Kent and Medway Cancer Collaborative

Thyroid Tumour Site Specific Group meeting
Thursday 7th March 2024
Orida Hotel, Maidstone, ME14 5AA
09:30 - 12:30
Final Meeting Notes

Present	Initials	Title	Organisation
Chris Theokli **(Chair)**	**CT**	Consultant ENT Thyroid Surgeon	EKHUFT
Vikram Dhar **(Co-Chair)**	**VD**	ENT / Head and Neck Consultant Surgeon	EKHUFT
Tolga Senel **(Guest Speaker)**	**TS**	Business Development Officer	Macmillan / Crossroad
Eranga Nissanka-Jayasuriya	**ENJ**	Consultant Head & Neck Histopathologist	EKHUFT
Muhammed Eraibey	**ME**	Consultant Radiologist	EKHUFT
Robert Hone	**RH**	ENT Consultant	EKHUFT
Sue Honour	**SH**	Macmillan Lead Head & Neck and Thyroid CNS	EKHUFT
Mazhar Choudhry	**MC**	FY2 Doctor	EKHUFT
Ali Al-Lami	**AAL**	Consultant ENT / Head & Neck Surgeon	EKHUFT
Karen Glass **(Minutes)**	**KG**	Administration & Support Officer	KMCA & KMCC
Jonathan Bryant	**JB**	Clinical Lead / GP	KMCA / NHS Kent & Medway ICB
Colin Chamberlain	**CC**	Administration & Support Officer	KMCC
Gemma McCormick	**GMc**	Consultant Oncologist	KOC / MTW
Navdeep Upile	**NU**	Consultant Otolaryngologist Head and Neck Surgeon	MFT & QVH
Maria Acosta	**MA**	Consultant Physician in Nuclear Medicine	MFT
Jeremy Davis	**JD**	ENT Consultant	MFT
Emma Bourke	**EB**	Macmillan Personalised Care and Support Facilitator	MFT
Susan Wildish	**SW**	Care and Support Worker	MFT
Suzanne Bodkin	**SB**	Cancer Service Manager	MFT
Debbie Hannant	**DH**	Macmillan Head & Neck CNS	MFT
Louise Black	**LB**	Macmillan Deputy Lead Cancer Nurse	MFT
Amy Cass	**AC**	MDT Co-ordinator	MFT
Lorraine McManus	**LMc**	Cancer Navigator	MFT
Luisa Roldao Pereira	**LRP**	Nuclear Medicine Superintendent & Advanced Clinical Practitioner Project Lead	MTW
Apologies			

Edmund Lamb	**EL**	Consultant Clinical Scientist / Clinical Director of Pathology	EKHUFT
Alistair Balfour	**AB**	Consultant ENT, Head & Neck and Thyroid Surgeon	EKHUFT
Nicola Chaston	**NC**	Consultant Cellular Pathologist and Associate Medical Director for Diagnostics	EKHUFT
Ritchie Chalmers	**RC**	Medical Director	KMCA
Annette Wiltshire	**AW**	Service Improvement Lead	KMCC
Sabita Pokharel	**SP**	Senior Clinical Research Practitioner/Research Nurse	MFT
Mary Boyle	**MB**	Consultant Pathologist	MTW
Milena Truchan	**MT**	Head & Neck CNS	MTW
Melanie Suseeharan	**MS**	Core Surgical Trainee ENT	Royal Surrey County Hospital

Item		Discussion	Agreed	Action
1.	**TSSG Meeting**	**<u>Apologies</u>** • The formal apologies are listed above. **<u>Introductions</u>** • CT welcomed the members to today's face to face meeting and the group introduced themselves. • If you attended this meeting and are not captured on the attendance list above please contact karen.glass3@nhs.net directly and she will update the distribution list accordingly. • CT mentioned this was his second meeting as the Chair for the Thyroid TSSG. CT referenced the lack of clinical and admin representation from MTW at today's meeting. Moving forwards CT is keen to have consensus and collaboration from all of the members to ensure these meetings are more dynamic and interesting. CT also raised the importance of conducting audits across the trusts so they can publish and present their findings which is key to providing a better service for their patients. **<u>Review previous minutes</u>**		

