

Present:

Christine Allmark	Leeds Teaching Hospitals NHS Trust
Sarah Hannam	
Vicki James	
Sally Scales	
Kate Smith	
Marion Allinson (Chair)	User Partnership Group
Mitzi Blennerhassett	
Hugh Butcher (Chair)	
Sue Cooke	
Moira Dailey	
Rodney Dailey	
Anthony Hall	
Susan Keir	
Madge Parker	
Alan Rawson	
Jan Roberts	
Alan & Dorothy Smith	
Jill Karen Stead	
Pamela Whitaker	
Clair Irving	Yorkshire Cancer Network
Colin Sloane	
June Toovey	

Apologies

Veronica Allinson, Jane Archer, Margaret Jennings, Francesca Pendino, Diana Robinson, Fiona Stephenson, Reva Underwood

1. Welcome, Introduction & Apologies			
Log No	Action	Lead(s)	Deadline
46	Hugh Butcher welcomed three new members to the group, Jill Karen Stead, Tony Hall and Sarah Hannam. Clair Irving to ensure name plates are made for the new members and that Sue Keir's name plate is amended from Susan to Sue.	C Irving	02/06/2009
47	The group were informed that Sally Scales will be leaving her current role and congratulated her on her new post in Bradford. Colin Sloane thanked her for all her hard work and commitment to the group. Clair Irving will also be leaving the group to go on maternity leave. Marion Allinson thanked Clair for all her work as the UPG's support officer. Emma Jehan will be supporting the group during Clair's maternity leave. Hugh Butcher reminded the group of the code of confidentiality.	N/A	N/A

2. Any Other Business - Urgent Items			
Log No	Action	Lead(s)	Deadline
48	<p>► Supportive & Palliative Care guidance - national monitoring</p> <p>June Toovey informed the group that the guidance has now been agreed and needs to be implemented by December 2009. A stock take of the current position against the guidance is to be submitted nationally on Monday 9th February 2009.</p> <p>Clair Irving to circulate the priorities with the action log.</p>	C Irving	13/02/2009
49	June Toovey to keep the group informed with any updates.	J Toovey	02/06/2009
50	<p>► Leeds Cancer Locality Group - call for interest</p> <p>Colin Sloane informed the group of the invitation to join the Leeds Cancer Locality Group as a second service user to represent the Yorkshire Cancer Network User Partnership Group. They are looking for one person from the Leeds Partnership group and one from the Yorkshire Cancer Network Partnership Group.</p> <p>Colin Sloane to email the group with a brief to include further details of the proposal.</p>	C Sloane	24/02/2009
51	Members interested need to contact Colin Sloane at colin.sloane@ycn.nhs.uk or on 01423 555786 or Vicky James at vicki.james@leedsth.nhs.uk or on 0113 2067646.	All	02/02/2009
3. Matters arising			
3.1 Confidentiality statement NSSG/NCCG Handbook			
Log No	Action	Lead(s)	Deadline
52	<p>Colin Sloane tabled the code of confidentiality statement. A group discussion followed and it was agreed that they are used as guidelines to raise awareness rather than as a signed agreement. The group established that any sensitive issues are to be flagged to establish a group consensus on how best to move forward. New users' training packs are to be amended to emphasise the importance of this.</p> <p>Colin Sloane to remove the signing section on the statement and to update the training packs accordingly.</p>	C Sloane	02/06/2009
53	<p>Colin Sloane informed the group that the NSSG/NCCG Handbook is currently being finally formalised and will be available on the YCN web shortly.</p> <p>Clair Irving to post the generic handbook on the YCN web once it has been finalised.</p>	C Irving	02/06/2009
3.2 Lancaster University/ Macmillan Research Project update			
Log No	Action	Lead(s)	Deadline
54	<p>Hugh Butcher reminded the group of the project and informed members that all interviews have now taken place and a report has now been submitted to Macmillan who are to decide how to move forward with the information.</p> <p>Hugh Butcher is to ask for access to the report to check for any inaccuracies and will share the final report with the group once this is received.</p>	H Butcher	02/06/2009

