NHS
Wessex
Cancer Alliance

Primary Care Audit of Lung Oesophageal & Pancreatic Cancers diagnosed 2023/24 in Wessex

This report aims to provide a comprehensive overview of the challenges and good practice examples within the primary care pathway for Lung, Pancreatic and Oesophageal Cancers in Wessex, providing key recommendations and generating a clear action plan for future improvements.

This primary care audit has been designed and developed by:

Wessex Cancer Alliance

With support from:

Dorset ICB

Hampshire Isle of Wight ICB

Hampshire and Isle of Wight and Dorset Primary Care Networks (PCNs)

Dorset Intelligence and Insight Service (DiiS)

Content page

Background

Cancer remains a leading cause of death in the UK and early diagnosis is key in improving survival. Primary care plays a critical role in recognising early signs and symptoms, initiating investigations and referring patients promptly via urgent suspected cancer (USC) pathways. However, there are still often delays in primary care pathways, likely due to the complexity of patient presentation and challenges with non-specific symptoms. Wessex Cancer Alliance (WCA) are keen to explore these challenges with the aim of identifying opportunities to support primary care and wider health system with timely referrals, where possible. To fully understand the challenges, it is important to look at real life cases of patients that have received a cancer diagnosis to see what led up their referral and diagnosis. Auditing cancers allows evaluation of how effectively primary care identifies, investigates and refers patients with potential red flag symptoms in line with NICE NG12 Guidance. Audit also gathers vital information on patient demographics and risk factors that allows further exploration of risk stratification and targeted interventions.

Lung Cancer was highlighted as a national priority in the Cancer Alliance planning pack for 2023/24 largely due to it being the most common cause of cancer death in the UK and survival strongly linked to stage of diagnosis. Oesophageal and Pancreatic Cancers were identified as local priorities based on high numbers of late-stage diagnoses. For this reason, these were the cancers selected for a local primary care audit as part of a Prevention and Early Diagnosis Local Improvement Scheme - Welcome to Wessex Cancer Alliance for Primary Care Networks (PCNs) in Dorset and Hampshire and the Isle of Wight.

This audit aims to:

- Characterise the patient population diagnosed with lung, pancreatic and oesophageal cancers including demographic information and known risk factors
- Consider the symptom presentations of the three cancers and how these align with current referral guidelines
- Assess the frequency and timeliness of primary care referrals
- Understand the current use of investigations and results in the diagnostic pathway
- Identify delays in the diagnostic process highlighting common patterns across the region
- Explore how the data may inform future planning, education and system wide improvements

Methods

As part of the WCA Local Improvement Scheme and Dorset Local Incentive Scheme, Primary Care Networks were paid 15p per patient (based on weighted list size) for five requirements relating to cancer prevention and early diagnosis. The clinical audit was one of the requirements included. For the audit element of the scheme, a clinical cancer lead for the PCN or nominated clinician were asked to complete a standardised data collection template (Appendix A) on all eligible patients.

Timeframe and eligibility

Hampshire and Isle of Wight PCNs were asked to audit a full 12-month period of eligible patients including all patients with a lung, oesophageal or pancreatic primary cancer diagnosis between 1st April 2023 and 31st March 2024. Dorset PCNs were asked to audit 6 months of eligible patients diagnosed between 1st October 2023 and 31st March 2024.

Data collection

Standardised clinical system searches were developed and given to all PCNs to ensure consistency of the application of search criteria. This included a search for SystmOne and EMIS web for each tumour site.

The audit templates requested information that could be obtained on the patient records on the practice clinical system about patient demographics, known risk factors, symptom presentation prior to referral, route and stage of diagnosis, investigations and clinical contacts prior to referral and reported delays to diagnosis. A data tab on the spreadsheet provided further information on each indicator to provide additional clarity. A webinar was held prior to data collection for all clinical PCN cancer leads to talk through what was required and have an opportunity to ask questions, and a supporting document was created and sent to all PCNs with additional supporting information (Appendix B).

This audit specifically focused on the primary care presentation interval within the pathway, gathering insight from the patient record up to the point of diagnosis. It did not include information about the secondary pathway post diagnosis.

Once PCNs had completed their data collection template for their eligible patients, a secure data transfer process took place, and full guidance was provided and in line with GDPR (Appendix C).

Data analysis

Once all quantitative data was submitted by all PCNs, information was collated, cleansed and a data dashboard was created by Dorset Intelligence and Insight Service (DiiS) and descriptive statistics produced using Power BI.

Qualitative data was reviewed by two WCA GPs who generated themes from the comments and analysed the data.

NHS
Wessex
Cancer Alliance

Primary Care Lung Cancer Audit on patients diagnosed with Lung Cancer in 2023/24 across Wessex

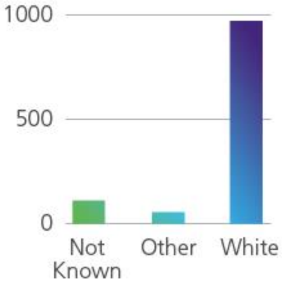
As part of a Wessex Cancer Alliance Local Improvement Scheme, PCNs across Hampshire, Isle of Wight and Dorset completed a standardised audit template reviewing lung cancers diagnosed between April 1st 2023 to March 31st 2024. These findings were analysed by WCA GPs, and a summary of findings are below.

1,082

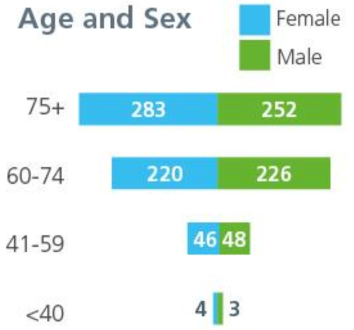
Total Patients

Demographics

Ethnicity

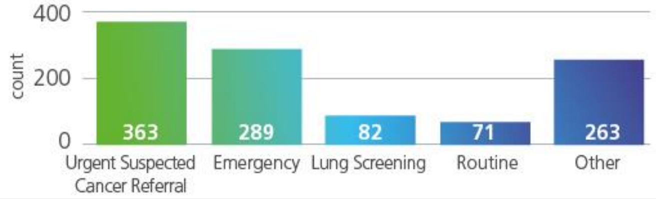


Age and Sex



Diagnosis

Route to Diagnosis

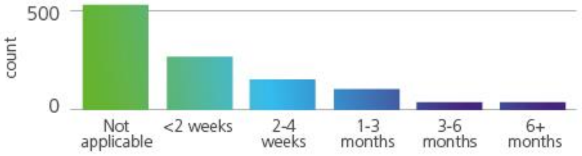


Stage at Diagnosis

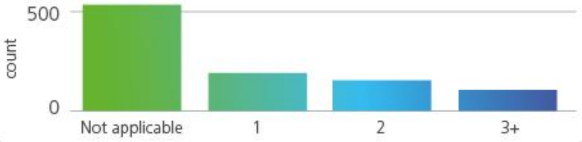
* at time of audit, Lung Cancer Screening was 40% rolled out across Wessex

Primary Care Interval

Time from first clinical contact to first referral



Number of clinical contacts prior to referral



*where the clinician identified the consultation as related to the lung cancer diagnosis

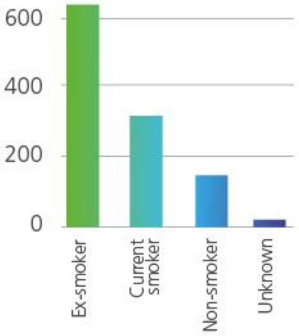
Risk Factors

% with Occupational Exposure
10%

% of Patients with COPD
37%

% with Family History of Lung Cancer
5%

Smoking



Investigations

16% had raised platelets
12% had a normal Chest X-Ray (CXR)
*excludes those not seen in primary care prior to diagnosis

Primary Care Interval

26% had 3 or more consultations prior to referral
8% took longer than 3 months before referral
*excludes those not seen in primary care prior to diagnosis

Symptom Presentation

% with shortness of breath	% with new or worsening cough	Other symptoms %	% with weight loss	% with persistent chest/shoulder pain	% that are tired all the time	% with no symptoms	% with haemoptysis
48%	44%	32%	25%	20%	19%	18%	9%

Delay Themes

based on qualitative analysis of audit report (in order of frequency they occurred)

Delays

% where there was a delay

11%

1. Symptom presentation

highest cause of delay for referral was due to non-specific nature of presentation.

2. Secondary care delays

25 cases reported secondary care delays, which were varied*.

3. Normal CXR

26 patients had a normal CXR which falsely reassured patients and/or clinicians.

4. COPD delay

23 causes of delay were due to diagnostic overshadowing from COPD.

5. Shoulder/ back pain

20 cases delayed by this presentation.

6. Patient delays

various causes

7. Language

5 cases highlighted a language barrier

8. Other factors

including Long Covid

* this audit focused on reviewing the primary care interval only and did not explore the pathway beyond the point of referral.

Next Steps / Recommendations

- **Support for primary care around safety netting, lung cancer education and clinical system templates**
- **Full roll out of Lung Cancer Screening by 2029**
- **Increase public awareness of lung cancer symptoms via lung campaigns and public engagement**
- **Improve primary care access to investigations**
- **Identify opportunities to reduce smoking rates across Wessex**

Lung Cancer

Lung cancer is the 3rd most common cancer in the UK with around 49,200 new lung cancer cases every year. Incidence rates increase with age, with 45% of all new cases in the UK diagnosed in those aged over 75.

It is estimated that 79% of lung cancer in the UK are preventable, with the highest cause being smoking. Other preventable risk factors include workplace exposure and air pollution.

Early detection is key to improved survival. For those diagnosed at stage 1, 65% will survive their cancer for 5 years or more in comparison to only 5% of those diagnosed at stage 4.[1]

Lung cancer screening (LCS) aims to detect lung cancer early. It is currently in the process of rolling out nationally, transitioning to a national screening programme by 2030. It has already shown a shift in earlier stage lung cancer diagnoses, and this is only expected to increase. This is a key measure in improving lung cancer survival and improving earlier diagnosis.

However, at the time of audit LCS was only available in a few areas in Wessex and will achieve full coverage in the region by 2029. Additionally, there are still many who sit outside of the screening eligibility (it is for those aged 55-74 who have ever smoked). Therefore, the findings from this audit are important in identifying further learning and recommendations.

This audit reviewed a total of 1082 patients diagnosed with Lung cancer in Wessex between 1st April 2023 and 31st March 2024 and the results are summarised below.

Patient demographics – demographic data were collected to understand the population characteristics of those diagnosed with lung cancer. This included age, sex and ethnicity.

Age *- The audit collected data on age in specific age groups to ensure that patients weren't identifiable by date of birth.*

The audit found that nearly half of the lung cancers were diagnosed in those over 75 years (49%) but also a large number diagnosed in the 60 -74 age group (41%). Around 9% were under 60 years old.

Age Group (years)	***Number of patients***
<40	7
41-59	94
60-74	446
75+	535
	1082

Sex *–The audit collected data to identify the sex of the patients diagnosed with lung cancer.*

The audit found that there were similar numbers of male and female patients diagnosed with lung cancer with there being 24 more females than males. An 'Other' option was included to capture any transgender patients, but no patients were reported in this category.

Sex	***Number of patients***
Male	529
Female	553
Other (including transgender)	0
	1082

Ethnicity – *The audit collected data on the ethnicity of patients based on clinical system records, where known.*

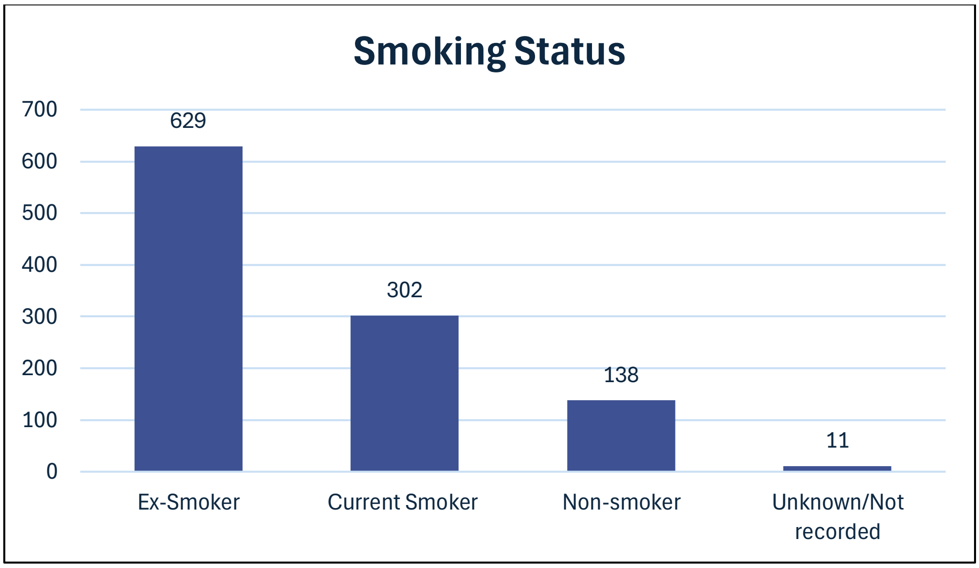
Ethnicity	***Number of patients***
African	2
Any other Asian background	3
Any other Black / African / Caribbean background	1
Any other ethnic group	5
Any other mixed / multiple ethnic background	4
Any other White	27
Asian or Asian British group	6
Chinese	5
English / Welsh / Scottish / Northern Irish / British	939
Indian	1
Irish	4
Not Known	81
White and Black African	1
(blank)	3
	1082

This table shows that the majority of patients (87%) had their ethnicity recorded as 'English/Welsh/Scottish/Northern Irish/ British.' The next highest was 'Any other White' which represented 2% of patients. Around 7% of patients in the audit had no recorded ethnicity.

<u>Risk factors</u> – Information on specific risk factors relating to lung cancer were collected to understand opportunities for future risk stratification.

Smoking Status *– smoking status was extracted from the GP clinical system based on most recent available record.*

This graph shows that over half patients (58%) were Ex-Smokers and at the time of the audit 30% patients were current smokers. 13% of patients were Non-Smokers.



Smoking status shows that 86% of patients had a smoking history with 28% of patients still current smokers at time of diagnosis. This is in line with research that demonstrates a strong link between smoking and lung cancer and therefore efforts to reduce smoking rates are still important in reducing the number of lung cancer diagnoses. However, it is also worth noting that a significant proportion of these patients were non-smokers (13%). With lung cancer screening (LCS) being targeted at smokers and ex-smokers and NICE Guidelines for referral being heavily weighted towards those with a smoking history, there may be a risk that non-smokers are overlooked.

