Kent and Medway Cancer Collaborative

Thyroid Tumour Site Specific Group meeting
Monday 20th September 2021
Microsoft Teams
09:30-12:30

Final Meeting Notes

Present	Initials	Title	Organisation
Jeremy Davis (Chair)	**JD**	Consultant ENT Surgeon	MFT
Mohamed Kenawi	**MK**	Consultant Radiologist	MFT
Debbie Hannant	**DH**	Macmillan Head & Neck CNS	MFT
Jennifer Priaulx	**JP**	Macmillan Cancer Transformation Project Manager	MFT
Maria Acosta	**MA**	Consultant Physician in Nuclear Medicine	MFT
Ellie Thomas	**ET**	Deputy Director of Operations for Planned Care	MFT
Deborah Owen	**DO**	Macmillan Head & Neck CNS	MFT
Anya Selwyn	**AS**	ENT SpR – on maternity leave	MFT
Delphine Nkuliza	**DN**	ENT Clinical Fellow	MFT
John Kyle	**JK**	Implementation Consultant	CIVICA
Shwetal Dighe	**SD**	Consultant Upper GI & Thyroid Surgeon	DVH
Alistair Balfour	**AB**	Consultant ENT, Head & Neck and Thyroid Surgeon	EKHUFT
Robert Hone	**RH**	Consultant ENT Surgeon	EKHUFT
Ali Al-Lami	**AAL**	Consultant ENT / Head & Neck Surgeon	EKHUFT
Eranga Nissanka-Jayasuriya	**ENJ**	Consultant Cellular Pathologist	EKHUFT
Vikram Dhar	**VD**	Consultant ENT Surgeon	EKHUFT
Sue Honour	**SH**	Macmillan Lead Head and Neck & Neck and Thyroid CNS	EKHUFT
Claire Mallett	**CM**	Programme Lead – LWBC/PC&S	KMCA
Karen Glass (Notes)	**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	KMCC
Gemma McCormick	**GM**	Consultant Clinical Oncologist	MTW
Evelyn Bateta	**EB**	Head & Neck CNS	MTW
Bana Haddad	**BH**	Macmillan GP & Cancer Lead / Clinical Lead – LWBC/PC&S	NHS Kent & Medway CCG / KMCA
Chris Singleton	**CS**	Senior Programme Manager – KMCA	NHS Kent & Medway CCG
Navdeep Upile	**NU**	Consultant Otolaryngologist Head and Neck Surgeon	QVH
Apologies			
Lesley Northam	**LN**	Lead Sonographer	DVH

Chris Theokli	**CT**	Consultant ENT / Head & Neck Surgeon	EKHUFT
Pippa Miles	**PM**	Senior Service Manager – CCHH Care Group	EKHUFT
Sarah Stevens	**SS**	Macmillan Speech & Language Therapist	EKHUFT
Edmund Lamb	**EL**	Consultant Clinical Scientist / Clinical Director of Pathology	EKHUFT
Elizabeth Hall	**EH**	Principal Clinical Scientist	EKHUFT
Chris Hopkins	**CH**	Cancer Compliance Manager	EKHUFT
Mandy Griffin	**MG**	ENT Operations Manager	EKHUFT
Sandra Holness	**SH**	Cancer Pathway Tracking Coordinator	EKHUFT
Sue Drakeley	**SD**	Oncology (Solid Tumour) Research Team Leader	EKHUFT
Abbi Smith	**AS**	Head & Neck CNS	EKHUFT
Serena Gilbert	**SGi**	Cancer Performance Manager	KMCA
Katherine Steele	**KS**	SpR / Teaching Fellow	MFT
Ann Courtness	**AC**	Macmillan Primary Care Nurse Facilitator	NHS Kent & Medway CCG
Jack Jacobs	**JJ**	Macmillan GP & Cancer Lead	NHS Kent & Medway CCG
Sona Gupta	**SGu**	Macmillan GP & Cancer Lead	NHS Kent & Medway CCG
Rakesh Koria	**RK**	Macmillan GP Associate Advisor for Kent and Medway & NHSE GP Appraiser	NHS Kent & Medway CCG

Item		Discussion	Agreed	Action
1.	**TSSG Meeting**	**<u>Apologies</u>** • The apologies are listed above. **<u>Introductions</u>** • JD welcomed Gemma McCormick as a new member to this meeting and confirmed she would be taking over from Nick (Rowell) at MTW as the Thyroid Oncologist. JD welcomed the attendees to the meeting. • 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. **<u>Review previous minutes</u>** • JD confirmed the minutes from the previous meeting on the 16th March 2021 could be signed off as a true and accurate record.		

