

HAEMATOLOGY NETWORK SITE SPECIFIC GROUP

MINUTES OF A MEETING HELD ON FRIDAY 23rd SEPTEMBER 2011
AT 1400 HOURS AT THE RAMADA JARVIS HOTEL, WETHERBY

PRESENT

Dr D Allsup
Dr L Bond
Ms E Chambers
Dr G Cook
Dr S Feyler
Ms C Hood
Dr R Johnson (Chair)
Ms S Liebersbach
Mr S Ljubojevic
Ms A Millett
Mrs J Richardson (Scribe)
Dr H Sayala
Dr E Thomas
Mr P Townsend
Mrs P Whitaker
Dr D Wright
Mrs L Wright

DESIGNATION

Consultant Haematologist, HEYHT
Consultant Haematologist, HEYHT
Portfolio Development Manager, YCRN
Consultant Haematologist & Myeloma Lead, LTH
Consultant Haematologist, C&HT
Lead Nurse, Therapeutic Apheresis, YCN
Consultant Haematologist, LTH
CNS, Long Term Follow-up, LTH
Cancer Research Network Manager, HYCCRN
Service Improvement Facilitator, YCN
P.A. to the Network Director, HYCCN
Consultant Haematologist, HEYHT
Consultant Clinical Oncologist, LTH
Assistant Network Director, HYCCN
Patient Representative, YCN
Consultant Haematologist, MYH
Clinical Nurse Specialist for Haematology, HFT

In attendance:

Mr C Hurst

Macmillan Patient Experience Manager, HYCCN

APOLOGIES

Dr S Ackroyd
Dr S Ali
Ms M Allcock
Ms K Beadle
Mr S Bilton
Dr C Burton
Dr G Bynoe
Dr A Edwards
Dr M Gesinde
Dr D Gilson
Ms S Guest
Dr C Hall
Dr E Harris
Ms E Horn
Professor M J Lind
Mr E McGowan
Mr P Melling
Mrs N Montague
Dr L Newton
Mrs M Opoku-Fofie
Dr R Patmore
Dr K Rothwell
Ms C Sleigh
Ms K Stubbs
Ms J E Taylor-Clark
Ms J Watson

DESIGNATION

Consultant Haematologist, BTH
Consultant Haematologist, HEYHT
Haematology Specialist Nurse, HEYHT
Haematology Nurse Specialist, HEYHT
Business Manager, SNEYHT
Consultant Haematologist, LTH
Consultant Haematologist, HFT
Consultant in Palliative Care, YCN
Consultant Haematologist, YCN
Consultant Clinical Oncologist, LTH
Chemotherapy Nurse Specialist for Haematology, HEYHT
Consultant Haematologist, HFT
Consultant Haematologist, HFT
Haemostasis Consultant, YCN
Medical Director, HYCCN
Patient Representative, YCN
Network Information Manager
Transplant Lead Nurse, HEYHT
Consultant Haematologist, BTH
Network Pharmacist, HYCCN
Consultant Haematologist, HEYHT
Consultant Haematologist, YCN
Senior Trial Co-ordinator, YCRN
Clinical Research Nurse, HEYHT
Director, HYCCN
Chemotherapy Nurse Specialist for Haematology, HEYHT

ABBREVIATIONS

BTH
C&HT
HEYHT
HFT
LTH
MYH
NHS ERY
NHS H
HYCCN
HYCCRN
HMHTFT
NHS NL
NELCTP
NL&GHFT
NHS NYY
SNEYHT
YCN
YCRN

DEFINITIONS

Bradford Teaching Hospitals NHS Foundation Trust
Calderdale & Huddersfield NHS Trust
Hull & East Yorkshire Hospitals NHS Trust
Harrogate & District NHS Foundation Trust
Leeds Teaching Hospitals NHS Trust
Mid Yorkshire Hospitals NHS Trust
NHS East Riding of Yorkshire
NHS Hull
Humber & Yorkshire Coast Cancer Network
Humber & Yorkshire Coast Cancer Research Network
Humber Mental Health Teaching Foundation Trust
NHS North Lincolnshire
North East Lincolnshire Care Trust Plus
Northern Lincolnshire & Goole Hospitals NHS Foundation Trust
NHS North Yorkshire & York
Scarborough & NE Yorkshire Healthcare NHS Trust
Yorkshire Cancer Network
Yorkshire Cancer Research Network

Action

Dr Johnson opened the meeting; the order of the agenda was amended to enable Mr Hurst to give his presentation at the beginning of the meeting.

