

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

Minutes of the Meeting held on
Thursday 27th May 2004
Conference Suite, Arthington House, Cookridge Hospital

Present:	Alison Britland Karen Cooke	Airedale NHS Trust
	Helen Gormley Bev Sutton	Children's Community team, Bradford
	Ann Brady Gill Sharpe	Calderdale & Huddersfield NHS Trust
	Pam Rogerson	Eastern Wakefield PCT
	Margaret Riley	Hull & East Yorkshire Hospitals NHS Trust
	Sue Burchill Catherine Cullinane Martin Elliott Alison Franklin Martin Hemmingway Denise Hodson Rachel Hollis Sally Kinsey Linda Phelan Sue Picton (Chair) Barbara Pymer Stephen Richards Neil Shaw Angela Stephen David Thomas Heather Waite	Leeds Teaching Hospitals NHS Trust
	Alistair Falconer	Scarborough Hospital
	David Walton	Service Improvement Team
	Richard Feltbower	University of Leeds
	Jill Crampton Sandra Shann Angie Walker	York Hospitals NHS Trust
	Lucy Carroll Barry Tinkler	Yorkshire Cancer Network

1. Apologies for Absence:

Apologies were received from Trish Annal, Robin Ball, Ian Beddis, Aruna Chakrabarty, Paul Chumas, Alison Essex-Cater, Andrew Jack, Adam Glaser, Ian Lewis, Sue Morgan, Mike Miller Mark Powis and Roly Squire.

2. Minutes of the Previous Meeting

The minutes from the last meeting were agreed as a true and accurate record.

3. Matters Arising

There were no matters arising

4. Clinical Audit

Sue Picton circulated audit papers that detailed all the new patients, patients that had relapsed and those patients that had died from 01/11/03 to 01/05/04. Due to patient confidentiality this discussion cannot be minuted.

Following the sudden, unexpected death of a brain tumour patient from Hull it was acknowledged that it was important to determine the cause of death, but the child did not die in Hull

Sue Picton suggested the possibility of producing a formal questionnaire to gain peoples views on how beneficial they felt it was as a Network to discuss 'Clinical audits' and explained that the purpose of this agenda item was to confirm that the data that they had collected over the last 6 months was correct.

Sue Picton informed the group that Mike Miller had recently been appointed as a Paediatric Palliative Care Consultant who would be based at Martin House and noted that he would also be working for The Leeds Teaching Hospitals NHS Trust. Mike Miller had formally been invited to attend the Paediatric and Adolescent meeting however had sent his apologies and will try to attend the next meeting.

ACTION: Sue Picton to find out who is the coroner for the specific region

5. Tumour Banking & Epidemiology

Sue Burchill informed the group that they continued to secure tumour material for local and national tumour banks. She highlighted that there were a number of tumours that were not currently available for biological studies as the consent was still outstanding. Sue Burchill noted that a large number of tumours had now been registered retrospectively with the UKCCSG Tumour Bank.

Sue Burchill gave the group an update on the recent developments within tumour banking. She particularly highlighted that the mechanism for payment for tumours registered with the UKCCSG tumour bank had changed; in the future there will be an annual payment to each centre that is linked to the predicted number of tumours likely to be banked in any one year. Banking of material by each centre will be monitored year on year. Catherine Cullinane questioned how this money was used, where it was mailed. Sue Burchill was not sure who received the monies but it was her understanding that it was used to support in part the salary of Mr Richard Seabrook, employed by the University of Leeds to help with tumour banking and tissue culture.

Sue Burchill informed the group that the bid by UKCCSG for a Biomedical Scientist position in Leeds had been unsuccessful.

ACTION: Alison Franklin to chase consent on all patients that have tumour banked as a priority

Tumour banking team to meet and establish guidelines for banking/consent process in Leeds

Alison Franklin to determine the UKCCSG Tumour Payment monies trail

Yorkshire Children's Tumour Registry

Richard Feltbower informed the group that they had re-applied for a continuation of the Candlelighters project grant for the Yorkshire Specialist register, from April 2005 for 5 years, with a decision likely after summer. Richard Feltbower highlighted that the future plans over this period included; looking at the long-term relapse patterns, evaluating teenagers/young adults perceptions of care, creating stronger ties with other specialist registers e.g. the Northern Region.

