Annual Report for Lung Cancer Clinical Nurse Specialists

Kent and Medway 2023-2024

Introduction

There are 3 million people living with cancer in the UK. It is predicted that this number will rise to approximately 4 million by 2030. Lung cancer is the third most common cancer in the UK with 46,400 people diagnosed each year *(Macmillan 2020).* This is 13% of all new cancer diagnosis.

The estimated lung cancer prevalence across England is broken down in the table below and forecast forward by year, and amount of people expected to be diagnosed.

	2020	2025	2030	2040
England	70,000	80,000	100,000	130,000

Lung cancer mortality rates are projected to fall by 9% in the UK between 2023-2025 and 2038-2040. (*Cancer research UK).* Meaning people are living longer with lung cancer.

The Kent and Medway Cancer Alliance (KMCA) covers a population of around 1.9 million in the South East.

The Kent and Medway Cancer Alliance brings together clinicians and managers from health, social care and other services to transform the diagnosis, treatment and care for cancer patients. These partnerships enable care to be more effectively planned across local cancer pathways.

The Alliance is made up of multiple stakeholders including healthcare providers from across Kent and Medway, commissioners, hospices, patient representatives, voluntary and charitable organisations and the National Institute for Health Research. It also has strong links with neighbouring Cancer Alliances in South East London, Surrey and Sussex.

The main Cancer Centre for the Kent & Medway Cancer Alliance (KMCA) is the Kent Oncology Centre which forms part of Maidstone and Tunbridge Wells NHS Trust (MTW).

Role of Clinical Nurse Specialist (CNS)

The CNS has expert knowledge and experience in lung cancer. The CNS forms part of the team of healthcare professionals who provide support, information and advice during investigations, diagnosis, treatment and palliative care.

Guidance from the Department of Health and Macmillan Cancer Support (shown below) summarises many (but not all) of the key contributions made by CNSs to cancer care across the pathway.

CNS teams are vital in supporting patients through their diagnostic pathway and cancer journey whilst ensuring continuity of care is maintained.

Current Workforce (FTE)

	DGT	EKUHFT	MFT	MTW
CNS	3	3.7	3	3.5
CSW	0	0.8	1	1
STT	1	1	1	0
ANP	0	0	0	0.7

As per the Lung Cancer Pathway, the recommended ratio of patient to CNS is currently 1 CNS per 80/100 patients newly diagnosed. This is currently under review by LCNUK as it dos not reflect the total number of patients on our caseload.

Qualifications

DGT	EKUHFT	MFT	MTW
Advanced communication skills	Advanced communication skills	Advanced communication skills	Advanced communication skills
IRMER	IRMER	IRMER	Consultation and Physical Examination
SACT administration	Palliative care	SACT administration	Non-medical prescribing
Mentorship	End of life care	Consultation and Clinical Examination	SACT administration
Critical Care	Sage and Thyme	Palliative care	Cancer Care
	Cancer Care	Critical Care	End of life care
	Health Promotion	Mentorship	Mentorship
	Mentorship	Sage and Thyme	Health Promotion

Demographics

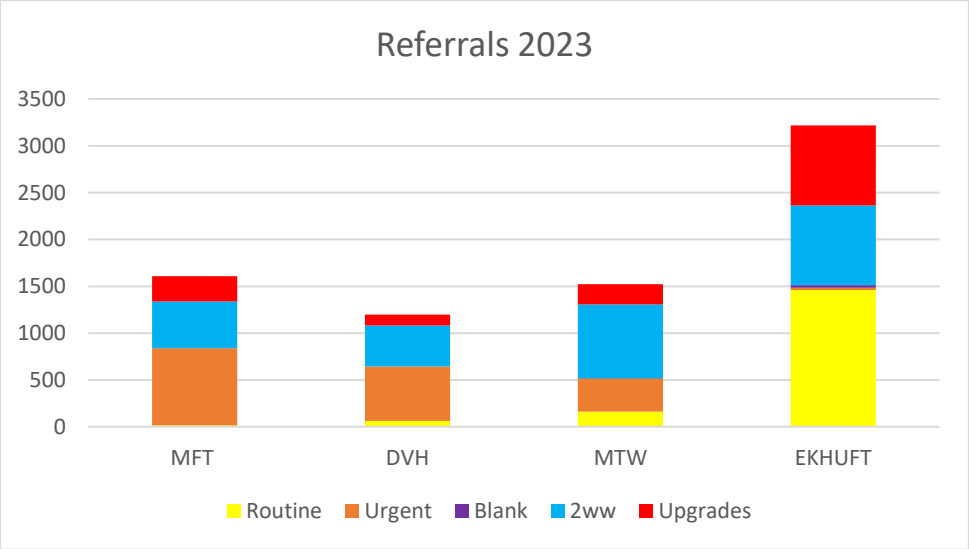
Each site covers particular areas within their scope.

