Kent and Medway Cancer Collaborative

Thyroid Tumour Site Specific Group meeting
Tuesday 29th March 2022
Microsoft Teams
09:30-12:30

Final Meeting Notes

Present	Initials	Title	Organisation
Chris Theokli (Chair)	**CT**	Consultant ENT Thyroid Surgeon	EKHUFT
Sue Honour	**SH**	Macmillan Lead Head & Neck and Thyroid CNS	EKHUFT
Vikram Dhar	**VD**	Consultant ENT Surgeon	EKUHFT
Muhammad Eraibey	**ME**	Consultant Radiologist	EKHUFT
Rob Hone	**RH**	Head & Neck Otolaryngology Consultant	EKHUFT
Nicola Chaston	**NC**	Consultant Cellular Pathologist	EKHUFT
Bikram Bhattacharjee	**BB**	Consultant CD Radiologist	DVH
Shwetal Dighe	**SD**	Consultant Upper GI & Thyroid Surgeon	DVH
Claire Mallett	**CM**	Programme Lead – Personalised Care & Support	KMCA
Susan Green	**SG**	Project Manager – Personalised Care & Support	KMCA
Karen Glass (Minutes)	**KG**	Administration & Support Officer	KMCC & KMCA
Colin Chamberlain	**CC**	Administration & Support Officer	KMCC
Annette Wiltshire	**AW**	Service Improvement Facilitator	KMCC
Tracey Ryan	**TR**	Macmillan User Involvement Manager	KMCA
Maria Acosta	**MA**	Consultant Physician in Nuclear Medicine	MFT
Debbie Hannant	**DH**	Macmillan Head & Neck CNS	MFT & DVH
Coimbatore Praveena	**CP**	Consultant H&N, Thyroid & ENT Surgeon	MFT
Julian Hamaan	**JH**	Consultant ENT & Thyroid Surgeon	MTW
Evelyn Bateta	**EB**	Head & Neck CNS	MTW
Siva Sivappriyan	**SS**	Consultant Physician in Diabetes & Endocrinology	MTW
Luisa Roldaopereira	**LR**	Therapy Lead and Advanced Practitioner in Nuclear Medicine Physics	MTW
Gemma McCormick	**GM**	Consultant Clinical Oncologist	MTW
Chris Singleton	**CS**	Senior Programme Manager – Cancer Commissioning	NHS Kent & Medway CCG / KMCA
Bana Haddad	**BH**	Macmillan GP & Cancer Lead / Clinical Lead – LWBC/PC&S	NHS Kent & Medway CCG / KMCA

Nav Upile	**NU**	Consultant Otolaryngologist Head and Neck Surgeon	MFT & QVH
Apologies			
Padmini Manghat	**PM**	Consultant - Biochemistry	DVH
Pippa Enticknap	**PE**	Senior Service Manager – CCHH Care Group	EKHUFT
Edmund Lamb	**EL**	Consultant Clinical Scientist / Clinical Director of Pathology	EKHUFT
Alistair Balfour	**AB**	Consultant ENT, Head & Neck and Thyroid Surgeon	EKHUFT
Eranga Nissanka-Jayasuriya	**ENJ**	Consultant Cellular Pathologist	EKHUFT
Ali Al-Lami	**AAL**	Consultant ENT / Head & Neck Surgeon	EKHUFT
Jeremy Davis	**JD**	Consultant ENT Surgeon	MFT
Debbie Owen	**DO**	Macmillan Head & Neck CNS	MFT
Mohamed Kenawi	**MK**	Consultant Radiologist	MFT
Cynthia Matarutse	**CM**	Lead Cancer Nurse	MFT
Ann Fleming	**AF**	Consultant Histopathologist	MTW
Mary Boyle	**MB**	Consultant Cellular Pathologist	MTW

Item		Discussion	Agreed	Action
1.	**TSSG Meeting**	**Apologies** • The apologies are listed above. **Introduction** • CT kindly agreed to chair today's meeting in the absence of JD who sent his apologies. CT welcomed the members to the meeting and asked them to introduce themselves. • If you attended this meeting and are not captured on the attendance list please contact karen.glass3@nhs.net separately and she will update the distribution list accordingly. **Review previous minutes** • CT confirmed the previous minutes from the meeting which took place on the 20th September 2021 could be signed off as a true and accurate record.		

