

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

Minutes of the Meeting held on
Thursday 25th November 2004, 2.00pm
Arthington House Conference Suite, Cookridge Hospital

Present:	Karen Cooke Dawn Grigg	Airedale NHS Trust
	Des Ginby	Bradford Hospitals NHS Trust
	Amanda White	Children's Community team, Bradford
	Nicola Lockwood Angie Walker	Children's Community Team, York
	Gill Sharpe	Calderdale & Huddersfield NHS Trust
	Martin Elliott Alison Franklin Martin Hemmingway Densie Highfield Miranda Hodgkin Rachel Hollis Sally Kinsey Sue Picton (Chair) Barbara Pymmer Mike Richards David Thomas Trish Thomas	Leeds Teaching Hospitals NHS Trust
	Mike Miller	Martin House
	Alistair Falconer	Scarborough Hospital
	Jill Crampton	York Hospitals NHS Trust
	Pat Ansell	York University
	Helen Ryan	Yorkshire Cancer Network
	Keith Ferguson	Yorkshire Cancer Network User Group
	Christopher Button	Yorkshire Cancer Research Network

1. Welcome and Introductions

Sue Picton welcomed Keith Ferguson, parent representative to the group. Introductions were made by those present.

2. Apologies for Absence

B Allagoa, Mark Baker, A Britland, Robin Ball, Ian Beddis, Sue Burchill, Paul Chumas, Anne Cuthbert, George Dublon, Richard Feltbower, Adam Glaser, Heather Martin, Margaret Riley, Hannah Smith, Barry Tinkler.

3. Minutes of the Last Meeting

Were agreed as being an accurate record.

4. Matters Arising

None.

5. Clinical Audit

Clinical audit papers were tabled that detailed all new patients, patients that had relapsed, those patients that had died and new patient shared care centres from 01/05/04 to 01/11/04. Due to patient confidentiality the discussion was not minuted.

Sally Kinsey explained the ALL trial to the group and highlighted that the reason for parents refusing entry onto the trial is mainly due to parents declining patient randomisation.

Sue Picton informed the group that a number of trials have closed including non-hodgkin's lymphoma, low grade glioma and osteosarcoma trials. Alison Franklin confirmed that the next osteosarcoma trial is currently going through ethics.

Sue Picton highlighted that shared care for young adults is an issue highlighted in the NICE Guidance. An arrangement has been established with the adult oncologists at Hull to provide shared care for young adults.

The group agreed that the data presented was correct, there were no discrepancies.

6. Tumour Banking

Nothing to report.

7. Yorkshire Children's Tumour Registry

Sue Picton explained that Richard Feltblower had sent an update on the paediatric register prior to the meeting.

1. Funding for the Yorkshire Young Persons register has been extended in the interim up until March 2006 (previously expiring in March 2005) until Candlelighters Trust has a chance to review the project grant.

Sue Picton explained that the NICE Guidance highlights the fact that there is no National Young Persons Registry; however there is one in Yorkshire which has been running for a number of years.

2. The CNS Epidemiology paper comparing incidence and survival patterns between children under 15 and young adults aged up to 30 has just appeared in 'Paediatric Oncology and Haematology'. Although low incidence rates of CNS tumours were found in young adults, their overall survival was much worse.
3. It is hoped that a grant proposal will be submitted in the near future investigating patient's views on their treatment in cancer focusing in particular on adolescents straddling the paediatric and adolescent ages and to determine their perceptions of care, what treatment they had and the reasons for the large survival discrepancy in young adults.
4. A paper looking at the long term relapse patterns is currently being drafted looking at patients diagnosed since the mid 1970's, examining the impact of recent more intensive treatments on the relapse pattern.

8. Shared Care

- **Huddersfield/ Halifax**

The community nursing staff are carrying out some work on blood taking pre-chemotherapy.

- **Airedale**

No major problems to report.

- **Scarborough**

There are currently only two patients on active treatment, which the community nurses are managing.

- **York**

Jill Crampton informed the group of the delay in obtaining blood from St James's for blood transfusions. The SJUH blood transfusion policy is currently being updated and will be circulated to shared care hospitals.

- **Martin House**

No major problems to report.

9. Yorkshire Cancer Research Network

Christopher Button Yorkshire Cancer Research Network (YCRN) Manager informed the group that the YCRN supports clinical research within the NHS.

The National Cancer Research Network (NCRN) provides the NHS with the infrastructure to support clinical trials in England. The NCRN aims to improve speed, quality and integration of research, ultimately to improve patient care.

There are 34 Research Networks in England, each maps onto the existing service Networks. The United Kingdom Children's Cancer Study Group (UKCCSG) has been classed as the 35th Network, the only specialist Network.

The UKCCSG supports 22 main treatment centres within the UK and Ireland, 16 are situated in England and each of these are located within existing Research Networks.

Christopher Button highlighted that each Research Network has a Research Manager to address the main aims of the NCRN.

