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THAMES VALLEY AUDIT OF PATIENTS DIAGNOSED WITH CANCER FOLLOWING AN EMERGENCY PRESENTATION






FOREWORD

Cancer survival rates in England have been reported to be lower than in comparable health economies for many years, as is documented in multiple national reports including the 2015 Independent Cancer Taskforce Report – 'Achieving World-Class Cancer Outcomes, a Strategy for England 2015-2020'. In England overall 20% of cancers are diagnosed through emergency presentation; analysis of survival rates for this group of patients has shown notably poorer outcomes than for those diagnosed through other routes, particularly two-week wait referral pathways.

Previous analysis of patients diagnosed following emergency presentation has generally focused only on the patient journey leading up to the emergency presentation; there has been limited work looking at the continuation of the pathway up to the point of diagnosis in secondary care.

This report gives a detailed and timely in-depth exploration of the experience of patients in Thames Valley diagnosed through the emergency route in 2012-14. The findings suggests that in a small subsection of this population there may be opportunities for earlier diagnosis, improving survival, and details the areas where work will be needed to achieve this. Also highlighted are the areas where improvement in communication at all levels will aid better and faster patient care; this is likely to contribute to a better experience for patients and their carers, even in those situations where no improvement in survival is likely. All professionals, in all sectors, share the responsibility for communicating effectively about patients in their care; this work has demonstrated an area of weakness in the interface between sectors. Awareness of the importance of effective communication is essential in the delivery of truly patient-centred care.

I am very pleased to share this report with you and hope that the insights contained within it will capture your interest and energy. The action plans being developed following this report will aim to ensure that improvement work addresses these important issues.

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EXECUTIVE SUMMARY

BACKGROUND

People may be diagnosed with cancer through various routes. One in five people in England with cancer are diagnosed through an emergency presentation route (NCIN 2016). Survival for these people has been shown to be lower than for those diagnosed through other routes (McPhail, Elliss-Brookes et al. 2013; NCIN 2016). Interest is growing around establishing the circumstances that lead to an emergency presentation (EP). To address this, qualitative analysis has begun to investigate the content of the primary care consultations prior to EP (Mitchell, Rubin et al. 2013; Mitchell, Rubin et al. 2015). Thames Valley Strategic Clinical Network (TVSCN) commissioned Cancer Research UK (CRUK) to carry out an audit of patients who were diagnosed with cancer following an emergency presentation using the Royal College of General Practitioners (RCGP) Significant Event Audit (SEA) template, exploring both the factors leading to this mode of presentation, and their pathway during that initial hospital admission.

AIMS AND METHODS

The aim of the project was to identify and understand common themes for late diagnosis of cancer in patients diagnosed following an emergency presentation, investigate if this leads to challenges in management within hospital and agree recommended improvement actions.

All 296 GP practices in the TVSCN were invited to participate. The acute trusts were asked to identify all patients who had been diagnosed with cancer following an emergency presentation between 1st April 2012 and 31st March 2014. Participating GP practices were asked to complete between one and three SEAs on their patients included in this list, choosing cases where they felt the most learning could be made. In addition to SEAs from primary care, a sub sample of patients had Trust SEAs completed on them in all six of the Thames Valley Trusts, using a template specifically designed for this project.

A qualitative approach was taken to analyse the account of the cancer diagnosis and the reflections of the GP and Trust regarding the cancer journey using framework analysis (Ritchie and Spencer 1994). Common themes were identified from the dataset related to key elements along the diagnostic pathway.

FINDINGS

Summary of the cancer journey

Of the 296 practices approached, 83 practices participated and provided 204 completed SEAs. Following the exclusion of some of these SEAs in the final analysis due to them not fitting the audit criteria 184 SEAs were analysed from a total of 78 practices. All 6 acute trusts participated and generated 35 Trust SEAs. The SEAs covered a wide range of patient age, cancer type and cancer journey experience. Symptoms experienced ranged from vague or atypical symptoms to recognised red flag symptoms. Most patients had had contact with primary care before the emergency presentation, with the most common being a face to face consultation with a GP at the practice.

Some patients had been investigated before their EP; some of these referrals were via the 2week wait route. The patient may have been investigated with no cancer diagnosis established, but in some the EP may have happened before the outpatient appointment had occurred.

The Trust SEAs reported a similar proportion of EPs were diagnosed following an urgent GP referral compared to those where patients self-presented to A&E. CT scans and biopsies were the most common investigations before diagnosis. Many different teams were involved with the patient after an EP and in most cases this included the oncology service. About four fifths of the Trust sample received palliative care rather than treatment with curative intent, especially in cases found to have advanced stage cancer.

Thematic analysis

Analysis of the GP SEAs identified 3 different types of cases;

- those where it **would not have been possible** to change the route to diagnosis or the outcome (even after SEA reflections);
- those where an earlier and different route to diagnosis **could have been possible** but where the **prognosis** was likely to have been the **same**; however, the **patient's experience may** have been improved.
- those where **missed opportunities** for an **earlier diagnosis** and potentially a **better prognosis** were identified.

The factors which led to the EP were grouped into three broad areas;

- Tumour
- Patient
- System and healthcare professionals (including primary and secondary care).

Figure 1 is a thematic map of the causal mechanisms found to underpin the SEAs analysed in this study. The individual paths to the EP were diverse across the sample, some experiencing only one reason why the diagnosis came through an emergency route while others experienced many reasons. Tumour and system factors seemed particularly relevant for determining the EP route.

Learning points put forward by the GP practices and the acute trusts were grouped into the different underlying factors that were identified and are summarised in Table 1. The interface between primary and secondary care was identified as a particular area of challenge with five themes identified:

- issues with diagnostics;
- uncertainties over who was responsible for the patient;
- poor communication;
- complex presentations lacking a holistic approach;
- inappropriate pathways being taken.

Analysis of these challenges has led to recommendations for action to address the interface issues identified between primary and secondary care and can be found in the appendix of the full report.

CONCLUSION

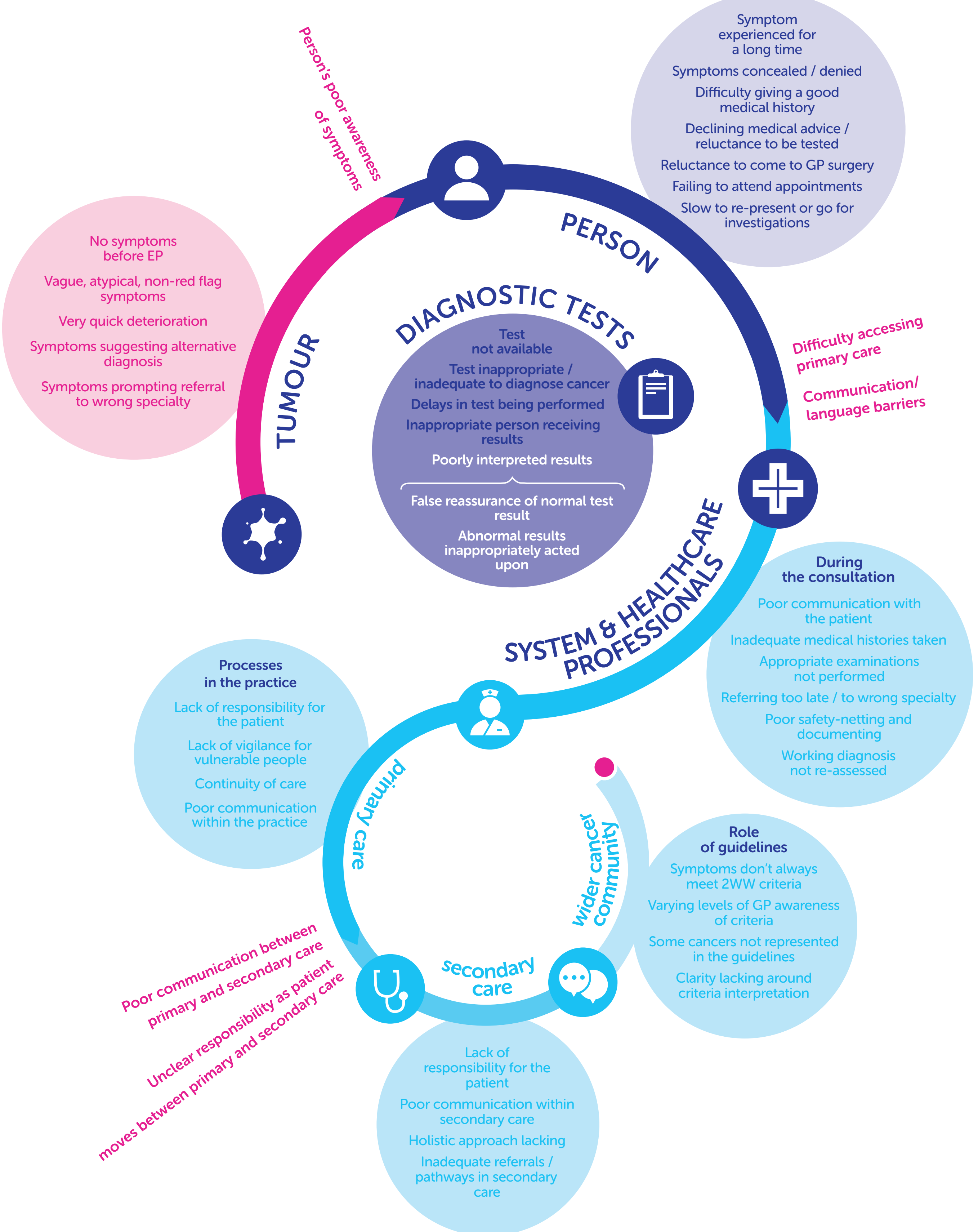
Not all emergency presentations of cancer can be prevented. The findings of this project identified some cases where it may have been possible to establish diagnosis earlier. Earlier diagnosis of cancer and avoidance of emergency presentation could contribute to a less traumatic experience for the patient and their family, even in cases where the overall prognosis is poor.

A number of factors can contribute to the likelihood of cancers being diagnosed via an EP. Some factors may be modifiable by changes in professional practice, but it is vital that patients are also fully engaged to maximise the opportunity for earlier diagnosis.

FIGURE 1: THEMATIC MAP OF CAUSAL MECHANISMS.

DIAGNOSIS OF CANCER THROUGH AN EMERGENCY PRESENTATION*

THEMATIC MAP OF CAUSAL MECHANISMS



PERSON

- Symptom experienced for a long time
- Symptoms concealed / denied
- Difficulty giving a good medical history
- Declining medical advice / reluctance to be tested
- Reluctance to come to GP surgery
- Failing to attend appointments
- Slow to re-present or go for investigations

Person's poor awareness of symptoms

Difficulty accessing primary care

Communication/ language barriers

TUMOUR

- No symptoms before EP
- Vague, atypical, non-red flag symptoms
- Very quick deterioration
- Symptoms suggesting alternative diagnosis
- Symptoms prompting referral to wrong specialty

DIAGNOSTIC TESTS

- Test not available
- Test inappropriate / inadequate to diagnose cancer
- Delays in test being performed
- Inappropriate person receiving results
- Poorly interpreted results
  - False reassurance of normal test result
  - Abnormal results inappropriately acted upon

SYSTEM & HEALTHCARE PROFESSIONALS

During the consultation

- Poor communication with the patient
- Inadequate medical histories taken
- Appropriate examinations not performed
- Referring too late / to wrong specialty
- Poor safety-netting and documenting
- Working diagnosis not re-assessed

primary care

Processes in the practice

- Lack of responsibility for the patient
- Lack of vigilance for vulnerable people
- Continuity of care
- Poor communication within the practice

secondary care

- Lack of responsibility for the patient
- Poor communication within secondary care
- Holistic approach lacking
- Inadequate referrals / pathways in secondary care

Poor communication between primary and secondary care

Unclear responsibility as patient moves between primary and secondary care

wider cancer community

Role of guidelines

- Symptoms don't always meet 2WW criteria
- Varying levels of GP awareness of criteria
- Some cancers not represented in the guidelines
- Clarity lacking around criteria interpretation

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*Emergency presentation includes presentation via Emergency department / A&E, emergency GP referral, transfer, admission or attendance.

Based on: The Thames Valley audit of people diagnosed with cancer through an emergency route

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TABLE 1: KEY LEARNINGS AND RECOMMENDATIONS FOR ACTIONS ARISING FROM THE PRIMARY CARE SEAS

Area	Key learnings and recommendations for actions in primary care
Tumour factors	• Be aware of common physical and mental conditions that can mask cancer • Have systems in place to monitor vulnerable groups • In the medical record code for symptoms to enable the patient's narrative to be followed • Consistently re-assess the working diagnosis • Practice the 'three strikes and you're in' rule • Trust gut feeling and if in doubt speak to a colleague / consultant
Patient factors	• Raise patient awareness about cancer symptoms through information provided in the practice • Implement processes to increase uptake of healthy life choices and screening • Implement processes to target screening defaulters • Record medical history from carer's viewpoint also when appropriate • Mark in medical record any communication barriers, address these through longer consultation slots or ensuring person is accompanied at consultations • Always ascertain and record patient's wishes in terms of medical intervention and end of life planning • Establish reasons behind non attendance for patients who frequently miss appointments in primary and / or secondary care • Ensure patient understands next steps at the end of the consultation by supplying appropriate patient information leaflet.
Primary care - during the consultation	• Ensure all staff know how to access translation services • Provide a detailed medical record as this is necessary in order to be able to follow the patient's narrative • Review patient's history before consultation, especially for home visits • Use risk profiling tools • Ask patient about red flag symptoms during history taking • Use READ codes rather than free text • Ensure all consulting rooms have weighing scales and regularly weigh patients where there is clinical concern • When there is clinical suspicion, do the appropriate examination at that time, ie rectal exam, neurological exam • Ensure consistent practice of recording examinations in the medical notes • Advise patients and record in notes that they should return if symptoms persist • Ensure that patients understand that 2WW referral is to rule out cancer • Note in the medical record whether patient attended referral appointment and outcome • Keep 2WW log for co-ordinating attendance and follow up • When referring a patient on the 2WW pathway GPs to clearly state their concerns and provide more detail when symptoms don't fit a specific referral criteria

Area	Key learnings and recommendations for actions in primary care
Primary care -processes in the practice	• Identify high risk patients and consider annual health checks / blood tests for these patients • Ensure patients on long term medications are seen at least once a year • GPs to take blood taking equipment to home visits if confident that they can take blood. • Where possible consider a system where each patient has a named GP. • Patients attending frequently over a short period of time should see the same GP when ever possible. • Train reception staff to recognise people who are unwell and need same day attention • Ensure patient's contact details are up to date • Implement systems to ensure that patients' records are transferred speedily when someone changes GP practice • Create opportunities to discuss difficult cases either in routine meetings or coffee-break sessions • Record communication with other health professionals in the patient record and ensure GP actions from discharge summaries are acted upon • GPs advised to question hospital attempt to downgrade 2WWs, and express their concerns about the patient and reasons for referral
Diagnostics	• Agree within the GP practice, protocols for requesting certain tests, undertake training sessions to understand the use of / and limitations of common diagnostic tests for cancer such as the PSA and CA125 • Where possible make provision within the practice for same day testing for investigations such as urgent blood tests and ECGs • Ensure ongoing CCG communication with regards access to tests • Use diagnostics in parallel with a 2WW referral where appropriate • Ensure patients know how and when they will receive results and record in the medical record that patient has received results • Provide as much detail as possible on the test request form including if GP is suspicious of cancer • Have system in place to decide who has responsibility for receiving and acting on test results in the GP practice • Ensure abnormal results are followed up and re-assess working diagnosis if clinical picture no longer fits • Put system in place for tracking normal test results so as to be able to identify changes that might be happening and which could alert the GP to investigate further. • Re-assess working diagnosis if symptoms persist despite normal test results
Cancer community – role of guidelines	• Ensure all clinical staff including locums have ready access to cancer referral guidelines and 2WW forms during consultations • Retain a high index of clinical suspicion and do not always wait for patients to fulfil the two week wait criteria before referring • Note within the practice differences between the NICE and any local guidelines • Seek advice from secondary care where there are no guidelines available or clarity is needed for guideline criteria

INTRODUCTION

In England there are several routes for people to receive a diagnosis of cancer. Other than the national screening programmes, the main routes to diagnosis are urgent two week wait referrals from the GP (2WW), routine referrals from the GP, onward referral from another specialty and emergency presentation (EP). Emergency presentation includes presentation via A&E, emergency referral from GP, emergency Consultant outpatient referral, emergency transfer and emergency referral for admission. One in five people in England with cancer are diagnosed through an emergency presentation route (NCIN 2016). Survival for these people has been shown to be lower than for those diagnosed through other routes (McPhail, Elliss-Brookes et al. 2013; NCIN 2016).

Interest is growing around the detail of the circumstances that led to an emergency presentation. For example, for colorectal cancer, a study reported that most of those (84%) diagnosed through an EP had seen their GP within six months before diagnosis (Sheringham, Georghiou et al. 2014) it recommended that patients should be encouraged to return to their GP if symptoms worsened, and suggested that in the discussions with the patient the uncertainties surrounding diagnostic results should be clearly discussed. Qualitative analysis has begun to address the content of the primary care consultations prior to EP (Mitchell, Rubin et al. 2013; Mitchell, Rubin et al. 2015). The findings from these studies confirm that there is frequently GP contact prior to the EP but they also highlight the complexity of the presentation and the influence of patient factors. More detailed work is needed in this area to develop recommendations that could increase earlier referral and help avoid emergency presentation.

Thames Valley Strategic Clinical Network (TVSCN) commissioned Cancer Research UK (CRUK) to carry out an audit of patients who were diagnosed with cancer following an emergency presentation. The aim of the project was to identify and understand common themes for late diagnosis of cancer in patients diagnosed following an emergency presentation and agree recommended improvement actions.

