Kent & Medway Cancer Collaborative

Haematology Tumour Site Specific Group meeting Monday 16th October 2023 Microsoft Teams 09:00-12:30			
Final Meeting Notes			
Present	**Initials**	**Title**	**Organisation**
Lalita Banerjee (Chair)	**LBa**	Consultant Haematologist	MTW
Deborah Willcox	**DW**	Senior Haematology Research Nurse	MTW
Victoria Harris	**VH**	Clinical Trials Coordinator for Haematology and Lymphoma	MTW
Lorna Miller	**LMi**	Immunology Laboratory Manager	MTW
Simeon Blackbourn	**SB**	MDT Coordinator	MTW
Emma Richardson-Smith	**ERS**	Haemato-oncology CNS	MTW
Claire Herbert	**CH**	Haematology CNS	MTW
Carolyn Gupwell	**CG**	Haemato-oncology CNS	MTW
Hazel Spencer	**HSp**	MDT Coordinator	MTW
Tracy Symonds	**TS**	Haematology & Lymphoma Research Practitioner	MTW
Evangelia Dimitriadou	**ED**	Consultant Haematologist	MTW
Victoria Earl	**VE**	Clinical Trials Coordinator for Colorectal/Upper GI	MTW
Michelle Janney	**MJ**	Research Nurse	MTW
Charan Basra	**CB**	Macmillan Lead Haematology CNS	DVH
Leman Mutlu	**LMu**	Immunology Consultant	EKHUFT
Jayne Osborne	**JO**	Consultant Haematologist	EKHUFT
Lavinia Davey	**LD**	Senior Clinical Trials Coordinator	EKHUFT
Stephanie Goodchild	**SG**	Macmillan Lead CNS - Haemato-oncology and Lymphadenopathy	EKHUFT
Sree Munisamy	**SM**	Consultant Haematologist	EKHUFT
Claire Mallett	**CM**	Programme Lead – LWBC/PCS	KMCA
Ritchie Chalmers	**RC**	Medical Director	KMCA
Jonathan Bryant	**JB**	Primary Care Clinical Lead	KMCA
Annette Wiltshire	**AW**	Service Improvement Lead	KMCC/KMCA
Colin Chamberlain (Notes)	**CC**	Administration & Support Officer	KMCC
Karen Glass	**KG**	Administration & Support Officer	KMCC
Hayley Paddock	**HP**	E-Prescribing Pharmacist	KMCC
Michelle Archer	**MAr**	Pharmacy Technician	KMCC
Ella Guthrie	**EG**	Senior Policy and Public Affairs Officer	Leukaemia Care
Joy Ezekwesili	**JE**	Advanced Specialist Pharmacist	MFT
Gayzel Vallerjera	**GV**	Senior Clinical Research Practitioner	MFT
Handunneththi Mendis	**HM**	Consultant Haematologist	MFT
Apologies			
Heather Smith	**HSm**	CNS in Anticoagulant/Non-malignancy Haematology Nurse	DVH

Natalie Heeney	**NH**	Consultant Haematologist	DVH
Skye Yip	**SY**	Consultant Haematologist	DVH
Kevin Bonham	**KB**	NSS MDM Coordinator	DVH
Pippa Enticknap	**PE**	Senior Service Manager (CCHH Care Group)	EKHUFT
Francesca Farrer	**FF**	Haematology CNS	EKHUFT
Miguel Capomir	**MC**	Haemato-oncology Pharmacist	EKHUFT
Sarah Collins	**SC**	Operations Director – CCHH Care Group	EKHUFT
Pramila Krishnamurthy	**PK**	Consultant Haematologist	King's College Hospital
Tracey Ryan	**TR**	Macmillan User Involvement Manager	KMCA
Helen Downs	**HD**	Aria System Administrator	KMCC
Emma Bourke	**EB**	Macmillan Personalised Care and Support Facilitator	MFT
Sarah Arnott	**SA**	Consultant Haematologist	MFT
Musab Omer	**MO**	Consultant Haematologist	MFT
Maadh Aldouri	**MAl**	Consultant Haematologist	MFT
Denise Thompson	**DT**	Head of Clinical Effectiveness	MFT
Louise Black	**LBl**	Macmillan Lead Cancer Nurse	MFT
Clare Wykes	**CW**	Consultant Haematologist	MTW
Dhalvir Midda	**DM**	Lead Oncology and High Cost Drugs Pharmacist	MTW
Helen Graham	**HG**	Research Delivery Manager (Cancer)	NIHR

