

Actions of the meeting held on
Tuesday 26 January 2010, 12:00

Yorkshire Cancer Network

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

Present:

Reva Underwood	Bradford Cancer Support Centre
Vicki James	Leeds Teaching Hospitals NHS Trust
Josie Sharp	
Louise Wem	
Peter Allen	User Partnership Group
Marion Allinson (Co-Chair)	
Mitzi Blennerhassett	
Pamela Brewis	
Robert Brewis	
Hugh Butcher (Co-Chair)	
Lesley Conti	
Sue Cooke	
Moira Dailey	
Rodney Dailey	
Anthony Hall	
Helen Jones	
Susan Keir	
Anne Knight	
Christine Lockwood	
Edward McGowan	
Madge Parker	
Jan Roberts	
Alan & Dorothy Smith	
Pamela Whitaker	
Emma Jehan	Yorkshire Cancer Network
Lisa Parish	
Colin Sloane	

Apologies

Jane Archer, Sue Farr, Jane Garrud, Rachel Hollis, Helen Lancaster, Tom Mansell, Francesca Pendino, Alan Rawson, Jill Stead, June Toovey

1. Welcome, Introduction & Apologies			
Log No	Action	Lead(s)	Deadline
38	Hugh Butcher welcomed the Group and round table introductions were made. The Group welcomed new members Helen Jones and Chris Lockwood. To add new members to the Group membership.	E Jehan	09.02.2010
3. Action Log from the last meeting			
Log No	Action	Lead(s)	Deadline
39	The Action Log from the last meeting was agreed as an accurate record.	N/A	N/A

3. Action Log from the last meeting			
Log No	Action	Lead(s)	Deadline
40	<p>► Connected Programme Steering Group (Log 23)</p> <p>Mitzi Blennerhassett updated the Group on the Connected Programme Steering Group which she sits on as a User Representative; the Group has agreed that the 3 day course is essential and the only possibility of reducing this would be for Clinicians such as Radiologists who have less contact with patients.</p> <p>The Group expressed their concern that there are over 250 Clinicians currently on the waiting list for the Advanced Communications Skills Training course; Colin Sloane reported that the 6 facilitators have recently been accredited and a further 6 are currently in training. Each facilitator runs a minimum of 2 courses per year; so far 10 courses are booked for 2010 and this will increase as facilitators are accredited.</p> <p>To feedback the Groups concerns at the next Steering Group meeting.</p>	M Blennerhassett	Ongoing
41	<p>► Log number 33</p> <p>Jan Roberts reported that she is meeting with Jane Archer in the near future to discuss the leaflet on 2 week waits and urgent referrals that has been developed by the Calderdale & Huddersfield Locality Group</p> <p>To update the Group at the next meeting.</p>	J Roberts / J Archer	25.06.2010
4. A look back at 2009 - what have we done?			
Log No	Action	Lead(s)	Deadline
42	<p>Colin Sloane tabled a review of the work undertaken by the Group in 2009.</p> <p>1.1 Lancaster University/Macmillan Research Project: The final report has now been published and is available from Macmillan.</p> <p>1.2 Patient Experience Surveys: The Group were informed that the National Cancer Action Team are launching a one off national survey which will involve all Networks, this survey will be sent via the post to over 60,000 patients and results will be fed back to individual Trusts. This survey is being taken forward by the Picker Institute who will be able to compare the results with the 2000 and 2004 surveys.</p> <p>The YCN Lead Team have made the decision to put the YCN survey on hold until 2011 while the national survey is ongoing. The SNAP software purchased to take the surveys forward will be developed and can be used by Trusts for other local surveys.</p> <p>The Patient Experience Sub Group will reconvene shortly to begin developing the YCN surveys.</p> <p>To send copies of the research project report to the Group.</p>	E Jehan	26.02.2010
43	To book a meeting for the Patient Experience Sub Group.	E Jehan	09.02.2010
44	<p>1.5 LINKS Event: Colin Sloane requested members of the Group contact him with ideas of the next LINKS event.</p> <p>To send any ideas for the event to colin.sloane@ycn.nhs.uk or 01423 555756.</p>	All	Ongoing

