

Haematology Tumour Site Specific Group meeting
Wednesday 17 th November 2021
Microsoft Teams
09:30-13:00
 Final Meeting Notes

Present	Initials	Title	Organisation
Lalita Banerjee (Chair)	LB	Consultant Haematologist	MTW
Annabel Page	AP	Clinical Trials Coordinator – Haematology/Lymphoma	MTW
Hayley Sears	HS	Haematology Research Nurse	MTW
Claire Williams	CW	Chief Pharmacy Technician - Education & Training	MTW
Evangelia Dimatriadou	ED	Consultant Haematologist	MTW
Victoria Stables	VS	Consultant Haematologist	MTW
Deborah Willcox	DW	Senior Haematology Research Nurse	MTW
Kavi Robinson	KRo	Haematology CNS	MTW
Emma Richardson-Smith	ERS	Research Nurse	MTW
Joanna Simpson	JSi	Haematology CNS	MTW
Naomi Butcher	NB	General Manager – Cancer Services	MTW
Zacharoula Galani	ZG	Consultant Haematologist	DVH
Soleman Patel	SP	Lead Cancer and Clinical Trials Pharmacist	DVH
Lian-Wea Chia	LWC	Consultant Haematologist	DVH
Natalie Heeney	NH	Consultant Haematologist	DVH
Jayne-Marie Osborne	JMO	Haematology Registrar	DVH
Joyce Van Den Camp	JVDC	Macmillan Haemato-oncology CNS	DVH
Michelle McCann	MM	Operational Manager for Cancer & Haematology	DVH
Olumide Olufuwa	001	Lead Research Nurse	DVH
Skye Yip	SY	Consultant Haematologist	DVH
Lavinia Davey	LD	Senior Clinical Trials Coordinator	EKHUFT
Moya Young	MY	Consultant Haematologist	EKHUFT
Stephanie Goodchild	SGo	Macmillan Lead CNS - Haemato-oncology and Lymphadenopathy	EKHUFT
Jindriska Lindsay	JL	Consultant Haematologist	EKHUFT
Sarah Howland	SHow	Senior Operations Manager – Haematology & Haemophilia	EKHUFT
Pippa Miles	PM	Senior Service Manager – CCHH Care Group	EKHUFT
Robin Sanderson	RS	Consultant Haematologist	King's College Hospital
Claire Mallett	СМ	Programme Lead – LWBC	KMCA
lan Vousden	IV	Programme Director	KMCA
Colin Chamberlain (Notes)	CC	Administration & Support Officer	KMCC
Michelle Archer	MAr	Pharmacy Technician	KMCC
Annette Wiltshire	AW	Service Improvement Facilitator	KMCC
Karen Glass	KG	Administration & Support Officer	KMCC



Hayley Paddock	HP	E-Prescribing Pharmacist	KMCC
Maadh Aldouri	MAI	Consultant Haematologist	MFT
Margaret Williams	MW	Haematology MDT Coordinator	MFT
Handunneththi Mendis	HMe	Consultant Haematologist	MFT
Nahla Osman	NO	Consultant Haematologist	MFT
Sue Green	SGr	Macmillan Recovery Package Facilitator	MFT
Natasha Wilson	NW	Macmillan Haemato-oncology CNS	MFT
Sarah Blizzard	SB	Haematology Cancer Support Worker	MFT
Agne Sadauskaite	AS	Specialist Cancer Pharmacist	MFT
Gayzel Vallejera	GV	Clinical Trials Practitioner	MFT
James Shaw	JSh	Head of Cancer Services and Compliance	MFT
Holly Groombridge	HG	Cancer Commissioning Project Manager	NHS Kent & Medway CCG
Bana Haddad	BH	Macmillan GP & Cancer Lead / Clinical Lead - LWBC	NHS Kent & Medway CCG
Kate Regan	KRe	Macmillan Primary Care Nurse Facilitator	NHS Kent & Medway CCG
Zuzana Volkova	ZV	Locum Consultant Haematologist	University Hospital Southampton NHS Foundation Trust
Apologies			
Vijay Dhanapal	VD	Consultant Haematologist	DVH
Sreetharan Munisamy	SM	Consultant Haematologist	EKHUFT
Sandra Holness	SHol	Cancer Pathway Tracker Coordinator	EKHUFT
Miguel Capomir	MC	Haemato-oncololgy Pharmacist	EKHUFT
Angie Gundry	AG	Clinical Nurse Specialist	Heart of Kent Hospice
Pramila Krishnamurthy	PK	Consultant Haematologist	King's College Hospital
