

**Yorkshire Cancer Network
Paediatric & Adolescent Haematology & Oncology Group**

Minutes of the Meeting held on
Thursday 20th November 2003
Paediatric Oncology and Haematology staff room, Children's Day Hospital,
ST James University Hospital

Present:	Alison Britland Karen Cooke	Airedale NHS Trust
	Helen Gormley Amanda White Liz Lyles	Children's Community team, Bradford Children's Palliative Care team, Bradford
	Ann Brady	Calderdale & Huddersfield NHS Trust
	Ian Beddis Margaret Riley	Hull & East Yorkshire Hospitals NHS Trust
	Trish Annal Sally Burnell Martin Elliott Serena Farrah Alison Franklin Rachel Hollis Ian Lewis Bob Phillips Sue Picton (Chair) David Thomas Heather Waite	Leeds Teaching Hospitals NHS Trust
	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 Mark Baker, Sue Burchill, Alison Essex-Cater, Alistair Falconer and Gill Sharpe.

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. Yorkshire Children's Tumour Registry

Richard Feltbower informed the group on the three abstracts 'Geographic mobility following cancer treatment in Yorkshire', 'International parallels in leukaemia and diabetes epidemiology' and 'Hospital attendance patterns in long term survivors of cancer' and highlighted that these would be available in Archives of Disease in Childhood shortly.

Barry Tinkler asked Richard Feltbower to forward these abstracts to Lucy Carroll so they could be put onto the Yorkshire Cancer Network website.

ACTION: Richard Feltbower to forward the abstracts to Lucy Carroll – (Done 25th November 2003)

5. Clinical Audit

Sue Picton circulated an audit paper produced by Alison Franklin that detailed all the new patients, patients that had relapsed and those patients that had died from 01/05/03 to 01/11/03.

The information data recorded on the new patients was the referral date, whether they had entered a trial or not, the time taken to complete the trial forms, time taken for registration and the name of the shared care centre if there was one.

It was noted that Bradford and Mid Yorkshire have not yet joined the shared care network. Sue Picton highlighted that she had written to the Paediatric Consultants at these hospitals about four years ago and at that time they did not want to become active in shared care but felt that this was something that could be pursued again.

Ian Lewis informed the group that the NCRN had produced list on the number of patients entered into a trial by tumour group which showed that the paediatric and adolescent had a higher percentage of people entered into phase three clinical trials compared to the other tumour groups. It was highlighted that the percentage of patients entered into phase three clinical trials from the paediatric and Adolescent tumour group was smaller last year compared to previous years as a result of a number of the trials being closed.

Ian Lewis said that one question that was continuously raised was how quickly people are seen for a blood count. This prompted a group discussion on service and in particular the possibility at looking at producing a Network 'model' of service to help improve their long term vision of how service could be improved.

The group discussed individual patients that had relapsed and those that had died between 01/05/03 and 01/11/03. Due to patient confidentiality this discussion can not be minuted.

The group discussed approaching parents to carry out a post mortem on their child. Sue Picton informed the group that The Royal College of Pathologists and The Royal College of Paediatric and Child Health had produced a video made by parents and a pathologist who asked parents their feelings on carrying out a post mortem on their child. Sue Picton felt that this would not be an appropriate video to play to parents when their child had first died but felt that health professionals would find it beneficial.

Concerns were raised that the mortuary was not 'child friendly' environment and therefore many people chose to use Martin House. Sue Picton highlighted that the pathology department were prepared to accept a body from Martin House so they were able to carry out a post mortem and the take the child's body back to Martin House.

Bradford Palliative Care Team: Amanda White updated the group on some recent figures that had been collected on the activity of the community Nurses in Bradford between October 2002 – October 2003, these were 168 Intervention, 61 Support Visits (no intervention), 16 MDT's (with more than 2 professionals). The figures from October 2003 – the present date were 31 interventions, 8 support visits, and 3 MDT's.

ACTION: Barry Tinkler to invite Chris Button from the NCRN to attend the next meeting.

6. Tumour Banking

Alison Franklin explained to the group that they were currently trying to register spare tumour for the national tumour bank as well as for local projects that are based in Leeds.

Alison Franklin stated that the HMDS had agreed to send all their lymphoma samples to them to be registered providing there is enough tumour.

Sue Picton informed the group that a bid for money to employ a Biomedical Scientist had been submitted however it was uncertain as to whether they had been successful. Ian Lewis highlighted that part of this bid was to increase the proportion of hours for a data manager.

7. Shared Care

- **Hull**

Sue Picton informed the group that she had received a letter from Dr Alvi a Paediatric Endocrinologist at St James University saying that she had spoke to Dr Habib about doing joint Endocrinology clinics in Hull.

Ian Lewis highlighted the problem of cover when Ian Beddis was not there. Ian Lewis said that having some additional nursing input had been discussed at the Regional Childrens commissioning group. Ian Lewis felt that the Paediatric & Adolescent Haematology & Oncology group should have a significant influence on regional commissioners to support shared care initiatives. If a particular Trust felt they needed additional support for running oncologist services in order to support a specialist service Ian Lewis thought it would be very helpful if the Paediatric and Adolescent Haematology & Oncology group discussed this first.

- **Huddersfield/Halifax**

No problems were reported.

- **Airedale**

Alison Britland informed the group that on the 3rd February they would be going from 5 consultants to 3 and they had an emergency contingency plan ready.

- **Scarborough**

No representative from Scarborough was present.

- **Northallerton**

No representative from Northallerton was present.

- **York**

Representatives from York updated the group on the 5 new patients they had.

Ian Lewis prompted a discussion on adolescents as many of the paediatric units only take children up to the age of sixteen. The group agreed that further discussions needed to take place to discuss appropriate services for adolescents above sixteen.

ACTION: Sue Picton to write to Ian Beddis with the proposal of a joint Endocrinology Clinic in Hull.

8. Immunisation guidelines

The group were informed that the immunisation guidelines for patients was currently being changed to come in line with the RCPCH guidelines. This document was been developed by Suzanne Coulson. Some of the main changes made were highlighted in particular the changes made for children that came into contact with people with chicken pox.

ACTION: Guidelines to be displayed on the Network website when available.

9. Any Other Business

Sue Picton informed the group that there was a new ALL 2003 trial and patients had registered onto the new study that week.

Sue Picton highlighted that the new updated antibiotic policy was coming out shortly.

10. Date of next meeting

The group agreed the dates for the 2004 meetings. **Please note the change of time and venue.**

27th May 2004, 2.00pm

25 November 2004, 2.00pm

**The next Paediatric & Adolescent and Haematology & Oncology meeting will be taking place on 27th May 2004, 2.00pm, Arthington House, Cookridge Hospital
Lunch will be available from 1.30pm**