

Haematology Tumour Site Specific Group meeting Monday 15th April 2024 Mercure Great Danes Hotel - Maidstone 09:00-12:30

Final Meeting Notes

Present	Initials	Title	Organisation
Lolly Banerjee (Chair)	LB	Consultant Haematologist	MTW
Emma Richardson-Smith	ERS	Haematology CNS	MTW
Sharon Plumridge	SPI	Haematology Clinical Support	MTW
Tracy Symonds	TS	Research Practitioner	MTW
Michelle Janney	MJ	Research Nurse	MTW
Deborah Willcox	DW	Senior Research Nurse	MTW
Sylvia Amofa-Kra	SAK	Assistant General Manager – Cancer Performance	MTW
Claire Herbert	CH	Haematology CNS	MTW
Jamie Carter	JC	Deputy General Manager – Haematology	MTW
Evangelia Dimitriadou	ED	Consultant Haematologist	MTW
Simeon Blackbourn	SBI	Haematology MDM Coordinator	MTW
Sarah Updyke	SU	Fast Track Haematology Diagnostics CNS	MTW
Arunodaya Mohan	AM	Consultant Haematologist	MTW
Alexis Corrigan	AC	Consultant Radiologist	MTW
Michelle McCann	MM	Operational Manager for Cancer & Haematology	DVH
Charan Basra	СВ	Macmillan Lead Haematology CNS	DVH
Charmaine Walker	CW	Cancer Performance Manager	DVH
Adeyinka Pratt A		MDM Streamlining Project Manager	DVH
Skye Yip		Consultant Haematologist	DVH
Stephanie Goodchild	SGo	Lead Haematology CNS	EKHUFT
Melene Locke	ML	Senior Research Nurse	EKHUFT
Jayne Osborne	JO	Consultant Haematologist	EKHUFT
Denise DeLord	DDL	Consultant Rheumatologist	EKHUFT
Moya Young	MY	Consultant Haematologist	EKHUFT
Jin Lindsay	JL	Consultant Haematologist	EKHUFT
Leman Mutlu	LM	Consultant Immunologist and Allergist	EKHUFT
Tracey Ryan	TR	Macmillan User Involvement Manager	KMCA
Jonathan Bryant	JB	Primary Care Cancer Clinical Lead	KMCA
Colin Chamberlain (Notes)	CC	Administration & Support Officer	KMCC
Annette Wiltshire	AW	Service Improvement Lead	KMCC
Hayley Paddock	HP	Chemotherapy e-Prescribing Pharmacist	KMCC



Michelle Archer	MAr	Senior Pharmacy Technician	KMCC		
Karen Glass	KG	Business Support Manager	KMCC/KMCA		
Joy Ezekwesili	JE	Cancer Pharmacist	MFT		
Tolga Senel	TS	Business Development Officer	Macmillan		
Kerry Michelsen	KM	Lead Haematology CNS	MFT		
Stacey Sanders	SS	Haematology CNS	MFT		
Sabita Pokharel	SPo	Research Nurse	MFT		
Gayzel Vallejera	GV	Research Nurse	MFT		
Suzanne Bodkin	SBo	Cancer Service Manager	MFT		
Sudarshan Gurung	SGu	Consultant Haematologist	MFT		
Odelia Eke	OE	NHSE Pharmacy Manager – Kent & Medway	NHSE		
Amanda Harris	AH	Patient Partner			
Apologies					
Maadh Aldouri	MAI	Consultant Haematologist	DVH		
Natalie Heeney	NH	Consultant Haematologist	DVH		
Marie Payne	MP	Macmillan Lead Cancer Nurse	DVH		
Sree Munisamy	SM	Consultant Haematologist	EKHUFT		
Sarah Howland	SH	General Manager	EKHUFT		
Pramila Krishnamurth	y PK	Consultant Haematologist	King's College Hospital		
Tina George	TG	Early Diagnosis Clinical Lead	KMCA		
Ritchie Chalmers RC		Medical Director	KMCA		
Claire Mallett	CM	Programme Lead – Living With and Beyond Cancer	KMCA		
Sarah Arnott	SA	Consultant Haematologist	MFT		
Victoria Harris	VH	Clinical Trials Coordinator for Haematology and Lymphoma	MTW		
Maria Blanco-Criado	МВС	Deputy Chief Pharmacist - Cancer & Technical Services	MTW		
Alison Watkins	AWa	Faster Diagnosis Team Leader	MTW		
Dhalvir Midda	DM	Lead Oncology and High Cost Drugs Pharmacist	MTW		
Fathi Al-Jehani	FAJ	Consultant Haematologist	MTW		
Joanna Simpson	JSi	Haemato-oncology CNS	MTW		
John Schofield	JSc	Consultant Pathologist	MTW		
Item	Discussion		Action		
1 TSSG Meeting	Introductions	es are listed above. In the members to the meeting and asked them to introduce themselves.			
	Action log Review				



