



Peninsula Cancer Alliance

Meeting of the Peninsula Cancer Alliance Haemato-Oncology Site Specific Group (SSG)

Thursday 25th May 2017 12:00-13:30

The Arundell Arms Hotel, Fore Street, Lifton, PL16 0AA

THIS MEETING WAS SUPPORTED BY PFIZER, AMGEN, GILEAD, ADIEENE AND JNJ

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).

SSG Chair: Patrick Medd

	DRAFT Notes (to be agreed at next Haemato-Oncology SSG meeting)	Action
1	<u>Welcome and Apologies</u> Please refer to separate list for attendees and apologies here .	N/A
2	<u>Minutes/Actions of Meeting held on 20th October 2017</u>	
2.1	Minutes from last meeting The minutes of the last SSG were considered and accepted by the group.	N/A
2.2	Actions from last meeting (2.2) In view of Annie Charles retiring, the group will consider if there are any “ <i>Living with and Beyond</i> ” champions that could be invited to attend the next meeting.	All
2.3	(2.2) At the last meeting, concern was raised with regards to prescribing thalidomide and funding in relation to this; also whether or not a pre-existing protocol (such as that of the Thames Valley Cancer Alliance group) could be adopted. Funding issues have been raised and the group are happy that Thalidomide can be prescribed.	Action closed
2.4	(2.2) Clinical guidelines for lymphoma; it was agreed that a consensus has not been reached on the format that the clinical guidelines for the group will take. NK to look at the SWAG/Thames Valley clinical guidelines and collate feedback from the group as to what changes would be required in order to adopt/adapt these guidelines with the relevant amendments/permissions (to be ratified at the SSG meeting).	JC/AF/ NK

2.5 **Audit**

(2.2) Due to work pressure, an audit of the conversion rates for 2ww across North Devon District Hospital and the Royal Devon and Exeter Hospital was not undertaken. It is hoped that this work will be carried out prior to the next SSG. JC/CF/M B/Loretta Ngu

It was proposed that alongside re-auditing the 2ww's, trusts could also audit upgrades at the same time. It was noted that secretaries had been trained to identify when a patient may need upgrading and that they had been doing so effectively. All

2.6 **Poor Recruitment to Trials**

(2.2) Issues regarding recruitment to trials were discussed by the group; it was felt that early phase trials recruited well. It was thought that what one considers to be the definition of a trial may have an impact on recruitment statistics (such as scoring for blood sample collection). Heavy workloads were considered as a barrier to putting patients forward for trials, and it was felt that clinicians may wish to look to their own department for studies. All

Barriers to patients engaging with clinical trials were discussed and included geographical challenges and patients being too unwell. It was also noted that communications across the Peninsula with regards to trial availability could be improved by posting information about the trials on one website (such as the South West Clinical Network-SWCN- or the National Institute of Health Research-NIHR- website). It was agreed that the group would look at what is available on the NIHR website and that information about when trials open/close should be posted on the SWCN website.

2.7 **On-call rota for TTP Apheresis**

(2.2) There is currently no on-call rota for TTP apheresis in the South West. Examples were shared of patients having to travel from as far as Cornwall to Bristol for treatment in circumstances where this is far from ideal. An apheresis rota is needed for the region; however funding/contractual arrangements for this are unclear. The group agreed to discuss the matter further this afternoon and come to an agreement. PM to discuss with Tim Noakes, JC and Desmond Creagh

2.8 **MATRIX**

(6) A standardised approach to Myeloma from Exeter perspective has been agreed and this action has been closed. Action closed

2.9 **Patient Pathways**

(7) The patient pathways from Plymouth are to be shared with the group and agreed prior to the next SSG. PM/KM

2.11 **Service User Representatives**

(8) The group agreed that a service user representative will be invited to the next SSG and that the group will rotate this so that the Peninsula is fairly represented. It was also noted that a previous patient representative had questioned what the purpose of the group was. NK agreed to email a copy of the Alliance "User Representative Brief" to SG to inform future representatives. NK to liaise with CNSs

2.12 **Specialised Integrated Haematological Diagnostic Service (SIHDS)**

There is no SIHDS across the Peninsula network and that provision of such a service would involve major restructuring at Trust level. There has been a Peninsula Pathology Partnership, however the group disbanded and there has been nothing since. Exeter cytogenetics and MRD go to Bristol, it was noted that each hospital has their own protocol for this. The group discussed systems of doing this across the Trusts, comparing MRD with Aria, and whether there could be a uniformed approach. It was noted that this issue could not be resolved within the group and that previously this issue had been escalated to Trust board level without resolution. N/A

3 **Changes to Membership**

Members to add

NK

Kelly Morgan-Staff Nurse-Plymouth Hospitals NHS Trust

Members to remove:

None.

4 **Clinical Guidelines**

(As documented in 2.3)

5 **Patient Pathways**

(As documented in 2.9)

6 **Patient breaches**

PM agreed to look at the current state of breaches across the Peninsula and that the number of breaches and reasons for them was a possible area for future audit. PM

It was noted that breaches in Exeter tended to occur prior to receiving the patient (from other specialities).

7 **Quality of Life (QOL) Surveys**

It was acknowledged that the research nurses carry out QOL surveys, however this was not routinely being undertaken. It was suggested that Dr Hannah Hunter may be able to look further at the Patient Experience across the Peninsula. HH

- 8 **Living with and Beyond Cancer**
- The group discussed when Holistic Needs Assessments (HNA) should be undertaken, and the pros/cons of different tools used to capture this information (ranging from paper assessments to the utilisation of apps). It was noted that a HNA should be offered to all patients, and that undertaken HNA's were useful, but time consuming. N/A
- 9 **Treatment Summaries**
- Exeter use a template that CNSs fill out, which accompanies the clinic letter. It was acknowledged that treatment summaries would not work for all patient groups, and that specific cohorts needed to be identified. All
- 10 **Service Development/Training Opportunities**
- Due to the nature of Haemato-Oncological diseases, it was noted that work on making early diagnoses was difficult. N/A
- The SSG links with the "Blood Club" and the registrars meet monthly. There are also Myeloma and BMT meetings, and a South West lymphoma group.
- 11 **Quality Surveillance (Formerly Peer Review)**
- The new peer review measures were briefly discussed. NK agreed to update PM if there are any specific requirements. NK
- 12 **Any of Business**
- None raised.
- 13 **Next SSG meeting**
- The group agreed that the SSG will meet again on 19th October 2017 at 12:00. NK to liaise with BP. NK
- 14 **Sponsorship**
- NK had been approached by Paul Horne of Novartis regarding future SSG sponsorship. It was agreed that their support would be welcomed and NK will liaise with PH prior to the next meeting. NK