METHODOLOGY

Data collection tool - Significant Event Audits

Significant Event Audits (SEAs) were used to collect data from GP practices in the Thames Valley area. SEA use as a technique to improve quality is already widely established within general practice. The standardised, cancer-specific SEA developed originally by Mitchell and Macleod (Mitchell, Rubin et al. 2009; Mitchell, Rubin et al. 2012) was used for this study, this was based on the structure recommended by the National Patient Safety Agency (Mitchell, Rubin et al. 2015) - see appendix A. This SEA was designed specifically to capture a deeper understanding of the circumstances that surround the pathway to diagnosis for cancer. The SEA is divided into five areas:

- what happened,
- why it happened,
- learnings from the case,
- actions taken by the GP practice and
- reflections on the use of the SEA.

To ensure high quality of the completed SEA templates, all participating practices were asked to send one clinician to a training session on how to complete the SEA template.

Secondary care were also asked to use a similar SEA template, with whole team input, reflection and discussion covering the cancer journey from the emergency presentation. The template used for this data collection was designed in partnership with representatives from the acute trusts at a workshop held in December 2014. The final template consisted of both a quantitative and a qualitative section (see appendix B).

Primary Care Recruitment

All 296 GP practices in the TVSCN were invited to participate in the audit and were given a project brief, outlining the objectives and requirements of the audit. Practices expressing an interest in the audit were then visited by one of the Cancer Research UK Facilitators working in the TVSCN to discuss the audit and its objectives in more detail.

In total 83 GP practices agreed to take part, see table 2.

Table 2: Number of practices agreeing to take part by region

Region	Number of practices in region	Number taking part	Percentage
Berkshire	107	21	20%
Buckinghamshire	56	26	46%
Milton Keynes	27	9	33%
Oxfordshire	81	11	14%
Swindon	25	16	64%
Total	**296**	**83**	**28%**

Each GP practice participating in the audit was asked to complete between one and three SEAs on patients who had been diagnosed with cancer following an emergency presentation. The practices were offered a small remuneration fee for each template they completed and submitted.

Secondary Care Recruitment

Letters of invitation to participate in the audit were sent to the Trust Cancer Managers and the lead cancer clinicians from the Director of the Strategic Clinical Network. All six of the Thames Valley Trusts agreed to participate in the audit. It was agreed that each acute trust would complete six or seven audits on the same cohort of patients on whom primary care had completed an SEA.

Case identification

At the start of the project the acute trusts were asked to identify all adult patients who had been diagnosed with cancer following an emergency presentation between the 1st April 2012 and 31st March 2014 as defined by the Routes to Diagnosis work (Elliss-Brookes, McPhail et al. 2012).

Definition of an emergency presentation:

- Emergency presentation via Emergency Department / Accident and Emergency
- Emergency GP referral
- Emergency transfer
- Emergency consultant outpatient referral
- Emergency attendance or admission

The acute trusts identified 1,506 patients and allocated pseudonymised numbers to each patient[1], they sent each participating practice the NHS numbers of their identified cases and the pseudonymised number. From the list of patients practices received from their acute trust, they were asked to select those cases they felt offered the greatest opportunities for learning.

Coding difficulties and staff capacity issues in several of the acute trusts, led to some challenges and delays in identifying these cases from their databases. After discussion it was agreed that some GPs would identify appropriate patients from their own database. Therefore the final sample had emergency presentations taking place between Feb 2012 and April 2015. In total 204 SEAs were submitted by GP practices, see Table 3.

Table 3: Number of cases identified by secondary care and passed to primary care

Region	Number of cases identified	SEAs completed
Berkshire	689	50
Buckinghamshire	424	65
Milton Keynes	573	26
Oxfordshire	28*	23**
Swindon	216	40

* Oxford University Hospital only identified patients for the relevant practices signed up to the audit
** some of these patients were identified by the GP practices themselves

A total of 35 Trust SEAs were submitted from the six acute Trusts.

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[1] The acute trusts were asked to allocate the patients with pseudonymised numbers so that the CRUK facilitators were later able to match up the SEAs completed by primary care with those completed by the trusts. Pseudonymised numbers were needed so that the patient identity and NHS numbers were not shared or available to the CRUK facilitators.

Data analysis

To ensure there was no patient or health professional identifiable data all SEAs completed were anonymised. Before coding each GP SEA, a decision was made as to whether an 'Index' consultation was identifiable or not.

An index consultation was defined as the consultation where a first sign or symptom of the future diagnosed cancer was presented to the GP practice. These were usually identified by the GP using terminology such as the 'presenting symptom' or 'initial consultation'. Any consultations prior to the index were marked as 'pre-index' consultations. The remaining GP SEAs were marked as having no index consultation. Each GP SEA was reviewed and a coding frame was developed based on the data in the early GP SEAs and on previous research undertaken in this area (Mitchell, Rubin et al. 2009; Mitchell, Rubin et al. 2011; Mitchell, Rubin et al. 2012; Mitchell, Rubin et al. 2013; Lyratzopoulos, Vedsted et al. 2015; Mitchell, Rubin et al. 2015). To ensure the reliability of the coding and the coding frame, the first 10 GP SEAs for each coder were reviewed in detail by the lead analyst.

The coded GP SEAs were loaded into QSR NVivo 10 software (QSR International 2016) in order to organise and analyse the data. The 35 Trust SEAs were analysed using an 'interpretive matrix' approach previously utilised in another study analysing SEAs (Mitchell, Rubin et al. 2009). A qualitative approach was taken to analyse the account of the cancer diagnosis and the reflections of the GP and the Trusts regarding the route to diagnosis using framework analysis (Ritchie and Spencer 1994). Common themes were identified which emerged from the dataset regarding key elements along the diagnostic pathway.

In the next part of the report quantitative data from the GP and Trust SEAs have been used to describe the sample. Appendix D of the report presents the qualitative findings from the framework analysis of both the GP and Trust SEAs.

SAMPLE DESCRIPTION

204 GP SEAs were originally submitted however 17 were not deemed to be a cancer diagnosis through an emergency presentation and so were excluded from the sample, as were two other SEAs as they were for children, and a further one further SEA as it was a duplicate, resulting in 184 SEAs included in the sample.

Characteristics of GP practices

In total 184 SEAs were included from 78 different GP practices, see Table 4. The average practice size was 11,255, while for the region the average is approximately 8,692 compared to the England average of just under 7,000 (Health and Social Care Information Centre 2013). Most practices (79%) would be described as of medium size, between 5,000 and 15,000 patients, while 17% were large (over 15,000) and only 4% were small (less than 5,000 patients). The average number of full time equivalent (FTE) GPs in each practice was 6.8 with a range of between 3 and 20. Based on the number of FTE GPs, 28% of practices had more than 8 FTE GPs, 37% had between 5 and 8 and 35% of the GP practice sample had less than 5 FTE GPs.

Table 4: Description of the 78 practices that provided SEAs included in the final analysis.

Characteristic		Number (%)
Number of registered patients	Range	<5,000 - >25,000
	Average	= 11,255
	Median	~ 10,000
List size	Large (15,000 +)	13 (17%)
	Medium (5,000-15,000)	62 (79%)
	Small (<5,000)	3 (4%)
FTE GPs	Range	<3 - >20
	Average	6.8
	Median	~ 5.6
Practices by FTE	High (8+)	22 (28%)
	Middle (5-8)	29 (37%)
	Low (<5)	27 (35%)
Training practice	Yes	52 (67%)
	No	21 (27%)
	DK	5 (6%)
Practice teaches medical students	Yes	42 (54%)
	No	30 (38%)
	DK	6 (8%)
Total QOF points	Range	<800 - ~900
	Average	= 866.25
	Median	~ 875

About two thirds (67%) of the GP practices identified themselves as being training practices; across the Thames Valley area just under half (45%) of practices are training practices, so there is a slightly higher participation of training practices than may be expected. Medical students were taught in just over half (54%) of the practices taking part. QOF scores ranged from under 800 to around 900 with the average score being 866.25 for the 2013 / 14 measurement year.

Table 5: Description of the people diagnosed with cancer through an emergency presentation

(184 completed GP SEAs)

Characteristic		Number (%)
Sex	Male	90 (48.9%)
	Female	94 (51.1%)
Age at diagnosis	Range	17-96 years
	Average age	68.6 years
	Median age	71 years
	Young (under 60)	45 (24.5%)
	Middle (60-75)	64 (34.8%)
	Old (75+)	72 (39.1%)
	Don't know age	3 (1.6%)
Status at time of GP SEA	Alive	45 (24.5%)
	Deceased	132 (71.7%)
	Don't know	7 (3.8%)
Region	Berkshire	45 (24.5%)
	Oxfordshire	21 (11.4%)
	Buckinghamshire	64 (34.8%)
	Milton Keynes	16 (8.7%)
	Swindon	38 (20.7%)
Cancer site diagnosed	Lung	46 (25.0%)
	Bowel	39 (21.2%)
	Pancreas	15 (8.2%)
	Haematological	11 (6.0%)
	Liver	10 (5.4%)
	Stomach	9 (4.9%)
	Oesophagus	7 (3.8%)
	Prostate	7 (3.8%)
	CUP* & other	7 (3.8%)
	Ovarian	6 (3.3%)
	Brain & CNS	6 (3.3%)
	Kidney	5 (2.7%)
	Bladder	4 (2.2%)
	Breast	3 (1.6%)
	Mesothelioma	3 (1.6%)
	Pleura	1 (0.5%)
	Cervix	1 (0.5%)
	Tonsil	1 (0.5%)
	Small Intestine	1 (0.5%)
	Skin	1 (0.5%)
	Testis	1 (0.5%)

*Cancer of unknown primary

Characteristics of GP SEA cases

A description of the sample of 184 SEAs can be found in table 5. There were nearly an equal number of female and male cases (94 females compared with 90 males). The age range was from 17 to 96 with an average age of 68.6 years. Around a quarter of the sample were under 60, while just over a third (35%) were between 60 and 75 and 39% were over 75. A quarter (25%) of the sample were still alive at the time the GP SEA was completed, in 7 cases the status was not known at the time of the GP SEA, usually because the patient was no longer at the practice. Just over a third (35%) of the sample was from Buckinghamshire GP practices with a quarter (25%) from the Berkshire region, 21% from Swindon, 11% from Oxfordshire and 9% from Milton Keynes.

A quarter of the cases were for those diagnosed with lung cancer. The next largest group was bowel cancer (21%) and then pancreatic cancer (8%). These three sites together made up over half the sample and reflect well the cancers that are most commonly diagnosed through the emergency route. Prostate cancer and breast cancer which are amongst the four most common cancers (Cancer Research UK 2016) have a low proportion diagnosed through an emergency route (NCIN 2016) so as would be expected they represent only small numbers within the sample (prostate 3.8% and breast 1.6%).

Table 6: Description of the patients diagnosed with cancer through an emergency presentation (35 completed Trust SEAs)

Characteristic		Number (%)
Sex	Male	20 (57%)
	Female	15 (43%)
Age at diagnosis	Range	28-91 years
	Average age	61.9 years
	Median age	61 years
	Young (under 60)	15 (43%)
	Middle (60-75)	13 (37%)
	Old (75+)	7 (20%)
Status at time of GP SEA	Alive	9 (26%)
	Deceased	26 (74%)
Cancer site diagnosed with	Lung	10 (29%)
	Bowel	5 (14%)
	Pancreas	4 (11%)
	Liver	3 (9%)
	CUP & other	2 (6%)
	Oesophagus	2 (6%)
	Ovarian	2 (6%)
	Biliary tract	2 (6%)
	Haematological	1 (3%)
	Kidney	1 (3%)
	Prostate	1 (3%)
	Tonsil	1 (3%)
	Testis	1 (3%)

Characteristics of Trust cases

Table 6 shows the characteristics of the 35 Trust SEAs. Thirty of the 35 have a corresponding GP SEA while five cases where selected by the Trust independently. There were more males (57%) than females (43%). The average age was 62 years which is younger than the GP sample of 69 years. A similar proportion of people were alive at the time of the SEA being completed in the Trust sample as in the GP sample (Trust -26%, GP - 25%).

Just over a quarter (29%) of the cases were for those diagnosed with lung cancer. The next largest group was bowel cancer (14%) and then pancreatic cancer (11%). As with the GP sample, these three sites together made up over half the sample. In the Trust sample the combined sites for upper GI are the most common grouping whilst in the GP sample lung and other respiratory cancers was the most common grouped site.

FINDINGS

The cancer journey – GP SEAs

The median survival for all GP SEAs, where all dates were known, was 138 days (see table 7). The length of time between the emergency presentation and the diagnosis ranged from 0 to 73 days with a median of 4.5 days. In all but three SEAs there was some contact with primary care in the year before diagnosis.

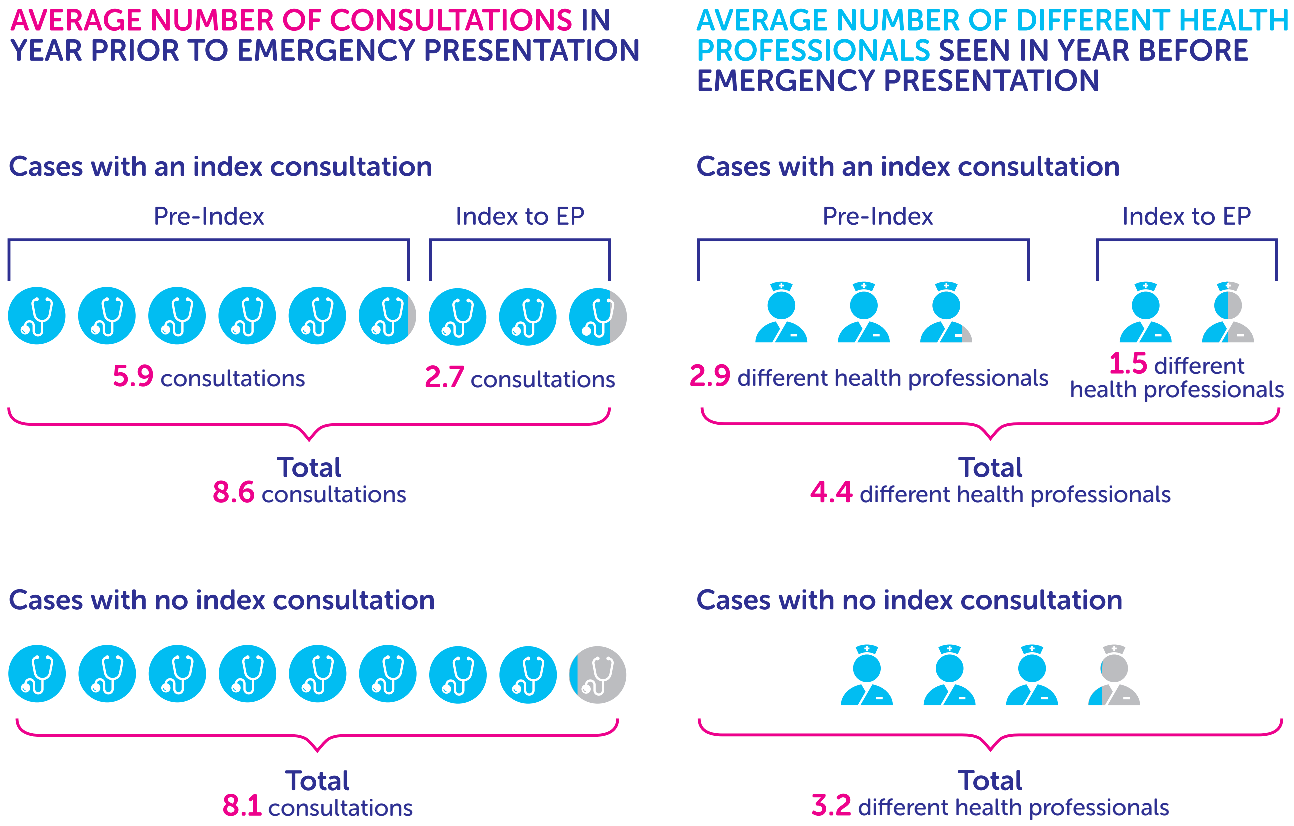
Table 7: Characteristics of the cancer journey - GP SEA sample

Characteristic		Number (%)
Survival*	Range	1-1174 days
	Average	285.7 days
	Median	138 days
Length of time between emergency presentation and diagnosis	Range	0-73 days
	Average	8.6 days
	Median	4.5 days
Index consultation** identifiable	Yes	145 (78.8%)
	No	39 (21.2%)
Any GP practice contact in 12 months prior to EP	Yes	181 (98.4%)
	No	3 (1.6%)

* Length of time between diagnosis and death or diagnosis and date of SEA completion if patient was still alive at this point (based on 175 SEAs where all relevant dates known)
**index consultations are considered to be those where a first sign or symptom of the future diagnosed cancer has been presented to the GP practice

For nearly 80% of the cases an Index consultation was identified by the coders from the information provided in the SEA. It can be seen in Figure 2 that in the year leading up to diagnosis there were on average 8-9 consultations whether an Index consultation was identified or not. This compares with data collected by the Health and Social Care Information Centre (HSCIC) which shows on average people have six consultations per year at the GP practice, while the elderly have 12-14 consultations (HSCIC 2016; RCGP 2016). In the Thames Valley sample, face to face consultations were the most common type of consultation, with home visits and telephone consultations making up only a small proportion of the total consultations. The number of different health professionals seen by a patient in the GP practice in the year before EP was on average just over 4 for those with an Index consultation and around 3 if there was no Index consultation; for both groups GPs were the main health professional seen in primary care.

Figure 2: Average number of consultations and number of different health professionals seen in year prior to emergency presentation



The cancer journey - Trust SEAs

In the sample of 35 cases there was a near even split between cases which had the emergency presentation through an emergency GP referral route (16 cases – 46%) and those where the patient had self-presented to A&E (15 cases – 43%), see Table 8.

