

Humber and Yorkshire Coast Cancer Network

Yorkshire Cancer Network

HAEMATOLOGY NETWORK SITE SPECIFIC GROUP

**MINUTES OF A MEETING HELD ON FRIDAY 12TH MARCH 2010, 1400 - 1600
AT THE RAMADA JARVIS, WETHERBY**

PRESENT

DESIGNATION

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| Dr L Bond | Consultant Haematologist, YHFT |
| Mr D Buchanan | Research Nurse |
| Dr C Burton | Consultant Haematologist, LTH |
| Ms G Castle | Haematology Research Nurse |
| Dr G Cook | Regional Director of Transplantation Haematology, LTH |
| Ms V Drew | Research Sister, BTHFT |
| Ms R Foster | Lead Cancer Research Sister, BTHFT |
| Dr M Gesinde | Consultant Haematologist, blood and transplant, LTH |
| Dr D Gilson | Consultant Clinical Oncologist, LTH |
| Dr C Hall | Consultant Haematologist, H&DFT |
| Dr E Harris | Consultant Haematologist, H&DFT |
| Dr R Johnson (Chair) | Consultant Haematologist, LTH |
| Ms L Kenyon | Research Sister, BTHFT |
| Dr D Kraemer | Consultant Haematologist, HEYHT |
| Ms G Laing | Haematology Research Nurse, |
| Mrs S Lewis | Cancer Manager, NLGHFT |
| Ms S Liebersbach | Chair HYCCN & YCN haematology Group, LTH |
| Mr E McGowan | Patient Representative |
| Mr P Melling | Network Information Manager, YCN |
| Ms A Millett | Service Improvement Facilitator, YCN |
| Dr L Newton | Consultant Haematologist, BTHFT |
| Mrs M Opoku-Fofie | Network Pharmacist, HYCCN |
| Dr R Patmore | Consultant Haematology, HEYHT |
| Dr H Sayala | Consultant Haematologist, HEYHT |
| Dr C Subash | Consultant Haematologist, HEYHT |
| Dr G Smith | Consultant Haematology, LTH |
| Mr D Thomson | Network Pharmacist , YCN |
| Dr E Thomas | Consultant Histopathologists, C&HFT |
| Mrs P Whitaker | Patient User Group, YCN |
| Dr D Wright | Consultant Haematologist, Mid Yorks NHS Trust |

APOLOGIES

DESIGNATION

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| Dr J Ashcroft | Consultant Haematologist, Mid Yorks NHS Trust |
| Dr G Bynoe | Consultant Haematologist, H&DFT |
| Dr C Carter | Consultant Haematologist, HEYHT |
| Dr A Edwards | Consultant in Palliative Care, Wheatfields Hospice |
| Dr M Howard | Consultant Haematologist, YHFT |
| Dr S Jalihal | Consultant Haematologist, NLGHFT |
| Dr L Munro | Consultant Haematologist, YHFT |
| Ms C Sleight | Senior Trial Co-ordinator, YCRN |
| M A Stichler | Research Nurse |
| Mrs L Wood | Clinical Nurse Specialist Haematology, H&DFT |

DEFINITIONS

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| BTHFT | Bradford Teaching Hospitals NHS Foundation Trust |
| C&HFT | Calderdale & Huddersfield NHS Foundation Trust |

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| H&DFT | Harrogate & District NHS Foundation Trust |
| HEYHT | Hull & East Yorkshire Hospital NHS Trust |
| HYCCN | Humber & Yorkshire Coast Cancer Network |
| HYCCRN | Humber & Yorkshire Coast Cancer Research Network |
| LTH | Leeds Teaching Hospitals NHS Trust |
| SNEYHT | Scarborough & North East Yorkshire Healthcare NHS Trust |
| YHFT | York Hospitals NHS Foundation Trust |
| YCN | Yorkshire Cancer Network |

