

Present:

Martin Child	
Janet Harrison	Airedale NHS Trust
Reva Tray	Bradford Cancer Support Centre
Charlotte Rock	Bradford Teaching Hospitals NHS Foundation Trust
Paul Kerr	Macmillan Cancer Support
Julie Ann Carter	St Gemma's Hospice
Marion Allinson (Chair)	User Partnership Group
Christine Allmark	
Mitzi Blennerhassett	
Hugh Butcher (Chair)	
Joan Lesley Conti	
Sue Cooke	
David Howe	
Aline Nowell	
Keith Nowell	
Patricia Oates	
Alan Rawson	
Ruth Rider	
Jan Roberts	
Diana Robinson	
Peter Sale	
Barbara Shuttleworth	
Colin Sloane	
Alan & Dorothy Smith	
Maggie Clough	York Hospitals NHS Foundation Trust
Colinne Sheard	Yorkshire Cancer Network
Fiona Stephenson	
June Toovey	

1. Apologies

Veronica Allinson, Rodney & Moira Dailey, Christine Holman, Margaret Jennings, John Revely, Lynne Russell, Sally Scales, Sadie Smith, Pamela Whitaker, Marie Wilde

1. Welcome, Introduction and Apologies

Marion Allinson introduced herself as co-chair of the group and chaired the meeting. She welcomed everyone there and people introduced themselves.

Colin Sloane, who has recently stood down as co-chair, was thanked for his contribution to the group over the last 3 years and for the enormous amount of work he had done in the role. His commitment and achievements were acknowledged by the group with a healthy round of applause.

2. Minutes from last meeting

Agreed by the group, but points of accuracy were raised by Mitzi Blennerhassett in item 5. Changes to the minutes were agreed and two action points for taking forward were added. Amendments will be made and the minutes recirculated.

3. Matters arising

The Questions Patients Ask document was raised as still outstanding. It was agreed that this would be taken to the Information Sub Group for discussion.

Action: Colinne Sheard to add this to the agenda of the next information sub-group meeting on 3rd Sept.

4. Facilitators Report

4.1. Colorectal & Urology Representation

Colorectal and Urology representation on the NSSGs:

Martin Child asked the group for volunteers with experience of colorectal or urology cancer to join the NSSGs. It was also suggested that that the local user partnership groups be asked for volunteers.

**Action: Volunteers to join the NSSGs to contact Colinne Sheard.
Colinne Sheard to contact the chairs of the local user partnership groups to ask for volunteers.**

4.2. New Oncology Wing Visit

Martin Child informed the group that visits to NOW needed to take place before the end of September.

6 places were available at 9 am on Tuesday 4th Sept - David Howe, Hugh Butcher, Colin Sloane, Reva Tray, Diana Robinson and Marion Allinson said they might be able to attend.

A sheet was circulated at the meeting for anyone else who would wanted to visit the NOW.

**Action: Colinne Sheard to contact the relevant people at the NOW for further details and inform the group members.
Colinne Sheard to co-ordinate with the NOW possible dates and times between 10.30am and 2pm for other group members to attend and then inform them.**

4.3. Birmingham Facilitators Meeting

There was nothing to report from this meeting.

5. Work Programme - for Ratification by this Group

The work programme, for the next 2 years, circulated with the agenda was agreed and endorsed by the group. It was discussed and agreed that if some other relevant work came to light it could be added to the work programme.

In the absence of a User Facilitator at the Network in the next few months Hugh Butcher suggested that group members volunteer to produce a 'think paper' relating to specific items on the work plan for discussion at the next UPG. The papers would include thoughts about how the item could be taken forward and what needed to be considered. A discussion took place and group members volunteered.

**Action: Colinne Sheard to remove draft from the work programme.
Colinne Sheard to identify the volunteers from the meeting against the specific items on the work plan and circulate with the minutes of the meeting.
Any other members of the group willing to volunteer to help with this work to contact Colinne Sheard and identify which item/s on the work plan want to be involved in by 20th August.
All volunteers to produce the papers and send them to Colinne Sheard for circulation with the agenda of the next meeting by 5th September.**

6. Format of Future Meetings

The paper produced by Hugh Butcher and circulated with the agenda was discussed and agreed. It was also agreed that a 15 minute slot would be allocated at the beginning of each meeting to allow discussion of urgent items that came up outside of the 3-week deadline for submitting supporting papers. (refer to Hugh Butcher's paper).