The other four cases were: one emergency medical specialist / consultant referral, one emergency transfer and two classed as ‘other’. The breakdown of the emergency GP referral route had eight of the 16 cases presenting at an Acute / Emergency Medical Unit, seven presenting at A&E and one coded as ‘other’. Of the 15 self-presentations, 14 of them presented at A&E while one presented to an Acute / Emergency Medical Unit.

This sample is not representative of all emergency presentations but it does indicate that cases which are considered to be emergency GP referrals have two main places of presentation in secondary care – A&E or the Acute / Emergency Medical Unit. This also indicates that presentations at A&E are a combination of self-presentations and emergency GP referrals.

Table 8: Characteristics of the cancer journey - Trust SEA sample

Characteristic		Number (%)
Category of presentation	Emergency GP referral / admission	16 (46%)
	Self-presentation at A&E	15 (43%)
	Other	2 (6%)
	Emergency transfer	1 (3%)
	Emergency medical specialist /consultant referral	1 (3%)
Place of presentation	A&E (Emergency Department)	22 (63%)
	Acute / Emergency medical unit	10 (29%)
	Medical outpatient department	2 (6%)
	Other	1 (3%)
Stage of disease	IIA	1 (3%)
	IIB	1 (3%)
	IIC	1 (3%)
	IIIA	4 (11%)
	IIIB	2 (6%)
	IIIC	2 (6%)
	IV	21 (60%)
	Not able to stage	3 (9%)
Treatment	Curative intent	7 (20%)
	Palliative	28 (80%)

About one third of the sample (12 cases) had had no contact with secondary care (A&E presentations, outpatient or inpatient episodes or investigations) in the 12 months prior to their emergency presentation. The rest of the cases had had contact ranging from one to 13 contacts, some cases included up to four prior A&E visits, up to four outpatient episodes, up to ten episodes as an inpatient and up to four investigations in secondary care.

From emergency presentation to cancer diagnosis was generally considered fairly fast by the accounts in the Trust SEAs, a median of 11 days, though this ranged from being on the same day as the EP to three months after EP. In 31 of the 35 cases the date when the patient was told their diagnosis was recorded, in the remaining four cases it is not clear if or when the patient was told. Thirty of the 35 Trust SEAs indicated which investigation had confirmed the cancer diagnosis was provided,, the most common confirmatory investigation being a CT scan and the second most common being a biopsy.

There were usually many different teams involved, a variety of tests and one or more multi-disciplinary team (MDT) meetings along the patient's diagnostic journey. In this sample most cases received palliative care (28 of 35 cases) rather than treatment with curative intent, correlating with the late stage of disease at the time of diagnosis (21 of 32 cases which could be staged were stage IV, eight cases were stage III), see table 8. However, not every patient with stage III or stage IV cancer received palliative care, two of those with stage III and two at stage IV were recorded as receiving treatment with the intent to cure. In twenty-seven cases the length of time between emergency presentation and appropriate treatment starting was provided, the median length of time was 23 days and ranged from one day to five months.

There did not always seem to have been contact with the oncology service; in eight of the 35 cases no clear date for any contact was recorded. Of the remaining 27 cases the median time to contact with the oncology service after emergency presentation was 12 days, however this ranged from one day to five months. In all cases there was evidence that the patient was discussed at an MDT meeting but in three cases it was not clear when this happened. For the other 32 cases the median time from emergency presentation to an appropriate MDT meeting was 11.5 days and ranged from three days to two months.

Symptoms presented in primary care and at emergency presentation

The recommendations from the recent NICE guidelines have been organised by cancer site as well as by symptoms and investigative findings (NICE 2015). The symptoms described in the consultations prior to diagnosis are shown in Figure 3 and Table 9 and are based on data from the GP SEAs. Figure 4 shows the symptoms presented at the emergency presentation from the Trust SEAs.

Regardless of the tumour type diagnosed, people presented to primary care with a range of symptoms most commonly abdominal, respiratory or generalised systemic (e.g. loss of weight).. The two tumour types that differ slightly from this are the brain and CNS tumours which had predominantly neurological type symptoms and male genital tumours which manifested mainly urological type symptoms (Table 9).

Within each symptom grouping, the symptoms are ordered from most common to least common and then 'other'. For example for respiratory type symptoms, cough is the most commonly presented symptom, shortness of breath is the next most common respiratory symptoms and these are recorded across many of the tumour types diagnosed. For non-lung cancer type tumours this could be either because the cancer has metastasised to the lung and therefore respiratory symptoms are apparent or that the cough is completely unrelated to the tumour diagnosis.

Figure 3 shows for the more common symptoms how people diagnosed with different tumour sites across the whole sample presented the symptom at any point in the year before diagnosis. Overall the most common symptom presented to the GP in this sample was abdominal or side pain, the second most common symptom was back or joint pain.

Both gynaecological and urological cancers seemed to present with many gastrointestinal symptoms and perhaps fewer than expected gynaecological and urological symptoms respectively (Table 9). Other common symptoms for all tumour types are pain in the abdomen, side or back, weight loss, cough, shortness of breath and general fatigue and deterioration (Figure 3).

For the Trust SEAs there were also a wide variety of symptoms which had been recorded as present at the emergency presentation. The most common symptoms were shortness of breath, weight loss, abdominal pain and back pain. As with the GP SEAs these symptoms were apparent across a range of tumour sites (see Figure 4).

Figure 3: Symptom by Site - most common symptoms presenting to primary care (based on 184 GP SEAs).

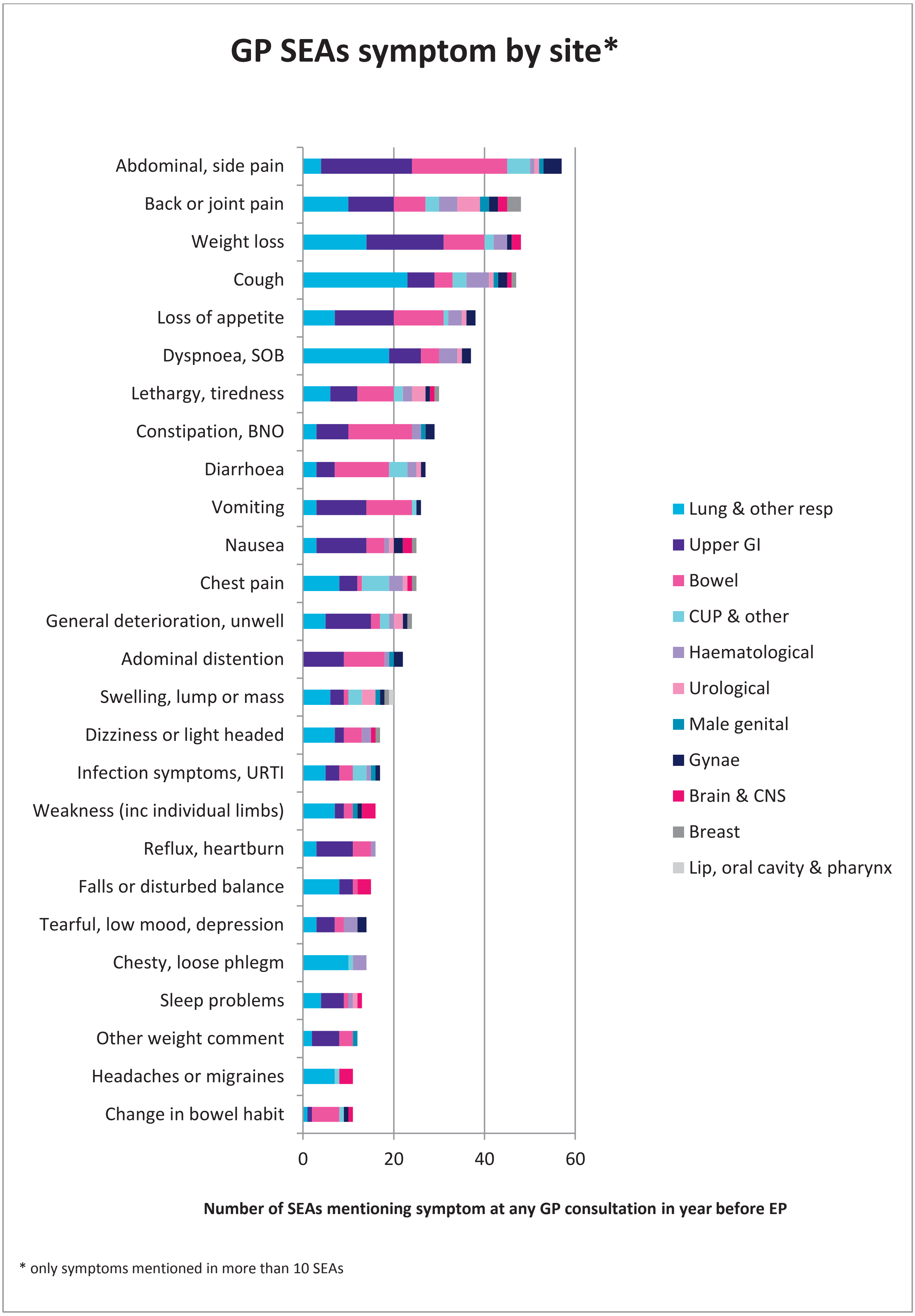


Figure 4: Symptom by Site - most common symptoms at time of emergency presentation
(based on 35 Trust SEAs)

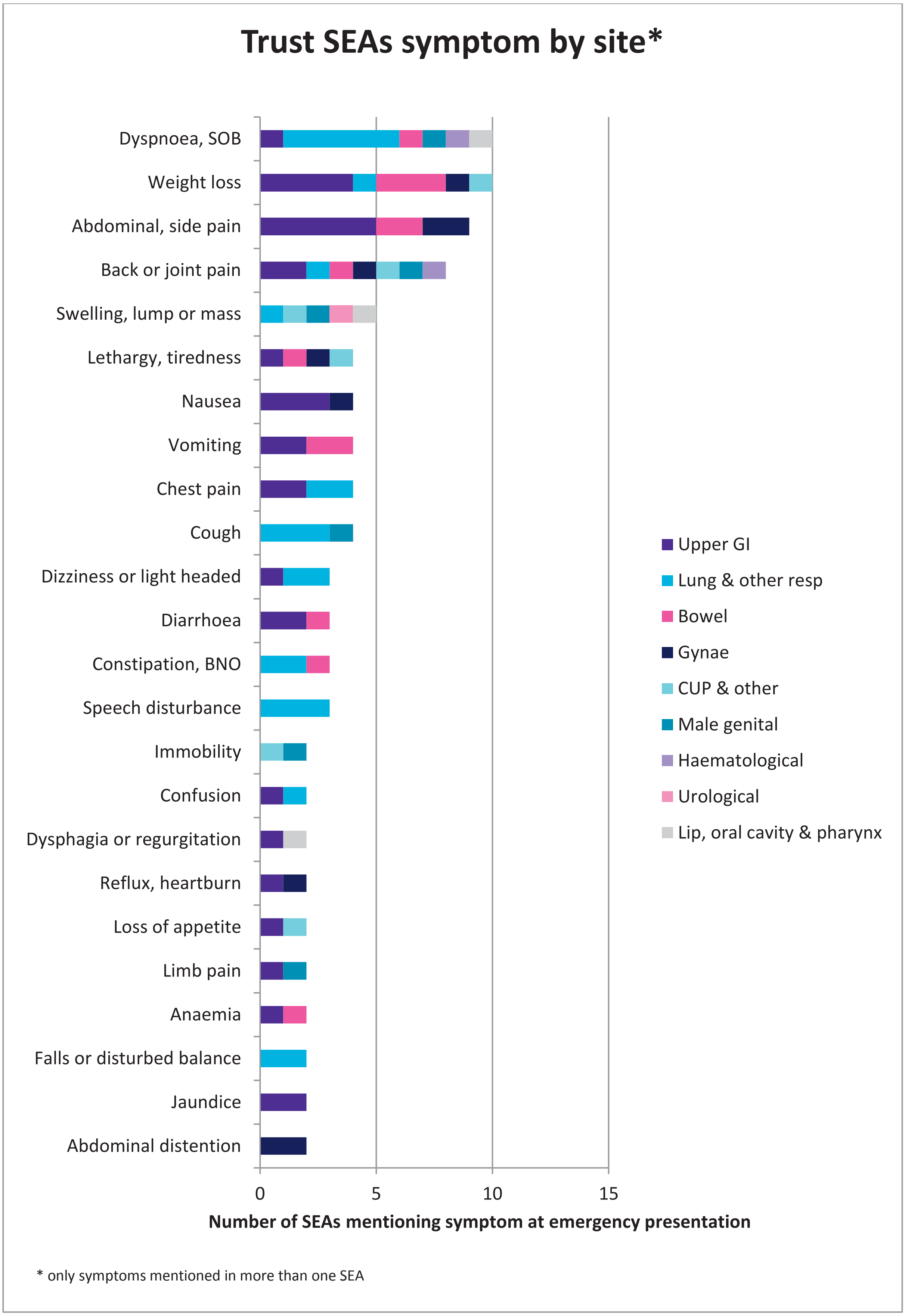


Table 9 Symptom by site – presenting symptoms

(based on 145 SEAs where there was an index consultation)

In Table 9, only the SEAs where an Index consultation was identified have been included. The darker dot indicates that the symptom appeared at any consultation in the year before emergency presentation while the lighter dot represents symptoms at the Index consultation, i.e. 'presenting symptoms' for this sample.

●Small number to the left is the number of cases where that symptom was mentioned in <u>any</u> of their consultations.
●Small number to the right is the number of cases where that symptom was mentioned in their <u>Index consultation</u> so is therefore the presenting symptom(s).

	Lung & other respiratory (32)	Gynae-cological (7)	Bowel (32)	Upper GI (36)	CUP & other (8)	Male genital (5)	Brain & CNS (6)	Breast (3)	Haemato-logical (10)	Urological (6)	Lip, oral cavity & pharynx (1)
Respiratory symptoms											
Cough	21 ● ● 11	2 ●	2 ● ● 2	5 ● ● 1	2 ● ● 1		1 ●	1 ●	5 ● ● 2	1 ●	
Dyspnoea, SOB	16 ● ● 7	2 ● ● 1	3 ● ● 1	7 ● ● 2					4 ● ● 2	1 ●	
Chest pain	6 ● ● 2		1 ●	4 ● ● 1	5 ● ● 3		1 ●		3 ●	1 ●	
Chesty, loose phlegm	10 ● ● 3				1 ●				2 ● ● 1		
Infection symptoms, URTI	3 ●	1 ●	2 ●	3 ● ● 1	1 ●				1 ● ● 1		
Wheezy	4 ● ● 2	1 ● ● 1			1 ●						
Pleural effusion	3 ●	1 ●			1 ●						
Tachycardia				1 ●	1 ●						
Heart attack symptoms	1 ●			1 ●							
Allergy, rhinitis			1 ●								
Haemoptysis	1 ●										
Low oxygen saturation				1 ●							
Other respiratory, chest symptoms	6 ● ● 3		4 ● ● 1	6 ● ● 1	2 ●					1 ●	
Gastro-intestinal symptoms											
Abdominal, iliac fossa pain	2 ● ● 1	4 ● ● 2	20 ● ● 11	18 ● ● 10	2 ●				1 ●	1 ●	
Weight loss	11 ● ● 5	1 ●	9 ● ● 3	16 ● ● 4	2 ●		2 ● ● 2		3 ● ● 2		
Loss of appetite	5 ● ● 3	2 ●	10 ● ● 3	13 ● ● 3	1 ●				2 ● ● 1		
Constipation, BNO	3 ● ● 1	2 ●	13 ● ● 6	7 ● ● 3					2 ● ● 1		
Vomiting	2 ● ● 1	1 ●	10 ● ● 2	10 ● ● 3	1 ●						
Diarrhoea	2 ●	1 ●	10 ● ● 4	4 ● ● 2	2 ● ● 1				2 ● ● 1	1 ●	
Nausea	1 ●	2 ● ● 1	4 ● ● 1	10 ● ● 3			2 ● ● 1		1 ●	1 ●	
Abdominal distention		2 ● ● 1	7 ● ● 1	9 ● ● 4					1 ●		
Reflux, heartburn	1 ●		4 ● ● 1	8 ● ● 4					1 ●		
Other weight comment	1 ● ● 1		3 ● ● 1	6 ● ● 3		1 ●					
Change in bowel habit	1 ●	1 ● ● 1	6 ● ● 3	1 ●			1 ●				

	Lung & other respiratory (32)	Gynae-cological (7)	Bowel (32)	Upper GI (36)	CUP & other (8)	Male genital (5)	Brain & CNS (6)	Breast (3)	Haemato-logical (10)	Urological (6)	Lip, oral cavity & pharynx (1)
Gastro-intestinal symptoms continued											
Rectal bleeding			7 ● ● 3	1 ● ● 1							
Jaundice				5 ● ● 3							
Dysphagia or regurgitation				4 ● ● 1							
Haema-temesis or GI bleed				4 ●							
Black stools			1 ●	2 ● ● 1	1 ●						
Wind		2 ● ● 1	1 ● ● 1	1 ● ● 1							
Haemorrhoids			3 ● ● 1						1 ● ● 1		
Obstruction			2 ●								
Burping			2 ●								
Anal pain									1 ●		
Other gastro-intestinal symptoms			3 ●	10 ● ● 7			1 ●		1 ●	1 ●	
CNS / neurological											
Lethargy, tiredness	5 ● ● 4	1 ●	8 ● ● 5	5 ●	1 ● ● 1		1 ● ● 1	1 ●	2 ● ● 2	1 ●	
Dizziness or light headed	6 ● ● 4		3 ●	2 ● ● 1			1 ● ● 1		2 ●		
Weakness (inc individual limbs)	5 ●	1 ● ● 1	1 ●	2 ●		1 ●	3 ● ● 1				
Falls or disturbed balance	6 ● ● 2		1 ●	2 ●			3 ● ● 1				
Headaches or migraines	5 ● ● 2						3 ● ● 2				
Confusion	3 ●			2 ●			1 ●				
Speech disturbance	4 ● ● 1			1 ●			1 ●				
Neuralgia (pain)	1 ●						2 ● ● 1	1 ●	2 ●		
Flushing, sweating, febrile	1 ●			1 ●	2 ● ● 2				1 ●		
Visual disturbance	3 ●						1 ●		1 ● ● 1		
Numbness	2 ● ● 2						1 ●		1 ●		
Facial disturbance	3 ●										
Collapse, loss of conscious.				2 ●							
Stroke symptoms	2 ●										
Hallucinations	1 ●			1 ●							
Immobility							1 ● ● 1				
Other CNS or neurological	6 ●		1 ●				2 ● ● 1				