Serena Gilbert	SGi	Cancer Performance Manager	KMCA
Helen Downs	HD	Aria System Administrator	KMCC
Tracey Ryan	TR	Macmillan User Involvement Manager	KMCC
Elizabet Sanchez	ES	Service Manager for Oncology & Haematology	MFT
Ola Okuwa	OOk	Senior Oncology Pharmacist	MTW
Jack Jacobs	JJ	Macmillan GP & Cancer Lead	NHS Kent & Medway CCG
Sona Gupta	SGu	Macmillan GP & Cancer Lead	NHS Kent & Medway CCG
Ann Courtness	AC	Macmillan Primary Care Nurse Facilitator	NHS Kent & Medway CCG
Hamish Miller	HMi	Consultant Haematologist	Royal Free London NHS Foundation Trust

Item		Discussion	Action
1	TSSG Meeting	Apologies The apologies are listed above.	
		 Introductions of new members LB welcomed the attendees to the meeting. LB asked the attendees to notify the group of new staff members and requested they email AW/CC their email addresses 	



		so they can be added to the Haematology TSSG mailing list.	
		Action log Review	
		 The action log was reviewed, updated and will be circulated to the members with the final minutes from today's meeting. 	
		Review previous minutes	
		 The final minutes from the previous meeting which took place on 19.05.2021 was reviewed and agreed as a true and accurate record. 	
2	HOG	 accurate record. Action: HP to provide CC with a summary of today's HOG discussions which he will then circulate to the group. 	НР
3	PSFU CLL update	Update provided by Skye Yip and Claire Mallett	
		 At the last meeting, there were discussions around the need for process mapping and developing a protocol for this workstream. A number of CLL meetings have taken place since the last Haematology TSSG in order to: agree draft measures, formulate eligibility criteria, define what questions should be incorporated in to a questionnaire from a patient advocacy perspective and identify what communication is required and how often patients need to be seen. The next step will be to prepare the necessary documentation and develop a Patient Portal (with input from patient advocacy groups). CM highlighted the need to have a consensus with regard to whether the Trusts are happy with the outline of the guidance. SY stated the SOP will need to be updated after each phase and is therefore not a finalised document. Patient input will also need to be included. SY believes the guidance, along with the Oxford discharging document, can be followed in conjunction. This piece of work will be trialled at DVH and Canterbury initially. Funding for a Support Worker has been allocated to support this workstream from an administrative perspective. Some patients will need surveillance long-term and SY believes this is where the remote monitoring piece will be helpful whereas discharged patients could benefit from PIFU. SY highlighted the importance of the guidance having clear safety netting measures in place. SY believes the SOP should be utilised/viewed as a template from which the technical phase can be drawn – something which the Trusts agreed with. CM emphasised the importance of having clinical follow-up processes in place in order to move forward with the digital work. 	
4	Oxford discharging	If the Trusts have any patients who would like to support this piece of work then they should link them in with AW/TR.	