Chronic Obstructive Pulmonary Disease (COPD) *– previous research has shown COPD to be an independent risk factor for lung cancer. The audit collected data on patients with a known diagnosis of COPD.*

The results showed that out of the 1082 patients included in the audit 402 patients had diagnosis of COPD (37%). This is in line with previous research that highlights COPD as an independent risk factor for lung cancer. Greater awareness among patients and health professionals and opportunities within annual reviews and post exacerbation reviews may support the earlier identification of symptoms of lung cancer.

Occupational exposure – *the audit collected data on patients with known occupational exposure based on clinical system records.*

The results showed that 10% of patients had occupational exposure recorded on the GP record. Occupational exposure to certain agents that are strongly linked to lung cancer are important to consider during initial primary care work up.

***Family History** – data was collected on patients in the audit with a known family history of lung cancer as recorded in the patient record.*

The results showed that 5% of patients had a family history of lung cancer recorded. Having a first-degree relative with lung cancer is known to increase the risk of lung cancer independent of smoking status.

It is not possible to say how accurate the recording of risk factors on the GP record is from this audit, but accurate recording of risk factors such as family history, occupational exposure and smoking history could provide important information when reviewing lung cancer risk.

Symptom presentation

% with Shortness of Breath	**48%**
% New or Worsening Cough	**44%**
% Other Symptoms	**32%**
% with Weight Loss	**25%**
% with Persistent Chest/Shoulder Pain	**20%**
% that are Tired all the Time	**19%**
% with no Symptoms	**18%**
% with Haemoptysis	**9%**

The symptoms at presentation were wide and varied. They included many of the predictable and classically taught presentations of lung cancer such as new or worsening cough (44%), shortness of breath (48%), haemoptysis (9%) but also weight loss (25%). Some symptoms are non-specific to lung cancer such as tiredness and some patients had vague symptoms. 18% of patients had no symptoms and these were cancers discovered incidentally as part of unrelated investigations, screening surveillance CT for other primary cancers or from Lung Cancer Screening. Locally, lung cancer is the most common diagnosis on a recent audit of outcomes from the Rapid Investigation Service (RIS) clinic, which is the service for patients with non-specific symptoms. This demonstrates the non-specific nature of a lung cancer presentation and highlights the challenge for primary care.

The more surprising presentation in 20% of cases was of shoulder and chest pain. The number of patients presenting with shoulder pain or chest pain was a significant group.

Diagnosis – Clinicians were asked to record the route in which the patient was diagnosed and the stage of diagnosis, where known.

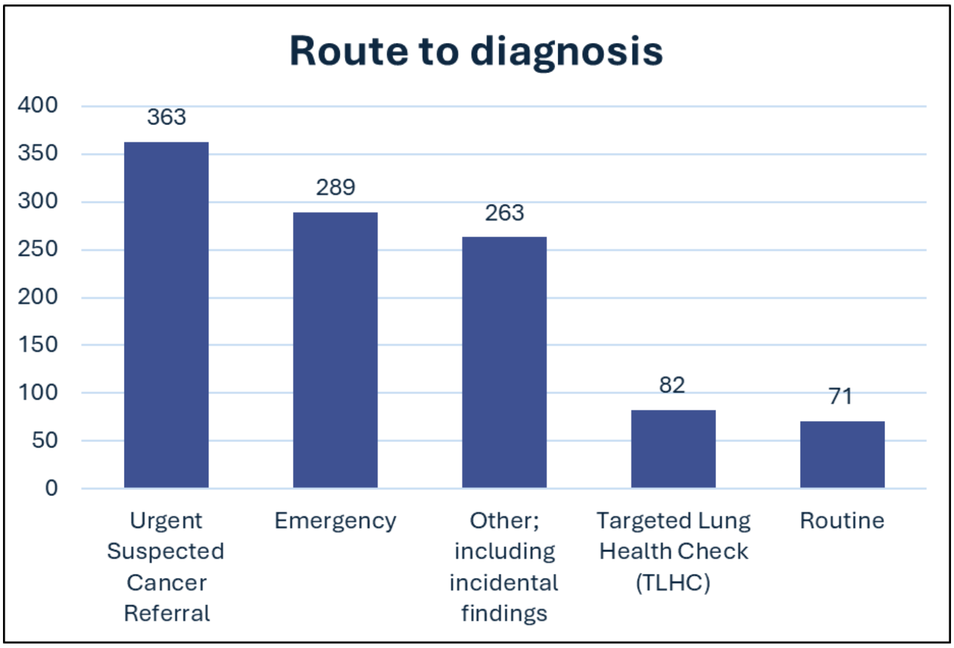
Route to diagnosis

Most of the patients (34%) were diagnosed following an Urgent Suspected Cancer Referral (USC) which is the most appropriate pathway for a suspected lung cancer following a symptomatic presentation. However, a significant proportion (27%) were diagnosed as an emergency. Diagnosis in an emergency setting is often linked to late state presentations and poorer outcomes.

A small amount (8%) were diagnosed through Lung Cancer Screening (Formally Targeted Lung Health Checks). This is the optimal pathway for patients that are asymptomatic and have a smoking history. At the time of audit, LCS was only available in a small area and continues to be fully rolled out locally. Once this is fully established, it is expected that the number of patients diagnosed through this route will be much higher. As many of the patients diagnosed through LCS are asymptomatic, the stage of diagnosis is shown to be earlier with better outcomes for patients.

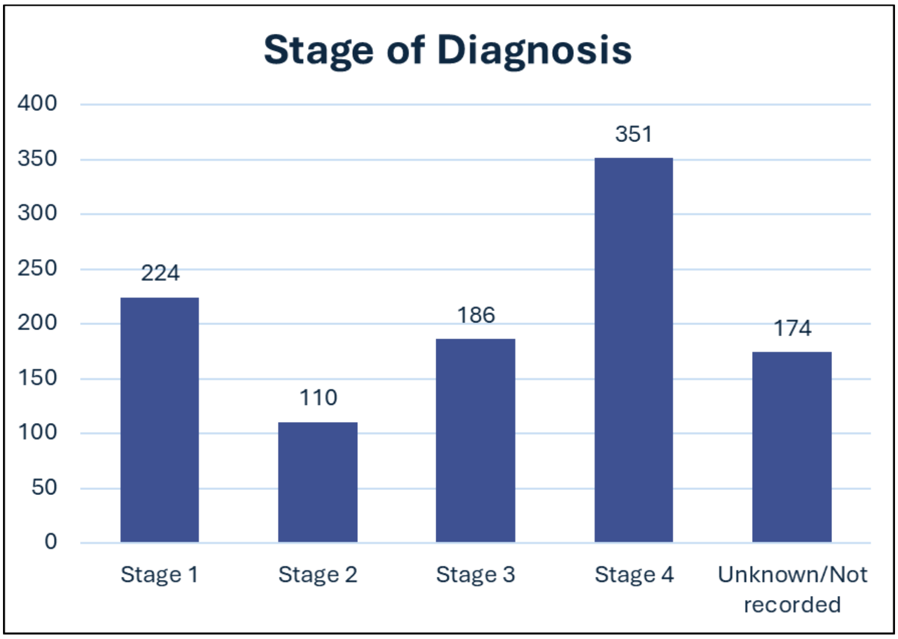
The other large group were lung cancers which were found incidentally, predominantly in patients as a second primary when they were having surveillance CT for other primary cancers or having a CXR for an unrelated presentation. This would support the more frequent use of CXR in Primary Care and the increased use of CT scan as a screening tool for lung cancer via increased uptake of the LCS programme.

It would have been interesting to look at the cases where lung cancer was identified incidentally and review whether these patients would have been eligible for lung cancer screening. Unfortunately, due to the age brackets used in data collection it was not possible for this to be assessed. This is a limitation of the data collection template and in retrospect should have been considered.



Stage

Lung Cancers diagnosed at stage 3 & 4 are known to lead to much poorer outcomes and limited treatment options. This audit shows that most of these cancers were diagnosed at stage 4 (34%). This report reflects further on some of the common delays to identify opportunities for earlier diagnosis.



<u>Investigations –</u> clinicians reported results on investigations requested in primary care. Note: this does not include results from secondary care investigations.

Raised platelets (thrombocytosis) – *where records show levels >400*

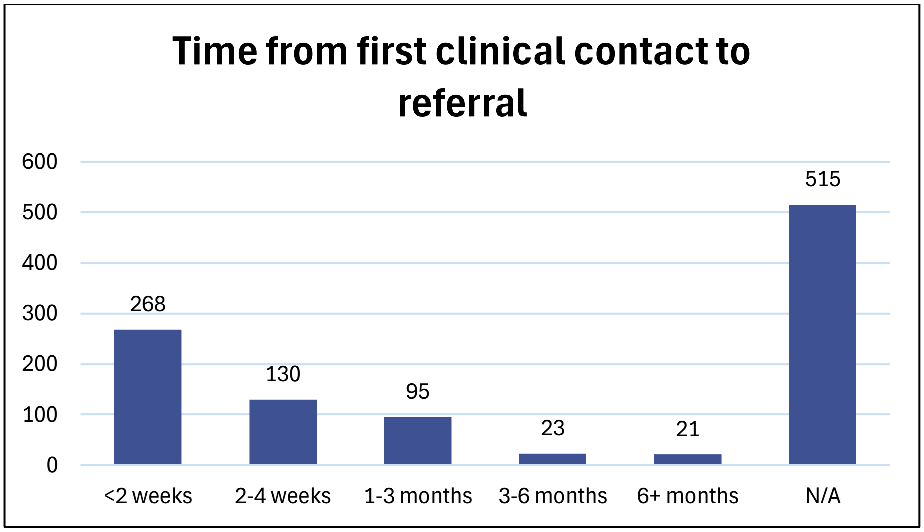
687 patients had a full blood count (including platelet check) completed in primary care. Of these 16% (107) of patients had raised platelets. Previous evidence had demonstrated a link between thrombocytosis and lung cancer and that it may also indicate a poorer prognosis. Out of the 107 patients with raised platelets 56% were diagnosed at stage 4 compared with 30% of patients with no raised platelets which may indicate a link between high platelets and poorer outcomes, however numbers are too small to draw any significant conclusions. Primary care education is starting to include more information about raised platelets, and this outcome highlights the importance of raising awareness of the link between raised platelets and lung cancer further.

Chest X-Ray – *results from chest x-ray, where requested in primary care prior to referral*

A total of 458 (42%) patients had a chest X-ray requested in primary care prior to referral and subsequent diagnosis. The results showed 57 of those came back with a normal result (12%). Evidence has suggested that around 20-25% of lung cancers are missed due to a false negative result.[2] Although this audit results are less than that, it is still a concern, and this is explored further when qualitatively analysing causes of delay later in the report.

Primary Care Interval - This includes time from first clinical contact in primary care to referral and number of clinical contacts in primary care prior to referral

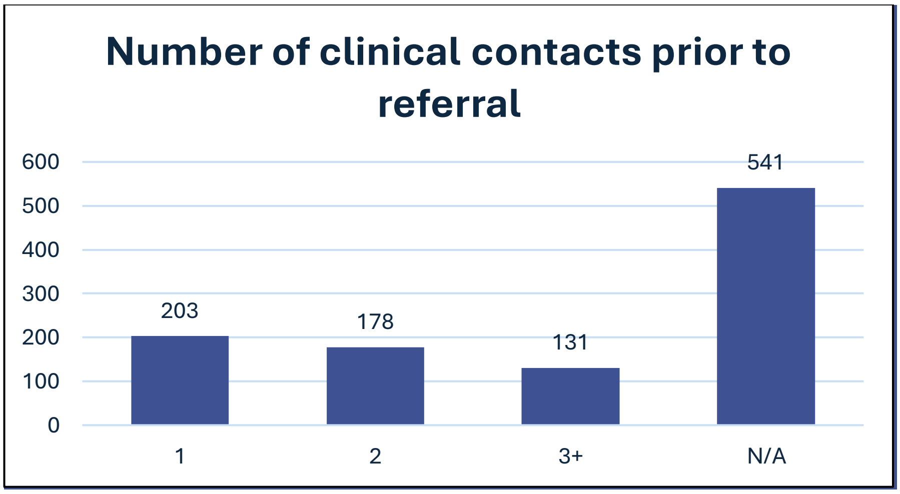
Time from first clinical contact



For patients seen in primary care, 50% were referred less than 2 weeks from first presentation which indicates a prompt recognition and referral. However, there were many diagnosed after a much longer period. Around 8% took longer than 3 months from first presentation to referral. Further themes and causes of delay are explored later in this report.

Number of clinical contacts prior to referral

For patients seen in primary care, 26% had 3 or more consultations relating to their diagnosis prior to referral. It is known that continuity of care enhances patient care and this is an area where seeing the same practitioner for follow up may lead to faster referral.[3,4] Some of the multiple consultation themes will be explored further in this report.



Delay

11% of patients were judged by the clinician completing the audit template as having a delay in diagnosis. Despite only 11% of cases having the box ticked to confirm a delay in diagnosis it was decided to complete a qualitative analysis of the comments box as there appeared to be many cases where further delays were described.

The main themes here are interesting and worth reflecting on for liaison with the Clinical Advisory Groups (CAGs) future education emphasis, looking at the Primary/Secondary Interface and improving patient outcomes in future.

Examination of qualitative themes for delayed diagnosis

All 1082 cases were reviewed by two WCA clinicians who identified themes from the qualitative data provided in the comments and free text sections of the data collection template. Some cases identified more than one theme.

This table shows the themes identified from the qualitative analysis and the number of times that theme occurred. A total of 12 key themes were identified during the analysis. Some of the themes are discussed below:

Themes from qualitative analysis	***Actual count***
Vague Symptoms	29
Secondary care delay	28
Normal CXR	26
Diagnostic delay	24
COPD delay	23
Shoulder/Back pain/MSK presentation	20
Referred to another tumour USC pathway (ENT, Head and Neck, Gynae)	19
Patient delay	17
Chest infection - No CXR	9
Communication barriers	5
Low sodium - CXR	2
Long Covid	2

There were multiple reasons for delayed diagnosis. The following have been grouped into 8 main categories;

1. *Symptom presentation* – 29 presented with vague symptoms which contributed to a delay in their referral. In 19 cases the patient was referred on an Urgent Suspected Cancer (USC) pathway but not a Lung pathway. The other pathways referred into were ENT, Gynae and Head and Neck. The non-specific nature of symptoms led to delays in patient referral. The Alliance will continue to engage with secondary care through the CAGs and the Wessex Imaging Networks to ensure GIRFT principles and best-timed pathway principles are adopted as well as awareness of the local Rapid Investigation Service (RIS). There may also be a need for greater education for primary care around non-specific symptoms and red flags.