		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.	**Endocrine GIRFT**	**Endocrinology – GIRFT Programme National Specialty Report - update by Chris Theokli** • CT highlighted the national GIRFT document which has been circulated prior to the meeting. He emphasized some of the key areas which include the patient pathway and what constitutes good patient care for thyroid surgery / outcomes. This looks specifically at variation across the trusts depending on the volume of surgeries. • High volume Centre's are classified as such due to them performing over 100 thyroid procedures per year. This also includes complications and the length of stay of the patient. • There is reference to the experience of the surgeon which is also defined by the number of procedures carried out. The immediate recommendations are for each surgeon to perform 20 thyroid surgeries per year. CT is confident most of their surgeons would fall into this category. VD assumed that has been the case for many years. • CT explained the more experienced trusts in terms of volume and hypocalcaemia equates to lower re-admission rates for patients. • CT continued over the next 2-3 years every surgeon should aim to perform at least 50 individual thyroid procedures per year to include both hemi and total thyroidectomies which he is not sure how realistic that target would be. • The document suggests that the training posts should be offered to the Centre's who perform over 100 thyroid surgeries per year. CT is positive that both MFT and EKHUFT fall under that umbrella. JH stated MTW also perform approximately 120 per year. CT and JH agreed that Covid has had an impact on training and their ability to operate. CT highlighted these are the ideal recommendations going forward. The Centre's that do best tend in terms of managing thyroid complications such as hypocalcaemia have clear		**Presentation circulated to the group on the 5th April 2022.**

		protocols and SOP in place – hypocalcaemia flowchart on P97 of the report. • CT highlighted on P26 – recommendations for the ideal of length of stay following surgery: i) Parathyroidectomy – 90% of cases should be performed as day cases • General consensus from the group is the patient is kept in overnight for observation due to hypocalcaemia and a neck drain. Each additional day that the patient stays in hospital is costing the NHS £339. **<u>Action</u>: CT suggested asking a junior doctor from each trust to explore the practice adopted across the patch and look at the calcium level for day 1 post surgery. VD agreed as long as all sites were willing to collaborate with this study. CT added this would be a good opportunity for them to potentially change their practice to do day case parathyroid surgery. This could also improve the patient pathway and have possible financial savings for the NHS. VD agreed to email the trusts and AW to help coordinate.** • Discussion followed regarding hemithyroidectomy for which they agreed patients should be kept in hospital overnight to be monitored.		**VD / AW**
3.	**BAETS-UKRETS**	• RH explained this update has been presented previously and was not sure why it was back on the agenda for today. • CT added the GIRFT recommendation states they should be entering surgeon-specific data to the national framework - the BAETS-UKRETS database. • RH added not everyone has been updating to GIRFT and asked if this was a TSSG recommendation. JH explained he does not, but is happy to do so as long as MTW can provide him with access to the BAETS database. JH is adamant if this becomes mandatory it should be funded by the trusts and added he is not a BAETS member. As a BAETS member this would be free. • CT suggested as a TSSG they should be encouraging everyone to enter the data onto BAETS and those that do have a better understanding of any complications and where		

