

Minutes of the PCA Haematology SSG

Thursday 23rd May 2019

The Arundell Arms Hotel, Fore Street, Lifton, Devon

FREEDOM OF INFORMATION

This group will observe the requirements of the Freedom of Information Act (2000) which allows a general right of access to recorded information including minutes of meetings, subject to specific exemptions. No one present today had any objections to their names being distributed in the minutes.

Draft Meeting Minutes**Chair: Jason Coppell**

Consultant Haematologist, Royal Devon and Exeter NHS Foundation Trust

Reference	Notes
1.0	Welcome and Introductions.
1.1	Please refer to separate record of attendance via the SWCN website.
2.0	The minutes of the meeting held on 13 th September 2018 were considered.
2.1	Please note that the scheduled January meeting was cancelled due to adverse weather conditions.
2.2	Matters Arising;
2.3	The list of Sub-speciality leads for the different areas of Haematology may need some corrections. The aim of this list is to encourage the sharing of information and to identify "go to" people (Ref:2.3.1) <ul style="list-style-type: none">• Adam needs removing from Lymphoma• David Veale has asked to be removed from ALL
2.4	The group has been trying to agree on regional guidelines to share across the Peninsula. Where there are existing, treatment guidelines that the group agrees on, they should be adopted. The group agreed that the <i>Thames Valley/Oxford Guidelines</i> are very comprehensive and easily accessible.
2.4.1	ACTION: BK to send JC an example of where other Site Specific groups have used a statement with hyperlinks to existing guidelines on other websites as their clinical guidelines.
2.4.2	ACTION: JC to contact the network manager for the area that Thames Valley falls under to obtain permission to refer to their clinical guidelines and put links onto the SWCN website.
2.4.3	ACTION: Once permission has been obtained, BK to upload onto the SWCN website.

3.0 Staffing Updates from across the Peninsula

3.1 Plymouth

The service is still acting down on the SpR rota, but this should improve in August. All posts have been filled and there are currently no vacancies to consultant posts.

3.2 Exeter

Currently one vacant consultant post, but the team have an improved middle grade tier.

3.3 Truro

Desmond Creagh will retire/ return at the end of August. There are currently two vacancies.

4.0 SSG Matters/Alliance Updates

4.1 *External Review of Haematology Services*

As a speciality, haematology operates differently to other specialities: with pending lists and capacity can be challenging. Discussions need to be had about how we work.

4.2 Haematology and Blood Club are to remain once every quarter, with Exeter due to arrange the next blood club meeting.

4.2.1 The next meeting is due in October and the group agreed that the network manager will continue to organise the sponsorship for both meetings

4.3 *2ww Audit Head and Neck lump 2ww referral proforma*

The group agreed to leave the form as it is as there is no advantage in changing it.

5.0 AOB

5.1 JC attended a regional meeting about Myeloproliferative Neoplasms (MPN); the first meeting was good with education content and discussion.

5.2 JC discussed with the group the availability across the Peninsula for pegylated interferon for MPN.

6.0 Lymphoma Pathway

6.1 The group looked at the Lymphoma pathways utilised at RCHT pathways. All pathways are referenced by BSH/BJH or on the Thames Valley website.

6.1.1 The group will assume everyone is happy with this unless they hear otherwise.

6.1.2 **ACTION:** BK to add to the SWCN website and to circulate with the minutes.

7.0 Genomics Presentation and Update – Guest Speakers

John McGrath (*Consultant Urologist, Royal Devon and Exeter NHS foundation Trust*)

Chris Wragg (*Head of Molecular Cytogenetics, North Bristol NHS Trust*)

Ana Juett (*SW GMC Programme Lead, Royal Devon and Exeter NHS Foundation Trust*)

7.1 Haematology is one of the three groups where whole genome sequencing will become a full test.

7.2 13 genomic centres have been created across England. The Southwest Genomic Centre is working with 7 trusts across a large geographical area in order to increase the access to genomic testing.

7.3 *100,000 Genomes Update*

7.3.1 Patients were recruited from Devon and Cornwall, across 40-50 pathways, working with various different teams.
The target was to sequence 1490 patients. The project obtained 1536 samples by the end of the project (3% over target)

7.4 Test directory for whole genome sequencing will start with all paediatric tumours, all sarcomas and for ALL/AML in haematology.

7.4.1 13 trusts have come together across the region, representing the genomic medicine service for the SW, with two labs in Exeter and Bristol.

7.5 **Next Steps**

- Establish WGS pathways regionally for AML/ALL
- Consider fit with current SOC
- Education and training requirements
- Patient consent “record of discussion” -how much information to provide and consent
- Return of results-who do they go to, and how are they reported back?
- Genomic Tumour Advisory Boards (GTAB)
- Supporting MDTs
- Opportunities for influence

7.6 Opportunities are available to obtain clinical feedback at a national/local level and for a CNS to map the patient pathways one day a week.

7.7 Chris Wragg discussed the first AML result from the project, recently received back and discussed at the Tumour board last week.

NB: details of this case will not be included in the minutes in order to protect patient confidentiality.

7.7.1 Discussions arose regarding the ethics of clinicians having knowledge of results, which may or may not affect family members in later life, and what to

do about these results. Much discussion is still required to gain consensus on these issues. GATB will need assistance from clinical experts to help guide what pathway of the future will need to look like.

7.8 JM asked the group if any members would like to assist in developing these pathways.

8.0 **LWBC Update**

Claire Fox (*Clinical Nurse Specialist, Royal Devon and Exeter NHS Foundation Trust*)

8.1 Established across the Peninsula, but delivered differently, it is a SSM pathway, delivered alongside a treatment pathway. There are KPIs and cancer support workers have been appointed to help the CNS; in driving the agenda forward.

8.1.1 There are a number of aspects:

- **Holistic Needs Assessment**-using a concern checklist and sign posting patients to the appropriate services.
- **Health and Wellbeing Clinics**- in Exeter this is an educational package delivered by the CNS team.

9.0 **Patient Experience Survey**

Key issues identified in this survey were parking, finance and pharmacy times

10.0 **Research Update**

10.1 RM has circulated a leaflet with updated trial information.

11.0 **Date of next meeting :**

Thursday 17th October 2019

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