Kent & Medway Cancer Collaborative

Cancer of Unknown Primary (CUP) & Non-Specific Symptoms (NSS) Tumour Site Specific Group meeting Thursday 9th October 2025 Microsoft Teams 13:30-16:30			
Final Meeting Notes			
Present	**Initials**	**Title**	**Organisation**
Hannah Weston-Simons (Chair)	**HWS**	NSS GP Lead	DGT
Nazima Chokoury	**NCho**	Macmillan Acute Oncology CNS	DGT
Adedolapo Odah	**AO**	NSS Pathway Coordinator/Administrator	DGT
Carrie Barton	**CBa**	NSS CNS	DGT
Marie Payne	**MPay**	Lead Cancer Nurse	DGT
Michelle Moody	**MM**	Early Diagnosis Coordinator	DGT
Claire Whiteley	**CW**	Macmillan Lead NSS/Acute Oncology Nurse Practitioner	EKHUFT
Nicola Chaston	**NCha**	Consultant Cellular Pathologist and Associate Medical Director for Diagnostics	EKHUFT
Declan Cawley	**DC**	Palliative Care/Acute Oncology Consultant	EKHUFT
Emma Lloyd	**EL**	Cancer Pathways Improvement Project Manager	KMCA
Chris Singleton	**CS**	Senior Programme Manager for KMCA Commissioning	KMCA
Bana Haddad	**BH**	Clinical Lead	KMCA
Jonathan Bryant	**JBr**	Primary Care Cancer Clinical Lead	KMCA
Karen Glass	**KG**	PA/Business Support Manager	KMCA/KMCC
Colin Chamberlain (Notes)	**CC**	Administration & Support Officer	KMCC
Samantha Williams	**SW**	Administration & Support Officer	KMCC
Rosemary Chester	**RC**	Consultant in Palliative Medicine	Medway Community Healthcare
Erica Simpson	**ES**	Community Palliative Care Team Lead	Medway Community Healthcare
Mayank Patel	**MPat**	Consultant - NSS Pathway	MFT
Bobbie Matthews	**BM**	TBC	MFT
Louise Farrow	**LF**	Macmillan Lead Cancer Nurse	MFT

Suzanne Bodkin	**SB**	Cancer Service Manager	MFT
Jade Barton	**JBa**	Faster Diagnosis Admin Team Lead	MTW
Victoria Earl	**VE**	FDS NSS Navigator	MTW
Ryan Johnson	**RJ**	Pathway Navigator	MTW
Karen Walker	**KW**	Therapy Radiographer	MTW
Julie-Ann Moreland	**JM**	Academic and Clinical Diagnostic Radiographer	Oxford University Hospitals NHS Foundation Trust
Georgia Black	**GB**	Professor of Applied Health Research	Queen Mary University of London
Apologies			
Kevin Bonham	**KB**	NSS MDM Coordinator	DGT
Sarah Howland	**SH**	Operations Manager - CCHH Care Group	EKHUFT
Claire Bingham	**CBi**	Macmillan Personalised Care Facilitator	EKHUFT
Danielle Mackenzie	**DM**	Macmillan Lead Nurse for Personalised Care	EKHUFT
Jacob Verghese	**JV**	Cancer Pathway Navigator	MFT
Jenny Weaver	**JW**	Macmillan Immunotherapy CNS in Acute Oncology	MTW
Maher Hadaki	**MH**	Consultant Clinical Oncologist	MTW
Mathilda Cominos	**MC**	Consultant Clinical Oncologist	MTW
Megan Lumley	**ML**	CUP CNS	MTW
John Schofield	**JS**	Consultant Pathologist	MTW
Stefano Santini	**SS**	NSS GP Lead	MTW
Abdul Nakouzi	**AN**	Medical Consultant	MTW
Ruth Palfrey	**RP**	FDS NSS Nurse Specialist	MTW
Tracey Spencer-Brown	**TSB**	Head of Nursing for Oncology & Cancer Performance	MTW

Item		**Discussion**	**Action**
1	**TSSG Meeting**	**<u>Introductions</u>** • HWS introduced herself to the group as the new Chair for the CUP & NSS TSSG and asked the members to introduce themselves in the Chat section of Microsoft Teams. **<u>Apologies</u>** • The apologies are listed above.	