Item		**Discussion**	**Action**
1	**TSSG Meeting**	**<u>Apologies</u>** • The apologies are listed above. **<u>Introductions</u>** • LBa welcomed the members to the meeting and asked them to introduce themselves. **<u>Action log Review</u>** • The action log was reviewed, updated and will be circulated to the members along with the final minutes from today's meeting. **<u>Review previous minutes</u>** • The final minutes from the previous meeting were reviewed and agreed as a true and accurate record.	
2	**Introduce new Cancer Alliance Medical Director**	**<u>Update provided by Ritchie Chalmers</u>** • RC believes strong collaborative clinical leadership is imperative for driving the TSSGs forward and would like to make this forum the repository of expertise in the region. • RC highlighted the importance of identifying the specific problems KMCA have and identifying what she described as 'sticking points', areas requiring more input from specialties to expedite issues.	

	Cancer Alliance update	• RC stated there is an aim to develop a clinical strategy which dovetails with the ICB clinical strategy and KMCA (which will be hosted by NHS Kent & Medway ICB from December 2023) believe the TSSG is the most appropriate forum to drive this forward for the region. • RC emphasised the importance of reviewing available data in order to help inform the clinical strategy. She believes resource could be directed towards trying to improve the low myeloma survival rates in Kent & Medway. • RC is keen for the TSSGs to introduce lead roles such as a Lead Radiologist, Lead Pathologist and Lead CNS and she welcomes views from others regarding implementing these. • RC welcomes any feedback from colleagues regarding ideas for improvement. • RC believes KMCA are exemplary with regard to implementing the national cancer strategy. • RC and the wider KMCA team are keen to support MDMs, the standardisation of pathways and for mutual aid to be provided where possible. • RC introduced JB to the group as the Primary Care Clinical Lead for KMCA. JB is keen to improve the relationships/communication between primary and secondary care and is especially interested in working with GP colleagues to improve the quality of referrals (of which there is a great variation). • LMu stated there are national myeloma tools available to GPs and it is therefore important they are part of the clinical strategy so as to work towards addressing the high emergency presentation rates for myeloma patients across Kent & Medway. • JB referred to the EROS system, due to come online shortly, which aims to deploy a digital solution that will enhance and optimise referral processes and enable timely decision making, support, care, and access to treatment for patients throughout the healthcare system in Kent & Medway. It aims to ensure the right patients are seen in the most appropriate service with appropriate clinical workup and information. • **<u>Action</u>: RC stated it would be helpful for the Haematology TSSG to have sub-groups and suggested expressions of interest be sent out in order to see who would be happy to support them.** **<u>Cancer Alliance update</u>** • This item was not discussed.	**LBa/AW**
3	**HOG Rapid rate rituximab**	**<u>Update provided by Hayley Paddock & Michelle Archer</u>** • HP noted there is a disparity across the patch with regard to Rapid Rate Rituximab (RRR) utilisation, with EKHUFT being the outlier in terms of practice. SM stated EKHUFT will change their practice to bring it in to line with what the other Trusts are doing. • Midostaurin is now on Aria as a supportive care regimen. • MAr stated the new immunotherapy guidelines are now viewable on the KMCC website. • The next HOG meeting will be scheduled in the new year. A representative from each Trust will be required to ensure quoracy. • MAr will provide the group with a more comprehensive HOG update for circulation to the group along with the final minutes from today's meeting.	

