

YORKSHIRE CANCER NETWORK
USER PARTNERSHIP GROUP

Minutes of the meeting held on
Monday 12th December 2005
Room 1, YCRN Conference Room, Cookridge Hospital

Present: (alphabetically)	Jane Archer	YCN Patient Information & Support Manager
	Pauline Atha	YCN Office Manager
	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
	Carol Ferguson	YCN Service Improvement Lead
	Jane Garrud	Medical Illustrator, Cookridge Hospital
	Tina Greatorex	YCN User Involvement & Patient Information Lead (Lung)
	Christine Holman	Service User, Leeds
	Pat Hope	Carer, Wakefield
	Phil Mitchell	Patient Information Officer, Cookridge Information Centre
	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
	Peter Sale	Bradford Cancer Patient/Carer Forum
	Sally Scales	Modern Matron, Leeds Teaching Hospitals NHS Trust
	Colin Sloane (Co-Chair)	Former Service User / Bradford Cancer Support
	Fiona Stephenson	YCN Project Manager
	Reva Tray	Cancer Information Co-ordinator, Bradford Teaching Hospitals
Apologies	Veronica Allinson	YCN User Involvement & Patient Information Lead (Breast)
	Jo Bewley	Business Manager, LTHT
	Suzanne Curry	Patient Information Officer, York Hospitals NHS Trust
	Margaret Jennings	YCN User Involvement & Patient Information Lead (Colorectal)
	Nic Gomersal	Macmillan CNS, Skipton Hospital
	Jeanette Halligan	Service User, Harrogate
	Peter Harvey	Clinical Psychologist, SJUH
	Roy Howard	Former Service User, Harrogate
	Cath Miller	Lead Nurse, York Hospitals NHS Trust
	Gwen Moore	Service User, Barnoldswick
	Aline Nowell	Carer/ Cameo / CHARD Steering Group
	Keith Nowell	Service User / Cameo / CHARD Steering Group
	Jan Richardson	Former Service User/Airedale Support Group
	Diana Robinson	Carer / PSA / York Hospital Information Steering Group
	June Toovey	YCN Acting Lead Nurse /Lead Nurse, Bradford Teaching Hospitals
	Lynne Russell	Former Carer / Bentham Looking Well Support Group
	Kate Smith	YCN User Involvement & Patient Information Lead (Upper GI)
	Sadie Smith	Information Support Co-ordinator, St James's University Hospital
	Karen Stocks	Macmillan Radiographer, Cookridge Hospital

1. Welcome and Introductions

Action

Introductions were made at the start of the meeting for the benefit of new members to the group and apologies recorded.

Colin Sloane formally welcomed new members; Pat Hope, carer and Martin Child, the new User Involvement Facilitator for the Yorkshire Cancer Network.

Sincere condolences were recorded for Diana Robinson, who's husband John recently passed away.

Action

On behalf of the Group, Colin Sloane thanked Pauline Atha for her administrative support to the group since the outset and welcomed Helen Ryan, Network Support Officer who will be assuming this responsibility with immediate effect.

2. Minutes of the last meeting & matters arising

Agreed as a true record.

▪ Cancer Information Portal Update

Following the presentation at the last main group meeting, Jane Garrud gave a brief update. A meeting took place with David Fox (Asst Director of Operations at Cookridge) and Sally Scales. In summary, financial constraints within Leeds Teaching Hospitals NHS Trust (LTHT) prevent the project from going ahead, although Tribal have been asked for a quote and this is still outstanding.

Jane Garrud announced that the Information Strategy Group for Radiotherapy have formed a sub-group called "Electronic Information Strategy Group" who will be designated the task of looking at developing the LTHT website to make it more user friendly.

Jane Archer added that Macmillan have worked with and recommend an organisation called "JamKit" to develop patient information in this type of portal/interface format. She explained that she will be looking to scope this as a project with Locality Information Leads input to develop this as a Network project. Anyone interested in being involved in this type of project can contact Jane Archer (jane.archer@leedsth.nhs.uk or Tel: 0113 3924158).

ALL

3. Chair's Review

Colin Sloane summarised some of the Group's activity throughout the year, which considering the staff changes that have taken place at the Network, have remained quite strong.