2	**Review of action log and previous minutes**	• The minutes from the previous meeting were not reviewed but had been agreed as a true and accurate record by TSB who chaired the last CUP & NSS TSSG. • The action log was reviewed, updated and will be circulated to the group with the final minutes from today's meeting.	
		NSS	
3	**Overview of NSS Structures at Each Trust**	**EKHUFT service model – update provided by Claire Whiteley** • CW described the EKHUFT team as a small group led by herself, Dr Carlo Nunes, and Navigator Sam Jones. • Approximately two-thirds of referrals are from GPs, with the remainder internal, mainly MUO. • Most patients are seen in clinic first, although some are straight-to-test cases. • The team triages referrals, reviews diagnostic outcomes and manages the patient, redirects them to appropriate pathways or sends them back to the GP with recommendations. **DGT service model – update provided by Carrie Barton** • CBa reported a recent team change with a new acute physician and outlined the team structure, including herself as CNS, Leanne Warren, and navigator Adedolapo Odah (AO). Referrals are mostly from GPs, with additional sources such as A&E and the lung CT pathway. Triaging is handled by CBa or Leanne Warren, who gather missing information and decide on face-to-face or straight-to-test approaches. Protocols are being developed for incidental adrenal lesions and iron-deficiency anaemia. **MFT service model – update provided by Mayank Patel** • MPat explained that MFT lost its CNS in June 2025 which resulted in some operational challenges. MPat and Dr Hannah Taylor have been managing the referrals, with most now triaged by MPat. The team faces challenges with Navigator turnover and data tracking, resulting in delays for first-link appointments. Most patients are now seen face-to-face, and inappropriate referrals are returned or redirected. Protocol development has stalled due to staffing constraints, but there are plans to resume work on anaemia and negative qFIT pathways. **MTW service model**	

		• No update was provided by an MTW representative. **<u>Action</u>: CC to email the MTW NSS team to request a written update.** **<u>Summary of additional discussions</u>** • With regard to referral and triage practices, all three Trusts represented reported a trend towards more face-to-face initial assessments, moving away from STT models. Each team is in the process of developing protocols for handling specific referral types and managing incomplete workups, with a focus on efficient triage and appropriate pathway allocation. • NCha raised questions around the efficiency and workload implications of handling abnormal imaging referrals within the NSS pathway, with HWS explaining the DGT process and the rationale for trying to develop specific protocols for incidental findings. • NCha inquired about the process for abnormal imaging referrals, and HWS clarified that abnormal chest X-rays trigger automatic CT scans, with results filtered by a Respiratory Consultant. Non-lung suspicious findings are referred to NSS, which has prompted a desire to develop protocols for incidental adrenal lesions and IPMNs to manage recurring incidental findings efficiently. • With regard to workload and efficiency, NCha expressed concerns about the potential for overwhelming NSS teams with incidental findings, while HWS noted that the current volume is manageable but acknowledged the risk if the number of incidental findings increases significantly.	**CC**
4	**Reflections & Key Learnings from Recent NSS Research**	**<u>National Research and Best Practices in NSS Pathways – update provided by Georgia Black</u>** • GB presented findings from her research on NSS pathways, discussing key activities, pinch points, optimal service models, and policy challenges, with active engagement from participants including NCha and CS on the implications for local practice. • GB outlined nine critical pinch points in NSS pathways, including referral assessment, pathway appropriateness, investigation planning, multidisciplinary input, tracking results, accessing specialist advice, estimating cancer risk, monitoring, and communicating results. She emphasised the variation in practices across sites and the impact on patient safety and care quality.	

