Kent & Medway Cancer Collaborative

Haematology Tumour Site Specific Group meeting
Wednesday 26th April 2023
Great Danes (Mercure) Hotel - Maidstone
09:00-12:30

Final Meeting Notes

Present	Initials	Title	Organisation
Lalita Banerjee (Chair)	**LBa**	Consultant Haematologist	MTW
Kavi Robinson	**KR**	Haemato-oncology CNS	MTW
Jo Simpson	**JSi**	Haemato-oncology CNS	MTW
Deborah Willcox	**DW**	Senior Haematology Research Nurse	MTW
Michelle Janney	**MJ**	Research Nurse	MTW
Angela Percival	**AP**	Oncology Clinical Trials Coordinator for Lung & Melanoma	MTW
Evangelia Dimitriadou	**ED**	Consultant Haematologist	MTW
Clare Wykes	**CW**	Consultant Haematologist	MTW
Fathi Al-Jehani	**FAJ**	Consultant Haematologist	MTW
Richard Gale	**RG**	Consultant Haematologist	MTW
Nicola Morris	**NM**	Macmillan Haematology CNS	DVH
Charan Basra	**CB**	Macmillan Lead Haematology CNS	DVH
Skye Yip	**SY**	Consultant Haematologist	DVH
Lian-Wea Chia	**LWC**	Consultant Haematologist	DVH
Stephanie Goodchild	**SGo**	Macmillan Lead CNS - Haemato-oncology and Lymphadenopathy	EKHUFT
Kerry Harrison	**KHa**	Patient Services Director	Heart of Kent Hospice
Tara Rampal	**TRa**	Consultant Anaesthetist	King's College Hospital
Reuben Benjamin	**RB**	Consultant Haematologist	King's College Hospital
Claire Mallett	**CMal**	Programme Lead – LWBC/PC&S	KMCA
Colin Chamberlain (Notes)	**CC**	Administration & Support Officer	KMCC
Annette Wiltshire	**AW**	Service Improvement Lead	KMCC
Karen Glass	**KG**	Administration & Support Officer	KMCC
Hayley Paddock	**HP**	E-Prescribing Pharmacist	KMCC
Michelle Archer	**MAr**	Pharmacy Technician	KMCC
Suzanne Bodkin	**SBo**	Cancer Service Manager	MFT
Kerry Michelsen	**KM**	Haemato-oncology CNS	MFT
Sarah Blizzard	**SBl**	Haematology CSW	MFT
Lauren Caston	**LC**	Haematology CSW	MFT
Clarissa Madla	**CMad**	Senior Clinical Research Practitioner	MFT
Gayzel Vallerjera	**GV**	Senior Clinical Research Practitioner	MFT
Maadh Aldouri	**MAl**	Consultant Haematologist	MFT

