



Humber and Yorkshire Coast Cancer Network

Yorkshire Cancer Network

HAEMATOLOGY NETWORK SITE SPECIFIC GROUP

**MINUTES OF A MEETING HELD ON FRIDAY 4TH SEPTEMBER 2009, 1400 - 1600
AT THE RAMADA JARVIS, WETHERBY**

PRESENT

Dr C Burton
Dr A Edwards
Mr S Duffy
Dr S Feyler
Dr C Hall
Dr A Hill
Dr M Howard
Dr R Johnson (Chair)
Dr D Kraemer
Mr S Ljubojevic
Mr E McGowan
Mr P Melling
Ms A Millett
Dr R Patmore
Mrs J Richardson (Scribe)
Mrs H Rossington
Dr K Rothwell
Ms C Sleigh
Dr J Sayala
Dr C Subasih
Ms J Toovey

DESIGNATION

Consultant Haematologist, LTH
Consultant in Palliative Care, Wheatfields Hospice
Medical Director, YCN
Consultant Haematologist, C&HFT
Consultant Haematologist, HDFT
Consultant Haematologist, BTHFT
Consultant Haematologist, YHFT
Consultant Haematologist, LTH
Consultant Haematologist, HEYHT
Cancer Network Research Manager, HYCCRN
Patient Representative
Network Information Manager, YCN
Service Improvement Facilitator, YCN
Consultant Haematologist, HEYHT
PA to the Network Director, HYCCN
Quality & Information Manager, HYCCN
Consultant Haematologist, C&HFT
Improvement & Development Manager, YCRN
Consultant Haematologist, HEYHT
Consultant Haematologist, HEYHT
Nurse Director, YCN

APOLOGIES

Dr S Ali
Dr D Allsup
Dr L Bond
Dr D Bowen
Dr G Bynoe
Dr C Carter
Ms V Dixon
Dr D Gilson
Dr E Harris
Dr Q Hill
Mrs S Millington
Dr L Munro
Dr L Newton
Dr G Smith
Miss J E Taylor-Clark
Ms P Whittaker

DESIGNATION

Consultant Haematologist, HEYHT
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Consultant Haematologist, YHFT
Consultant Haematologist, LTH
Consultant Haematologist, H&DFT
Consultant Haematologist, BTHFT
Lead Macmillan CNS, Haematology & Chemotherapy, SNEYHT
Consultant Haematologist, LTH
Consultant Haematologist, H&DFT
Consultant Haematologist, LTH
Trials Nurse, HEYHT
Consultant Haematologist, YHFT
Consultant Haematologist, BTHFT
Consultant Haematologist, LTH
Cancer Network Director, HYCCN
Patient Representative

Mrs L Wood

CNS - Haematology, H&DFT

DEFINITIONS

BTHFT	Bradford Teaching Hospitals NHS Foundation Trust
C&HFT	Calderdale & Huddersfield NHS Foundation Trust
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 & NE Yorkshire Healthcare NHS Trust
YHFT	York Hospitals NHS Foundation Trust
YCN	Yorkshire Cancer Network

Actions

09.09.01

APOLOGIES

Apologies were noted as above.

09.09.02

MINUTES OF THE LAST MEETING

The minutes of the meeting held on 12th June 2009 were accepted as a true and accurate record.

09.09.03

MATTERS ARISING

09.09.03.1

Network Guidelines

Dr Johnson informed the meeting that the only part of the guidelines to be completed was CML. There are a few typographical issues to be clarified and then the guidelines will be posted on the website.

A process for storing, reviewing and updating the guidelines on the website was proposed, however it was considered it may not be possible technically to support this process. Mrs Rossington expressed a governance concern regarding the old versions of the guidelines being available on the website. It was agreed to store the 'live' document and the update document on the Yorkshire Cancer Network website and the archive document on the members' area of the HMRN website.

Action: The 'live' guidelines and the update document to be posted on the Yorkshire Cancer Network website and the archive documents on the member's area of HMRN website.

R Johnson

09.09.03.2

Network Pathway Development

Mrs Millett tabled a pathway document and she reported that at the meeting held on 12th June there had been discussion around the CLL and Indolent Lymphoproliferative Disorders pathway and the multiple myeloma pathway. These pathways were sent out with the action log for comment. It was reported that not comments had been received. As these documents have been agreed by the NSSG they will be made available on the YCN website. They will also go to the YCN Commissioning Group on the 18th November 2009 for approval.

In addition to these two pathways, there is the patient information pathway

which will also be available on the YCN website by the end of the month.

Action: Pathways as noted above to be made available on the YCN website.

A Millet

Mrs Rossington reported that HYCCN is approaching pathway development slightly differently and are still exploring with commissioners the role of the NSSGs in relation to the Network Board and in relation to commissioning. There is a Board Time Out on 30th September 2009, which is to determine the relationship between the Cancer Network Board and the Trust Boards and the expectations and roles of NSSGs. It was requested that the pathways developed by the joint group are also discussed by the HYCCN commissioners.