- Consultation by Palliative Care nurses regarding staff uniforms at LTHT
- Input into the New Oncology Wing design (continuing)
- Peer Review preparation for the Network and his own involvement as an external reviewer for another Network
- Consultation by WYMAS regarding changes to patient transportation
- Yorkshire Cancer Research Network proposed web-forum which has been designed and implemented called "Research & Me" (<http://www.researchandme.org.uk/>)
- Formation of Research User Group (Rachael Dixey thanked Colin Sloane for his determination and effort in pursuing this)
- Attendance at National Network Development Programme
- A number of presentations have been made to the group on Cancer Waiting Times; Nutrition; YCRN; Information Portal
- Generic Patient Information workshop
- User Away-Day to focus the aims and work planning for the group
- Strengthening of the User Information sub-group with the appointment of Jane Archer
- Publication of the YCN User Partnership Group promotional leaflet

Rachael Dixey added that it was testimony to the strength of the Group that this work has been achieved considering the difficult year, with the illness and loss of some members and changeover within the Network team.

Rachael Dixey also thanked members who had been involved in the work carried out at the Leeds Metropolitan University which has resulted in a module for health professionals led by Users.

4. Peer Review feedback

Fiona Stephenson reported that it was a positive review. A draft report has been issued for comments which has been completed. Once the report is in the public domain it will also be circulated across the Network, which is expected ~April 2006.. The Network will be required to

produce an action plan for areas that require improvements and further development.

Action

Fiona Stephenson thanked those members who participated directly in the review of the User Partnership Group; Marion Allinson, Hugh Butcher, Rachael Dixey, Christine Holman, Peter Sale and Colin Sloane.

Feedback from the peer reviewers indicated good leadership from co-chairs, a mature group, an excellent balance of health care professionals and users-carers and a joint agenda.

Areas of work that we need to consider further are:

- Strengthening links with localities
- Production of a patient information strategy
- Further consideration of the quality control of support groups
- Strengthen links with NSSGs to ensure user voice is heard (eg. attendance of users-carers at meetings is more effective)

Examples of good practice were commended:

- Communications audit tool
- Involvement in reconfiguration of surgical services and pathways
- Involvement in the new Information Centre at Cookridge
- Representation at Management Board
- Representation on professionals interviews
- Involvement in education and training of professionals
- Supported and involvement in setting up locality groups
- Work of the communication and information sub-group, particularly "Questions Patients Ask" and information pathways

Fiona concluded that the Group should be very proud of their achievements.

Fiona Stephenson agreed to produce an Action Plan in collaboration with localities and present it to the group at a future meeting.

FS

As previously reported, Marion Allinson raised concern of the measure relating to the quality control of support groups and re-iterated there was some Network-wide concern highlighted at the NDP in March 2005 and perhaps this measure should be reviewed.

Fiona Stephenson agreed to speak with Marion Allinson (for the national view) and others in preparation for the next meeting, where it was agreed that ½ hr would be allocated to discuss this measure further and the other areas of work requiring development. It is also possible to influence the removal of measures that are not appropriate.

FS

5. User Involvement Strategy

Martin Child firstly thanked everyone for their support in his first few weeks in his new post. He explained the purpose and need for a User Involvement Strategy.

The strategy should be concise and explicit document, a framework for users which can also be used to assist in the recruitment of users, ie. so they have a document to refer to; to help them understand user involvement; to define how they can use their experience and skills. It is also a framework for health care professionals to understand how they are engaged in the process. It was proposed that the action plan for the forthcoming year be included in the strategy and updated annually and/or be part of the induction pack.

Martin Child proposed setting up a small steering group in collaboration with Network staff to help define the strategy and asked for volunteers.

In addition to the Network staff, the following members put themselves forward: Marion Allinson; Peter Sale & Pat Oates. Christine Holman agreed to speak with Martin Child separately.

**MA/PS/
PO/CH**

Martin Child also raised the issue of user representation on the site-specific group meetings (see

item 7).

Action

Colin Sloane asked that the draft strategy be brought to the main group for input and final approval.

Martin Child agreed to organise a meeting for January/February.

MC

6. Developing links with Localities

Martin Child referred to the links between the Network User Partnership Group and the locality user groups and how they can be strengthened. He suggested organising a workshop in the new year, inviting members of this group and the localities to explore how to improve the two-way communication in/out of the Network with the aim of learning what work is being carried out and where.

