

YORKSHIRE CANCER NETWORK
USER PARTNERSHIP GROUP

Minutes of the meeting held on
Monday 30th January 2006, 11.00am
Room 1, YCRN Conference Room, Cookridge Hospital

Present: (alphabetically)	Brian Atkins	Former Service User / Chair of YCN Communication sub-group / Castleford & District Cancer Self Help Group
	Marion Allinson	Service User / Airedale User Partnership Group
	Hugh Butcher	Service User, Tadcaster
	Martin Child	YCN User Involvement Facilitator
	Lesley Conti	Service User / Airedale User Partnership Group
	Rachael Dixey (Co-Chair)	Service User, Leeds
	Cheryl Downes	Chemotherapy Nurse Specialist, Cookridge Hospital
	Carol Ferguson	YCN Service Improvement Lead
	Peter Harvey	Clinical Psychologist, SJUH
	Christine Holman	Service User, Leeds
	Lorraine Hunt	Urology CNS, Cookridge Hospital
	Aline Nowell	Carer/ Cameo / CHARD Steering Group
	Keith Nowell	Service User / Cameo / CHARD Steering Group
	Pat Oates	Service User, Halifax / Calder & Hudds User Group
	Francesca Pendino	User Involvement Facilitator, Mid Yorkshire Hospitals NHS Trust
	Alan Rawson	Service User, Harrogate
	Ruth Rider	Service User, Halifax / Calder & Hudds User Group
	Carole Ritson	Service User, Leeds
	Helen Ryan	YCN Network Support Officer
	Colin Sloane (Co-Chair)	Former Service User / Bradford Cancer Support
	Jan Richardson	Former Service User/Airedale Support Group
	Diana Robinson	Former Carer / York Hospitals Information Steering Group
	Barbara Shuttleworth	Former Carer / Bentham Looking Well Support Group
	Reva Tray	Cancer Information Co-ordinator, Bradford Cancer Support
Apologies	Jane Archer	YCN Patient Information & Support Manager
	Suzanne Curry	Patient Information Officer, York Hospitals NHS Trust
	Pat Hope	Carer, Wakefield
	Margaret Jennings	YCN User Involvement & Patient Information Lead (Colorectal)
	Lynne Russell	Former Carer / Bentham Looking Well Support Group
	Peter Sale	Bradford Cancer Patient/ Carer Forum
	Sally Scales	Modern Matron, Leeds Teaching Hospitals NHS Trust
	Fiona Stephenson	YCN Project Manager
	Karen Stocks	Macmillan Radiographer, Cookridge Hospital

1. Welcome and Introductions

Action

Rachael Dixey welcomed members to the meeting and introductions were made by those present.

2. Minutes of the last meeting & matters arising

Were agreed as being an accurate record.

3. Improving outcomes in urological cancers – pathway development –report on progress

Leeds, York and Harrogate – Colin Sloane

Colin Sloane explained that the specialist urological cancer services for the Yorkshire Cancer Network have been centralised onto three sites at Bradford, Leeds and Mid Yorkshire.

A urology pathways steering group has been formed to develop pathways for the transfer of radical surgery (bladder and prostate cancer) from Harrogate and York to Leeds.

Two productive multi-disciplinary meetings have taken place with representatives from Leeds, York

and Harrogate Trusts. Ron Browne and Colin Sloane are service user representatives on the steering group.

Action

West Yorkshire – Carol Ferguson

Carol Ferguson highlighted that a similar steering group is looking at the service for Airedale, Bradford and Calderdale and Huddersfield urology patient pathways. There are service user representatives involved in the pathway work from each of the localities.

4. Links with NSSG and Management Board

Urology Group feedback – Hugh Butcher

Hugh Butcher informed members that he attended the YCN Urology Group for the first time on 25th January and gave an overview of the meeting.

Hugh Butcher explained that on reflection there was a lot of highly technical information exchange, much of the agenda was focused on information sharing rather than action and more papers would have been useful to support the issues discussed. He suggested considering a two way mechanism of communication between the user partnership group and the NSSG's.

Keith Nowell shared some of his experiences of being a member of the YCN Haematology Group. He referred to the standard questionnaire produced by the Network to help Network group members understand the needs of users coming onto NSSG's and to help service users attending NSSG meetings. A mentor was also provided which is extremely valuable.

The group agreed that a user perspective should permeate each of the agenda items rather than being a stand alone item.

Gynae Group feedback – Cheryl Downes

Cheryl Downes highlighted that at the last YCN Gynaecology meeting on 13th January 2006 she asked the gynaecology group members for their thoughts and comments on user representation. The gynaecology group were very positive and would openly welcome a service user. It was suggested that the user or carer need not be a gynaecology cancer patient but should be female, to introduce a user to the service improvement group as a transitional step and to explore the option of going to the user group should there be views that the group seek agreement on.

Keith Nowell highlighted that the gynaecology group should also consider the carer/ support perspective as their perception of information and support is equally as important.

Cheryl Downes highlighted that the gynaecology nurses are arranging a study day in May to focus on four areas of gynaecological surgery. They have invited a patient and carer to speak on their experiences.

Cheryl Downes announced that the Leeds gynaecology oncology surgical department will be moving into the New Oncology Wing, this will allow surgical procedures to be carried out over a 12 hour day which will help cancer waiting times.