4	Oxford discharging guidance	 Oxford discharging guidance - update provided by Lalita Banerjee LB referred to the Oxford University Hospitals NHS Foundation Trust's Lymphoma Clinic Discharge Guidelines which provide an overview of the recommended discharge of patients with: Burkitt lymphoma, Diffuse large B-cell lymphoma, Peripheral T cell lymphoma, Follicular lymphoma, Hairy Cell Leukaemia, Hodgkin lymphoma, Marginal Zone lymphoma and Waldenstrom Macroglobulinaemia. LB stated MTW will adopt this guidance within their practice. SY stated the PIFU piece is currently not in place at DVH. Safety netting, audit processes and process mapping will need to be factored in/worked on before the guidance can be adopted. There is a need to have separate codes in place for discharged patients so staff are aware they are on the PIFU pathway and can come back in to hospital and be slotted in urgently (something which will need to be sorted out with the booking system and ERS). Meetings with BI have taken place regarding this matter and their operational manager is now trying to move this forward. SY feels DVH are below-par with regard to tracking patients so before the Trust take this piece of work forward there will need to be some process mapping work undertaken. Furthermore, he believes when this workstream is initiated they 	



	Lymphadenonathy	 should proceed with high-grade lymphomas initially (those who are being discharged and do not require surveillance). VS stated MTW are also below-par with regard to tracking patients and she feels if they had a data manager and database they could manage them better. EKHUFT have had PIFU in place for both high-grade and low-grade lymphoma for a number of years and have SOPs for both. MY feels there is room for improvement with regard to database management. Action: MY to send CC the EKHUFT PIFU SOP which can then be shared with the group. EKHUFT have a list of patients who they have seen in the last 5 years, separated by diagnosis, and are developing a database which they can then use to track patients better. MY believes Support Workers could help to maintain this database. MY stated when the EKHUFT team are ready to send patients to the PIFU pathway, they ideally get them to see a nurse specialist 4 months later where HNAs and Treatment Summaries can be carried out. The patients are given the PIFU information leaflet and telephone numbers of nurse specialists who can be called if and when they may experience issues. The information leaflet states which symptoms patients should look out for and when to contact the team. Some patients simply require reassurance whereas others may need to come in to hospital for scans and be seen in clinic. MAI stated it would be helpful to have a unified approach where discharging patients is concerned. 	MY/CC
	Lymphadenopathy pathway	 The Alliance have been tasked with moving forward with rapid diagnostic pathways/centres. They have financially supported work within different pathways, including the VISS service at DVH and the Rapid Lymphadenopathy Service at EKHUFT. With regard to the Rapid Lymphadenopathy Service, there has been an agreement to fund and support the rollout of the service to West Kent this year. If rollout works well, this piece of work can then be moved forward for the rest of Kent & Medway. LB believes it would be helpful to meet with relevant colleagues outside of this meeting in order to try and have a unified approach to moving this workstream forward across the patch. VS believes MTW have a potential pathway from a haematological perspective but thinks this can only be moved forward with funding. IV suggested VS get in touch with NB who he has liaised with regarding the funding piece (and which he has tentatively agreed to provide). VS believes there is a need to think about what West Kent want the pathway to look like and how to have good GP engagement, especially given the issues they have experienced with the types of referrals received. IV suggested the East Kent team link in with the West Kent team to discuss how their service has evolved. He also believes it would be ideal if there were similar pathways, referral processes and services across the sites - although there may be good reasons why variations exist. SGo stated she would be happy to be the point of contact at East Kent. MY stated Buckland Hospital has received funding to have an investigation hub and they are looking to see if this could be utilised. With regard to Galleri GRAIL, IV stated the detailed guidance document/protocol should give clarity around what should happen to patients who come in to secondary care in terms of relevant tests and how far they should be investigated. If the guidance is unclear, IV mentioned he would be happy to contact the Galleri GRAIL trial team di	
5	How to empower practice nurses to complete cancer care reviews	KRe had yet to join the meeting when this item was due to be discussed so an update was not provided.	



6	Borformonco	DVH undete provided by Michelle McCopp	
6	Performance	 <u>DVH – update provided by Michelle McCann</u> Please refer to the performance slide pack for an overview of the Trust's data. 	
		 SY stated a lot of referrals are inadequately completed by GPs and a number of patients are referred in without having had a face to face appointment of their practice. The term is not haven up and a number of patients are referred in without having had 	
		a face-to-face appointment at their practice. The team is not, however, able to reject these referrals as per NICE and CWT	
		guidance. HG mentioned patients can be downgraded but a discussion with the referring GP has to take place before this	
		can happen – something which can be very challenging. HG and colleagues will work on putting together an audit to	
		articulate the challenges they have, the results of which can be shared with GPs in order to try and expedite these issues.	