2. *Secondary Care/Diagnostic delays* - There were delays in secondary care described in 25 cases. These were described in a variety of ways or no explanation given so no clear themes were identifiable. There were 24 cases where a diagnostic delay was reported, cases included delays in radiology reporting or conversion from an abnormal CXR to a CT scan. In 3 cases a CXR had been performed but not reported by the time the patient presented as an emergency. This audit did not specifically look at the patient journey beyond the point of diagnosis, but it is helpful to understand where in the cancer pathway delays can occur.

3. *Normal CXR* - 26 had a normal CXR which may have falsely reassured patients and clinicians about cancer as a potential cause. This highlights the importance and need for safety netting processes following negative CXR to ensure that patients are aware that persistent symptoms may need to be reevaluated.

4. *COPD delay* - The large numbers of patients with a history of COPD fit with the evidence that this is an independent risk factor for lung cancer. 37% of patients diagnosed with lung cancer had a history of COPD and 23 causes of delay were diagnosed due to diagnostic overshadowing from COPD. There are several learning points to be highlighted here, the first is that COPD annual reviews are an important opportunity to review the need for CXR or referral into USC pathway if patient is experiencing worsening cough, weight loss or other red flags. The other is that patients continuing to cough or experience worsening shortness of breath despite rescue medications in infective exacerbation should be considered for referral for CXR to exclude lung cancer and if the suspicion remains high despite normal CT they should be referred to secondary care for consideration of a CT.

5. *Shoulder/Back pain (Musculo-skeletal (MSK) presentations*) – as previously mentioned, 20% of patients in the audit reported shoulder/chest pain as a symptom. In 20 cases this presentation led to a delay in referral. More recently there has been an increased use of First Contact Physiotherapy Practitioners through the ARRS scheme, meaning that many patients are likely to be seen in a MSK appointment rather than with a doctor or Advanced Nurse Practitioner (ANP). This finding has highlighted a need for

Lung cancer to be more prominent in professional education and ongoing CPD for this professional group to ensure red flag cancer symptoms are acted on promptly.

6. *Patient -related factors* - Patients factors again were varied including factors such as dementia where a carer was advocating for and supporting the patient journey in a couple of cases. Understanding these factors could help design interventions that support patients in accessing care promptly.

7. *Communication Barriers*- 5 cases highlighted a language barrier as a cause of delay. This highlights the importance of ensuring inequalities are not built into primary care systems for patients for whom English isn't a first language or who have communication difficulties such as the deaf community. This would also apply to neurodivergent patients or patients with learning disabilities.

8. *Other factors*: Other factors that occurred more than once that is worth mentioning is that 2 patients were missed due to symptoms being attributed to long Covid. There were a couple of cases where the person reporting for the audit reflected that the diagnosis was found during investigation for hyponatraemia (low sodium) where the CXR had not been ordered or reported as an urgent suspected cancer request, hence causing delayed diagnosis.

Next Steps

As a result of the analysis of the audit results the Wessex Cancer Alliance has shaped its work for this and next year in the following ways:

- The incidental findings of lung cancer in asymptomatic patients and the positive outcomes from the Lung cancer screening, WCA are committed to a full roll out of Lung Cancer Screening by 2029.
- With 37% of patients audited having a diagnosis of COPD and the reported delays because of the challenges in diagnosis for these patients, WCA have included COPD & Lung Cancer education and red flag intervention in this year's LIS. This aims to encouraging greater awareness of red flag symptoms for lung cancer during COPD reviews. A Link to the recording can be found in Appendix D.
- Lung Cancer Red Flags code has been added to the new COPD post-exacerbation template that is due to be shared shortly on Ardens as a prompt for clinical staff to think about cancer following COPD exacerbation.
- To address delays caused by negative CXR false reassurance, a safety-netting text message template developed for those with a normal CXR to be used by primary care. See Appendix E.

- WCA developed an awareness campaign with a focus on lung cancer signs and symptoms to improve public awareness – the ‘Know the Signs’ Lung campaign ran in June 2025
- WCA has focused primary care education on key areas identified in the audit e.g. cancer in never-smokers & normal CXR, raised platelets
- A training webinar is in development focused on red flags in MSK presentations
- An information leaflet is in development for patients with COPD providing information on red flag symptoms in relation to their COPD and when to be concerned.
- Audit findings have been shared with primary care via communities of practice and will be presented at the Lung Clinical Advisory Group for further discussion.
- Direct access to CT in future may also benefit earlier diagnosis for these patients and the Alliance continues to engage with the Wessex imaging network around this access which remains inconsistent across the Wessex area.
- Identify opportunities to decrease smoking rates across Wessex.

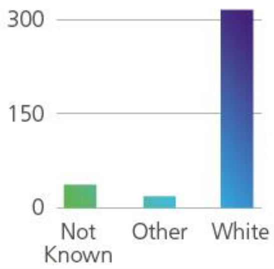
NHS
Wessex
Cancer Alliance

Primary Care Pancreatic Cancer Audit

As part of a Wessex Cancer Alliance Local Improvement Scheme, PCNs across Hampshire, Isle of Wight and Dorset completed a standardised audit template reviewing pancreatic cancers diagnosed between April 1st 2023 to March 31st 2024. These findings were analysed by WCA GPs, and a summary of findings are below.

Demographics

Ethnicity



% with diabetes

30%

of these

29%

were diagnosed with diabetes in last 12 months

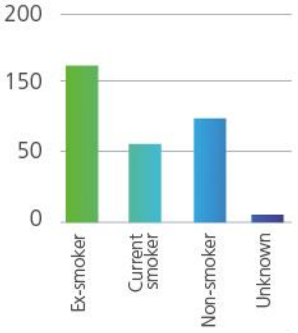
356 Total Patients

Risk Factors

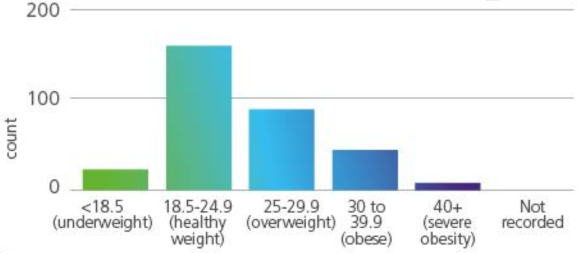
% with Family History of Pancreatic Cancer **3%**

% with Family History of other Cancers **10%**

Smoking

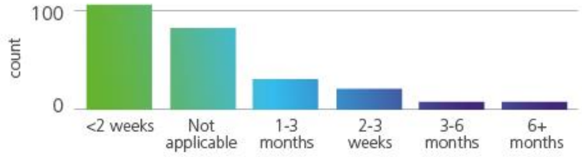


BMI

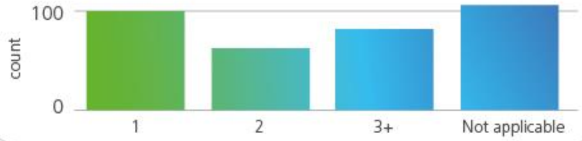


Primary Care Interval

Time from first clinical contact to first referral



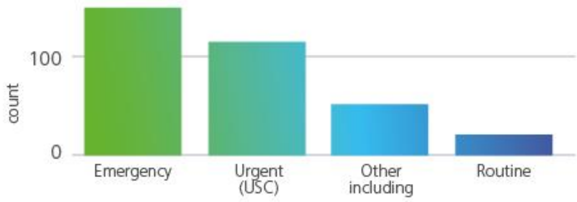
Number of clinical contacts prior to referral



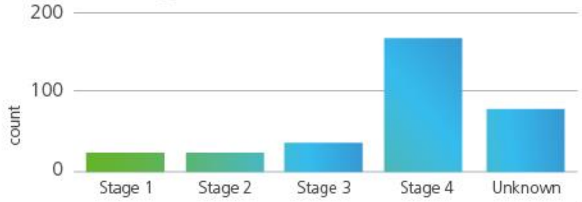
*where the clinician identified the consultation as related to pancreatic cancer diagnosis

Diagnosis

Route to diagnosis



Stage to diagnosis



Symptom Presentation

% with abdominal pain	% with weight loss	Other symptoms %	% with jaundice	% with nausea and/or vomiting	% with diarrhoea	% back pain	% with no symptoms
59%	49%	45%	31%	30%	25%	21%	7%

Delay Themes

based on qualitative analysis of audit report
(in order of frequency they occurred)

Delays

% where there was a delay

16%

1. Age not meeting criteria

59 cases of patients who were <60 years old and diagnosed with pancreatic cancer (17 %) and 18 (31%) of them were marked as having a delay in their diagnosis.

2. Primary Care delays

23 cases reported to have various primary care delays including vague symptoms, lack of continuity of care, lack of safety netting and deviation from NICE guidance.

3. Referrals to other tumour groups

Due to symptoms overlapping with other tumour sites and positive investigation findings suggestive of alternative tumour pathways (e.g. Ca125 and FIT) there were delays to diagnosis in several cases

4. Secondary care delays

e.g. delay in reporting

5. Imaging Delays

There is variability in length of wait for ultrasound scans and also variability across Wessex around direct access to CT.

6. Patient factors

e.g. patient choice and wanting a private referral

Next Steps / Recommendations

- **Promotion of the SAFE-D research study**
- **Promotion of EUROPAC to eligible patients (patients with family history)**
- **Increased Primary Care Education – e.g. Diabetes and Pancreatic Cancer**

Pancreatic

Pancreatic cancer is the 10th most common cancer in the UK, accounting for 3% of all new cancer cases. Incidence rates have been increasing over time with projections that they will rise a further 5% in the UK between 2023-2025 and 2038-2040.

Pancreatic cancer has the lowest survival of all common cancers, with 5-year survival less than 7%.[5] The majority of cases are diagnosed at a late stage, with only 28.5% diagnoses at an early stage in 2023/24.[6]

37% of pancreatic cancer cases in the UK are thought to be preventable with risk factors including smoking, alcohol and overweight and obesity. There are also links to medical conditions such as pancreatitis and diabetes as well as a family history (first degree relatives). [7] This audit reviewed a total of 356 patients diagnosed with Pancreatic cancer in Wessex between 1st April 2023 and 31st March 2024 and the results are summarised below.

Patient demographics – demographic data were collected to understand the population characteristics of those diagnosed with pancreatic cancer. This included age, sex and ethnicity.

Age *- The audit collected data on age in 'age groups' to ensure that patients weren't identifiable by date of birth.*

The audit found that the majority of pancreatic cancers were diagnosed in patients over 75 years (46%) but also a fairly large number of patients were diagnosed in the 60-74 age group (38%). It is worth noting however, that 17% of the patients were under 60 years of age when diagnosed. This age group (under 60) is not covered in NICE guidance unless the patient is jaundiced when the recommendation is urgent referral for over 40 years of age and this is discussed further in the report.

Age Group (years)	***Number of patients***
<40	4
41-59	55
60-74	135
75+	162
	356

Sex *–The audit collected data to identify the sex of the patients diagnosed with pancreatic cancer.*

The audit found that there were slightly more males (54%) diagnosed with pancreatic cancer than female patients. An 'other' option was included to capture any transgender patients, but no patients were reported in this category.

Sex	***Number of patients***
Male	*192*
Female	*164*
Other (including transgender)	*0*
	356

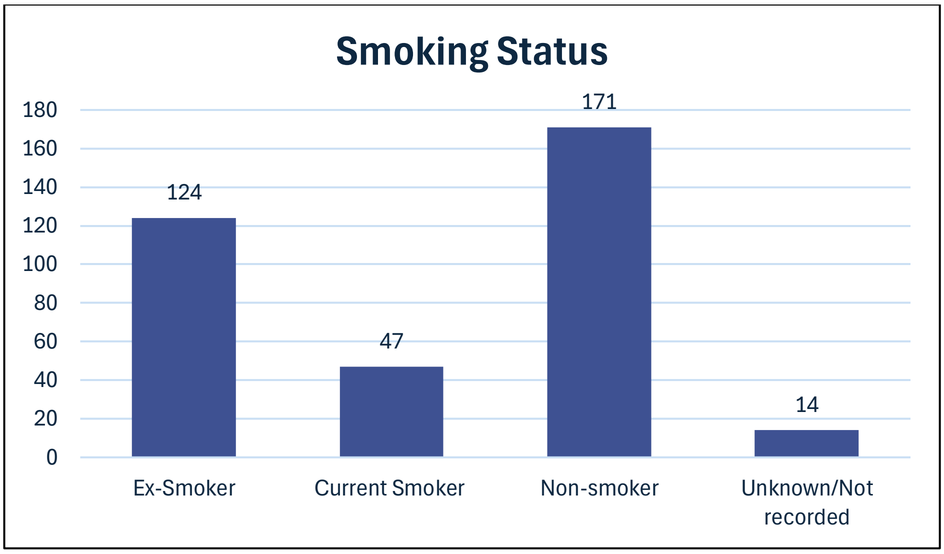
Ethnicity – *The audit collected data on the ethnicity of patients based on clinical system records, where known.*

Ethnicity	***Number of patients***
African	1
Any other Asian background	1
Any other Black / African / Caribbean background	1
Any other ethnic group	1
Any other mixed / multiple ethnic background	2
Any other White	19
Asian or Asian British group	2
Bangladeshi	1
English / Welsh / Scottish / Northern Irish / British	305
Indian	2
Irish	1
Not Known	19
(blank)	1
	356

This table shows that the majority of patients (86%) had their ethnicity recorded as 'English/Welsh/Scottish/Northern Irish/ British.' The next highest was 'Any other White' which represented 5% of patients. Around 5% of patients in the audit had no recorded ethnicity.