Following the last census, between 2011 and 2021 there has been an increase in numbers within the local areas. The national average population increase is 6.6%. Some of the areas covered are listed below.

DGT	EKUHFT	MFT	MTW
Dartford 20%	Canterbury 4.1%	Medway 6.0%	Maidstone 13.3%
Bexley 6.3%	Ashford 12.5%	Swale 11.7%	Tonbridge and Malling 9.4%
Gravesham 5.1%	Thanet 4.8%		Tunbridge Wells 0.2%
	Dover 4.2%		Sevenoaks 4.9%
	Folkestone and Hythe 1.7%		

Referrals in 2023

As a lung cancer CNS, we support the patients at the start of their referral journey irrespective of their final diagnosis. Two thirds of these referrals will not have a cancer diagnosis; however, we ensure they have support throughout this anxious time. We are involved in arranging tests and investigations, liaising with other health care professionals and contacting those patients who have been referred as two week wait/ urgent suspected cancer referrals including any inpatient referrals. Referrals are triaged and offered an appointment with a consultant or STT CNS. The number of referrals received for 2023 are reflected in the table and graph below.

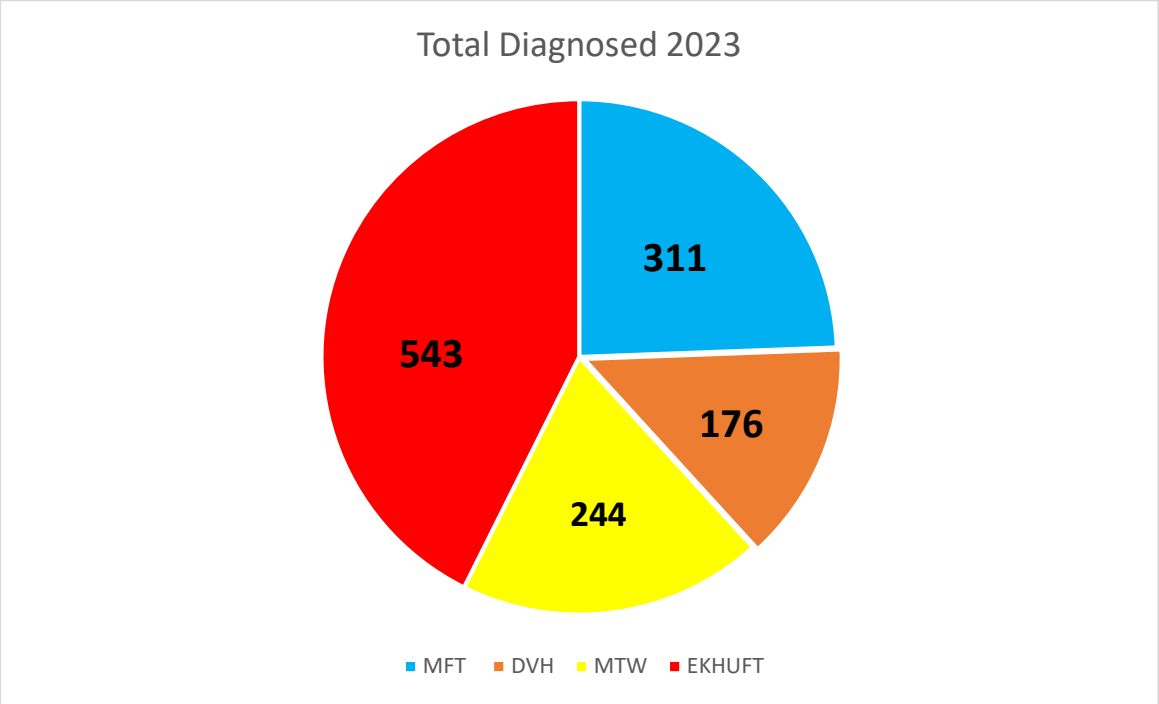


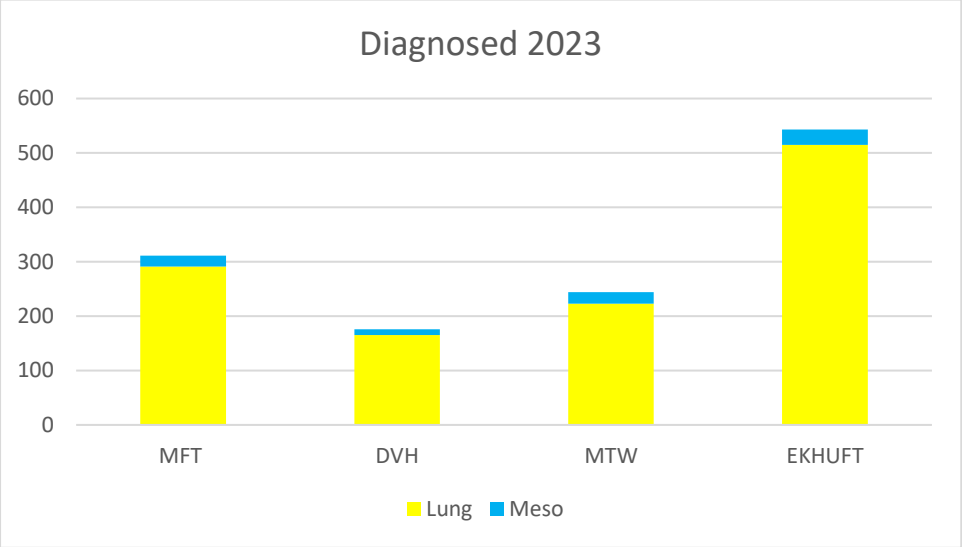
Referrals 2023	MFT	DVH	MTW	EKUHFT	Totals
Routine	13	64	161	1461	1699
Urgent	826	581	355	23	1785
Blank	0	0	1	27	28
2ww	498	437	791	854	2580
Upgrades	270	114	213	854	1451
Totals	1607	1196	1521	3219	7543

Please note 2ww (Two week wait) referrals and now named USC (urgent suspected cancer) referrals

Diagnosed in 2023

