

Present:

Martin Child	
Reva Tray	Bradford Cancer Support Centre
Veronica Allinson	Calderdale and Huddersfield NHS Foundation Trust
Angie Craig	Leeds Teaching Hospitals NHS Trust
Trish Hewitt	
Lorraine Hunt	
Vicki James	
Pam Jackson	Mid Yorkshire Hospitals NHS Trust
Saminah Yunis	
Mitzi Blennerhassett	User Partnership Group
Hugh Butcher	
Sue Cooke	
Rodney & Moira Dailey	
David Howe	
Aline Nowell	
Keith Nowell	
Alan Rawson	
Jan Roberts	
Diana Robinson	
Peter Sale	
Barbara Shuttleworth	
Colin Sloane (Chair)	
Maggie Clough	York Hospitals NHS Foundation Trust
Helen Ryan	Yorkshire Cancer Network
Fiona Stephenson	
June Toovey	

1. Apologies

Marion Allinson, Jane Archer, Brian Atkins, Pat Marsden, Patricia Oates, John Revely, Jan Richardson, Ruth Rider, Lynne Russell, Sally Scales, Sadie Smith, Pamela Whitaker, Marie Wilde

2. Minutes of last meeting

Were agreed as being an accurate record.

3. Matters arising

•NICE Diagnosis and Treatment of Spinal Cord Compression

Members of the group who have had or cared for someone with spinal cord compression and would like to comment on the NICE Guidance should contact Martin Child for the relevant paper. Comments are to be sent directly to NICE by the end of August.

• Understanding the NHS and Commissioning

Fiona Stephenson thanked those members who had returned the forms identifying the priority areas around commissioning and organisation of the NHS.

Fiona Stephenson has produced an outline and will approach an appropriate commissioner to come and present to the group after the summer once the commissioning organisations are more established.

•Colorectal Straight to Test

It was agreed that Jane Archer would produce an feedback paragraph to circulate to the group before she goes on maternity leave.

Action: Jane Archer to circulate feedback paragraph on Colorectal Straight to Test with the minutes.

4. New Oncology Wing Update

Trish Hewitt attended the meeting to give an update on the programme and building progress of the New Oncology Wing.

It is anticipated that the building will be officially finished on 14th December 2007 when the Trust will take occupation of it and the first patient day will be 27th December 2007. The exact moving dates will be finalised shortly.

Action: Martin Child to liaise with Trish Hewitt and organise a visit to the New Oncology Wing in November/ December 2007 once the building work is nearer completion.

5. Intercoms on Radiotherapy Machines

Mitzi Blennerhassett gave the background to the issue raised at the YCN User Partnership Group meeting last May 2006: that patients are not told intercoms in radiotherapy rooms are 2-way and they can use them in an emergency.

Angie Craig, Operational Head of Radiotherapy at Cookridge gave an update on the situation informing the group that all patients are not routinely told about the two way intercoms and highlighted some of the problems associated with their use. These included

- Treatments are very short.
- The treatment machines are very loud so it is not always possible to hear.
- Some patients e.g. head and neck patients are not able to speak due to the masks they have to wear.

It was reported that the intercoms are used for paediatric and very nervous patients.

The group were also told that all patients are informed to use non verbal communication by raising their hand or foot and of the routine practice for radiographers to be protected against interruption to allow them to watch patients continuously via the CCTV links during treatment.

The group agreed that it was important that patients are aware of the two way intercom and that they could use it in an emergency.

Angie Craig went on to inform the group that the information about intercoms is given in a standard paragraph as agreed by the Leeds InFOP Group and will be put into all leaflets as they are reviewed, updated and reprinted.

Mitzi Blennerhassett quoted the Royal Marsden's patient information booklet that is explicit about patients being able to use the two-way intercoms as an example of good practice.

Angie Craig informed the group that due to the move to the New Oncology Wing leaflets will be reprinted once the move has taken place and suggested that the wording used in the Royal Marsden's Information leaflets could be used.

Diana Robinson suggested that stickers carrying this wording could be added to leaflets as an interim measure.

Mitzi Blennerhassett highlighted the importance of 2 way intercoms in the wider context of radiotherapy safety and informed the group of some national work and tabled 2 articles; Radiotherapy: developing a world class service for England – Department of Health (http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_074575) and Radiotherapy Near Misses, Incidents and Errors: Radiotherapy Incident at Glasgow (Clinical Oncology (2007) 19:1-3)

Angie Craig has produced some detailed information about patient safety during radiotherapy at Cookridge Hospital. This is available on request from Martin Child.

Action: Angie Craig (Operational Head for Radiotherapy at Cookridge) to compare the wording used in the Leeds and Royal Marsdens' booklets and make any appropriate changes.

Angie Craig to investigate the use of stickers to add the above information into the current information leaflets.