Colin Sloane pointed out that a meeting of the User Group Chairs has taken place in the past and found to be beneficial. The group agreed that it would be worthwhile. Martin Child agreed to organise a date early 2006 and circulate an invite.

MC

7. Network site-specific groups (NSSGs) user involvement & patient information leads (UILs)

Fiona Stephenson explained that she held a very positive meeting with the NSSG UILs to discuss how we can work together in the future. All the UILs will raise user involvement and patient information at their next site-specific meeting (each group meets approx 2-4 times per year) and ensure it forms part of discussions on all items on the agenda, where relevant. Meetings are currently taking place on the development of patient pathways, for Upper GI and Urology cancers and users are a part of this process.

Fiona Stephenson asked the Group their opinion on how best to use the UILs time. Tina Greatorex suggested the UIL explains the format and structure of the NSSG and meets with the user beforehand to support and brief them. She felt that the user representative did not have to have that specific cancer since the fundamental principles were common across all sites.

Martin Child emphasised the importance of increasing user representation on the NSSGs and indicated that Urology and Colorectal groups are ready for involvement. Agendas can be adjusted where necessary so that users do not need to attend the whole meeting if required. The following people expressed an interest in receiving more information. It was pointed out that this could be as an observer in the first instance if preferred.

Urology: Hugh Butcher
Haematology: Pat Hope
Colorectal: Alan Rawson, Christine Holman
Lung: Lesley Conti

Any other members who would like to express an interest should contact Martin Child (Tel: 0113 3927557 or martin.child@leedsth.nhs.uk). An email will be circulated to this effect.

**ALL
MC**

8. Patient information & feedback from User Information sub-group

Brian Atkins gave a brief update on the last information sub-group meeting on 17th November (notes still to be circulated – *sent 16.12.05*).

June Toovey produced the sample patient information packs which have been piloted in Bradford – 90% of users are happy with the information provided. Jane Archer and Reva Tray plan to re-examine the content of the pack and ensure it is still valid. Discussion took place on how this could be rolled out across the Network.

A discussion took place on making information available in public libraries. Jane Archer will look into this with the locality information leads, but there are very complex issues surrounding this.

An in-depth discussion took place on welfare and financial issues, however it was too vast a topic to achieve in this meeting, therefore a separate meeting will be convened to discuss this further and

invite benefit advisers from the localities to attend.

Action

Jane Archer reminded members of the previous dialogue on the subject of being a review group for patient information and the complexities associated with this. A paper was tabled at the sub-group, however it was felt that the main group should be involved in this decision. She agreed to circulate the document with the minutes to help form further discussion at the next main group meeting.

JA

9. Communication Audit Tool

Fiona Stephenson referred to the Communications Audit Tool produced by the User Communications sub-group and led by Peter Harvey. As the group currently do not meet, the work carried out on the audit tool has also come to a halt, however it is a piece of work that has not been completely finished.

It needs to be put on the YCN website and needs promoting across organisations and could be more effective if championed by users.

Peter Harvey compiled an evaluation form which should also be available on the website for feedback on the audit tool from those who use it.

It was agreed to circulate a copy of the audit tool to all members, specifically for the benefit of those not involved and new members and to establish if Peter Harvey will be at the next meeting to discuss this with the group with the aim of progressing this work to the final stage.

PA

10. Any other business

Members were advised not to park their cars on the road leading to Arthington House car park if it can be avoided as this was an area where a number of car break-ins have occurred.

Carol Ritson proposed table name badges for future meetings. Helen Ryan agreed to produce these for the next meeting. YCN will retain them and issue them at each meeting.

HR

Peter Sale suggested a time limit for each agenda item.

Marion Allinson noted that the YCN Breast Cancer educational event held on 23rd November was excellent and requested that the group continue to be notified of future events. It would be helpful if a diary of future events could be produced and made available in advance.

MC

Rachael Dixey announced that the Leeds Met were presenting work carried out by architectural students who have designed a "Maggie Centre" on Thursday 15.12.05 all day in the Brunswick Building and everyone is invited.

11. Date of next meetings:

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

Main Group:	Monday 30 th January, 11.00 – 1.30pm
Information sub-group	Monday 20 th February, 10.30 – 12.30pm

Dates for 2006 attached