In 2023, 31.6% of the total combined 2ww (USC) referrals and upgrades were diagnosed with cancer, either lung cancer or mesothelioma. This is further broken down by Trust and diagnosis below.





Diagnosed 2023	MFT	DVH	MTW	EKUHFT	Totals
Lung	291	165	223	515	1194
Meso	20	11	21	28	80
Totals	311	176	244	543	1274

Using the current patient to CNS ratio, MFT and EKUHFT are both under staffed. This ratio is currently under review as it is argued this is not correct due to the nature of complex patient needs. This is only looking at patients newly diagnosed and not the current total amount of patients.

Clinics per week

There are a variety of clinics held within the suspected and confirmed Lung Cancer service. They range from USC clinics to Breaking Bad News (BBNs) clinics. For those diagnosed with cancer, clinics then range from thoracic surgery clinics to oncology clinics. We also offer Health Needs Assessment Clinics to address the needs of our patients to offer the most relevant support.

	DGT	EKUHFT	MFT	MTW
USC (2ww)	5	8	Combined clinic 3 per week	7
BBN	2	5		3
Oncology	4	7	7	7
Thoracic Surgery	1	2	1	1
HNA	2	3	1	

Virtual clinics are still held in some areas. Although there is a place for virtual clinics, face-to-face clinics are still preferred. There have been some challenges with virtual clinics which will be discussed further.

Multi-Disciplinary Meetings (MDM)

Regular Multi-Disciplinary Meetings are held to discuss patients' diagnostic pathways, results and management plans. Whilst also discussing known cancer patients whom need an MDM opinion to optimise and support ongoing cancer management.

