

Cancer of Unknown Primary (CUP) & Non-Specific Symptoms (NSS) Tumour Site Specific Group meeting
Thursday 30th April 2026
Microsoft Teams
09:20-12:30

Final Meeting Notes

Present	Initials	Title	Organisation
Hannah Weston-Simons (Chair)	HWS	NSS GP Lead	DGT
Leanne Warren	LW	FDS NSS Navigator	DGT
Carrie Barton	CB	NSS CNS	DGT
Sesh Siddavaram	SS	Medical Consultant	DGT
Marie Payne	MPay	Macmillan Lead Cancer Nurse	DGT
Holly Aldous	HA	NSS CNS	EKHUFT
Claire Whiteley	CW	Macmillan Lead NSS/AONP	EKHUFT
Sophie West (Microsoft Teams)	SWe	Consultant Radiologist	EKHUFT
George Arealis (Microsoft Teams)	GA	Consultant Trauma and Orthopaedic Surgeon	EKHUFT
Bana Haddad	BH	Clinical Lead for Kent & Medway Cancer Alliance	KMCA
Emma Lloyd	EL	Cancer Pathways Improvement Project Manager	KMCA
Karen Glass	KG	PA/Business Support Manager	KMCA/KMCC
Colin Chamberlain (Notes)	CC	Administration & Support Officer	KMCC
Samantha Williams	SWi	Administration & Support Officer	KMCC
Erica Simpson	ES	Community Palliative Care Team Lead	Medway Community Healthcare
Jo Carrim	JC	Locum Consultant in Palliative Medicine	Medway Community Healthcare
Mayank Patel	MPat	Consultant - NSS Pathway	MFT
Bobbie Matthews	BM	Macmillan Lead AONP	MFT
Afroditi Karathanasi	AK	Consultant Medical Oncologist	MFT

Charlotte Moss	CM	Consultant Medical Oncologist	MTW
Ruth Palfrey	RP	FDS NSS Nurse Specialist	MTW
Victoria Earl	VE	FDS NSS Navigator	MTW
Megan Lumley	ML	CUP CNS	MTW
Zoe McDonald-Burrows	ZMB	Consultant – NSS	MTW
Vicky Stables	VS	Consultant Haematologist	MTW
Jenny Pang	JP	Consultant Clinical Oncologist	MTW
Laura Mullens	LM	Rare Cancers Clinical Nurse Lead,	MTW
Kelly Bonner	KB	FDS Admin Team Leader	MTW
Ryan Johnson	RJ	Cancer Performance Service Manager	MTW
Apologies			
Denise O'Malley	DO'M	Head of Hospice Outreach Service	Hospice in the Weald
Ann Courtness	AC	Macmillan Primary Care Nurse Facilitator	KMCA
Chris Singleton	CS	Senior Programme Manager for KMCA Commissioning	KMCA
Tracey Squire	TS	Macmillan User Involvement Manager	KMCA/KMCC
Rosalyn Yates	RY	Clinical Lead - Specialist Palliative Care Services	Medway Community Healthcare
Rosemary Chester	RC	Consultant in Palliative Medicine	Medway Community Healthcare
Tracey Spencer-Brown	TSB	Head of Nursing for Oncology & Cancer Performance, Cancer Services Division	MTW
Pia Amsler	PA	Medical Director & Consultant in Palliative Care	Pilgrims Hospice
Item		Discussion	Action
1	TSSG Meeting	<p><u>Welcome and apologies for absences</u></p> <ul style="list-style-type: none"> HWS welcomed the members to the meeting. The apologies are listed above. <p><u>Cancer dashboard and treatment variation review</u></p>	