Actions

- 10.03.01 APOLOGIES**
Apologies were noted as above.
- 10.03.02 MINUTES OF THE LAST MEETING**
The following amendments to the attendance record were requested:
Dr Di Gilson is a Consultant Clinical Oncologist, not a Consultant Haematologist
Dr David Wright attended the previous meeting but was not recorded in the attendance record.
The minutes of the 4th September 2009 were otherwise considered to be a true and accurate record.
- 10.03.03 MATTERS ARISING**
10.03.03.1 Network Guidelines
Dr Johnson informed the meeting that the guidelines were now available on the YCN website. The web address had been circulated via email. The guidelines page includes the current version as well as useful links including a link to historic versions of the guidelines. There is also an email icon that should be used to submit any amendment requests or highlight inaccuracies. The requests received will be reviewed at each NSSG.
Action: Updates and amendment requests to guidelines to be submitted via email using the link on the guidelines page of the YCN website. All
- 10.03.03.2 Arrangements for YCN and HYCCN Haematology Nurses Group**
Ms Liebersbach provided an update to the group that the YCN and HYCCN nurses would come together twice a year for educational meetings. The first of these meetings is scheduled for 1st May 2010. The HYCCN nurses group would be supported by the HYCCN Team. The YCN nurses group will meet twice a year in addition to the educational meetings. These meetings will be supported by Lucy White at the YCN.
- 10.03.04 SHA BONE MARROW TRANSPLANTATION GROUP**
Dr Patmore provided an update to the NSSG. The SHA Haematology Transplant Consortium now includes the whole of the Yorkshire and Humber SHA as it now includes North Trent Cancer Network. In addition to JACIE requirements transplant units will need to be designated as such by the SHA. Currently there is a piece of work being undertaken around the re-costing of transplants. It was highlighted that the outcome of this work could have implications on non-transplant centres. Further details will be provided to the group when available.
- 10.03.05 POPULATION BASED REGISTRY OF PATIENTS WITH CML**
Dr Smith highlighted that everyone should have received a letter regarding participation in the ETOS (European Treatment Outcomes Survey). This is looking at European wide registration of CML cases and

treatment responses. Richard Clark has requested Yorkshire, Manchester and Liverpool to contribute to the register all newly diagnosed patients with CML with 1 and 2 year follow-up information. There will be a data manager based in Liverpool who will collate the data but there needs to be further clarification around the input needed locally as there will be requirements above the data collected by HMRN. The issue of consent also needs to be agreed. Dr Smith highlighted that more information would be available shortly and it was likely there will be a formal launch of this initiative locally.

10.03.07 TYA AGE RANGE AND POLICY UPDATE

Dr Johnson highlighted that there is now clarity regarding the referral pathway for TYA services in haematology. The latest version of the joint network guidelines includes a clear pathway that has been agreed between the TYA service and the Haematologists. The key principles were outlined:

- If a patient is 17 or younger the patient must be referred to a paediatric oncology centre for management
- From the day of a patient's 18th birthday patients with a haematological cancer must be referred to the TYA MDT through an adult haematologist in Leeds (usually Rod Johnson for lymphomas and David Bowen for leukaemias). They will be reviewed at both the Leeds TYA and adult haematology MDTs and managed by the adult haematologists within the TYA facilities.
- Patients from the age of 19 to 24 should be offered the choice of referral to the TYA service and there should be a review of care in the TYA MDT on the same basis as 18 year olds, but the treatment does not necessarily have to be managed by the TYA service.
- Over the age of 25 patients remain with the local adult haematology services.

There are still discussions around non-malignant disease in those under 18, such as presentation with lymphadenopathy when the diagnosis is initially uncertain and this may be seen locally as per each trust's paediatric protocols.

It was agreed that Dr Johnson would produce a joint letter from himself, as Chair of the NSSG and Dan Stark highlighting these pathways for haematology and the section in the guidelines that would be circulated to all members of the NSSG. Dr Patmore highlighted that that is a national group looking at the 19-24 age group patients and how they can be supported to make an informed choice about where to have their treatment.