3. Matters arising			
3.3 NSSG Handbook Cancer Action Newsletter			
Log No	Action	Lead(s)	Deadline
55	Colin Sloane tabled the page of the Cancer Action Team newsletter to show the article written on the success of the NSSG Handbook. The group were informed that this has been shared for adaptation with other Networks. June Toovey and Marion Allinson thanked Colin Sloane for putting this document together.	N/A	N/A
4. Annual Review & updates from sub groups			
Log No	Action	Lead(s)	Deadline
56	Colin Sloane tabled the Annual Review Report and gave a brief overview of the role and functions of the sub groups, encouraging members to come forwards should they wish to join any of these groups. In particular, since Trish Thornton has now left the Implementation group to pursue voluntary work overseas, a new member is needed for the Implementation sub group which meets once a month. Anyone wishing to express an interest in joining any of the sub groups are to contact Colin Sloane at colin.sloane@ycn.nhs.uk or on 01423 555786.	All	Ongoing
57	<p>► A1 - Broadening methods for collecting service user feedback</p> <p>Colin Sloane informed the group that the Patient Experience survey responses have all being received back. Once they have been approved by the ethics committee they will be ready to pilot with a couple of NSSG groups. Namely the Colorectal and Urology groups and possibly the Gynaecology group. Approximately 20 patients per site will be involved.</p> <p>The group were also informed that money has been identified at the Network to develop a web based database to enable patients to fill out the questionnaire online which will include a 'live feedback' option and the ability for data analysis.</p> <p>Sue Cooke asked if information was available on those patients who do not fill out the surveys as this may have a significant influence on the final interpretation.</p> <p>A group discussion followed on exactly how the questionnaires would be used in practice in terms of how often and at what stage of treatment they would need to be given out. Christine Allmark commented that there is the potential for a lot of developmental research surrounding this.</p> <p>June Toovey suggested that the results obtained from the surveys need to be general enough to compare but need to be team specific to ensure ownership is taken and that changes are made.</p> <p>Colin Sloane to keep the group updated on this work.</p>	C Sloane	02/06/2009
58	<p>► A2 - Consolidate service user involvement in the work of NSSGs and relevant NCCGs and through them into patient pathways and service development</p> <p>Colin Sloane informed the group that two NSSG training days have already been successfully held and that there are plans to continue running these.</p> <p>Colin Sloane is to organise another NSSG training day once enough new members have been recruited.</p>	C Sloane	Ongoing

4. Annual Review & updates from sub groups			
Log No	Action	Lead(s)	Deadline
59	Colin Sloane pointed out the groups where user representation is required. Rod and Moira Dailey offered to join the Head and Neck Specialists group. Clair Irving to send Rod and Moira Dailey the Head and Neck site specific NSSG handbook, to link them to the group and to inform them of future meetings.	C Irving	06/02/2009
60	Mitzi Blennerhassett expressed an interest in joining the Pathology group. Colin Sloane to supply Mitzi Blennerhassett with more information on this group.	C Sloane	06/02/2009
61	Members wishing to express an interest in joining any of the Network groups are encouraged to contact Colin Sloane on 01423 555786 for more information.	All	Ongoing
62	▶ A3 - Engage with and gain an understanding of the process of commissioning services in the NHS Colin Sloane informed the group that at the moment at Network level the commissioning process is very complex and has been going through some change in 2008 so the situation will be monitored, ensuring engagement where possible is achieved. At a National level there is a commitment to obtain user involvement in this process. Colin Sloane to keep the group updated with any developments or opportunities of work streams to become involved in.	C Sloane	02/06/2009
63	▶ A4 - Influence the implementation of NICE Improving supportive and Palliative Care for Adults with Cancer Colin Sloane informed the group that Marion Allinson and Sue Cooke have had a great influence on the High Level Supportive Care Pathway which has now been signed off at Board level. The Specialist pathway is now in development which will again involve user input. Colin Sloane to keep the group updated on progress.	C Sloane	02/06/2009
64	▶ A6 - Hospital Travel Costs and Car parking Colin Sloane reminded the group that there are now free prescriptions available for cancer patients from April 2009. The issue of car parking arose and it was pointed out that parking at the Bexley wing is free for patients who are receiving ongoing treatment however members felt that this information was not readily available. Vicki James to take this issue back to Leeds to ensure this information is made widely available to patients.	V James	02/06/2009
65	The group raised concerns that this is an issue that needs to be picked up in all localities. Colin Sloane is to email all Locality Group Chairs to ask if there would be interest to form a small working group to take this issue forwards and to write a paper for discussion at the next meeting.	C Sloane	02/06/2009
66	▶ A7 - Support and training for user Involvement at all levels Colin Sloane asked members how they felt the groups and sub groups were working and encouraged those with any ideas or suggestions for improvement are to contact Colin Sloane on 01423 555688 or colin.sloane@ycn.nhs.uk.	All	Ongoing

