NHS

Kent and Medway Cancer Collaborative

Gynaecology Tumour Site Specific Group meeting Thursday 5th May 2022 Microsoft Teams 13:30-16:30
Final Meeting Notes

Present	Initials	Title	Organisation
Rema Iyer (Chair)	**RI**	Consultant Gynaecological Oncologist	EKHUFT
Asma Bitar	**AB**	Radiology Registrar – ST3	EKHUFT
Katrina Harrison	**KH**	Radiology Registrar – ST1	EKHUFT
Katherine Entwisle	**KE**	Consultant Radiologist	EKHUFT
Vicky Morgan	**VM**	Macmillan Lead Gynae-oncology CNS	EKHUFT
Hristina Hristova-Angelova	**HHA**	Consultant Radiologist	EKHUFT
Edmund Inetianbor	**EI**	Gynae-oncology ATSM Specialist Registrar	EKHUFT
Claire Bingham	**CB**	Macmillan Recovery Package Facilitator	EKHUFT
Rob MacDermott	**RM**	Consultant Obstetrician, Gynaecologist and Urogynaecologist	DVH
Katrina Harrison	**KH**	F1	DVH
Michelle McCann	**MM**	Operational Manager for Cancer & Haematology	DVH
Emily Farrell	**EF**	Gynae MDT Coordinator	DVH
Elizabeth Stewart	**ES**	DGT Practical Support Assistant (Doer)	DVH
Samantha Daniels	**SD**	Macmillan Gynae-oncology CNS	DVH
Adam Shaw	**AS**	Consultant Clinical Geneticist	GSTT
Sarah Barker	**SBa**	Project Manager – Early Diagnosis	KMCA
Claire Mallett	**CM**	Programme Lead – Personalised Care & Support	KMCA
Tracey Ryan	**TR**	Macmillan User Involvement Manager	KMCC
Annette Wiltshire	**AW**	Service Improvement Facilitator	KMCC
Karen Glass (Minutes)	**KG**	Administration & Support Officer	KMCC & KMCA
Colin Chamberlain	**CC**	Administration & Support Officer	KMCC
Hany Habeeb	**HH**	Consultant Gynaecologist	MFT
Suzanne Bodkin	**SBo**	Cancer Pathway Manager	MFT
Jennifer Priaulx	**JP**	Macmillan Cancer Transformation Project Manager	MFT
Karen Flannery	**KF**	Macmillan Gynae-oncology CNS	MFT
Michelle George	**MG**	Macmillan Gynae-oncology CNS	MTW
Kannon Nathan	**KN**	Consultant Clinical Oncologist	MTW
Ying Ying Lou	**YYL**	Consultant Obstetrician & Gynaecologist	MTW
Gary Rushton	**GR**	Consultant Pathologist	MTW
Roxani Dampali	**RD**	Gynae-oncology Clinical Fellow	MTW

Gemma Levett	**GL**	Staff Nurse	MTW
Stephen Attard-Montalto	**SAM**	Consultant Gynaecologist and Gynae-oncology Surgeon	MTW
Andreas Papadopoulos	**AP**	Consultant Gynaecologist & Gynae-oncological Surgeon	MTW
Rema Jyothirmayi	**RJ**	Consultant Clinical Oncologist	MTW
Rebecca Nelhams	**RN**	Programme Manager - Cancer Workforce - KMCA	NHS Kent & Medway CCG
Sona Gupta	**SG**	Macmillan GP & Cancer Lead	NHS Kent & Medway CCG
Bana Haddad	**BH**	Macmillan GP & Cancer Lead	NHS Kent & Medway CCG
Laura Alton	**LA**	Senior Programme Manager – KMCA	NHS Kent & Medway CCG
Jack Jacobs	**JJ**	Macmillan GP & Cancer Lead	NHS Kent & Medway CCG
Holly Groombridge	**HG**	Cancer Commissioning Project Manager	NHS Kent & Medway CCG
Apologies			
Anca Gherman	**AG**	Clinical Trials Research Nurse	DVH
Andy Nordin	**AN**	Consultant Gynaecologist & Gynae-oncologist	EKHUFT
Cathy Finnis	**CF**	Programme Lead – Early Diagnosis	KMCA
Serena Gilbert	**SG**	Cancer Performance Manager	KMCA
Justin Waters	**JW**	Consultant Medical Oncologist	MTW
Omer Devaja	**OD**	Consultant Gynaecologist & Consultant Gynae-oncology Surgeon	MTW
Kate Regan	**KR**	Macmillan Primary Care Nurse Facilitator	NHS Kent & Medway CCG
Liz Shannon	**LS**	Macmillan Primary Care Workforce Support	NHS Kent & Medway CCG

