Kent and Medway Cancer Collaborative

Thyroid Tumour Site Specific Group meeting
Tuesday 6th September 2022
Great Danes (Mercure) Hotel, Maidstone, ME17 1RE
09:30-12:30

Final Meeting Notes

Present	Initials	Title	Organisation
Jeremy Davis (Chair)	**JD**	Consultant ENT Surgeon	MFT
Chris Theokli	**CT**	Consultant ENT Thyroid Surgeon	EKHUFT
Sue Honour	**SH**	Macmillan Lead Head & Neck and Thyroid CNS	EKHUFT
Ali Al-Lami	**AAL**	Consultant ENT / Head & Neck Surgeon	EKHUFT
Alistair Balfour	**AB**	Consultant ENT, Head & Neck and Thyroid Surgeon	EKHUFT
Basim Wahba	**BW**	Specialist Registrar	EKHUFT
Muhammad Eraibey	**ME**	Consultant Radiologist	EKHUFT
Nicola Chaston	**NC**	Consultant Cellular Pathologist	EKHUFT
Sarah Reeves	**SR**	Consultant Biomedical Scientist	EKHUFT
Carol Hammond	**CH**	Biomedical Scientist Cytology	EKHUFT
Hannah Brann	**HB**	Cancer Pathway Navigator	EKHUFT
Karen Glass (Minutes)	**KG**	Administration & Support Officer	KMCC & KMCA
Annette Wiltshire	**AW**	Service Improvement Facilitator	KMCC
Tracey Ryan	**TR**	Macmillan User Involvement Manager	KMCA
Debbie Hannant	**DH**	Macmillan Head & Neck CNS	MFT & DVH
Maria Acosta	**MA**	Consultant Physician in Nuclear Medicine	MFT
Coimbatore Praveena	**CP**	Consultant H&N, Thyroid & ENT Surgeon	MFT
Suzanne Bodkin	**SB**	Cancer Pathway Manager	MFT
Mohamed Kenawi	**MK**	Consultant Radiologist	MFT
Adam Gaunt	**AG**	Specialty Registrar Otolaryngology, Head and Neck Surgery	MFT
Navdeep Upile	**NU**	Consultant Otolaryngologist Head and Neck Surgeon	MFT & QVH
Evelyn Bateta	**EB**	Head & Neck CNS	MTW
Siva Sivappriyan	**SS**	Consultant Physician in Diabetes & Endocrinology	MTW
Luisa Roldao Pereira	**LR**	Nuclear Medicine Superintendent and Advanced Clinical Practitioner Project Lead	MTW

Jesse Kumar	**JK**	Consultant Endocrinologist & Diabetologist	MTW
Chris Singleton	**CS**	Senior Programme Manager – Cancer Commissioning	NHS Kent & Medway ICB / KMCA
Bana Haddad	**BH**	Macmillan GP & Cancer Lead / Clinical Lead – LWBC/PC&S	NHS Kent & Medway ICB / KMCA
Apologies			
Pippa Enticknap	**PE**	Senior Service Manager – CCHH Care Group	EKHUFT
Edmund Lamb	**EL**	Consultant Clinical Scientist / Clinical Director of Pathology	EKHUFT
Robert Hone	**RH**	Head & Neck Otolaryngology Consultant	EKHUFT
Sarah Stevens	**SS**	Macmillan Speech and Language Therapist	EKHUFT
Susan Green	**SGr**	Project Manager – Personalised Care & Support	KMCA
Supriya Joshi	**SJ**	Consultant Chemical Pathologist	MTW
Gemma McCormick	**GM**	Consultant Clinical Oncologist	MTW
Mary Boyle	**MB**	Consultant Cellular Pathologist	MTW
Sona Gupta	**SGu**	Macmillan GP and Cancer Lead	NHS Kent & Medway ICB