In absentia, Dr Johnson welcomed Lishel Horn to the Network Group. Lishel Horn is the new Haemophilia Director at Leeds Teaching Trust, who has taken up post on 5th September 2011. YCN is delighted to find someone with her field of speciality. Her apologies were noted for this meeting.

11.09.01

APOLOGIES

Apologies were noted as recorded above.

11.09.02

MINUTES OF THE PREVIOUS MEETING (06.05.11)

11.05.03.1 PPI Lead

Ms L Wright is the YCN Lead for Patient Information not Mr L Wood. With this amendment, the minutes of the last meeting were agreed a true and accurate record.

Action: To complete the above identified action.

J Richardson

11.09.03

MATTERS ARISING

YCN Research Lead

It was confirmed that Dr Peter Hillmen is the Research Lead for YCN.

Service Improvement Lead

Ms Millett had circulated the Service Improvement role description. In the past Service Improvement for the NSSG had sat with Dr Johnson, who felt that it would be better if someone would specifically take on this role. The group agreed that after the meeting Dr Johnson will email out to the NSSG with the role description to see whether anyone would like to volunteer for this role.

It is planned to hold an additional meeting in November with just a few members of the group to formulate the Work Programme for the next year. The Service Improvement Lead would be integral to that discussion in that meeting.

Action: To complete the above identified actions.

R Johnson

NICE Technological Appraisal for Multiple Myeloma

The final NICE TAG is expected to be published next week. Bortezomib was on the CDF. The Y&H regional panel agree to take it off the CDF list for it to go into routine commissioning by PCT's since the final FAD had been published. It is down to individual trusts to make sure that they are nice NICE compliant. An update will be put on the YCN & HYCCN Guidelines on the website. Dr Johnson asked if a member of the group would write a short addition to the guideline and email it on the Guideline website to be ratified at the next meeting.

Action: To complete the above identified action.

R Johnson

11.09.12 USER INVOLVEMENT

11.09.12.1 HYCCN PPI Model (presentation)

Mr Colin Hurst, Macmillan Patient Experience Manager, gave a presentation on the results of the National Patient Experience Survey. A further survey will be carried out in October-December 2011. Copies of the presentation were tabled at the meeting and will be emailed out to the NSSG.

Action: To complete the above identified action.

C Hurst

11.09.12.2 HMRN User Group

The group of approximately 1600 receives a regular newsletter, which will be going out very soon; to update them on what is going on within the Network in respect of research etc. The users are invited to take part in research and focus groups held in localities looking at reported symptoms, when people are diagnosed etc. The database also provides a resource for different projects.

11.09.03.1 Education Event

Nothing further to report.

11.09.03.2 Kay Kendall Outreach Project Update

At the last meeting it was reported that there had been an application to extend the project by six months which has now been granted.

11.09.04 NSSG CHAIR REVIEW / REPORT / WORK PROGRAMME UPDATE

The Annual Review of the NSSG had been held earlier today and was attended by Dr Johnson (Chair), Dr Cook (Vice-Chair), Ms Wright (PPI Lead), Mr Duffy, Professor Lind and Mr Townsend. The review was felt to be quite positive and the group is functioning fairly well. The actions points from last year had been completed although Peer Review feels slightly unfinished because the Measures have not yet been published. There are no major concerns; a lot of work has been completed in the last eighteen months and it was felt the group should be pleased with that.

A letter will be sent out confirming the discussions at the Annual

Review.