	BiTE	**BiTE** • It was noted that SY and Jin Lindsay are leading on the development of BiTE treatment protocol work locally. • LBa believes it would be helpful to collect data on this and for it to be presented at a future meeting when there is robust data for presentation. LMu highlighted the need to be mindful that a long-term complication associated with the treatment is immunodeficiency. • LMu stated an immunodeficiency clinic in East Kent will be developed to provide patients with immunoglobulin. Steer from the NHS Kent & Medway ICB will be needed with regard to considerations such as the setting up of referral pathways.	
4	**Performance**	**Performance Questions** • Kent & Medway currently sit tenth nationally with regard to FDS performance. • Kent & Medway currently have the second best 62d performance nationally. • Kent & Medway currently have the ninth fewest number of USC backlogs nationally. **DVH – presentation provided by Michelle McCann** • Please refer to the performance slide pack for an overview of the Trust's data. **EKHUFT – presentation provided by Stephanie Goodchild** • Please refer to the performance slide pack for an overview of the Trust's data. **MFT – presentation provided by Handunneththi Mendis** • Please refer to the performance slide pack for an overview of the Trust's data. **MTW – presentation provided by Simeon Blackbourn** • Please refer to the performance slide pack for an overview of the Trust's data.	
5	**Leukaemia Care**	**Presentation provided by Ella Guthrie** • Leukaemia Care is the UK's leading leukaemia-specific charity and support people with leukaemia, MDS or an MPN. • EG's presentation provided the group with an overview of: - The signs and symptoms of leukaemia as per NICE NG12 guidance. - The research work Leukaemia Care has carried out to scope the impact of leukaemia on patients. Their research last year focussed on barriers in access to blood testing and they found: only one-third of patients reported they got a blood test straight away after seeing a GP about their symptoms; 23.5% of acute leukaemia patients stated it took three to four months after first presenting to the GP with leukaemia symptoms to get a blood test; and their GP advisors informed them that the system and capacity pressures they face stop them from conducting full blood counts every time they see a patient with the symptoms in the NG12 guidelines. • With regard to policy recommendations, Leukaemia Care believe:	

		- All stakeholders should promote training available for GPs and HCPs about diagnosis of leukaemia and encourage uptake. - There should be creation of improved decision support tools based on inputting the symptoms experienced by the patient (including non-specific leukaemia symptoms). - Local and national NHS bodies need to work together to ensure GPs and HCPs have better access to advice and guidance from haematology and access to education around interpreting full blood counts. - There should be improved access to blood tests for those experiencing symptoms of leukaemia through government investment in diagnostic capacity and workforce. - Pharmacists should also receive training on signs and symptoms and be able to refer patients for an urgent GP appointment. • Earlier this year Leukaemia Care relaunched their #WatchWaitWorry campaign, based on the challenges they hear from CLL patients regarding their experience of Watch and Wait. Their survey research found: - 41% are left without a full understanding of the reasons behind Watch and Wait after diagnosis. - One-third did not receive any written information on Watch and Wait despite wanting it. - Almost nine in ten patients on Watch and Wait stated they would have liked to have had support after diagnosis. Unfortunately, 60% of these patients were not offered any additional support from their hospital. - A quarter of Watch and Wait patients felt their GP was not given enough information about their condition and half of patients stated the GP could have done more or was of no help. • EG highlighted the importance of: - Improving timely signposting to resources to help patients better understand their diagnosis and Watch and Wait. - Improving doctor-patient communication to ensure patients are better informed and feel more involved in their care. - The NHS developing best practice guidance for healthcare professionals, on how to support clinical needs and aid patients to navigate the challenges involved with Watch and Wait. - Ensuring patients on active monitoring are adequately accounted for in Government and NHS planning. - Implementing a target for all CLL patients to have access to a named key-worker, normally a CNS – this target has now been set, as was announced in the new workforce plan in England this year. • EG encouraged clinical staff to: share the scale of the problem with colleagues; think about what they can collectively do differently at the point of diagnosis e.g. review the resources/support in place for patients; work with Leukaemia Care to address the wider changes needed to cancer care; and challenge the traditional view of cancer. • Services/resources available from Leukaemia Care include emotional support; practical and financial support; and patient information booklets. • EG is happy to share the links to Leukaemia Care data reports if anyone would like to see these.	
6	**Clinical Pathways**	**<u>dwMRI vs PET scanning SOP</u>** • dwMRI provision is in place at DVH but is not at MTW. • SM believes dwMRI should not be considered a priority treatment modality.	