Item		Discussion	Agreed	Action
1.	**TSSG Meeting**	**<u>Apologies</u>** • The apologies are listed above. **<u>Introductions</u>** • JD welcomed the members to today's face to face meeting. JD explained this would be his last meeting as the Chair of the Thyroid TSSG. He congratulated and thanked CT for taking over this role. • If you attended this meeting and are not captured on the attendance list please contact karen.glass3@nhs.net directly and she will update the distribution list accordingly. **<u>Review previous minutes</u>**		

		• JD confirmed the previous minutes from the meeting which took place on the 29th March 2022 could be signed off as a true and accurate account of the meeting. **<u>Review action log</u>** • The action log was reviewed, updated and will be circulated to the members along with the final minutes from today's meeting.		
2.	**Stratified Pathway** **Discussions**	**<u>Update by Chris Theokli and Bana Haddad</u>** • CT provided a detailed update on the supported self-management pathway for Thyroid cancer patients. CT mentioned a working group was set up – which was an action from the previous Thyroid TSSG meeting. CT and BH would be keen to get this pathway signed off at today's TSSG meeting. • The supported self-management pathway is a complete pathway of personalised care for the patient which includes holistic needs assessments and a complete package of care. 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. This would create additional clinical time for those patients who may really need it. • CT explained at the 12-month post-surgery Consultant led appointment a decision would be made together with the patient regarding progressing onto the Personalised Stratified Follow Up (PSFU) and supported self-management (SSM) pathway. Patients deemed eligible for SSM would be followed up remotely for a total of 10 years. They would have an annual thyroglobulin blood test and still remain under the care of Secondary Care. After 10 years the patient will be discharged from SC. • Patients will be provided with a treatment summary and any of the following red flags would trigger a recall back into clinic:		**Document circulated to the group on the 7th September 2022**

		i) Lumps ii) Difficulty swallowing iii) Voice changes iv) Abnormal results • Patients will have access to the patient summary and a plan going forward and they would be eligible to opt in and opt out of SSM. Only those patients appropriate to go onto SSM should have a good understanding, good psychological overview and be willing to agree to the remote follow up. • Safety netting will be in place to capture patients who do not answer their telephone or DNA face to face appointments – such as blood tests. The GP will be contacted directly to chase those patients. **Actions:** **i) A patient letter / leaflet will be created and standardised for K&M trusts to use with the exception of direct details for each trust.** **ii) Review the updated NICE Guidelines (due late 2022) at the next meeting. Modify any recommendations as necessary.** • CT outlined the Thyroid PSFU inclusion, exclusion and red flag criteria. This would allow patients to drop in and out of the pathway as required. JD asked if the inclusion criteria could be made clearer to include radioactive iodine and to define the blood tests in more detail. • CT explained eligible SP patients would flow back and forth from Consultant led to ACP/Nurse led to Supported Self-Management as required. • Pregnant women would have their TSH levels reviewed every 6 weeks and would be closely monitored under the Obstetric Endocrine service. • It was noted that the PIFU (Patient Initiated Follow Up) pathway was **NOT** appropriate for patients with Thyroid cancer. CT explained there will be rare cases of patients who would not be suitable for the SP and these patients would continue to be seen face to face. No patients would be put at risk and their safety is paramount.		**Trusts / CT / AW**

		• Benefits outlined of the SSM include: i) Free up valuable resources for the consultant plus additional clinic time ii) Patient does not need to travel – save having time off of work and parking costs etc iii) Patient choice – there has been excellent feedback to date iv) National Cancer Alliance ongoing funding – to be opened up to all tumour groups. • MA was concerned regarding the inclusion criteria and discharging patients with nodal end disease as these patients often recur. CT confirmed these patients would continue to be closely monitored. • BH explained there is no IT package yet in place. However, once the inclusion / exclusion criteria have been signed off, this will go to the digital InfoFlex team and onto the design workshop. One of the trusts (EKHUFT, MFT or MTW) would then be chosen to take forward the pilot. • BH explained that Cancer Alliance transformational funding has paid for 2 x new band 4 Clinical Support Workers at MFT and EKHUFT. Part of their role will be to chase and safety net those patients who have missed or have abnormal blood test results. This will trigger a digital red alert when the pathway has been set up. Patients will have no access to the IT system. • **The members agreed the sign off of the supported self-management pathway for Thyroid cancer patients at today's meeting. Further updates will be provided in due course.**		
3.	**Audit – One Stop Clinic**	**<u>Thyroid Rose – update by Sarah Reeves and Carol Hammond</u>** • SR explained the ROSE clinic is: i) Rapid On Site Evaluation – real time assessment. ii) Immediate feedback, guidance and communication with the clinician iii) Confirmation of diagnostic sampling – 6 groups of 10 or more well preserved cells.		**Presentation was circulated to the group on 7th September 2022**