Item		Discussion	Agreed	Action
1.	**TSSG Meeting**	**Apologies** • The apologies are listed above. **Introductions** • RI welcomed the members to the spring meeting and hoped the next autumn meeting would be held face to face. **Action log Review** • The action log was reviewed, updated and will be circulated together with the final minutes from today's meeting. **Review previous minutes**		

		• The minutes from the previous meeting, which took place on the 4th November 2021 were agreed and signed off as a true and accurate record. **<u>Faster Diagnostic Standard – update provided by Rema Iyer</u>** • The 28-day FDS has now been in place for the last 12-18 months. The aim of this standard is to reduce the time from referral to diagnosis and inform the patient if they have cancer or not within 28 days. Additionally, to reduce the variation across the country, improve the current 2ww first appointment target and to be a more patient centered standard. The initial threshold set by NHSE for 28-day FDS is 75%. • Approximately 9% of all 2ww referrals in 2020 were for gynae cancers. In 2018 ovarian cancers had some of the longest waits between referral and start of treatment – average 69 days. Between 2018 and 2020 only 72% of patients diagnosed with gynae cancer started treatment within 62-days of a referral. • K&M FDS performance data for February 2022 was 63.4% which is below the England average of 68.2%. • RI explained the referral process for those patients that meet the NG12 criteria. The importance of Primary Care informing their patients about the FDS pathway, to be told they are being referred on a suspected cancer pathway and the timelines involved. Additionally, that the patient should be available within the next 9 days for appointments and tests. RI explained if the patient is going to be away on holiday they should not be referred in until they return as it causes unnecessary delays. • RI provided an overview of the minimum dataset required to be included within the referrals. • Once the referral has been received in Secondary Care it is important that they are triaged by a CNS who is able to order imagining such as CT. Patients can then be triaged into one of the three clinic services. Patients requiring a face to face appointment should have the necessary tests done on the same day to avoid repeat visits or for the tests to take place the following day. • Patients should be asked what additional information they require, be given appropriate leaflets and the contact details for the care navigator. • RI outlined the investigations, 28-day FDS flowchart and audit tool.		**Slides circulated to the group on the 6th May 2022.**

		• RI explained the current practice in place at EKHUFT: i) CNS's triage the referrals ii) Cancer radiology escalation email for urgent scans iii) The trackers send regular reminder emails to the clinicians to review results and if the patient needs to stay on the cancer pathway iv) Standard 28-day result letters are sent to patients if they have been found to not have cancer. There is a different template for those patients going on to have further investigations to exclude cancer. • RI thought these were quite ambitious targets but will do their best with the limited resources available. • HH mentioned at MFT they see women on day 7 of the referral rather than day 14. Their issues tend to be where they are reliant on other specialties such as radiology or pathology. Any interventional procedure can take up to 4 weeks. • RI stated EKHUFT do not have any problems getting biopsies done but are experiencing delays in getting pathology reports completed on time due to staffing issues due to covid. • RM mentioned they have had agreement from the CCG that they will not accept any PMB (Post-Menopausal Bleeding) referrals at DVH without an ultrasound scan attached. If there is a high chance of cancer the patient will be seen quickly. RB stated their radiology department is moving towards a 7-day standard for cancer for CT's etc. There is talk of collaborative working within radiology across K&M which may help iron out any issues. RM concluded that he liked the 28-day FDS document and he felt it could be achieved through hard work, dedication and commitment.		
2.	**Audit of rapid access clinics at MFT**	**<u>Presentation provided by Hany Habeeb</u>** • HH mentioned he has also presented this audit internally at MFT in October 2021. HH explained they received a lot of referrals during the pandemic and suggested this was due to GP's being unable to refer patients through any other route. As a result, they have increased their clinics from 3 per week to 7 and the rationale behind conducting this audit. • HH explained they see women in a Rapid Access Clinic by day 7. According to their figures they diagnose 3-5% of their referrals with a gynaecological cancer.		**Slides circulated to the group on the 6th May 2022.**

- The aim of the quality improvement project was to reduce the number of “avoidable” referrals. They looked at the RAC referrals from 1st May 2021 – 14th June 2021 for which there were 200 cases. There was a range of methodology used including age of patient, reasons for referral, final diagnosis and the appropriateness of the referral.