		Review previous actions • The action log was reviewed, updated and will be circulated with the final minutes from today's meeting.		
2.	**Personalised Care & Support**	**Presentation provided by Claire Mallett & Bana Haddad** • BH alluded to a short meeting which took place a few weeks ago regarding personalised care and follow up for thyroid patients. BH agreed to elaborate further today regarding both the national and local context and whether this would be appropriate for Kent & Medway thyroid patients. • BH mentioned the Breast stratified pathway is now fully functional across K&M. Colorectal has been set up in EKHUFT with the other trusts to follow shortly. They are waiting for the prostate patient portal to be set up in Q3. Nationally they have been asked to set up an additional 3 cancer pathways and to fully implement one pathway by March 2022. • BH explained the importance of setting up the Patient-Initiated Follow Up (PIFU) / Stratified Pathway is to improve the patients' outcome and experience throughout their cancer pathway. • BH asked for the groups thoughts and if it would be appropriate to set up a remote monitoring follow up pathway at this time for their thyroid patients. BH understood the service may be led differently across the patch, as either nurse or consultant led. The numbers of thyroid patients going through the follow up pathway is much smaller compared to prostate and breast patients. • BH explained there has been very good clinical engagement from the other tumour groups and for thyroid they would require a standardised protocol to be set up across the patch to include: i) inclusion and exclusion criteria ii) process for managing tests remotely iii) triggers for recall iv) who holds the responsibility for the follow-up? v) auditing vi) agreement of the standard letters and templates vii) Personalised care interventions package (HNA) viii) Treatment Summaries ix) Health and Wellbeing provision plans		**KG circulated this presentation on the 21.09.2021**

		• BH mentioned they have started working with a number of Lymphoma patients and have had very good clinical engagement. They hope to have the protocol signed off by November 2022, followed by the InfoFlex design and finally piloting the stratified pathway. • BH highlighted the steps along the digital journey from May 2018 to April 2021. BH wondered if the group thought this would be a good time to embark on the Thyroid stratified pathway but insisted there needed to be good clinical engagement. BH added they have had transformational funding to help set up the thyroid stratified pathway. • JD stated he thinks this is something they can do and should do for their patients. JD questioned the funding available. JD admitted he did not personally have the time to engage at the moment as needed. JD suggested there should be a doctor, clinician and CNS involvement initially and for it to be signed off at the next TSSG meeting. • BH explained the transformation funding would help with the additional workforce such as cancer support workers. • CM mentioned there is national work being done regarding the payment system. The remote way of working within cancer has been acknowledged for some time and has been put in the Long-Term Plan. There is a national push for remote follow up for patients but only when it is appropriate and needs to match the funding model. • VD asked if the patient groups have been consulted. BH admitted not currently for thyroid patients they would approach the clinicians first and with agreement then consult the patients. However, they have actively involved the patients for breast, colorectal and prostate. BH added most eligible patients have been very positive but remote monitoring is not appropriate for all patients. • SH mentioned she has been doing telephone nurse led follow up with patients for about 4 - 5 years which is working well particularly with the younger patients. SH agreed the remote monitoring can work with the right low risk patients but they should still have access should they need it. SH would be very happy to be part of the Thyroid Working Group. • AAL highlighted the financial benefit and efficiency of this service to the trusts which he would be an advocate of as it would free up appointment slots for other patients. He added they would also need protected admin time for letters etc. AAL begrudgingly agreed to help if there was nobody else due to having a heavy workload. MA and DH also agreed to help. DH mentioned she would need secretarial support as she currently has none.		