		<u>Stanmore Pathway</u> • **<u>Action</u>: Meeting with Stanmore colleagues to be arranged in order for Kent & Medway colleagues to articulate their concerns with the pathway which needs to be more robust. All interested parties are encouraged to attend.** **<u>Myeloma POC for sign off</u>** • **<u>Action</u>: LBa asked AW to arrange a Microsoft Teams meeting with the appropriate representatives from each Trust to finalise this document within two weeks.** **<u>Leukaemia POC draft document</u>** • **<u>Action</u>: SM suggested the Pan-London guidance be utilised for the updating of this document. AW/LBa to discuss this further with JO.** **<u>Joint Haematology and Palliative Care Clinic – presentation provided by Jayne Osborne</u>** • JO stated the following was considered when deciding to establish the joint haematology and palliative care clinic: - There is a need to provide a holistic approach which is key to providing excellent care. - There is an increasing number of older patients with complex needs. - The increasing success of treatment resulting in multiple lines of treatment. - More patients are living with an incurable disease. - Historically, palliative care input has taken place late in the patient pathway. • With regard to the structure of the clinic: - It takes place monthly at William Harvey Hospital. - A one hour appointment is in place for patients (of which there are three per clinic). - The clinic team comprises of JO and Michelle Bevans. - The clinic is designed to be a one-off face-to-face appointment with telephone follow-up. - Patients will be contacted prior to the appointment by Michelle Bevans in order to explain the role of the clinic. - Prior to the appointment, patients will be sent an information leaflet and a QoL questionnaire. • In terms of referral criteria, the clinic is for patients with bone marrow failure syndromes (MDS/AML/MPN/AA) who are expected to be within the last year of life. Patients can be receiving palliative chemotherapy. • The aim of the clinic is to improve palliation of patients in a timely fashion, discuss disease progression and death, discuss when to stop treatment and to discuss/complete TEPs and DNAR. • With regard to the assessment of the clinic: - Validated QoL assessments will be given at various time points to both patients and relatives. - Patients and relatives are provided with feedback questionnaires. - If patients are happy the team will contact their relatives after the patient's death in order to gain feedback. - The impact of patient deaths will be audited in due course. • In relation to clinic outcomes:	**LBa/AW** **AW** **AW/LBa**

		- TEPs and DNARs can be completed as can referrals to the palliative care team and other services (such as for counselling). - GPs can be contacted to request a supply of anticipatory medications. - Michelle Bevans follows up with patients via telephone clinics. • The service, which has received very positive feedback, has reviewed 17 patients since September 2022 with TEPS and DNARs completed. • There are plans to expand the service to other sites within the Trust, hold some clinics in the hospice and provide blood transfusions to MDS patients in the hospice setting. • JO believes patients tend to have a better quality of life/live longer if referred in sooner rather than later to palliative care.	
7	**Research update**	**DVH** • REMoDL-A is open to recruitment. **EKHUFT** • LD's presentation provided the group with an overview of: - The current portfolio commercial myeloma trials including EXCALIBER-RRMM, MAGNETISMM-5 and MajesTEC-7. - The current portfolio of academic myeloma studies including RADAR: Myeloma XV, COSMOS and FITNESs: Myeloma XIV. - The current portfolio of lymphoma studies including REMoDL-A, PETReA, RAINBOW and Foundation UK. SKYGLO is a commercial trial coming in November 2023. - Current myeloid studies including REPAIR-MDS. • In terms of overall recruitment activity for 2023 Q1 and Q2, 15 patients have been recruited in to portfolio studies (three of which are commercial trial patients). • Challenges to recruitment and activity have been impacted by: - The Research Nurse complement being down. - The global hold on recruitment in to the MajesTEC-7 study since last year due to safety concerns. It was recently re-opened to recruitment. - The planned interruption to recruitment into EXCALIBER upon completion of Part 1 of the study to identify the optimal dose for IBERDOMIDE. Part 2 is due to reopen in November 2023. - The decommissioning and installation of the PET scanner at William Harvey Hospital. - The merger of the East Kent Oncology Research team with Haemato-oncology in March 2023 and the impacts this has had.	