		• GB identified multidisciplinary team working, a focus on learning and skills development, and the use of clinical-background patient navigators as key features of effective NSS services. She highlighted the importance of generalist knowledge, regular team meetings, and explicit learning opportunities. • GB discussed the lack of clarity in national policy regarding the scope of NSS pathways, the challenge of meeting the 28 day faster diagnosis standard, and the potential for unintended consequences such as over-testing. She suggested that NSS pathways may require different performance metrics due to their complexity. • CS described efforts within the Kent & Medway Cancer Alliance to standardise service specifications, referral forms, and clinical leadership models across Trusts, while GB noted the national trend of service variation and the risk of decommissioning face-to-face clinics in favour of remote models. • NCha and GB discussed the balance between thorough investigation and accepting diagnostic uncertainty, with GB noting that services led by GPs or with a culture of risk-holding were more comfortable discharging patients with some residual uncertainty, while others pursued exhaustive testing. **<u>Oxford NSS Pathway Research and Outcome – update provided by Julie-Anne Moreland</u>** • JM shared research from the Oxford NSS pathway, detailing service design, patient demographics, cancer and non-cancer outcomes, incidental findings, and the development of a biobank for multi-cancer early detection research. • JM described the Oxford NSS pathway as initially staffed by a radiographer and consultant, with triage and patient contact managed by Navigators. Referrals are accepted from primary care, with a structured process for clinical history, CT, blood tests, and biobank consent. The pathway includes close links with haematology and a multidisciplinary clinic for complex cases. • Analysis of over 4,800 patients showed a predominance of female and older patients, with an 8.8% cancer conversion rate. The most common cancers diagnosed were lung, pancreatic, colon, and breast. Non-cancer outcomes included gastritis, interstitial lung disease, and iron-deficiency anaemia, with a significant proportion of incidental findings such as lung nodules. • Approximately one-third of patients are consented to the biobank, which supports research into multi-cancer early detection tests. JM highlighted the need for more diverse patient representation in research cohorts and discussed ongoing projects using biobank samples for test development.	

		• Attempts to build a risk prediction model based on age, gender, and blood tests were inconclusive due to limited data. JM noted that unexplained test results, especially elevated CA-125, had the highest PPV for cancer, but also flagged the need to consider non-cancer causes of raised CA-125. • JM raised questions around the appropriateness of the 28 day target for NSS, the management of incidental findings, and the need for more research into patient experience and health literacy within NSS pathways. • Members led a discussion on the challenges and appropriateness of applying the 28 day FDS to NSS pathways, with consensus emerging that the standard may not fit the complexity of NSS cases and could drive unnecessary investigations. • The members discussed how the pressure to meet the 28 day target can lead to more aggressive or scattergun investigation strategies, potentially exposing patients to unnecessary tests and not always aligning with best clinical judgment for stepwise investigation. • JM highlighted that delays in NSS can affect downstream cancer pathways, such as lung cancer, by starting the 62d clock earlier and potentially impacting treatment decisions and trial eligibility. • AK suggested that NSS and MUO/CUP services should advocate for a separate approach to performance targets, recognising the unique patient population and diagnostic complexity, and prioritising patient care over rigid adherence to the FDS.	
5	**Breakout Session (Mixed Sites)**	**Discussion around key questions:** • *What is the most effective way of triaging/initial assessment of NSS referrals?* • *How should we manage referrals with incomplete blood tests?* • *Are there referral types for which a protocol could be developed?*	
6	**Feedback from discussions**	**<u>Breakout Group feedback and recommendations</u>** • HWS facilitated feedback from NCha, JBr and DC who summarised discussions on triage, MDT input, patient ownership, access improvement, and the need for a more nuanced approach to NSS pathway metrics. **Triage and MDT input** • NCha's group emphasised the importance of early triage, regular MDT discussions, and clear patient ownership to avoid patients being bounced between teams. They advocated for a logical, stepwise approach to investigation rather than a scattergun strategy driven by targets.	