		The action log was reviewed, updated and will be circulated to the members along with the final minutes from today's meeting. Add Company Compan	
		 LB and AW will contact action owners on a monthly basis to request updates on how they are progressing with the actions they are responsible for. 	
		 Review previous minutes The final minutes from the previous meeting were not reviewed but had been previously agreed as a true and accurate record. 	
	HOG	Update provided by Hayley Paddock and Michelle Archer	
		A summary of the HOG discussions will be shared once it has been completed by HP/MAr.	
	Update on	With regard to the BiTE pathway, this is an ongoing action and there is a protocol safe to use.	
	BITE antibody &	 MTW have it built on ARIA and EKHUFT have protocols for this and an A&E protocol in place. DVH have an 	
	CRS protocol	updated SOP for the unwell patient pathway which is being drafted, however the BiTE pathway is shared with King's	
	Onto protocor	College Hospital and is not done locally. MFT have also drafted a SOP and training is ongoing.	
}	MDT	Presentation provided by Skye Yip	
	Streamlining /	MDT working is considered the gold standard for cancer patient management.	
	MDT Reform	The number of patients to be discussed in MDT meetings has grown significantly, as has the complexity of patients.	
		MDT meetings are often lasting for several hours, with only a few minutes available to discuss each patient.	
		With regard to recommendations from CRUK:	
		- The UK's health services should work to identify where a protocolised treatment pathway could be applied. Every Cancer Alliance or devolved cancer network should develop their own approach.	
		Cancer Alliance or devolved cancer network should develop their own approach. - MDTs for tumour types for which a protocolised approach has been developed should agree and document their	
		 Cancer Alliance or devolved cancer network should develop their own approach. MDTs for tumour types for which a protocolised approach has been developed should agree and document their approach to administering protocols. This could include a 'pre-MDT triage meeting'. National requirements for individual minimum attendance should be reviewed and amended where necessary, with 	
		 Cancer Alliance or devolved cancer network should develop their own approach. MDTs for tumour types for which a protocolised approach has been developed should agree and document their approach to administering protocols. This could include a 'pre-MDT triage meeting'. National requirements for individual minimum attendance should be reviewed and amended where necessary, with an emphasis on ensuring all required specialties are present at a meeting. 	
		 Cancer Alliance or devolved cancer network should develop their own approach. MDTs for tumour types for which a protocolised approach has been developed should agree and document their approach to administering protocols. This could include a 'pre-MDT triage meeting'. National requirements for individual minimum attendance should be reviewed and amended where necessary, with an emphasis on ensuring all required specialties are present at a meeting. The UK's health services should lead the development of national proforma templates, to be refined by MDTs. MDTs should require incoming cases and referrals to have a completed proforma with all information ready before 	
		 Cancer Alliance or devolved cancer network should develop their own approach. MDTs for tumour types for which a protocolised approach has been developed should agree and document their approach to administering protocols. This could include a 'pre-MDT triage meeting'. National requirements for individual minimum attendance should be reviewed and amended where necessary, with an emphasis on ensuring all required specialties are present at a meeting. The UK's health services should lead the development of national proforma templates, to be refined by MDTs. MDTs should require incoming cases and referrals to have a completed proforma with all information ready before discussion at a meeting. 	
		 Cancer Alliance or devolved cancer network should develop their own approach. MDTs for tumour types for which a protocolised approach has been developed should agree and document their approach to administering protocols. This could include a 'pre-MDT triage meeting'. National requirements for individual minimum attendance should be reviewed and amended where necessary, with an emphasis on ensuring all required specialties are present at a meeting. The UK's health services should lead the development of national proforma templates, to be refined by MDTs. MDTs should require incoming cases and referrals to have a completed proforma with all information ready before discussion at a meeting. MDTs should use a database or proforma to enable documentation of recommendations in real time. 	
		 Cancer Alliance or devolved cancer network should develop their own approach. MDTs for tumour types for which a protocolised approach has been developed should agree and document their approach to administering protocols. This could include a 'pre-MDT triage meeting'. National requirements for individual minimum attendance should be reviewed and amended where necessary, with an emphasis on ensuring all required specialties are present at a meeting. The UK's health services should lead the development of national proforma templates, to be refined by MDTs. MDTs should require incoming cases and referrals to have a completed proforma with all information ready before discussion at a meeting. 	