	Lung & other respiratory (32)	Gynae-cological (7)	Bowel (32)	Upper GI (36)	CUP & other (8)	Male genital (5)	Brain & CNS (6)	Breast (3)	Haemato-logical (10)	Urological (6)	Lip, oral cavity & pharynx (1)
Urological symptoms											
Frequency or urgency of urination	2 ● ○ 1	1 ●		1 ●	1 ●	2 ● ○ 1				2 ● ○ 2	
Dark urine			1 ● ○ 1	5 ● ○ 3							
Haematuria			1 ● ○ 1			2 ● ○ 1				3 ● ○ 2	
Incontinence	2 ●		1 ●			1 ●	1 ●				
Nocturia			2 ● ○ 1	1 ●		1 ● ○ 1				1 ● ○ 1	
Dysuria	1 ●	1 ●			1 ●	1 ●					
Urinary retention, difficulty urinating	1 ●	1 ●	1 ●			1 ● ○ 1					
Offensive urine	1 ●									1 ●	
Other urological symptoms	3 ● ○ 1	3 ●	5 ●	2 ●	2 ● ○ 1	2 ●			1 ●	4 ● ○ 1	
Gynae-cological symptoms											
Dyspareunia		1 ● ○ 1									
Per vagina bleeding				1 ● ○ 1							
Menopausal symptoms		1 ● ○ 1									
Other gynae-cological symptoms		1 ● ○ 1									
General symptoms											
Back or joint pain	7 ● ○ 3	2 ●	4 ● ○ 2	10 ● ○ 5	1 ● ○ 1		2 ● ○ 1	2 ● ○ 1	4 ● ○ 3	4 ●	
General deterioration, unwell	4 ●	1 ●	1 ●	9 ● ○ 3	1 ● ○ 1			1 ●	1 ● ○ 1	1 ●	
Swelling, lump or mass	3 ●	1 ●	1 ●	3 ●	2 ●			1 ● ○ 1		2 ● ○ 1	1 ● ○ 1
Tearful, low mood, depression	2 ● ○ 1	2 ● ○ 1	2 ●	3 ●					3 ●		
Sleep problems	1 ●		1 ●	5 ● ○ 1			1 ●		1 ●	1 ●	
Limb pain			1 ●	2 ●	1 ●	1 ● ○ 1		1 ● ○ 1	2 ●	1 ●	
Anaemia	1 ●		2 ● ○ 1	3 ● ○ 1	1 ●						
Pale	1 ●		3 ● ○ 1	2 ●	1 ●						
Anxiety	2 ●		1 ●	1 ●				1 ●			
Itching, pruritus, rash			1 ●	2 ●					1 ●		
Diet	2 ●			2 ●							
Shivery, shaky	1 ● ○ 1								1 ●	1 ● ○ 1	
Oedema				2 ● ○ 1						1 ● ○ 1	
Abnormal bloods	1 ●								1 ●		
Dehydration or not drinking			1 ●	1 ●							

	Lung & other respiratory (32)	Gynae-cological (7)	Bowel (32)	Upper GI (36)	CUP & other (8)	Male genital (5)	Brain & CNS (6)	Breast (3)	Haemato-logical (10)	Urological (6)	Lip, oral cavity & pharynx (1)
General symptoms continued											
Varicose veins	1 ●				1 ●						
Sore throat				1 ●							1 ● ● 1
Difficulty weight bearing						1 ●					
Alcohol consumption				1 ● ● 1							
Agitated, irritable	1 ●										
Other general symptoms	14 ● ● 5	4 ● ● 1	4 ● ● 1	13 ● ● 3	5 ● ● 2	3 ●	1 ● ● 1	1 ●	8 ● ● 6	4 ● ● 2	

Any individual may present to the GP with symptoms that are unrelated to their cancer and could indicate a short term illness such as an upper respiratory tract infection or they may relate to longer standing illnesses. Many of the SEAs mentioned that the patient had an existing co-morbidity.

From the GP SEAs the most commonly mentioned co-morbidities were COPD, heart conditions, urinary tract infections and diabetes. Trusts routinely collect co-morbidity data; from their SEAs the most common co-morbidities were hypertension, COPD, diabetes and heart conditions. Only four of the 35 Trust SEAs did not record any co-morbidity for the patient.

Contributing factors to emergency presentation

Walter's Model of Pathways to Treatment (Walter, Webster et al. 2012) outlines three underlying contributing factors; patient factors, healthcare provider and system factors, and disease factors. Each SEA was read as a case study and assigned to the contributing factor of the tumour, the patient or the system. When more than one factor was felt to contribute then the SEA was assigned to the overlapping area as shown in the Venn diagram (Figure 5) and in Table 10.

As can be seen in Figure 5 and in Table 10 all seven areas had cases but they were not equally distributed. The GPs had been specifically asked to select cases that could provide learnings for the GP practice so there would be an expectation that cases which had any 'system' element would predominate.

Fifty-three SEAs (29%) were designated as having both the tumour and the system as the contributing factors leading to emergency presentation; 'system only' and 'tumour only' each had 43 SEAs, representing just under a quarter of the sample each (23.4%).

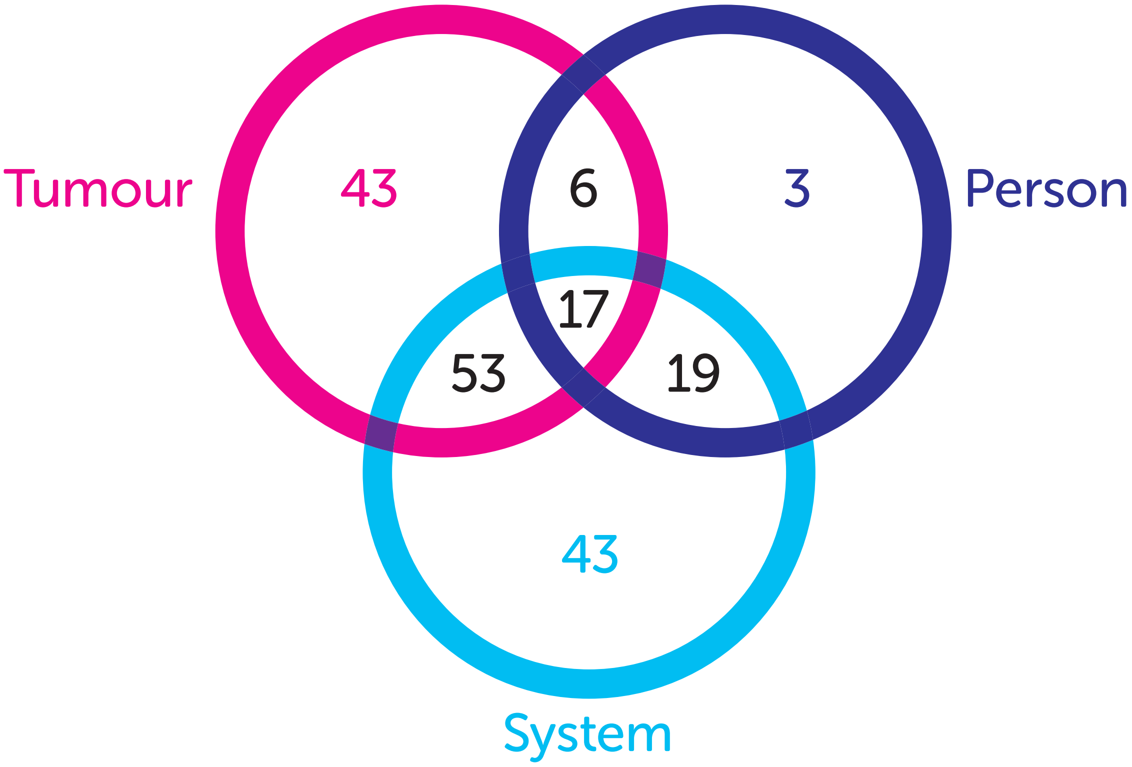
Around 10% of the sample were in the overlapping 'person and system' area, with a further 17 SEAs (9.2%) in the group where all factors were deemed to have contributed to the pathway to diagnosis. The smallest groups were 6 SEAs in the 'both person and tumour' group and 3 SEAs in the 'person only' group.

Overall a quarter of all SEAs identified person factors as having contributed in some way to diagnosis via an emergency presentation while tumour factors had a role in 65% of the SEAs, and the system played a part in 71% of the cases (see Table 10).

Table 10: Factors contributing to emergency presentation

Contributing Factor	Number of SEAs	Percentage of SEAs
Person only	3	1.6%
System only	43	23.4%
Tumour only	43	23.4%
Person and system	19	10.3%
Person and tumour	6	3.3%
Tumour and system	53	28.8%
Person, system and tumour	17	9.2%
Any person	45	24.5%
Any system	132	71.7%
Any tumour	119	64.7%

Figure 5: Distribution of GP SEAs by Contributing Factors (Tumour, Person, System)



There is some variation seen across the groups in terms of the distribution by sex and age with those categorised as 'system only' seeming to be more males and younger (see Table 11); females are more common in the 'system and tumour' and 'person and tumour' groups. The group with the oldest average age was the 'person and system' group.

There is a marked variation as to whether an index consultation was identifiable in the cases in the group or not, with the lowest proportion of identifiable index consultations being in the ‘tumour only’ group and the highest in the ‘system only’ group. There is also considerable variation regarding the status of the case with only 5.9% of the ‘person, system and tumour’ group being alive at the time of the SEA review while 37.2% of the ‘system only’ group were still alive.

The length of time between index consultation and emergency presentation is notable for the ‘tumour only’ group with an average of 13 days while all other groups have averages over 100 days, suggesting that perhaps aggressive tumour biology is recognised by the GPs and results in short times to emergency presentation. The groups ‘person only’ and ‘both tumour and person’ have been excluded from the table because of the small size of these groups.

Table 11: Contributing factor groups by selected study variables

Venn area	% Male	Average age	Median age	% with an Index consultation	% Alive at time of GP SEA	Average number of days Index to EP*	Median days Index to EP*
ALL	48.9%	68.6	71	79%	24.5%	142	64
System only (43 SEAs)	60.5%	63.1	66.5	97.7%	37.2%	213	139
Tumour only (43 SEAs)	48.8%	69.5	69.5	62.8%	20.9%	13	5
System and tumour (53 SEAs)	41.5%	68.8	72	77.4%	28.3%	115	60
Person and system (19 SEAs)	42.1%	76.7	79.5	90%	10.5%	231	119
Person and system and tumour (17 SEAs)	52.9%	70.9	75	64.7%	5.9%	177	66

*for those with an Index consultation

SUMMARY OF QUALITATIVE FINDINGS (FOR MORE DETAIL SEE APPENDIX D)

Tumour factors

Theme	Key findings
No symptoms	• Sometimes no symptoms related to the cancer were experienced. • Some cancers were found incidentally. • Many GPs recorded when a symptom was not present. • Some GPs expected that there would be a symptom present if patient had cancer.
Vague, atypical or non-red flag symptoms	• Several types of cancer were 'notorious' for having no or a typical symptoms and presenting 'late'. • Vague symptoms meant difficult to know which specialty to send the 2WW referral to.
Quick deterioration	• Sometimes symptoms became worse quickly, this should set alarm bells ringing. • A number of attendances in a short space of time could be 'considered as a red flag'
Symptoms suggesting an alternative diagnosis	• Often symptoms presented to the GP suggested an alternative diagnosis. • If person treated for the symptom and an improvement was seen this led to false reassurance. • Pain could often be explained by an earlier injury. • The cancer could be 'masked' by the alternative diagnosis. • On reflection more could have been done to question the working diagnosis. • GPs suggested in the SEAs that many primary care procedures were reasonable in light of the symptoms presented with.
Symptoms prompting referral to 'wrong' specialty	• Co-morbidities made it difficult to ascertain which symptom was attributable to the eventual cancer. • Symptoms sometimes prompted referral to 'wrong' specialty

Person factors

Theme	Key findings
Awareness of symptoms	• Interpretation of symptoms impacts person's behaviour. • Most people presented to primary care in the year before EP. • Bereavement can impact symptom interpretation.
Length of time symptoms experienced	• Length of time symptoms experienced before seeking medical advice generally varied from a few days to a few months. • Delay in presenting symptoms to primary care was not a major contributor to the emergency route to diagnosis.
Concealing / denying symptoms	• People who don't want to make a fuss sometimes minimised symptoms. • Some people may have ignored symptoms.
Difficulty giving a good medical history	• Some people found it difficult to provide a comprehensive medical history due to co-morbidities, such as mental health problems, Alzheimer's and alcohol abuse. • Problems could arise when the translator was a relative.
Declining medical advice / reluctance to be tested	• Some people did not take responsibility for their own health. • GPs felt that in some circumstances it was important to consider the person's wishes. • There were a group of people who were not keen on hospital attendance or investigations. • Alternative tests should be considered when people are reluctant to undergo specific tests.
Reluctance to come to the GP surgery	• Some people were 'infrequent' attendees, or missed screening appointments. • Reasons for reluctance to attend the surgery included no clear medical need and people finding GP visits stressful.
Failing to attend appointments	• Missed appointments may be due to person's poor health.
Slow to re-present or go for investigation	• Some people will wait for an appointment with their preferred GP. • Some people did not appreciate the seriousness of their condition. • People can be falsely reassured after a normal test result.
Difficulty accessing primary care – physical barriers and communication barriers	• Some people had home visits as they could not attend the GP practice. • When people moved surgeries it could take up to 6 weeks to obtain their medical records. • Communication barriers included language differences and mental health problems.

System and healthcare professional factors – Primary care - During the consultation

Theme	Key findings
Communication with the patient	• Generally communication between the GP practice and the patient was good. • Communication barriers included language problems, mental health problems, issues with memory impairment and reluctance of the patient to engage. • GP had to rely on inaccurate information in some cases. • Communication with the patient extended to communication with the family • Important aspect of care especially with end of life planning.
Taking medical histories	• Challenges include communication problems, memory issues, mental health problems, reluctance to engage with primary care and restriction of consultation time available • Ability to review previous history during a home visit was limited. • Important to review previous consultations and results for the context of the medical history.
Examinations in primary care	• Often correct examinations were performed and recorded. • Certain examinations were sometimes not performed or not recorded. • General opinion was to always examine the patient and note in the medical record. • Normal examination could lead to false reassurance.
Referrals	• Referral to 'wrong specialty' can lead to patient being discharged back to primary care. • Sometimes multi specialty referral led to lack of ownership of the patient. • Sometimes unclear which specialty to refer to, due to the non-specific nature of the symptoms and trying to follow the guideline criteria. • Back pain was a difficult symptom to decide whether to refer for investigation or not. • Referral made was sometimes inappropriate based on symptoms recorded. • Opportunity for earlier or speedier referral had been missed in some cases. • Some patients refused referral while others self-referred to A&E. • Local targets may have influenced referral patterns.

System and healthcare professional factors – Primary care - During the consultation continued

Theme	Key findings
Safety-netting and documenting in the medical record	•On occasion good safety-netting had been used well or appropriately. •Safety-netting was more challenging when main contact was carer or family member. •Safety-netting sometimes identified as being poor or absent may have contributed to the patient being slow to return to the GP if a symptom continued or worsened. •Some cases with no record of an examination being performed or no working diagnosis led to difficulties making future comparisons and following the patient's narrative. •Occasionally safety-netting recorded but not followed up by the next doctor the patient saw. •Follow up was a key factor; following up results or ensuring that the patient returned for a follow up visit.
Re-assessing working diagnosis	• Some cases with hindsight would have had the same route and outcome. • 'Nondescript worry' should be considered a clinical sign. • Cancer diagnosis masked by other conditions. • Missing the importance of weight loss as a symptom could impact on the working diagnosis. • Minimal contact with the patient made re-assessing the working diagnosis challenging. • Sometimes lack of key symptom meant working diagnosis not re-assessed. • More education needed re current NICE guidelines. • Much overlap in symptoms and signs of some cancers.

Primary care – processes in the practice

Theme	Key findings
Responsibility for the patient	• Some positive comments about the care that GP practices took of patients during the time leading up to diagnosis. • Sometimes a lack of 'ownership' and responsibility towards the patient. • Home visits sometimes rushed and consulting GP only has a summary output of the medical notes. • Potential conflict in terms of person's wishes and best medical care.
Lack of vigilance for high risk groups	• Groups identified as high risk included those with extensive co-morbidities, previous cancer diagnoses, mental health problems, alcohol issues, infrequent attendees and those reluctant to engage, those with high BMI and the elderly. • Communication issues with patients recognised as potentially increasing the risk of a delayed cancer diagnosis. • Some groups, such as smokers, were 'high risk' patients but not always considered as such during their consultations.
Continuity of care	• Continuity of care desirable but sometimes difficult to achieve. • Continuity of care threatened when patient changed practices. • Good record keeping and documentation meant continuity of care was less of an issue.
Communication within the practice	• Communication within the practice includes the role of administrative staff, record keeping and GPs discussing cases with each other. • Not always clear if the examination had not been performed or it had not been recorded. • Other health professionals were seen in the primary care setting during the time leading up to diagnosis and needed to be communicated with. • Discharge summaries from the Out of Hours service sometimes needed better follow up.

