

**Actions of the meeting held on  
Tuesday 10 February 2009, 10:00**

**Yorkshire Cancer Network**

**St Gemma's Hospice**

**Present:**

Mrs J Thogersen	Bradford Cancer Support Centre
Ms T Hiley	Bradford Teaching Hospitals NHS Foundation Trust
Ms S Smith	Leeds Teaching Hospitals NHS Trust
Mrs L Wem	
Mrs M Coleman	Mid Yorkshire Hospitals NHS Trust
Mr H Butcher	User Partnership Group
Mr A Hall	
Mrs S Keir	
Mr A Rawson	
Mrs J Stead	
Mrs J Archer (Chair)	Yorkshire Cancer Network
Mr C Sloane (Chair)	
Mrs J Toovey	

**Apologies**

Ms M Allinson, Mrs C Allmark, Mrs S Cooke, Mrs C Downes, Mrs H Hey, Mrs M Jennings, Mr P Mayor, Ms S Morgan, Ms J Roberts, Mrs L Wood

<b>1. UI/PI Leads Only 10.00-10.30</b>			
Log No	Action	Lead(s)	Deadline
65	This section of the meeting was postponed as only one of the User involvement/Patient Information leads was present at the start of the meeting.	N/A	N/A
<b>2. Welcome and Apologies</b>			
Log No	Action	Lead(s)	Deadline
66	Colin welcomed all to the meeting, particularly those attending for the first time.	N/A	N/A
<b>3. Action Log from the last meeting</b>			
Log No	Action	Lead(s)	Deadline
67	The group went through the action log from the last meeting and they were accepted as a true record	N/A	N/A

<b>4. Matters arising</b>			
Log No	Action	Lead(s)	Deadline
<b>68</b>	<p>Colin pointed out just one matter arising from the last action log. Page 3 log No 60.</p> <p>Christine Allmark was going to attend today to feedback on this item but unfortunately was unable to attend. Colin reported that he had attended a meeting with the Yorkshire Cancer Research Network and members of Cancer Research UK. The two organisations are beginning to look at developing a Consumer Research Group. Colin is keen to invite service users who have an interest in cancer research to join the group. Anyone interested in finding out more can contact Colin. Colin will also send out an invitation top all YCN UPG members.</p> <p>Colin to invite members of the YCN UPG to get involved in this new group.</p>	Sloane, C	17/03/09
<b>5. YCN Patient &amp; Support Website - update</b>			
Log No	Action	Lead(s)	Deadline
<b>69</b>	<p>June Toovey explained to the group that the website project is currently on hold due to long term sickness leave of the Web Content Manager. However, good progress has been made in spite of this long term absence and 2 consultations have been completed to help towards the design, look and feel of the website. The Network should be in a position to begin moving the project forward again at the beginning of March 2009. A further update will be provided at the next meeting of this group.</p> <p>Put Website Update on the agenda for the next meeting of this group (May 11th 09)</p>	Sloane,C	11/05/09
<b>6. Information Workshop (Feb 27th 2009)</b>			
Log No	Action	Lead(s)	Deadline
<b>70</b>	<p>Colin and Jane informed the group that the workshop will now take place in early March. Due to unforeseen circumstances it has not been possible to keep to the original date of Feb 27th.</p> <p>The new date has now been confirmed as 23rd March 09. An invitation to the workshop will be sent out in the next few days to all NSSG UI/PI Leads, Local MDT UI/PI Leads, Local cancer information centres, Service users representing on the NSSG/NCCG's, Lead nurses in each of the Local Trusts and other key individuals working in the cancer information field.</p> <p>Programme to be drafted and invitations to be sent out.</p>	Archer, J	17/02/09