Louise Black	**LBl**	Macmillan Deputy Lead Cancer Nurse	MFT
Emma Bourke	**EB**	Macmillan Personalised Care & Support Facilitator	MFT
Sudarshan Gurung	**SGu**	Consultant Haematologist	MFT
Apologies			
Joy Galani	**JG**	Consultant Haematologist	DVH
Jayne-Marie Osborne	**JMO**	Consultant Haematologist	DVH
Joyce van den Camp	**JVDC**	Macmillan Haematology CNS	DVH
Miguel Capomir	**MC**	Haemato-oncology Pharmacist	EKHUFT
Nipin Bagla	**NB**	Consultant Pathologist	EKHUFT
Moya Young	**MY**	Consultant Haematologist	EKHUFT
Jindriska Lindsay	**JL**	Consultant Haematologist	EKHUFT
Sandra Holness	**SH**	Cancer Pathway Tracker Coordinator	EKHUFT
Sree Munisamy	**SM**	Consultant Haematologist	EKHUFT
Catherine Roughley	**CR**	Consultant Haematologist	EKHUFT
Pramila Krishnamurthy	**PK**	Consultant Haematologist	King's College Hospital
Cathy Finnis	**CF**	Programme Lead – Early Diagnosis	KMCA
Tracey Ryan	**TRy**	Macmillan User Involvement Manager	KMCA
Kirsty Hearn	**KHe**	Service Manager	MFT
Vicky Hinchcliffe	**VH**	Deputy General Manager - General Surgery	MTW
Elvis Aduwa	**EA**	Consultant Haematologist	MTW
John Schofield	**JSc**	Consultant Pathologist	MTW
Benjamin Willis	**BW**	Principal Pharmacist-Chemotherapy Electronic Prescribing	MTW
Carolyn Gupwell	**CG**	Haemato-oncology CNS	MTW
Joanne Patterson	**JP**	Lead Clinical Trials Pharmacist	MTW
Moosa Qureshi	**MQ**	Consultant Haematologist	MTW
Jeff Summers	**JSu**	Consultant Clinical Oncologist	MTW
Emma Richardson-Smith	**ERS**	Haemato-oncology CNS	MTW
Ann Courtness	**AC**	Macmillan Primary Care Nurse Facilitator	NHS Kent & Medway ICB
Holly Groombridge	**HG**	Cancer Commissioning Project Manager	NHS Kent & Medway ICB
Hamish Miller	**HM**	Consultant Haematologist	Royal Free London NHS Foundation Trust

Item		Discussion	Action
1	**TSSG Meeting**	**<u>Apologies</u>** • The apologies are listed above. **<u>Introductions</u>** • LBa welcomed the attendees 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. **Review previous minutes** • The final minutes from the previous meeting were reviewed and agreed as a true and accurate record. • LBa highlighted the need for the quality of GP referrals to improve. At the last meeting an educational session was proposed by AC which LBa believes is still required. • LBa feels it would be helpful for this proposed educational session (which could be recorded) to include items such as malignant and non-malignant topics, clotting and the quality of 2ww referrals as mentioned above. • SGo stated she would be happy to provide a presentation on lymphadenopathy at the proposed educational session. • If you are interested in attending this session once it has been organised, please email AW.	
2	**HOG** **BiTE** **Nordic protocol**	**Update provided by Hayley Paddock & Michelle Archer** • Please refer to the HOG summary document for an overview of the discussions. • The next HOG meeting is scheduled for 21.09.2023. • SY referred to the utilisation of BiTE (Bispecific T-cell Engager) antibodies for the management of complications. **Action: CW believes it would be useful to utilise another Trust's established BiTE pathway. LBa to arrange a meeting with Andrea Kuhnl (Consultant Haematologist – King's College Hospital) to discuss the BiTE protocol further.** • The Nordic protocol has been signed off with an agreement to use standard dose CHOP.	**LBa**
3	**Clinical Pathway Discussion**	**Leukaemia POC** • JMO is currently on maternity leave and has been unable to update the document. In view of this, LBa asked who would be prepared to update the document in her absence. CW stated she would be happy to do this along with MQ. **Myeloma POC** • **Action: The document will be circulated to the group with feedback/comments to be sent to JG by 05.05.2023.** • It was suggested that it would be worth asking JG to look at the St Luke's protocol which could potentially be included in the document.	**All**
4	**Performance**	**Performance Questions** • Data from multiple sources, both local and national published sources, show Kent & Medway has lower survival and a higher proportion of emergency presentations for myeloma compared to the England average. • Kent & Medway has the lowest 1-year survival rate from myeloma in England. • The differences in myeloma survival by Trust are not statistically significant. • The demographic characteristics of myeloma patients in Kent & Medway appears similar to England overall: - 58% were male and 42% female.	