	DGT	EKUHFT	MFT	MTW
Number	1 per week	2 per week	1 per week	1 per week

Specialists in the MDM

- Respiratory consultants
- Thoracic Surgeon (based at Guy's hospital)
- Medical / Clinical Oncologists
- Histopathologists
- Radiologists
- Lung and Mesothelioma CNS
- Straight to Test CNS
- Multi-disciplinary Team Coordinator
- Lung Navigator
- Palliative Care Teams

Mesothelioma MDM

A specific MDM is required to ensure every patient with Mesothelioma is discussed by a specialist team to ensure correct diagnosis and treatment plans are reviewed. This will ensure there is fair access to all trials and treatments.

MDT - Regional

There is no regional MDT at present. However, in late 2023 the TSSG and the Kent Cancer Alliance agreed to support this. In 2024, Louise and Toni will be driving this forward and have writing of referral guidelines, referral proformas and an MDT specification / business case.

MDT - Local MDT meeting

All patients with a suspected mesothelioma are discussed at one of five local MDT's across Kent. (Note: East Kent Hospital Trust hold 2 MDT's at Kent and Canterbury Hospital and the William Harvey Hospital). All five MDT's are joint Mesothelioma and lung cancer cases.

TSSG Regional – Louise / Toni have an established protected agenda slot on the Lung Cancer regional meeting held twice yearly – This provides an opportunity to disseminate information and education, share practice, present on-going and new audits and show case Mesothelioma UK.

This has already been discussed at length and is on the action log of the Lung TSSG. Kent has 2 Mesothelioma UK Nurses posts. Based at MTW Band 7, 30 hrs / 0.8 WTE.3 days per week – Tuesday 8am–6.30pm, Wednesday 8am–6.30pm, Thursday 8am–6.30pm15 hours funded by Meso UK Based at KCH 2 days Band 7 funding by Meso UK The post holder collaborates with the KMCC via the site-specific tumour group (TSSG) as well as many other groups to include:

Kent TSSG – Clinical Nurses Forum

British Oncology Group

British Thoracic Society

Lung Cancer Nursing Forum

ITONF

MESO Update 2023 - 2024

83 patients were diagnosed with mesothelioma across 4 NHS Trusts / 7 Hospital sites within Kent. This number does not include those diagnosed within the private sector which on average is about a further 5 per year. The number diagnosed is likely to increase further, following several patients whom we thought were a radiological diagnosis but whom we are awaiting post mortem results.

The list below illustrates how many patients were diagnosed by each NHS Trust and also compares West versus East Kent patient numbers

Hospital / Trust Number Diagnosed Jan 1st to Dec 31st 2023

Darenth Valley – West Kent 13

Maidstone and Tunbridge Wells NHS Trust -West Kent 20

Total West Kent 33

Kent and Canterbury – East Kent Hospitals NHS Trust 32

Medway East Kent 18

Total East Kent 50

Grand Total - KENT WIDE 83

.

Successes - Audits - C45 – ICD Diagnosis - Regional Audit – Ongoing which has improved data collection. The Study – Health Companion– Meso app helps to provide patient with information on the study and consent. Current audits: Regional asbestos / exposure audit, Exploring the Meso UK-CNS presence in Regional Oncology Clinic, Patient referrals to supportive charities for benefits/ compensation advise. There is a working group for re-developing, capturing and implementing the Meso UK CNS Activity data. There is a Nurse Adviser for pan London/Kent Educational Forum.

Presentations given at World Lung conferences - Internationally on Mesothelioma.
Appointed as a National Nurse Consultee for NICE

Challenges - remain with poor communications with the local coroner's office to access post mortem results. One of the East Kent Meso UK CNS seconded to another non-Mesothelioma Post. Support Group clashes once per month with Regional oncology Clinic. Setting up and implementing a regional MDT has remained an on-going challenge. Rolling out and recruiting patients to the Meso/Lung Health companion Patient App has been difficult with a slow uptake.

Treatment

Treatments vary from watch and wait, surgery, active cancer treatments, palliative, and best supportive care. The data below is pulled from Infoflex for the year of 2023. This shows the total numbers per Trust per First Treatment.