- HH stated it would be fully appropriate to refer women aged 40 – 80 to a RAC. He struggled with the rationale behind the referral of a woman aged 30-40. The largest number of referrals to the RAC was for endometrium (120 referrals) with ovarian and cervical approximately 20 referrals for each.

- HH explained out of the 200 referrals they diagnosed 11 cancers – 5.5%, 189 referrals were benign. There were 4 cases of endometrial cancer, 6 ovarian cancer and 1 pancreatic cancer - this patient was referred to the UGI team for ongoing management.

- In terms of avoidable referrals there were 80 (40%) with 120 appropriate referrals which fulfilled the criteria of age and symptom presentation. 40% of these referrals could have been avoided which equates to around 2 RAC per week. All confirmed cancer cases were for women over the age of 40. 34% of referrals for suspected ovarian cancer were the most appropriate which was a good pick up rate. 35 women on the endometrial pathway were on HRT and had benign findings.

- HH confirmed their referrals have improved since undertaking the audit and they have more capacity within the general gynae clinic. HH provided his future recommendations:

  i) Continue to monitor RAC referrals on a monthly basis
  ii) Consider triage in the event of increasing volumes
  iii) Suitability of candidates < 40 – see slides
  iv) Feedback to GP’s in a separate letter
  v) Continue to engage in GP teaching / education
  vi) Offer more support for urgent referrals via emergency clinics
  vii) Advice and guidance to GP’s
  viii) Menopause clinics good alternative for women bleeding on HRT
  ix) VISS (now NSS) may help with delays for women with vague symptoms

- RM mentioned they downgrade 1/3 of their referrals every month at DVH. RM stated they are doing an audit for GP practices to provide feedback on the inappropriate referrals and provide some teaching. RM mentioned he tends to write to the patient directly and copies in the GP with an action box. DVH are looking into supporting alternative computerised pathways in collaboration with the GP’s.

		• BH emphasised the importance of gut instinct as a GP and they see on average 40 patients per day. BH mentioned there is very little alternative for GP's to refer into - 2ww and a routine referral which has lengthy wait times. The numbers of 2ww referrals will come down if there are alternative clinics to refer into such as the menopause clinic. • HH and JJ agreed the importance of Primary and Secondary Care working closely together.		
3.	**Performance**	**DVH – update provided by Rob MacDermott** • Please refer to the circulated performance slide pack for an overview of the Trust's data. • RM mentioned he will be doing an extra RAC each week from the summer instead of a general gynae clinic to cope with the extra referrals. • RM explained they are struggling to meet the 62-day and looking at the breach reasons there is no common theme. They are good at getting the diagnostics done quickly. Imaging is taking 14-18 days and pathology can take 10-14 days. Additionally, there are often complex pathways which take additional time. **EKHUFT – update provided by Rema Iyer** • Please refer to the circulated performance slide pack for an overview of the Trust's data. • RI explained EKHUFT have had issues getting scans on time which has affected their 28-day FDS. • RI shared some additional slides detailing the breakdown of 254 gynae cancers diagnosed at EKHUFT from April 2021 – March 2022. The largest cancer diagnosis was 119 endometrial cases. 60% of these referrals were via the 2ww pathway, 35% routine referrals and 4% urgent from A&E and screening. In 13% of the cases staging details were missed. They are not so good at recording residual disease in ovarian cancer – 5 out of the 43 cases. RI thought this had been recorded in the wrong section of InfoFlex which they need to address. RI concluded they have recorded the performance status well, only missing 39 out of 254 cases – 15%. **MFT – update provided by Hany Habeeb** • Please refer to the circulated performance slide pack for an overview of the Trust's data.		**Performance slides circulated to the group on the 6th May 2022.**