		 The mean length of the 624 patient discussions observed in this study was 3.2 minutes. The mean number of people contributing to each discussion was only three. In 7% of discussions observed, decisions were deferred due to missing information. In over 75% of meetings there was no verbal contribution from nurses at all. Only eight of the 624 MDT discussions observed mentioned clinical trials at all. 48% of MDT (less than half) members felt their MDT has a process in place which is sufficient for improving their effectiveness. 	
		 Audit of recent MDT's (January–February 2024) Average number of patients listed (48/50/68/67): 58.25 patients per list. Length of MDT: 2 to 2.5 hours. Noting cases (at time of list sending out) (1/5/4/6): 4 patients per list, actual number much higher. Average deferred cases: 17 patients. Inappropriate cases: private patients, review of imaging only and non-haematology cases. MDT cut-off times to add to list: Maidstone - Thursday 10:00. Medway - Wednesday 15:00. Darent Valley - Wednesday 15:00. EKHUFT do not currently have a dedicated MDM Coordinator. MDM Coordinators from other tumour sites are providing support on an ad-hoc basis. EKHUFT are experiencing issues with radiology reporting. MY stated that pre-MDM meetings are helpful and triage is very important. DVH undertake a pre-triage of cases before the MDM takes place. MFT have introduced a pre-MDM radiology meeting where scans are reviewed prior to the main meeting. Action: Microsoft Teams meeting to be arranged for West Kent colleagues (but MY from EKHUFT is welcome to join) in order to articulate their concerns around MDMs and to discuss what can potentially be 	LB/AW
	Histopatholo gy discussions	 done to streamline the meetings. Update provided by Lolly Banerjee There are currently no permanent Histopathologists for West Kent. JSc (Consultant Pathologist – MTW) is currently supporting the service two days a week until the newly appointed Histopathologist starts in May or June 2024. Nipin Bagla is the Histopathologist for EKHUFT. 	
4	Performance	Kent & Medway sit 9 th out of 21 Cancer Alliances for FDS performance.	