		• TR explained patients are reassured that if they need to see a professional this service is still available to them. There are cost implications for the trusts and also patients who have to take time off of work. The patients like to take back control of their treatment and to still have access as required. • JD stated as a result of the feedback from the group he would like to go ahead with the Thyroid Stratified Pathway. **Action - BH explained the next steps would be to bring those interested parties together to start the pathway mapping using details from the other national Cancer Alliances where appropriate and tailor them for K&M. A meeting to take place in 6-8 weeks to decide what will work and to sign off the final protocol at the next Thyroid TSSG meeting in the Spring 2022.** • JD thanked BH and CM for their update today and asked to be included in these meetings going forward for oversight. **Action - SH also agreed to email the national Thyroid CNS forum to see if they had started this work.**		**BH / CM / JD** **SH**
3.	**National survey of thyroid MDT's**	**<u>Presentation provided by Anya Selwyn</u>** • AS explained this report was accepted by Clinical Otolaryngology and it is in the final review process. Publication date unsure. • AS stated they looked at all of the UK thyroid MDT's in which she was involved in the data analysis and writing of the paper with JD and RH collating the data. • The aims of the survey were to: i) Assess the provision of thyroid MDTs services in the UK and compare these to the guidance ii) Make recommendations from the findings • The 3 main governing bodies for Thyroid MDT's are: i) National Cancer Peer Review Programme (NCPR) ii) British Thyroid Association (BTA) iii) The British Association of Thyroid and Endocrine Surgeons (BAETS)		

		• AS highlighted the NHSE 28-day Faster Diagnosis Standard which requires faster delivery of outcomes and supports to clarify the current guidance on MDT frequency. • AS explained the methods / results of the national survey of 138 completed questionnaires, 7 surgical specialties, 297 surgeons, UKRETS contribution and the core membership. They looked at 45 MDT's, the frequency of these MDT's, types of cases discussed and the MDT composition of core members. • Key points and recommendations from the findings include: i) They identified ambiguity in the current guidance on thyroid MDT's and nationwide variation in compliance ii) All thyroid surgeons should complete a minimum of 20 thyroid procedures per year and form part of the surgeons' annual appraisal iii) All surgeons should contribute data to UKRETS, be part of the surgeons' annual appraisal and be audited by individual MDT's and regional cancer networks iv) Thyroid MDT's should be held weekly where possible with a minimum frequency of fortnightly v) The core membership of thyroid MDT's should include thyroid surgeons, specialist radiology, endocrinology, nuclear medicine, nurse specialists, histopathology +/- cytology and clinical oncology. • AAL confirmed the thyroid MDT in EKHUFT is fortnightly in which they discuss a lot of patients and he feels this is sufficient frequency. AAL mentioned they have a One Stop clinic on a Monday which helps speed up the diagnostic pathway for the patients. • JD mentioned West Kent MDT is currently twice per calendar month. JD feels this should be kept under review and should be revisited in 6 months' time with the view to meeting fortnightly. **Action – AS agreed to email KG her report but KG to hold fire circulating to the group until the report has been finally published.**		**AS / KG**
4.	**Biochemistry update**	**<u>Clinical Biochemistry Report Update provided by Edmund Lamb</u>** • EL sent his apologies for this meeting but provided the following update for the group. • "EKHUFT clinical biochemistry has been providing an in-house service for thyroglobulin testing since 09.06.2020. Since April 2021 they have been receiving samples from North Kent		