		• SR outlined the process for setting up the clinic and technique used. SR added they are a small team of only 2 now. • The adequacy rate (pre-ROSE) at the WHH for thyroid was around 62% (Aug 2017 – Aug 2018). ROSE started in May 2019 – adequacy rate was 91%, 89% in 2020 and 83% in 2021. They are seeing more complex cases now and as such the adequacy rate has gone down. • Learning outcomes include: i) Optimal patient list ii) Complex cases iii) Communication is key iv) Assessment without pressure v) If 'borderline' take another pass. • The group agreed this was an excellent service. • SR confirmed it is best to use <u>no</u> suction to get an adequate sample and by using capillary pressure. The estimated time with each patient is about 14 minutes to obtain 2 passes. **Action – It was agreed to update the Clinical Diagnostic Imaging Network Board in order to improve the learning and to obtain the best smearing techniques across the patch. Sarah agreed to offer some additional training.**		**CS / SR**
4.	**Nice – Thyroid Cancer Draft published**	**<u>Update by Jeremy Davis</u>** • JD provided an update on the national requirements for the management of 2ww referrals. JD emphasised the importance of not taking a patient off of the 2ww pathway if it is an inappropriate referral without discussing first with the referrer. Only the referrer can downgrade or withdraw a referral. • JD highlighted that Thyroid cancer cannot be ruled out within 28-days. It is imperative to get the patient into the system as early as possible.		**Presentation was circulated to the group on 7th September 2022**

		• The updated version (v12) of NICE guidelines is due out at the end of this year early next year.		
5.	**62-day pathways and likely changes** **2ww guidance summary**	**Update by Jeremy Davis** • If a Consultant upgrades a patient for a first primary cancer the 62-day period starts (day 0 and not date of referral) as the Consultant upgrade date. Only those upgrades with a newly diagnosed cancer will go on to treatment and need to be reported. The clock stop for the 62-day standard is at the point when the patient receives their first definitive treatment for cancer. • The Cancer Alliance have agreed the format for 2ww is: i) Telephone Consultation with patient – Consultant led ii) Contact PC provider – to reject the referral and PC have accepted the rejected referral iii) Patient to be consulted iv) Telephone appointment with the patient – to be recorded • Please see document sources below: • **CWT v11 Current National Cancer Waiting Times Monitoring Dataset (england.nhs.uk)** • **Clarification of cancer waiting times guidance during the COVID-19 pandemic - NHS Digital** • **CWT v12 Proposed Changes to the CWT Dataset (england.nhs.uk)**		
6.	**US Guidance**	**Update by Nicola Chaston** • NC provided an update on Thyroid Cytology grading since her visit to Boston 3 years ago. • Thyroid Cytology grading – several systems are used internationally with Bethesda the best known for reporting FNA cytopathology. NC highlighted the difference of Bethesda 2009 compared to Bethesda 2017.		**Presentation was circulated to the group on 7th September 2022**

