

YORKSHIRE CANCER NETWORK
USER PARTNERSHIP GROUP

Minutes of the meeting held on
Thursday 27th July 2006, 1.00pm
Room 1, YCRN Conference Room, Cookridge Hospital

Present: (alphabetically)	Marion Allinson	Service User / Airedale User Partnership Group
	Veronica Allinson	YCN User Involvement & Patient Information Lead (Breast)
	Brian Atkins	Former Service User/ Chair of YCN Information Sub-group/ Castleford & District Cancer Self Help Group
	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
	Wendy Hodge	Leeds User Partnership Group
	Christine Holman	Service User, Leeds
	Aline Nowell	Carer/ Cameo / CHARD Steering Group
	Keith Nowell	Service User / Cameo / CHARD Steering Group
	Pat Oates	Service User/ Halifax / Calder & Hudds User Group
	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
	Colin Sloane (Co-Chair)	Former Service User / Bradford Cancer Support
	Fiona Stephenson	YCN Project Manager
	Saminah Yunis	Mid Yorkshire Hospitals NHS Trust
Apologies	Jane Archer	YCN Patient Information & Support Manager
	Mitzi Blennerhassett	Former Service User / Cancer Concern
	Jeanette Halligan	Service User, Harrogate
	Peter Harvey	Clinical Psychologist, SJUH
	David Howe	Service User/ Airedale User Partnership Group
	Lorraine Hunt	YCN User Involvement & Patient Information Lead (Urology)
	Margaret Jennings	YCN User Involvement & Patient Information Lead (Colorectal)
	Pat Marsden	Gynaecology Clinical Nurse Specialist, Calderdale
	Sarah Parish	Service User, Bradford
	Francesca Pendino	User Involvement Facilitator, Mid Yorkshire Hospitals NHS Trust
	Alan Rawson	Service User, Harrogate
	Diana Robinson	Former Carer/ North Yorkshire Alliance R&D Committee
	Peter Sale	Bradford Cancer Patient/ Carer Forum
	Sally Scales	Modern Matron, Leeds Teaching Hospitals NHS Trust
	Kate Smith	YCN User Involvement & Patient Information Lead (Upper GI)
	June Toovey	Acting YCN Lead Nurse
	Reva Tray	Cancer Information Co-ordinator, Bradford Cancer Support

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. Matters arising

Action

• Working with PCT's

Martin Child informed the group that he has started the process of engaging PCT's in user involvement. Martin Child is attending a West Yorkshire Patient and Public Involvement (PPI) Leads meeting on 20th September and will keep the group informed of any developments.

• New Oncology Wing (NOW)

Volunteers from the group visited the NOW mock-up room on 15th July and fed back their views to the group. It was agreed to invite Trish Hewitt to a future meeting to update the group on progress of the NOW.

MC

Rachael Dixey informed members that she recently attended a 'Topping Out Ceremony' of the NOW. The business case regarding support for the NOW art strategy has been presented to the Trustees.

Rachael Dixey asked for volunteer(s) to attend the NOW Arts Steering Group at Leeds as she is not always able to attend the meetings. Martin Child agreed to circulate the dates of future meetings to the group for those interested in attending.

MC

4. Mini Workshop – To define training needs & support for working on NSSG's or other working groups

The group divided into smaller working groups to discuss and feedback on the following questions:

1. Do you feel there is a need for some form of training/ preparation or support from the YCN before you feel confident participating in NSSG meetings or similar?
2. What specific areas would you like this training/ preparation to cover?
3. How would you like this training/ preparation to be delivered?

Martin Child thanked the group for their valuable contributions, the responses to the questions will be extremely useful in taking forward the preparation needs and support for Service Users/ Carers on Network Groups.

5. Mechanism to nominate & endorse service users joining NSSG's (Network Site Specific Groups)

Martin Child asked the group to consider a process required for nominating and endorsing service users joining NSSG's and a discussion followed.

The group discussed the level of activity in-between NSSG meetings. Fiona Stephenson suggested looking back at 6 NSSG's over the last 6 months at the type (i.e. email, phone, post) and level of communication in-between meetings.