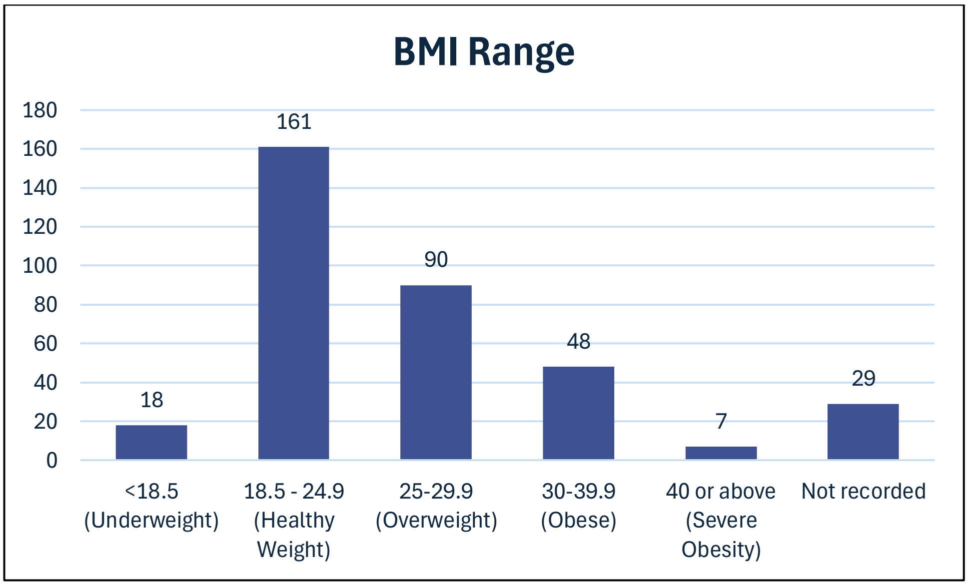
Risk factors – Information on specific risk factors relating to pancreatic cancer were collected to understand opportunities for risk stratification.

***Smoking Status** – smoking status was extracted from the GP clinical system based on most recent available record.*



This graph shows that (35%) were Ex-Smokers and at the time of the audit and 13% were current smokers at the time of diagnosis. Most patients were recorded as Non-smokers (48%). Cigarette smoking is one of the strongest modifiable risk factors for pancreatic cancer. Smoking cessation is a key preventative strategy in reducing the incidence of pancreatic cancer.

***BMI range** – Body mass Index (BMI) was extracted from the GP clinical system based on most recent available record.*



The majority of patients were recorded as being in the healthy weight range (45%) but still a large number of patients who were recorded as overweight or obese (41%).

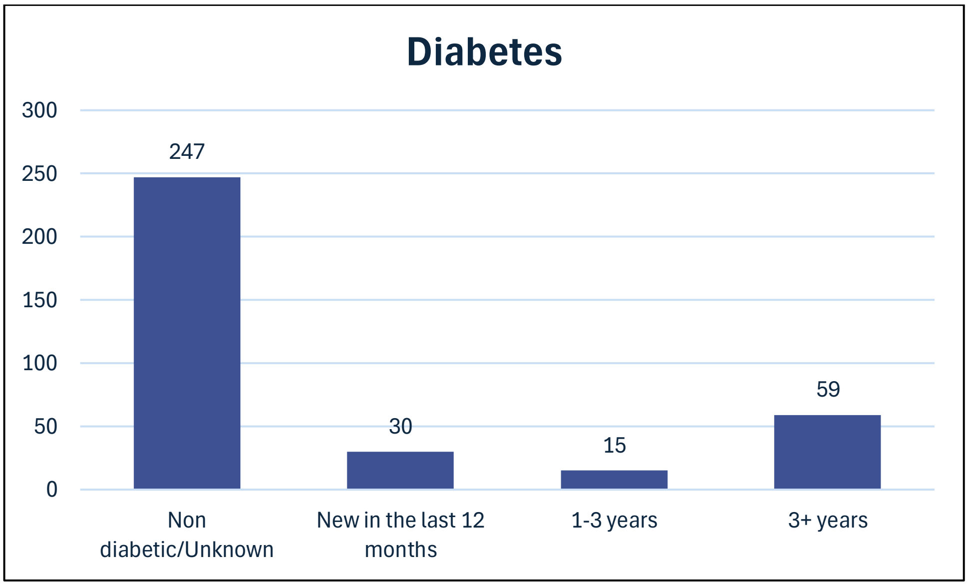
A small number of patients were underweight (5%). It is important to note that these patients may have presented following significant weight loss as this is a common symptom of pancreatic cancer and therefore it is challenging to distinguish between obesity as a risk factor and potential weight loss as a symptom from the pancreatic cancer.

Family History *– information was collected on patients in the audit with a known family history of cancer and more specifically those with a family history of pancreatic cancer as recorded in the patient record.*

The results showed that 10% of patients had a family history of cancer recorded and 3% of these were a family history of pancreatic cancer. This is in line with research that suggests that 10% of pancreatic cancers are linked to inherited genetic factors (Pancreatic Cancer UK).

EUROPAC is a research study aiming to understand inherited conditions of the pancreas. It recruits people with a family history of pancreatic cancer and people who have been diagnosed and offer secondary pancreatic cancer screening to those who are considered to be at a higher risk of developing pancreatic cancer.[8] University Hospitals Southampton is one of the screening sites for EUROPAC and WCA have been encouraging recognition and referral of eligible patients.

Diabetes – *Those with type 2 diabetes are at an increased risk of developing pancreatic cancer but also pancreatic cancers can cause New Onset Diabetes. Information was collected from the GP record about a diabetes and length of time since diagnosis.*



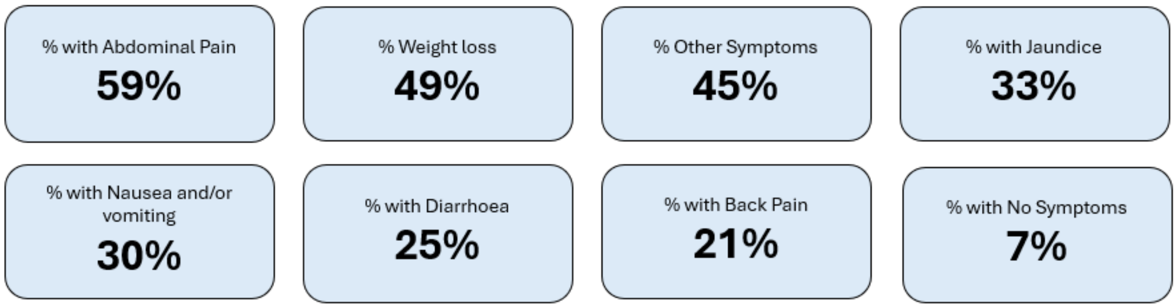
Diabetes is a well-established risk factor for pancreatic cancer with 30% of audited patients having a diagnosis.

New Onset Diabetes – when the diagnosis of pancreatic cancer has been made within the last 12 months - is thought to be a consequence of the pancreatic cancer and if picked up could detect those at an early stage of cancer. The audit data showed that of the 30% of all the patients that had a diagnosis of diabetes 17% of those had been diagnosed within the last year.

It is also important here to recognise the association of pancreatic cancer and weight loss and note that within the audit that 46% patients were recorded with a healthy/average BMI. Further research is needed into this area as it is increasingly patients with a new onset of diabetes with a normal BMI <25 (who may have had some weight loss) who are being diagnosed with pancreatic cancer. There is evidence to suggest that the risk for these people of having pancreatic cancer is even higher.[7]

Diabetic nurses may be in an ideal position to detect early signs and symptoms in their new diabetic and annual reviews, so introducing and improving education for them around red flags for pancreatic cancer may help to detect it earlier.

Symptom presentation



% with Abdominal Pain	% Weight loss	% Other Symptoms	% with Jaundice
59%	**49%**	**45%**	**33%**

% with Nausea and/or vomiting	% with Diarrhoea	% with Back Pain	% with No Symptoms
30%	**25%**	**21%**	**7%**

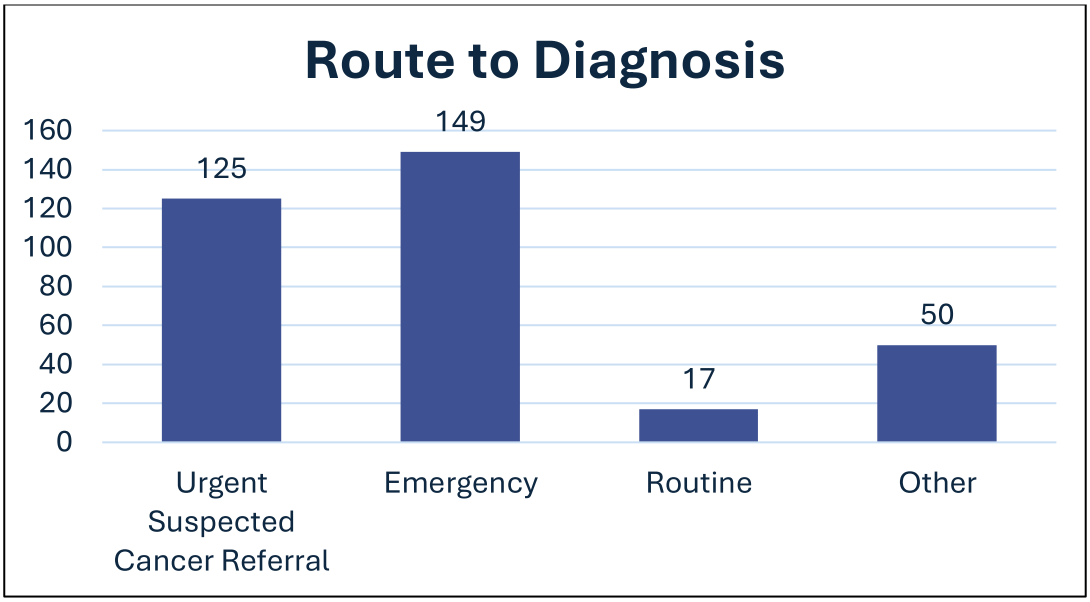
Pancreatic cancer is often a diagnostic challenge as patients present with multiple symptoms which are often vague and non-specific and lead to a diagnosis at a late stage.

The two most common symptoms recorded in the audit were abdominal pain (59%) and weight loss (49%) which can both be related to multiple possible underlying diagnoses and can therefore lead to a delay in suspecting and diagnosing pancreatic cancer. Other symptoms (45%) and findings recorded included bloating, other non-specific abdominal symptoms, anaemia and deranged LFTs.

Jaundice, which is the only symptom recommended by NICE as requiring an urgent suspected cancer referral for those aged over 40 was recorded in a third of the patients (33%). This is often a late presenting symptom with a poor outcome. With current 5-year survival rates of pancreatic cancer being less than 5%, recognition and investigation of symptoms need to happen much earlier for patients.[10]
Nausea and vomiting, diarrhoea and back pain were seen in 21-30% of patients. 7% patients had no symptoms which means they were picked up incidentally when being investigated for something else.

Diagnosis – Clinicians were asked to record the route in which the patient was diagnosed and the stage of diagnosis, where known.

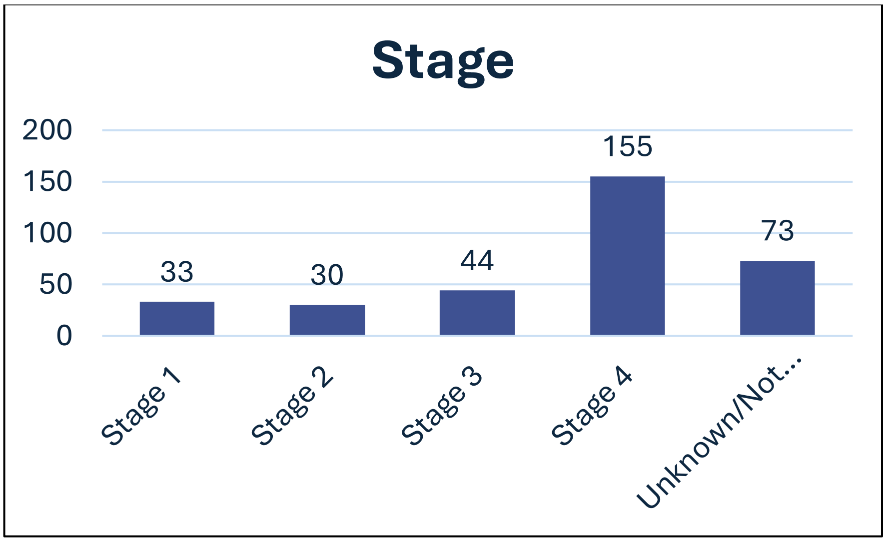
Route to Diagnosis



The majority of patients were diagnosed with pancreatic cancer via an emergency route (44%). Diagnosis through emergency routes often means a later stage diagnosis and poorer outcomes. Only 37% of patients were diagnosed via an Urgent Suspected Cancer Referral (USC) which would be the most appropriate for a suspected pancreatic cancer.

Stage

The audit requested information on the stage of diagnosis for patients diagnosed with pancreatic cancer (where available.) The highest proportion of pancreatic cancers, 46% were diagnosed at stage 4.



Investigations – clinicians reported results on investigations requested in primary care. Note: this does not include results from secondary care investigations.

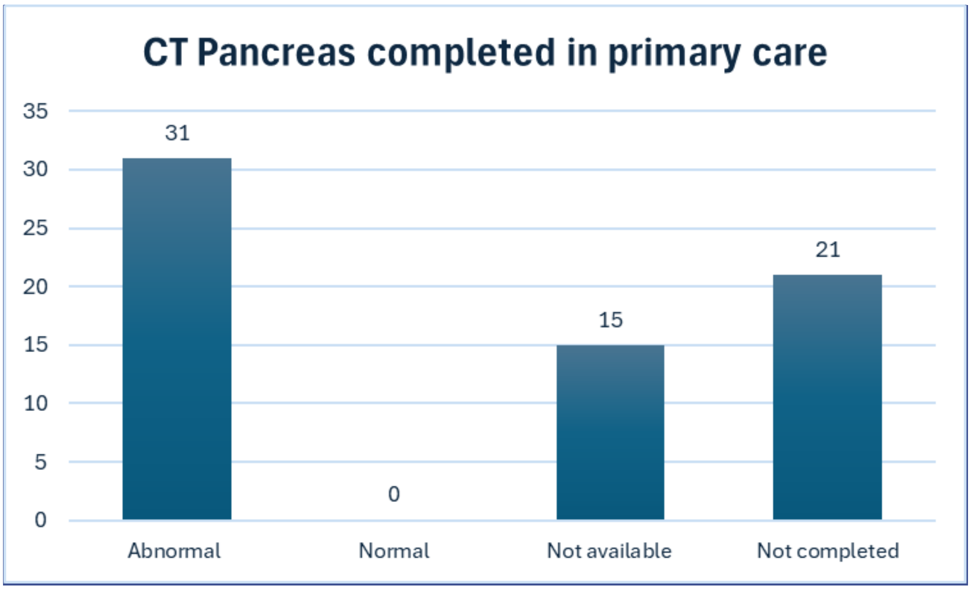
NICE Urgent Suspected Cancer Referral Guidelines recommend that GPs consider an urgent, direct access CT scan, or an urgent ultrasound scan if CT is not available, to assess for pancreatic cancer in people aged 60 and over with weight loss and any of the following:

- Diarrhoea
- Back pain
- Abdominal pain
- Nausea/ vomiting
- Constipation
- New Onset Diabetes.