		- Similar age distribution. - Similar deprivation distribution. • Queries were raised as to where the data pertaining to the melanoma performance was sourced from and who is responsible for uploading this information. • LBa stated she would be interested in knowing what constitutes an emergency presentation and what patients present with specifically. • CW questioned what the mortality rate was for those who presented to secondary care through the 2ww route. • SY and CB believe the 1-year survival from myeloma rates presented for DVH are comparable to those of the other Trusts and they therefore believe the data presented is incorrect. • There are ongoing issues regarding patients getting a GP appointment, with CNS' often having to email GPs on their behalf. • **<u>Action</u>: AW to link LBa in with David Osborne regarding answering the queries raised in relation to 1 year survival rates from myeloma.** **<u>Performance data</u>** **<u>DVH – presentation provided by Charan Basra</u>** • Please refer to the performance slide pack for an overview of the Trust's data. • There have been delays due to diagnostics and reporting. • DVH sometimes receive late referrals from other tumour sites which can result in breaches. **<u>EKHUFT - presentation provided by Stephanie Goodchild</u>** • Please refer to the performance slide pack for an overview of the Trust's data. • Breaches include: complex diagnostic pathways, patients being referred late from other tumour sites, diagnostic delays and patient choice (cancelling appointments). • Work is underway to support improvement. This includes working with the other tumour sites to encourage expediting investigations and referrals to haematology if they suspect it could be a haematological malignancy. Daily escalation calls to radiology to highlight patients which need to be booked are taking place. • Delays to vetting, booking and reporting diagnostics remains a significant risk but pathway mapping and changes are being investigated to agree sustainable solutions. • There are currently 6 week waits for an ultrasound-guided biopsy. • There are delays in radiotherapy slots at MTW. **<u>MFT - presentation provided by Suzanne Bodkin</u>** • Please refer to the performance slide pack for an overview of the Trust's data.	**AW / LB**

		• With regard to the FDS, small patient numbers can result in breaches. • In relation to the 62d standard, 1 patient was initially referred to head and neck, sent to haematology on day 40 and needed further investigations prior to a treatment. **MTW - presentation provided by Lalita Banerjee** • Please refer to the performance slide pack for an overview of the Trust's data. • Implementation of hot weeks has ensured MTW are seeing new patients quickly, often within 7 days of referral. • MTW's FDS target is challenging to achieve due to the turnaround times of bone marrow biopsies and complex histology which they send off to King's College Hospital. Turnaround times for PET scans also fluctuates, often exceeding 10 days. • Radiotherapy treatment capacity is challenging. • Complex diagnostic pathways have meant achievement of the 62d target is challenging. • Late referrals from other tumour groups have also resulted in breaches. • With regard to the 62d figures, LBa highlighted there is a significant amount of missing data which she believes requires further investigation. • There are issues with patients coming through to haematology from other specialties (such as ENT), the need for repeat biopsies and fitting patients into clinics. • **Action: All Trusts to send CW their serum free light chains data.**	**All Trusts**
5	**Heart of Kent Hospice**	**Services and referral pathway updates – update provided by Kerry Harrison** • The Heart of Kent Hospice is located at Preston Hall (Aylesford). • The Hospice has a 10 bed inpatient service. • 1973 patients were cared for last year. • 217 patients were interacted with in the care home setting. • 389 palliative care patients were looked after as were 319 dementia patients. • There is an outpatient space at the Hospice. • Living Well sessions have been provided. • KHa stated she had brought Hospice Hub leaflets to today's meeting and encouraged the members to take some with them before leaving. • Home visits cannot be offered to individuals out of Heart of Kent Hospice's catchment area. • A Hospice Hub drop-in is available on both Mondays and Thursdays between 10:00-13:00. • Welfare, social work, spiritual and financial support is in place for service users. • A Dementia care - Making Memories® programme takes place on Tuesdays between 09:30-15:00. No referral is needed for this. • A bereavement drop-in service is available on Wednesdays between 10:00-11:30. There is no government funding available for this and is only for those being cared for by the Hospice.	

