AO & CUP Forum Tumour Site Specific Group meeting
Monday 20th May 2019
Tutorial Room (Postgraduate Centre), William Harvey Hospital
09:30 – 12:30

Final Meeting Notes

Present	Initials	Title	Organisation
Afroditi Karathanasi (Chair)	**AK**	Consultant Medical Oncologist	MFT
Anne-Marie Acheson	**AMA**	CUP MDT Coordinator & PA to Afroditi Karathanasi	MFT
Cherie Neill	**CN**	AOS CNS	MFT
Deirdre Cooke	**DC**	AOS/CUP CNS	MFT
Stergios Boussios	**SB**	Medical Oncologist Consultant	MFT
Amy Peacock	**AP**	AOS CNS	DVH
Nicola Bonthron	**NB**	Lead Nurse – AO & SPC	DVH
Stacie Main	**SM**	AOS CNS	DVH
Jacqueline Motta	**JM**	Lung CNS	EKHUFT
Tracey Spencer Brown	**TSB**	Macmillan Acute Oncology Matron	EKHUFT
Bana Haddad	**BH**	Macmillan GP & LWABC Clinical Lead	KMCA
Claire Mallett	**CM**	Programme Lead – Living With and Beyond Cancer	KMCA
Annette Wiltshire	**AW**	Service Improvement Facilitator	KMCC
Colin Chamberlain (IT & Notes)	**CC**	Admin Support	KMCC
Andrew Brown	**AB**	AOS/CUP CNS	MTW
Erika Wade	**EW**	AOS CNS	MTW
Rosie Baur	**RB**	Head of East Kent Cancer and Specialised Commissioning Services	SKC CCG
Apologies			
Michelle Jee	**MJ**	Strategic Cancer Lead for North Kent CCGs	DGS CCG
Karen Connolly	**KCo**	Specialist Nurse Practitioner (Cancer Services)	DVH
Marie Payne	**MP**	Macmillan Lead Cancer Nurse	DVH
Penny MacFarlane	**PM**	Upper GI CNS	DVH
Carolyn Gupwell	**CG**	Haematology CNS	EKHUFT
Catherine White	**CWh**	Site Coordinator Nurse	EKHUFT
Jane Blofield	**JB**	Haematology CNS	EKHUFT
Jennifer Jewell	**JJ**	Macmillan Acute Cancer Matron	EKHUFT
Lavinia Davey	**LD**	Research Nurse	EKHUFT
Naomi Webb	**NW**	Cancer Services Manager	EKHUFT
Serena Gilbert	**SGi**	Programme Lead – Early Diagnosis	KMCA
Tracey Ryan	**TR**	Macmillan User Involvement Manager	KMCC
Debbie Pyart	**DP**	Head of Quality & Safety	Medway CCG
Alison McKeand	**AM**	Pathway & CUP MDT Coordinator (Acute Oncology)	MFT
Alistair Lindsay	**AL**	General Manager	MFT

Kerry Michelsen	**KM**	Senior Sister	MFT
Kolera Chengappa	**KCh**	Chest Physician	MFT
Maadh Aldouri	**MA**	Locum Consultant Haematologist	MFT
Margaret Woodford	**MW**	Haematology MDT Coordinator	MFT
Amit Goel	**AG**	Consultant Histopathologist	MTW
Charlotte Abson	**CA**	Consultant Clinical Oncologist	MTW
Charlotte Wadey	**CWa**	Lead Cancer Nurse	MTW
Christos Mikropoulos	**CMi**	Consultant Clinical Oncologist	MTW
Dominic Chambers	**DCh**	Consultant Histopathologist	MTW
Evangelia Dimitriadou	**ED**	Consultant Haematologist	MTW
Gemma Craig	**GC**	Lead Cancer Nurse	MTW
Henry Taylor	**HT**	Consultant Clinical Oncologist	MTW
Jenny Anderson	**JA**	General Manager for Cancer & Haematology	MTW
Lauren Paciej	**LP**	Acute Oncology CNS	MTW
Mathilda Cominos	**MC**	Consultant Clinical Oncologist	MTW
Ola Okuwa	**OO**	Haematology Pharmacist	MTW
Ravish Mankragod	**RM**	Consultant in Respiratory and General Medicine	MTW
Riyaz Shah	**RS**	Consultant Medical Oncologist	MTW
Rosalyn Yates	**RY**	Cancer Matron	MTW
Katrina Sung	**KS**	Data Liaison Manager	NCRAS
Sona Gupta	**SGu**	Macmillan GP	Newton Place Surgery
Kay Jones	**KJ**	Project Coordinator	NIHR
Rachel Jones	**RJ**	Director of Acute Strategy & Partnerships	Swale CCG
Sally Allen	**SA**	Head of System-wide Commissioning	West Kent CCG
Stefano Santini	**SS**	Macmillan GP & Cancer Lead	West Kent CCG