Number of first treatments for lung cancer and mesothelioma at Kent & Medway Trusts in Jan-Dec 2023

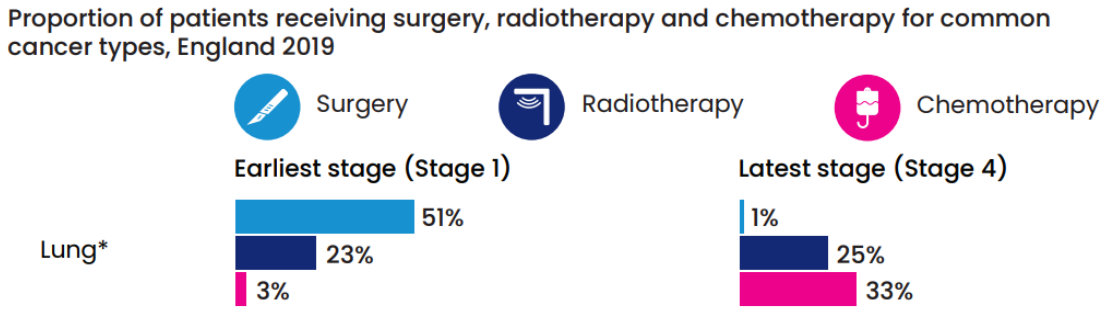
Source: Cancer Waiting Times dataset, provider-based data

First treatment	DGT		EKHUFT	
	Lung	Meso	Lung	Meso
02 Anti-Cancer Drug Regimen (Cytotoxic Chemotherapy)	20		55	
04 Chemoradiotherapy				
05 Teletherapy (Beam Radiation excluding Proton Therapy)				
07 Specialist Palliative Care	22	3	79	2
08 Active Monitoring (excluding Non-Specialist Palliative Care)	6	1	21	1
09 Non-Specialist Palliative Care (excluding Active Monitoring)			62	2
14 Anti-Cancer Drug Regimen (other)	1		8	
15 Anti-Cancer Drug Regimen (Immunotherapy)	3	2	5	6
21 Biological Therapies (excluding Immunotherapy)				
23 Surgery (excluding enabling treatment)	2		2	
24 Surgery (enabling treatment)			1	
97 Other treatment (not listed)	1		9	

First treatment	MFT		MTW	
	Lung	Meso	Lung	Meso
02 Anti-Cancer Drug Regimen (Cytotoxic Chemotherapy)	51	1	32	
04 Chemoradiotherapy			46	
05 Teletherapy (Beam Radiation excluding Proton Therapy)			153	3
07 Specialist Palliative Care	8		24	4
08 Active Monitoring (excluding Non-Specialist Palliative Care)	9		22	3
09 Non-Specialist Palliative Care (excluding Active Monitoring)	38	2	18	
14 Anti-Cancer Drug Regimen (other)	1		6	
15 Anti-Cancer Drug Regimen (Immunotherapy)	7	6	4	8
21 Biological Therapies (excluding Immunotherapy)			1	
23 Surgery (excluding enabling treatment)	1		1	1
24 Surgery (enabling treatment)	1			
97 Other treatment (not listed)	8		5	

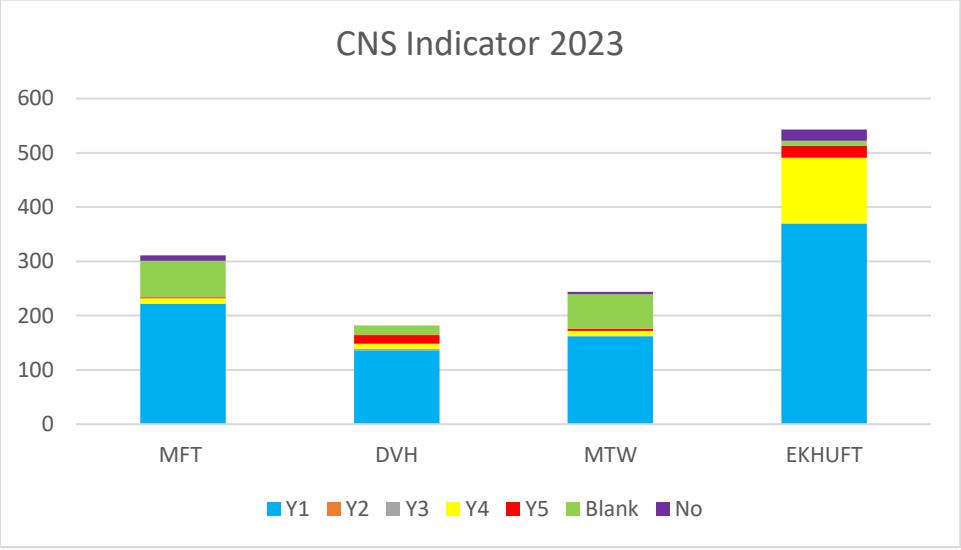
However, on interpreting this data, the results are questionable. For example, more than 1-3 patients per Trust had lung cancer resections in 2023. There is a need for data quality to be accurate and of high quality so reliance can be placed on it. Without accurate and up to data, it is difficult to