Action: To complete the above identified action.

P Townsend

11.09.05 HAEMATOLOGY NSSG KEY DOCUMENTS

The Peer Review Measures is expected to be published in due course. The group has however decided to work on the three key documents in advance of this happening.

11.09.05.1 HAEMATOLOGY NSSG CONSTITUTION

Dr Johnson has been in post for three years, which is a full term of office. The succession concept is that when the Vice-Chair becomes Chair, then someone from HYCCN will be asked to take on the Vice-Chair role.

The Constitution was not a new or a radically changed document. The plan is to circulate the completed document by the middle of October with a deadline for responses, after which time it will become ratified.

**P Townsend /
R Johnson**

Action: To complete the above identified action.

11.09.05.2 HAEMATOLOGY NSSG ANNUAL REPORT

The draft Annual Report was felt to be slightly unfinished, needing one or two sections to be added to it.

Action: To complete the above identified action.

R Johnson

11.09.05.3 HAEMATOLOGY NSSG WORK PROGRAMME 2011-12

The Work Programme – there will be a small group of people meeting in November to work on the Work Programme. The meeting will be set up by HYCCN and whoever takes the Service Improvement Lead will need to attend too. Volunteers were invited for this meeting.

A draft Work Programme will be circulated at the end of November.

**P Townsend /
R Johnson**

Action: To complete the above identified actions.

11.09.06 GUIDELINES

11.09.06.1 Comments / update requests received

The web based guidelines and the alerts are functioning without any problems. There are a number of issues that were raised:

- As an addendum to viral screening and HIV testing we have received more detailed guidance from the HIV service in Leeds. These will be added to the guideline for comment in the usual way.
- Dr Johnson will put the pathway onto the Guidelines and he Will also add a reminder about the serology process.
- The South Yorkshire HIV Network pathway for those suspected of having lymphoma will be added to the Guidelines for people to comment on.
- A document had been circulated concerning increased HIV testing in general and also in high risk patients. This had been audited briefly and uptake was fairly low. Hopefully future audit will show better uptake following the new guidance.

Potential guideline changes and topics for full applications to the CDF list of approved regimens:

- Use of Rituximab in non-follicular indolent lymphoma (marginal zone lymphoma) is variable. LTH have to go to the PCT for each case as there is no high quality data to support routine prescription. There has been patchy use in some areas and it was agreed that if it would benefit the population and should be applied for.
- Dr Johnson will add CHOP 14 as an option for 1st line DLBCL to the guidelines for comment at the next meeting.
- EBV+ve lymphoma (PTLD) apply for rituximab to be added to the CDF (with or without CHOP).
- CHOP R and R Maintenance in Mantle Cell Lymphoma, the data was presented at ASCO + Lugano this year and was quite impressive. The LY05 data is being presented at ASH and this could be put to the CDF in Jan 2012.
- Brentuximab vedotin (SGN-35) - An option (now with a licence) for relapsed / refractory Hodgkins patients - gives quite good responses even in refractory patients. It is for a small number of patients and this could go forward to the CDF.

R Johnson

Action: To complete the above identified actions.

11.09.07

AUDIT GROUP UPDATE

11.09.07.1

Network pathway priorities for audit

A draft report was tabled looking at population group incidence and survival of all haematology malignancies across the Network, broken down by disease by Trust and by MDT. The next draft will be put on the website, password protected, and all members invited to view it and to submit comments, which will be fed back to the audit group. The Audit Group will meet and prepare the final report and it will then be distributed to individual trusts, PCTs and commissioners.

H Sayala

Action: To complete the above identified actions.

11.09.07.2

AML Audit Report

Nothing further to report.

11.09.07.3

Myeloma Transplant Audit Report

Dr Cook has the protocols from Phase 1 and Phase 2 part of this audit and there has been no feed back on it at all, which leaves it pending.

11.09.08

HMDS ISSUES - UPDATE

Currently, nothing further to report.