		they are as a surgeon. JH asked if funding could be provided. **Action – CT agreed to discuss with AW outside of this meeting whether individual funding could be provided and where this would come from.**		**CT / AW**
4.	**PIFU** **Stratified Pathway**	**<u>Update provided by Chris Theokli</u>** • CT explained the patient stratified pathway has taken off in the last year and they are looking at a way of being able to stream-line post-cancer follow-up for patients safely and remotely. This is not the same as the PIFU route which CT does not feel is appropriate for their patients. They will still be able to monitor their patients be it consultant or nurse-led from a remote standpoint and not face to face every year. • CT suggested that follow up patients have their thyroid surgery / radioactive iodine and treatment and then would be deemed to be complete. 9 - 12 months following treatment a dynamic risk stratification which involves a stimulated thyroglobulin and Ultrasound scan would then take place. There is talk over the next year to stop the stimulated thyroglobulin. • From the first year of follow up to 10 years this could be conducted remotely with an annual thyroglobulin and annual thyroid function. Patients will be informed that they are still under the care of their trust, they have not been discharged and will have access to their nurse specialist. If patients experience any of the red flags – lumps, difficulty swallowing or voice change they will be recalled to clinic. • There will be safety netting put in place in case the patient does not answer their telephone or DNA face to face appointments. In this scenario they will contact the GP directly to chase the patient. Any abnormal results will trigger a letter for the patient to be recalled to clinic or a telephone clinic. • CT elaborated on the PSFU eligibility criteria for inclusion / exclusion and the red flags for recall. CT added they will only be dealing with adults over the age of 18 as children will be managed in specialist tertiary Centre's. They propose to do the remote follow up for 10 years – every year and after 10 years will be discharged from secondary care. The patient will flow between consultant – nurse and supported self-management dependent		

		on their results. • Patients who would be appropriate for the supported self-management would be those that have a good understanding / good psychological overview and are also willing to have remote follow up. CT thinks it is a good way of managing these patient's long term. Many thyroid cancer follow-up patients are straightforward to manage in terms of their care and they do not need to see them regularly face to face. Thyroglobulin is so sensitive that it now gives them more confidence to manage these patients remotely. • CT confirmed those patients who still want reassurance to be seen face to face will still have that option and every patient will be different. CT's experience is there are a lot of his patients who are very happy to be seen remotely. • JH asked the reason why and what the merit is in taking this forward. JH admitted it is easier for him to see his patients face to face, to examine their neck and this provides reassurance for the patient. He understands they would save clinic space and also the patient travelling to the hospital. CT understands but explains they will be freeing up valuable resources with consultant and clinic time, face to face appointments and the patient does not need to travel, parking costs etc. JH agreed there should be flexibility but is important that it should come down to patient choice with perhaps less frequent face to face appointments. • SH explained she has been doing nurse led follow up appointments for approximately 5 years and has only had a couple of patients who have asked for a face to face appointment – which was organized. They have picked up some recurrences due to the sensitivity of the thyroglobulin. SH added these are generally younger patients who are working and overall has been very well received. Over time she has been able to cancel down the face to face appointments as they have not been required. • MA mentioned her concern regarding the inclusion criteria and discharging patients with nodal end disease as often these patients recur. CT agreed everyone needs to be happy with the inclusion / exclusion criteria and can look further into this. He added these patients would not be discharged as they would still be monitored. • TR explained she has qualitative data from patients who would prefer a telephone call rather than coming into hospital for results, as long as they have the reassurance they		

		can see the clinician if required. TR has details of 2 thyroid patients and is happy to ask their views. • JH was not convinced this would be revolutionary with regards to massive savings for the NHS but can understand the benefits to the patients. He does not think it is a completely bad idea and agreed patients should be able to opt in and out as required. • CM confirmed they have been working to implement the supported self-management pathways in other tumour groups including prostate at DVH for approximately 6 years. CM agreed there are lots of positive points raised by patients and it would be appropriate for new patients to go on the pathway then build up other patients to transfer over. CM explained the supported self-management pathway is a complete pathway of personalized care for the patient which includes holistic needs assessments and a complete package of care for these patients. The patient would also receive a treatment summary which would be more patient and GP friendly. This would cover diagnosis, treatment, prognosis, common side-effects, red flags, GP actions, medication and also articulates the secondary care management pathway for a 10-year period. CM highlighted this would create additional clinical time for those patients who may really need it. • LR asked where it is stated as nurse-led it should also include ACP led or simply ACP which covers all professions. CM agreed to take this forward. **Action: It was agreed for CM to re-set up the working group to include those involved previously and also any others who are keen to discuss further. CT suggested MA was also involved in those discussions. CT would be keen for this to be signed off at the next TSSG meeting.**		**CM**
5.	**Research**	**<u>HoT Trial</u>** • CT confirmed after speaking to AB, EKHUFT will no longer be participating in this trial and asked AW to remove this from the research topics. This is due to the logistics of moving forward with this trial. **<u>Any other research</u>**		