Richard Feltbower announced that the paper 'Diagnosing childhood cancer in primary care – a realistic expectation' had recently been published in the British Journal of Cancer. He explained that this paper emphasised the difficulty GPs have in spotting malignant disease given that they would only come across a new case once every 20 years. Please see supporting paper.

Also two papers were being considered for publication, one of the papers examined correlations between the occurrence of ALL and diabetes across Yorkshire, and another that highlighted poorer survival chances for young adults aged 15-29 years with CNS tumours compared with those diagnosed under the age of 15.

6. Shared Care

- **Hull**

Sue Picton informed the group that she had a meeting planned with Prof Lind and Dr Beddis to discuss shared care for adolescents.

- **Huddersfield/Halifax**

There were no major problems to report.

- **Airedale**

Nothing to report

- **Scarborough**

There were no major problems to report.

Alistair Falconer prompted a discussion on the breakdown in communication between departments and gave an example of a child that his colleague had discharged who later turned up at the Paediatric Inpatient Care Unit. He highlighted that generally the chain of communication was excellent, however it was noted that the letter of discharge summary did not always happen.

ACTION: Sue Picton to address the delay in producing discharge summaries from Leeds

- **Northallerton**

No representative from Northallerton was present

- **York**

Jill Crampton said that Robin Ball had asked her to inform the group that piperacillin could not be obtained now even though it was part of the antibiotic protocol. The group confirmed that the protocol had been changed to incorporate tazocin instead.

Jill Crampton said that there was still some confusion as many people were contacting the community centre when it should be the ward and noted that the flowchart that was being used would have to be reviewed.

ACTION: David Thomas to amend the flow charts appropriately

7. The Role of the Research Network

Barry Tinkler said that he would try to get a representative from the Research Network to attend the next meeting

Service Improvement Team – David Walton

Barry Tinkler introduced David Walton, Service Improvement Facilitator to the group.

David Walton tabled and summarised the paper 'Background Information about the Service Improvement Team' (please see supporting paper).

Barry Tinkler gave examples of some of the successful projects that the Service improvement had been involved in, e.g. Mid Yorkshire had reduced their Trust waiting times for biopsies significantly and waiting times were now within 2 weeks.

Rachel Hollis questioned if the Service Improvement could assist with the Home ALL maintenance project. David Walton said he would be happy discuss this further.

Barry Tinkler explained that if any members were wanting to submit a proposal for a project then they would have to agree their priority within their Trust and then to approach their local modernisation team.

ACTION: Rachel Hollis to call David Walton to discuss the Home ALL project

8. Immunisation Policy – David Thomas

David Thomas circulated the power point handout paper 'Guidelines for the protection of immunosuppressed children' and highlighted the changes that had been made (please see supporting paper).

9. Home ALL maintenance project – Rachel Hollis

Rachel Hollis circulated and discussed the paper 'Maintenance chemotherapy for children and teenagers with Acute Lymphoblastic Leukaemia' (please see supporting paper).

Rachel Hollis highlighted that they had funding to appoint an individual on a short-term basis to research this project. It was noted that there was a possibility that this research project may result in the publication of their findings.

10. Any other business

- **Network Central venous Line Guidelines – Rachel Hollis**

Rachel Hollis informed the group that the Chemotherapy Guidelines Sub-group were currently working on the fourth draft of the Guidance for the Management of Central Venous Catheters.

ACTION: Draft Central Lines Guidelines to be circulated with minutes for comment.

David Thomas announced that the Shared Care Study day was taking place on 28th June 2004 at St James's University Hospital.

11. Date of next meeting

**Thursday 25th November 2004, 2.00pm, Arthington House, Cookridge Hospital
Lunch will be available from 1.30pm**