<b>7. Network Patient Information Resources</b>			
Log No	Action	Lead(s)	Deadline
71	<p>Jane talked to the group about the Information resources currently going through the YCN process these include,</p> <ol style="list-style-type: none"> <li>1.Bone Marrow Aspiration and Biopsy</li> <li>2.Information About Your Skin Tunnelled Catheter</li> <li>3.Information Following Treatment for Patients with Early Breast Cancer</li> <li>4.Information for patients diagnosed with skin cancer</li> <li>5.with skin cancer</li> <li>6.Introducing Radiotherapy in Early Breast Cancer</li> <li>7.Lung Cancer : Managing Your Symptoms</li> <li>8.Lung Cancer and Smoking</li> <li>9.Lung Cancer Clinical Trials</li> <li>10.Lung Investigations</li> <li>11.Managing nutrition when eating and swallowing is difficult</li> <li>12.Operations for Lung Cancer</li> <li>13.Sentinel Lymph Node Biopsy</li> <li>14.Small Cell Lung Cancer</li> <li>15.Surgery for Cervical Cancer - Radical Hysterectomy</li> <li>16.Surgery for Cervical Cancer (Trachelectomy) - information for patients</li> <li>17.Surgery for Endometrial Cancer</li> <li>18.Surgery for Ovarian Cancer</li> <li>19.The Haematology Clinic</li> <li>20.The Leeds Cancer Centre Gynaecology Cancer Services</li> <li>21.Ward 28 - Gynae Cancer Surgical Ward</li> <li>22.What is a Neck Dissection?</li> <li>23.When Your Treatment Is Completed</li> </ol> <p>The group suggested that the completed resources, as well as being distributed to the Local trusts, are also sent out to the Locality Cancer Information centres. It was also agreed that it would be useful for them to hold copies of the completed information pathways for each of the sites.</p> <p>Cancer information Centres to be included in the distribution list for all completed information resources</p> <p>Completed Cancer Information Pathways to be distributed to Cancer Information Centres</p>	Archer, J	ongoing

<b>8. Information Prescriptions agenda</b>			
Log No	Action	Lead(s)	Deadline
72	<p>At our last meeting Jane presented the live link to the National Cancer Information Delivery system which at the time was open for access to everyone. Unfortunately access to the website is now password protected and only those Trusts who are part of the phase 2 pilots can access it. At a recent meeting of the East Midlands and North East Cancer Information and Support Managers, concern was raised that not being able to access the website would hinder the managers ability to keep up to speed and be aware of progress being made with the National Project. These concerns have been passed on to the National Cancer Action Team.</p> <p>Jane explained to the group about the phase 2 pilots for the National information prescriptions project. There are 39 Trusts involved and the cancer sites in phase 2 are breast, bowel, prostate, lung, ovary, uterus, vagina, vulva, and cervix. Early feedback suggests there have been some delays in getting the pilots up and running.</p> <p>It was agreed that the Network should keep an eye on the developments at National level but should continue to concentrate on finalising our information pathways which should form the basis of information prescriptions in the future.</p> <p>It is also anticipated that in the future the Trusts in the Yorkshire Cancer Network will have improved communication channels through systems like the Patient Pathways Manager (PPM) which is currently under development. This will enable much better sharing of patient records and will allow health professionals to see which information patients have been offered at different points on their pathway.</p>	Archer, J	ongoing
<b>9. Progress on the YCN Patient Information Pathways</b>			
Log No	Action	Lead(s)	Deadline
73	<p>Jane reported to the group that a great deal of work has been in progress with the development of the cancer information pathways across most sites in the Yorkshire Cancer Network. Jane has been working closely with most of the NSSG's and many of the pathways are near to completion.</p> <p>Jane has been working with Philip Melling to develop a database which will hold all of the pathways and will have direct links to the recommended pieces of information on each pathway. The pathways and the links to the information will be available on the YCN website. Three Colorectal pathways will be the first to be uploaded.</p> <p>Following on from the work undertaken by Sadie Smith and Reva Underwood, each of the pathways will now also have a section of information in alternative formats where available.</p> <p>The deadline for completion of all information pathways is March 2009.</p> <p>The group agreed that the next step is to start thinking about how the information pathways can be implemented and we ought to look at how that could be achieved. The group agreed to start developing some guidance on implementation.</p> <p>Jane and Colin to put together a draft guide for the implementation of information pathways and circulate for comment</p>	Archer, J and Sloane,C	23/02/09
<b>10. Editorial Panel</b>			
Log No	Action	Lead(s)	Deadline
74	<p>Jane informed the group that there are now 29 members on the editorial panel. There are currently 9 pieces of information going through the process. The documentation for the panel has recently been reviewed and updated and the group agreed that all members should be sent an up to date editorial panel pack.</p> <p>YCN to send out updated editorial packs to all members of the panel.</p>	Archer, J	23/02/09