		• Bethesda 2017: i) No real change in grading groups but risk of malignancy and management has been updated. ii) The main reason for the change (both of risk and management) is molecular testing on FNA samples. • Comparison of the systems – Royal College of Pathologists, Bethesda, Italian, Australian and Japanese. Japanese is very complex, whereas Australian and Bethesda are very similar. • NC highlighted that the cost is an issue – which is going up and has implications. Comparing the cost of testing to undertaking diagnostic hemithyroidectomy. Additionally, many patients will go on to have surgery anyway.		
7.	**CNS Updates**	**<u>EKHUFT - update by Sue Honour</u>** • SH confirmed they have recruited a patient representative who will support the Thyroid stratified pathway. • The Cancer Support Worker (Anna) will be supporting work on the patient information leaflets, HNA's and treatment summaries. **<u>MFT & MTW - update by Evelyn Bateta</u>** • LRP (from MTW) would be leading on the stratified pathway (as an ACP, instead of nurse-led). • Patient leaflets are yet to be agreed. • Plan to re-start HEADSTART – the patient support group in December across all sites. • The Health and Well Being events with Macmillan are due to re-start at MFT – these were stopped due to Covid.		

8.	**Research**	**<u>Update provided by Maria Acosta</u>** • MA provided an update on the HoT clinical trial which is a US based company – hemithyroidectomy versus total thyroidectomy randomised 6-year trial. This has been approved and 20 Centre's have opened across the UK with patients initiated into the trial. • MA referenced the INSPIRE clinical trial which could potentially allow for personalised treatment planning when using radio-iodine for thyroid cancer.		
9.	**CA Update**	**<u>Update by Chris Singleton</u>** • CS highlighted the national cancer programme priorities, which were outlined in the NHS Planning Guidance published earlier in the year. • CS provided a brief overview of the current K&M position regarding these priorities, focusing where relevant on tumour site specific aspects which will be of most interest. • The Cancer Alliance continues the roll-out of comprehensive NSS pathways across K&M. In October it is anticipated that 2 out of the 4 NSS pathways will be live, with the remaining to follow in due course. EKHUFT and DVH will be the first to go live. These will incorporate Rapid Lymphadenopathy and MUO pathways. RL pathway will be below the clavical, so no impact on Thyroid or H&N pathways. They are taking a K&M approach to ensure consistency across the system. This will put K&M in a good position to substantively commission from 2024 onwards. • The CA is supporting the introduction and roll-out of new best practice timed pathways, with H&N and gynae recently published, as well as supporting further development of Straight to Test pathways. • In terms of early diagnosis, the Galleri GRAIL pilot will start its second round for K&M in		**Presentation was circulated to the group on 7th September 2022.**

		October. First round was successful, and whilst there is no national outcome data yet, there is anecdotal evidence of cancers being diagnosed at an early stage before symptoms. • K&M will be launching the first stage of the Targeted Lung Health Check (TLHC) programme in one locality of East Kent later in the year. • Early Diagnosis colleagues held a successful HUHY campaign focusing on skin in coastal locations during the summer. • Also working on testing for lynch syndrome and liver surveillance. • Primary Care cancer dashboard was produced and circulated to local PCNs to help them understand and analyse their cancer data. • From a treatments' and personalised care perspective, key focus is rolling out PSFU pathways in colorectal and prostate, as well as developing remote monitoring for thyroid, gynae and skin pathways. This is all supported by local InfoFlex colleagues building systems to enable this. • Crosscutting themes include promoting uptake of cancer patient experience surveys and under 16 CPES. CA and ICB have appointed a Cancer Workforce Programme Lead (Becky Nelhams) to develop cancer workforce strategy and plan, as well as take forward issues identified in the AO project last year. Also supporting NSS patient navigators with training and upskilling. • Lastly, CA is finalising health inequalities toolkit to inform specific areas for focus.		
10.	**AOB**	• AB mentioned on behalf of EL there was an error recently regarding thyroglobulin levels – he reassured the group that this has had no impact on patient care and all patients were checked and their levels corrected.		

11.	**Next Meeting Date**	• To be agreed after the Head & Neck TSSG meeting and the date will be circulated to the group.		**KG to circulate invites when the date has been confirmed.**