Item		Discussion	Agreed	Action
1	**TSSG Meeting**	**<u>Introductions</u>** AK welcomed the members to the meeting and asked everyone to introduce themselves. **<u>Apologies</u>** The apologies are listed above. **<u>Review actions from previous minutes</u>** • The minutes from the last meeting were reviewed and accepted as a true and accurate record. • AK expressed her gratitude to the members for completing their respective Trust's AOS Directory. She specified that before they are taken forward she would like each Trust to include a comment on how the service works and the best hours for communication. AK asked for these additions to be made by 31/05/2019 and to include CC when returning them so that he can integrate these in to the directory. • It was agreed that each Trust would send CC any staff changes they may have had on a quarterly basis. He will then upload the updated directory to the KMCC website. • AK highlighted that the directories from all 4 Trusts would need to be merged in to a single document and that she would like this put on the website by June 2019. • AK made reference to the AOS scoping document. TSB and NB specified that they needed to make some changes to the displayed spreadsheet. AK stated that this needs to be complete by 31/05/2019. • AK queried whether clinical indicators should be included on the scoping document as she believes they are obvious requirements. • The last CNS meeting, scheduled to be at William Harvey, did not go ahead but TSB outlined that she does appreciate the importance of having these on a regular basis. • **<u>Action:</u> TSB to send June 2019 dates around to respective colleagues for the next sub-group meeting.** • TSB specified that she is happy to be a deputy chair to this meeting. **<u>Action:</u> AW to send TSB the relevant documentation pertaining to vice chairmanship.** • AK outlined that there is work to be done on the operational policy, work plans and Terms of Reference and that she hopes these are complete ahead of the next TSSG meeting. She did, however, state that the AO guidelines are in place. • TSB shared that she is happy to take the work plans and operational policy to the sub-group meeting in order to take them forward in that forum. • **<u>Action:</u> AK and AW to arrange to meet to discuss the documents further.** • With regards to CUP guidance, local guidelines are currently in place across the patch. MTW have no CUP consultant and AK mentioned that she would need to meet with the consultants who run the CUP MDT meetings. It was noted that MFT and EKHUFT follow the same guidelines.		**ALL** **CC** **TSB** **AW** **AK/AW**

2	**Horizon Scanning**	This item was merged with the previous agenda item while discussing the future actions.		
3	**Performance**	**<u>Clinical Indicators - AO & CUP</u>** • AK raised the question of who is completing the clinical indicators self declaration at each Trust. • TSB advised that her team do this at EKHUFT and are working alongside Dr Andy Nordin. She also mentioned that the AO Navigator will assist with administrative tasks. • AK highlighted that the Trusts are meant to be providing their performance data to the KMCA. • NB stated that organising an AO group meeting, which AK advised should happen every 6 months, is very difficult and that they have never had one due to key members', namely consultants', conflicting schedules. • NB specified that DVH provide AO & CUP updates and feedback to the Cancer Board and A&E. She also made reference to a new medical consultant who is scheduled to start next week. • NB outlined that palliative care representation is lacking at their Sepsis and EOL Board meetings. • AK suggested that an Implementation Group should be formed in order to discuss pathways and guidelines. • AK emphasised the importance of being functional and moving matters forward and knowing when and who to escalate to. • AK outlined that MFT have one service with five members sitting in different directorates and have two different governance paths. She also highlighted that they have fixed goals for next year. • AB highlighted the need to meet with Henry Taylor to discuss the concerns they are experiencing as they are not meeting the clinical indicators at MTW. • With regards to the CUP MDT at MTW, AB specified that they lack palliative care consultant representation there. • It was established that MFT discuss weekly MUO's, DVH and MTW do not and at EKHUFT they go through the UGI MDT. • AK stated that on the diagnostic pathway making recommendations does not always mean that they are implemented unless the member of staff can follow the patients through the pathway. • NB advised that MUO's are sent to Victoria Donovan and stated that everything they clinically do is entered on to InfoFlex. RB highlighted that it is vital to ensure the MDM Coordinator puts them on the Patient Tracking List (PTL). Moreover, a patient that comes through with incidental findings needs further investigation. • AK outlined that most of the K&M Trusts CUP MDTs do not include MUO's.		
4	**CNS Updates**	**DVH** • Steve Nicholson has now left. • Running a 7 day nurse-led service.		