		• HH confirmed that MFT are achieving the 28-day FDS for February and March 2022. HH praised the support of the admin staff. HH mentioned they also have cross cover in place for consultants. • HH referred to a dip in 62-day performance target which is due to the BH's and patients being sick. However, in February and March he is pleased to confirm they were 100% compliant. **MTW – update provided by Andreas Papadopoulos** • Please refer to the circulated performance slide pack for an overview of the Trust's data. • AP admitted he had not seen these performance slides before with the different layout. • AP mentioned overall there were no real issues meeting the 28-day FDS or the 62-day performance target. AP referred to some patients with a complex history which will delay the pathway such as additional cardiac investigations. • AP shared some additional slides on gynae cancer from West Kent's perspective from March 2021 – February 2022. • AP provided a breakdown of the 251 gynae cancers diagnosed into staging, grade, WHO and treatment. Overall, they were recording the data more accurately. AP highlighted the breakdown of the gynae cancers - Endometrial – 164, Cervix – 52, Vulvo/Vaginal – 20, and Ovarian – 107.		
4.	**PIFU**	**PIFU for high-intermediate to high-risk endometrial cancer – presentation provided by Kannon Nathan** • KN provided an overview of PIFU for high-intermediate and high risk, evidence, BGCS & US recommendations and local recommendations. • KN explained they do not have any high-quality data evidence that any specific follow up protocol will improve outcomes. KN explained what evidence is available. • KN highlighted the TOTEM study which was published in 2021 which looked at randomising all stages of endometrial cancers and stratify into low and high risk.		**Slides circulated to the group on the 6th May 2022.**

- KN suggested as an amalgamation of the US and BGCS recommendations he proposed:

  i) Year 1-2 – 3 monthly follow up – alternate telephone and f2f
  ii) Year 3 – 6 monthly follow up – alternate telephone and f2f
  iii) Consider imaging at 3-4 months post end of all treatment as baseline – tailored to individual patients
  iv) Consider baseline imaging at year 3 before PIFU
  v) If suitable – PIFU at year 4-5.
  vi) Re-enter at end of year 5 – for final review
  vii) Reassess at year 5 – exit review and discharge
  viii) Capture all PIFU patients in local database
  ix) Ensure clear summary letter at year 3 for PIFU for patients and primary care.

- KN suggested how they could implement locally:

  i) Clear education for patients – booklet / app
  ii) Signs to look for
  iii) Access points – carelines / CNS
  iv) Identify suitable patients – based on HNA
  v) One Stop emergency clinics for PIFU patients – so not adding to 2ww – important that patients take responsibility
  vi) Audit on a yearly basis to see what works and what does not.

- RI agreed the TSSG should come to a general consensus on the understanding that treatments are evolving rapidly. RI suggested doing a baseline scan at the end of year 3 before the patient goes onto PIFU. To do a follow up scan at the end of five years after discharge to ensure there are no occult recurrences.

- AP personally thought the year 1 scan was important as a baseline for comparison and then to skip year 2 and go to year 3 unless the patient had symptoms. AP added from year 1 – year 3 it would be a mixture of telephone and face to face consultations. Beyond year 3 to be governed by the patient's symptoms. RI agreed that would be a reasonable approach and added having a baseline scan at the end of all treatment. KN agreed and to have a scan one year after to capture the patients that relapse within 18 months – 2 years. To be followed up in year 3 and year 5 as an exit scan. RI agreed.

- It was agreed and documented at the MDT if a patient is suitable for PIFU which will help both staging and risk.

<u>Finalise protocol – update provided by Claire Mallett</u>

		• The TSSG group agreed they were happy to sign off the guidelines as outlined below for low-risk endometrial cancer patients: i) Adopt BSG guidelines for 5 year – follow up - EKHUFT has now agreed for consistency ii) Stratify for PIFU at 6-8 weeks post-surgery consultant appointment iii) 3-4 months letter and HNA offered iv) Telephone HNA if accepted (MFT – F2F) v) Annual reminder letter vi) Discharge at 5 years to GP – option to refer straight back • AP clarified at MTW they do not do a CT scan after 5 years for low risk patients. CM noted this. • CM referred to treatment summaries and making the information accessible for both patients and GP's. CM mentioned she has been working closely with the CNS' to standardise the letters but there needs to be additional input from patients and GP's and may need to differ depending on the levels of risk. **<u>National Timed Pathways – update by Sarah Barker</u>** • SB explained this was initially put on the agenda for Serena Gilbert to discuss but she is unable to attend the meeting today. SB suggested this agenda item had been discussed sufficiently by RI earlier in the meeting.		**Slide circulated to the group on the 10th May 2022.**
5.	**Clinical Pathways**	**<u>Update by Rema Iyer</u>** • RI referred to the Ovarian Cancer guidelines and she would like to add in a section that both BRCA and HRD testing is now available. At EKHUFT they have been sending off tissue samples for all newly diagnosed patients. RI mentioned germline testing for BRCA and other mutations are to be arranged locally rather than sending to GSTT. This is yet to be arranged at EKHUFT as they need to find someone to be able to run the service. RJ confirmed a familial clinic has been set up at MTW. **Action – RI agreed to make the document changes and circulate to the group, any comments to be directed back to RI.** • RI confirmed there are no new changes to be made to the endometrial or cervical cancer		**Slides circulated to the group on the 6th May 2022** **RI**