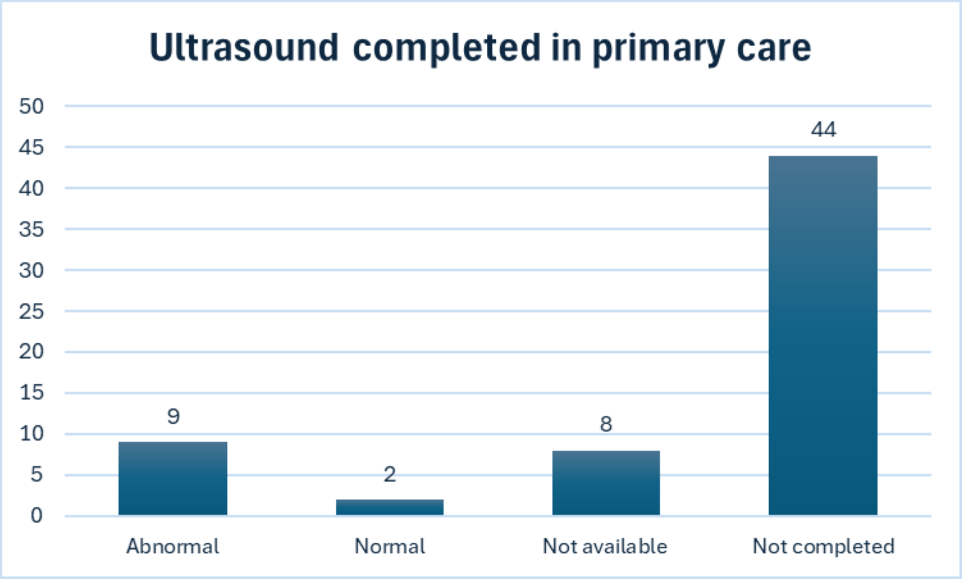
Direct access CT pancreas is only available in some areas in the region, and many GPs will still need to refer for this via an USC referral.

The data in this section should be viewed with caution as on review of the data there was concern that this section was not always completed accurately.

CT Pancreas*- results of CT pancreas, where requested in primary care*



***Ultrasound Scan (USS)–** results of ultrasound scan, where requested in primary care*

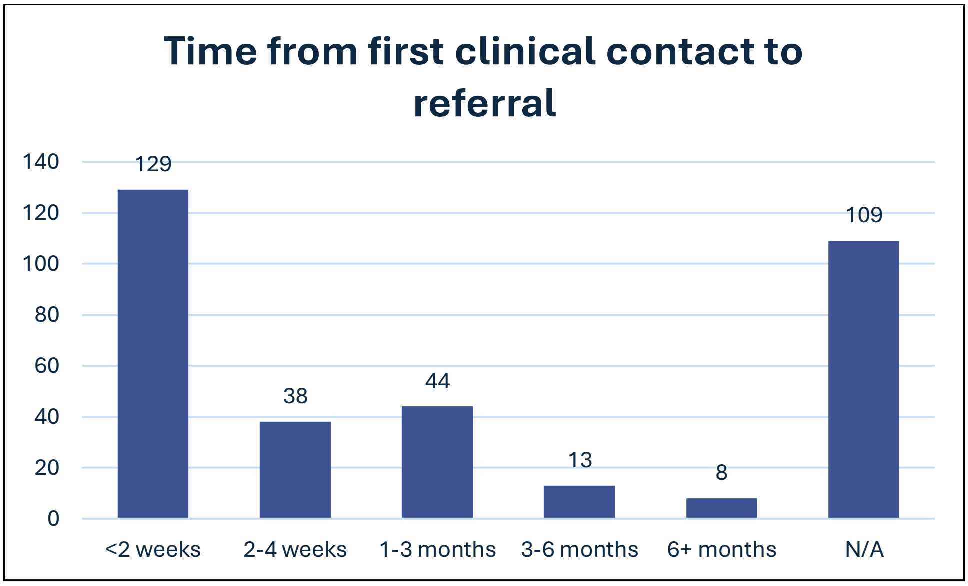


Across Wessex the access to direct access CT Pancreas is variable and so this makes these results difficult to interpret as not everyone is available to request a CT scan. However, what it does show is that all the patients who did have a CT scan had an abnormal result. We know that abdominal ultrasound has limited sensitivity for detecting pancreatic cancer, particularly for small tumours or those located in the tail of the pancreas. Studies have shown that up to one-third of pancreatic cancers may be missed on initial ultrasound imaging. Ultrasound imaging can be limited in visualising pancreatic cancer because it depends on the operator's skill, patient's anatomy, size of the tumour and visualisation which can be limited if obstructed by bowel gas. This all supports the need for the patient having quick access to a CT scan of the pancreas; whether by direct access from general practice (as recommended by NICE) or via the Urgent Suspected Cancer referral pathway.

Primary Care Interval - This includes time from first clinical contact in primary care to referral and number of clinical contacts in primary care prior to referral

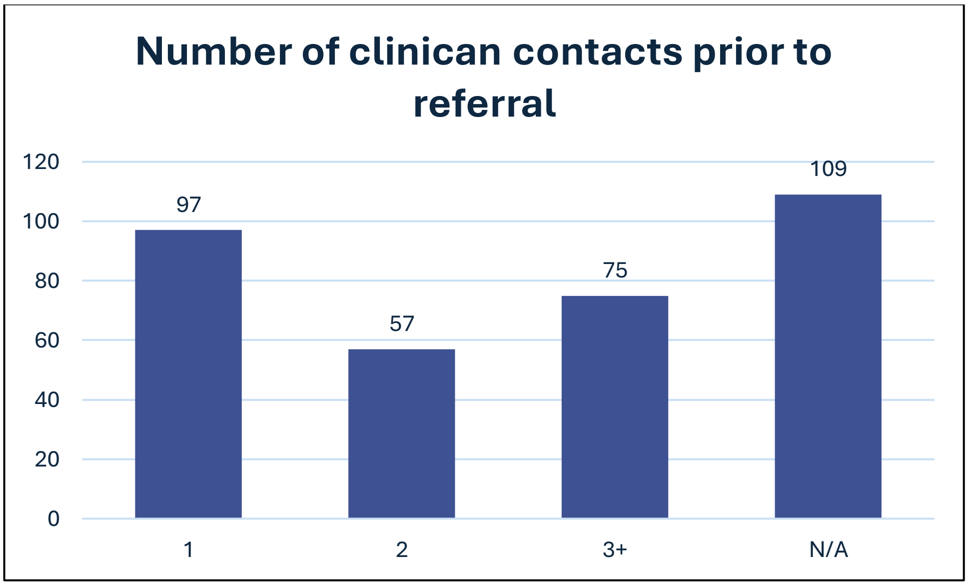
Time from first clinical contact

For patients seen in primary care, the majority were referred less than 2 weeks from first presentation. However, for 9% of patients it took over 3 months from first presentation to referral. Further in this report, primary care delay themes are reported to better understand the reasons for these delays.



Number of clinical contacts prior to referral

For patients seen in primary care, 22% had 3 or more consultations relating to their diagnosis prior to referral. Some of the multiple consultation themes will be explored further in this report.



Delays

Clinicians reported there to be a delay in 16% of cases. These delays are further explored in the qualitative analysis within this report. During analysis, it was found that even though 16% of cases had been documented as having a delay there were more comments found during the free text and explanation that also suggested a delay, and these have also been included in the further discussion.

Examination of qualitative themes for delayed diagnosis

All 356 cases were reviewed by two WCA clinicians who identified themes from the qualitative data provided in the comments and free text sections of the data collection template. Some cases identified more than one theme.

This table shows the themes identified from the qualitative analysis and the number of times that theme occurred. A total of 14 key themes were identified during the analysis.

Some of the themes are discussed below:

Themes	**No. of times theme occurred**
Age - not meeting criteria for referral	18
Referred to another tumour USC pathway	7
Vague Symptoms	7
Primary Care delay	6
Secondary Care delay	5
Patient factors	4
Imaging	4
Lack of continuity of care	4
Lack of safety netting	4
Positive FIT	4
Urinary symptoms	4
Deviation from NICE	2
Raised Ca125	2
Incidental findings	1
Treated diabetes	1

There were multiple reasons for delays to diagnosis. We have grouped them into 6 main themes;

1. *Age not meeting criteria* - The most common reason for a delay in diagnosis in the audit was that the age did not meet the referral criteria. NICE guidance says that patients >60 with weight loss and one or more of diarrhoea, back pain, abdominal pain, nausea, vomiting, constipation or New Onset Diabetes should be referred for a direct access CT scan or an USS if CT is not available. There were 59 cases of patients who were <60 years old and diagnosed with pancreatic cancer (17 %) and 18 (31%) of them were marked as having a delay in their diagnosis.

2. *Primary Care delays*- Amongst the delays to pancreatic cancer diagnosis there were 23 cases (6.5%) reported to have various primary care delays including vague symptoms, lack of continuity of care and lack of safety netting and deviation from NICE guidance.

7 patients were reported as having vague symptoms and 4 of these were initially treated for something else – gallstones, dyspepsia and pancreatic cysts which were monitored.

6 had a reported primary care delay with the reasons for this including multiple contacts with different GP's and awaiting a FIT or blood result before referral.

4 attended their GP or emergency department multiple times before they were diagnosed. This again highlights the importance of continuity of care and also having an appropriate second opinion or review when needed.

4 were reported as not having had any safety netting. This was a recurring theme throughout all 3 tumour groups we audited. NG12 highlight key recommendations around safety netting patients with suspected cancer with the aim of avoiding patient delays.

2 were reported as having deviated from NICE Guidance.

Due to the diagnostic challenge often faced the audit has emphasised the need for continuing to deliver and update and educate our primary care workforce not only on signs and symptoms but the importance of safety netting.

3. *Imaging* - Out of the delays reported 3 patients were referred for an ultrasound scan (not direct access CT) and 1 had a normal USS so was reassured. Awaiting an Ultrasound scan can cause delays as there are often longer waits in getting the imaging and subsequent result reported and then if it is normal, this can be falsely reassuring. NICE Guidance recommends a direct access CT pancreas within 2 weeks or an USS if CT not available. Currently there is variability across Wessex around direct access to CT. The audit report will be taken to the WCA Clinical Action Group for Hepatobiliary Cancers so this inequality can be reviewed.

4. Referrals to other tumour groups – 7 patients were referred to another tumour group (Lower GI, Upper GI, Urology, Gynaecology). 4 patients had a positive FIT and were referred on an urgent suspected cancer pathway to Lower GI. These patients had been appropriately referred to Lower GI following a positive FIT based on NICE recommendations however in these cases the colonoscopy was negative, and they were later diagnosed with pancreatic cancer. This finding was interesting given the publication of a recent paper which demonstrated 1 year all-cause and non-colorectal cancer mortality rates were almost doubled in people who had a positive symptomatic FIT result.[9] This is an area that needs further research and understanding but is one that WCA should follow closely, as in time it may extend the use of symptomatic FIT beyond colorectal cancer investigation or impact the onward management of those who are FIT positive, colonoscopy negative. In the meantime, the plan is to continue to empower primary care to provide good and effective safety netting for their patients.

2 patients had raised CA125 and were initially referred to gynaecology before later being diagnosed with pancreatic cancer. This is interesting because recent evidence has shown that CA125 can be raised with other tumour groups aside from ovarian, including pancreatic cancer.[12]

5. *Secondary care delays* – There were 5 patients reported as having a delay in secondary care. Reasons for delays in secondary care included an USC referral being downgraded to urgent and the patient not being seen for 4 months, a delay in reporting on results and follow up, an initial referral to gastroenterology being declined so the patient went privately, a patient had an endoscopy under USC referral which was normal so they were discharged but they did not have a CT scan and lastly a patient had a CT that described an atrophic pancreas and the patient was not investigated further.

6. *Patient factors* – these included difficulties for a patient with dementia, patient choice and wanting a private referral.

Next Steps –

As a result of the analysis of the audit results the Wessex Cancer Alliance has shaped its work for this and next year in the following ways:

- WCA plan to promote recruitment into the Safe-D research study at University Hospital of Southampton. This study is aiming to recruit people between 50-84 who have recently been diagnosed with Type II Diabetes within the last 6 months. They will then be randomised to have a blood test that looks for biomarkers of pancreatic cancer. Due to the diagnostic difficulty with pancreatic cancer, with symptoms often presenting late and non-specifically there is a clear need for new technology and testing to support earlier diagnosis. If this trial is successful, then there is the possibility that in the future it could be a useful investigation for those newly diagnosed with Type II Diabetes and help achieve earlier diagnosis.
- WCA are exploring the option of a local audit following the current National Case finding work which is identifying patients over 60 who have a new diagnosis of diabetes and weight loss and referring them for further investigation (CT scan and blood tests). This could also help develop new pathways for newly diagnosed diabetic patients to try and improve earlier diagnosis.
- Encourage patients to register for EUROPAC, a study looking at the genetics of pancreatic cancer for those with a family history.
- Wessex Cancer Alliance aim to provide effective education for primary care on pancreatic cancer but particularly targeted at practice nurses who often lead on diabetes and review the patients when they are first diagnosed.
- The audit findings will be presented at the next HPB Clinical Advisory Group so the age limit for referrals can be discussed, and direct access CT scan can be reviewed to try and deliver an equitable service throughout the Alliance.
- Further evidence, national guidance and recommendations on developing pathways for patients who have a positive FIT but a negative colonoscopy are awaited, in the meantime WCA will continue to empower primary care to provide good and effective safety netting for their patients.