	data discussions	 With regard to 62d performance, Kent & Medway are third in the country for this metric. Kent & Medway have the fourth fewest number of USC backlogs in the country. MTW are currently experiencing issues in terms of getting dates for PET scans and reporting is also a problem. Biopsy slots at EKHUFT are currently at two to three weeks and there is a lack of Interventional Radiologists. Action: The number of Consultant Haematologists at MTW (9 or 10) is not sufficient to meet the workload. In view of this, LM believes this is a health inequality and should be raised with the NHS Kent & Medway ICB as such. 	LB
5	Clinical Pathways	 dwMRI vs PET scanning SOP LB asked EKHUFT, DVH and MFT colleagues to advise on whether they utilise dwMRI or PET. In response to this: EKHUFT confirmed they use PET. DVH confirmed they use both PET and dwMRI. MFT confirmed they use PET or loaded CT. In view of the above responses, LB concluded that there is no consensus as to what the superior option is for scanning. 	
		 Stanmore Pathway Action: Representatives from each Trust required to meet regarding discussion around myeloma spines and what should be done for local patients instead of sending them on to the Stanmore pathway which is currently overloaded. CC to facilitate this meeting by sending out a poll. JL to represent EKHUFT; LB, Elvis Aduwa and FAJ to represent MTW; SA to represent MFT; and TBC to represent DVH at this meeting. 	сс
		Myeloma POC for sign off – presentation provided by Leman Mutlu LM highlighted that: Emergency presentations for myeloma are higher in Kent & Medway than England and have increased since the pandemic.	
		 Survival for myeloma in Kent & Medway is significantly lower than England and although survival from myeloma is increasing nationally, the gap for Kent & Medway is consistent over time. Kent & Medway has lower incidence and higher mortality for myeloma compared with England. 	
		 The Kent & Medway Myeloma Working Group have now met twice since its formation. The next meeting will be in June 2024 (date TBC). MGUS follow-up has yet to be decided upon. GPs are currently unable to request SFLC. LM highlighted that there is a consensus that integrative reporting for paraproteins across Kent & Medway is the 	
		 EM rightighted that there is a consensus that integrative reporting for paraproteins across Kent & Medway is the aim. SFLC testing is essential and is to be introduced but needs to be done on a step-by-step basis with a business case supporting this. This may not come in to fruition for 12 months. The intention is for laboratories to reflex request SFLC testing to an external laboratory. 	



	With regard to the pathway, LM welcomes any feedback on what could be incorporated/changed.	
	 Action: LM to provide an update at the next meeting on how the pathway has progressed. 	LM
	Leukaemia POC draft document	JO
	 Action: JO stated she had completed this document and sent it to LB/AW. JO to resend. 	30
Research update	Recruiting Portfolio – All Trusts	
	<u>DVH</u>	
Recruiting	DVH have:	
Portfolio	- Recruited to STATIC.	
	- Completed the UK EPIC trial.	
	- Failed to recruit to the REMoDL-A trial.	
	- Had a site visit from the MAHOGANY trial team.	
	EKHUFT – presentation provided by Melene Locke	
	The current portfolio of commercial myeloma trials includes EXCALIBER-RRMM and MajesTEC-7.	
	 The current portfolio of recruiting academic myeloma studies includes RADAR: Myeloma XV and COSMOS. 	
	 The current portfolio of lymphoma studies includes REMoDL-A, PETReA and RAINBOW. 	
	 The current portfolio of lymphoma studies includes SKYGLO (commercial), Beigene - BGB-3111-LTE1 	
	(commercial), Foundation UK and STATIC.	
	Current myeloid studies include REPAIR-MDS.	
	 Commercial studies coming soon include Magnetismm-32 I study, SPARK and BEIGENE BGB-11417-301. 	
	 In terms of overall recruitment activity for 2023/24: 	
	- Patients recruited into portfolio studies - 28.	
	9 commercial trial patients.	
	19 academic study patients.	
	Challenges to recruitment and activity:	
	- Inexperienced new starters within the research nursing team, although this is an improving situation.	
	- The global hold on recruitment in to the MajesTEC-7 study since 2022 due to safety concerns (reopened to	
	recruitment October 2023 but recruitment stopped again Q1 2024 due to USM).	
	- The de-commissioning and installation of the PET scanner at William Harvey Hospital which has now been delayed.	
	This has impacted on recruitment in to the PETReA trial reducing EKHUFT's annual recruitment by approximately eight patients.	
	 EKHUFT are open to cross-site referrals. Please contact the PIs or ML for further information about any of their 	
	studies.	EKHUF1
	 Action: EKHUFT research team to share a quarterly trials newsletter with MTW colleagues. 	Researc
	Action. Little i research team to share a quarterly thats newsietter with wir w coneagues.	team



