

**YORKSHIRE CANCER NETWORK AND
HUMBER & YORKSHIRE COAST CANCER NETWORK
Paediatric & Adolescent Haematology & Oncology Group**

Minutes of the Meeting held on
Thursday 9th March 2006, 2.00pm
YCRN Meeting Room 1, Ida Nurses Home, Cookridge Hospital

Present:	Karen Cooke Debbie Moore	Airedale NHS Trust
	Andrew Cassan Martin Elliott Richard Feltbower Martin Hemmingway Denise Highfield Miranda Hodgkin Sally Kinsey Michelle Kwok-Williams Bob Philips Sue Picton (Chair) Barbara Pymer Stephen Richards David Thomas	Leeds Teaching Hospitals NHS Trust
	Hazel Clough	Martin House Children's Hospice
	Margaret Riley	Royal Hull Hospitals NHS Trust
	Lucy Carroll Fiona Stephenson	Yorkshire Cancer Network
	Jill Crampton Angie Walker	York Hospitals NHS Trust

1. Apologies for Absence

Apologies were received from Pat Ansell, Alison Britland, Ann Brady, Sue Burchill, Ann Cuthbert, Adam Glaser, Ian Lewis, Mike Miller and Roly Squire.

Sue Picton welcomed Michelle Kwok-Williams, Consultant Clinical Oncologist, Cookridge Hospital to the group.

2. Minutes of the Last Meeting

Were agreed as being an accurate record.

Sue Picton reported that she had met with Sean Duffy, YCN Medical Director prior to the meeting to discuss the future plans of the group. It was felt that the Network group may not be the most appropriate forum for discussing epidemiology, research, tumour banking etc and therefore she will discuss with relevant colleagues the possibility of holding a separate Leeds based group. Sue Picton agreed to also review the membership of the Network Group noting there should be a minimum attendance of the Lead Nurse and Lead doctor from each shared care centre.

Sue Picton explained that the main priority for the group will be to work towards the Peer Review which is expected to take place in 2008.

Fiona Stephenson explained that following the publication of the IOG Quality Measures will be produced. The Peer Review can take place six months after the publication of these measures. Fiona Stephenson also updated the group on the production of the action Plan. A national meeting of key stakeholders will take place in April 2006 to identify the content of the Action Plan. It is likely that a baseline audit of current services will be required. Further clarification of this will be circulated in due course.

David Thomas reported that a new post funded by Candlelighters for 3 years has been advertised to assist with the co-ordination of the maintenance service for children with ALL and to develop shared care. A Clinical Educator post for the unit has also been advertised.

Sue Picton highlighted the importance they have streamlined referral and treatment pathways.

ACTION: Sue Picton to discuss the future remit of the group with relevant colleagues

Sue Picton to review the group membership

3. Matters Arising

- **ALL Maintenance Project**

Miranda Hodgkin informed members the pilot scheme was now coming to an end. She summarised their findings i.e. how this had improved the service by reducing clinic time and noted that the concerns they have encountered in pharmacy are being addressed.

The final report has been circulated and anyone wanting a copy can contact Miranda Hodgkin direct.

4. Clinical audit

Clinical audit papers detailing new patients, patients that had relapsed, those patients that had died and new patients in shared care centres from 21.10.05 to 28.02.06 were tabled. Data for Mid Yorkshire had been included. Due to patient confidentiality the discussion was not minuted.

5. Yorkshire Children's Tumour Registry

Richard Feltbower updated members on work undertaken by the Yorkshire Children's Tumour Registry.

It is hoped grant proposals will be approved to fund an investigation on teenagers and young adult perceptions of their care and a study to look at vitamin D status in relation to leukaemia (molecular epidemiological study in conjunction with Paul Turner from the University).

Work with the Northern region registry to look at the similarities and geographical occurrence of ALL and Type 1 diabetes and the descriptive epidemiology of haematological tumours under the age of 25 is being undertaken.

Richard Feltbower and Ian Lewis are members of the NCRI clinical development group who are looking at setting up a national registry for teenage and young adult cancers.

Sue Picton reported that a case controlled pilot study is being undertaken in the North West, Leeds and Manchester to look at children with brain tumours.

6. Shared Care

There were no major concerns to report from the shared care centres.

Martin House have data on the number of children who have died from the shared care centres. Anyone wanting this information can contact Hazel Clough direct.

7. Any other business

- David Thomson tabled the working document 'Policy for paediatric palliative care drug boxes' and summarised the content. This will be circulated again when finalised.
- Sue Picton presented 'Making Leeds Better, Tertiary Pathways' that Ian Lewis had provided on her behalf of Making Leeds Better Children's and Maternity Steering Group. A group discussion followed regarding work that is going to be undertaken to take this forward. Sue Picton summarised who will be involved at local level noting that Ian Lewis will meet with these people to progress this work. Fiona Stephenson highlighted the importance that the YCN Group links into this work.

The 'Activity summary for tertiary pathway by economy' paper was circulated. Sue Picton asked colleagues to review this paper and identify work that can be moved to local centres. A in-depth group

discussion followed. Sally Kinsey felt it may be more beneficial if they look at average figures over a few years.

- Sue Picton informed members that a service user had shown an interest in joining the group. Fiona Stephenson summarised the Network process for having user representation on a Network group highlighting that Martin Child, User Facilitator has been appointed by the Network. She agreed to inform the YCN User Partnership group that this group had welcomed this idea and will ask Martin Child to approach the interested service users.
- Sue Picton asked if Miss Carroll could arrange another meeting with her and Sean Duffy to discuss the Network's approach to the implementation of the IOG.
- David Thomson gave feedback from the Children's Palliative Care meeting he had attended. Teams are now in the final year of secured funding and are having to evaluate their service and apply for an extension to their funding. He asked if the Network could support them in this process if approached.

ACTION: Fiona Stephenson to speak to Martin Child regarding having a service user representative on the group.

8. Date of next meeting

**Thursday 20th July 2006, 2.00pm, YCRN Meeting Room 1,
Ida Nurses Home, Cookridge Hospital**