		<ul style="list-style-type: none"> • Access to the KMCA Cancer Dashboard can be granted by emailing David Osborne (Data Analyst – KMCA) whose email address is david.osborne11@nhs.net. • The datasets are live and updated on a regular basis, pulling data from a number of systems including InfoFlex and PAS. • The FDS target has been increased from 75% to 80% (as of March 2026). • FDS performance has fallen in the last 6 months from 73.4% to 54.9%. • The wide variation suggests systemic bottlenecks and inconsistent pathways. • There was a suggestion to undertake a deep dive at the next TSSG to identify bottlenecks, share best practice and explore pathway alignment. • Please refer to the circulated data pack for a more in-depth overview of performance. 	
2	CRG Update & Review of Activity	<p><u>Updates from sites on NSS & CUP MDTs</u></p> <p><u>DGT</u></p> <ul style="list-style-type: none"> • There is no dedicated NSS MDT. • Complex patients are managed through multidisciplinary team discussions involving the GP Lead, Consultant and CNS. • Imaging is reviewed as needed, with input from the on-call Radiologist. • Advice is often sought from other specialist teams, particularly Upper GI and Haematology. • There is no dedicated CUP MDT. Some patients may be referred to site-specific MDTs if imaging findings or symptoms suggest a particular specialty link. • Most CUP patients are discussed within the Upper GI MDT meeting. • Occasionally, cases are discussed in other site-specific MDTs when the presentation suggests a likely origin. • The CUP CNS attends as appropriate. • Relevant tumour-site MDT members are involved in discussions. <p><u>EKHUFT</u></p> <p>NSS</p>	

		<ul style="list-style-type: none"> • There is no formal NSS MDT. • There is a weekly NSS team catch-up to discuss patients and concerns and decisions are made through team discussion with the Medical Consultant. • Further opinions are sought as needed from oncology, haematology, orthopaedics, radiology, TSSG teams, other in-house specialties (e.g. endocrinology, neurology) and tertiary centres when additional specialist input is needed. <p>CUP</p> <ul style="list-style-type: none"> • There is a dedicated CUP MDT and this sits within the Upper GI MDT. • There is a designated MUO slot at the start of the meeting and CUP cases are discussed within the histology section. • The MDT membership comprises of the NSS team, upper GI gastroenterology consultants, a radiologist, a histopathologist, oncologists, the CNS team, MDT coordinators and trackers, the upper GI surgical team as well as tertiary input from King's HPB and Guy's OG/stomach teams. • The MDT takes place weekly on a Monday or Tuesday during Bank Holiday weeks. <p>Overall</p> <ul style="list-style-type: none"> • NSS cases are managed through structured but informal multidisciplinary discussions, drawing on a wide network of specialist and tertiary advice. CUP has a well-established, weekly MDT embedded within the Upper GI MDM, with broad local and tertiary representation. <p><u>MFT</u></p> <ul style="list-style-type: none"> • The MDT comprises Respiratory Physicians, Radiologists, Nuclear Medicine specialists, a Histopathologist, Medical and Clinical Oncologists, a Lung CNS/CUP CNS and a Cardiothoracic Surgeon. • The Lung/CUP MDM discusses cases, reviewing imaging and histology with appropriate specialty input. The MDT aims to identify the primary site if at all possible. • Key benefits for NSS/MUO includes: <ul style="list-style-type: none"> - Rapid access to multi-specialty expertise for complex cases. - Faster diagnostic clarification. 	
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		<ul style="list-style-type: none"> - Streamlined decisions on investigations and management. - Early direction into site-specific pathways, improved pathway efficiency and support for performance targets and stronger integration with lung and oncology services. <p><u>MTW</u></p> <ul style="list-style-type: none"> • At present, MTW do not have a formal NSS MDT in place. In place of a formal MDT structure, the following processes are in place: <ul style="list-style-type: none"> - In the first instance, cases are discussed with the NSS Consultant. - Where required, Consultants will seek further specialist input and advice from other healthcare professionals on a case-by-case basis. - The CUP MDT currently operates on an ad-hoc basis, according to individual patient needs. Cases are generally only discussed once histology is available. • When convened, the CUP MDT is attended by the CUP CNS, Consultant Oncologist, Consultant Radiologist, Pathologist and Navigator. <p><u>Key conclusions</u></p> <ul style="list-style-type: none"> • There is a lack of formal NSS MDTs across the region. • There is inconsistent access to radiology and specialist input. • CUP lacks a unified forum. • There was discussion on the ambition to explore a Kent-wide MDT for CUP and possibly NSS. <p><u>System gap</u></p> <ul style="list-style-type: none"> • There is a lack of local diagnostic “spoke” centres in Kent. • The group were encouraged to consider development of local diagnostic centres and improve integration with tertiary MDTs. • Following discussion, it was suggested that it may be helpful for NSS teams without a dedicated MDT to compile a list of radiologists and other specialists with contact details, for ease of whole team reference - e.g. MSK radiologist, upper GI radiologist, interventional radiologist and so on. 	
3	Lymphoma Presentations	<u>Update provided by Victoria Stables</u>	

