

YORKSHIRE CANCER NETWORK
USER PARTNERSHIP GROUP

Minutes of the meeting held on
Tuesday 28th March 2006, 11.00am
Room 1, YCRN Conference Room, Cookridge Hospital

Present: (alphabetically)	Jane Archer	YCN Patient Information & Support Manager
	Brian Atkins	Former Service User / Chair of YCN Communication sub-group / Castleford & District Cancer Self Help Group
	Mitzi Blennerhassett	Former Service User / Cancer Concern
	Hugh Butcher	Service User, Tadcaster
	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
	Rachael Dixey (Co-Chair)	Service User, Leeds
	Cheryl Downes	Chemotherapy Nurse Specialist, Cookridge Hospital
	Carol Ferguson	YCN Service Improvement Lead
	Trish Hewitt	Senior Development Manager, Leeds Teaching Hospitals NHS Trust
	Pat Hope	Carer, Wakefield
	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
	Carole Ritson	Service User, Leeds
	Lynne Russell	Former Carer / Bentham Looking Well Support Group
	Helen Ryan	YCN Network Support Officer
	Brenda Sher	Service User, Leeds
	Sally Scales	Modern Matron, Leeds Teaching Hospitals NHS Trust
	Barbara Shuttleworth	Former Carer / Bentham Looking Well Support Group
	Kate Smith	YCN User Involvement & Patient Information Lead (Upper GI)
	Fiona Stephenson	YCN Project Manager
	Helen Woodburn	Cancer Information Co-ordinator, Jayne Garforth Support Centre
Apologies	Marion Allinson	Service User / Airedale User Partnership Group
	Veronica Allinson	YCN User Involvement & Patient Information Lead (Breast)
	Francesca Pendino	User Involvement Facilitator, Mid Yorkshire Hospitals NHS Trust
	Jan Richardson	Former Service User/Airedale Support Group
	Diana Robinson	Former Carer / North Yorkshire Alliance R&D Committee
	Colin Sloane (Co-Chair)	Former Service User / Bradford Cancer Support
	Reva Tray	Cancer Information Co-ordinator, Bradford Cancer Support

1. Welcome and Introductions

Action

Rachael Dixey welcomed members to the meeting and introductions were made by those present for the benefit of new members.

2. Minutes of the last meeting & matters arising

Were agreed as being an accurate record.

3. Matters arising

None.

4. Two way intercoms in radiotherapy treatment rooms and in CT and MRI scanning

Action

Mitzi Blennerhassett informed the group of problems experienced regarding the inappropriate use or lack of use of intercoms in CT scans, MRI scans or radiotherapy.

Most radiotherapy rooms at Leeds have two way intercom systems; however patients are not informed of this facility. Mitzi Blennerhassett brought the issue to the YCN User Partnership Group for discussion and action.

The group agreed that it is vital for radiotherapy patient information to include information on two way intercoms. Sally Scales agreed to raise the issue with the Head of Radiotherapy at Leeds. Jane Archer agreed to work with Sally Scales and the Radiotherapy Team to ensure that the information is included in a structured way.

**SS &
JA**

Trish Hewitt confirmed that two way intercoms will be available in every LINAC accelerator in the New Oncology Wing (NOW).

5. NOW update and Bed area mock-ups

Trish Hewitt attended the meeting to provide an update on progress of the NOW. Completion date is scheduled for December 2007 and the occupational move will take place in January 2008.

The interior design of every room in the NOW is currently being finalised. Two bed area mock-up rooms have been set up at Seacroft Hospital to give colleagues an opportunity to comment on the positioning of equipment. Pictures of the mock-up rooms were displayed for the group to make comments directly to Trish Hewitt at the meeting.

Members of the YCN User Partnership Group are welcome to visit the mock-up rooms at Seacroft Hospital. Anyone interested should contact Sam Rowlinson on 0113 2062046.

A discussion took place on the excessive costs associated with Patient Line, the patient entertainment system. The group agreed to write to Mike Richards, National Cancer Director, National Cancer Action Team to highlight their concerns.