MFT MFT have: Recruited one patient to the RAINBOW trial. Recruited four patients to the CADENCE Registry. Recruited 14 patients to the UK Adult ITP Registry. MTW Commercial studies open for recruitment include IMpactMF. Non-commercial studies open for recruitment include RADAR and REMoDL-A. Expression of Interest studies include XPORT, MODIFY, Glora, IDH1 mutated MDS study and PASS. Site selected studies include PETReA, PROPEL and Repair MDS. In terms of updates from the trials team, the aseptic unit based at the Tunbridge Wells Hospital site is extremely short of staff due to circumstances beyond their control. Measures are being put in place to maintain a service, however, any new clinical trial which involves the aseptic preparation of a product will have to be put on hold for the time being. Updates will be provided regularly regarding whether their capacity to take on these types of trials changes. Please do not hesitate to contact the research team with any queries or if you wish to discuss a particular trial. FITNESS closed on 04.02.2024 and the total recruitment for this was 19 patients. The ELECTRIC observational CLL study closed on 31.03.2024. MTW over-recruited to this trial with a total of three patients, after greenlight was given on 27.02.2024. Management Presentation provided by Denise DeLord of HLH The presentation provided the group with an overview of: What HLH is. HLH presents to multiple medical specialties and unless diagnosed and treated early it can make patients progressively and critically unwell. If left untreated all cases of HLH are fatal. Anakinra which is a medicine that works by blocking the main driver of the hyperinflammation, interleukin1 (IL1). Anakinra in HLH is usually only needed for a short period of 3-14 days on average. The incidence of HLH between 2003 and 2018. The dueling clinical criteria for HLH (traditional 2004 criteria v modified 2009 criteria). The MDcalc H score. The types and triggers of HLH. The treatment of pHLH and sHLH. The 2022 Kent & Medway HLH MDT set-up. The February 2023 Regional Kent & Medway HLH MDT set-up. Lack of resource for this has been challenging. 21 cases have been referred since February 2023 and 12 patients (out of a population of 1.46 million) were diagnosed with HLH. The SECARD referral form.





			I
		 EKHUFT An advertisement for a new CNS post closed yesterday and it is envisaged that the successful applicant will mainly treat myeloid patients. The Haematology CNS group are trying to meet bi-annually. SGo has been leading on the Treatment Summaries work and this has been reviewed by TR from a patient perspective. 	
		 MFT The team comprises of 4.2 WTE CNS' (one of which is an Alliance-funded post until December 2024). They also have a Band 7 nurse post to appoint to. The service has two Band 4 CSWs. 	
		 MTW There are 5 CNS' in place for the service (although one full-time CNS is currently on sick leave). The team also has one Band 4 CSW and are appointing another one. The CNS team have been unable to attend the last two network CNS meetings predominantly due to capacity issues. LB believes this should be raised with Tracey Spencer-Brown (Lead CNS – MTW) for resolution. 	
	Patients Partners Engagement	 Patients Partners Engagement TR highlighted the importance of ensuring information relayed to patients is comprehensible. Following on from this, she informed the group there is an Alliance Patient Group who are involved in the review of patient documentation. TR introduced Amanda Harris to the group. Amanda was previously diagnosed with leukaemia and supports the Alliance from a Patient Partner perspective. 	
		 Action: LB to find out if the Trusts have a dedicated policy for letter writing regarding patient outcomes. TR to be informed of any updates. TR asked the members to contact her if they have any patients who may be interested in joining the Patient Group. TR's email address is tracey.ryan1@nhs.net. 	LB
	East Kent treatment summaries	 East Kent treatment summaries Action: SGo asked the members to review the four treatment summaries which were circulated to the group after the meeting and to feed back any comments by close of play on 29.04.2024, at which point they will be formally signed off. 	All
)	Crossroads Care Kent/Macmill an	Presentation provided by Tolga Senel Crossroads Care Kent help unpaid carers to make a life of their own outside caring by providing quality care services offering peace of mind while they enjoy some time to themselves. Their mission is to keep loved ones and	