Diagnostic tests

Theme	Key findings
Availability of the test	• Not all GPs can send their patients for all the tests that they may want to have undertaken. • Some GPs do not want more access to tests. • Many cancers were diagnosed through CT scans but not all GPs could access these and some cancers were not identifiable on CT scans. • GPs suggested alternative ways of accessing specific tests; eg sending the patient to physiotherapy may enable access to MRI.
Appropriateness / adequacy of the test	• The test requested has to fit the person's symptoms or be prompted by lifestyle factors, i.e. a chest x-ray for a smoker. • The appropriateness of specific tests such as the PSA and CA125 were questioned.
Receiving results	• Who received and filed the test results impacted on appropriate action being taken. • The patient was informed about test results in various ways, including by phone, by letter and at the next consultation.
Timing of the test	• GPs questioned how long a wait was acceptable for certain tests to be undertaken. • Some GPs commented that appointments for some tests in secondary care took too long.
Interpretation of results	• On occasions there had been false reassurance of a normal test result. • Normal results should prompt further action when symptoms remain unexplained rather than simply filing as 'normal, no action'. • Even normal results may show a change over time which should be noted. • Abnormal results could lead to diagnosis of another condition, which could mask the cancer. • It was important to provide detailed information from the medical history and the suspected diagnosis when a test was requested or discussed with secondary care. • Abnormal results should always prompt an action.

Secondary care

Theme	Key findings
Responsibility	• Issues of responsibility were present when the patient moved between primary and secondary care. • Confusion over who was responsible for patient with regards to safety netting/chasing results once a patient had been referred to secondary care. • Discharge back to primary care – questions over how responsibility was handed back to the GP. • A&E did not always provide an action plan to GPs. • GPs perceived varying levels of care provided by secondary care. • On occasion it was appropriate for primary and secondary care to share the responsibility for the patient. An example of this was when a patient was under the care of a consultant for one condition but the GP was issuing antibiotics for other reasons. On this occasion the responsibility was felt to be shared. In another case, when blood tests had been performed in A&E they were not followed up. On reflection it was felt that this should have been the responsibility of both the GP and A&E.
Communication	• There are examples of good and poor communication between primary and secondary care. • There should be promotion of the usefulness of seeking advice from secondary care. • When patient is referred as much information as possible should be provided by the GP. • Secondary care should provide as much information as is appropriate when discharging the patient or providing test results. • Recording of information across the primary-secondary interface (including the private sector) can be problematic. Reports of missing information, or information not received in a timely manner. • From the GP's perspective the patient should be told of their cancer diagnosis in secondary care.
Complexity of presentation – taking a holistic approach	• Re-assessing the working diagnosis was also relevant in secondary care and out of hours when the presentation was complex.
Referrals / pathways in secondary care	• Multiple referrals to different secondary care specialties can lead to unclear patient responsibility and delay. • A&E not always acting thoroughly on abnormal results. • Speed of referral can be delayed (e.g. due to choose and book issues, or 2WWs being 'bounced back') • Some GPs rely on gut instinct that something is wrong to push for referral.

The role of guidelines

Theme	Key findings
Symptoms not meeting criteria	• Symptoms don't always meet requirements for 2WW referral, but warrant timely investigation. • Some patients were admitted to A&E whilst waiting for a 2WW appointment. • Sometimes symptoms fulfil criteria for the 'wrong' specialty. • Some GPs 'found ways around the system'. • Guidelines can sometimes be unhelpful and irrelevant. • There can be missed opportunities for referral under 2WW.
Awareness of criteria	• Some GPs lacked awareness of criteria for some 2WW referrals. • Occasionally there were differences between NICE guidelines and local guidelines.
Cancers without guidelines	• No guidelines available for some cancers (e.g. multiple myeloma).
Interpretation of criteria	• Lack of clarity around interpretation of guidelines. • Clinical decision support tools were used to aid referral decisions but occasionally identified patient as only at low risk.

Trust SEAs

Theme	Key findings
Investigations	• The audit found that there were cases where both primary care and secondary care had seen the patient in the year before the EP and as a result had ordered tests and investigations. Analysis of this information found variation of the number of investigations occurring before and after EP. Some tests before EP should have happened sooner. • Some pre-EP test results should have prompted further investigation. • Generally timing of tests after EP was appropriate. • Delays in testing either due to capacity issues or patient's poor health. • On a few occasions the test after EP was considered inappropriate. • Some cancers were found incidentally while testing for another condition.
Responsibility for the patient	• The issue of responsibility mainly occurred when the patient moved between primary and secondary care. • Generally, Trusts considered team working in secondary care was very good. • The Acute Oncology Service, Advanced Nurse Practitioners and Clinical Nurse Specialists all played important roles in taking responsibility for the patient. • Pre-diagnostic phase was an important time to be clear about who had responsibility for the patient. • Comparison of matched GP and Trust SEAs showed discrepancies in information held and the perceived responsibility. • Shared responsibility between primary and secondary care would have benefitted some patients. • Responsibility in the community post treatment should also be considered.

Trust SEAs continued

Theme	Key findings
Communication	• Communication with the patient was particularly important during the pre-diagnostic phase. • Not all patients had a date for when they were informed of their cancer diagnosis. • There were barriers to communication such as language differences and social issues. • Examples of both good and poor communication with the patient's GP practice. • Perceptions of communication between primary and secondary care did not always coincide between the matching GP and Trust SEAs. • Both GPs and Trusts felt written and verbal communication needed improving between primary and secondary care. • Within secondary care there were occasions where the medical record could not be found. • Previous test results from the same hospital, other hospitals and the private sector were not always available.
Complexity of symptoms – taking a holistic approach	• Opportunities for re-assessing the working diagnosis exist in both primary and secondary care. • After EP when symptoms suggested cancer then the pathway was appropriate. • When cancer was 'masked' by other conditions delays could occur.
Pathways	• Many patients had previous secondary care contact before the EP so there were some potential opportunities for earlier diagnosis. • Generally a clear pathway existed from EP to diagnosis. • Delays on the pathway included capacity to perform a test, delay in receiving results, patient's frailty, MDT issues and patient's co-morbidities. • Most patients had contact with oncology but this was not always timely. • Most patients received palliative care.

DISCUSSION

Using SEAs for audit purposes

Significant Event Audits are routinely used within primary care to reflect on an event, learn from the experience and undertake changes within the practice to improve patient care. More recently SEAs have been used for research purposes or as an audit tool as has been done in this study. The use of SEAs allowed the detailed analysis of people who had been diagnosed with cancer through an emergency presentation. This has explored the pre-diagnostic part of the cancer journey in primary care through both the events which took place and the reflections of GPs and other staff within the practice. GPs have identified both learnings and actions from the cases which they performed an SEA on, leading to recommendations for action plans by the project team.

Study limitations

There are potential limitations with the study as the group of cases submitted are potentially a non-representative group and so caution should be taken when considering generalisability of the findings. The SEAs covered many different cancer sites with lung, colorectal and pancreatic cancer making up over half the cases, this may have biased the findings to the experiences of people with those particular cancers. It may also be that the GP practices that agreed to take part are those who are more engaged with research and interested in cancer and so may exhibit best practice rather than average practice.

Summary of the cancer journey

The sample participants were a diverse group of people in terms of age, cancer site and cancer journey experience with not just one pattern emerging. The range of symptoms experienced was varied with vague and atypical symptoms presented by some and red flag symptoms presented by others; a small group had no symptoms at all before either the cancer was found incidentally or a major symptom prompted the emergency presentation. The majority of the cases had had a primary care consultation before the emergency presentation leading to the cancer diagnosis. The most common type of consultation was a face to face consultation with the GP at the GP surgery but contact was also made between the GP practice and the patient by phone, email, letter and home visit. The patient was also recorded as seeing other non-GP health professionals from the GP practice such as practice nurses and district nurses.

Blood tests stood out as the most common investigation made for this sample followed by chest x-rays. Examples of other investigative tests ordered included; ultrasound, MRI, sigmoidoscopy, urine tests and other (non-chest) x-rays. The results of the tests showed that the patients received both normal and abnormal results. The patients were informed of the results by a variety of methods such as by letter, by phone or at another appointment either planned or opportunistic. The patient was often advised to return or planned follow up was arranged; from the medical record it was not always clear if another appointment was booked at the time of the consultation.

Many of the patients in the sample had been referred before their emergency presentation; the referral appointment did not always take place if the emergency route happened very quickly after the initial referral was made. Referral destinations included other health professionals within the practice as well as outside the practice, such as physiotherapists and mental health centres, also there were referrals to A&E (other than the time leading to diagnosis), gastroenterology, chest clinic, urology, gynaecology or other secondary care departments. Some of these referrals were two week wait referrals while some were recorded as urgent or routine. There was usually some information provided regarding the outcome of the referral appointment, which could have been that nothing was found or that further investigation was needed.

During the time leading up to diagnosis the patient had contact with health professionals outside primary care including out of hours, in- and out-patient appointments as well as some patients choosing to make private appointments. The GPs also sometimes contacted other health professionals about the condition and care of their patient; this included others within the GP practice, radiologists, physiotherapists and consultants in secondary care.

From the Trust SEAs sample it can be seen that a similar proportion had an emergency presentation through an emergency GP referral route as self presented to A&E. The cases which were considered to be urgent GP referrals had two main places of presentation in secondary care – A&E or the Acute / Emergency Medical Unit. The time to diagnosis following the emergency presentation was a median of 11 days. A variety of investigations took place before diagnosis with CT scans and biopsies being the most common to confirm cancer. In most, but not all, of the Trust SEAs a date was provided for when the patient was told of the diagnosis. From the GP SEAs it was also found that not all the patients had been informed in the secondary care setting of their cancer diagnosis.

From the Trust SEAs details were provided of the many different teams involved after the emergency presentation. Not all cases had had contact with the oncology service but for those that did this happened with a median of 12 days after emergency presentation; there was a similar length of time for the patient to be discussed at an appropriate MDT meeting. In both the GP and the Trust samples most cases received palliative care rather than treatment with curative intent; this was usually due to the advanced stage of disease at the time of diagnosis. From the Trust SEAs where dates were available the median length of time between emergency presentation and treatment starting (whether curative or palliative) was 23 days.

Underlying factors

This SEA analysis shows that routes to diagnosis can be influenced by many mechanisms; either contributing in isolation or in combination. The main three factors identified are tumour factors, person factors and system & healthcare professional factors. System factors are further broken down into what happens during the consultation, procedures within the practice, secondary care and finally the wider cancer community, i.e. the Clinical Commissioning Group or NICE. Diagnostics were considered to be impacted by all three factors (see figure 1).

For this study a case analysis was undertaken which placed each SEA into one of seven groups dependent on the GPs reflections as to why the person's route to diagnosis was an emergency presentation (see figure 5). The seven groups were based on the identified factors;

- tumour only;
- person only;
- system only;
- combination of tumour and person;
- combination of system and person;
- combination of tumour and system;
- combination of all three factors (tumour, person and system).

SEAs were placed into all seven groups but were not distributed evenly. Within this sample the factors of tumour and system seemed to be more impactful than the person factors. On one level this was understandable as the GPs had been asked to select cases that were particularly able to produce learnings so there would be an expectation that cases which had any 'system' element would predominate. However, in this sample there were an equal number of cases which were 'any system' and 'any tumour' factor, with the largest group being the one where the case was an emergency presentation due to a combination of system and tumour factors. This would indicate that tumour factors play an important role in determining the emergency presentation route to diagnosis, perhaps more so than in other routes to diagnosis.

Within each factor there were many elements apparent but none were notable as being the main cause that could describe a large part of the sample. Detailed inspection of the SEAs showed that there were many possible causes which acted either independently or in combination with other mechanisms to lead to an emergency presentation. This emphasises the complex nature of cancer presentation and how something can go 'wrong' in so many parts of the journey and how the route to diagnosis can be dependent on so many different mechanisms.

The GPs were asked in the SEA to reflect on what happened and in many cases the sentiment was that the diagnosis could not have happened earlier or through another route due to the nature of the symptoms (or lack of) that were presented to primary care. There were then some SEAs where upon reflection it was felt that diagnosis could have happened sooner, usually only a few days or a week, but that this would not have had any impact on prognosis but it may have had some impact on the patient's experience at the end of their life by avoiding the trauma and stress associated with an emergency presentation, and allowing time for the development of an end of life plan. There was also a group of SEAs where it was acknowledged that the diagnosis could have happened sooner and through a different route and that this may have had an impact on prognosis.

Potentially unavoidable emergency presentations

Some GPs acknowledged that even with the benefit of hindsight they would not have been able to act sooner and have an earlier diagnosis for the patient. The swiftness of the cancer journey was commented on by a few GPs. For those people where the cancer diagnosis was described as incidental it was usually also considered to not have been possible to bring forward the date of diagnosis. For cases where the diagnosis was made through an emergency route but from an inpatient starting point there was also not felt to be anything which primary care doctors could have done to make the diagnosis happen quicker. The GPs often described how the cancer diagnosed with was notorious for not having any symptoms until late stage disease.

Earlier diagnosis possible but no impact on prognosis

The possibility of earlier diagnosis with no corresponding improvement in outcome was mentioned on a few occasions. Often the amount of time which could have been saved was a matter of days or only a few weeks which was considered not to have had clinical significance. Sometimes the GPs commented in the SEAs that the person was already very ill by the time of their diagnosis; this may have been due to the cancer or other co-morbidities.

The cancer's aggressiveness was often commented on in the context of there being little likelihood to impact on prognosis. Despite there not having been any chance of an improved outcome there was still a strong feeling amongst GPs completing the SEAs that it was desirable to avoid emergency presentation and that there could have been improvements in the quality at the end of someone's life if their diagnosis had happened through a different route. It was not always clear from the SEAs whether the person died in their preferred place but it seemed that when a plan was in place then the person "died peacefully at home" (F, 90, CUP).

Earlier diagnosis possible

For the cases where it was considered that earlier diagnosis could have been possible the factor or factors were usually given. When the factor was solely the tumour there was generally little option for an earlier diagnosis. However, GPs often took the opportunity in these cases to discuss what their practice could do in the future regarding prevention measures such as smoking cessation advice or addressing lifestyle behaviours, as well as considering what could be done in terms of early diagnosis through encouraging uptake of screening invitations.

Patient factors

The patients involved in these cases did not take part in the audit. Any discussion was based on what the GPs proposed might be explaining certain behaviour. However, much research has been done into the issues surrounding seeking medical advice (Smith, Pope et al. 2005; Whitaker, Macleod et al. 2015) which generally supports the GPs' views. When the late diagnosis was attributed to the patient it was for one of several reasons. It may have been that the patient was unaware of the symptom, either because they did not realise the potential seriousness of the symptom or the symptom was masked by their other co-morbidities. How the patient then behaved once they had recognised that there was a symptom may have been to deny or conceal the symptoms. The reasons for this could be many fold, such as fear of finding out that something was wrong or reluctance to undergo invasive investigations. It was acknowledged that co-morbidities such as mental health problems and dementia make it difficult for some patients to recognise symptoms and seek appropriate healthcare advice.

The speed at which the patient responded to getting investigations done was commented on by some GPs as they questioned whether the person had appreciated the seriousness of the situation. Some patients were described as not wanting to have any investigations done while some seemed to only object to certain investigations. The adverse impact of false reassurance was mentioned with regards to patients as well as GPs; it was highlighted that there had been possible missed opportunities for earlier diagnosis if a patient was slow to re-present to primary care after being investigated previously and having had a negative test result. The investigations included blood tests and chest x-rays but also screening tests, as well as being referred to secondary care and then discharged with no explanation having been found for the symptoms experienced. On occasions it was the alternative diagnosis and treatment for that condition, that may have led to the false reassurance for the patient and the GP. This finding is similar to research by Renzi and colleagues who found that a previous non cancer diagnosis led to false reassurance and delays in help seeking when symptoms persisted or new symptoms appeared (Renzi, Whitaker et al. 2016).

When the factor was to do with the patient there was a limit to the impact which GPs could have within primary care to address these but there were some measures which could be taken. GP practices could support cancer awareness measures by health professionals discussing these with patients when they attend the practice for any reason and by providing written literature and perhaps videos in the waiting areas. There may be opportunities when someone is denying a symptom such as weight loss to weigh the patient and record this in the medical record. Patients who have difficulties providing good medical histories could be asked to attend with carers or be allowed to have longer consultations. If someone is reluctant to undergo testing then alternatives should be considered and a better understanding sought as to why the patient is avoiding the test. It is the GP’s responsibility to appropriately communicate to the patient the urgency with which a test should be performed and how important it is for them to attend an appointment. Effective safety-netting within the GP practice can be used to avoid false reassurance of negative test results rather than relying on the patient to have to go back to the GP on their own accord.

System factors – GP practice – during the consultation

There were many elements during the consultation which were highlighted by GPs as being relevant to affect the time leading up to diagnosis, these were; taking medical histories, undertaking examinations, ordering investigations, referring the patient on to others, safety-netting, communication with the patient and family, and opportunities to reassess the working diagnosis.

The impact of what happened during the consultation was a focus of many of the SEAs. Often there were considered to be opportunities for earlier diagnosis if the symptoms had been responded to with more of a sense of urgency by the GPs involved in the patient’s care. Being able to take a good medical history was considered important and if the patient was described as a poor historian this was often implied to have led to a delay in diagnosis as the GP did not have enough clinical information to make accurate clinical decisions. The examinations performed and documented were commented on by the GPs, with occasionally an examination, such as a rectal examination, not being performed considered to be a missed opportunity to realise that something was wrong and refer appropriately. Lack of regular weight taking for patients who were attending often was put forward as a missed opportunity to spot weight loss and refer for further investigation.