make meaningful comparisons both locally and nationally and make valid cases for additional resource, and indeed demonstrate effective performance.



Non-small cell lung cancer only. Cancer Research, Cancer in the UK Overview 2024

CNS contacts



	2023				
CNS code 2023	MFT	DVH	MTW	EKHUFT	Totals
Y1 - Yes, Including nurse present when patient given diagnosis	241	109	196	414	960
Y3 - Yes - Clinical Nurse Specialist not present when patient given diagnosis but saw patient during same Consultant Clinic Session	2	1	1	6	10
Y4 - Yes - Clinical Nurse Specialist not present during Consultant Clinic Session when patient given diagnosis but saw patient at other time	18	21	5	84	128
Y5 - Yes - Clinical Nurse Specialist not present when patient given diagnosis but the patient was seen by a trained member of the Clinical Nurse Specialist team	2	29	2	5	38
Blank	20	10	72	37	139

No	9	6	3	49	67
Totals	292	176	279	595	1342

These figures are variable across the Trusts. Documentation in different areas within Infoflex, makes it difficult to collate and reflect an accurate figure.

Some teams predominately use Infoflex to document patient interactions, whereby others use KOMS (Kent Oncology Management System).

The CNS indicator code records whether a nurse was present at diagnosis, however it does not record the amount of time spent and level of intervention required per contact. This would be very helpful to ascertain as it would provide evidence of the growing CNS workload and need for additional resources.

More recently the Cancer Alliance has added fields to Infoflex to help collect this date. From the time spent per episode of patient contact, to the level of intervention required.

HNAs

After receiving a cancer diagnosis, patients can feel overwhelmed with emotion, questions and worries about how they can manage their diagnosis and what this means to them and their loved ones.

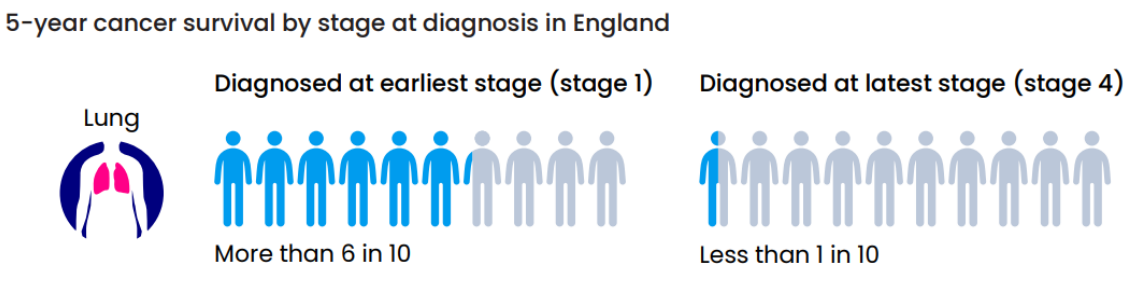
Health Needs Assessments are a way of asking a patient what their concerns and prioritises are and how to address them. They are formally documented and can be shared in the form of a care plan with other healthcare professionals.

This is a holistic patient centred approach ranging from clinical symptom management to emotional, financial, spiritual and family support.

Below are the total numbers of HNA's offered in 2023 per Trust.

	DGT	EKUHFT	MFT	MTW
Total Number	148	0	690	5

More patients are living with and beyond cancer.



Cancer Research, Cancer in the UK Overview 2024

Patient Satisfaction Survey PSS

A patient satisfaction survey had not been performed for years before and during the COVID pandemic. The previously used survey was amended and updated collectively during our CNS meetings. It was agreed the survey would be sent out over a 6-month period, to those patients newly diagnosed with cancer. There was a total of 23 questions.