R. Johnson

Action: Dr Johnson to write a joint letter with Dan Stark to all NSSG members clarifying the pathway for TYA services for haematological cancer patients.

10.03.08 AUDIT GROUP

Dr Patmore provided an update from the audit group meeting in February. The HMRN database now contains over 10,000 patients; death certificate data is now available so the database is being updated with survival information. There is an article in the recent issue of the British Journal of Haematology which outlines the progress to date, it is anticipated further publications will follow shortly. The main focus of discussion at the meeting had been around continuation of funding. Discussions are ongoing with a number of pharmaceutical companies regarding commitment of long-term funding. In the interim some short term projects

may be run with pharmaceutical companies to obtain some short term funding until the long-term arrangements are resolved. In addition HMRN may obtain some NHS funding through joint work with the NCIN.

Dr Patmore encouraged all NSSG members to register with the members section of the website and regularly use the data. The minutes and papers of all audit meetings, including the results of audits will now only be available via the members section of the website.

Action: all NSSG members to register with the members section of the HMRN website. ALL

Audit reports that should shortly be available include the rolling audit of patients discussed at MDT. In addition the acute myeloid leukaemia audit is being finalised as is the 2nd phase of the myeloma transplant audit. Mrs Rossington to write to Dr Patmore regarding the myeloma transplant audit to ensure there is a clear document trail in relation to the immediate risk raised during the 2007 Peer Review visit.

Action: Mrs Rossington to write to Dr Patmore regarding the myeloma transplant audit H. Rossington

10.03.08 NETWORK PATHWAYS – COMMISSIONER SIGN-OFF

Mrs Millet stated that the pathways were signed off by the YCN Commissioning Group on 10th February 2010 as long as there is no significant financial impact. Localities have been requested to discuss and agree how compliance with the pathways will be assessed. The pathways will be available on the YCN website with just the YCN logo until the HYCCN Board has also signed off the documents. There was a discussion regarding how these pathways will be commissioned and audited and how the commissioning will translate into local contracts. YCN is also undertaking a piece of work with health economist support to cost the pathways.

10.03.09 HMDS/ USER GROUP ISSUES

HILIS 4 is in final development and it being tested in house. It is anticipated that the update will be available soon. There were no other issues reported at the meeting.

10.03.10 CHEMOTHERAPY/ PHARMACY ISSUES

10.03.10.1 YCN Gateway Group

Mr Thomson explained that the YCN Gateway Group had met and so far has reviewed 5 drugs. The recommendations from the group had been shared with the SHA and the other 2 Cancer Networks within the SHA. A proposal for a single SHA-wide group with a single process that will result in 1 commissioning decision across the SHA is being taken forward by the SHA Specialist Commissioning Group (SCG) and it is anticipated that this SHA-wide group will be established by June 2010. The YCN Board has supported this proposal. The YCN Gateway Group has halted its work programme in light of this way forward.

The joint SHA group will propose a challenge as the group will need a clinical consensus on the drugs to be discussed and how these drugs will be used. This will mean the Haematology NSSG will need to link with the North Trent group to agree clinical consensus for all haematology proposals to the group. It will also require better horizon scanning so that decisions can be made as close to licensing as possible.

It is envisioned that there will be a 3 stage process dependent upon the

cost implications. Those drugs with significant cost impact will have a full impact review undertaken by Sheffield University following a similar process to NICE, with independent health economic models being developed. The second level will be an SMC type process with pharmaceutical company health economic models being used. The third level for changes in regimens that may have a limited financial impact would be a business case that would need to be submitted. All drugs and regimen changes will need to be considered against their financial impact to PCTs.

10.03.10.2 HYCCN Drugs Policy Group

Mrs Opoku-Fofie stated that Mr Thomson has covered all the recent developments that related to both the HYCCN and YCN groups. It was highlighted that the HYCCN Drug Policy Group work plan would continue for the moment and the SCG proposal for a single SHA-wide group would be going forward to the HYCCN Board at the end of April 2010.