Christopher Button explained that his overall responsibility is to advise and affect change within the YCRN. Lisa Pigeon, Network Manager for the UKCCSG facilitates the functioning of the UKCCSG Networks.

The YCRN receives an annual budget of approximately £650,000 which currently supports 26 individuals across the Network, working on front-line research in oncology, haematology and non-surgical oncology. Around 80% of YCRN budget is for staff, there is a core administrative team working at the Centre at Cookridge, research nurses and data managers are employed at the co-ordinating centre and at the 7 Trusts across the Yorkshire Cancer Network.

The staff that are appointed include predominantly oncology haematology research nurses, a whole time equivalent paediatric research nurse at St James's, a whole time equivalent in psycho-oncology and research activity in the clinical genetics department at St James's is also supported. There are staff that work in individual units and across the whole Network to help improve communication.

Christopher Button highlighted that part of the remit of the YCRN is training and education. All research staff are currently undergoing a training education appraisal programme to look at the needs of the whole Network. The YCRN are running a core programme of training and education which will eventually be tailored with the

appraisal of staff across the whole Network. The local training and education programme complements the NCRN programme.

Christopher Button asked about the accessibility of the UKCCSG educational days for paediatric and adolescent oncology. Alison Franklin explained that all are encouraged to attend the events however only one person from each Centre is usually funded by UKCCSG. Christopher Button highlighted that the YCRN maybe able to assist with travel costs for attending such events.

Other areas of YCRN work include Research and Development, ethics and Network Site Specific Groups.

Christopher Button informed the group of trial recruitment figures and referred to the YCRN website at www.ycrn.org.uk.

10. Home ALL Maintenance Project Update

Miranda Hodgkin gave a presentation to the group regarding the Home ALL Maintenance Project. After the presentation the following issues were discussed:

- How to promote the project to the families who are on treatment particularly
- Familiarity for parents and families
- The value of local clinics for full blood counts run in the afternoon to maintain children in school.
- Teaching parents to take blood.
- The devolution of management of ALL maintenance to shared care centres will have to link to reporting into trials.
- Electronic prescribing for consistency and reliability.
- Parent choice approach?
- Local negotiation for funding.

Sue Picton explained that electronic prescribing is a big issue; North Thames is the first Network to have funded ChemoCare an electronic prescribing system across the Network for adults and children. The group agreed that electronic prescribing is required in the YCN. Christopher Button agreed to take the issue back to Barry Tinkler and Keith Ferguson agreed to raise the issue at the User Partnership Research Sub-group meeting.

11. Immunisation Policy

The policy will be circulated shortly.

12. NICE Guidance on Child and Adolescent Cancer Services

Sue Picton informed the group that the first consultation of the service guidance for Improving Outcomes in Children and Young People with Cancer is now available on the NICE website at <http://www.nice.org.uk/page.aspx?o=33917>.

Sue Picton highlighted to the group the key elements for shared care outlined in the NICE Guidance:

- Co-ordinated care supported by appropriate structures and process. One of the structures relates to MDT discussion in the treatment Centre and an MDT group in the local Centre, the two MDT's should communicate.
- A named consultant in the principle treatment Centre with overall responsibility for shared care and a named consultant who takes responsibility at a local level.
- An identified nursing lead at the non-principle Centre.
- Robust two way system of communication.
- Age appropriate environment.
- Written guidelines to support the level of care agreed.

- Education and training programmes for staff in all settings.
- Arrangements for unexpected admissions in the Shared Care Centre.
- Identified contacts for family.
- Identified funding.

Sue Picton highlighted that there is a section in the Guidance regarding other locations of care which relates to community nursing.

A discussion followed regarding the definition of the MDT.

The group were encouraged to comment on the NICE Guidance through one of the registered stakeholders listed on the NICE website. The deadline for comments is 9th December 2004.

Christopher Button highlighted that the Guidance will be published in July 2005 therefore Mark Baker has included Paediatric and Adolescent Cancer in the Specialist Regional Services programme for 2004-2009 to go to the Specialist Commissioning Group.

Sue Picton explained that Ian Lewis is working with the Modernisation Agency on the Children's Network to bid for national funding.

13. Any Other Business

- **Patient and Family Information**

David Thomas highlighted that a working party will be established to review patient and family information from Leeds. He explained that it would be useful to have information from each Shared Care Centre and Children's Community Nursing Service which could be produced alongside the Leeds information.

The parent held record will be a separate piece of work.

- **Yorkshire Cancer Network**

Sue Picton, on behalf of the group, thanked the YCN for their support to the group and for organising the successful educational event on 18th November.

14. Dates for 2005 Meetings

Date	Time	Venue
Thursday 28th April	2.00pm	Arthington House Conference Suite, Cookridge Hospital
Thursday 3rd November	2.00pm	Arthington House Conference Suite, Cookridge Hospital