		Pathology Services (Dartford and Medway). Excluding quality assessment samples and samples which were insufficient or received in a wrong container, they have processed 571 patient samples over this period, including 111 samples for NKPS. Since September 2021 they have been receiving samples from MTW, although some samples from the Maidstone oncologists had already been coming to EKHUFT. • All samples are tested for thyroglobulin and thyroglobulin antibody. Samples with a raised thyroglobulin antibody concentration may give false negative (low) results when measured by the EKHUFT assay. Such samples are referred to Birmingham for thyroglobulin measurement by a radioimmunoassay, although it should be noted that this assay may produce false positive (high) thyroglobulin results in the presence of antibody. This situation is not ideal and they have been continuously reviewing this practice. • Currently all samples with an antibody concentration ≥3 kU/L are referred to Birmingham, resulting in 20% of samples being referred. To date, the lowest antibody concentration they have observed to be associated with negative interference in the EKHUFT assay is 13 kU/L. They propose increasing the antibody cut-off for referral to ≥5 kU/L. This will reduce the proportion of samples being referred to 13%, meaning that more patients will get a final report sooner and the cost will be reduced. In the light of further clinical experience they may be able to extend this limit and would be interested in the TSSG's view on this proposal. • For many years they have insisted on the provision of a plain clotted (red top) vacutainer for thyroglobulin measurement as this was the sample type the Birmingham service required. This always caused some confusion and they regularly had to reject SST (gold top) samples. Early in 2021 they verified the performance of both the thyroglobulin and thyroglobulin antibody assays in gold top vacutainers and confirmed no difference in results compared to the red top tubes. From 1st April 2021 they have been accepting gold top tubes for thyroglobulin and thyroglobulin antibody measurement. This has reduced the number of times they have had to reject samples." • **Action - JD asked for KG to feedback to EL that the TSSG support raising the threshold to 5 kU/L and continuing to monitor and potentially raising the threshold to a higher level at a later date if this continues to be appropriate. JD thanked EL and his colleagues for setting up the service which has made a major contribution to good clinical care of thyroid cancer patients in Kent & Medway.**		**KG / JD – action completed**
5.	**Clinical Pathway Discussion**	**<u>High Operational Policy</u>** • AW explained the areas of the document which had been changed and were highlighted in red		**AW to update the changes agreed today**

		and for the changes to be agreed at the Thyroid and Head & Neck TSSG meetings today. • The group reviewed the document and the following changes were made: i) 5.0 – MDT Clinical Oncologists - Gemma McCormick to replace Nick Rowell for both East (Kannon Nathan) and West Kent (Andriana Michaelidou) ii) Nuclear Medicine Specialist – Maria Acosta for both East and West Kent iii) Surgeons – add Navdeep Upile and Praveena Coimbatore for West Kent **Action – DH agreed to email AW directly as there have been some changes with the CNS's named on the HOP document.** **iv) 14.0 – All Young People change from 16 to 18 – 24 years of age. SH and JD to discuss off line if this is 18th or 19th birthday** v) DH – confirmed they have a named CNS for TYA in West Kent (DH to confirm) and SH confirmed they will be interviewing in the next couple of weeks for this position. vi) Revision history – add JD – August 2021 vii) Mohamed Kenawi asked to be included as the MDT Radiologist for West Kent		**DH** **SH / JD** **AW**
6.	**Research**	• JD mentioned at MFT they are trying to get going with the Hemithyroidectomy - HoT trial. AB confirmed this trial is currently on hold at EKHUFT to acquire particular data before they can enter the trial.		
7.	**Audits for 2021**	**<u>Re-audit of thyroid ultrasound data – update by Delphine Nkuliza</u>** • JD explained DN has completed a re-audit of the thyroid ultrasound scans based on her previous audit presented at the last thyroid TSSG meeting. It was felt that the lack of u-grading needed to be re-audited to see if there had been an improvement. • DN confirmed in the re-audit they have looked at thyroid ultrasound scans, FNAC results and histology correlation. • The aims of the re-audit were to review the correlation with U and Thy grading to malignancy rates in the North Kent region between January and July 2021. • The objectives were to:		

		i) Improve the rate of reporting of U grading in thyroid USS by 20% from 60% to 80% ii) Compare thy grading to malignancy rates of thyroid nodules • The results showed that between January and July 2021: i) Total 69 operations • All with histology results • 53 with thy graded nodules pre-op • All had thyroid USS: 60 with U graded nodules from USS report • DN compared the results with the previous audit including comparable data with both UCL and Sheffield. JD is pleased to see their results have improved. • AB mentioned they did the same audit in EKHUFT a few years ago and this gave a 38% conversion to malignancy rate for thy 3F's and out of that they excluded the 15% addition of micro papillary carcinoma. Their thy 3A rate was 26%. AB asked if micro papillary was excluded from the re-audit data. DN confirmed they were and there were 3 to make it simpler. • JD thanked DN for the re-audit and stated this audit could now be closed.		**KG actioned and closed.**
8.	**Future developments**	**<u>Medullary thyroid cancer–query supra-regional discussion – update by Jeremy Davis</u>** • JD mentioned GIRFT refers to the centralisation of medullary thyroid cancer. **Action - JD added Kate Newbold is considering setting up a pan London service and possibly opening up to other sites as well. JD agreed to speak to KN and suggested this could be discussed further at a future TSSG meeting.** • JD stated medullary thyroid cancer is uncommon, is complex to treat and can be often over or undertreated. JD is keen they continue to do this and to ensure they are doing it well. • AB confirmed they do not have any particular concerns at EKHUFT with regard to surgical management of medullary thyroid cancers and they have always liaised very closely with the Royal Marsden.		**JD / AW / KN**