		• Nina Williams (Medical Consultant) is due to start in the near future. She will be the clinical lead for the service. • The CNS' recently attended an event in Manchester to present on a 7 day service. • They are making good progress with the vague symptoms pilot which will be running for one year. They will have a CNS focusing 10 hours a week on this and have put a referral form together; concerns were raised about cover and time taken away from AOS and CUP Services. • They will be interviewing for administrative support next week. • NB specified that at the end of the pathway there are generally 3 routes, the third of which she has concerns with: 1) Patient does not have cancer. Refer back to GP. 2) Patient has cancer. Put on relevant MDT. 3) Patient does not have cancer but does have other concerning health issues. **EKHUFT** • An AONP has gone on indeterminate leave. • Currently running a 5 day nurse-led service. • They have 2 Acute Oncology Matrons in place. Have recruited to 3 WTE Band 7s, 1 WTE Band 6 and a Band 4 Pathway Navigator. • Have scoped for a 7 day service but this will be further discussed with Dr Andy Nordin in due course. • Going to consultation with palliative care team, which they intend on rotating around the hospital sites. • They will no longer be managing the CNS workforce – this is now to be managed by the Governance Matron. • Manage cancer care line which operates from 9am – 5pm seven days a week. TSB shared that the navigator will assist with this and that they intend on moving this service to 24/7. • A process is in place for 'red' calls. • TSB outlined that turnaround times for calls are very good and are regularly audited. • RB stated that it would be ideal to have a centralised K&M cancer care line. • Patient feedback on the care line has been good overall and they are working with Macmillan to compile questionnaires to be sent out to patients. **MFT** • CN has joined the team since the last meeting and they are hoping to get another nurse. • They currently have a 5 day service but are trying to move towards making this 7 days. • The respiratory team has been very supportive on linking together the Lung and CUP MDT and the chemotherapy and AO lines function well. AK outlined that the CNS' and Coordinator have been working very hard and are a credit to the service. • AK advised that the CUP service is well organised and functions well. • The IT team is creating an inpatient and outpatient database. • The Trust has a switchboard which diverts all calls to them relevant or not when the		