		• A Motor Neurone Disease Group takes place on Fridays between 10:00-14:00. • On the first Saturday of each month, there is a Dementia café in place between 10:30-12:30. • Heart of Kent Hospice have links in with the Palliative Care MDT at MTW. • Referrals can be made to the Heart of Kent Hospice via their website, by telephone or by completing a printed copy of the referral form. • CMal mentioned there is a Supported Care MDT at DVH. • SY feels it would be useful to have a Kent & Medway Health and Wellbeing service for myeloma patients who have had transplants. • With regard to psychosocial support, CMal highlighted there are both counsellors and social workers in place across the patch. There are also health and wellbeing events at both MFT and DVH.	
6	**Clinical Audit**	• None of the Trusts provided an audit at today's meeting. In view of this, LBa requested they do so for the next meeting and let her and AW know what exactly it is they will be conducting an audit on.	
7	**Research update**	**DVH** • The team are working on database/data collection trials. **EKHUFT** • No update provided. **MFT** • The following trials are open: UK Adult ITP Registry, CHIP and CADENCE Registry. • The following trial is in set-up: RAINBOW. **MTW** • The following trials are open: REMoDL-A, IMpact-MF, Myeloma XIV, RADAR, MoMMent and ECHELON-3. • LWC asked if it would be possible for DVH to work with MTW who are doing well with regard to recruitment to haematology trials, which LBa agreed they could. **Action: Clinical Research Working Group to be set up for the Trusts to work together to support where required.** • MFT are experiencing some issues with regard to imaging/radiology which is impacting on their ability to proceed with the setting up of some trials.	
8	**CNS Updates**	**DVH - update provided by Charan Basra** • There are 3 full-time CNS' and a Chemotherapy Support Worker in place for the service. • 1 non-malignant CNS is in place for the service. • HNA clinics are in place and 74 haematology patient HNAs have been undertaken. • Telephone clinics take place on Tuesday mornings. • The team would like to recruit an additional CNS in order to support the service so will therefore work on completing a business case to this effect. • Oral clinics take place all day on Tuesdays as well as Thursday mornings.	

		• A business case has been completed for a sickle cell nurse role. • A full-time thrombosis nurse has been recruited. • 2 registrars are providing support to the bone marrow clinics which take place on Wednesdays, although it is felt by a number of colleagues that these clinics need to take place 3 days a week. • The CNS' support with ward rounds and in outpatient clinics. **EKHUFT - update provided by Steph Goodchild** • There are 4 full-time CNS' and 2 Cancer Support Workers in place for the service. • As of yesterday, there were 75 patients on the CLL stratified pathway. • The team are looking to recruit an additional CNS via KMCA funding. • Telephone clinics are in place. • SGo highlighted the need for there to be more joint working on the treatment summaries piece. **MFT - update provided by Kerry Michelsen** • 2 part-time CNS', 2 full-time CNS' and 2 Cancer Support Workers are in place for the service. One of the CNS' is a prescriber. • CNS' are supporting bone marrow clinics. • The service is looking to improve HNA completion and increase the number of CNS' (with an Alliance funding bid to support this). **MTW - update provided by Zavi Robinson** • There are 5 part-time CNS' in place for the service. • 5 telephone clinics and 1 bone marrow clinic take place each week. • Chemotherapy takes place in the Chartwell Suite/Unit at Maidstone Hospital. • 2 clinics at Tunbridge Wells Hospital take place by telephone. • A number of projects are currently being worked on including ones for a pre-transplant database and an oral pathway (which is due to go live on 05.05.2023). • SUNRISE process mapping work is underway. • SGo stated the Kent & Medway haematology CNS' have not met as a group since before the pandemic. She will therefore work on setting this up within the next 2 weeks.	
9	**Remote monitoring for chronic haematology conditions**	**Presentation provided by Reuben Benjamin** • RB provided the group with an overview of: - The current set-up at King's College Hospital with regard to MGUS monitoring. - The NIHR i4i challenge which uses digital health to transform the management of long-term conditions in the NHS. It assesses real-world patient experience and empowerment and makes improvements to productivity and capacity. - The development of Ascelus™ in 7 key haematological diseases testing at 3 hospital sites (King's College Hospital, Guy's and St Thomas' Hospital and Sheffield Teaching Hospital). The 7 haematological diseases include: MGUS,	

