

YORKSHIRE CANCER NETWORK
USER PARTNERSHIP GROUP

Minutes of the meeting held on
Friday 6th October 2006, 11.00am
Room 1, YCRN Conference Room, Cookridge Hospital

Present: (alphabetically)	Marion Allinson	Service User / Airedale User Partnership Group
	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
	Julie Crossley	Mid Yorkshire Hospitals NHS Trust
	Moira Dailey	Carer/ Bradford Cancer Support
	Rodney Dailey	Service User/ Bradford Cancer Support
	Julie Harrington	Appeal Director, Yorkshire Cancer Centre
	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
	Lynne Russell	Former Carer / Bentham Looking Well Support Group
	Helen Ryan	YCN Network Support Officer
	Peter Sale	Bradford Cancer Patient/ Carer Forum
Sally Scales	Modern Matron, Leeds Teaching Hospitals NHS Trust	
Brenda Sher	Service User, Leeds	
Colin Sloane (Co-Chair)	Former Service User / Bradford Cancer Support	
June Toovey	Acting YCN Lead Nurse	
Reva Tray	Cancer Information Co-ordinator, Bradford Cancer Support	
Fred Walker	Former User / Castleford & District Cancer Self Help Group / Wakefield & District Joint Group Users & Carers	
Pam Whitaker	Carer / Airedale User Partnership Group	
Apologies	Lesley Conti	Service User / Airedale User Partnership Group
	Rachael Dixey (Co-Chair)	Service User, Leeds
	Tina Greatorex	YCN User Involvement & Patient Information Lead (Lung)
	Christine Holman	Service User, Leeds
	Lorraine Hunt	YCN User Involvement & Patient Information Lead (Urology)
	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
	Diana Robinson	Former Carer/ North Yorkshire Alliance R&D Committee
	Kate Smith	YCN User Involvement & Patient Information Lead (Upper GI)
	Barbara Shuttleworth	Former Carer / Bentham Looking Well Support Group
	Fiona Stephenson	YCN Project Manager
Karen Stocks	Macmillan Radiographer, Cookridge Hospital	

1. Welcome and Introductions

Action

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

2. Minutes of the last meeting

Were agreed as being an accurate record.

3. Facilitators Update

Action

3.1 Revalidate 'Questions Patient's Ask' Document

The 'Questions Patients Ask' document produced by the YCN User Partnership Information Sub-Group (adapted from work by Northampton User Partnership Group) was circulated to the group for revalidation to ensure the document reflects the current views of the group.

Jane Archer asked the group for their comments on the document and amendments were suggested regarding the format and content. The group was asked to contact Jane Archer with further questions to be included in the document. Jane Archer agreed to make the necessary amendments and take the document to the YCN User Information Sub-group.

ALL/JA

3.2 Primary Care Trust/ Mental Health Trust Update

Martin Child informed the group that following the recent reorganisation of PCT's there are now 6 PCT's within the YCN including Bradford and Airedale Teaching PCT, Calderdale PCT, Kirklees PCT, Leeds PCT, North Yorkshire and York PCT and Wakefield District PCT.

A discussion took place regarding the new PCT structure and ways of improving links with PCT's. It was agreed to write to the 6 new PCT Chief Executives and Chairs to introduce and raise the profile of the YCN User Partnership Group.

MC

Colin Sloane agreed to forward the new PCT Chair and Chief Executive appointments to Martin Child for circulation to the group for information.

CS/MC

Martin Child informed the group that he attended the West Yorkshire Patient and Public Involvement (PPI) Leads meeting on 20th September which was the last of the West Yorkshire Group meeting due to the reorganisation of PCT's. Martin Child will continue to attend the meetings in the new format.

Martin Child confirmed that he has made contact within Leeds Mental Health Trust due to ongoing discussions regarding the mental health issues around cancer. Martin Child will keep the group updated.

3.3 Terms of Reference

Martin Child proposed that the terms of reference would be reviewed once the YCN User Involvement Strategy has been produced. There was unanimous support from the group.

3.4 Away Day

Martin Child informed the group that the YCN User Partnership Group Away Day has been arranged for Tuesday 12th December 2006 at the Chevin Country Park Hotel (the away day will replace the December YCN User Partnership Group meeting scheduled for 14th December).

It was agreed that the Away Day would be for patient, carer and professional members of the Network User Partnership Group only.

Helen Ryan agreed to circulate an invitation and registration form to the group.

HR

3.5 Locality Links Workshop

Martin Child confirmed that an event to improve links with the locality groups across the YCN would be arranged in the new year.

MC

3.6 YCN User Partnership Group Leaflets

Copies of the re-printed YCN User Partnership Group leaflets were distributed to group members.

3.7 Medical Library Access

Martin Child has negotiated an agreement with Cookridge Hospital Library for service users and carers from the YCN User Partnership Group to access the library. Those interested should contact Martin Child who will then contact Christine Reid, Cookridge Librarian to arrange a convenient time to visit the library.

4. NSSG Support Needs Mini-Workshop – Feedback and Next Steps

Martin Child highlighted that the NSSG support needs work carried out at the last meeting would be collated and incorporated into the YCN User Partnership Group Away Day.