		• The minutes from the previous meeting which took place on the 20th September 2023 had been reviewed previously and were signed off as a true and accurate account of the meeting. **Review action log** • The action log was reviewed, updated and will be circulated to the members along with the final minutes from today's meeting.		
2.	**Parathyroidectomy as a day case re-audit**	**Presentation provided by Mazhar Choudhry** • MC thanked Melanie (Suseeharan) for the slides he will be presenting today. • MC explained there is mounting evidence to support carrying out parathyroidectomy's as day case surgery. Only 10% of NHS Trusts across the country are reporting this. At EKHUFT all parathyroidectomy surgeries have minimum overnight stays. • GIRFT recommendation states where clinically appropriate, lengths of stay for surgical procedures should be reduced. Trusts should review their patient pathway with a view to achieving the following target for elective admissions within 6-months – 90% of patients having parathyroid surgery for primary hyperparathyroidism to be discharged with zero-night stay (day case). • MC highlighted the current length of stay for parathyroidectomies range from 0 - 4 days. • The current practice at EKHUFT was outlined. Total number of patients from October 2019 – October 2022 totalled 107 patients. Demographics included: i) 77 Female / 30 Male patients ii) Mean age: 66 years iii) Age range: 22 – 90 years • MC confirmed the calcium range did not differ much for 6 hours or 12 hours post op.		**Presentation circulated to the group on Friday 8th March.**

		• 93% of patients stayed 1 night. The 7% of patients who stayed over 1 night was due to: i) 2 x cases of post-operative haematoma – immediate return to theatre. ii) 1 x case of increased drain output. iii) 4 x cases due to anaesthetic / co-morbidities. • Implications for current practice at EKHUFT: i) Day case generally favoured by patients. ii) Increase bed availability. iii) Scope for increased case turnover. iv) Cost savings from overnight surgery > day case surgery. v) Reduced costs of unnecessary repeat blood test (every parathyroid hormone (PTH) costs £8). • The aim is to convert inpatient parathyroidectomies to day case parathyroidectomies for appropriately selected patients. Suggested interventions include: i) Selecting patients appropriately using a checklist proforma. ii) Provide patients with information leaflets about common complications. iii) Omit second post-operative Calcium level in lieu of 6-hour post-operative Calcium level. iv) Use the BAETS checklist for hemi-parathyroidectomies to help guide the formulation of the checklist. • MC referred to 2 x post-operative patient information leaflets for Hypocalcaemia and Haematoma. • Initial impressions: i) Successful acceptance of day case parathyroidectomies amongst Consultant cohort, but more awareness is needed amongst Juniors to ensure no delays in discharge. ii) Most successful utilization of checklist proforma. iii) **Day Case Parathyroidectomies are safe** – with no increase in complications or		

		mortality reported in the limited cases. • Next steps: i) Raise awareness of implementation of day case parathyroidectomy across the whole clinical team. ii) Continue data collection to complete 12-month – aim to present full results across one year. • VD raised his concern about haematoma's developing 6 hours post-surgery or after the patient has gone home. CT reassured VD there has been no issue to date at EKHUFT. They are now actively doing day-case parathyroidectomies.		
3.	**Update on pathology guidance**	**<u>Update provided by Eranga Nissanka-Jayasuriya</u>** • ENJ referred to the World Health Organization (WHO) 5th edition guidelines which have had new entities added. • JD explained Mary Boyle had sent him the updated guidelines. It is important for the clinicians to be able to interpret these complicated guidelines. **Action – Eranga and Mary to provide a Pathology update at the next meeting to include the WHO guidelines for Thyroid Cancer.**		**ENJ / MB**
4.	**Stratified Pathway** **Patient Leaflets**	**<u>Stratified Pathway update provided by Vik Dhar</u>** • VD outlined the process following completion of Radioactive Iodine Therapy (RAI) at MFT. This includes: i) Patient will have a face-to-face with the consultant after 6-months. ii) Dynamic Risk Stratificiation (DRS) will take place 9-12 months post RAI. iii) Request TFTs, Tg, Tg Ab blood tests (patients normally have TFTs and Tg checked		**PSFU presentation and copy of the patient leaflets were circulated to the group on Friday 8th**

		post-RAI by MA so no need to repeat at this point). iv) Request USS neck. v) Both will be requested to take place at a time equivalent to 9-12 months post-RAI. vi) They will dictate a letter to their secretary / copy thyroid MDM Coordinator to discuss USS and blood results at MDM once available. • Regarding the DRS outcome, if Tg <0.14 and USS is clear they will be documented as low risk, then: i) CNS will schedule a telephone follow-up. ii) Reduce levothyroxine with a view to aim for TSH between 0.3–2.0 iii) Speak to patient regarding PSFU • If there are any issues with regards to the points above the patient will not be deemed suitable for PSFU. • The presentation provided an overview of the EKHUFT PSFU timetable as well as the inclusion and exclusion criteria at 12-months. • MFT is now ready to go live with PSFU. • EKHUFT Thyroid MDM takes place on a weekly basis. VD mentioned DRS is discussed at their MDM. GMc disputed this decision due to MDT's being streamlined. • SH explained after the MDM if a patient is classed as low risk with low TSH levels she will call the patient and encourage them to go onto a Stratified Follow Up pathway. Patients will be discharged after 5-years and not 10-years as previously agreed. SH highlighted the importance of safety netting and not all patients are suitable to go onto SFU pathway. **<u>Update on patient's leaflets provided by Sue Honour</u>** 1) EKHUFT – Introduction to supported self-management for thyroid cancer patients – information for patients from the Head and Neck / Thyroid Cancer Nursing Team. 2) EKHUFT – supported self-management for thyroid cancer patients - information for patients		**March.**