		Action: **AW to contact MA to request an update on any other research projects.**		**AW**
6.	**Audit**	**<u>Hemithyroidectomy – update provided by Vikram Dhar</u>** • VD explained he has not made any progress on setting up this audit which he had followed up on 3 separate occasions to encourage further involvement. VD added this needed to be a simple, doable and comparable audit across the trusts. • VD suggested they stick to this simple audit and present at the next TSSG meeting. JH agreed but added they will be relying on their trainees / middle grades to do the audit. VD suggested sticking with their registrar as the SHO's move on after 4-6 months. • The group agreed to stick with the parathyroid audit across the patch. It was agreed to clarify with JD as they did not think that they do PTH routinely for parathyroid at MFT and thought this was done later as an outpatient. **Action** – **CT suggested they still take this audit forward to ensure best practice across the patch. Update at the next meeting.**		**VD**
7.	**Galleri Grail Trial**	**<u>Presentation provided by Chris Theokli</u>** • CT explained Galleri Grail is a national trial and is a revolutionary blood test which aims to pick up early signs of cancer. The aim is to recruit 140,000 people over the course of the next year. NU stated it is circulating micro DNA's in the bloodstream. • CT explained the blood test can pick up many different types of cancer which are hard to diagnose and includes both thyroid and head & neck. • Grail is a US based company working alongside Cancer Research UK and the NHS. There are 8 regions nationally involved in the trial with SE London and K&M being part of this.		

		• Inclusion criteria – participants must be: i) Age 50-77 years old ii) Registered at a GP within a participating Cancer Alliance and iii) Not diagnosed with cancer in the past 3 years or currently under diagnostic follow up / treatment for cancer • Patients are selected through Primary Care. CT explained the process of when the blood is taken there are two arms to the study – control arm and interventional arm. The interventional arm means the blood is shipped to GRAIL whereby a test is performed to see if a signal is detected or not. If a signal is detected the patients GP is informed whereby a 2ww referral is triggered by the trial team to determine cancer or not. If a signal is not detected – there is no further action. • CS emphasised the 2ww referrals are made directly by the GRAIL trials unit and not the GP and they are hosted by GSTT. The patient will be referred directly to the relevant 2ww tumour group pathway at the trust closest to them. CS added GP's are aware of the trial but are not involved with the onward referral. • NU highlighted the trial started in Dartford and are currently in Medway. They have had 5 referrals as a consequence 3 have proven to be cancer 2 H&N and 1 rectal - in asymptomatic people. • CP mentioned they have had 11 referrals with 4 that have come back as cancer in patients that have also been totally asymptomatic. CP supports GRAIL and thinks it is the future. CP stated he is getting the referral from the GP's and not from the trials team directly. **CS agreed to pick up any operational issues and discuss with the trials team at their weekly meeting**. • CS provided some additional details in that 70,000 participants nationally have now been recruited. In terms of location the Grail team are currently in Thanet, previously in Dartford in October, then Medway, Sittingbourne and is due to go to Maidstone on the 7th April, back to Sittingbourne again due to some operational issues and then onto Ashford. There is a smaller Grail van which is currently located in Folkestone. The trial has received a lot of positive political feedback. CS concluded the trial is under constant review with the aim to roll out as a national programme in the future.		