MC

Trish Hewitt explained that more work is required on signage for patients throughout the NOW and agreed to attend another YCN User Partnership Group meeting to discuss this further.

Rachael Dixey asked for a volunteer(s) to attend the NOW Arts Steering Group as she is not always able to attend the meetings.

6. NDP (Network Development Programme) Feedback

Colin Sloane attended the Network Development Programme on 2nd and 3rd March at the Renaissance London Heathrow Hotel on behalf of the YCN User Partnership Group. A brief feedback paper was circulated with the agenda.

The next NDP will take place on 29th & 30th June 2006. If any members are interested in attending a future NDP please contact the Network, places are available on a first come first served basis.

7. Links with the Network Site Specific Group's (NSSG's) and Management Board

Breast Group Feedback

Martin Child informed the group that a last minute request was received from the Chair of the YCN Breast Cancer Group for a Service User representative to attend the breast cancer meeting on 16th March at the Pavilions of Harrogate. Marion Allinson agreed to attend the meeting which was extremely successful.

Haematology Group Feedback

Keith and Aline Nowell attended the YCN and Humber and Yorkshire Coast Cancer Network Haematology Group meeting on 10th March 2006.

The Network Guidelines for the Management of Haematological Malignancies were signed off by the group.

Action

The Network has received a draft project plan confirming that the review of Haemato-oncology locality services in the YCN will take place the week beginning 4 December 2006. The review of the joint Humber and Yorkshire Coast and YCN Network Group will take place on 19 December 2006.

Chemotherapy regimes for haematological malignancies were also discussed and signed off by the group.

Upper GI Group

Kate Smith highlighted that at a recent YCN Upper GI meeting she raised service user/ carer involvement. The upper GI group supported the idea and agreed that the representative does not necessarily have to have experience of Upper GI Cancer.

8. Update on User Involvement Strategy

A productive user involvement strategy meeting took place following the YCN User Information Sub-group meeting on 20th February. The group decided to base the strategy on work carried out in Bradford, which Peter Sale brought along to the meeting.

Another strategy meeting will be arranged shortly and it is anticipated that a draft strategy will be circulated to the group with the agenda for the next main YCN User Group meeting.

MC

9. Benefits Talk by Cecile Levine, reminder of dates

Martin Child reminded the group that Cecile Levine, freelance benefits trainer is hosting a series of sessions on benefits and financial issues for families affected by cancer. The next session will take place on Tuesday 4th April at 10.30-12.30pm or 14.00-15.30pm.

10. Election of Co-chairs

Rachael Dixey and Colin Sloane will come to the end of their three year tenure as Co-Chairs of the group in June. Rachael Dixey asked the group to consider nominations for Co-Chairs, who would receive full support from the Network team.

Martin Child agreed to circulate a nomination form for Co-Chairs to the group.

MC

11. YCN Budget for User Involvement

Martin Child highlighted that there is approx. £7,000 available in the YCN User Involvement budget.

Hugh Butcher suggested producing a transparent YCN budgetary framework for User Involvement, the group agreed that this would be very useful.

12. Any other business

- Keith Nowell asked for an updated YCN User Partnership contact details list, of consented members, to be re-circulated to the group. Helen Ryan agreed to circulate a list with the minutes.
- The group discussed arranging another YCN User Group Away Day in the spring/ summer to focus on the content of the User Involvement Strategy.
- Jane Archer confirmed that a calendar of YCN and external events is available on the YCN website under 'Diary Dates' (www.ycn.nhs.uk/cgi-bin/calendarix/calendar.php).
- Jane Archer gave a final request for volunteers to register their interest in the YCN Patient Information Editorial Panel. Anyone interested should contact Jane Archer.
- Martin Child referred to the 'Research and Me' website (www.researchandme.org.uk). If anyone has an interest in research and an experience in website design the YCRN User Group are

HR

prepared to pay a user for up to two hours a week to update the website. Anyone interested should contact Martin Child.

Action

13. Date of next meetings:

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

Information sub-group: Tuesday 25th April, 10.30-12.30pm

Main Group: Wednesday 24th May, 1.00 – 3.00pm