		from the Head and Neck / Thyroid Cancer Nursing Team.		
5.	**RAI refractory**	**<u>RAI - Resistant thyroid cancer – update provided by Vik Dhar</u>** i) MA mentioned she has seen more of these cases recently and relapses are rarely seen in new patients. Those who do tend to will relapse within 10-years. **Action – MA suggested bringing back an audit on recurring disease to the next TSSG meeting and will contact relevant colleagues to take this forward.** ii) RAI resistant disease - the problem: iii) RAI is the cornerstone of treatment for DTC iv) 5-15% of high-risk DTC become refractory to RAI (RAI-R) v) 50% of metastatic DTC become RAI-R vi) RAI-R disease with metastases has a 10-year survival of 10% vii) Mean life expectancy is between 3-5 years. • VD explained the definition of RAI-R. • Treatment options - Tyrosine Kinase Inhibitors (TKI) i) Include Lenvatinib and Sorafenib. Approved by NICE as the only TKI's available on the NHS. ii) Lenvatinib - SELECT trial: PFS of 18.3 months (treatment group) vs 3.6 months (placebo). iii) Sorafenib – DECISION trial: PFS of 10.8 months vs 5.8 months. • Treatment progression: i) There can be significant side effects. ii) Treatment should continue until there is evidence of tumour progression or manifestation of severe side effects.		**Presentation circulated to the group on Friday 8th March.** **MA**

		iii) Both the SELECT and DECISION trials noted that nearly all participants experienced unwanted effects (99.6% and 98.6% respectively). iv) The most serious side effects were hypertension for Lenvatinib; hand and foot sores for Sorafenib. v) Other side effects include: weight loss / fatigue / alopecia / proteinuria / mucositis / rash / diarrhoea.		
6.	**Thyroid Performance Data**	**<u>Update provided by Vik Dhar – slides provided by David Osborne (Data Analyst for K&M CA)</u>** • Faster Diagnosis (28-day referral to diagnosis) - coding of Thyroid under this standard has improved at EKHUFT in the last 6 months. • MFT are still the only Trust in West Kent that regularly code referrals as "Thyroid" under the FDS Primary Cancer Site field in the last 6 months. • VD navigated through the slides for 31-day (decision to treat to treatment) and 62-day (referral to first treatment) performance for East and West Kent. **Action - JD suggested it would be helpful if David Osborne could separate the MFT/DVH data from that of MTW as they are all labelled under West Kent. SB agreed to take this action away and speak to DO offline.** • The performance data captured has been taken from the number of referrals on the head and neck pathway having thyroid ultrasound and / or thyroid biopsy and / or thyroidectomy. The source of the data has come from the ICB data warehouse (Cancer waiting times dataset linked to inpatient and outpatient datasets). The ICB data warehouse is an entirely separate data source from InfoFlex. Incidental findings and benign symptoms will not be captured within this data. • The general consensus of the group was the data was still not accurate in terms of the number of thyroid patients seen. VD mentioned per year they have approximately 45 - 50 thyroid cancer patients at EKHUFT. There are 15 thyroid patients discussed at their weekly MDM. The majority of thyroid cases are benign.		**Presentation circulated to the group on Friday 8th March.** **SB**