The timeframe it was sent varied per Trust due to delays with governance and audit teams. The PSS did not run at EKUHFT.

This data was presented at the Lung TSSG in March 2024.

More recently the results from the National Cancer Audit 2024 have been published. There were 4 questions that were comparable to those used in the PSS.

See the below table showing that comparison.

	PSS	National Average	DGT	EKUHFT	MFT	MTW
Family Member present at diagnosis	82%	82.9%	80.8%	79.2%	83.9%	79.1%
Diagnosis given sensitively	94%	74.4%	75.9%	72.5%	75%	80%
Point of contact for the team	96%	92.9%	89.3%	87.2%	90.3%	97.8%
Supported by the GP	16%	42.3%	18.8%	44.1%	27.3%	42.9%

Support groups

Support groups are important to help with emotional and practical support for those going through a cancer journey whether a patient, carer or loved one. Evidence suggests that being around others who understand what they are going through can be really beneficial for them. Not only by peer support, sharing experiences and offering a listening ear but also by befriending. Currently within Kent and Medway the support groups held are listed below.

DGT	EKUHFT	MFT	MTW
1 per month **Lung Cancer and Mesothelioma** Bexley	1 per month **Mesothelioma** Canterbury	2 per month **Lung Cancer and Mesothelioma** x1 Rainham x1 Isle of Sheppey	2 per month **Mesothelioma** Tunbridge Wells and Uckfield

Representation from Mesothelioma UK, LASAG (London Asbestos Support and Awareness Group) and HASAG Asbestos Disease Support also join these support groups.

Patients are able to talk openly and honestly about their feelings in a safe, relaxed environment. They can share common experiences, get emotional support and learn more about their disease if they wish to.

The support groups help patients and their families realise they are not alone. This can help to reduce stress, depression and anxiety.

The support groups also give the Lung CNSs an opportunity to carry out informal holistic needs assessments and ensure that any additional support required is put into place.

It is also an opportunity for patients and their carers to speak to the Lung CNSs face to face about any problems/issues they may have.

Successes

Listed specifically per Trust, then those applicable to all Trusts

DGT	EKUHFT	MFT	MTW
Support group	TLHC	Support groups	Expanding nurse-led oncology SACT and TKI f/up clinics
STT nurse increased band from 6 to 7	Support group	Radical CT surveillance clinic	Development of nurse led TKI clinic at Pembury
Set up a pre-MDT		Increased HNA uptake at initial diagnosis and improving uptake on follow up HNAS with set HNA clinics.	Set up of the immune related toxicity review and IO f/up nurse led clinics at MTW
		Health and Well-Being Events	Band 6 rotational post
		Reduced Band 6 -1.0 WTE for 6 months and still maintaining a good service	The lung cancer nursing service was maintained despite decreased number of CNS hours for part of the year
			Introduction of immune toxicity review clinic and immunotherapy follow up clinics
			Introduction of KOMS telephone assessment which generates appts so can help audit our workload
			Development in KOMS to differentiate Lung CNS contact rather than nursing review has aided communication. The electronic assessment tool for reviewing patients on TKI / Immunotherapies continues to be used throughout Kent Oncology Centre and Kent wide.
			Sandra Wakelin continue to lead nationally in the field of nurse-led clinics for patients with lung cancer.

- ctDNA now accessible across all sites in Kent and Medway. More accessibility to cancer treatments.
- Recruitment of STT CNS and cancer support workers.
- CNS support from referral to diagnosis, treatment, end of life.
- Patient satisfaction survey – see above
- Good collaborative working within the Lung CNS TSSG with regular meetings and updates
- The Lung CNS' continue to have an instrumental influence on the development of the lung cancer pathway and in its implementation and success.
- See page 8, successes within Mesothelioma

