

YORKSHIRE CANCER NETWORK
USER PARTNERSHIP GROUP

Minutes of the meeting held on
Wednesday 24th May 2006, 1.00pm
Room 1, YCRN Conference Room, Cookridge Hospital

Present:	Marion Allinson	Service User / Airedale User Partnership Group
(alphabetically)	Jane Archer	YCN Patient Information & Support Manager
	Martin Child	YCN User Involvement Facilitator
	Lesley Conti	Service User / Airedale User Partnership Group
	Moira Dailey	Carer/ Bradford Cancer Support
	Rodney Dailey	Service User/ Bradford Cancer Support
	Jeanette Halligan	Service User, Harrogate
	Pat Hope	Carer, Wakefield
	David Howe	Service User/ Airedale User Partnership Group
	Aline Nowell	Carer/ Cameo / CHARD Steering Group
	Keith Nowell	Service User / Cameo / CHARD Steering Group
	Pat Oates	Service User, Halifax / Calder & Hudds User Group
	Alan Rawson	Service User, Harrogate
	John Revely	Service User, York
	Ruth Rider	Service User, Halifax / Calder & Hudds User Group
	Helen Ryan	YCN Network Support Officer
	Peter Sale	Bradford Cancer Patient/ Carer Forum
	Colin Sloane (Co-Chair)	Former Service User / Bradford Cancer Support
	Fiona Stephenson	YCN Project Manager
	June Toovey	Acting YCN Lead Nurse
Apologies	Mitzi Blennerhassett	Former Service User / Cancer Concern
	Suzanne Curry	Patient Information Officer, York Hospitals NHS Trust
	Rachael Dixey	Service User, Leeds
	Cheryl Downes	Chemotherapy Nurse Specialist, Cookridge Hospital
	Christine Holman	Service User, Leeds
	Margaret Jennings	YCN User Involvement & Patient Information Lead (Colorectal)
	Francesca Pendino	User Involvement Facilitator, Mid Yorkshire Hospitals NHS Trust
	Jan Richardson	Former Service User/Airedale Support Group
	Carole Ritson	Service User, Leeds
	Lynne Russell	Former Carer / Bentham Looking Well Support Group
	Sally Scales	Modern Matron, Leeds Teaching Hospitals NHS Trust
	Brenda Sher	Service User, Leeds
	Barbara Shuttleworth	Former Carer / Bentham Looking Well Support Group
	Kate Smith	YCN User Involvement & Patient Information Lead (Upper GI)
	Reva Tray	Cancer Information Co-ordinator, Bradford Cancer Support
	Helen Woodburn	Cancer Information Co-ordinator, Jayne Garforth Support Centre

1. Welcome and Introductions

Action

Colin Sloane welcomed members to the meeting. Introductions were made by those present and apologies recorded.

The group sent their best wishes to Carole Ritson who was unwell.

2. Minutes of the last meeting

Were agreed as being an accurate record.

3. Matters arising

Action

• Two way intercoms in Radiotherapy Treatment Rooms

Following concerns expressed at the last meeting Martin Child gave an update which he had received from Karen Stocks.

Leeds has a two way intercom facility in all of the machines; all are working apart from two, which are currently waiting for parts.

Leeds Radiotherapy Team is taking this issue very seriously and there should be a marked improvement in the facility. Radiotherapy patient information will be updated to include explicit details on the two way intercom system.

The group suggested that updated patient information should be submitted to the YCN User Information Sub-group for comment. Martin Child agreed to feed this back to Karen Stocks.

MC

4. Co-Chair Nominations

A co-chair nomination form was circulated to the group with the agenda to be returned to the YCN by 30th May 2006. Colin Sloane encouraged the group to consider taking on the role, full support would be provided by the Network Team.

All

5. Volunteer for YCRN Co-Chair

David Howe announced that he has taken on the role of Chair of the Yorkshire Cancer Research Network (YCRN) User Partnership Group and gave a brief overview of the group. He explained that a co-chair for the group is also required, anyone interested in taking on this role should contact Carol Sleight at YCRN (0113 3924372).

All

6. Cancer Voices Training – A Network Approach

Colin Sloane explained the cancer voices training two day programme to the group and suggested hosting a Network training approach for new members of the locality groups and Network group, the group supported this proposal.

Keith Nowell suggested holding a short training session following the YCN User Partnership Group meetings for users and professional to focus on a particular area of interest. A brain storming session will be held at the beginning of the next meeting to take this issue forward.