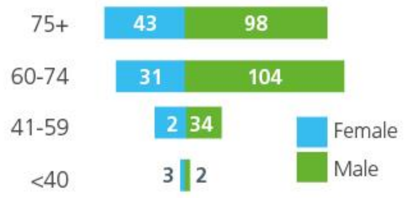
NHS
Wessex
Cancer Alliance

Primary Care Oesophageal Cancer Audit

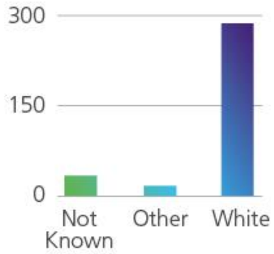
As part of a Wessex Cancer Alliance Local Improvement Scheme, PCNs across Hampshire, Isle of Wight and Dorset completed a standardised audit template reviewing oesophageal cancers diagnosed between April 1st 2023 to March 31st 2024. These findings were analysed by WCA GPs, and a summary of findings are below.

Demographics

75% of patients were male



Ethnicity



318 Total Patients

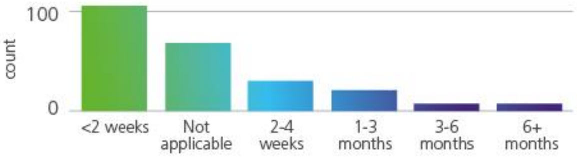
Investigations

7% Raised Platelets
18% with previous endoscopy in the last 5 years

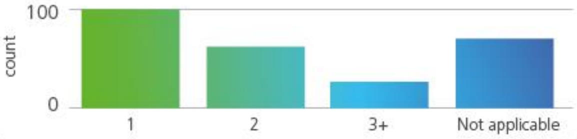
*excludes those not seen in primary care prior to diagnosis

Primary Care Interval

Time from first clinical contact to first referral



Number of clinical contacts prior to referral

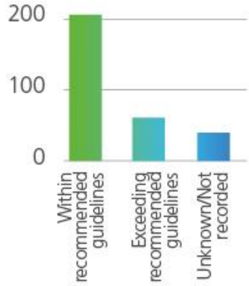


Risk Factors

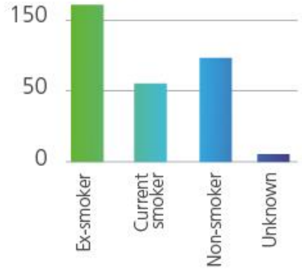
% with Barrett's oesophagus **16%**

% of patients with GORD **30%**

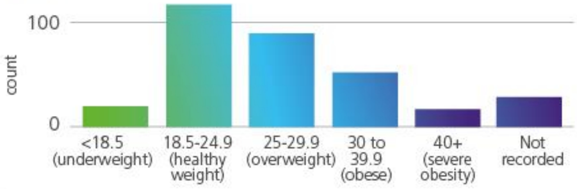
Alcohol



Smoking



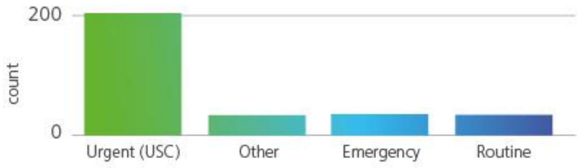
BMI



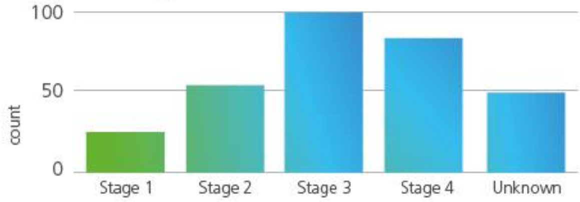
*where the clinician identified the consultation as related to oesophageal cancer diagnosis

Diagnosis

Route to diagnosis



Stage to diagnosis



Symptom Presentation

% with dysphagia	% with weight loss	% with reflux	% with dyspepsia	% with upper abdominal pain	% with other symptoms	% with nausea and/or vomiting	% with haematemesis	% with no symptoms
61%	48%	40%	39%	32%	25%	21%	3%	7%

Delay Themes

based on qualitative analysis of audit report
(in order of frequency they occurred)

Delays

% where there was a delay

16%

1. Age not meeting criteria

59 cases of patients who were <60 years old and diagnosed with pancreatic cancer (17 %) and 18 (31%) of them were marked as having a delay in their diagnosis.

2. Primary Care delays

23 cases reported to have various primary care delays including vague symptoms, lack of continuity of care, lack of safety netting and deviation from NICE guidance.

3. Referrals to other tumour groups

Due to symptoms overlapping with other tumour sites and positive investigation findings suggestive of alternative tumour pathways (e.g. Ca125 and FIT) there were delays to diagnosis in several cases

4. Secondary care delays

e.g. delay in reporting

5. Imaging Delays

There is variability in length of wait for ultrasound scans and also variability across Wessex around direct access to CT.

6. Patient factors

e.g. patient choice and wanting a private referral

Next Steps / Recommendations

- **Promotion of the SAFE-D research study**
- **Promotion of EUROPAC to eligible patients (patients with family history)**
- **Increased Primary Care Education – e.g. Diabetes and Pancreatic Cancer**

Oesophageal

Oesophageal cancer is the 14th most common cancer is the UK. It has a higher incidence in men, where it is the 9th most common cancer. 41% of all new cases are diagnosed in those aged 75 and above.

Earlier diagnosis is linked with improved survival, however, in England in 23/24 only 29.6% were diagnosed at an early stage.

59% of cases are preventable with risk factors including smoking, overweight and obesity, alcohol and gastro-oesophageal reflux disease. Those with Barrett's oesophagus are at higher risk of developing oesophageal adenocarcinoma, with around 3-13% of those with the condition delivering this in their lifetime.[13]

This audit reviewed a total of 317 patients diagnosed with Oesophageal cancer in Wessex between 1st April 2023 and 31st March 2024 and the results are summarised below.

Patient demographics – demographic data were collected to understand the population characteristics of those diagnosed with oesophageal cancer. This included age, sex and ethnicity.

Age *- The audit collected data on age in 'age groups' to ensure that patients weren't identifiable by date of birth.*

The audit found that the slight majority of oesophageal cancers were diagnosed in those over 75 years (44%) but also a similarly large number diagnosed in the 60 -74 age group (43%).

Age Group (years)	***Number of patients***
<40	5
41-59	36
60-74	135
75+	141
	317

Sex *-The audit collected data to identify the sex of the patients diagnosed with oesophageal cancer.*

The audit found that the majority of patients diagnosed with oesophageal cancer were male (75%) Oesophageal cancer shows higher incidence in men, largely due to exposure to significant risk factors linked to oesophageal cancer. Men are more likely to smoke, consume alcohol heavily, and higher rated of obesity – all of which increase risk. An 'other' option was included to capture any transgender patients, but no patients were reported in this category.

Sex	***Number of patients***
Male	*238*
Female	*79*
Other (including transgender)	*0*
	317

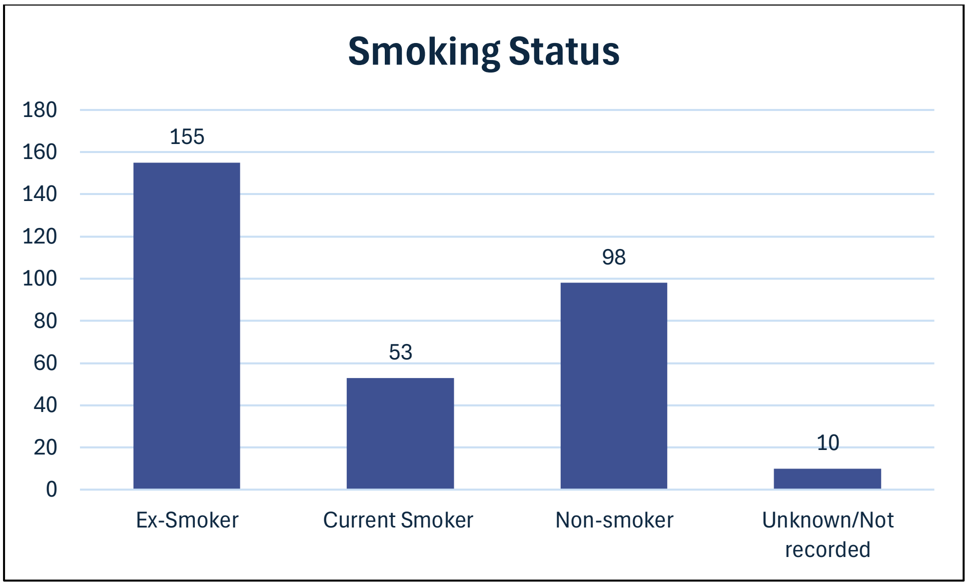
Ethnicity – *Data was collected on the ethnicity of patients based on clinical system records, where known.*

Ethnicity	***Number of patients***
Any other ethnic group	1
Any other mixed / multiple ethnic background	3
Any other White	11
English / Welsh / Scottish / Northern Irish / British	282
Indian	1
Not Known	18
White	1
	317

This table shows that the majority of patients (89%) had their ethnicity recorded as ‘English/Welsh/Scottish/Northern Irish/ British.’ The next highest was ‘Any other White’ which represented 3% of patients. Around 6% of patients in the audit had no recorded ethnicity.

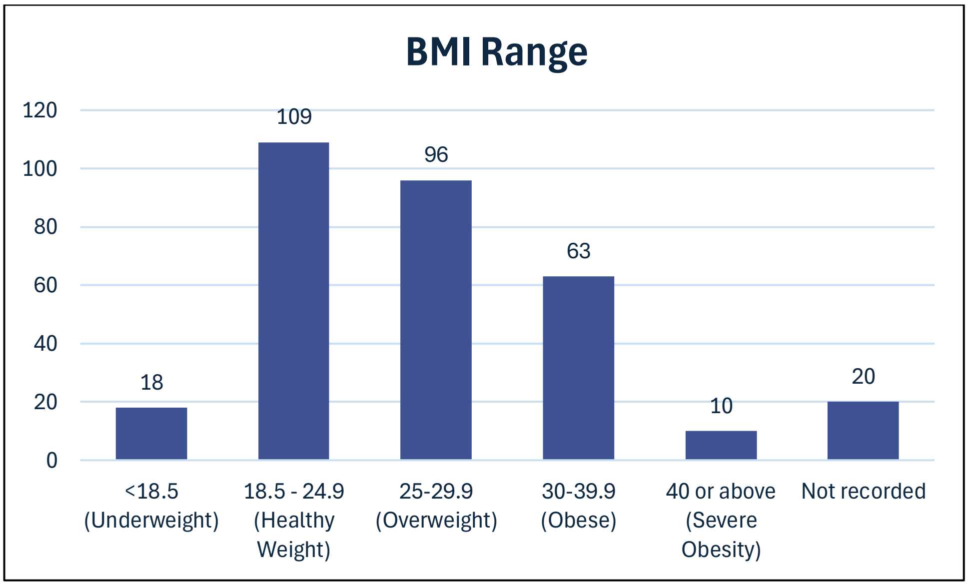
Risk factors – Information on specific risk factors relating to oesophageal cancer were collected to understand opportunities for risk stratification. The first few risk factors are all modifiable and work on prevention and education around healthy lifestyle is paramount to try and reduce the risk associated with oesophageal cancer. All three risk factors (smoking, obesity and alcohol) can cause reflux which if it persists can result in the changes to the cells lining the oesophagus and cause cancer.

***Smoking Status** – smoking status was extracted from the GP clinical system based on most recent available record.*



This graph shows that just under half patients (49%) were Ex-Smokers and at the time of the audit 17% were current smokers. (31%) were Non-Smokers. Smoking is a major risk factor for oesophageal cancer as it directly damages the cells lining the oesophagus and is particularly associated with squamous cell carcinoma. Around 35 out of 100 oesophageal cancer cases (around 35%) in the UK are caused by smoking. Someone's risk increases the longer they smoke.[14]

***BMI range** – Body mass Index (BMI) was extracted from the GP clinical system based on most recent available record.*



34% of patients in the audit were recorded as having a healthy weight. Over half (53%) were recorded as having Overweight, Obesity or Severe Obesity. More evidence is showing that central obesity, is associated with adenocarcinoma of the oesophagus.[15]

Alcohol

68% of patients were reportedly drinking within recommended Government guidelines. 19% exceeded Government guidelines. Alcohol is strongly associated with Squamous cell carcinoma of the oesophagus. Even light drinkers have an increased risk but the more you drink the higher your risk increases.[16]

Barretts Oesophagus

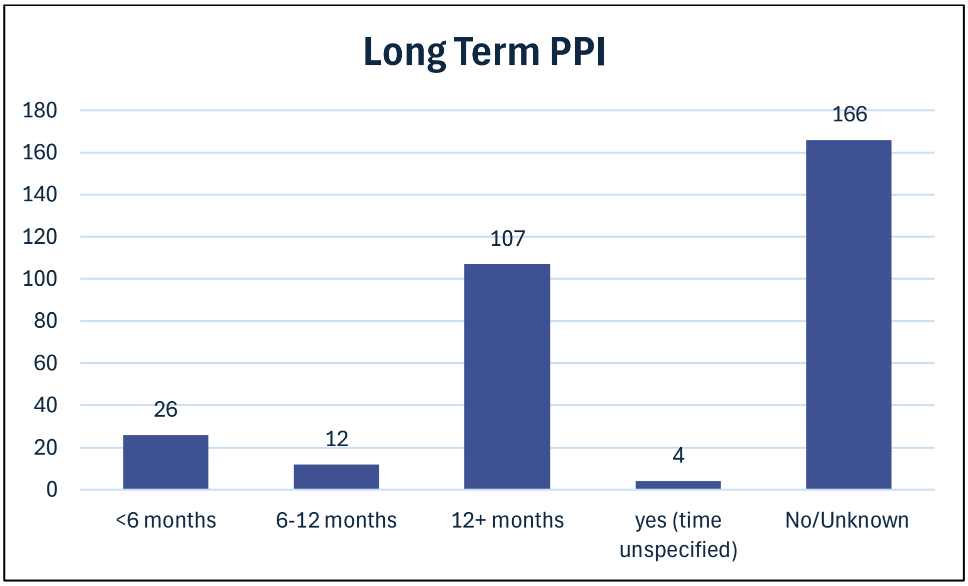
16% of patients had Barretts Oesophagus. Barrett's Oesophagus is a condition where the lining of the oesophagus becomes inflamed, and the cells become abnormal. This process is linked to Gastro-oesophageal reflux disease. In a small number of people this can lead to oesophageal cancer. Patients who are diagnosed with Barrett's oesophagus should have surveillance endoscopies every 3 years to monitor their condition and check it has not become cancerous.