		MFT • CADENCE Registry is currently open. • RAINBOW will be opening soon. **MTW** • In terms of commercial studies, ECHELON-3 and IMpactMF is currently open to recruitment. • With regard to non-commercial studies, MYELOMA XIV, RADAR and REMoDL-A are open to recruitment. • Expression of Interest studies include Abbvie ELECTRIC. • Site selected studies include AbbVIe, M20-638 and PETReA. • LD stated that on the first Thursday of each month a research session for all cancer types is delivered by Helen Graham and Rebecca Herbertson from NIHR.	
8	**CNS Update**	**DVH** • The team have three CNS' in place and one CSW. • Treatment summaries have commenced for CLL patients. • A Physician Associate will be starting in November 2023. Specialist Registrars are also now in place for the service. • 800 chemotherapy patients were seen in 2022, an increase from the previous year. • The team believe they need to recruit an additional CNS due to workload demands. **EKHUFT** • DVH, EKHUFT and MTW CNS teams met on 04.10.2023 and the meeting was supported by GSK. The MTW team were unable to attend the meeting due to workload pressures. • The teams are collectively looking at treatment summaries as part of the recovery package piece and what education sessions they would like to have. • The group plan to meet every six months. The last time they had met was in 2019. **MFT** • The nursing team comprises of four CNS' (3.0 WTE). • There are two Band 4 CSWs in place for the service. • KMCA have provided funding for a Lymphadenopathy CNS who the team hope to have in post within the next two months. • The team plan on moving from one nurse-led clinic per week to two due to demand on the service. • There are currently 45 patients on the CLL pathway. • There is a CNS in place who is taking on bone marrow cases.	

		MTW • The team comprises of five part-time CNS' (3.7 WTE). • A CSW is in place for the service. • An FDS CNS will be starting with the team this month. • Transplant clinics are in place. • Due to challenges no HNAs, audits or study days have been completed.	
9	**Clinical Audit updates**	• No clinical audits were provided.	
10	**AOB**	• It appears not everyone who attended today's meeting signed the registration form and therefore the attendance list on page 1 of the minutes may not be exhaustive. If you attended the meeting but your name is not listed above, please email c.chamberlain3@nhs.net who will include you. **Patient Partners Engagement** • Tumour Site Specific Groups should ideally have two patient partners per group. • Patient Partners are experts by experience and are an invaluable part of cancer improvement and service design. • TR (User Involvement Manager – KMCA) would like the help of the group in finding Patient Partners as they see and know their patients, and if the time is right for them to support. • TR's ask is for staff to ask their patients if they would be interested in this opportunity and if they would mind her contacting them. If so, TR asks for their details to be sent to her so she can contact them. Her email address is tracey.ryan1@nhs.net. **Serum Free Light Chains – presentation provided by Leman Mutlu** • LMu provided the group with an overview of the guidelines on the diagnosis, investigation and initial treatment of myeloma. Her slides particularly focussed on: - Diagnostic criteria for myeloma, smouldering myeloma and non-IgM MGUS. - The initial investigations for patients with suspected and confirmed myeloma particularly in relation to screening tests, tests to establish diagnosis and tests to eliminate tumour burden and prognosis. - SLiM-CRAB criteria. - Prognostic factors for diagnosed myeloma. • With regard to recommendations: - Renal biopsy should be considered if SFLC <500 mg/l and myeloma is being considered as the cause of renal impairment. - Skeletal survey should not be used to assess bone disease in myeloma – PET-CT/MRI. - Urine albumin:creatinine ratio along with troponin and NT-proBNP can be a useful screening tool for detecting amyloid.	

		• Treatment options include: - Proteosome inhibitors – bortezomib, carfilzomib, ixazomib. - Cyclophos / steroids / vincristine / melphalan. - Autologous bone marrow transplant. - Thalidomide / lenalidomide. - Daratumumab. - Potentially CAR-T. • **<u>Action</u>: RC highlighted the need to have data in order to support a business case for bringing serum free light chain data testing/reporting in to Kent & Medway as part of a myeloma screening service plan. LMu to discuss this further with RC outside of this meeting, including the funding element for such a plan.** **<u>QuestPrehab</u>** • Following a presentation by Tara Rampal from the QuestPrehab service (formerly called Kent & Medway Prehab) at the last meeting, LBa stated the service they provide is highly valued. • It was noted that the Prehab form, which is embedded within InfoFlex, can also be added to the Sunrise system. • LBa stated it would be helpful to audit Prehab data sourced from InfoFlex in order to articulate the impact it has had on patients across Kent & Medway. • The Prehab presentation which was provided at the recent Colorectal and Urology TSSG meetings will be shared with this group.	**LMu/RC**
	Next Meeting	• Monday 15th April 2024 (09:00-12:30) – Orida Hotel, Bearsted Road, Maidstone, ME14 5AA	