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4. A look back at 2009 - what have we done?			
Log No	Action	Lead(s)	Deadline
45	<p>1.7 Peer Review: The Group were informed that User Reviewers are still required. Last year 13 Service Users got involved in the Peer Review Internal Validation panels, with 3 of them also representing at Network level. Colin Sloane requested interested Services Users contact him, another training day will be run this year if necessary.</p> <p>To contact Colin Sloane if interested in being a User Reviewer.</p>	All	Ongoing
46	Colin Sloane thanked the Group for all their hard work throughout 2009.	N/A	N/A
5. The Future 2010 - whats in store for this year?			
Log No	Action	Lead(s)	Deadline
47	<p>Colin Sloane tabled a overview of work that will be taken forward in 2010.</p> <p>A bid to Macmillan for 2 Outreach Workers has been successful and the posts will go to advert shortly; these will be part time 18 months project posts, one post will focus on BME groups (Black Minority Ethnic) and the other will focus on people with Learning Disabilities groups.</p>	N/A	N/A
48	<p>Colin Sloane split the Group into 3 working groups and asked each group to prioritise the work streams for 2010.</p> <p>Each group fed back what they classed to be the main priorities for the year:</p> <p>Group 1</p> <ul style="list-style-type: none"> • Moving On Project • Patient Experience Surveys • Patient Information <p>Group 2</p> <ul style="list-style-type: none"> • Patient Experience Surveys • Patient Information • Recruitment • Equality & Diversity <p>Group 3</p> <ul style="list-style-type: none"> • Moving On Project • Equality & Diversity • Patient Experience Surveys <p>Colin Sloane informed the Group that all planned work streams will be taken forward but the focus will be on; Moving On Project, Patient Information, Equality & Diversity and the Patient Experience surveys.</p> <p>An expressions of interest form was tabled and Group members were asked to highlight which sub groups (if any) they wanted to be involved in.</p> <p>To send expressions of interest to all members of the Group.</p>	E Jehan	09.02.2010

6. Radiotherapy - support services for patients/carers			
Log No	Action	Lead(s)	Deadline
49	<p>Louise Wem informed the Group that following a patient survey she is setting up an after treatment clinic, this will be a 6 week rolling programme and will be supported by radiographers and nurses.</p> <p>The next step of the project will be to audit patient/carer concerns at end of treatment and then at follow up.</p> <p>Hugh Butcher suggested linking into the Moving On Project.</p> <p>To feedback any suggestion to Louise Wem: louise.wem@leedsth.nhs.uk.</p>	All	Ongoing
50	To circulate the survey and project proposal to the Group.	E Jehan	09.02.2010
7. Any Other Business			
Log No	Action	Lead(s)	Deadline
51	<p>► Information, Care & Support Officer</p> <p>Colin Sloane informed the Group that Tom Mansell has joined the Leeds Cancer Information & Support Centre as Information, Care & Support Officer, this is a 3 year project post to develop services in Leeds.</p> <p>To invite Tom Mansell to the next Group meeting.</p>	E Jehan	09.02.2010
52	<p>► New Perspectives Course</p> <p>Sue Cooke informed the Group that the Macmillan 6 week New Perspectives course will be running at the Robert Ogden Centre, Leeds from February 3rd and there are 3/4 places still available. This is a free course open to patients at any stage of the cancer pathway, several Group members reported attending this course and finding it very beneficial.</p> <p>Interested Group members to contact Louise Fisher 0113 2066498.</p>	All	Ongoing
53	<p>► NSSG Representation</p> <p>Colin Sloane informed the Group that the Pathology Group are seeking another User Representative to sit on the Group, Mitzi Blennerhassett currently sits on the Group.</p> <p>Interested Group members to contact Clair Irving (clair.irving@ycn.nhs.uk).</p>	All	Ongoing
54	<p>► Arts Steering Group</p> <p>Vicki James informed the Group that there is an Arts Steering Group at St. James's who are looking to recruit a Service User to help in choosing the artwork to display in the Bexley Wing. Meetings of this Group take place on the last Friday of the month at 10.30am.</p> <p>Interested Group members to contact Vicki James (vicki.james@leedsth.nhs.uk).</p>	All	Ongoing

7. Any Other Business			
Log No	Action	Lead(s)	Deadline
55	<p>Hugh Butcher reported he had seen an article regarding the new Cyber Knife which is not yet available through the NHS. Louise Wem informed the Group that the Cyber Knife is similar to the Gamma Knife which delivers radiotherapy to lesions within the brain.</p> <p>► Post meeting note</p> <p>Following the meeting Louise Wem contacted the YCN with accurate information; the Cyber Knife is slightly different to the Gamma Knife as it treats other areas - the Gamma Knife only treats areas within the brain.</p> <p>The Cyber Knife is not yet available in the NHS because of the vast expense of acquiring & maintaining it which at present cannot be justified in terms of the numbers of people it would benefit.</p>	N/A	N/A

Date of Next Meeting(s)

Wednesday 31st March 2010 9:30am
 St Gemma's Hospice, Moortown, Leeds, LS17 6QD [Away Day]

Wednesday 26th May 2010 9:30am
 St Gemma's Hospice, Moortown, Leeds, LS17 6QD [Links Event]

Friday 25th June 2010 12:30pm
 St Gemma's Hospice, Moortown, Leeds, LS17 6QD

Tuesday 28th September 2010 12:00pm
 St Gemma's Hospice, Moortown, Leeds, LS17 6QD