In some areas in Wessex patients with Barrett's Oesophagus are being invited for a new investigation called 'Cytosponge' which is a small capsule that patients swallow, and it detects if there is a tumour marker (TFF3) that is associated with precancerous changes. This may be beneficial in the future as it can be done in the community, as a quicker, more comfortable investigation for patients and has the potential to reduce the demand on endoscopies allowing more capacity for the higher risk patients to have access to an endoscopy more quickly.

Gastroesophageal reflux Disease (GORD)

30% of patients had GORD. Damage to the oesophageal lining occurs with recurrent persistent reflux which is why it is important to get investigated and treated. It is not only a risk factor but can be one of the symptoms caused by oesophageal cancer, so if a patient is not responding to their treatment and is having break through symptoms with a Proton Pump Inhibitor (PPI) they need further investigation. Education on safety netting in primary care is key here to prevent delays in diagnosis. We will explore this more in our recommendations.

Long Term Proton Pump Inhibitors (PPIs)



47% of patients were recorded as using Proton Pump Inhibitors (PPIs) prior to referral with 34% of patients recorded as using them for more than 12 months prior to referral.

On reflection after analysis of the data use of a PPI for over 12 months is too broad a timeframe and is not necessarily reflective of long-term PPI use. It would have been better to have more options for the time frame of use of a PPI over a longer time period. This is a limitation of the data collection.

As previously mentioned above when looking at GORD, it can be very difficult to know if a patient's reflux is a symptom of GORD that needs treating or a symptom of oesophageal cancer because of persistent GORD. Patients who are on a long-term PPI should be invited for a medication review every year to review whether their medication should still be continued and if they are having any side effects. This is sometimes done by a doctor or a pharmacy technician or other AHP who can prescribe. It is a good opportunity to review if the patients are getting any breakthrough symptoms or if they could have a trial off medication to see if any symptoms return and need investigating and this is discussed further in the recommendations and next steps.

Symptom presentation

% with Dysphagia
61%

% with Weight Loss
48%

% with Reflux
41%

% with Dyspepsia
39%

% with Upper Abdominal Pain
32%

% with Other Symptoms
25%

% with Nausea and/or Vomiting
21%

% with Haematemesis
3%

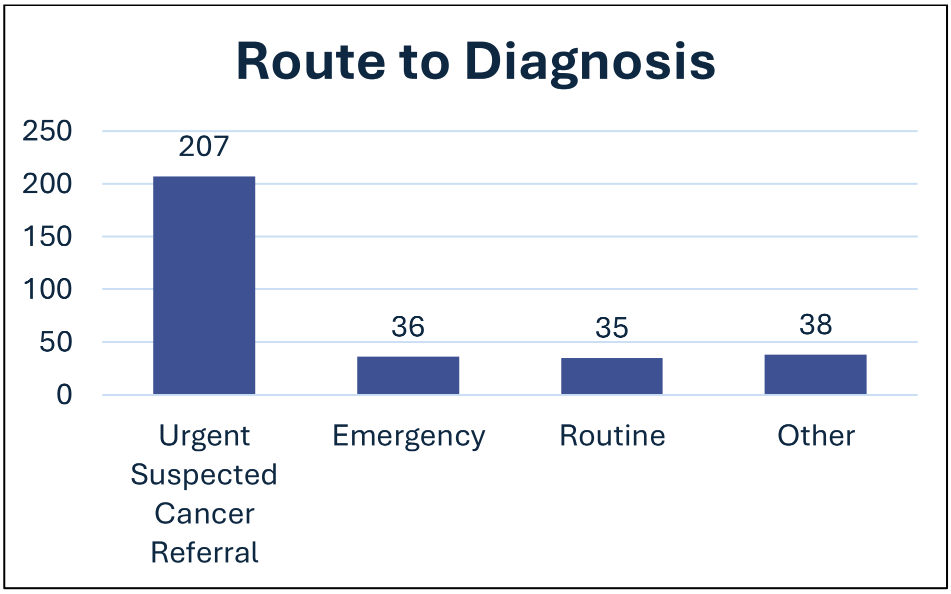
% with no symptoms
7%

The data shows that the majority of oesophageal cancers were diagnosed at a late stage. This is not surprising as the most common presenting symptoms recorded were dysphagia (61%) and weight loss (48%) which are both late-presenting symptoms. It reinforces the need for earlier identification and referral for patients with reflux, dyspepsia and abdominal pain alone. This is why an emphasis on education and ensuring we follow-up these patients and their response to any treatment started is important.

25% patients had other symptoms which again shows why it does often present a diagnostic challenge for clinicians and is not always diagnosed early.

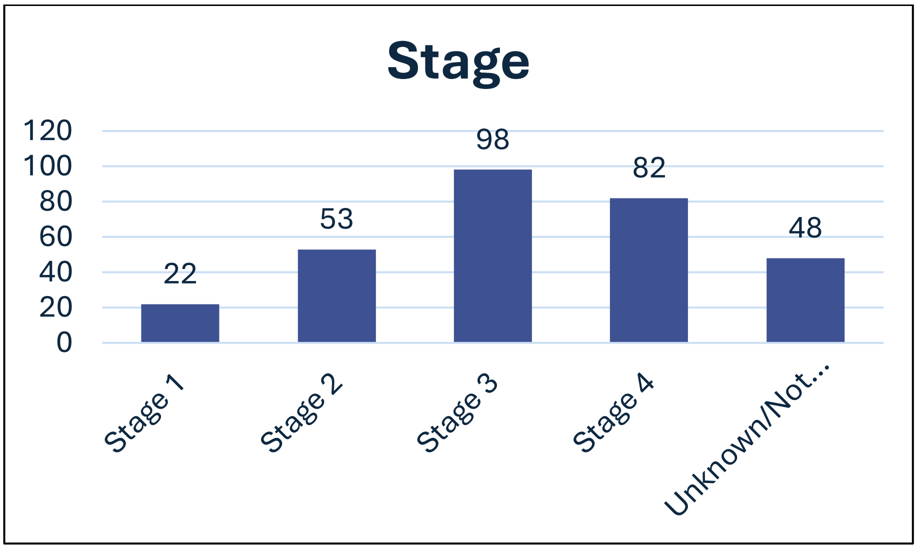
There was a 21% association with nausea and vomiting. Only 3% patients had haematemesis but 7% were recorded as having no symptoms and were picked up incidentally.

Diagnosis – Clinicians were asked to record the route in which the patient was diagnosed and the stage of diagnosis, where known.



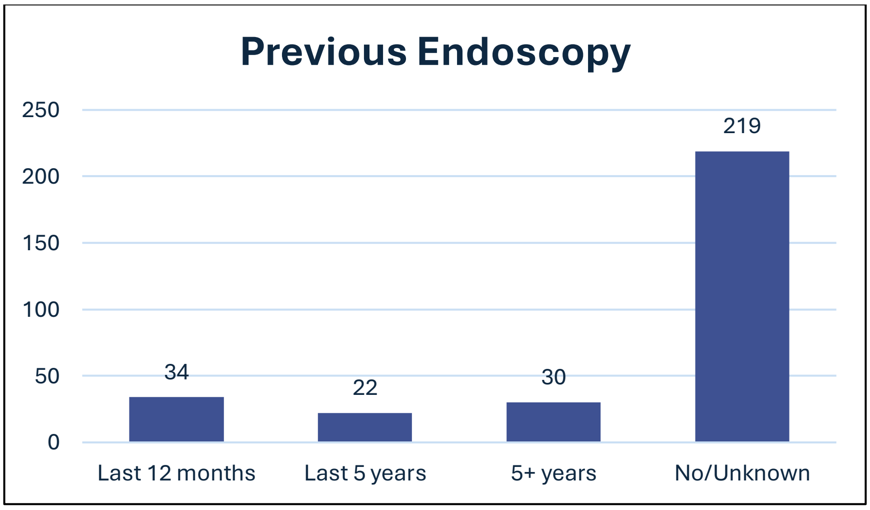
The majority of patients were diagnosed via an Urgent Suspected Cancer Referral (66%) but unfortunately 59% of patients are still diagnosed at stage 3 & 4 despite this. This is because clinicians recognise the need to urgently refer patients with dysphagia or weight loss (the two most common reported presenting symptoms in the audit) but we know that these symptoms do generally present late in the disease and therefore despite the urgent referral patients are still being diagnosed at a late stage of disease.

It was also found that 3.8% of the cancers were diagnosed as an incidental finding. These cancers were often discovered during lung screening, via scans for other cancers (e.g. melanoma, lymphoma, ENT) and during hospital admissions for unrelated conditions.



Investigations – clinicians reported results on investigations requested in primary care. Note: this does not include results from secondary care investigations.

Previous endoscopy



28% of patients had a previous endoscopy with only 18% having had one in the last 5 years.

Of those on a long-term PPI (12 months +) only 42% had a previous endoscopy recorded. This is a challenging area as there are no current guidelines on whether all these patients should have an endoscopy and if so when and how often. However, throughout this audit it has highlighted the need to make sure that if starting someone on a PPI they have adequate follow up to check their response to treatment and they have safety netting to ensure that they know when to come back.

It raises the question that if a patient has been on a PPI for 12 months and continues to need it and is unable to stop it without their symptoms returning that they would need further investigation. Currently this would require them being referred for an endoscopy which as a service is already stretched with the demand for investigation. The current development and analysis of the diagnostic tool called a cytosponge/capsule endoscopy which was discussed previously (see Barrett's Oesophagus) may be able to assess and triage these patients in future, but this is not yet within the guidelines.

We will discuss how useful medication reviews can be at following up these patients in our next steps and recommendations.

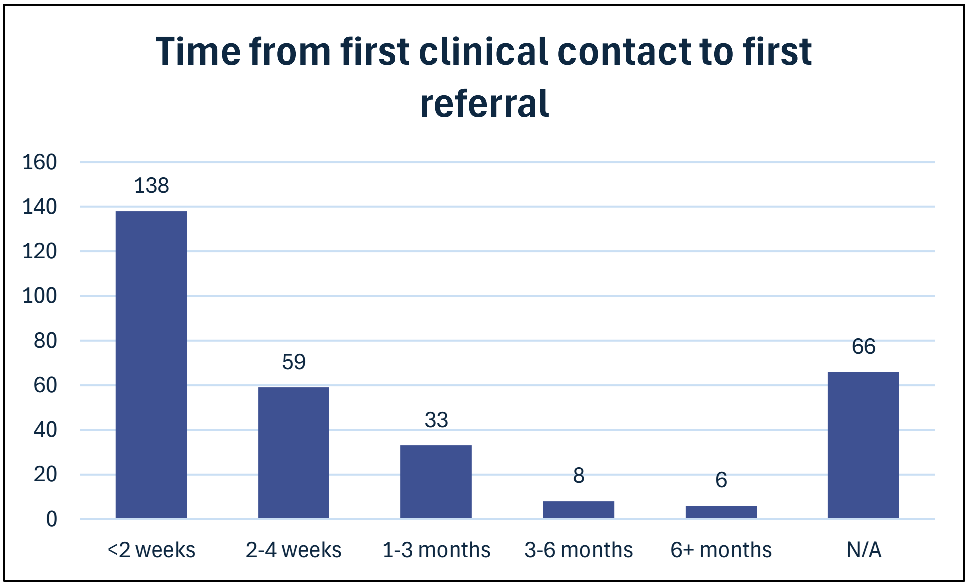
Raised Platelets (>400)

265 patients had a full blood count (including platelet check) completed in primary care. Out of these, 7% of patients had raised platelets. Previous evidence had demonstrated a link between thrombocytosis and oesophageal cancer and NICE guidance recommends further investigation if patients also had any of the red flag symptoms that would warrant an urgent suspected cancer referral. Education in primary and secondary care regarding raised platelets and the association with some cancers is another important area to try and improve earlier diagnosis.

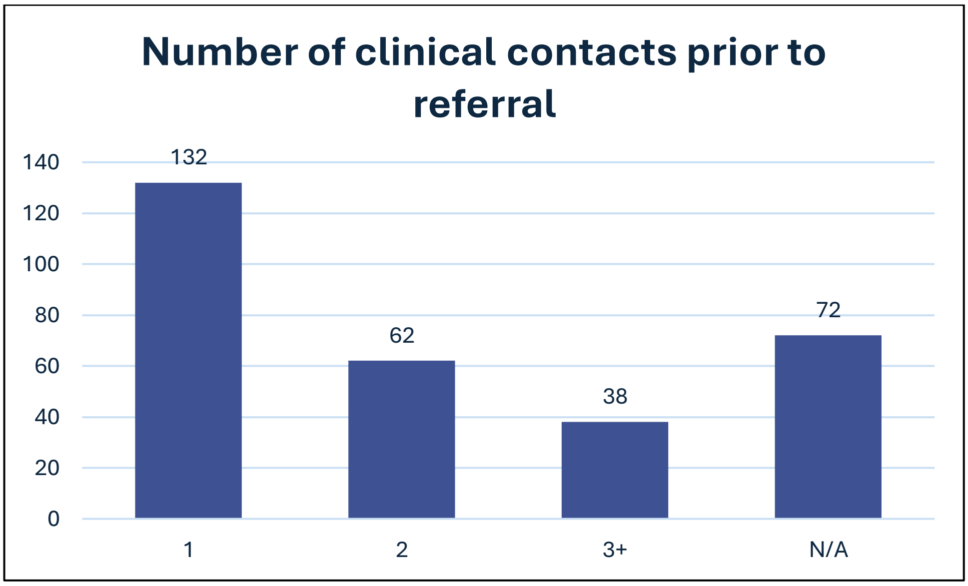
Primary Care Interval

For patients seen in primary care, the majority were referred less than 2 weeks from first presentation (57%). A small percentage (6%) took longer than 3 months from first presentation to referral.

Time from first clinical contact



Number of contacts prior to referral



Where patients were seen in primary care, 57% had 1 clinical contact prior to referral. The most common symptoms that patients presented with required urgent referral according to NICE guidance, so this is reassuring. In 16% of cases, patients had 3 or more clinical contacts prior to referral, and this highlights the importance of continuity of care and seeing the same clinician.