MC/FS

Martin Child reminded the group that at a previous meeting some members volunteered to join NSSG's. As there are a number of new members Martin Child agreed to re-circulate the list to the group so that it could be updated.

MC

6. The Key Worker

Deferred until the next meeting.

7. Volunteers for Airedale Cancer MDT's Celebration Day (2nd October 2006)

Marion Allinson informed the group of the Cancer MDT (Multi-Disciplinary Team) Celebration day at Airedale General Hospital on 2nd October 2006 and tabled a programme.

Helen Ryan agreed to circulate the programme to the group. Those interested in attending were asked to contact Marion Allison at smithhallinson@btopenworld.com or 01535 636894.

HR

The YCN agreed to fund the travel expenses for those service users/ carers from the group attending the celebration day.

Action

It was agreed to feedback the main issues from the day and invite Sean Duffy, YCN Medical Director to present at the next meeting.

MC

8. Difficulty in obtaining parking permits in Leeds

Deferred until the next meeting.

9. Payment of expenses – What do Service Users want?

Martin Child and Fiona Stephenson highlighted that the YCN aims to encourage user involvement and recognises that over time the level of service user/ carer engagement, commitment and input and generation of expenses has changed. Members were asked for their recommendations on payment of expenses to take back to the Network Lead Team.

Colin Sloane noted that there should be no problem for YCN User Partnership Group members to claim expenses, relating to travel and consumables used at home (e.g. paper, ink jet cartridges) for YCN business.

The group discussed the current mileage allowance and it was agreed that rate should be increased from 35p/ mile to 40p/ mile.

MC

Helen Ryan highlighted that the YCN Administration Team are willing and able to print out lengthy documentation in hard copy on request.

10. Work Planning Event/ Time-out event

The group agreed to hold a combined one day work planning and 'time-out' event in the Autumn at a similar venue to the 'Away day' at Burnsall and to invite service users/ carers from the YCN User Partnership Group and those health care professionals actively involved in the group.

Martin Child and Helen Ryan agreed to source a suitable venue and date (at the end of October/ November) for the event.

MC/HR

11. Autumn time-out event

Discussed above.

12. Feedback from YCRN User Partnership Group

Deferred until the next meeting.

13. Feedback from YCN User Information Sub-group

Brian Atkins gave a brief update of the last information sub-group meeting on 18th July 2006.

The group agreed to elect a Co-Chair to support Brian Atkins and will be producing a work programme for the coming year and terms of reference.

14. Local support directory

Martin Child, on behalf of Jane Archer, asked the group for their thoughts on producing a directory for local support services across the YCN to be available electronically on the YCN website.

The group supported the proposal. Jane Archer will take this work forward.

JA

15. Locality links event

Martin Child highlighted that he is keen to improve links with the 7 locality groups across the YCN. An event will be arranged for late 2006 including representation from the professionals and service users/ carers in the locality groups and the Network Group to address ways of collaborative two way working.

Martin Child explained that he has asked the locality groups to submit their minutes to the YCN to upload onto the YCN website. Most of the locality groups have agreed to this.

Action

16. Election of Co-Chairs

Colin Sloane highlighted that no nominations have been received for co-chairs and encouraged the group to consider taking on this role.

ALL

Colin Sloane confirmed that he is prepared to remain as Co-Chair until another member of the group volunteers.

It was agreed to address the role of the co-chair(s) at the work planning event in the Autumn.

17. Terms of reference

The YCN User Partnership Group Terms of Reference were circulated with the agenda for review. Comments, additions and amendments should be sent to Martin Child.

ALL

18. Any other business

- The group discussed the increase in visitor pay and display charges at some Trusts across the YCN.

Colin Sloane explained that the Bradford and Airedale User Groups have recently been discussing health costs including car parking charges and have agreed to write to their local MP's highlighting their concerns. Colin Sloane has agreed to share the letter with the group (enclosed with the minutes).

CS

- Martin Child confirmed that he has started work on making medical libraries available to service users and will feedback at a future meeting.

MC

19. Date of next meetings:

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

Information sub-group: Friday 22nd September 2006, 10.30am

Main Group: Friday 6th October 2006, 11.00am – 1.00pm