

Present:

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|-------------------------|------------------------------------|
| Reva Tray | Bradford Cancer Support Centre |
| Vicki James | Leeds Teaching Hospitals NHS Trust |
| Marion Allinson (Chair) | User Partnership Group |
| Christine Allmark | |
| Brian Atkins | |
| Hugh Butcher | |
| Joan Lesley Conti | |
| David Howe | |
| Aline Nowell | |
| Keith Nowell | |
| Patricia Oates | |
| Alan Rawson | |
| John Revely | |
| Ruth Rider | |
| Diana Robinson | |
| Peter Sale | |
| Barbara Shuttleworth | |
| Colin Sloane (Chair) | |
| Alan & Dorothy Smith | |
| Martin Child | Yorkshire Cancer Network |
| Helen Ryan | |
| Fiona Stephenson | |

1. Apologies

Veronica Allinson, Jane Archer, Sue Cooke, Rodney & Moira Dailey, Rachael Dixey, Cheryl Downes, Christine Holman, Lorraine Hunt, Margaret Jennings, Jan Roberts, Lynne Russell, Sally Scales, Sadie Smith, Kate Smith, June Toovey

2. Minutes of last meeting

Were agreed as being an accurate record.

3. Matters arising

- Colorectal Straight to Test

Members of the group asked for feedback at a future meeting from Jane Archer regarding the Colorectal Straight to Test patient letters previously circulated to the YCN Editorial Panel.

Action: Jane Acher to feedback on Colorectal Straight to Test letters at the next meeting.

David Howe to forward copies of Airedale colorectal straight to test letter to Jane Archer.

4. Understanding the NHS and commissioning

Following discussions at the last meeting on the groups understanding and awareness of the commissioning process and the recent organisational changes of the NHS, it was agreed that a presentation on commissioning cancer services would be helpful.

Fiona Stephenson explained that before asking a commissioner or a member of the YCN lead team to come and speak to the group it would be more productive to give speakers some key questions and a tighter brief on what the group wanted to know and an indication of what is already understood.

Fiona Stephenson presented to the group a paper on 'Understanding the NHS and Commissioning' outlining 3 questions to help the group guide the speakers around the background to national health policy that influences cancer services commissioning and delivery, the structure of the NHS and commissioning of cancer services. An in-depth group discussion followed.

Action: All to look through questions and prioritise 3 areas for each question that requires clarification and add further comments. Paper to be returned to Fiona Stephenson by Friday 11th May 2007.

Helen Ryan to circulate Macmillan Cancer Reform Strategy with the minutes and the link for the Cancer Campaigning Group (www.cancercampaigninggroup.org.uk).

Helen Ryan to circulate 'Understanding the NHS and Commissioning' paper electronically.

5. Facilitator Update

5.1. Update on User Involvement Action Plan

Martin Child is in the process of producing a User Involvement Action Plan for the YCN based on the YCN User Involvement Strategy. The Action Plan will be submitted to the YCN Management Board on 30th April 2007.

Action: Martin Child to circulate final draft Action Plan to the group once complete.

5.2. Solnetwork.org.uk

Martin Child highlighted that the YCN User Partnership Group is now a member of the Solnetwork website (www.solnetwork.org.uk). The website will support 'Shaping Our Lives' vision of an equal and fair society where people have the same opportunities, choices, rights and responsibilities. A society where people have choice and control over the way they live and the support services they use. The website is particularly aimed at user controlled organisations.

5.3. Visual Equipment Aides

Martin Child informed the group that Kathy Thompson, Occupational Therapist based at Cookridge Hospital has asked for the group to review 3 sets of photographs which attempt to demonstrate to patients what hospital equipment looks like in a domestic setting.

The visual equipment aides were displayed at the meeting for the group to make comments using a questionnaire directly to Martin Child.

Action: Martin Child to feedback groups comments to Kathy Thompson.

5.4. Fundraising CD

Martin Child informed the group of a fundraising CD produced by Mitzi Blennerhasset and a colleague of poetry and music inspired by the cancer experience.

Action: Martin Child to circulate information to the group.

5.5. Proposal of new Co-Chair

Martin Child encouraged the group to consider taking over Colin Sloane's role of Co-Chair of the YCN User Partnership Group.

Action: Nominations for Co-Chair to Martin Child.

6. Local Partnership Group Links Event

Colin Sloane highlighted that a 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 the links between the Local and the Network User Partnership Groups and between the Network Site Specific Groups.

It is important that the Chair of the Local User Partnership Groups attend the event and there is sufficient capacity to allow each Local User Partnership Group to nominate 5 Service User/ Carer representatives to attend the event. Colin Sloane asked the group to encourage members from their Local User Partnership Groups to attend.

A programme and registration form will follow shortly.

7. Oncology Health Centre, Hull

Keith and Aline Nowell gave an overview of the visit to the Oncology Health Centre at Hull and a discussion followed.

Action: Martin Child, Colin Sloane and Marion Allinson to liaise with Keith and Aline Nowell to organise a visit of appropriate representatives to the Hull Oncology Health Centre.

8. Educating the Public in the Use of Cancer Services

Diana Robinson highlighted that as a member of the Primary Care Clinical Studies Development Group (part of the National Cancer Research Network Group) she has been asked by the Chair of the group to help gather information for the Cancer Reform Strategy on 'educating the public to use health services more intelligently'.

The concept is related to using hospital and primary care facilities as intelligently as possible. Strategies are required to improve the 'performance' of patients, providers and the health service including education in the use of cancer services.

Diana Robinson asked the group for any comments to be sent directly to her by email by the end of April 2007.

Action: Comments regarding educating the public in the use of cancer services to be sent to Diana Robinson at dyorkiedip@aol.com.

9. NDP Feedback

Martin Child, Colin Sloane and David Howe attended the Network Development Programme on 8th and 9th March 2007 at the Renaissance London Heathrow Hotel on behalf of the YCN User Partnership Group.

Action: Colin Sloane to forward NDP report to Helen Ryan for circulation with the minutes.

10. Any Other Business

•NICE Diagnosis and Treatment of Spinal Cord Compression

Martin Child highlighted that NICE (National Institute for Clinical Excellence) are currently consulting on guidance for the treatment and diagnosis of spinal cord compression and would like patients and carers to be involved.

It was agreed that Aline and Keith Nowell would represent the group and feedback at a future meeting.

• Publishing Local User Partnership Group Minutes on the YCN Website

Martin Child informed the group that as part of a process to improve two way communication and information flow between the YCN and Local Partnership Groups, consent forms have been sent to Local User Partnership Group Chairs to allow copies of the minutes and agendas to be publicised on the YCN website.

• YCN Palliative Care Group

Diana Robinson fed back to the group from the recent YCN Palliative Care Group meeting on 26th March 2007.

Action: Comments regarding diagnosis and treatment of spinal cord compression to be sent to Keith and Aline Nowell to feed into the NICE consultation group.

11. Date of Next Meeting(s)

Monday 21st May 2007 1:00 pm
YCRN Conference Room 1, Ida Nurses Home, Cookridge Hospital

Thursday 24th May 2007 10:00 am
Chevin Lodge Hotel, Leeds [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