		 MAI stated MFT have noticed an increase in referrals from ANPs and clinical pharmacists. He believes a number of these referrals, if they had been discussed with GPs beforehand, would not have been sent in to secondary care. Further, MAI 	
		believes they should utilise Consultant Connect or get the GPs to review the referral before it is sent – something which he	
		feels the CCG should be made aware of – especially if the referral guidance is not being adhered to.	
		 NHS Digital have set up a system whereby relevant staff can request access to GP bypass numbers and their direct email 	
		 And Digital have set up a system whereby relevant stan can request access to GP bypass humbers and then direct email addresses. NH has started to use this system and found it extremely helpful in getting through to either a GP or duty doctor. 	
		Action: NH to send CC the link to this system which he will then circulate to the group.	NH/CC
		 SGo stated it was formerly agreed a digital downgrade letter could be put in place which MY confirmed EKHUFT are using. 	
		 SY outlined that there have been problems with 2ww office staff shortages at DVH, with some referrals being sent to the 	
		team a week after they were received by the 2ww team.	
		EKHUFT – update provided by Pippa Miles	
		 Please refer to the performance slide pack for an overview of the Trust's data. 	
		 At EKHUFT all 2ww referrals come through ERS and are triaged within 24 hours. At DVH the ERS system does not 	
		currently have the capacity to follow suit in this respect. MAI stated MFT also use ERS.	
		MFT – update provided by James Shaw	
		Please refer to the performance slide pack for an overview of the Trust's data.	
		MTW – update provided by Naomi Butcher	
		 Please refer to the performance slide pack for an overview of the Trust's data. 	
		 Following a review of the data, VS stated there have been issues with: diagnostics, capacity, lack of adequate MDT 	
		Coordinator time (often an issue where they have to be shared with other tumour sites) or there being no MDT Coordinator	
		in place, things not getting pulled through the pathway quick enough/in time for MDT, patient choice and the number of	
		referrals (although the team are working at full capacity to see the 2ww patients within 14 days).	
		The clinic proforma has been changed and the team have not been informed of any concerns with regard to 2ww	
		performance.	
		• VS believes there needs to be improvement with regard to what MTW do with inappropriate/inadequate referrals.	
		Where referrals are incomplete or inadequate, JL believes there needs to be an increase in the vetting of these and stated	
		she would be happy to link in with MTW to discuss what they do at EKHUFT. Further, JL believes better engagement with	
		GPs is required to try and expedite these issues.	
		 VS stated administrative issues have had an impact on the pathway and she believes it would be sensible to liaise with the other Trusts' management teams to see if this can be expedited. 	
7	Addition of Blood	• The group agreed it would be sensible for MY to speak to KOMS in order to request a tick box be added to the action sheet	
	Transfusion	on the system.	
	Notification completed		



	to KOMS action sheet		
8	Management of gastric lymphomas and complications	 Presentation provided by Robin Sanderson RS provided a presentation on Bowel perforation intestinal lymphoma and stated: there are no recent publications for this, it is not mentioned in the London Lymphoma Guidelines and there is no specific SOP at King's College Hospital on this. RS referred to a retrospective review (published in 2013) from Mayo Clinic and this provided an overview of: Between 1975-2012 there were 1062 patients with biopsy proven GI involvement with lymphoma. 9% of patients developed a perforation, 55% of which occurred after chemotherapy. The median day of perforation was 46 days post-chemotherapy (with a range of 2-298 days). 44% of the perforations occurred within the first 4 weeks of treatment. DLBCL was the most commonly associated pathology accounting for 59% of cases. The small intestine was the most common site affected, accounting for 59% of cases. 	
9	Clinical Pathway Discussion	 RS stated Kings College Hospital only admit patients at risk of tumour lysis (for fluids and monitoring of electrolytes) but otherwise patients are seen in an outpatient setting with instructions on what to do if they become unwell. King's College Hospital have seen a lot more refractory DLBCL cases due to the CAR-T programme. RS stated patients are given prednisolone 100mg orally as standard, although he is aware variation exists with regard to dosage. RS mentioned there had been some discussion around the idea of introducing pre-phase steroids – although this is not particularly defined and opinions differ amongst consultants regarding this. With regard to mantle cell-GI involvement, RS mentioned some patients have bowel symptoms and an endoscopy can therefore be carried out for the purpose of staging and treatment response. Pan London Guidelines AW stated she requires clarity as to where the Pan London Guidelines links need to be situated on the various KMCC documents. 	