9.	**Self-management Pathways**	**<u>Presentation provided by John Kyle</u>** • JK and his colleagues have been project managing InfoFlex now called CIVICA for the last 10 years in Kent & Medway. For the last 3 or 4 years they have been working on a series of initiatives to upgrade InfoFlex from a desktop application to a web-based one. • JK referred to the Cancer Care Pathway Management for which data has been collected through InfoFlex for the last 15 years or so. They have introduced a clearer, improved layout out and user friendly InfoFlex desktop interface. • JK mentioned they were approached nationally about 3 - 4 years ago to build a stratified follow up design interface for the lead tumour groups. These were generally breast, colorectal, prostate and to a lesser extent lung. • JK provided a visual update showing the layout and details available on InfoFlex for the stratified follow up pathway for breast, colorectal and prostate tumour groups. JK hoped the detail presented would help with the relevance for the thyroid stratified pathway. • JK highlighted they started the stratified follow up for breast in K&M 2 years ago, piloting colorectal a couple of months ago with prostate being imminent too. • JK mentioned they are working closely with the prostate group and patient representatives to set up a patient portal. The project aim is to move this across to InfoFlex to be able to have access to test results. They have been building the portal over the last 18 months. Any prostate patients on a stratified follow up will have access to their PSA results and treatment summaries which come automatically ontto the InfoFlex database. The patients will be prompted to complete the regionally developed Macmillan Prostate HNA or PROMS - EPIC-26 questionnaire. All this data is readily viewable by the clinical teams and they will action in house. • JK highlighted the Cancer Care Map which is an online directory on the patient portal which is an available resource for patients, family and friends. • JK mentioned they are integrating with the K&M Care record and he understands that the pathology results will be transferred onto that record. This will be accessible in the next few weeks through InfoFlex without a separate sign in for their patients. • CM explained when the results come into the portal the patient would not be able to view them until they have been reviewed by the Clinician and then archived.		

		• CM stated that cancer support workers have an important role to play in monitoring results and admin of the system as well as supporting HNAs and care plans. • JD thanked JK for his time and this has been very useful.		
10.	**Endocrine GIRFT report**	**<u>Update provided by Jeremy Davis</u>** • JD suggested to the group if they Google "Endocrine GIRFT" report this recommends that thyroid MDTs should not be less than fortnightly. **https://www.gettingitrightfirsttime.co.uk/medical-specialties/endocrinology/** **Action – JD suggested that Endocrine GIRFT could be discussed more fully at the next Thyroid TSSG meeting when people have had the opportunity to read the published report.**		**JD / AW**
11.	**CNS Updates**	**<u>MFT & MTW – update by Debbie Hannant</u>** • DH confirmed that Pauline Mortimer will be retiring in October and wanted to thank her for all her hard work over a number of years. • DH introduced Debbie Owen as the new 2nd Head & Neck CNS at MFT. • DH mentioned Ruth Casey is the Oncology nurse specialist and she will be picking up some of their radiotherapy patients. Additionally, Eve Bateta is the new Head & Neck CNS at MTW. • NU explained PM's role which was divided between MTW and QVH will become at least two separate roles. NU added there will a QVH post and MTW post both to be appointed. **<u>EKHUFT – update by Sue Honour</u>** • SH hoped to appoint a new Thyroid Cancer Support Worker who will also do some H&N work but will be responsible for ensuring HNA's are completed. This will be an essential role for all future projects as discussed today. SH added there are CSW within H&N and they are working really well. **<u>QVH – no update provided</u>**		