		guidelines. • With regards to the vulval cancer guidelines, RI will add in the new FIGO staging which was introduced in 2021. • RI is yet to review the follow-up guidelines to include PIFU which she will do in the next 2-3 months once all the details have been agreed.		
6.	**Audit**	**<u>The Role of MRI in Atypical Endometrial Hyperplasia: a prospective study – provided by Asma Bitar and Katrina Harrison</u>** • KH provided an update on the background of the audit and the meaning of endometrial hyperplasia, which can be a precursor for endometrial cancer if left untreated. • EKHUFT local practice for the management of Atypical Hyperplasia includes an Ultrasound evaluation of the uterus and pelvic MR imaging as routine practice. • KH explained the objectives for the audit were to assess the accuracy and usefulness of MRI in the management of patients diagnosed with endometrial atypical hyperplasia (AH). They have looked to see if the MRI findings are in concordance with post-operative histology – post-hysterectomy or further follow up biopsies. • AB explained they identified 30 patients through the Gynae-Oncology MDM from January 2020 – November 2021. The average age of the patient was 58 years old, but cases ranged from 26 – 89. • AB identified the strengths and limitations of their study. In conclusion: i) Inconsistent date in the literature on the value of MRI in Atypical Hyperplasia ii) Local experience indicates MRI is better at predicting the presence of invasive features than ruling them out iii) Change in management: reduction of time to surgery to two weeks, the surgical intervention itself remains the same iv) The role of MRI in the management of Atypical Hyperplasia remain doubtful v) Larger-scale studies are needed to make confident evidence-based clinical recommendations.		**Slides circulated to the group on the 6th May 2022.**

7.	**CNS Updates**	**DVH** • No update provided. **EKHUFT – update provided by Vicky Morgan** • VM explained their main update is setting up the genetics and family history clinic and are looking into recruitment. **MFT – update provided by Karen Flannery** • KF explained they are in the process of getting the PIFU paperwork ratified. They have a new band 4 starting with the team on Monday which will be a good addition to their service. **MTW – update provided by Michelle George** • MG explained their mainstream genetics testing service started this week with Vickie Gadd leading. They have the enhanced care clinics set up for patients that do not fit into the palliative care group. • MG is working on a patient satisfaction survey on PIFU. RI asked when this was completed if she could provide an update for a future TSSG meeting. MG agreed.		
8.	**Lynch Diagnostics & Surveillance**	**Presentation provided by Laura Alton & Sarah Barker** • LA explained that Lynch Syndrome has now appeared in the national planning guidance for 2022/23. The ask is to ensure that Lynch Syndrome testing is in place for colorectal and endometrial cancer. • NICE Guidance: i) DG42 – endometrial cancer and Lynch Syndrome ii) DG27 – colorectal cancer and Lynch Syndrome • Cathy Finnis has done some initial K&M data analysis work based on the K&M population of 1.8 million, a prevalence of Lynch Syndrome of approximately 8,220 cases. An initial pull on PC data identified 156 patients of whom 64 of these were also on the cancer register. This has		**Slides circulated to the group on the 6th May 2022.**