There were instances where the GPs stated that a two week wait referral should have taken place earlier. On occasion the patient had been referred via the two week wait pathway but it was to the inappropriate specialty as the symptoms determined where to refer to; this would have delayed the diagnosis as the patient was given the 'all clear' from one specialty and then discharged back to primary care with symptoms which were still being experienced. The speed of the referral was commented on in some SEAs where it was felt that a routine referral should have been a two week wait referral and would therefore have led to a speedier diagnosis. In other cases no referral had been made before the emergency presentation and it was noted by the reviewing GPs that a referral should have happened based on the symptoms presented and sometimes test results received.

The importance of safety-netting was described in many SEAs by GPs where it was believed that the lack of safety-netting led to a delayed diagnosis. In some SEAs comments were made about record-keeping and that if this was insufficient and the patient's narrative was difficult to follow then this could have been the reason for delay as inappropriate clinical decisions were made by the GPs who were consulted. Taking a holistic approach was felt to have been missing on several occasions with often people being investigated or treated for individual symptoms as they presented. Taking the patient's co-morbidities into consideration, but not assuming that the new symptoms were due to these, was expressed on a couple of occasions as being a reason for the diagnosis not happening earlier. On some occasions it was the initial 'working diagnosis' that was focussed on meaning that the consideration of an underlying malignancy was missed.

There are many elements during the consultation between the patient and the GP that could impact the route to diagnosis. All of these can be addressed through influencing GP behaviours in primary care. The quality of taking medical histories and the frequency of performing examinations could be audited within individual practices. GP education is important to be able to stay familiar with the latest guidelines regarding referral and ordering of investigations and the GP should be able to discuss difficult cases with colleagues. The frequency of safety-netting and the quality of recording information on the medical record should be monitored within the practice to ensure that it is of a high enough standard. The way in which the patient and their family are communicated with could be observed by having GPs shadow other GPs on occasion although this may be very difficult to do. Opportunities to reassess the working diagnosis of difficult cases should be made possible both during and outside of the consultation.

System factors – GP practice – processes within the practice

The impact of the processes within the practice on the speed and route to diagnosis was multi-faceted. This included the sense of responsibility that GPs had for their patients, the level of vigilance which was apparent for vulnerable people with consideration being given to the patient's co-morbidities and lifestyle behaviours, how many different health professionals were seen regarding the same symptoms and the quality of the communication within the practice both verbally and in writing.

Many patients diagnosed through an emergency route were identified through the SEAs as being at high risk of cancer. This was either through their lifestyle behaviours such as smoking or the way in which they engaged with medical care, with, for example, some patients on prescribed repeat medication going for long periods without being seen in the practice. Lack of continuity of care when the person saw many different health professionals was cited on a few occasions as being the reason for the route of the diagnosis. The GPs in the SEAs outlined how if there had been more opportunities to discuss a difficult case with colleagues then an appropriate investigation or a speedier referral may have taken place.

Many of the elements to do with processes within the GP practice can be addressed through influencing the leadership team within primary care settings. Identifying people who are at high risk and ensuring that they are seen often enough within the practice and if possible are perhaps highlighted on the medical record may be helpful. Some practices in the audit had highlighted how they had moved to a list system where people had named doctors and appointments were made to ensure that the named doctor was seen at least once in every three consultations. Meetings took place in all GP practices but some described how they had a number of opportunities to discuss difficult cases, including coffee break sessions, specific meetings about cancer cases and agenda slots on regular meetings to discuss patients where the consulting GP was unsure of the appropriate action to take.

System factors - diagnostics

There were several elements to the impact of investigative tests on the route to diagnosis. There was the availability and appropriateness of the test, the timing of the test, who received the results and how these results were interpreted. The availability and appropriateness of certain tests and how this impacted the route to diagnosis was one of the few areas in the study where there were mixed points of view from the GPs completing the SEAs. There were a few occasions where the GPs explicitly stated that access to certain diagnostics would have led to a speedier diagnosis through a different referral pathway. CT / MRI scans were mentioned particularly, but some GPs said that they would not want access to these scans as they believed that it could delay the process as the results were awaited and it would be better sometimes to refer via two week wait to the specialists in the secondary care system so that the investigations were both performed and interpreted in secondary care. There also seemed to be varying opinions as to tests such as the PSA test for prostate cancer and the CA125 marker for ovarian cancer, with some GPs favouring those tests while others were more cautious over their use. The GPs often had little control over when a test took place but the timing of the test and speed of receiving the result was considered relevant in some cases and was felt was influential in the presentation being an emergency one.

The impact of the response to the test result was often dependent on who received the results. There were several occasions where a GP other than the requesting GP had received the results and then they had not been acted upon appropriately, thus missing the opportunity for earlier diagnosis. This issue was tied in with continuity of care as well as documenting in the patient's medical record the 'working diagnosis' and the reason for requesting the investigation. It was noted that sometimes a 'normal' result did require further action and this was easily missed if someone else was filing the results and the medical record was either not consulted or did not give enough detail to allow the physician looking at the results to make the best clinical decision. In addition some SEAs commented on the fact that there was no record that the results had been communicated to the patient or that they had been discussed.

How the GP responded to test results was one of the more common themes that impacted on the speed and route to diagnosis. There were potential issues with both normal and abnormal test results; a normal result could lead to false reassurance and no further action being taken while an abnormal result could imply an alternative diagnosis so the opportunity to diagnose the cancer sooner was missed until the symptoms worsened, new symptoms presented or the treatment for the initial diagnosis was found to be ineffective. On several occasions when reflecting on the sequence of events leading up to diagnosis the GPs commented on there being outstanding positive test results or symptoms which had not been explained and there was a sense that more thorough investigations should have continued or a referral should have been made as the problem had not been resolved in primary care.

There is some opportunity to address issues surrounding diagnostic testing within the primary care setting. The practice should have established protocols as to when tests are performed and if it is felt that a test should be available which is currently not this should be discussed with the local CCG. Practices can implement a system whereby the test result is received by the requesting doctor or there is sufficient detail in the medical record explaining why the test is being performed and actions depending on outcomes so that the doctor looking at the results can make the best clinical decisions. Further details on actions related to diagnostic testing can be found in appendix E the Primary and Secondary Care Interface Action Plan.

System factors – secondary care

In this study it has been possible to analyse the impact of secondary care from both the perspective of the GPs and the perspective of clinicians within secondary care. Apart from diagnostics there were four other main elements to the secondary care part of the system factor these were: taking responsibility for the patient both in secondary care and during the time the patient moves between primary and secondary care; communication between secondary and primary care as well as communication within secondary care; the opportunity to re-assess the working diagnosis and consider the patient holistically; and the referrals and pathways taken in secondary care.

In some SEAs it was the actions taken in secondary care which were highlighted as the reasons for missed opportunities to diagnose sooner. This was especially the case when the patient attended appointments in secondary care but was then discharged without a conclusive test result or diagnosis. Often in these cases the GPs felt that responsibility should have remained within secondary care. There was also indication within some of the SEAs that on occasion secondary care had not taken the patient's condition as seriously as they should have done, and there was a lack of a sense of urgency to investigate and take ownership of the patient.

Communication was a key theme from both the Trust and the GP SEAs with the recognition that at times communication was poor in terms of both verbal and written communications, especially discharge summaries. It was acknowledged that there was much room for improvement in the levels of communication between primary and secondary care. The breakdowns in communication demonstrated could have led to the cancer diagnosis being an emergency one. The issue of re-assessing the working diagnosis was mentioned in both the Trust and GP SEAs as it was something relevant to both.
In terms of the pathways, in secondary care the SEAs sometimes indicated that there were

insufficient investigations undertaken based on the symptoms which the patient had. In one SEA it was the 'choose and book' system which was believed to have caused the delay as it was felt to be 'not fit for purpose'. There were a few instances where the GPs commented that there were delays in secondary care for the patient to receive an appointment for an investigation or a referral, and this was believed to have led to a diagnosis later than it could have been. In one case the hospital downgraded the two week wait referral and this was not challenged by the requesting GP; this was cited as being the reason for the delayed diagnosis. In another case it was 'unhelpful' advice from the medical registrar which was considered to have delayed the referral and urgent investigations

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Primary care practitioners can have some impact on what is happening in secondary care if they keep in close contact with the patient to ensure that the appointments are received and attended. It was also recommended that the GP when requesting tests or referrals gives as much information as is possible regarding the patient's condition and includes their working or suspected diagnosis. Education was put forward as the best way to ensure that all doctors (primary and secondary care) were aware of the possible presentations of cancer. GPs should challenge any request for a 2WW to be downgraded. Appendix E, the Primary and Secondary care Interface Action Plan provides more details on actions which can be taken within primary care and beyond to impact on the cancer journey within secondary care.

System factors – the wider community

The wider cancer community includes for example CCGs and NICE who formulate the guidelines for cancer investigations and referrals. The role of guidelines and targets being set for referrals could impact on the timing of the diagnosis. One particular practice stated that their referrals were being monitored by their local CCG and as they were over their target there may have been "an attempt to do in-house investigations in order to avoid a referral" which would have led to a missed opportunity for earlier diagnosis. There were several elements under the role of guidelines which included symptoms not always meeting the criteria, the level of awareness of the guidelines by the GP, some cancers not being represented by guidelines and the difficulty in interpreting some of the criteria.

Referral guidelines were often identified as possibly slowing the speed of diagnosis as the GP was often unable to refer if the criteria for a two week wait referral were not met. This was despite the GP having clinical concerns about their patient. This meant often the route to diagnosis became an emergency one because of the sudden deterioration in the patient's health. However, during the SEA process it was found that some GPs had been mistaken about some aspect of the guideline and the person did in fact qualify as a 2WW. Some SEAs pointed out that for selected cancer types such as multiple myeloma there were no guidelines at the time the patient was being investigated, and for other cancers there was no guidance available if the person was under a certain age. There was discussion in some SEAs how the guidelines were open to interpretation and the correct decision was not always clear which led to potential delays.

GPs are not able to re-write the guidelines but they should be aware of both the national and local guidelines; practice protocols and education sessions can be put in place to aid decision making when the criteria are not clear. Many GPs in the audit described how they found ways to refer patients on the 2WW path even if their symptoms did not meet all the criteria or they referred in order to have an investigation performed which they could not directly request.

CONCLUSION

Not all emergency presentations of cancer be prevented; cases have been identified in this audit where it may have been possible to establish diagnosis earlier. Earlier diagnosis of cancer and avoidance of emergency presentation could contribute to a less traumatic experience for the patient and their family, even in cases where the overall prognosis is poor.

This work has shown that an emergency presentation can happen due to many diverse reasons. Within Thames Valley further work will be undertaken to address the themes identified as contributing to the diagnosis of cancer following an emergency presentation.

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GLOSSARY OF TERMS AND ABBREVIATIONS

2WW / 2WR:	two week wait / two week rule
A&E:	accident and emergency
ANP:	advanced nurse practitioner
AOS:	acute oncology service
BMI:	body mass index
BNO:	bowel not opening
CA125:	cancer antigen 125
CCG:	clinical commissioning group
Choose and book:	system by which hospital appointments can be booked online
CNS (tumour):	central nervous system
CNS (practitioner):	clinical nurse specialist
COPD:	chronic obstructive pulmonary disease
CT scan:	computed tomography scan
CUP:	cancer of unknown primary
DVT:	deep vein thrombosis
ECG:	electrocardiogram
ESR:	erythrocyte sedimentation rate
ETOH:	ethyl alcohol
EP:	emergency presentation
Index consultation:	an index consultation was defined as the consultation where a first sign or symptom of the future diagnosed cancer has been presented to the GP practice
FTE:	full time equivalent
f/u:	follow up
IHD:	ischaemic heart disease
LFT:	liver function tests
MDT/MDM:	multi disciplinary team / multi disciplinary meeting
MRI:	magnetic resonance imaging
NICE:	National Institute for Health and Clinical Excellence
NHL:	non-Hodgkin lymphoma
OGD:	oesophago-gastro duodenoscopy
OOH:	out of hours service
QOF:	Quality Outcome Framework
RCGP:	Royal College for General Practitioners
PET scan:	positron emission tomography scan
PPI:	proton pump inhibitor
PR:	per rectum
Problem titles:	the READ code used on the medical record during the consultation to identify the patient's presenting problem
PSA:	prostate specific antigen
READ:	The Read Clinical Classification system which allows clinical information to be coded and stored in computer systems
SOB:	shortness of breath
SEA:	significant event audits / analysis
SVC:	superior vena cava
TIA:	transient ischemic attack
TVSCN:	Thames Valley Strategic Clinical Network
Upper GI:	upper gastrointestinal cancers including oesophagus, stomach, pancreas, liver and other biliary tract cancers (ICD10 C15-C17, C22-C26)
URTI:	upper respiratory tract infection
USS:	ultrasound scan

APPENDIX A

CANCER SEA – GPs

Significant Event Audit (SEA) of Cancer Diagnosis

Cancer SEA Report Template

Audit of patient diagnosed with cancer following emergency admission

1 template per patient

Please complete electronically and return to your CRUK facilitator

SIGNIFICANT EVENT AUDIT OF CANCER DIAGNOSIS

Advice on completing the template

An SEA done well is worth the effort for the benefits it can bring for you, your patients, and the practice as a whole. Describing and analysing a significant event is an important skill that will be scrutinised in your appraisal and revalidation. This pilot gives you and your practice colleagues an opportunity to develop this skill. Here are some tips for completing your SEA:

1. Choice of case is important:

Choose a case that requires significant reflection, and is likely to generate learning and change to practice. Good examples are a delayed diagnosis or a patient diagnosed after an emergency admission. Avoid cases that are unlikely to provoke new learning, such as a patient with a breast lump appropriately referred on first presentation. Only consider cases involving external problems (e.g. hospital delays) if the practice can demonstrate that, as a consequence of that case, it has been instrumental in attempts to remedy the external problem.

2. An effective SEA is a practice activity:

SEA is best done as a practice activity, perhaps in the course of a practice team meeting. It should specify who participated and who was responsible for actioning any changes. The SEA report should say whether all relevant individuals attended and whether the conclusions should be discussed with any other staff inside or outside the practice.

3. Action the actions:

An effective SEA not only identifies the learning points and actions to be taken but puts those changes into effect and monitors their impact. Specify who in the practice (staff member or groups) will be responsible for your action points and decide how their impact will be monitored.

SIGNIFICANT EVENT AUDIT OF CANCER DIAGNOSIS

Cancer SEA Report Template

Pseudonymised patient number:	
Diagnosis:	
Date of diagnosis:	
Age of patient at diagnosis:	
Sex of patient:	
Is the patient currently alive (Y/N):	
If deceased, please give date of death:	
Date of meeting when SEA discussed:	

N.B.: Please DO NOT include the patient's name in any narrative. Please anonymise the individual involved at each stage by referring to them as GP1, GP2, Nurse1, Nurse2, GP Reg1 etc.

1. WHAT HAPPENED?

Describe the process to diagnosis for this patient in detail, including dates of consultations, referral and diagnosis and the clinicians involved in that process. Consider for instance:

■ The initial presentation and presenting symptoms (including where if outwith primary care). ■ The key consultation at which the diagnosis was made. ■ Consultations in the year prior to diagnosis and referral (how often the patient had been seen by the practice; for what reasons; the type of consultation held: telephone, in clinic etc; and who - GP1, GP2, Nurse 1 - saw them). ■ Whether s/he had been seen by the Out of Hours service, at A&E, or in secondary care clinics. ■ If there appears to be delay on the part of the patient in presenting with their symptoms. ■ What the impact or potential impact of the event was.

2. WHY DID IT HAPPEN?

Reflect on the process of diagnosis for the patient. Consider for instance:

■ If this was as good as it could have been (and if so, the factors that contributed to speedy and/or appropriate diagnosis in primary care). ■ How often / over what time period the patient was seen before a referral was made (and the urgency of referral). ■ Whether safety-netting / follow-up was used (and if so, whether this was appropriate). ■ Whether there was any delay in diagnosis (and if so, the underlying factors that contributed to this). ■ Whether appropriate diagnostic services were used (and whether there was adequate access to or availability of these, and whether the reason for any delay was acceptable or appropriate).

3. WHAT HAS BEEN LEARNED?

Demonstrate that reflection and learning have taken place, and that team members have been involved in considering the process of cancer diagnosis. Consider, for instance:

■ Education and training needs around cancer diagnosis and/or referral. ■ The need for protocols and/or specified procedures within the practice for cancer diagnosis and/or referral. ■ The robustness of follow-up systems within in the practice. ■ The importance and effectiveness of team working and communication (internally and with secondary care). ■ The role of the NICE referral guidelines for suspected cancer, and their usefulness to primary care teams. ■ Reference the literature, guidance and protocols that support your learning points ■ Is the learning the same for all staff members or who does it apply to

Learning point 1:

Learning point 2:

Learning point 3:

Learning point 4:

4. WHAT HAS BEEN CHANGED?

Outline here the action(s) agreed and/or implemented and who will/has undertaken them.

Detail, for instance:

■ If a protocol is to be/has been introduced, updated or amended: how this will be/was done; which staff members or groups will be/were responsible (GPs, Nurses; GP Reg 1, GP2 etc); and how the related changes will be/have been monitored. ■ If there are things that individuals or the practice as a whole will do differently (detail the level at which changes are being/have been made and how are they being monitored). ■ What improvements will result/have resulted from the changes: will/have the improvements benefit(ed) diagnosis of a specific cancer group, or will/has their impact been broader. ■ Consider both clinical, administrative and cross-team working issues.

WHAT WAS EFFECTIVE ABOUT THIS SEA?

Consider how carrying out this SEA has been valuable to individuals, to the practice team and/or to patients.
Detail for instance:
■ Who attended and whether the relevant people were involved ■ What format the meeting followed ■ How long the meeting lasted ■ What was effective about the SEA discussion and process ■ What could have made the SEA more effective in terms of encouraging reflection, learning and action.