12.	**CCG and CA Update**	**<u>Update by Chris Singleton</u>** • CS provided an overview of the National Cancer Programme priorities which were published in March 2021. These include: i) Impact of COVID-19 on cancer services. ii) Recovery priorities (2021/22 cancer services recovery aims, 2021/22 key actions and cancer recovery funding) iii) Getting people into the system ('Help us help you' campaign) iv) Investigate and diagnose (Rapid Diagnostic Centre pathways, Targeted Lung Health Checks and Accelerating innovation) v) Treat (Surgical hubs and 'COVID-friendly' treatments). • CS mentioned the CCG Commissioning and CA have been brought together as a single team. • CS highlighted some of the work they have been doing from a K&M perspective. The Rapid Diagnostic Services are working really well. The VISS pilot at DVH has shown some very positive results over the last 2 years and is being extended for a further year. They are looking to roll this service out to MFT and EXHUFT in the coming months. • The Rapid Lymphadenopathy pilot has been running in EKHUFT since September 2020 and has also shown some hugely successful and positive results, with a 15% conversion rate to cancer. They are looking to expand this service to MTW in the coming months. CS added both these services will be available nationally to all patients by 2024. A monthly RDS Oversight Group has been set up to support the implementation of both services across the trusts. • CS highlighted there is some focused pathway work going on for Lung, H&N and UGI to support the implementation of the 28-day Faster Diagnosis Standard cancer standard. This standard will be formally reportable from October 2021. • CS mentioned as part of the early cancer diagnosis work, K&M have been selected to be part of the NHS Gallery Grail programme which is due to commence in October 2021. This will offer selected patients, a blood test to pick up DNA markers which will identify the harder to diagnose cancers such as H&N and thyroid.		**KG circulated this presentation on the 21.09.2021**

		• They are waiting for national confirmation that K&M have been selected for the Targeted Lung Health Check (TLHC) programme. This will focus on areas of high smoking prevalence, initially starting at Dartford, moving to East Kent and then onto West Kent. • CS mentioned they are beginning to implement the recommendations from the Oncology Services Review which went to the Cancer Board in August 2021. They are also starting to develop a Cancer Digital Strategy for K&M following a successful face to face workshop on the 14th September 2021. • The CCG and CA are supporting their Integrated Care Partnership (ICP) colleagues to work through the implementation of the Community Diagnostic Hubs (CDH). These will cover a population of 300,000 and will hope to eventually have 6 CDH's in K&M. There is 1 site confirmed for East Kent and MTW initially. DVH and MFT will be in the second phase. • CS clarified there will be 2 CDH eventually in EKHUFT, the first being sited at Buckland Community Hospital in Dover.		
13.	**Day & time for future TSSG's (Monday/Tuesday)**	• **Tuesday 29th March 2022 – via MS Teams – 09:30 – 12:30** • **KG has circulated the meeting invites together with a follow up email to ensure maximum attendance.**		
14.	**AOB**	• JD mentioned the performance data was purposely not on the agenda as the majority of the trusts are still unable to separate the thyroid and H&N data. MFT have had some internal success in separating the two tumour groups and hopes this could be shared at a future meeting. • The group discussed a more convenient day for future meetings to ensure a fuller attendance. • VD suggested the group considered undertaking a TSSG-wide audit on follow-up of cancers treated with hemithyroidectomy alone. It would be interesting to know the variation across the trusts and would be of value. JD suggested asking John Shotton from MTW. **Action - VD agreed to put together a simple first audit cycle of what they are currently doing in EKHUFT.** • RH mentioned doing a BAETS – UKRETS data audit which has been previously discussed at		**VD / AW / JD**

		the TSSG. There is nowhere to present this data locally. RH suggested they present the last year / two years' worth data of thyroid patients for review and discussion. RH added this would be a 5 - 10-minute slot on the agenda. JD is not sure which colleagues do participate with BAETS and feels everyone should contribute as does GIRFT. JD added he is the President of BAETS and this could be a conflict of interest for him. AB recommended that each trust should participate as it is an overview of the quality of the service provided. JD agreed this should not be forgotten but should be discussed again in the future with perhaps a new chair. JD suggested an alternative of getting a Registrar to present the data so show how useful it is. • AW confirmed future meetings will continue to be via MS Teams but there is hope to reinstate face to face meetings perhaps one per year.		