		• SH referred to the issue of diagnostic delays at EKHUFT. Ultrasound biopsy results can take 2-3 weeks to come back.		
7.	**Research update**	**<u>Update provided by Maria Acosta</u>** • **HOT** clinical trial (USA) – risk of recurrent disease – hemi vs total thyroidectomy for low risk thyroid cancer patients. T1b and T2 to consider as long as there are no lymph nodes / aggressive features. 15 sites have opened across the UK. K&M have now recruited 5 patients (2 male / 3 female) and are still actively recruiting. The trial is due to close in Jan / Feb 2025. • MA mentioned she presented to the International Congress for Thyroid (and Breast) Cancer – dedicated to improving the care of patients with thyroid nodules and thyroid cancer. She referenced the importance of collecting more data and investigating further as there is evidence to support a link between Thyroid and Breast Cancer. • **NIFTy** clinical trial was open to people having total thyroid surgery, to remove the whole thyroid or completion surgery to remove the remaining lobe of their thyroid following a partial thyroidectomy. The aim of the trial was to find out whether using near-infrared fluorescence imaging could reduce the number of people whose parathyroid glands become damaged during thyroid surgery. • **INSPIRE** clinical trial – investigating radiation dosimetry for differentiated thyroid cancer patients. They have signed up to this trial but are yet to start recruiting.		
8.	**InfoFlex**	**<u>Thyroid InfoFlex data update from Chris Singleton – via email prior to the meeting</u>** • Ritchie and I had discussions with David Osborne and Ian about this, to try to work out why the InfoFlex data can't be split for thyroid and H&N. I also flagged that Hannah Washington had explained that when she tries to change the tumour type on InfoFlex, it defaults back to the original one. David and Ian explained that this had been an issue for a while and is an issue nationally. Various attempts to resolve it have been made. I did suggest that EKHUFT-based InfoFlex colleagues could sit with Hannah to see why her changes to the tumour site		

		are not being retained on the system. I'm not sure if this has progressed, and I understand that further discussions were to take place with InfoFlex.		
9.	**CNS Update all Trusts**	**<u>EKHUFT update by Sue Honour</u>** • The CNS team has now expanded to a team of 5. They have an additional band 6 CNS and a Cancer Support Worker. **<u>MFT update by Debbie Hannant</u>** • Sue has joined the Head & Neck team as a result of CA transformational funding. • Due to take forward stratified open access. • **No CNS update was provided by MTW or QVH.**		
10.	**Clinical Audit updates**	**Action - AAL and NU agreed to speak offline regarding future clinical audits to be presented at the TSSG meetings. They agreed to check buy-in at a regional level and if not compatible to take forward at a local level including the Hemithyroidectomy audit.**		**AAL / NU**
11.	**Crossroads Care Kent / Macmillan**	**<u>Presentation provided by Tolga Senel</u>** • Crossroads and Macmillan are working together to support cancer patients and carers. The number of carers has increased over the last 10 years. The only time this number decreased was due to the impact of Covid. • Crossroads help unpaid carers to make a life of their own outside of caring by providing quality care services which offers peace of mind and time to 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,		**Presentation circulated to the group on Friday 8th March.**

		relative, friend or neighbour who are unable to manage without the support of a carer. • More than a third of carers have experienced a change in the number of services they have received due to: i) Care or support arranged by social services was reduced, or closed with no replacement. ii) Cost has increased. iii) Personal budget no longer covers the cost. • It is crucial that informal carers are offered practical and financial support. • Unpaid carers are providing care worth £162 billion a year – higher than the annual NHS health service spending in England (2020/21 financial year) • The majority of recipients of unpaid care are older parents, spouses or partners. Due to the changes in the make-up of the population the number of dependent older people in the UK will increase by 113% by 2051. • Crossroads Care in Kent is able to offer the following for their clients: i) Regular short breaks ii) Health appointment replacement care iii) Crisis response iv) Dementia Outreach and Support v) Young Carers Project vi) Carers Counselling – up to 12 weeks free. • Macmillan Partnership offers: i) Trained, DBS-checked volunteers offer practical assistance and companionship at home or transportation to health appointments. ii) Provide a wide range of useful information and guidance, available in Kent & Medway, for patients and carers. iii) Free counselling with a counsellor in training, available for Carers and supporters of a cancer patient.		

		• The collaborative Macmillan / Crossroads service currently supports: i) Over 200 clients across K&M. ii) 270 active volunteers iii) 91 people get Macmillan grants (total - £32K) iv) 46 grants from other beneficiaries (total -£18K) v) 3,685 volunteer hours in 2023. • Anyone can refer, including self-referrals – via telephone, email or online. ○ 03450 956 701 ○ macmillan@crossroadskent.org ○ referrals@crossroadskent.org ○ counselling@crossroadskent.org • SH mentioned she has referred a lot of her patients to this service. The hospital transport is very limited but an excellent resource. TS confirmed the drivers are volunteers but are reimbursed for their fuel consumption (70p per mile).		
12.	**AOB**	• JD mentioned the upcoming BAETS Annual Meeting is taking place in London on the 3rd - 4th October 2024. Further details to follow in due course.		
13.	**Next Meeting Date**	• Date in September 2024 to be agreed in collaboration with the Head & Neck TSSG meeting which is taking place later today. **Action - KG to circulate the meeting invite to the group once the date had been confirmed.**		**KG**