5. Key Worker

A draft report produced by June Toovey regarding 'The Key Worker and Support for Patients along Their Pathway of Care' was circulated to the group with the agenda.

June Toovey summarised the paper and asked the group for their views on what is required from a key worker.

Following discussion it was agreed that:

- The Key Worker is very important
- The Key Worker needs to be someone that can sign-post
- The Key Worker does not necessarily have to be the Clinical Nurse Specialist but needs to be someone to find the answers to questions and get back to them or give contact details of where to get advice.
- It does not matter where the Key Worker is based as long as there are several phone numbers to call.
- Further discussion is required regarding weather the Key Worker would be a 24 hour/ 7 day contact number.

June Toovey agreed to amend the document in light of the discussion. The document will be used to inform the organisations across the YCN what is required from the Key Worker role to determine the most appropriate person. **JT**

6. Macmillan DVD

Colin Sloane informed the group of the Macmillan Cancer Support DVD, 'Working in Partnership' which shows good examples of working in partnership with service users and health care professionals. Free copies are available from Macmillan Cancer Support.

7. Macmillan Grant Update

Martin Child reminded the group that a grant application form was submitted to Macmillan Cancer Support on 19th June 2006. The application was successful and £6850 was received for the YCN User Partnership Group.

8. Support of Locality Event/ Projects

Martin Child highlighted that Macmillan has specified that the grant should be used to support the whole of the Network including the localities.

Martin Child asked the group to consider and feedback their views on the appropriate use of the grant. **ALL**

Colin Sloane asked for the Network to confirm the total amount of funds available in the YCN User Involvement budget. Martin Child agreed to take this forward and report back at the next meeting. **MC**

9. Feedback from Airedale MDT Celebration Day

Marion Allinson reported back from the successful Airedale MDT Celebration Day which took place on Monday 3rd October at Airedale General Hospital.

10. Mileage Allowance

Colin Sloane confirmed that from 1 December 2006 the mileage allowance for the YCN User Partnership Group would increase to 40p/ mile. A revised form would be circulated with the minutes. **HR**

11. YCRN User Partnership Group Update

David Howe informed the group that the Yorkshire Cancer Research Network (YCRN) is holding an awareness raising event on 7th October 2006 at the Bar Convent in York. This is primarily to raise the profile of service user involvement in research and to showcase the existence of the YCRN User Partnership Group.

12. YCN User Information Sub-group

Brian Atkins gave an update from the last YCN User Information Sub-group meeting on 22nd September 2006 (meeting notes were circulated to the group with the agenda).

The group agreed the proposed terms of reference and the work programme. It was agreed that the New Oncology Wing service planning, editorial panel, mapping, information and support provision and production guidelines should be taken up for the current year.

13. Macmillan Mobile Information Unit

Jane Archer informed the group of the concerns associated with the Macmillan mobile information unit around the location, planning cycle for the forth coming tour, publicity and staffing.

It was agreed to take this forward from a Network User Partnership Group perspective. Jane Archer agreed to work with Marion Allinson, the Locality Information Leads and the YCN Information Sub-group and produce recommendations supported by the main YCN User Group. **J/MA**

14. Any Other Business

- Julie Harrington, Appeal Director for the Yorkshire Cancer Centre (New Oncology Wing) introduced herself to the group. Julie Harrington has been appointed by the Leeds Teaching Hospitals Charitable Trustees to do a proactive appeal on the visions and values of the Yorkshire Cancer Centre and engage the public through fundraising.

Julie Harrington highlighted that it is the service users / carers who will have the most impact on the public domain in the appeal. Group members interested in being involved in the Yorkshire Cancer Centre appeal were asked to contact Julie Harrington at 0113 3926854 or julie.harrington@leedsth.nhs.uk.

- Mitzi Blennerhassett informed the group of a recent article in the Health Care Risk Report regarding 'How the NHS could better protect the safety of radiotherapy' (article enclosed with the minutes). **HR**
- Keith and Aline Nowell highlighted that Dr Russell Patmore, Chair of YCN Haematology Group is arranging for them to visit the Oncology Health Centre at Hull Royal Infirmary. Keith and Aline Nowell will feedback at a future meeting. **KN/AN**
- David Howe informed the group that he has been invited to attend the Yorkshire and Humber Strategic Health Authority planning committee for the Bowel Cancer Screening Programme.
- Martin Child highlighted that the University of Sheffield are carrying out an evaluation of the status of the palliative care services in Leeds. They are looking for user/ carer volunteers who have received palliative care to comment on the services within Leeds. Anyone interested should contact Martin Child.

- Martin Child referred to the Macmillan 'Living with Cancer Programme' and explained that Macmillan is looking for service users who may be interested in training as tutors to deliver this programme. Anyone interested should contact Martin Child.

15. Date of next meetings:

Information sub-group: Monday 27th November 2006, 10.30am at YCRN Conference Suite, Cookridge Hospital.

Away Day: Tuesday 12th December 2006, 10.00am at the Chevin Country Park Hotel