SOME INFORMATION ABOUT YOUR PRACTICE *

How many registered patients are there?						
How many F.T.E. GPs are there (inc. principals, salaried GPs, trainees etc.)?						
Is your practice a training practice?	Yes		No			
Does your practice teach medical students	Yes		No			
What were your QOF points last year?	Clinical		Organisation		Total	
OUT OF:		650		167.5		1000

* This information is useful when collating results across practices and/or localities

APPENDIX B

CANCER SEA – TRUSTS

Thames Valley Audit of patients diagnosed with cancer following an emergency admission, 2015

Significant Event Audit (SEA)

Template for Secondary Care

This template has been designed to be used by Secondary Care trusts in the Thames Valley. Trusts have been asked to complete 6-7 SEAs as part of the project '*Audit of patients diagnosed with cancer following an emergency admission*'. This project is being delivered by Cancer Research UK on behalf of the Cancer Strategic Clinical Network. The results of these audits will aid discussions between the hospital teams and primary care. They will enable agreement of the required actions and learning points to strengthen early diagnosis and the management of patients diagnosed following an emergency admission.

Please complete this form electronically – One form per patient

Please return completed form(s) (excluding any patient identifiable data) to

The form is in two parts. The first part is designed to gather relevant information about the case and what happened. Information for this part of the form may be found on electronic databases or as part of the patient's clinical records. Please gather as much information about the case as is possible.

The second part of the form is designed to be a ***reflective review*** on the patient's pathway. In this section please highlight areas that worked well and also identify any potentially avoidable delays in the journey to diagnosis and treatment. Where possible, this part of the form is best done as a **group activity**. Try to include people from all teams that formed part of the patient's care*, including their GP* if this is possible. The final SEA report should say whether all relevant individuals attended and whether the conclusions should be discussed with any other staff inside or outside the trust (e.g. patient's GP)

Choice of case is important: Choose a case that requires significant reflection and is likely to generate learning and change to current practice. Please also choose cases based on the following inclusion/exclusion criteria:

Inclusion criteria:

- Age – include a variety of age groups 18+ (ideally half >75, and half <75)
- Delay – Cases where there was the longest time from emergency presentation to a cancer diagnosis
- Cancer type – cover a range of different cancer types

Exclusion criteria:

- Children
- Acute Leukaemia

Choice of cases is limited to those that GPs have already audited and reviewed. Your CRUK Facilitator will give you the details of the patients (using the Pseudonymised patient number allocated by the Trust at the data pulling stage) who have already had an audit completed on them by their GP.

However, if the Trust has a case that it is felt would generate beneficial learning for both primary and secondary care, and this case was not selected for review by the GP, then it has been agreed that the Trust can elect to use this as one of their cases and include it as part of the audit. **In this instance please contact your CRUK Facilitator to inform them to enable them to engage the relevant GP/practice** so that a primary care Significant Event Audit can also be undertaken on the same patient.

***Please note: Your CRUK facilitator may also identify a couple of patients for the trust to audit based on the SEAs received back by primary care**

Section 1 - What Happened?

1. Demographics	
Hospital Trust:	
*NHS number:	
Pseudonymised patient number:	
*Date of Birth: (DD/MM/YYYY)	
Age:	
Gender:	
Ethnicity:	
*Patient's Post Code:	
GP practice Code:	
GP Practice Name:	
Tumour site:	
Cancer type/ICD-10 code:	
Is the patient currently alive (Y/N):	
If deceased, please give date of death:	

***Please remove the above patient identifiable data when returning this form**

The date of emergency presentation should be recorded as the date that the patient entered an emergency/unplanned pathway leading to their cancer diagnosis, in line with the NCIN definition:

NCIN Emergency Presentation definition:

- **Emergency presentation via ED**
- **Emergency consultant outpatient referral**
- **Emergency GP referral/admission**
- **Emergency transfer**
- **Emergency admission via OPA/Radiology**
    - **From CT to ED**
- **Emergency attendance**
    - **Even if not admitted**

2. Date of emergency presentation: **(DD/MM/YYYY)**	

3. Category of presentation / referral source	**Please tick one**
Self presentation at A&E	
Emergency GP referral/admission	
Emergency transfer	
Emergency medical specialist/consultant referral	
Other – please specify	

4. Place of presentation / referral route	**Please tick one**
A&E (Emergency Department)	
Acute/Emergency Medical Unit	
Medical Outpatient Dept – please specify dept	
Surgical Outpatient Dept – please specify dept	
Other – please specify	

5. Presenting symptoms at emergency presentation	
Symptom	**Reported Duration (days/weeks/months)**
1.	
2.	
3.	
4.	
5.	

6. Pre-existing co-morbidities: (please list)
1.
2.
3.
4.
5.

7. Teams involved (from emergency presentation to cancer diagnosis)*			
Team / Dept / Specialty	**Tick**	**Dates**	**Outcome / Action taken**
ED/A&E			
Medical Assessment Unit (MAU)			
Surgical Assessment Unit (SAU)			
Acute Oncology			
Oncology			
Respiratory			
Gastroenterology			
Urology			
Neurosurgery			
Haematology			
Palliative Care			
Other (please specify)			

***please note this should guide and inform who is invited to the reflective case review meeting**

8. Investigations (from emergency presentation to cancer diagnosis)				
Investigations	**Tick**	**Date requested (DD/MM/YYYY)**	**Date of investigation (DD/MM/YYYY)**	**Who requested**
CT				
PET CT				
MRI				
X-ray				
Ultrasound				
Endoscopy				
Bronchoscopy				
Biopsy				
Interventional radiology				
Laporascopy				
Blood tests e.g. tumour markers				
Other (please specify)				

9. Diagnosis	Tick	Day, month, year (DD/MM/YYYY)
Date results of investigation confirming cancer received		
Which investigation confirmed cancer		
Date of biopsy		
Date of histological confirmation		
Date of immunochemistry confirmation		
Date of MDT confirmation of diagnosis		
Date patient was told		
Other (please specify)		

10. Stage at Diagnosis			
TNM - Please tick as appropriate:			
0		IIIA	
I		IIIB	
IIA		IIIC	
IIB		IV	
IIC		Not able to stage	

11. WHO Performance Status (PS) assessment		
PS Level		**PS Score**
0	Able to carry out all normal activity without restriction	
1	Restricted in Physically strenuous activity but able to walk & do light work.	
2	Able to walk & capable of all self care but unable to carry out any work. Up & about more than 50% of waking hours	
3	Capable of only limited self care, confined to bed or chair more than 50% of waking hours	
4	Completely disabled. Cannot carry on any self care. Totally confined to bed or chair	

11a. Performance Status	Please tick
Curative	
Palliative	

12. Active Treatment (if applicable)	
Date of decision to treat (DD/MM/YYYY):	
Date of patient consent for treatment (DD/MM/YYYY):	
Date of treatment for the cancer commenced (DD/MM/YYYY):	

13. Treatment - Palliative (if applicable)	
Date of decision to treat (DD/MM/YYYY):	
Date of patient consent for treatment (DD/MM/YYYY):	
Date of treatment for the cancer commenced (DD/MM/YYYY):	

14. MDT meetings

Tumour Site	**Tick**	**Date referred to MDT**	**Date Discussed by MDT**	**Outcome / Action taken**
Lung				
Upper GI				
Lower GI				
Gynaecology				
Urology				
Myeloma				
Breast				
Brain				
Haematology				
Cancer of unknown primary				
Other (please specify)				

15. Previous contact with Secondary Care in the last 12 months (prior to emergency presentation)		
A&E / Emergency Dept		
Date of attendance	**Presenting symptoms**	**Outcome e.g. discharged to GP, admitted**

Inpatient admission			
Date of admission	**Primary diagnosis**	**Outcome e.g. discharged to GP, admitted**	**Discharge date**

Outpatient		
Date	**Specialty department**	**Outcome e.g. discharged to GP, admitted**

Investigations and/or tests			
Investigations/tests (please state)	**Date of investigation**	**Referred by**	**Outcomes/actions**

Section 2 – Why did it happen?

Reflective /Case Review Notes

This part of the audit form is designed to be a reflective review on the patient's pathway, and a chance to highlight areas that worked well and also to identify any potentially avoidable delays or areas for service improvement in the patient's journey to diagnosis and treatment.

This part of the form is best done as a group activity. Try to include people from all teams that formed part of the patient's care, including their GP if this is possible. The final SEA report should say whether all relevant individuals attended and whether the conclusions should be discussed with any other staff inside or outside the trust (e.g. patient's GP)

You may wish to use the graphic time line on the back of this template to help you map and visualise the patient's journey and the time frames between each stage.

Please note that the questions and prompts under this section are to guide and facilitate thinking and conversations. As long as you capture the relevant detail for this section somewhere on the template, you might not need to complete each part separately.

Date of Case Review Meeting (DD/MM/YYYY)	

Roles of case review participants	
Role	**Please tick**
Oncology Consultant	
Clinical Nurse Specialist	
Acute Medical Consultant	
Radiology	
Surgeon	
GP	
Other (please specify)	

1. Reflect on the patient’s journey from the date they first presented as an emergency to the point where they received a cancer diagnosis and prescribed treatment or palliative care.

How many days did it take from emergency presentation to:

First contact with Oncology service:	
Appropriate MDT:	
Confirmed diagnosis:	
Treatment start date:	

2 . Reflect on the process of diagnosis for the patient. Consider for instance:

•If this was as good as it could have been (and if so the factors that contributed to this quality of care), • how often/ over what time period the patient was seen before a diagnosis, • the patients pathway from presenting as an emergency to cancer diagnosis, • whether there was any delay in diagnosis (and if so the underlying factors that contributed to this), • whether the appropriate investigations were carried out and the right teams were involved , • the cancer type and the stage at diagnosis.

3. If there were any previous hospital episodes /contacts in the past 12 months, reflect on whether there were any opportunities for an earlier diagnosis? Consider for instance:

• The initial presentation and presenting symptoms, • Any consultations or prior contact with the Trust in the year prior to the patient presenting as an emergency and their eventual diagnosis, (how often the patient had been seen by the Trust, for what reasons and the type of appointment /investigations carried out, • Whether he/she had been seen in A&E before, whether any patient follow up was carried out by the Trust (and if so was this appropriate)

4. If there were any delays in the patient receiving their diagnosis and treatment, could any of these have been avoided? Consider for instance: • Information and communication flows between Trust teams, • information and communication with the patients GP, • whether appropriate diagnostic tests were used, • patient follow up, • If there appears to be delay on the part of the patient in presenting with their symptoms, • whether he/she had already been seen and possibly referred by their GP.

Section 3 – What has been learnt?

Demonstrate that reflection and learning have taken place, and that the relevant people have been involved in the process that has resulted in this patient's cancer diagnosis. Consider for instance: • Education and training needs, • the need for protocols and /or specified procedures within the Trust for speedy diagnosis and good management of patients presenting as an emergency, • the robustness of the internal and cross departmental systems and communication networks, • the importance and effectiveness of team working and robust communication (internally and with primary care and patients)	
Learning point 1:	
Learning point 2:	
Learning point 3:	

Section 4 – Opportunities for improvement

Outline suggested actions and/or recommendations to improve the management of patients presenting as an emergency. **Consider both clinical, administrative and cross team working issues including primary care.**	
Action 1:	
Action 2:	
Action 3:	
Action 4:	

Thank you for taking the time to complete this case review and participate in this Thames Valley SCN project. If you have any further comments or thoughts that you would like to share with the project team please note them here.

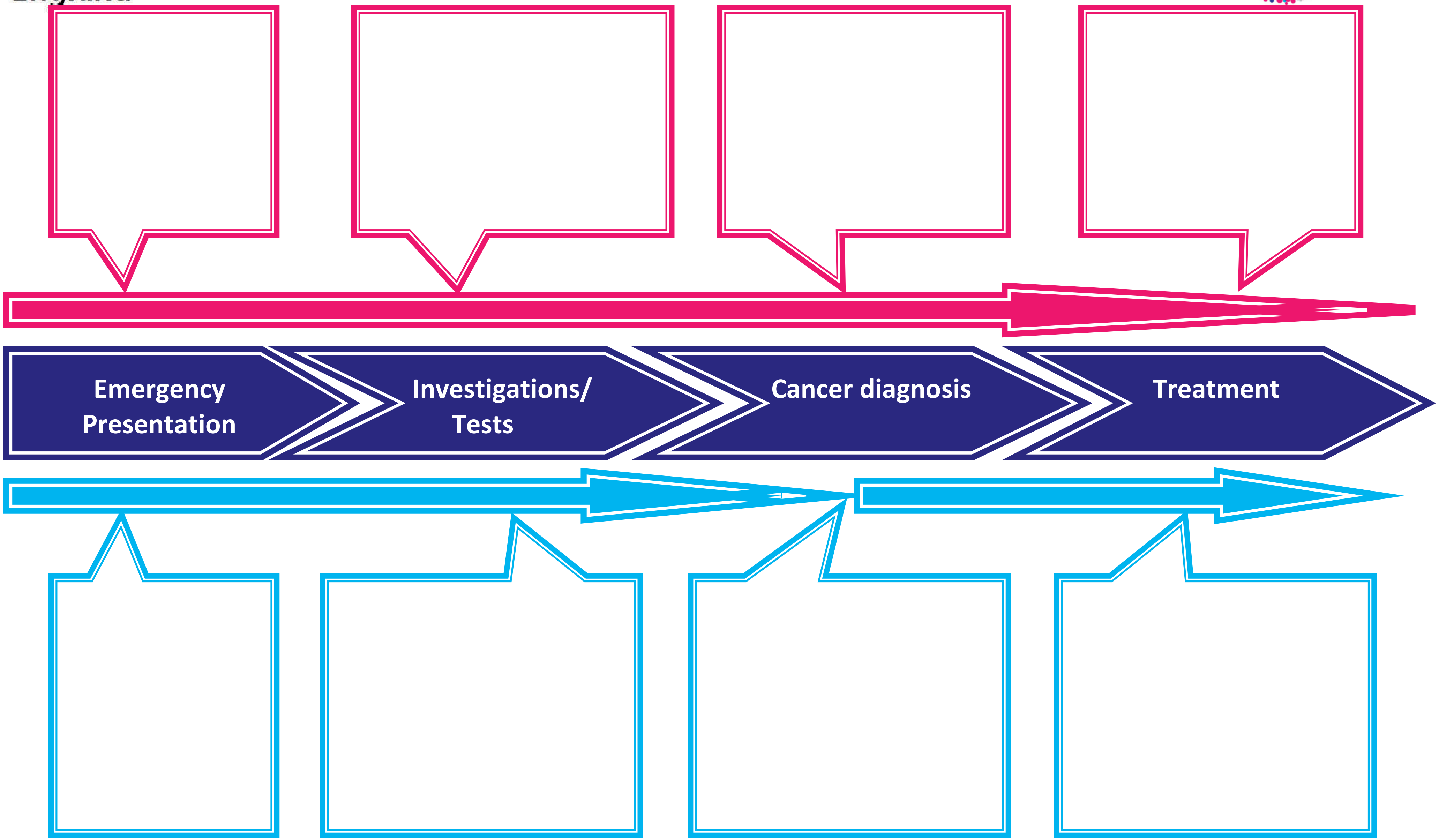
Name:	
Role:	
Signature:	
Date:	

Please return completed form(s) (excluding any patient identifiable data) to INSERT facilitator name CRUK Facilitator: INSERT Relevant Facilitator details

NHS England

CANCER RESEARCH UK

What went well – strengths of the patient pathway



What didn’t go so well – opportunities for improvement

APPENDIX C

PRIMARY CARE AND SECONDARY CARE INTERFACE: RECOMMENDATIONS FOR ACTION

AIM 1: TO IMPROVE AND STRENGTHEN THE KNOWLEDGE AND CAPACITY OF GPS TO INTERPRET AND RESPOND APPROPRIATELY TO TEST RESULTS

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
GPs do not always have enough information or a sufficient level of understanding about the limitations of certain tests. This can lead to GPs and patients being falsely reassured by negative test results. On occasions, abnormal test results can be inappropriately acted upon, or not acted on at all.	Macmillan GPs	Staff Time CPD opportunities	A series of GP master classes to be held across the TV to increase GP understanding and awareness of the diagnostic tests available and their limitations.		Reduced delay for patients in accessing tests and reaching a diagnosis More appropriate diagnostics being undertaken and GPs having a good understanding of the limitations of the results. GPs have a heightened awareness that when results are in the 'normal' range it is good practice to stay aware of changing patterns/trends, when compared with previous results.
	GPs	CPD opportunities	When requesting investigations, GPs to remain aware that sometimes a 'normal' result can require action.		