5. Survivorship initiative funding bid			
Log No	Action	Lead(s)	Deadline
67	<p>Hugh Butcher circulated a paper outlining the three proposals that Marion Allinson, Colin Sloane and himself have submitted to the Network to support the delivery of the Cancer Reform Strategy in terms of looking at new approaches to the care and management of cancer survivors.</p> <p>Members endorsed the proposals and were informed that applicants will be informed of the outcome by Friday 13th February 2009</p> <p>Clair Irving to circulate the paper outlining the proposals with the action log.</p>	C Irving	06/02/2009
68	Hugh Butcher to keep the group updated with the developments of the bids.	H Butcher	02/06/2009
6. Away Day 17th March 2009			
Log No	Action	Lead(s)	Deadline
69	<p>Colin Sloane informed the group that to link in with the Survivorship initiative funding bid, the theme for the Away Day will be 'Survivorship'.</p> <p>Some of the ideas put forward were to have Sue Cooke speaking on the Macmillan Living with Cancer project work, Christine Allmark to speak on research projects and Adam Glasier on the Children and Young people Late Effects of Cancer Treatment work.</p> <p>Members were asked to submit ideas to Colin Sloane at colin.sloane@ycn.nhs.uk or 01423 555786</p>	All	06/03/2009
70	<p>Colin Sloane suggested that a small working group be set up to take forward the planning of the Away Day and Links event.</p> <p>Any volunteers are to contact Colin Sloane.</p>	All	13/02/2009
71	Representatives of Local User Partnership groups are to contact Colin Sloane if there are any issues which they feel need to be on the agendas for the locality links event on the 19th May 2009.	All	ASAP
7. Any Other Business			
Log No	Action	Lead(s)	Deadline
72	<p>► Key Contact card</p> <p>Hugh Butcher informed the group that the York group are piloting a Key Worker contact card which is to be rolled out across other localities if it is successful.</p> <p>Hugh Butcher to keep the group informed of progress.</p>	H Butcher	02/06/2009
73	<p>► Mitzi Blennerhassett informed the group that radiotherapy patients are now able to use two way communications.</p> <p>► Colin Sloane advised that the National Chemotherapy Advisory Group report is out for consultation.</p> <p>Colin Sloane agreed to resend the NCAG report to the group for those who have not seen this.</p>	C Sloane	06/02/2009

7. Any Other Business			
Log No	Action	Lead(s)	Deadline
74	▶ CRUK funding Christine Allmark informed the group that the CRUK funding is to cease in 2 years and that her post will expire in April 2009. Hugh Butcher to write a letter of support from the YCN UPG to the CRUK, expressing our concerns that the funding is being cut and the impact that will have on future health and social care research.	H Butcher	02/06/2009

Date of Next Meeting(s)

Tuesday 17th March 2009 10:00am
St Gemma's Hospice [Away Day]

Tuesday 19th May 2009 10:00am
St Gemma's Hospice [Links Event]

Tuesday 2nd June 2009 12:00pm
St Gemma's Hospice

Wednesday 23rd September 2009 12:00pm
St Gemma's Hospice