7. Potential Dates to Visit New Oncology Wing (NOW) Mock-up Rooms

A number of potential dates were suggested to visit the NOW Mock-up rooms at Seacroft Hospital. It was agreed to arrange a group visit on Thursday 15th July 2006 at 1.00pm. The following members put themselves forward: Marion Allison, Rodney and Moira Dailey, Jeanette Halligan, Pat Hope, David Howe, Keith and Aline Nowell, Alan Rawson and Peter Sale.

Helen Ryan agreed to liaise with Trish Hewitt regarding arrangements for the visit and circulate confirmation and directions to Seacroft Hospital to the group of volunteers.

HR

8. Network funding of courses

Martin Child highlighted that there is approx. £7,000 available in the YCN User Involvement budget and asked the group for their thoughts on how best to equitably distribute the funds as there is currently no transparent YCN budgetary framework for user involvement.

A discussion followed regarding expenses for travel and for service users/ carers attending courses and conferences. It was agreed that more work is required by a smaller group on this issue.

MC/ CS

Martin Child confirmed that the Network will also be bidding for a Macmillan User Involvement grant. *(Post meeting note: a grant application form was submitted to Macmillan Cancer Support on 19th June 2006)*

MC

9. Forthcoming Events

Action

- **Network Development Programme (NDP)**

The Network Development Programme will take place on 29-30th June at the Renaissance Hotel, Heathrow, London. An email had been circulated previously by Pauline Atha; anyone interested in attending should contact the Network by Friday 19th May 2006.

HR

- **National Conference of Cancer Self Help Groups**

The 22nd National Conference of Cancer Self Help Groups will take place on 22-25th June 2006 at Owens Park, Manchester University. Colin Sloane encouraged members to attend.

Some members had not received any information about this event. Helen Ryan agreed to find out more details and circulate the information to the group.

10. The Value of the User Involvement Facilitator in the YCN

Colin Sloane informed the group that the YCN Facilitator Job Description has been through the NHS Agenda for Change (AfC) process and graded at a significantly lower band than expected. This is a result of it being matched against an inappropriate job profile. The Network will appeal against the decision of the AfC team; this may involve re-writing the job description of the YCN User Involvement Facilitator.

A discussion followed. Some members offered to review the job description and forward their views on the role of the YCN User Involvement Facilitator to the Network.

11. Any other business

- Lorraine Hunt informed the group that over the past 10 months she has piloted the communication audit tool in the nurse led treatment review clinics for prostate patients. The results are currently being collated. Comments regarding the communication audit told have been sent to Dr Peter Harvey.
- Keith Nowell suggested that future work of the group should include monitoring of user involvement in primary care. Martin Child confirmed that this would form part of the work programme for the forthcoming year.
- Pat Hope informed the group of the YCN Central Mid-Yorkshire Oesophago Gastric Referral Guidelines meeting she attended on 27th April 2006. The specialist treatment centres have been decided in Leeds and Bradford however the diagnosis and follow-up pathways are still being agreed. Any views from the group on the provision of diagnostic and follow-up services would be appreciated, comments to Pat Hope or Fiona Stephenson.
- Jane Archer explained that an YCN Patient Information Editorial Panel workshop session was held at the end of the YCN Information Sub-group meeting on 25th April to look at the need for an objective way of editing and assessing patient information produced in the YCN. The group piloted a set of dietary guidelines produced from the YCN Infection Group.

Subsequently Jane Archer and Martin Child met with Kevin Kerr, Chair of the YCN Infection Group to feedback comments from the editorial panel relating them to national guidance and policy. The process was very successful and worked well.

Jane Archer has developed terms of reference for the editorial panel, a patient information review tool and feedback sheet which will be circulated to members of the YCN Editorial Panel.

A YCN Editorial Panel agreement form has been circulated to those who expressed an interest. Document attached with the minutes.

HR

- Jane Archer highlighted that the Macmillan Mobile Information Unit is visiting the Network over the summer period; an itinerary can be downloaded from http://www.macmillan.org.uk/Get_Support/Find_information/MMCIC_itinerary.aspx. A hard copy will also be attached with the minutes.

HR

Marion Allinson, as Chair of the Airedale User Group, has written to Macmillan Cancer Support regarding concerns that the mobile information units are only visiting the localities where there are already Cancer Information Centres.

12. Date of next meetings:

To be held in Room 1, YCRN, First Floor, Ida Nurses Home, Cookridge Hospital

Information sub-group: Tuesday 18th July 2006 10.30-12.30pm

Main Group: Thursday 27th July 2006, 1.00 – 3.00pm