Action: Joint pathways to be discussed with HYCCN commissioners.

**H
Rossington**

09.09.03.3 Supra-Network Skin Lymphoma Service

The Supra-Network Skin Lymphoma Service meeting has been re-arranged for 12th October. The YCN Board has approved the draft model for the service. This model has been circulated to all networks involved and will be progressed further at the meeting in October. There was a discussion regarding the availability of the Standing Operating Procedure for the MDT as there was a request for this to be shared with dermatologists before the meeting. It was agreed to check with Dr Gilson as to whether this can be shared at this stage.

Action: Dr Johnson to check with Dr Gilson as to whether SOP can be shared and inform Mrs Rossington of the results of the discussion.

R Johnson

09.09.04 FUTURE OF THE HAEMATOLOGY NURSES GROUP AND SUPPORT IN YCN AND HYCCN

Dr Johnson had sent a letter out at the beginning of July regarding changes in support for haematology nurses and how it will work in the future.

Mrs Toovey explained that she and Mrs Bielby, HYCCN Lead Nurse, had agreed to discuss this with the nursing group to find the best way to move things forward. Some concerns were raised by the nurses and they are working to resolve this. There had been difficulties in arranging the meeting and therefore it was agreed to arrange the meeting at a convenient location between the two Networks when they would look at the future of the group, terms of reference, Work Plan and how that links into the NSSG.

It was acknowledged that both YCN and HYCCN nurses work differently; both groups had achieved some excellent pieces of work. Mrs Toovey and Mrs Bielby will be meeting to discuss how the groups can work together. Dr Johnson requested an update at the next meeting.

Action: Update on the future arrangements for the haematology nurses group

J. Toovey

09.09.05 NETWORK-WIDE MYELOID MDT FOR DIFFICULT CASES

Dr Bowen was unable to attend the meeting and therefore it was agreed to defer the item to the next meeting.

09.09.06 CHANGES TO YCN PALLIATIVE CARE GROUP

Dr Johnson had received a letter from Charlotte Rock detailing quite substantial changes in the remit of the YCN Palliative Care Group. The new arrangements will mean that fewer clinicians will be involved. An end of life care group has been set up, which is not purely for cancer and is led by the Lead Clinician, CEO from the hospice and a PCT representative. The structure has changed and end of life care links into the SHA strategy. YCN cannot promise a clinical lead will be attached to each NSSG. It is thought this should not affect haematology and the person speaking will maintain links between end of life care and the Haematology NSSG.

09.09.07 LEEDS REPRODUCTIVE MEDICINE UNIT

This issue was raised following an email discussion and the distribution of the results of a survey recently undertaken regarding the service. There will be a major review of the service and how it links into and supports the sites. The haematology NSSG was encouraged to have input into the review.

The current pathway had been circulated in conjunction with a letter regarding re-design of the service. There will be an improved service in two units at Seacroft by the end of December.

There was further discussion around semen storage. There is currently no agreed pathway for patients to be contacted when they are fertile again; no storage guidelines and the costs are not recuperated from commissioners for this goodwill service. Issues that exist with the service had been highlighted. It was agreed to continue with communication about this issue.

09.09.08 HAEMATO-PATHOLOGY SERVICES

09.09.08.1 Development of National Guidance

It was reported that this is unlikely to affect HMDS although other haematology pathology services could be affected quite dramatically.

09.09.08.2 HMDS User Issues

A number of suggestions had been received for improved user feedback and the provision of a facility on the new (HILIS 4) system would provide a facility for users to comment on the system.

09.09.09 HAEMATOLOGY RESEARCH UPDATE

09.09.09.1 Yorkshire Cancer Research Network

The YCRN report was submitted in a new format; recruitment over the last 8 years being highlighted on the front page. The figures for 2007-2008 include some paediatric figures, which will not be included from now onwards. There is a big improvement in recruitment in 2008-2009 and based on recruitment to date this year, predicted recruitment for 2009-10 is 156 patients.

The Cancer Networks are divided into cluster groups so that they can be performance managed on Networks of similar size in the structure.

Recruitment figures are given by trial in each of the Trusts within the YCRN together with annual projected recruitment. There are two trials open within the cluster group that are not actually open in Yorkshire, one is T-ANK AML a study which is open in London also the 18-30 study again opening in London.

It was commented that there is a slight lack in mainstream trials and that a lot of work is being done to recruit patients. The recruitment figures are not dissimilar compared to other Networks and there are no obvious gaps. The uptake around the country still hovers around 8 per cent.

There was some discussion around raising the profile of Yorkshire, which is actually in the top 5 recruiters for research studies. It was further commented that the YCN and HYCCN Networks are perceived as being very active.