10.03.11 SUPRA-NETWORK SKIN LYMPHOMA MDT DEVELOPMENT

Dr Gilson stated that the Skin Lymphoma has now met and is established. All patients with T-Cell skin lymphoma stage 2 or above should be referred to this MDT, although the MDT will review any other cases lower than this referred to them. Referral to the MDT should be via Dr Gilson and her secretary. The MDT is joint between HYCCN, YCN and NTCN. The MDT will be undergoing Peer Review in 2 weeks time. The pathway and SOP should be available on the YCN and HYCCN websites.

10.03.12 HYCCN/YCN HAEMATOLOGY PEER REVIEW

It was highlighted to the group that the revised haematology measures are not expected to be published by April. Consequently haematology will not be reviewed within the visit year 2010-2011. It is anticipated that the measures will be available for 2011-2012. The group suggested that work could commence on some of the documentation that will be needed. The 2 networks will also need to agree on when the visits for haematology will take place as YCN and HYCCN are at opposite ends of the visit cycle.

The group was made aware that the Acute Oncology measures should be available for consultation during the Summer 2010.

10.03.13 RESEARCH UPDATE

10.03.13.1 Yorkshire Cancer Research Network (YCRN)

The report from the YCRN has been circulated with the meeting papers.

10.03.13.2 Humber and Yorkshire Coast Cancer Research Network (HYCCRN)

Mrs Rossington stated that Mr Ljubojevic had requested that recruitment had improved in haematology in the HYCCRN but trials were not yet open in SNEYHT. Dr Sayala highlighted that there were major issues in relation to opening trials that required pharmacy support in SNEYHT. It was agreed to highlight this issue through the HYCCN and it was stated that this had been discussed at the recent HYCCN Commissioning Group meeting.

10.03.13.3 Clinical Trials Support within the Network

Mr David Buchanan highlighted a project being developed in the YCN to better support local units with trial work. A proposal and framework was being developed to compliment support systems for trials within local units. The proposal would involve support being provided from Leeds within sub-portfolio disease groups. This could involve training and providing continuity for trials staff to cover leave etc in local units. This approach was generally supported by the NSSG members. There were queries raised regarding the funding arrangements for the model. It was

confirmed that units would not be billed for this additional support and the funding arrangements would be established through the local research network.

10.03.14 USER INVOLVEMENT

10.03.14.1 Update from HYCCN Review

Mrs Rossington stated that the HYCCN has been undertaking a review of patient and public involvement and engagement within the HYCCN. A 360 review had been conducted with NSSG Chairs, User Representatives, Board members etc using a semi-structured interview process. The results of this review were presented to and discussed by the patient and public involvement leads of the statutory organisations within the HYCCN. The PPI leads have now suggested a proposed way forward. This proposal will be presented the HYCCN Board in April. The results and implications for NSSGs will be presented to each NSSG later in 2010 following the Board agreement.

10.03.14.2 HMRN User Group

The User Group has now met a couple of times and has produced 3 documents that were tabled at the meeting; a newsletter, a questionnaire and a covering letter. These documents once agreed will be sent out to patients on the HMRN database. It is anticipated that this will enable access to a broad range of users so that cohorts of patients can be approached for views on research projects, trial protocols etc. It was highlighted that this would not mean that the same patients were approached all the time.

10.03.15 CANCER WAITING TIMES

The cancer waiting times paper was tabled. Mr Melling guided the group through the tables in the report. It was highlighted that no significant issues were raised by the data available.

10.03.16 ANY OTHER BUSINESS

There was no other business discussed.

10.03.17 DATE AND TIME OF NEXT MEETING

It was agreed to make one last attempt at a VTC NSSG between sites at Leeds and Hull. The date of the next meeting may need to change to ensure VTC rooms are available. Confirmation of the dates and locations to be circulated via email.