<p>Relevant to NSS</p>	<p><u>Lymphoma</u></p> <ul style="list-style-type: none"> • Lymphoma, a malignancy of lymphocytes arising in lymph nodes or lymphoid tissue, can spread to bone marrow, the spleen, CNS, skin, and other organs. • It often presents vaguely and therefore diagnostic delay is common. <p><u>Types</u></p> <p>Hodgkin lymphoma</p> <ul style="list-style-type: none"> • Bimodal age: 20–30 and >50. • Male predominance. • Defined by Reed–Sternberg cells. • Strong association with Epstein–Barr virus. <p>Non-Hodgkin lymphoma</p> <ul style="list-style-type: none"> • Heterogeneous group (B-cell, T-cell, NK-cell). • Can be low-grade (indolent) or high-grade (aggressive). <p><u>Risk factors</u></p> <ul style="list-style-type: none"> • Immune dysfunction (immunodeficiency, autoimmune disease). • Infections such as EBV, HHV-8, HTLV-1, Hepatitis C, Helicobacter pylori. • Environmental exposures such as herbicides and pesticides. <p><u>Clinical presentation</u></p> <p>Typical features</p> <ul style="list-style-type: none"> • Painless lymphadenopathy (cervical, axillary, inguinal). • Splenomegaly → abdominal discomfort, early satiety. • B symptoms: fever $\geq 38^{\circ}\text{C}$, drenching night sweats and $\geq 10\%$ weight loss (6 months). • Fatigue, pruritus, cytopenias. • Alcohol-induced lymph node pain (rare). 	
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<p><u>Lymphoma red flags</u></p> <ul style="list-style-type: none"> • Lymph node >1–2cm. • Persistent >2–4 weeks or enlarging. • Hard, fixed, painless nodes. • Associated B symptoms. <p><u>Differential diagnosis of lymphadenopathy</u></p> <p>Infection (most common)</p> <ul style="list-style-type: none"> • Viral: Epstein–Barr virus, Cytomegalovirus, HIV. • Bacterial: Tuberculosis, syphilis. • Usually tender, bilateral, systemic symptoms. <p>Malignancy</p> <ul style="list-style-type: none"> • Lymphoma. • Metastatic cancer (hard, irregular nodes). <p>Reactive/inflammatory</p> <ul style="list-style-type: none"> • Autoimmune diseases: systemic lupus erythematosus, rheumatoid arthritis, sarcoidosis. • Drug reactions. <p>Extra-nodal disease</p> <ul style="list-style-type: none"> • Lymphoma may present without obvious lymphadenopathy. • GI tract: obstruction, nausea (mimics carcinoma). • Skin/scalp: rashes or masses. • Bone/muscle: pain, fractures. • Head and neck: tonsillar asymmetry, salivary swelling. • Can involve breast, testis, kidney, cervix, prostate. <p><u>Night sweats</u></p>

- Medical advice is recommended if clothes/bedding are drenched, the sweats are persistent/recurrent, if the sweating occurs in cool environments or if the sweats are accompanied by other B symptoms.
- Common benign causes include menopause, postpartum, anxiety, alcohol withdrawal, hyperthyroidism and medications such as SSRIs and steroids.

Assessment approach

History

- B symptoms.
- Lumps, infections, bruising.
- Autoimmune disease, immunosuppression, viral risks.

Examination

- Full lymph node exam.
- Liver and spleen.
- Node character: rubbery is indicative of lymphoma and hard/craggy is indicative of metastatic cancer.

Investigations

- Initial tests: FBC + blood film; LDH; renal, liver, bone profile; ESR; virology (HIV, HBV/HCV); and immunoglobulins ± SPEP/SFLC.
- Definitive diagnosis: Lymph node biopsy (core or excision). Do not use FNA.
- Imaging: PET-CT for staging. A bone marrow biopsy is often unnecessary if a PET-CT is done.