11.09.09

NURSES GROUP REPORT

A scoping exercise has been carried out as a joint YCN/HYCCN nurse led initiative. Details are included in a tabled document; no feedback included from Scarborough. The nurses are doing a lot more telephone clinics; a lot more pre and post chemotherapy counselling; more nurse led follow-up clinics and also more long term follow-up clinics and more prescribing.

For sharing good practice, there is a joint group that meets twice a year and everyone gets a 5 minute voice to say what is going on in their area. Recommendations are being looked at along with more telephone consultations; bloods done in the community from November; nurse led transfusion clinics (pending) etc.

The joint group has been going well, however the YCN group has dwindling attendance. Historically, it was open to any senior nurse who wanted to attend, however it is felt it needs to be changed to a CNS Group to make it more productive.

An update will be brought to the next meeting.

Action: To complete the above identified action.

**S Liebersbach /
L Wright**

11.09.10 CHEMOTHERAPY / PHARMACY ISSUES

11.09.10.1 Cancer Drugs Fund 2011/2012

Covered under item 11.09.06.1.

11.09.10.2 Haematology drugs reviewed at the recent Cancer Drugs Fund meeting

Clofarabine plus ARA-C for AML/high risk MDS was turned down but was felt to be highly likely to be approved on an individual basis; however it will not be put on the list as routine because they do not think it is very clear cut.

Bendamustine, for the treatment of indolent non-Hodgkins lymphomas as monotherapy in patients who have progressed during, or within 6 months following treatment with rituximab or a rituximab-containing regimen was approved for routine funding. Gemtuzumab was approved for the 1st line treatment of patients with core binding AML who are not on trial, in combination with standard therapy.

11.09.11 HAEMATOLOGY RESEARCH UPDATE

11.09.11.1 Yorkshire Cancer Research Network

Ms Chambers reported, in Ms Sleight's absence, and tabled a report for the YCRN. The first page sets out the year-on-year accrual into the haematology portfolio since the inception of the Network ten years ago. This year they have 133 patients recruited into Haematology, which equates to about 8 per cent of the national recruitment and 12 per cent of the local cancer incidence. The projection is 309 patients for 2011-12. Since pulling the report, there are now 154 patients recruited. Comparisons are given for like for like Networks, there are five in our Cluster to give an indication of recruitment locally. There is also a list of all the trials that are running across the Networks.

So far this year 94 patients have gone into over 33 Haematology studies across all trusts. 39 patients have gone into 23 Lymphoma studies across all trusts within the Network.

11.09.11.2 Humber & Yorkshire Coast Cancer Research Network

Mr Ljubojevic tabled a report for HYCCRN. Approximately 70 patients have been recruited throughout the Network. We are introducing a database and anticipate that fairly soon we will be produce reports similar to YCRN.

He confirmed that Dr David Allsup has been elected as Research Lead for HYCCRN and will be a member of the Steering committee.

11.09.13 CANCER WAITING TIMES

11.09.13.1 Presentation of latest data

Mr Townsend has been asked to raise, through the HYCCN Information Group about classification of transplant patients. The recent guidance that has come out from waiting times (version 7) says that Autograph is a treatment rather than the harvest and there is discussion about whether conditioning chemotherapy and transplant should be treated as a single course of treatment or 2 courses. It was felt important to establish a unified process and the two networks information leads were tasked with doing this to bring back to a future meeting.

Action: To complete the above identified action.

P Townsend

11.09.14 ANY OTHER BUSINESS

11.09.14.1 Radiotherapy

It was thought that across the two Networks there may already be inconsistencies in the service. National guidelines have recently been published and there is a small group who attend national meetings. There are discussions ongoing as to who they should/should not be treating. They are working towards a more uniform service.

Agreed to put this item on the next agenda.

Action: To complete the above identified action.

R Johnson

11.09.15 DATE AND TIME OF NEXT MEETING

Friday 16th December 2011, 1400 hours via VTC – Bexley Room, St James's, Leeds and Seminar Room 2 Queens Centre, Castle Hill.