		highlighted a gap in the data. • LA explained the four stages of the Lynch Syndrome pathway includes: i) Initial tumour test ii) Germline testing iii) Management of index case iv) Cascade testing and surveillance of family members. • LA asked the group to look at the different pathways and come back to them with any comments. • In order to develop and fully commission this service for K&M, LA had a set of questions which she asked the group to comment on. **Action – RI asked if LA could send the set of questions out to the leads of each of the trusts and for any comments to come back to KG. They can then form a group to start the project.** • RI did not think there was a field within InfoFlex to record Lynch Syndrome. Germline testing, they send to GSTT. • AS explained he is the national lead for the Lynch Syndrome work at GSTT and the aim is to identify the patients from a diagnostic biopsy. To build a CA dashboard and for individual MDT members to be able to view the data. It is currently 3 months behind real-time. They will be able to see how many of their patients are getting immuno-histochemistry and then subsequent tests such as the Lynch Syndrome gene panel. Secondly, they are looking to develop a Lynch network within the South East and a possible virtual MDT to be able to ask specific questions.		**LA / Trust leads**
9.	**Cancer Alliance update**	**Presentation provided by Laura Alton** • LA outlined the national cancer programme priorities for 2022/23. There is a key focus on Faster diagnosis and operational performance, early diagnosis, treatments and personalised care and cross cutting themes. • LA highlighted the roll out of the Non-Site-Specific pathway to additional sites across K&M with an aim to have full coverage by 2024. The CA will be supporting trusts to implement best-practice timed pathways for prostate, colorectal, lung and UGI pathways with new timed pathways for gynae and H&N.		**Slides circulated to the group on the 6th May 2022**

		• LA mentioned she has spoken to Ian Vousden regarding the introduction of the new timed pathways and now would be the right time to look at the NG12 forms. With the introduction of Ardens within Primary Care it is easier to amend the forms, remove the old ones and get them out to GP's much quicker. • LA referenced the Galleri Grail pilot which has been hugely successful with the results coming out in due course. Grail have achieved 70% participant recruitment. They are working closely with screening and imms colleagues to review service provision and uptake which has been quite low. Launch of the Primary Care Dashboard to support the PCN's and PC colleagues to understand key data metrics and looking at their own referral patterns. • Treatments and Personalised Care – ongoing personalised and stratified pathway work which has already been discussed. There is a new cancer workforce lead (Rebecca Nelhams) started in April to support workforce development and to take forward themes from the Kent Oncology review. The Health Inequalities toolkit is being developed to target those areas of low uptake particularly within screening.		
10.	**Listening and Learning**	**<u>Presentation provided by Tracey Ryan</u>** • TR presented the listening and learning audit, conducted by EK360 on a cohort of 76 patients attending endoscopy appointments. The audit explored the reasoning behind patient's reluctance to attend appointments with a view to improving future attendance. • TR explained the cohort of patients approached included men, BAME community, LGBTQ+, physical and mental disabilities. • The three main areas raised included: i) **Information / Communication** – step by step, reasons, videos ii) **Anxieties** – fear of the unknown, embarrassment, reassurance, helpful hints and patient stories iii) **Hidden factors** – including physical and mental disabilities, abuse. • TR explained with the information collated they have set up a focus group which includes endoscopy managers and screening teams. • They are looking at solutions to help patients attend future appointments:		**Slides circulated to the group on the 6th May 2022**

		i) Flag for patient with additional needs – referral form ii) FAQ's to be sent out to patients iii) Patient videos – diagnosed and non-diagnosed / for screening and symptomatic patients iv) Information formats v) Admin training – could ask key questions to help patients to help reduce DNA rates • TR referred to a quick win's trial at one K&M trust for a period of three months in order to review outcomes including DNA rates. Additionally, to work on creating videos, further information and training for the admin team. • TR emphasised the importance of remembering to ask the patient "what matters to you" and not just "what is the matter with you." TR referred to the important role of the support network around the patient. • TR explained if patients were aware their opinions / concerns were being acted upon where possible this would have a positive impact and would encourage future engagement with surveys etc. • TR agreed to share the final outcome with the group so this could be incorporated into their everyday work with their teams.		
11.	**AOB**	• RI thanked the group for their attendance and participation at today's meeting. • AP mentioned that Omer Devaja has sent his apologies for today's meeting. **Action - OD to present the sentinel node and endometrial data at the next TSSG meeting.**		**OD / AW**
12.	**Next Meeting Date**	• **Thursday 3rd November 2022 – 09:30 – 12:30 – Venue to be confirmed**		**KG has circulated the meeting invites.**