It was agreed to review the new format of future meetings process after 3 more UPG meetings.

Action: Colinne Sheard to incorporate 15 mins at the beginning of the next agenda AOB for urgent items and add a review slot to the agenda in three meetings time.

7. Dissemination of Major National & Local Documents to Members of the User Partnership Group

The paper produced by Martin Child and circulated with the agenda was discussed and the third option was agreed. This included having documents available on the YCN website in pdf format. Hard copies of any documents can be requested via the Support Officer or User Facilitator. A list of any new documents added to the website between meetings will be circulated with the UPG meeting agenda and whenever possible one hard copy of new documents would be made available at the meeting.

Action: Colinne Sheard to add to the agenda of the meeting in three meetings time for review.

8. Resuscitation Policy for People with Cancer

Diana Robinson tabled a paper at the meeting and gave a brief background to the issue which came to light in the Network Palliative Care Group, (NSSG). Charlotte Rock (CNS Palliative Care) gave background information on the issues and updated the group on progress made since the meeting.

A long and wide ranging discussion took place that highlighted the importance of good end-of-life care and covered the following areas:-

- The discussion of resuscitation status and decision between health professionals, patients and carers.
- The sharing of information between health professionals regarding patients and their Do Not Resuscitate (DNR) status and more general medical information
- The content and wording of the hand-over form to Out of Hours services
- The definitions of palliative in the context of cancer and end of life care
- Ambulance transport of patients near the end of life and DNR status
- Ethical and legal aspects of advanced directives and living wills.

It was recognised that this was huge topic that could not be finalised within the group meeting.

By enabling the UPG to become involved in this issue, Marion Allinson said that it showed it was worthwhile and vital having Service Users on NSSGs.

Action: Hugh Butcher to write a letter on behalf of the group to Charlotte Rock as chair of the Palliative Care Group highlighting the groups deeply felt concerns about the form in its current format and asking for an extension to the deadline for comments on the handover form to be sent in.

All to send comments on the content of the form and suggestions to Colinne Sheard to be forwarded to David Howe who has agreed to collate them on behalf of the group.

To organise an event in collaboration with the UPG and the Palliative Care Group to provide some background education around end-of-life care. To discuss and produce network recommendations for practice.

9. Process for Claiming Expenses

This item was deferred to the next meeting.

Action: To put expense claims on next agenda.

10. Report on the Local User Partnership Group Links Event, Chevin Lodge Hotel, May 2007

This item was deferred until the next meeting.

Action: To add to the next agenda.

11. Any Other Business

Reva Tray asked for volunteers to work as part of the information sub group. The next meeting is on Monday 3rd September 10.30 – 12.30.

Reva Tray also informed the group of a half-day event about developing a general information pathway for patients. The event is planned for Friday 12th October 12.00-16.00.

David Fox (Assistant Director of Operations/Head of Non-Surgical Oncology Clinical Management Team LTHT) informed the group that work had begun to choose a name for the NOW. The current name is The Yorkshire Cancer Centre and David Fox explained some of the difficulties with that and asked for help from the group in choosing an appropriate name for the NOW.

June Toovey distributed leaflets about the Macmillan Living with Cancer Programme held at the Robert Ogden Centre in Leeds beginning on the 28th September. This 6-week programme helps patients living with cancer to develop self-management skills. It is hoped that the Network will be able to identify cancer patients or carers to train as facilitators for the programme so that further programmes can be run in the YCN.

Marion Allinson and Hugh Butcher thanked Martin Child on behalf of the group for his hard work and dedication to service user involvement during his time in the post and wished him well for the future. The group responded with loud applause.

Action: Anyone interested in joining the group or attending the half day event to contact Colinne Sheard.

Anyone interested in being involved in helping choose the name of the NOW to contact Colinne Sheard as soon as possible.

To circulate the leaflets to the Locality User Partnership Group Chairs. Anyone interested to contact Lisa at Macmillan about the programme directly.

12. Date of Next Meeting(s)

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