		sickle cell disease, chronic lymphocytic leukaemia, myelodysplasia, haemochromatosis, smouldering myeloma and iron-deficiency anaemia. The use of Ascelus™ is justified as these diseases (which affect more than 1 million people in the UK) have chronic stable periods which require monitoring, interspersed with acute symptomatic episodes. - The work packages associated with this piece of work. The project is designed to assess real life implementation across a comprehensive series of domains in 11 interlinked work packages including: situational analysis; co-design of new pathways with Ascelus™; platform amendment and integration; clinical validation and safety study; patient acceptance, user experience and preference; barriers/motivators to clinician and speciality adoption; economic modelling and evaluation; digital inclusion; scoping of AI in MGUS; market dissemination and commercialisation; and project management and process evaluation. - The benefit of the app/programme for patients, hospitals/health systems and commissioners. - The data flow process from a hospital and patient perspective to the Ascelus™ platform. - The virtual clinic format. The clinical team (CNS/doctor/pharmacist/ANP) logs into 'digital' clinic, a list of patients with blood results and symptoms is displayed, a suggested outcome is shown based on a pre-set algorithm, the clinical team confirms or modifies the outcome, the outcome is sent to patients via the Ascelus™ app or a letter if preferred and telephone or face-to-face appointments are built in at regular intervals. - The timeline associated with the project. - His proposal to the TSSG. He believes there is a need to: Scope out the demand within haematology departments as well as the number of patients. Assess the current format in which patient interactions take place (face-to-face, telephone, nurse-led approach and GP care). Investigate local IT plans for implementing a new electronic health records system/alternative apps. Arrange a meeting with Dr Adrian Brown (CEO - Itecho Health). Explore funding streams if there is a wish to proceed with implementation of the app. • RB feels the costing associated with this project would not be unaffordable. • CW believes Physician Associates would be the ideal people to take this project forward within the Trusts as their numbers seem to increase more than any other clinical staff role. • SY believes there are a plethora of haematology conditions which this project could be of benefit to. • RB mentioned there is a health economist supporting this piece of work. • RB stated the Ascelus™ digital platform can pull on patient and clinician user applications fully integrated with existing hospital IT systems to improve the management of long-term conditions. • SY raised a query in relation to data storage. In response to this, RB confirmed a cloud-based system would be utilised and would go through an accreditation process. • RB believes the app should help to reduce the number of face-to-face appointments and the number of appointments to monitor haematological treatment. • LWC stated clinicians are keen to not lose the visibility of seeing their patients in person, although he agreed with the premise of the app. • The project will go live in July 2023, initially for MGUS, and the study will end in July 2025.	
10	**Kent and Medway**	**<u>Presentation provided by Tara Rampal</u>** • The Kent & Medway Prehabilitation service has been offered to around 1200 patients and was initially funded by the	