		 HOP The HOP was reviewed and AW outlined where she had updated the document and which areas she needs clarification on. She will include the feedback received and link in with LB to get this document finalised. Leukaemia POC JMO will work on updating this document. Myeloma POC JL will work on updating this document. Haemoto-oncological POC Action: JL stated she has a haemato-oncological pathway document which she will share with AW. She did, however, state this document (published in 2014) is out of date. 	JL
		 <u>Lymphoma POC</u> With regard to this document, SY believes the major change will be the inclusion of the Pan London Guidelines links. Further, he feels the only changes required are the updating of the personnel sections. 	



11 12	Clinical Audit CNS Updates	can be scheduled to discuss the Kent & Medway-wide portfolio. • Action: AW/LB to contact each Trust to request they present an audit at the next meeting. • DVH – update provided by Skye Yip • The team comprises of 4 CNS'. • The team hope to recruit a benign haematology nurse.	Trusts AW/LB
		 SY stated DVH do not have a dedicated naematology research nuise. <u>Action:</u> LD stated there is scope for improvement in Kent & Medway with regard to trials/studies. In view of this, she will try to get some support from the CRN in order to help with MFT's and DVH's recovery. Action: LD asked for the Trust's research team leaders to get in touch with her with their availability so a meeting 	LD LD / All
		 DVH SY stated DVH have opened a few trials and closed 2 observational ones, so he is not sure LD's presentation is completely accurate with regard to research activity for his Trust. DVH are hoping to open RADAR and are looking in to the feasibility of doing so. They are also hoping to open a mithridate study. DVH conducted the PiMMS trial with King's College Hospital. DVH also opened an ITP registry trial. LD suggested DVH look in to the REMODEL-A and APOLLO+ trials. SY stated DVH do not have a dedicated haematology research nurse. 	
		 MFT <u>Action:</u> Research activity has yet to recover at MFT, which MAI is concerned with. In view of this, he will link in with GV to see if they can work on resolving this. MFT are looking to open the CHIP trial shortly. The following trials are also in the pipeline: RADAR, MYELOMA-15 and APOLLO. 	MAI
		 MTW AP stated MTW had recruited 5 patients to MYELOMA-14 (exceeding the target of 3) and 16 patients to AML-18 (4 of which were recruited this year and exceeding the target). The team have 6 studies which will be opened soon (including interventional and observational ones) and hope to over-recruit to these in 2022 as well. The 6 studies are: ImpactMF, MOMENT, RADAR, REMODEL-A, PETReA and ECHELON-3. AP stated MTW are hoping to find some non-malignant trials to take forward and if the members know of any they are asked to inform her of this. 	
10	Research	 Presentation provided by Lavinia Davey Please refer to the circulated research presentation for a detailed overview of the haematological trials. LD provided an overview of the recruitment for the CRN KSS haemato-oncology and lymphoma trials in addition to the recruitment activity by hospital site and the activity by hospital site and trial for 2021/22. LD referred to the managed recovery studies which are deemed important to recruit to time and target – specifically Myeloma XIV (Fitness). LD outlined some studies currently in the pipeline. 	



		EKHUFT – update provided by Stephanie Goodchild
		The team comprises of 2 CNS'.
		 The Trust have advertised for 2 Band 7 CNS' and this has received a lot of interest. Interviews will be held next week.
		 The Trust have also advertised for 2 Band 4 Support Workers who will help the team set up the CLL PIFU workstream
		amongst other duties.
		MFT – update provided by Natasha Wilson
		Elizabeth Elliott has now retired, NW has just returned from maternity leave and Kerry Michelsen is due to go on maternity
		leave in January 2022.