6. Facilitator Update

6.1. Updated Questions Patients Ask Document

An updated version of the 'Questions Patients Ask' document produced by the YCN User Information Sub-group was circulated to the group with the agenda for comment.

Action: Comments on the 'Questions Patients Ask' document to be sent to Martin Child prior to the next meeting.

6.2. Proposal of new Co-Chair

Colin Sloane informed the group that he would be standing down as Co-Chair of the YCN User Partnership Group and proposed for Hugh Butcher to take on the role. The meeting unanimously supported the proposal and Hugh Butcher accepted the position.

Martin Child, on behalf of the YCN User Partnership Group, thanked Colin Sloane for his hard work over the past 3 and half years as Co-Chair of the YCN User Partnership Group.

6.3. Birmingham Facilitators Meeting

Martin Child fed back from a two day cancer network facilitators meeting he attended in Birmingham on 8-9th May 2007. There were 2 interesting workshops on recruitment of volunteers and confidentiality clauses, information relating to the workshops will be circulated once feedback has been received.

There was a useful session with Jonathan Tritter, Chief Executive of the National Centre for Involvement about making user involvement happen in health. Martin Child informed the group of the Patient Citizen Exchange website, the online network for sharing knowledge and experience of patient and public involvement in health (www.pcx.nhs.uk).

Action: Martin Child to feedback information from the meeting once a report has been circulated.

6.4. Huddersfield Celebration Event

Martin Child has been in discussions with colleagues involved in training health professionals in user involvement at the medical school in Leeds. As part of the discussions Martin Child has been invited along with 2 Service Users/ Carers to a celebration event at Huddersfield University on Thursday 28th June 2007, 10.00am - 1.00pm.

Action: Members of the group interested in attending Huddersfield Celebration Event on 28th June to contact Martin Child.

6.5. Cancer Reform Strategy - Extending Choice

A consultation paper on extending choice in cancer services, as part of the Cancer Reform Strategy, was circulated to the group prior to the meeting with a short consultation deadline of 25th May 2007.

Action: Martin Child to circulate to the group information regarding the Cancer Reform Strategy study day.

7. Membership Update

7.1. Network Group Development Project Report

A report produced by Marion Allinson from her attendance at the Yorkshire Cancer Network Groups Development Project Event on 17th April 2007 at Weetwood Hall, Headingley, Leeds was circulated to the group with the agenda for information.

Fiona Stephenson to liaise with Marion Allinson and Hugh Butcher to take forward discussions on the role of user involvement in the Network as part of the Network Group Development Project.

7.2. The Future of Cancer Networks

Deferred for a future meeting.

8. Local Partnership Group Links Event

The YCN Local User Partnership Group Links Event will take place on Thursday 24th May 2007, 10.00am-4.00pm at the Chevin Country Park Hotel, Otley, LS21 3NU.

The aim of the event is to strengthen links between the Local and the Network User Partnership Groups and between the Network Site Specific Groups.

Invitations have been circulated to the 7 Local User Partnership Group members via the Local User Partnership Group Chairs and to the YCN User Involvement and Patient Information Leads.

9. How Should the YCN Disseminate Documents Appropriately, Fairly and Economically?

An in-depth group discussion took place regarding the dissemination of YCN documents appropriately, fairly and economically.

Action: Martin Child to liaise with YCN Administration Team and Philip Melling, YCN Information Manager and bring back to a future meeting for discussion.

10. Future Meeting Format

The group discussed the format of future meetings including the organisation of agendas and the timing of meetings.

It was agreed that for YCN User Partnership Group meetings starting at 11.00am a working lunch should be incorporated into the middle of the meeting.

Action: Hugh Butcher to produce a paper regarding the organisation of YCN User Partnership Group meetings for discussion at the next meeting.

11. New Member Required for Colorectal NSSG

Martin Child informed the group that another user representative is required on the YCN Colorectal Group and on the YCN Urology Group.

Action: User/ Carer Representative volunteers for YCN Urology and Colorectal Groups to contact Martin Child.

12. Any Other Business

•Medicine and Me: Prostate Cancer Research

Diana Robinson informed the group of the Royal Society of Medicine Prostate Cancer day on 16 July 2007 at the Royal Society of Medicine, 1 Wimpole Street, London, W1G 0AE (<http://www.rsm.ac.uk/academ/mm-prostate.php>).

13. Date of Next Meeting(s)

Thursday 24th May 2007 10:00 am
Chevin Country Park Hotel [EVENT]

Tuesday 24th July 2007 1:00 pm
YCRN Conference Room 1, Ida Nurses Home, Cookridge Hospital

Wednesday 26th September 2007 11:00 am
YCRN Conference Room 1, Ida Nurses Home, Cookridge Hospital

Wednesday 12th December 2007 11:00 am
YCRN Conference Room 1, Ida Nurses Home, Cookridge Hospital