</p>	E Jehan	04.03.2010
53	To circulate to the Editorial Panel for comments by Friday 12th March.	E Jehan	04.03.2010

6. Resources in development			
6.4 Relaxation CD			
Log No	Action	Lead(s)	Deadline
54	<p>Colin Sloane reminded the Group that this piece of work is being taken forward by himself, Marion Allinson and Carole White, Clinical Specialist Occupational Therapist at York. The aim is for the relaxation CD to sit alongside the Managing the Stress of Cancer Booklet. Discussion followed regarding whether the CD should be included in the booklet or as a stand alone resource; the Group agreed the CD should be included in the Managing the Stress of Cancer Booklet but also be available separately.</p> <p>The Group were informed that Marion Allinson and Carol White are now working towards recording the CD.</p> <p>It is hoped the CD will be ready by the end of June.</p> <p>The Group agreed that the relaxation CD should be made available on the Patient Information & Support website once live.</p> <p>To update the Group at the next meeting.</p>	C Sloane	11.05.2010
6.5 Managing the stress of cancer			
Log No	Action	Lead(s)	Deadline
55	<p>Colin Sloane informed the Group that the resource has been through the Editorial Panel and changes have been made, the resource is now ready to be sent Medical Illustrations for printing.</p> <p>To send the final version of the resource to Jane Garrud.</p>	C Sloane	04.03.2010
56	<p>The Group were informed that Marion Allinson has developed an audio version of the booklet.</p> <p>The Group agreed that the booklet and the audio version should be made available on the Patient Information & Support website once live.</p> <p>To upload the booklet and audio version to the Patient Information & Support website once live.</p>	C Sloane	Ongoing
6.6 Paying for additional private treatment			
Log No	Action	Lead(s)	Deadline
57	<p>Colin Sloane explained that Sean Duffy, YCN Medical Director has been approached by the Yorkshire & Humber Specialist Commissioning Group (Y&H SCG) to produce a patient information leaflet to assist patients considering paying for additional private treatment.</p> <p>The draft resource has been sent to two consultants for their comments prior to it being sent to the Editorial Panel.</p> <p>To circulate to the Editorial Panel for comments.</p>	E Jehan	04.03.2010

7. Key Worker Card - update			
Log No	Action	Lead(s)	Deadline
58	<p>Jane Archer updated the Group on behalf of Paul Mayor who was unable to attend the meeting.</p> <p>The Key Worker Card pilot at York has been very successful and no significant changes have been made to the card.</p> <p>The Sub Group formed to create the card will be reforming to look at implementation over the coming months.</p> <p>To circulate the final version of Paul Mayor's report with the Action Log.</p>	E Jehan	04.03.2010
59	To update the Group at the next meeting.	P Mayor	11.05.2010
8. National Information Prescriptions update			
Log No	Action	Lead(s)	Deadline
60	<p>Following the in-depth presentation of the NCPIDS site at the last meeting, Jane Archer gave a short demonstration of the site for the benefit of Group members not in attendance at the last meeting.</p> <p>The National Team are currently working towards Phase 3 of the pilot which will be to go live and host the system on the NHS Choices website. Jane Archer informed the Group that Phase 4 (time frame unknown) will include making the information available in different languages. The National Team are also working towards a patient self prescribing system.</p> <p>The Group were informed that the Health Mandate Team will be updating on the April deadline for going live at the NCIF meeting next week.</p> <p>Reva Underwood raised concerns that part of the pilot involves patients being given their information prescription to take to the Information Centre; Bradford have not been involved in Phase 2a and no information on how to give patients the right information has been passed on prior to going live.</p> <p>To update the Group on the progress of Phase 3 following the NCIF meeting.</p>	J Archer	04.03.2010
61	To feedback concerns to the National Team.	J Archer	04.03.2010
62	<p>Jane Archer reported that she is working with the Lung and Colorectal Nurses Groups to develop a Network information prescription and will be working with LTHT to make this available on PPM.</p> <p>To update the Group at the next meeting.</p>	J Archer / C Sloane	11.05.2010
9. Information Steering Group Work Plan			
Log No	Action	Lead(s)	Deadline
63	<p>Jane Archer and Colin Sloane advised the Group that this will be the main agenda item at the next meeting.</p> <p>Jane Archer informed the Group that she will be leaving the Network in the coming months, this will have an impact on the Network and the work of the Group. It is likely that the Patient Information & Support Manager post will not be filled as it was a three year Macmillan funded post and funding ended in November 2009.</p> <p>To add the Work Plan to the next meeting agenda.</p>	E Jehan	04.03.2010

10. Any Other Business			
Log No	Action	Lead(s)	Deadline
64	<p>Marion Allinson advised the Group that the Gateway Group have suggested producing a patient information resource on why patients have been refused treatment. This work will be taken forward with Marion Allinson, Peter Allen, David Thomson, Greg Fell and Colin Sloane.</p> <p>To update the Group at the next meeting.</p>	M Allinson	11.05.2010
65	<p>Colin Sloane advised the Group that there is a National move to strengthen the Peer Review Measures around patient information. The draft measures will be circulated for a 3 month consultation shortly.</p> <p>To circulate the draft measures to the Group when available.</p>	E Jehan	Ongoing
66	<p>Jane Archer informed the Group that she and Colin Sloane are involved with an organisation called CHANGE who produce patient information for people with learning difficulties. A steering group is currently working on information for patients at all stages of the cancer pathway.</p> <p>Members of the Group were invited to be involved in this steering group.</p> <p>To contact Jane Archer or Colin Sloane if interested in joining the steering Group.</p>	All	Ongoing
67	To send CHANGE resources in development to the Group for comments.	J Archer / C Sloane	Ongoing

Date of Next Meeting(s)

Tuesday 11th May 2010 10:00am
 St Gemma's Hospice, Moortown, Leeds, LS17 6QD

Tuesday 17th August 2010 10:00am
 St Gemma's Hospice, Moortown, Leeds, LS17 6QD

Tuesday 16th November 2010 10:00am
 St Gemma's Hospice, Moortown, Leeds, LS17 6QD