		• The team have recruited 2 new members of staff (a Band 6 a Band 7) who will hopefully be in post before the end of this
		year. The Band 7 will be on a 1 year fixed-term contract and work part-time and the Band 6 will be permanent and work full-
		time.
		MTW – update provided by Joanna Simpson
		 The CNS team are now part of a focus group which is looking to streamline the bone marrow booking process in order to
		utilise all available capacity to meet the increased demand. An audit is being conducted regarding the number of bone
		marrow cases the service are undertaking, the appropriateness of these procedures and the time from electronic action
		sheet to procedure.
		 The team are planning to improve how they manage patients receiving oral chemotherapy and have been liaising with
		pharmacy colleagues regarding this. They have also set up meetings with oncology due to their having a successful
		pathway in managing these patients.
		The team have ongoing issues with leadership as there is no Matron currently in place.
		The service is trying to resolve issues for COVID-positive patients who require SACT and blood product support as the day
		units are green zones and there is no current provision for these patients – something they are liaising with management
		teams about.
		 The ambulatory day unit has a newly-appointed Band 7 and the CNS team are meeting soon to identify collaborative
		working.
		The service continues to undertake weekly clinics at both Maidstone Hospital and Tunbridge Wells Hospital for pre-SACT
		cycles, MPNs and pre-treatment information sessions.
13	Cancer Alliance update	Please refer to the circulated Cancer Alliance presentation which CM discussed at the meeting.
		With the emergence and subsequent impacts of COVID, a spotlight has been placed on the need for psychological support.
		In view of this, CM and BH have undertaken some scoping work by linking in with the Trusts' psychological support
		services in order to understand current practice/provision and to identify if and where there may be inequity across the
		patch.
		CM highlighted the importance of identifying opportunities to strengthen psychological support for people affected by cancer
		in both secondary and community care and to identify opportunities to strengthen CNS'/Cancer Support Workers' skills to
		manage distress.
		CM believes HNAs will help to identify what needs there are across the various tumour groups.
		CM and BH would welcome any comments and can be contacted by email should anyone wish to find out more about the
		work they have conducted.
14	CCG Update	Update provided by Holly Groombridge
	•	Local ICP teams are working with the relevant Community Diagnostic Hubs/Centres (of which there will be 6 for Kent &
		Medway), which can cover populations of up to 300,000. The Alliance is supporting this workstream from a cancer
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		 perspective. East Kent and West Kent are taking this forward initially and are currently in phase 1. MFT and DVH will follow suit in phase 2. From 01.04.2022, the CCG will be replaced by ICPs. Within the ICPs there will be PCN's which is where the GP practices will sit. The intention is to support system-level working and collaboration which is already in a good position from a cancer perspective. <u>Action:</u> NH asked whether there is a named GP who the teams could liaise with regarding updates to referral guidelines and GP education. HG informed NH that the link for North Kent is Stefano Santini and she will email her his email address. HG will also link in with Stefano Santini to ask him if he can join the next meeting. 	НG
15	Palliative Care update	 Update provided by Lalita Banerjee on behalf of the Heart of Kent Hospice The Heart of Kent Hospice was unable to send any representatives to today's meeting. Dr Georgina Parker did, however, provide LB with a written update which is as follows: The service is launching a rebrand of their Living Well Outpatient Centre as the hospice hub with a predominantly drop-in approach. An update in finer detail can be provided at the next meeting. The team would like to encourage colleagues to refer to them as early as possible and encourage patients to browse their website as all of their services are located there and self-referrals can be made. Part of Jane Marshall's (Consultant in Palliative Medicine – EKHUFT) remit is to foster connections with the Pilgrims Hospice (who have had a significant increase in the number of people being sent to them) in order to: Improve the integration of care between them and develop a better pathway. 	
16	AOB	• <u>Action:</u> NH asked whether any of the Trusts' COVID-positive inpatients had managed to access the Ronapreve antibody combination or whether they had a pathway for this. LB suggested NH link in with a colleague named Grace and to email the Trusts to identify whether there are any SOPs in place which make clear what to test for, who is eligible for treatment and when and how to use it.	NH
	Next Meeting Date	To be confirmed.	