09.09.09.2 Humber & Yorkshire Coast Cancer Research Network

The HYCCRN Report was tabled by Mr Ljubojevic, who reported that this year is much better than in previous years and it is hoped to triple recruitment this year. Now that Scarborough is up to complement in staff, it is anticipated that recruitment will commence in that area. It was identified that the recruitment figure of '9' in August for Familial CLL and Lymphoproliferative Disorders represents a genetic study on the South Bank. This is a big recruiter because there are plenty of patients suitable for inclusion.

09.09.10 HAEMATOLOGY AUDIT GROUP

The group had not met since the last NSSG and therefore there was no update to report.

09.09.11 CHEMOTHERAPY / PHARMACY ISSUES

The YCN Gateway Group will be holding a launch on 16th October 2009. The event will include a series of site specific brief presentations on suggestions for the drugs to be discussed by the Gateway Group in each tumour site. Dr Johnson will email round for views on drugs or therapies that the NSSG wants to highlight and then try to put forward through the Gateway Group.

Action: Dr Johnson will email out for views on the drugs that they believe the Gateway Group should be looking at for Haematology in the next 1-2 years.

R Johnson

09.09.12 USER INVOLVEMENT

Mrs Rossington informed the meeting that the HYCCN is about to undertake a network-wide review of patient and public involvement and engagement. One part of this process will be a 360° review of the current process. This will be conducted using a semi-structured interview and will involve Chairs of Network groups, Network Commissioners patient representatives.

The HMRN has approached Mr Sloane about obtaining more user involvement. They have a database of approximately 8,000 patients, which they have been recruiting to since 2004. There has been an

agreement to set up a partnership group with the HMRN. The HMRN will also be contacting the patients on their database to find out how much more involvement the patient would like to have and how this would happen. Another meeting will be held September/October and progress will be reported.

09.09.13 NURSING

This was covered under agenda item 09.09.04

09.09.14 CANCER WAITING TIMES

09.09.14.1 Presentation of the GFoCWT data for HYCCN and YCN

Revised copies of the GFoCWT data were tabled. The paper also included the details of the operational standards that were published in July 2009. The standards on page two of the report are the standards that all trusts will now be measured against. Most of standards are live the exception are 31-day standard for subsequent treatments for radiotherapy treatments and the two week wait for symptomatic breast referrals. The standards apply to all tumour sites together at one Trust and there is going to be no variation per tumour site.

The data was reviewed and the group agreed that the data around subsequent treatments did not look to be an accurate reflection of the treatments delivered. It was highlighted that clinical teams needs to assist data managers to ensure that data is recorded accurately, especially when patient's treatment regimens were changed due to disease progression or no response.

09.09.14.2 Haematology GFoCWT queries

Mrs Rossington raised some queries that had been flagged to her by data managers as to what can be classed as first treatments.

1. Are antibiotics an agreed treatment for low-grade lymphoma of the stomach?

This was agreed as an acceptable treatment

2. Can steroids be classed as 1st treatment for myeloma? (where pts are on a complex pathway and are elderly/weak or unable to tolerate chemo)

This was agreed as an acceptable treatment

3. Patient with Non Hodgkins Lymphoma has been diagnosed with a recurrence and was due to start chemotherapy but this was cancelled and the patient has been started on high dose Dexamethasone. Can you confirm if we it is an agreed a subsequent treatment for NHL?

This was agreed as an acceptable treatment

09.09.15 EDUCATIONAL EVENTS

The group was informed of the following upcoming educational event:

- 4th September 2009: HYCCN AML Launch being held at the Willerby Manor Hotel, Willerby at 1800 hours.
- 22nd September 2009: YCN AML Launch.

- 24th September 2009: Children & Young Adults Group. Ramada Jarvis Hotel, Wetherby.
- 11th September 2009: Non-Malignant Haematology education event at Cedar Court, Bradford.

09.09.16 ANY OTHER BUSINESS

09.09.16.1 Peer Review

Mrs Rossington flagged up the timescales for Peer Review.

The revised Haematology Measures had not yet been published. The information from the Zonal Advisory Group is that haematology, head and neck and colorectal revised measures are all due to be published before the end of the year. If they are published before the end of this year, then haematology will be reviewed next year, thus everyone needs to be aware that it is on the horizon and that it is the new format, which is the three key documents (constitution for an NSSG, annual work programme and an annual report plus guidelines). In this group we will need to work out how we do that to fulfil the Measures for both Networks and within the timescales. It was noted that HYCCN is reviewed in May and YCN in the following March.

09.09.17 DATE AND TIME OF NEXT MEETING

Friday 4th December 2009, 1400 – 1700 hours

This will be video-conferenced meeting between Leeds and Castle Hill Hospital.

Post meeting note – meeting date changed to Friday 18th December, location and time remains the same