Challenges

DGT	EKUHFT	MFT	MTW
Shortage of respiratory consultants meaning clinics cancelled and procedures being delayed	Inadequate working environment/office space	Remote oncology clinics	Staffing issues and loss of Band 7 post causing difficulty in maintaining service
	Not enough LCNS cover STT and the 2ww clinics/Oncology/Surgical clinics	Inadequate working environment/office space	Cessation of Pembury Clinical Oncology Clinics
	eHNA assessments (Lack of band 4 support workers)	Poor nurse to patient ratio	More complex patients and increase in caseload (please see data on page
		No allocated admin time	Increase in referral rate (please see data on page
		Lack of clinic room space to set up new clinics	Ongoing difficulties in primary care causing increased telephone contact to CNS team and delayed diagnosis
			At Pembury limited oncology cover and doctor support
			Increasing workload in pre-diagnostic phase of pathway due to cessation of pre-diagnostic nursing role.
			Lack of research nursing support

- CNS indicator codes (and PS data) is now the responsibility of CNS to add to infoflex, was previously MDM co-ordinators. Current data may not be accurate as this is a new change as of 2023.
- New level of intervention drop down on infoflex patient contact screen. It is a way to measure the simple to the most complex of patient interactions. This again is new and the reliability will depend of if teams use this.
- CNS shortfall. Cross cover with STT. Increased workload – patients diagnosed earlier due to TLHC and incidental findings, Gallari trial. Also, patients living longer with improved OS and targeted cancer treatment options.
- Consultants – shortage of oncology doctors, support resulting in more tasks falling to the CNS.
- TLHC
- To have the patient satisfaction survey agreed by governance and sent out in a timely manner as this impacted presentation of results.
- Increase in workload with ctDNA project and data collection
- Due to current advances to medical treatment, increased number of patients on treatment for longer
- Management of complex toxicities from immunotherapy

Service Developments

DGT	EKUHFT	MFT	MTW
Set up a post-surgical nurse led clinic	Set up a post-surgical clinic	Nurse-led clinic/service in Swale	Expand and develop the existing nurse-led oncology SACT and TKI f/up clinics
Develop the triage clinic	Further role out of TLHC across EK	Nurse-led oncology clinics – Small cell new patient and f/up clinics.	A new nurse led TKI clinic at Pembury
Expand the HNA clinic to match the capacity		Nurse-led oncology clinics- on treatment f/up, TKI and IO	Set up an immune related toxicity review and IO f/up nurse led clinic
		Additional HNA clinic capacity to match the total HNAs done weekly	Set up a post-surgical clinic at Pembury
			Develop Hybrid role for Research CNS

- Starting the specific Mesothelioma MDM
- Adapt the Patient Satisfaction Survey to focus on Lung CNS role and patient support
- Targeted Lung Health Check – rolling out across more locations within Kent and Medway
- Increase CNS workforce
- Development of support groups
- Streamline the radical CT surveillance across Kent and Medway and develop consistent CNS clinics to support this
- Build clear relationships and communication routes with Primary Care; GPs and Practice nurses

Conclusion

There are many ways in which the lung service could be improved, e.g. promoting a “buddying service” for surgical patients, further development of nurse-led clinics, more in-patient follow up, more participation in research etc.

A collaborative working relationship has been developed with the multi-disciplinary team, primary, secondary and tertiary care colleagues in order to give a quality service and maximise patient experience.

Improved data quality is required and the Lung TSSG have been working on this and with the increased use of infoflex across Kent and Medway we hope that data collection will start to improve moving forwards. Lung CNS are now responsible for completing sections on infoflex to try and have a more unformed approach and we hope that this will show in the data over the next year.

Nurse to patient ratio remains an on-going concern especially with the increase in patient numbers and the predicted increase in population over the next 10 years within Kent and Medway. Unfortunately funding within this service is restrictive but we hope that with the right support we can continue to grow our services to provide better care for our patients.

The mesothelioma MDT continue to push towards improvements in local and regional MDT’s. Again, data collection had historically been poor but with the great work from Meso UK nurses this has been greatly improved.

The Lung CNS TSSG continues to thrive with dedicated nurses from across Kent and Medway who meet twice a year and communicate effectively between the teams. Sharing knowledge and information with each other to try and support patients with the most up to date knowledge.

It is the hope that we can increase our workforce over the comings years to reflect on population growth and OS with improved treatments, plus earlier diagnosis and hope this can be for future consideration.

As this is the first report we can now build on our successes and challenges to continue to care for lung cancer patients across Kent and Medway and provide this annually.

Authors

Medway Lung CNS Team

Completed October 2024