		Improving access and awareness • JBr's group discussed strategies to improve access, including community and Trust-level awareness campaigns, leveraging patient stories, and using communications resources to highlight the value of NSS pathways for both cancer and non-cancer diagnoses. **Patient pathway and outcome focus** • DC highlighted the need to focus on patient outcomes beyond cancer diagnosis, ensuring that patients with ongoing symptoms are not discharged without support, and suggested using pathway pinch points as a more meaningful metric than the 28 day standard.	
		CUP	
7	**Key take home messages from the Liverpool Conference on Cancer of Unknown Primary**	**<u>Update provided by Claire Whiteley</u>** • CW presented key themes from the UK CUP conference, including the importance of dedicated NSS/MUO/CUP teams, multidisciplinary input, advances in molecular diagnostics, and the need for individualised, patient-centered pathways. • CW reported that conference attendees advocated for maintaining dedicated NSS and MUO pathways, especially in light of service disbandment in some regions. The integration of palliative care clinicians and multidisciplinary teams was highlighted as essential for managing complex CUP cases. • The conference covered advances in whole genome sequencing, liquid biopsies, and AI-driven diagnostic algorithms, with ongoing trials such as the EGGCUP trial in the north of England. The need to balance thorough investigation with timely treatment and resource constraints was emphasised. • Discussions addressed the high cost of CUP pathways, the importance of shortening diagnostic timelines without compromising care, and the need to focus on quality of life and appropriate use of advanced diagnostics for patients most likely to benefit. • CW noted upcoming international conferences and the global momentum in CUP research, with Germany and Australia making significant advances. The importance of structured pathways and dedicated teams for improving patient outcomes was reiterated.	
8	**Insights from the Royal College of**	**<u>Discussion of Royal College of Pathologist's Updated CUP Dataset – update provided by Nicola Chaston</u>**	

	Pathologist's CUP Dataset	• NCha provided an overview of the Royal College of Pathologists' updated CUP dataset, emphasising a stepwise, resource-conscious approach to diagnosis, the importance of MDT collaboration, and the growing role of molecular and liquid biopsy techniques. • NCha advocated for a logical, stepwise approach to CUP diagnosis, starting with basic immunohistochemistry markers and escalating only as needed, to conserve tissue for molecular testing and avoid unnecessary costs. • NCha stressed the importance of MDT discussions, integrating pathology, radiology, and clinical history to reach the most likely diagnosis, and cautioned against over-investigation when it would not change management, especially in rapidly deteriorating patients. • NCha highlighted the increasing utility of ctDNA testing, particularly when tissue samples are limited, and noted that some oncologists are now treating based on ctDNA results when traditional molecular testing is insufficient. • In response to AK's questions, NCha acknowledged the need for specialist CUP MDTs with interested pathologists and radiologists, and the value of clear referral processes and communication between teams to optimise patient management.	
9	**Group Discussion: CUP Pathway Challenges & Opportunities**	• This item was not discussed due to time constraints.	
10	**Feedback from discussions**	• This item was not discussed due to time constraints.	
11	**AOB**	• HWS thanked the members for joining today's meeting and encouraged them to contact her/CC if there is anything that they would like support from the TSSG on. • HWS encouraged the members to sign up to the Cancer Dashboard. David Osborne (Data Analyst – KMCA) is happy to support with registration. • HWS acknowledged the difficulty of working to a 28 day FDS with NSS patients, but reflected that it is not likely to be within the power of this group to alter this target, though we can change how we manage our work to fit it, and this may merit further discussion. • **<u>Action</u>: Consideration to be given to establishing a Kent & Medway-wide CUP/NSS learning forum to support professional development.**	**HWS/ALL**

		• **Post-meeting note:** CC sent a link to a survey to the members and asked if they could provide feedback on today's meeting.	
	Next Meeting	• To be confirmed.	