Key take-home messages

- Lymphoma can present in many different ways, including extra-nodal disease.
- Always consider infection, malignancy and autoimmune causes.
- Persistent or suspicious lymph nodes require further investigation.
- Diagnosis requires biopsy — never FNA.
- Maintain a high index of suspicion and systematic approach.

		<ul style="list-style-type: none"> • Action: HWS to take responsibility for organising a Myeloma session to be presented by Victoria Stables (if available). Victoria Stables is willing to talk a future meeting through a “Beginners guide to Myeloma”. This will be explored further at the next meeting. 	HWS
4	Bone Lesions: Incidental or Otherwise	<p><u>Radiological Assessment - update provided virtually by Sophie West</u></p> <p><u>Classification</u></p> <ul style="list-style-type: none"> • Bone lesions are classified by age, location in bone (diaphysis, metaphysis, epiphysis) and type (e.g. lytic lesions using mnemonic FEGNOMASHIC). <p><u>Good vs bad features</u></p> <ul style="list-style-type: none"> • Benign (“good”) features can include well-defined margins, narrow zone of transition, intact cortex, no periosteal reaction or marrow oedema and the presence of fat (which is reassuring). • Aggressive/malignant (“bad”) features can include: poorly defined margins, wide zone of transition, cortical destruction, periosteal reaction, marrow oedema, soft tissue component and lack of fat. <p><u>Imaging modalities</u></p> <p>Plain X-ray (first-line)</p> <ul style="list-style-type: none"> • Essential baseline test. • Shows lytic vs sclerotic lesions, fractures, calcifications. • Helps guide further imaging. <p>CT</p> <ul style="list-style-type: none"> • Best for bony detail. • Detects cortical destruction, calcification, small lesions. <p>MRI</p> <ul style="list-style-type: none"> • Best for soft tissue and marrow. • Differentiates cystic vs solid lesions. • Detects marrow oedema and spinal cord compression. 	

- Cannot distinguish lytic vs sclerotic lesions.

Nuclear Medicine (Bone scan/PET-CT)

- Sensitive for increased bone activity.
- Not specific (cannot reliably distinguish benign vs malignant).
- Poor for purely lytic lesions and myeloma.

MRI indicators

- Reassuring: presence of fat (seen on T1 and fat suppression sequences).
- Concerning: diffusion restriction or low T1 + high STIR signal (which suggests malignancy).

Problem solving approach

- Options include: watch and wait, follow-up imaging, additional imaging modalities, second opinion and biopsy.

Overall takeaway

- Start with plain films, assess benign vs aggressive features, and use CT/MRI selectively to further characterise lesions and guide management.

Orthopaedic Assessment - update provided virtually by George Arealis

Purpose of the presentation

- The purpose of the presentation was to outline a diagnostic approach for patients presenting in orthopaedics with possible cancer.
- There was a particular emphasis on deciding between local biopsy vs tertiary referral.

Structure of the pathway

- The presentation appears to be organised into 4 main sections:
 - Diagnostic approach.
 - Red flag identification.
 - Clinical importance.

		<ul style="list-style-type: none"> - Terminology and multidisciplinary understanding. <p><u>Core components</u></p> <p>Clinical assessment and triage</p> <ul style="list-style-type: none"> • Initial patient evaluation. • Identifying concerning features and prioritising cases. <p>Clinical pathway: bone lesions</p> <ul style="list-style-type: none"> • Structured workflow for investigating suspicious bone lesions. • Imaging, referral criteria, and escalation. <p>Biopsy decision framework</p> <ul style="list-style-type: none"> • Guidance on when and how to biopsy. • Balancing risks of local biopsy vs specialist centre involvement. <p>Local biopsy framework</p> <ul style="list-style-type: none"> • Standardised approach for safely performing biopsies locally. • Ensures diagnostic accuracy while avoiding compromising future treatment. <p><u>Supporting tools</u></p> <ul style="list-style-type: none"> • Use of structured templates, decision aids, and possibly digital systems. <p><u>Overall takeaway</u></p> <ul style="list-style-type: none"> • The presentation is about standardising and improving the early diagnostic pathway for suspected malignancy in orthopaedic patients, with a strong focus on early recognition of red flags, safe and appropriate biopsy decisions, reducing delays and inappropriate referrals and aligning local and specialist care pathways. 	
5	Sarcoma Pathway	<u>Presentation provided by Laura Mullens</u>	