- the caring unit together. An unpaid carer is a person of any age who provides unpaid help and support to a loved one, friend or neighbour, who cannot manage without the support of a carer.
- More than a third of carers asked by Carers UK (2019a) had experienced a change in the amount of services they received in the previous year because:
- Care or support arranged by social services was reduced, or closed with no replacement.
- The cost increased.
- Their personal budget no longer covers it.
- It is crucial to a system reliant on informal carers that both practical and financial support are available.
- Unpaid carers provide care valued at £162 billion annually, exceeding the entire NHS health service spending in England for the 2020/21 fiscal year.
- In 2021, the number of unpaid carers delivering 19 or fewer hours decreased compared to 2011. This decrease is attributed to higher rates of fatality during the Covid-19 pandemic. On the other hand, the number of carers providing 20-49 hours and 50+ hours per week increased. This imposes an additional burden on carers who require support.
- The majority of recipients of unpaid care are older parents or spouses/partners and changes in the make-up of the population indicate that the number of dependent older people in the UK will increase by 113% by 2051.

What's on offer for clients from Crossroads Care Kent?

- Regular short breaks for unpaid carers (any condition) via a Carer Support Worker Replacement Care.
- Health appointment replacement care carers use this time to attend medical appointments and treatment such as screening, tests and diagnostics.
- Crisis response can be overnight, as a result of an emergency hospital admission or end of life support for a lone Carer professional referral.
- Dementia Outreach & Support.
- Young Carers Project.
- Carers Counselling up to 12 weeks free.

Macmillan Crossroads Partnership

- The partnership represents a longstanding collaboration in local service delivery for Kent & Medway between two
 esteemed organisations: Macmillan Cancer Support, the nation's leading cancer support charity, and Crossroads
 Care Kent, Kent's premier local carers support charity.
- This collaboration merges the specialised cancer expertise of Macmillan Cancer Support with the local care support
 proficiency of Crossroads Care Kent, resulting in a powerful alliance, ensuring comprehensive care and assistance.



		Macmillan Partnership – what's on offer?
		 Trained, DBS-checked volunteers offer practical assistance and companionship at home or transportation to health appointments.
		Their experts provide a wide range of useful information and guidance, available in Kent & Medway, for patients and carers.
		They offer free counselling with a counsellor in training, available for carers and supporters of a cancer patient.
		Crossroads have:
		Supported over 200 clients across Kent & Medway.
		270 active volunteers. 11
		 Helped 91 individuals get Macmillan grants (totaling £32,000) and 46 grants from other beneficiaries (totaling £18,000).
		Provided 3,685 volunteer hours in 2023.
		Carers Counselling Service
		 The Carers Counselling Service offers up to 12 weeks, free therapeutic counselling for unpaid carers and supporters of cancer patients. Sessions are one-to-one with a fully supported counsellor-in-training and the service
		is available at locations across Kent & Medway, with options also available for online or telephone sessions remotely. This opportunity provides carers the chance to explore their own thoughts and feelings whilst learning
		strategies to help support them in their caring role. • The counselling sessions are held in a safe, confidential environment.
		 Anyone can refer to the carers counselling service and this includes self-referrals. Contact can be made by
		telephone call (03450 956 701), email (macmillan@crossroadskent.org; referrals@crossroadskent.org;
		counselling@crossroadskent.org), or by filling in the online form.
		The Macmillan Volunteer Service is in place for Kent & Medway.
		Crossroads services are available for the Kent population only.
11	AOB	LB thanked SY, who is leaving DVH shortly, for supporting the Haematology TSSG over the last few years.
12	Next Meeting Date	Monday 18 th November 2024 (09:00-12:30) – venue TBC.