8.	**Thyroid data**	• CT highlighted that he has looked at the Cancer Waiting Times dataset provided by David Osborne (CA Data Analyst) and unfortunately there has been no change which he finds extremely frustrating. There appears to still be incorrect and missing data from both MTW and MFT. The thyroid coding is being swallowed up by the H&N coding so as a consequence the data is vastly under reported. • **SH agreed to ask Hannah to send TR a copy of the generic letter which goes out patients on the 28-day FDS. TR agreed to run this past the patient group to see if there could be any improvements made. TR stated the importance of patients being an integral part of the co-design of the letters.** • CT highlighted that the 62-day data is more difficult to be compliant across both East and West Kent due to radiology delays, access to theatres, surgeon availability and Covid has also impacted. • SH mentioned they have 20 – 25, 2ww thyroid patients per week. Therefore, the data presented today is a massive underestimation to what they are also seeing in EKHUFT and is not good enough. • NU suggested the Cancer Alliance have a tracker to cover both East and West Kent. The figures across the trusts are so distorted they make no sense for both thyroid and H&N. CT mentioned they need to track the thyroid data to identify areas of weakness and delays and also help them evolve their service.		**Presentation circulated to the group on the 5th April 2022** **SH / TR**
9.	**CNS Update**	**<u>MFT – update provided by Debbie Hannant</u>** • Working on the thyroid stratified pathway and have recruited a Band 4 Cancer Support Worker to support their workload. • Headstart - the patient support group, is still currently on hold. They hope to run as face to face meetings from the summer onwards. **<u>MTW – update provided by Evelyn Bateta</u>**		

		• EB explained she has started in her new role within ENT at MTW. She is trying to set up the service and as such has no further update for the meeting today. **<u>EKHUFT – update provided by Sue Honour</u>** • The team are working on the thyroid stratified pathway and have recruited a patient to support this. • They have recruited a Cancer Support Worker (Anna) and she will be supporting work on patient information leaflets, HNAs and treatment summaries.		
10.	**CA/CCG Update**	**<u>Update provided by Chris Singleton</u>** • CS provided an update on the national planning guidance – cancer priorities for 2022/23 and the key themes include: i) Faster Diagnosis and operational improvement ii) Early Diagnosis iii) Treatments and Personalised Care iv) Cross Cutting Themes • CS explained the highlights and ongoing projects from a K&M perspective: i) Roll out of the Non-site-specific services (previously called VISS) across K&M – with the plan for there to be 100% coverage nationally. This also includes the Rapid Lymphadenopathy service. ii) Support best practice timed pathways for prostate, colorectal, lung and UGI and the roll out of newly published timed pathways for H&N and Gynae. iii) Galleri Grail pilot will continue in K&M until June 2022. iv) Targeted Lung Health checks will be launched in the summer in East Kent. v) Continue to support pilots including Cytosponge, Colon Capsule Endoscopy and the provision of Lynch Syndrome testing and Liver surveillance. vi) Treatments and Personalised Care – ongoing support to implement the patient stratified follow up pathway. Prostate and colorectal are running in some areas with ongoing work as discussed earlier for thyroid.		**Presentation circulated to the group on the 5th April 2022.**

		vii) Cross Cutting themes – new Cancer Workforce lead to support the Cancer Alliance / ICB and will start in April. viii) Promoting the uptake of the Cancer Patient Experience Survey ix) Ongoing work to target health inequalities across K&M.		
11.	**TSSG – Future Chair**	• CT confirmed JD will be stepping down as the Thyroid TSSG Chair from the next meeting. JD would like the group to be aware that AW will be sending out EOI to the group to see who would be interested in taking over from him.		
12.	**AOB**	• NC suggested conducting a TSSG wide audit across both East and West Kent regarding the adequacy and criteria of the FNAs and if they are over treating patients. NC added they are doing something already at EKHUFT but wondered if there was something similar conducted across West Kent. JH mentioned they do not generally do FNA – U2's in West Kent and there will be a specific reason if this does happen. **Action - NC agreed to check the current US guidance compared to her update from 2 years ago when she travelled to Boston regarding the thyroid FNA's. NC mentioned their categorization is slightly different to the UK. NC would be happy to update at the next TSSG meeting.** • AW thanked CT for chairing the meeting today.		**NC**
13.	**Next Meeting Date**	• Discussion followed regarding potential days for the future thyroid TSSG meetings. Suggestion was agreed to rotate the days which would help with future attendance from all trusts. • Date to be discussed separately with JD and also at the H&N meeting later today. If necessary AW to send out a doodle poll to canvas the best day of the week for the next meeting.		**AW / JD**