<p>Overview</p>	<ul style="list-style-type: none"> • LM informed the group that sarcomas are malignant tumours of connective tissue. They are rare cancers and are broadly divided into soft tissue sarcomas (more common) and bone sarcomas (rarer). • There are around 100 different subtypes, arising from tissues such as muscle, fibrous tissue, blood vessels, cartilage, or nerve (e.g. leiomyosarcoma, angiosarcoma, osteosarcoma, Ewing's sarcoma). <p><u>Symptoms and presentation</u></p> <ul style="list-style-type: none"> • Most commonly a lump that is growing or changing. • Other symptoms may include pain which is often worse at night, abdominal pain, swelling, early satiety, nausea or gastrointestinal bleeding. • Sarcomas often present late due to non-specific symptoms. <p><u>Sarcoma incidence and prognosis per year in the UK</u></p> <ul style="list-style-type: none"> • Soft tissue sarcoma: ~4,295 cases. 65% 5-year survival. • Bone sarcoma: ~662 cases. 53% 5-year survival. • This highlights sarcoma as a rare cancer with variable outcomes. <p><u>Case study</u></p> <ul style="list-style-type: none"> • A 70-year-old male with a rapidly enlarging thigh mass attends several GP appointments before an MRI shows that he has a 19cm tumour. • The patient has a biopsy and the mass is confirmed as high-grade pleomorphic sarcoma. He is initially treated with curative intent (radiotherapy and surgery), however lung metastases appear within 6 months and he is subsequently transitioned to palliative chemotherapy and given a prognosis of ~1 year. • This case study demonstrates the aggressive nature and relapse risk of high-grade sarcoma. <p><u>Management principles</u></p> <ul style="list-style-type: none"> • All suspected or confirmed sarcomas must be discussed at a specialist Sarcoma MDT and management should ideally take place at a specialist centre. 	
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		<ul style="list-style-type: none"> • Some treatments, for example chemotherapy or radiotherapy, may be delivered locally for reasons of practicality. <p><u>Kent patients</u></p> <ul style="list-style-type: none"> • Soft tissue sarcomas are treated at Royal Marsden Hospital and bone and some soft tissue sarcomas are treated at the Royal National Orthopaedic Hospital. • Any head and neck bone lesions need to go to UCLH rather than RNOH. All bone lesions elsewhere in the body go to RNOH. <p><u>Diagnostic and referral pathway</u></p> <ul style="list-style-type: none"> • Sarcoma is suspected on imaging and a referral is made to the specialist Sarcoma MDT. • A biopsy is performed at the specialist centre. This is deemed critical as the biopsy tract can be removed at surgery stage. • Specialist surgery ± radiotherapy is offered and follow-up takes place at the specialist centre. Exceptions include local biopsy in metastatic disease and local radiotherapy delivery. <p><u>Overall message</u></p> <ul style="list-style-type: none"> • Sarcoma is a rare, complex, and potentially aggressive cancer that requires early recognition, specialist referral, and MDT-led care to optimise outcomes. 	
6	<p>Group Discussion: Bone Pathway Development</p>	<ul style="list-style-type: none"> • Circumstances in which bone biopsies could be undertaken without referral to tertiary centres were discussed. A number of oncology consultants present reflected that in circumstances where a patient has multiple bony metastases an MDT might decide to organise a local biopsy without reference to RNOH. • GA felt that it was safer to involve tertiary centres in all decisions particularly regarding single lesions, but conceded that with MDT approval and in instances of multiple bone lesions, local biopsy could be appropriately undertaken locally. • LM reflected that tertiary London centres are keen to set up biopsy spoke centres more locally to help ease their workload and for patient convenience. • GA reflected on his experience in EKHUFT that this had not proven an easy thing to set up. 	

		<ul style="list-style-type: none">• LM clarified the nature of her involvement with patients receiving treatment at tertiary centres and the referral pathway to her team.	
7	AOB	<ul style="list-style-type: none">• There is a strong emphasis on improving joint working across Kent & Medway.• Variation in practice (especially MDT provision) was identified as a major issue. However, there was an agreement to explore a Kent-wide approach, particularly for CUP discussions.	
	Next Meeting	<ul style="list-style-type: none">• To be confirmed.	