	Cancer Prehabilitation service	KMCA. • TRa provided the group with an overview of an MDPI study on functional decline in cancer patients as well as a Nature Reviews Clinical Oncology article on cancer-related fatigue (particularly in relation to mechanisms, risk factors and treatments). • Cancer survivors' needs are diverse. Demonstrable evidence exists that tailored interventions are more effective than generic interventions. A systematic but individualised approach, which acknowledges and supports complex medical, social, and personal needs is required. • The number of cancer survivors is growing due to ageing populations and improved early detection and treatment. Yet current models of predominantly specialist-led care fail to adequately address the physical, psychosocial and supportive care needs of cancer survivors. • Despite improvements in oncology research to better capture quality of life in patient outcomes, most studies still focus on survival endpoints. • Prehabilitation is a process on the continuum of care which occurs between the time of cancer diagnosis and the beginning of acute treatment. It includes physical and psychological assessments that: establish a baseline functional level, identifies impairments and provides targeted interventions that improve a patient's health to reduce the incidence and the severity of current and future impairments. • Studies demonstrate that patients pre-ASCT have reduced exercise capacity and increased co-morbidities compared with a normal population yet most rehabilitative interventions are focused during and after treatment. • TRa referred to A Support Care Cancer article on maximising patient adherence to prehabilitation and what patients say. • Challenges include: - At a population level, many national targets are focused on cancer survival rates rather than more nuanced metrics reflecting positive and negative experiences of survivorship. - Policy makers often lack the data to make informed improvements to information systems, insurance or reimbursement programmes, and national cancer control programmes. • TRa provided an overview of: - The Kent & Medway Prehabilitation service patient journey from clinic onwards. - The measures in place in relation to physical optimisation, nutritional optimisation, psychological optimisation and health-related quality of life. - Intervention stratification (particularly in relation to health-related quality of life, frailty and behaviour modification). - The guidance and framework in relation to the central hub, select pathways and peripheral units. - The Kent & Medway Prehabilitation service telemedicine approach. There is at least 1 live streaming exercise session every day of the week covering different modalities. - The Craetus app. - Kent & Medway Prehabilitation service peer-review publications. - Kent & Medway Prehabilitation service outcomes, which include patients improving their self-rated health and fatigue after prehabilitation. - The age distribution of people utilising the telemedicine approach. - The e-peer support group. The outcomes of this gets fed back to the Prehabilitation Operational meeting.	

		- The potential future for telemedicine. - The figures for haematology referrals to the Kent & Medway Prehabilitation service (8 for 2022 and 19 by the end of February 2023). - A BJA article on the challenges and barriers to prehabilitation. The article reported on 01.01.2023 that high-quality evidence is still required for prehabilitation. • TRa believes improved models should shift from a predominant focus on detection of cancer recurrence and seek to improve the quality of life, functional outcomes, experience, and survival of survivors of cancer, reduce the risk of recurrence and new cancers, improve the management of comorbidities, and reduce costs to patients and taxpayers. • TRa provided an overview of the prehabilitation drop-in surgeries in place for those unable to access IT platforms. • TRa highlighted the need to develop integrated care pathways. • CMal believes it would be helpful to have prehabilitation discussions at the MDT meetings. • TRa mentioned there have been some studies suggesting prehabilitation has reduced solid rectal masses. • Exercise can be monitored and modified as required for each patient. • CMal mentioned all Trusts can refer patients to the prehabilitation service via a referral form on InfoFlex. GPs can also refer to the service as well as patients themselves.	
11	**Cancer Alliance update**	**<u>Presentation provided by Claire Mallett</u>** • CMal provided the group with an overview of the various projects relating to the following workstreams (please refer to the presentation circulated on 27.04.2023 for a detailed breakdown of what these are): - Faster diagnosis and operational performance. - Early diagnosis. - Treatment and care. - Cross-cutting. • CMal stated she is working with CNS' on the treatment summaries (which can be embedded in to InfoFlex) and has had good engagement in this respect, although she feels wider clinical engagement is required. • In relation to the personalised care sphere, there has been good engagement with the CLL remote monitoring piece and Trusts have been using it. The next meeting is scheduled for 23.05.2023, with discussions there to include taking forward the Patient Portal work. • CMal mentioned there is rich data coming out with regard to HNAs, although the numbers for haematology cases is low. • There have been a number of meetings/workshops pertaining to psychosocial support and scoping exercises have been carried out across the patch to identify existing capacity within teams and what their service needs are. • KMCA have been working with Macmillan regarding funding for additional posts. • National CNS Day is today with the Kent & Medway CNS appreciation event due to take place at the Great Danes (Mercure) Hotel in Maidstone tomorrow. This event will provide the opportunity to celebrate the work CNS' do.	
12	**AOB**	• The next TSSG meeting will take place on a Monday in November 2023. Further details to be confirmed.	
	Next Meeting	• Monday 16th October 2023 (09:00-12:30) Orida Hotel (Maidstone)	