Jess's Rule came into practice across England in September 2025. The principle of the rule is that if a patient sees their GP three times about the same symptoms without a diagnosis, the GP should pause, rethink and seek a second opinion. The aim is to prevent delays to diagnosis and improve quality of care for patients.

Delays

This audit analysed 318 cases of oesophageal cancer. Of these, 18% had a recorded delay in diagnosis. Additional cases included qualitative comments suggesting delays, so these were also considered in the analysis.

Examination of qualitative themes for delayed diagnosis

All 318 cases were reviewed by two WCA clinicians who identified themes from the qualitative data provided in the comments and free text sections of the data collection template. Some cases identified more than one theme.

This table shows the themes identified from the qualitative analysis and the number of times that theme occurred. A total of 12 key themes were identified during the analysis.

Themes	***No. of times theme occurred***
Lack of safety netting	8
Primary care delay	7
Deviation from NICE	7
Patient factors	7
Secondary Care delay	4
Vague Symptoms	4
Referred to another tumour USC pathway	3
Routine referral for OGD	3
IDA	2
Positive FIT	2
Negative histology at first OGD	2
GP trainees	1

There were many reasons for delays in diagnosis which we have grouped together into 4 main themes below;

1. *Primary Care delays*

40 cases (13%) were recorded to have a delay associated with primary care. 7 cases directly recorded as a 'primary care delay' included a two week wait to review an e-consult, dyspepsia that was treated for 3 months prior to referral, multiple

appointments before investigation, awaiting investigations in primary care and initially being treated for H Pylori.

7 cases were recorded to deviate from NICE guidance where the referral could have been made earlier. For example, a patient presented with dysphagia but was not referred straight away, another was not asked about weight loss, and another was managed in primary care despite weight loss being a red flag. 4 patients were recorded as having non-specific symptoms and were initially diagnosed with gallstones, fatty liver, abdominal pain and functional dyspepsia.

There were 8 cases recorded as lacking safety netting. An issue highlighted in the audit was that patients are being treated for dyspepsia without safety netting. This was a key focus area of the WCA's Oesophageal Awareness Campaign with Heartburn Cancer UK in February 2025 (Appendix F)

As a result, practices were encouraged to follow up their patients when they were started on PPI's. They were also advised to use medication reviews to check for breakthrough symptoms and ensure an OGD is arranged if symptoms persist or recur despite treatment. They were encouraged to review that their patients with Barrett's Oesophagus are coded correctly and receive appropriate surveillance.

Other primary care delays included 3 patients who were referred for a routine endoscopy (OGD) although it was unclear if this was clinically appropriate at the time. 2 patients presented with iron deficiency anaemia and were investigated for that before their oesophageal cancer was diagnosed and 1 case involved a GP trainee who did not follow NICE guidance.

2. *Secondary care delays*

There were 6 cases where delays were recorded in secondary care. There were 4 recorded delays due to a delay in surveillance of Barretts, interhospital referral routine not urgent and an OGD diagnosed an ulcer initially. There were also 2 that had negative histology on their OGD but were later diagnosed with cancer.

3. *Referral to other tumour groups*

3 patients were referred to other urgent suspected cancer pathways (respiratory for cough, urology and the rapid investigation service) and 2 had a positive FIT which led to a lower GI referral.

4. Patient factors

7 (2.2%) cancers were also delayed due to patient factors (e.g. not wanting to be investigated, delay in presentation, choice of appointment time).

Whilst some incidental findings and patient-related factors are unavoidable, a significant number of delays identified are potentially preventable.

Next steps

- Following the audit, one practice developed an effective AccuRx message for patient communication to review patients who have been on a long-term PPI. This has now been shared across the Alliance; (see Appendix G)
  This will help primary care with safety netting their patients and ensuring effective use of their medication reviews. WCA have also shared advice on which patients on long term PPIs may need review/ safety netting and consideration of further assessment.
- Hampshire and the Isle of Wight are involved in recruitment for the BEST-4 Trial which is jointly funded by Cancer Research UK and NIHR and is exploring the use of the capsule sponge test as a screening tool for patients on long-term heartburn medication. In the future the capsule sponge may be a helpful investigation to triage low risk patients and reduce the current challenges and demand on endoscopy capacity.
- Dorset have recently completed a primary care pilot of capsule sponge testing for surveillance of patients with Barrett’s Oesophagus, which will help to contribute to national learning on this.
- WCA has put IBA (Identification and Brief Advice) training on alcohol for all practices in this year’s LIS requirements following successful a successful VBA (Very Brief Advice) for smoking cessation initiative in 2023/24.
- WCA plan to raise awareness of Jess’s Rule in Primary Care to encourage clinicians to reflect, review and rethink if a patient presents three times with the same or escalating symptoms. This action is relevant to all cancers included in the audit.

Limitations

- As an Alliance, it was not possible to access the clinical systems to verify that all the eligible cases had been completed. WCA have obtained the number of lung cancers diagnosed across the region for 2023-24 financial year and this was 2119. From this, it assumed that approximately half of the patients diagnosed have been included within the audit.
- Some of the questions may be open to interpretation. Every effort was made to standardise the template and provide clear guidance on how to interpret the questions; however, it is not possible to guarantee that these have always been completed in the way it was intended.
- When all the data was collected, the cases were reviewed to remove any patients that did not meet the criteria e.g. those with another cancer that has metastasised to the lung, rather than a lung primary. However, this was only possible where information was written in the further comments/ reflection section of the template. There may be cases that remain that do not meet the audit inclusion criteria, however, there is no way of knowing if this is the case.
- Some of the issues with inaccurate case inclusion may have been down to clinical coding. For any future audit we will ensure that all searches created are carefully assessed for their accuracy. However, this cannot account for any issues with inaccurate coding at individual practice level

Overall conclusion

These 3 tumours were chosen to review as they are all more commonly diagnosed at a late stage and the aim was to identify opportunities to improve this.

This audit has provided a rich source of data on the primary care interval of the patient journey for these 3 tumour pathways. This is data that is not ordinarily collected and has provided areas for learning and improvement for the PCNs completing the audit. Whilst is some cases there will always be unavoidable delays the audit has highlighted numerous areas for improvement and education and has directed current and future work for Wessex Cancer Alliance.

The dashboard created by DiiS is a useful tool that can be used as a resource for the Alliance for future projects or queries on the pathway.

The audit re-emphasised that part of the issue with these tumour types is that symptom presentation often occurs when the cancer is already at a later stage or may be associated with vague symptoms that are harder to identify. However, with lung cancer it has been demonstrated (both in this audit and with other national and local data) that the introduction of LCS has provided an intervention that can lead to an improvement in early diagnosis. This is still lacking in both pancreatic and oesophageal cancer and WCA needs to be proactive in supporting innovation, research and piloting new approaches in these tumour pathways.

As with any audit to complete the cycle and assess for any improvements it would be useful to repeat this in 2 years' time (capacity allowing).

Acknowledgements:

With thanks to all the PCNs who took part in the audit for the time and dedication given to providing data, reflections and learning points.

References

1. Cancer Research UK, Lung cancer statistics | Cancer Research UK Accessed [Sept 2025]
2. Chest X-ray sensitivity and lung cancer outcomes: a retrospective observational study | British Journal of General Practice
3. The Kings Fund (2010) Continuity of care and the patient experience
4. RCGP (2016) Continuity-of-care-in-modern-day-general-practice1
5. Pancreatic Cancer UK, Pancreatic cancer statistics - Pancreatic Cancer UK [Accessed Sept 2025]
6. Rapid Cancer Registration Data: Incidence and treatment dashboard
7. Cancer Research UK Pancreatic cancer statistics | Cancer Research UK [Accessed Sept 2025]
8. EUROPAC, EUROPAC Researching Hereditary Pancreatic Diseases
9. Diabetes, Weight Change, and Pancreatic Cancer Risk - PubMed
10. Gastrointestinal tract (upper) cancers - recognition and referral | Health topics A to Z | CKS | NICE
11. All-cause and non-colorectal cancer 1-year mortality among people having a faecal immunochemical test in primary care for investigation of symptoms of suspected colorectal cancer: an English cohort study - The Lancet Primary Care
12. The diagnostic performance of CA125 for the detection of ovarian and non-ovarian cancer in primary care: A population-based cohort study - PMC
13. Cancer Research UK Oesophageal cancer statistics | Cancer Research UK [Accessed Sept 2025]
14. Cancer Research UK, Oesophageal cancer statistics | Cancer Research UK Accessed [Sept 2025]
15. Abdominal obesity and gastroesophageal cancer risk: systematic review and meta-analysis of prospective studies - PubMed
16. WHO, Alcohol consumption and upper aerodigestive tract squamous cell carcinoma: evidence from 28 prospective cohorts – IARC

Appendix

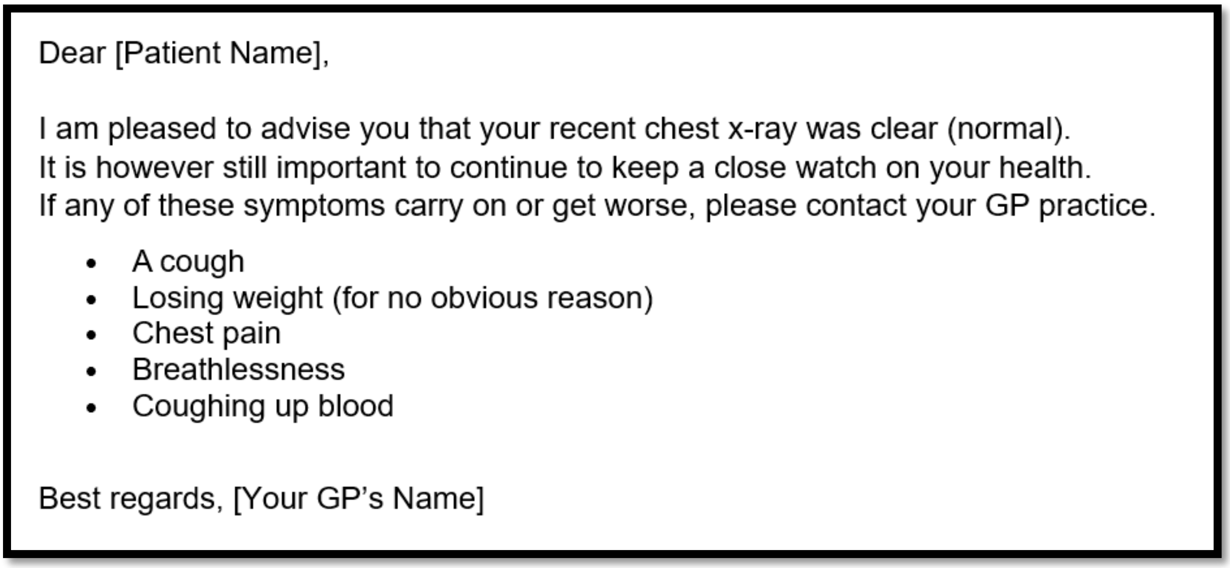
Appendix A: Audit template

Appendix B: Supporting documents for audit collection

Appendix C – Secure data checklist

Appendix D: COPD and Lung Cancer - A Webinar for Primary Care

Appendix E - Safety netting template text message:



Dear [Patient Name],

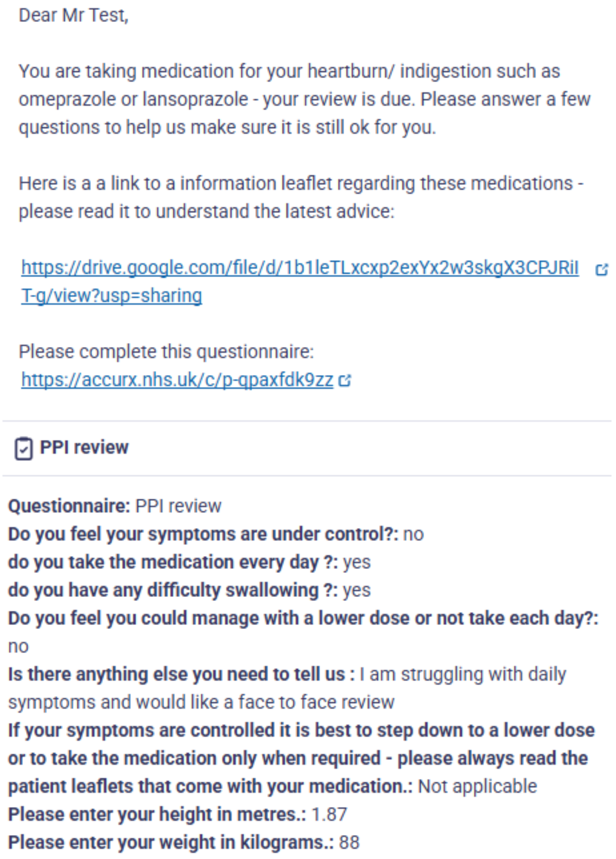
I am pleased to advise you that your recent chest x-ray was clear (normal).
It is however still important to continue to keep a close watch on your health.
If any of these symptoms carry on or get worse, please contact your GP practice.

- A cough
- Losing weight (for no obvious reason)
- Chest pain
- Breathlessness
- Coughing up blood

Best regards, [Your GP's Name]

Appendix F: Oesophageal Cancer webinar

Appendix G: AccuRx template for patients on long-term PPI



Dear Mr Test,

You are taking medication for your heartburn/ indigestion such as omeprazole or lansoprazole - your review is due. Please answer a few questions to help us make sure it is still ok for you.

Here is a a link to a information leaflet regarding these medications - please read it to understand the latest advice:

https://drive.google.com/file/d/1b1leTLxcxp2exYx2w3skgX3CPJRiIT-g/view?usp=sharing

Please complete this questionnaire:
https://accurx.nhs.uk/c/p-qpaxfdk9zz

PPI review

Questionnaire: PPI review
Do you feel your symptoms are under control?: no
do you take the medication every day ?: yes
do you have any difficulty swallowing ?: yes
Do you feel you could manage with a lower dose or not take each day?: no
Is there anything else you need to tell us : I am struggling with daily symptoms and would like a face to face review
If your symptoms are controlled it is best to step down to a lower dose or to take the medication only when required - please always read the patient leaflets that come with your medication.: Not applicable
Please enter your height in metres.: 1.87
Please enter your weight in kilograms.: 88