Preparation for joining an NSSG – Martin Child

Martin Child emphasised the importance in preparing users to join the NSSG and CCG's. As Cancer Voices training may not be available until May/ June 2006 he proposed for volunteers to meet with Network team representatives for an informal discussion regarding issues relating to working on Network groups followed up by a meeting with the Network Group Chair and the appropriate nursing staff. Martin Child would attend the first few Network group meetings to support the user representative(s)

There was a discussion regarding confidentiality issues for users joining NSSG's. Christine Holman informed the group that there are models of confidentiality agreements in other fields for volunteers and agreed to forward a model to Martin Child.

CH

Diana Robinson informed the group of a recently published Macmillan document involving users in priority setting and agreed to forward the document to Martin Child.

DR

Keith Nowell highlighted that it is fundamental for users joining Network groups to have access to the internet. A discussion followed around accessibility and the needs of visually impaired people.

Management Board – Rachael Dixey and Colin Sloane

Rachael Dixey informed the group of the main points of discussion at the YCN Management Board on 23rd January 2006.

The NICE licence for Herceptin in the early treatment of breast cancer is expected in October 2006. Yorkshire Cancer Network guidelines and a proforma for the use of Herceptin have been circulated widely. The issue of monitoring cardiac toxicity and capacity was not addressed.

A paper from David Thomson regarding levying prescription charges to cancer patients was discussed.

Cancer Waiting Times data was presented and there was an update on radiotherapy waiting times with an action plan from David Fox. Currently radiotherapy waiting times for prioritised treatments is 5 weeks and 13 weeks for others.

The board received a paper from Barry Tinkler detailing the YCN programme for 2006/07. The paper will form part of the background paper when the new SHA's and PCT's are formed.

Carol Ferguson reported on the Service Improvement Plan for 2006. Areas of work identified include [1] pathways that transcend organisational boundaries [2] developing the NSSG's and CCG's [3] tumour groups that were not subject to Peer Review, particularly skin, haematology and head and neck cancers and [4] help Leeds in taking forward service improvement work.

Carol Ferguson explained the 18 week target to the group. By the end of 2008 all patients should have their first definitive treatment within 18 weeks of referral. This will be a major challenge for the provider organisations.

5. YCRN User Partnership Group feedback – Colin Sloane

Diana Robinson confirmed that the terms of reference have been finalised and informed the group of the launch of the 'Research and Me' website www.researchandme.org.uk.

The next meeting is scheduled to take place on 23rd March 2006, 11.00 -1.00pm

6. Communication Audit Tool

Peter Harvey informed the group of the background and purpose of the communication audit tool.

The Audit Tool was developed by the Communications Sub-group of the YCN User Partnership Group. It was developed in response to feedback from service users' experiences of people and services and their desire to improve communication between professionals and users.

It has been designed for use in a variety of clinical settings. It can be used to assess a number of contexts in which communication is important: clinic reception, out-patients, diagnostic procedures, nursing and medical consultations would all be examples of where the tool could be used.

Peter Harvey explained that he would like to see the audit tool used more widely across the Network. Lorraine Hunt agreed to use the audit tool in her urology clinics for nurse led treatment review.

LH

The communication audit tool is available on the YCN website in the projects section of the YCN User Partnership Group page (www.ycnwebsite/html/groups/user/projects.htm). A hard copy would also be circulated to the group with the minutes.

HR

7. User Involvement Strategy

Martin Child informed the group that he would contact the volunteers, who had put themselves forward at the last meeting, to arrange a user involvement strategy steering group meeting in February.

MC

8. Developing links with localities

Action

Martin Child proposed setting up a full day workshop with professional and user representation from all the localities to define sustainable mechanisms of two way communication between the localities and the Network.

Martin Child asked group members to forward to him examples of locality group activity information.

ALL

9. Patient Information strategy and quality and control of support groups

Deferred until next meeting as Jane Archer was on annual leave.

10. Any other business

- Rachael Dixey and Colin Sloane reminded members that in June they will have been Co-Chairs of the group for three years. They asked the group to consider nominations for Co-Chairs to take over in June 2006.
- Carol Ferguson informed the group of the CSC 'IP' (Cancer Services Collaborative Improvement Partnership) Recognition of Achievement Awards. The National CSC team have invited clinical teams to present case studies to demonstrate work that has made significant and sustainable change over the past year. A presentation dinner will take place at the NDP in summer/ autumn 2006. Proposals from the YCN include the user involvement framework from Mid Yorkshire as an area of good practice.

Francesca Pendino added that the Mid Yorkshire User Involvement Framework was also submitted for a West Yorkshire Modernisation award and the judging panel are visiting the Trust on 31st January. The group agreed that it would be useful to feedback this work at a future meeting.

- Marion Allinson informed the group of the organisational changes taking place at Airedale. Airedale haematology services will be transferred to Bradford, the chemotherapy day unit will remain at Airedale.
- Marion Allinson informed the group that Airedale is running a pilot scheme, working with the prison service, on remote diagnosis.
- The issue of equity of access to lymphoedema services was raised.
- Keith Nowell raised the concern of two way patient information sharing between hospitals trusts across the Network. Carol Ferguson explained that Philip Melling is developing a Network Event Server designed to overcome some of these problems and suggested inviting him to a future meeting to explain the project.
- It was agreed to have an update on New Oncology Wing developments at the next meeting.
- Diana Robinson raised the issue of the effect of governors in Foundation Trusts on user involvement. Martin Child agreed to look into this.
- Martin Child asked group members to let him know if they had experienced inappropriate use or lack of use of intercoms when having CT scans, MRI scans or radiotherapy.

HR

HR

All

11. Date of next meetings:

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

Information sub-group Monday 20th February, 10.30 – 12.30
Main Group: Tuesday 28th March, 11.00 – 1.00