<b>11. 'Bowel Cancer Surgery' DVD York Hospital Trust</b>			
Log No	Action	Lead(s)	Deadline
<b>75</b>	<p>Diane Burwell (Colorectal CNS, York Hospital) had recently presented a DVD about Bowel Cancer Surgery at the YCN Colorectal education event and it was suggested that it may be a useful Network information resource.</p> <p>It was agreed that members of this group would take copies of the DVD and feedback their initial thoughts. Jill Stead, Tony hall, Louise Wem, Sadie Smith, Janet Thogersen and Tracy Hiley agreed to feedback. It was also agreed that Diane would take the DVD to the next Colorectal nurse meeting and then feedback to this group in May. Based on the feedback this group can then decide whether to adopt and/or adapt the DVD as a YCN resource.</p> <p>Jill Stead, Tony hall, Louise Wemm, Sadie Smith, Janet Thogersen and Tracy Hiley to feedback comments on the DVD to Colin by the 1st March 09</p> <p>Colin to pass comments on to Diane before the Colorectal Nurses meeting on the 4th March 09.</p> <p>Diane to feedback to the Information Steering group on 11th May 09.</p>	Sloane, C	01/03/09 then 03/03/09 then 11/05/09
<b>12. Any Other Business</b>			
Log No	Action	Lead(s)	Deadline
<b>76</b>	<p>June Toovey informed the group that the Supportive and Palliative Care Guidance deadline for full implementation is December 2009. The guidance has a section on cancer information and it was agreed that this should be a substantive item on the agenda for our May 11th 09 meeting</p> <p>Supportive and Palliative Care Guidance to be a main agenda item for the next meeting on May 11th 09.</p>	Archer, J	next meeting
<b>77</b>	<p>Jane informed the group that we now have the dates for the Macmillan Mobile Cancer Information Mobile Unit.</p> <p>The unit was due to be in the YCN area firstly on the 18th and 19th February concentrating on workplaces. The 18th was planned at york university but had to be cancelled and on the 19th the unit will be at leeds metropolitan university.</p> <p>The unit will then visit the area on 20th, 21st, 22nd and 23rd July 2009 and then 27th, 28th, 29th and 30th July 2009.</p> <p>We then have 4 days in November, 2nd, 3rd, 4th, and 5th November 2009. Last year (2008) the unit was in the area in September and visited York, Leeds, Wakefield, Skipton, Keighley, Selby, Huddersfield, Dewsbury and Pontefract. There were 870 visitors to the unit during its stay. Young people was a target group defined for the 2008 tour.</p> <p>If anyone has any suggestions for where the unit should/could visit in 2009 please forward on to Jane Archer</p> <p>Suggestions for mobile unit visits to Jane archer</p>	ALL	end of March 09
<b>78</b>	<p>Agenda items for the next meeting</p> <ul style="list-style-type: none"> <li>•Supportive and Palliative Care Guidance Implementation</li> <li>•YCN Support Directory</li> <li>•Feedback from 'Producing Effective Information for Patients' conference</li> <li>•Website update</li> <li>•Information Pathways - A guide towards implementation</li> <li>• Bowel Cancer Surgery DVD feedback</li> </ul>	Archer, J and Sloane, C	next meeting

**Date of Next Meeting(s)**

Monday 23rd March 2009 9:30am  
St Gemma's Hospice [Workshop]

Monday 11th May 2009 10:00am  
St Gemma's Hospice

Thursday 6th August 2009 10:00am  
St Gemma's Hospice

Friday 6th November 2009 10:00am  
St Gemma's Hospice