		caller says the word 'cancer'. AMA generally deals with these calls in the first instance but this is time consuming. • They have oncology beds with AK and SB rotating with regards to the rounds. • AK specified that a bigger team is needed to assist in fulfilling their potential. • It was felt that a Band 3 is needed in order to provide administrative support to the service. **MTW** • There are 3 full-time CNS' in place. They are going to attempt to cover Tunbridge Wells Hospital on Saturdays and working a little towards a 6 day service. • The Medical Infusion Unit is now responsible for the development area. AB conveyed that they are hoping to recruit 2 CNS' to work in this unit in the near future but they currently provide cover. • They do not currently have a clear plan where AO oncologist representation is concerned, with CMi (AO Lead) leaving in June 2019. • Ciara O'Hanlon-Brown (CUP Lead) will be returning from maternity leave in August 2019. • It was mentioned that a 60 bed stroke unit is to be implemented in due course.		
5	**Clinical Pathway Discussion**	**<u>MUO pathway discussion</u>** • AK outlined that MFT have approximately 70 MUO cases a year. • AK outlined that the pathway that she had circulated to the membership last week is a proposed one and that it most likely needs some more work. She also advised that it may be sensible to send it out when the directories are circulated if it is agreed. • AK highlighted the need for GPs to review the pathway and asked whether each Trust could commit to taking on the extra workload associated with delivering the MUO pathway. Furthermore, she questioned whether they all could be committed to that as a 2ww pathway. • TSB stated that EKHUFT already follow the red boxes detailed on the pathway for inpatients. With regards to the green pathway, TSB specified that the team already have such an extensive workload as it is and that she feels it would be unsafe to commit to this piece. AB added that MTW would also struggle to support the green pathway as it currently stands with the current staff. • AK noted that the pathway cannot be followed appropriately unless clinical teams are committed to it. • AK emphasised that Alliance support is needed with this piece of work and to make recommendations to each Trust's CUP MDT. • AK asked whether BH had further discussed the difficulties of the establishment of the MUO pathway at a higher level apart from the Alliance subgroup meeting that took place in March 2019 with management representation from all Trusts. BH stated that she had escalated to Ian Vousden who is aware. • RB specified that the oncologists are based at Maidstone and that it would therefore be sensible to have a centralised coordination service for CUP and MUO there. She stated		

		that a business case would need to be put together to take this forward and clinicians would need to be on board. CM conveyed that it would be worth collating input from each Trust relating to this piece and include it in a strategy to then bring to the Delivery Group and subsequently the JCC. She specified that she is aware that most of the transformational funds have been allocated to specific areas already but whether the funding remaining has been earmarked for other areas, she does not know. She advised the members that she will proceed to speak to Ian Vousden to find out more. • **<u>Action:</u> RB and AK to link in order to collate a document articulating the discussions had today and a plan to take forward.**		**RB/AK**
6	**Research**	**<u>CUPISCO trial – presentation by Dr Stergios Boussios</u>** SB made reference to the following during his CUP Research presentation: o Introduction o Management of MUO/CUP patients o Genetic testing for the guidance of patients management o Does Comprehensive Genomic Profiling improve outcomes? o Inclusion criteria and Exclusion criteria of CUPISCO o Primary and Secondary Endpoints of CUPISCO o CUPISCO study design – awaiting final UK approvals o UK Centres o Conclusions • SB outlined that CUP accounts for 3–5% of all cancers, and prognosis is poor for most patients, with a median survival of 6–9 months. • Clinical and pathological diagnostic work-up is required to determine whether patients belong to the favourable or unfavourable subset of CUP. • Only 15–20% of patients belong to favourable subsets and have responses to therapy and outcomes similar to those of patients with the equivalent known metastatic primary tumour. • For the patients in the unfavourable subsets (around 80–85% of CUP patients) treatment currently is chemotherapy. • Median survival is <1 year and clinicopathological management of these patients is not expected to improve outcomes further. However, two different approaches involving genetic testing to guide patient management have the potential to offer progress. The first approach is to use gene or methylation profiling tests to identify the tissue of origin, whereas the second supports identification of genomic aberrations that can be targeted therapeutically. • CUPISCO aims to show the benefit associated with the use of genomic profiling to allocate molecularly targeted therapies or immunotherapies compared with the standard treatment of platinum-based chemotherapy in patients with CUP. • AK advised the members that it would be worth considering referring suitable patients to this trial.		

7	**MSCC update**	• TSB specified that EKHUFT have no issues in getting patients MRI scans within 24 hours. • They have had some delays in getting patients referred to Kings – but TSB believes this issue could lie with the cover Coordinator at King's. She stated that it would be sensible to arrange a meeting with their team to discuss this matter further (what works well and what does not). • **<u>Action:</u> TSB to arrange quarterly MSCC meetings with Kings to include all Trusts' Coordinators.**		**TSB**
8	**Primary Care & Commissioning**	This item was partially discussed while the MUO pathway discussion took place.		
9	**AOB**	No one had anything to raise under AOB.		