AIM 2: TO IMPROVE AND STRENGTHEN THE SAFETY NETTING MECHANISMS IN BOTH PRIMARY AND SECONDARY CARE

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
There can sometimes be a lack of safety netting processes in place around follow up of results from diagnostic tests (both in primary care and secondary care), leading to a delay in diagnosis Planning of continuity of care between GPs is important in primary care settings if patients are likely to see a number of different GPs. There can be a discrepancy in who follows up results and this can lead to potential delays	Practices Practice Managers	Staff Time	Primary care to use clinical systems with alerts activated to flag that an investigation has been arranged and results to be followed up (e.g. Click-memo)		As above GPs using clinical systems effectively to safety net test results Fewer /no patients experience delays in diagnosis due to lack of follow-up/communication from primary and secondary care GPs routinely set alerts on their systems once an investigation has been ordered to follow-up if the appointment has been received – or ask the patient to let them know within a specified amount of time if an appointment isn't received. If test results are abnormal practices have systems in place that do not rely on patients to phone or attend a follow-up appointment.
			GPs to advise patients that if symptoms persist, even after a negative test result, they should return within a specified amount of time. E.g. GPs/receptionists offer to make follow-up appointment for patients directly after appointment.		
			Put systems in place to ensure patients understand how and when they will be given test results		
			Abnormal test results to be followed up and appropriate action has been taken by the GP who ordered the test.		
Secondary care do not routinely put safety netting processes in place and monitor their effectiveness	Cancer Managers	Staff Time	Secondary care to establish safety netting systems to i) confirm that patient attended appointment and ii) results are received on by GP and appropriate action has been taken.		As above Systems in place to ensure patient attends appointment and GP knows the outcome and next steps

AIM 3: TO ENSURE THAT PATIENTS RECEIVE THE MOST APPROPRIATE TEST AVAILABLE TO DIAGNOSE THEIR TUMOUR IN A TIMELY WAY

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
The TV audit found that on occasions certain tests were not available or that the tests undertaken were inappropriate or inadequate to diagnose cancer. In addition some tests were not undertaken quickly enough.	SCN CCGs CRUK Facilitators	Time	Circulate the up to date NICE guidelines and electronic learning modules identified for certain tests to improve knowledge and understanding.		GPs feel more knowledgeable and confident about the tests available to them. Electronic Learning modules identified and GPs from the TV completing it recorded.
It is not always clear who is best placed to order some investigations, and whether the investigation should be taking place in primary or secondary care. GPs do not consistently feel they have quick and ready access to a consultant /radiologist for advice about a patient's condition and what sort of test and referral pathway is most appropriate.	CCGs	Time	CCGs to review their systems and policies for practitioners to access urgent scans and communicate this to all their practices and Trusts		All GPs and Trusts in the TV feel clear and confident about how to access urgent scans when required
	Practices Radiologists	Staff Time Funding? (to set up system)	If there is a clinical concern about cancer that requires further investigation, then the GP should speak to the duty consultant radiologist about what the most appropriate investigations are and whether the person can be sent for 'urgent imaging'		Fewer urgent referrals " bounced back" Radiologists report an increase in more appropriate referrals.
	Cancer Managers Consultants		Consider establishing a Consultant /Radiologist "hotline" in each trust to provide easy access to GPs for support, information and advice.		Reduced delay in patients accessing appropriate tests and reaching a diagnosis

AIM 4: TO DEVELOP INFORMATION SHARING SYSTEMS ACROSS THE THAMES VALLEY SO THAT ALL GP PRACTICES CAN ACCESS TEST RESULTS FOR THEIR PATIENTS FROM SECONDARY CARE ELECTRONICALLY

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
The TV audit findings showed that systems could be improved to facilitate the sharing of diagnostic data/results between primary and secondary care. GP access electronically to the results of investigations undertaken in secondary care is limited to certain localities in the Thames Valley (MK and Swindon) A barrier to some practices accessing results electronically from secondary care is due to different IT systems and software.	CCGs and Cancer Managers	Staff Time Funding	GPs should have electronic access to the results from tests undertaken by secondary care so they can be aware of the full range of investigations carried out.		Reduced delay in GPs receiving investigation results and patients receiving a diagnosis. GPs able to see the full picture of their patients' investigations and results and act accordingly without delay.
			Practices in the Thames Valley to have access to hospital results so that when letters are received to action an abnormal hospital result the admin team are able to download the result into the patient's medical record as well.		

AIM 5: TO RAISE PATIENT AWARENESS ABOUT THE IMPORTANCE OF EARLY DIAGNOSIS

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
Patients do not always take responsibility for ensuring they have received an appointment following a referral or the results of a test or re-visit the GP if there is no improvement in their symptoms or they worsen. It is important in both primary and secondary care that patients know and understand the next steps in their pathway and what to expect from their referral /investigation	Patient forum chair CRUK Facilitators	Time Funding	A series of patient empowerment sessions could be delivered to help patients to feel informed and confident about following up test results and re-visiting the GP if necessary. These should aim to be inclusive and ensure they involve the hard to reach groups.		Patients who attend the workshops report feeling confident and more likely to follow up their test results and re-visit the GP if symptoms persist or new symptoms develop. A series of patient awareness and empowerment workshops have been held across the TV.
	Insert patient forums Voluntary Sector	Time Funding	Hold Patient Empowerment workshops to help patients feel able to make the most of their consultation with the GP.		Patients who have attended workshops report that they now feel confident and equipped to make the most of their appointment time when seeing their GP.
	Insert Public Health and Cancer charities	Time Funding	Hold Cancer Awareness workshops for patients on prevention, screening and signs and symptoms.		Increased awareness and understanding among patients who attend workshops about cancer risks, prevention and the benefits of screening programmes
	CCGs Practices		GPs to ensure they inform the patient, when making a 2WW referral, that it is to rule out the possibility of cancer and establish if there is any reason why they might not be able to attend an appointment within the next 2 weeks. GPs to provide the patient with a 2WW leaflet informing them about how to chase their appointment if necessary.		Reduced number of patients not attending their 2WW appointment. All patients referred for a 2 WW provided with a leaflet.

AIM 6: TO ACHIEVE GREATER CLARITY AND UNDERSTANDING BETWEEN BOTH PRIMARY AND SECONDARY CARE IN THE THAMES VALLEY AS TO WHERE THE RESPONSIBILITY FOR PATIENT FOLLOW-UP LIES

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
Once primary care has made a referral to secondary care the patient falls into a 'grey area' where the handover of responsibility for them between primary and secondary care can be unclear, sometimes resulting in neither sector following them up. There is a need for patients who are seen and then discharged, with further tests or results still pending, to be 'owned' by a key worker who can provide a point of contact for the patient, family and GP. There is often no-one overseeing a patient's care pathway as they move through the system, this can lead to confusion and delays	Cancer Managers	Staff Time	Acute trusts to implement safety netting measures to ensure that scan results are followed up appropriately and in a timely way and with relevant clinic appointments made. Trusts to communicate with the patient's GP to ensure they are involved and to discuss the support required by the patient.		Trusts able to evidence the safety netting measures put in place.
	Cancer Managers	Staff Time	Patients who are in the diagnostic phase of a cancer pathway should be given a point of contact (e.g. AOS or CNS) to help facilitate referrals and minimise the risk of 'falling through the net' Pathway Coordinator positions could be put in place within Trusts		All patients in the diagnostic phase of a cancer pathway have a 'Pathway Co-ordinator' as a point of contact. Better patient care and higher levels of patient satisfaction Patient care more joined up and fewer opportunities for delays as the patient progresses on
If a scan shows an incidental finding requiring referral, this should be done by the person who booked the scan (e.g. hospital consultant team) rather than referring back to the GP. Referring back to the GP builds in a risk that the referral will be missed	CCGs		CCGs to agree with their local trust that Consultants are able to make a direct new referral to another hospital team (specialist to specialist) rather than return the patient to the GP first. Any internal referrals should additionally be communicated to the GP		Reduced delays in diagnosis.

AIM 7: TO IMPROVE THE QUALITY AND TIMELINESS OF THE DISCHARGE SUMMARIES PRODUCED BY SECONDARY CARE AND TO ENSURE CONSISTENCY IN THE QUALITY ACROSS THE THAMES VALLEY

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
Discharge summaries often do not contain enough detail and specifics for the GP to follow up effectively and take the necessary actions, particularly if further appointments are required.	CCGs SCN Cancer Managers	Staff Time	Review discharge summary forms across all trusts and redesigned where necessary. Trusts should also consider giving a copy of the discharge summary to patients to empower them to ensure follow up actions are taken in timely way.		Reduced delay for patients who require follow up and further appointments. GPs are able to see quickly and clearly if they are required to take action.
	CCGs SCN Cancer Managers	Staff Time	A set of TV wide quality standards for discharge summaries could be identified and agreed by all stakeholders.		Improved consistency and quality of discharge summaries across the TV A benchmark and tool to monitor quality standards across the TV.
	Cancer Managers	Staff Time	All trusts undertake an annual audit to monitor the quality of the discharge summaries.		As above Trusts regularly monitor and improve their discharge summaries as required.
It is not uncommon for a GP to receive a discharge summary several days or even 2 – 3 weeks after the patient has been discharged from hospital	Cancer Managers	Staff Time	Trusts should review their administrative processes and systems to ensure all discharge summaries with GP action required are dispatched and acted on within the specified time period.		As above The timeliness of discharge summaries is included in the TV wide quality standards agreed for discharge summaries

	Cancer Managers		All trusts in the TV to put in place appropriate safety netting measures to ensure the GP has received the discharge information and that any follow up tests have been arranged.		As above Fewer cases where there is a delay in the follow up action required by the GP or the timeliness of follow up appointments
It is not uncommon for a GP to receive a discharge summary several days or even 2 – 3 weeks after the patient has been discharged from hospital.	Consultant team	Staff Time	When a discharge summary requires quick action to be taken by the GP it should be phoned through to the practice and the patient is given a copy for information and follow up if necessary.		Fewer delays experienced by patients when follow up tests and investigations are required following discharge from hospital. GPs report that they are receiving discharge summaries in a timely way allowing follow up and actions to be taken within specified time
Discharge summaries are often /usually completed by a junior Doctor who does not have enough information about the patient's journey prior to discharge or who does not fully understand the level of information the GPs require to follow up and take action.	Senior Clinical Staff within the MDT	Staff Time	Develop a quality standard (see above) to ensure that all discharge summaries are reviewed and signed off by a senior member of staff.		Quality of the discharge summaries completed by FY1 doctors improves Discharge summaries in the TV are of a high quality containing the relevant information for the GP in an appropriate level of detail.
	Deanery and Postgraduate Centres	Staff Time Funding	Consider putting in place a rolling training programme in place for FY1 doctors to help them understand the importance of the info required in a discharge summary and the information needs and limitations of primary care to act on them.		Quality of the discharge summaries completed by FY1 doctors improves. All FY1 doctors in the TV feel confident and equipped to complete a high quality discharge summary.

AIM 8: TO IMPROVE THE QUALITY AND APPROPRIATE LEVEL OF DETAIL RECORDED IN DOCUMENTATION AND THE PATIENT'S MEDICAL RECORD IN BOTH PRIMARY AND SECONDARY CARE

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
A number of GPs completing the SEA audit identified the lack of adequate safety netting, or noted the lack of detail recorded of the safety netting measures taken.	Macmillan GPs CRUK Facilitators CCGs	Facilitator Time Funding	Hold GP master classes on safety netting across the TV, and where appropriate or if requested on an individual practice level or through PLT sessions		GP practices in the Thames Valley are able to demonstrate robust and comprehensive safety netting measures are in place including information and training for locums. A significant number of primary care teams from local practices in the TV have had the opportunity to attend a safety netting workshop.
The TV audit findings identified that in both primary and secondary care, there were times when poor documentation, sometimes lack of any documentation, and inadequate history taking/recording was the cause of a delay in referral and diagnosis.	Practice Managers Cancer Managers	Time	Trusts and GPs should conduct regular SEA audits to help to monitor and track the consistency and quality of care		Patient notes are always completed and filed appropriately in secondary care.
Some patients can be reluctant to have certain investigations or be too unwell to undergo critical investigations		Time	Discussion about patients and family's wishes should be clearly documented in the medical record, including patient's reluctance to have investigations/ admission/care.		Patients/family wishes clearly documented.

AIM 9: TO IMPROVE COMMUNICATION WITH THE PATIENT BY PRIMARY AND SECONDARY CARE

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
Patients with communication difficulties or barriers such as language, literacy, learning difficulties, mental health problems or memory impairment (dementia) can make it challenging for health professionals to take an accurate and detailed medical history, and/or communicate to the patient the next steps in the pathway /process.	CCGs Practice Managers Local Authorities Local Charities	Time	Ensure that the local translation services are available and accessible to support primary and secondary care and to ensure they are well publicised. Practices and Trusts to ensure they have adequate access to advocacy services when family members / friends are not available. Provide Practices and trusts with access to translated and pictorial information leaflets for patients		Reduced barriers for vulnerable groups in accessing primary and secondary care services.
The way a person hears about their cancer diagnosis is very important and can impact on how they cope. The audit found there were a few occasions where the patient hadn't been told their diagnosis following investigations by secondary care and the GP was not aware of this.		Time	There should be clear communication to GPs from secondary care about the information that has been given to the patient to allow for the GP to provide the appropriate support and discussion with the patient about on-going tests and treatment. GPs to be sent a fax or email within 24hrs of a cancer diagnosis being made.		Improved patient experience.

AIM 10: TO IMPROVE COMMUNICATION BETWEEN PRIMARY AND SECONDARY CARE

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
On occasion, acute trusts reported that they would have welcomed a more detailed and accurate patient history on the referral form to inform the clinicians of the full picture for consideration. This would help them to understand why the referral had been made, especially in cases where the symptoms do not fit with the guidelines.	SCN Consultants Practices	Time	New 2WW referral forms should contain enough space and flexibility for GPs to provide more detail and explanation for referral Consultants in secondary care should not 'down grade' a 2WW referral without phoning and speaking to the referring GP first. GPs to be more explicit in the referral letter regarding the diagnostic versus the investigative nature of the referral.		Improved communication with primary care, mainly where patients have unexplained, longstanding symptoms. Fewer patients referred on a 2WW "bounced back" More appropriate 2WW referrals.
Level of detail and information about actions taken by secondary care and oncology involvement can be too limited and vague for GPs to fully understand the current situation and the next steps in the pathway / process, along with any actions required by them.	Cancer Managers Radiologists	Time	Radiologists to include more follow up thoughts in their reports to help GPs with clear next steps/actions highlighted Cancer MDTs / MDT Coordinators send a letter containing a copy of each MDT meeting minutes for each individual patient to their GP		Closer interaction between primary and secondary care teams (acute oncology) where warning signs of cancer are present.
Primary care and Secondary care clinicians and professionals rarely have the opportunity or the time to come together to; a) share learning and good practice across the TV and b) discuss and resolve current system weaknesses and frustrations.	SCN Cancer Managers CRUK Facilitators CCGs Patient Reps	Staff Time Funding	An annual (or bi-annual) workshop could be held for primary and secondary care to share good practice and trouble shoot current system and protocol frustrations and delays.		Improved efficiency and effectiveness of local NHS systems and processes to reduce delays along the pathway to diagnosis. Increased and improved communication between primary and secondary care. Monitoring and updating of this action plan.

AIM 11: TO RAISE AWARENESS OF THE POSSIBILITY OF CANCER WHEN REVIEWING PATIENTS WITH CO-MORBIDITIES OR VAGUE SYMPTOMS

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
Atypical presentations of cancer can result in difficulty in making a diagnosis particularly when presenting as an emergency. It is important for secondary care to be aware of the links between thrombotic disease and cancer Existing co-morbidities can mask the symptoms of cancer and it is possible a person to have multiple diagnoses.	Acute Trusts Macmillan GPs	Staff Time	Continued education to be offered by acute oncology team to emergency medicine and acute medical teams, especially Junior Doctors, including teaching on cancer associated thromboembolic disease		All trusts in the Thames Valley provide CPD sessions on cancer and likely scenarios for emergency presentations - for Junior doctors and the emergency medical teams
Patients with vague, atypical symptoms and no red flags, but who are clearly unwell and deteriorating, do not 'fit' any specific 2WW pathway and it is difficult for primary care to know how best to refer them. Previously well people, who attend the GP infrequently with sudden, severe symptoms should raise the index of suspicion for possible investigations.	CCGs SCN	Staff Time	Establish a central referral point for further investigations of this group of people. (e.g. ACE programme being piloted in Oxford)		GPs feel clear and confident about referral pathways in place for patients with vague and atypical symptoms. Fewer delays experienced by patients who do not fit the 2WW criteria.

AIM 12: TO RAISE THE AWARENESS OF THE IMPORTANCE OF REVIEWING THE WORKING DIAGNOSIS IN CASES WHERE SYMPTOMS PERSIST DESPITE TREATMENT, OR WHEN NEW SYMPTOMS ARISE

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
Patients attending for a number of day case related surgical procedures over a period of time may be better served by occasional senior outpatient clinical review.	Cancer Managers /Acute trusts	Staff Time	Assessment of any potentially changing clinical scenario to be in place for vulnerable and elderly patients. Guidance for patients to be reviewed in outpatient clinics between day case procedures, such that changing clinical scenarios can be assessed.		A more open supported environment for vulnerable or elderly patients to discuss symptoms.

AIM 13: TO ENSURE THAT ALL GPS AND LOCUMS IN A PRACTICE ARE FAMILIAR WITH THE LATEST 2WW REFERRAL GUIDELINES, AND HAVE READY ACCESS TO THE 2WW REFERRAL FORMS, AND HAVE SUPPORT AROUND MAKING REFERRALS

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
The primary care SEA audit found that there were times when GPs recognised that they were not familiar enough with the urgent and 2WW referral guidelines.	SCN Macmillan GPs CRUK Facilitators CCGs	Staff Time Funding	The new NICE guidance and any support resources should be widely circulated and training sessions arranged where necessary to help GPs understand and become familiar with the changes in them		GPs feel more familiar with the 2015 NICE guidance and confident in using the guidance to make 2WW referrals. Number of 2WW referrals goes up as the guidance has lowered the referral threshold from 5% to a 3% risk of cancer. All GPs in the TV have had the opportunity to attend a NICE guidance workshop and have been provided with the support resources electronically.
GPs often feel restricted by the current 'tick box' 2WW form and would like an opportunity to give further, relevant information about their concerns on the form. Sometimes additional 'referral letters' go astray There are different versions of 2WW forms currently in use across the Thames Valley	SCN CCGs	Staff Time Funding	Design a uniform 2WW referral form (with a free text box for additional information) for use across the Thames Valley		Reduced delay for patients in accessing tests and reaching a diagnosis GPs better able to communicate their concerns about a patient to secondary care. Consistency in information and quality of referral forms
2WW forms are not always easily accessible by GPs or locums		Staff Time	Current 2WW forms should be stored in an easily accessible place on practice systems		
Appropriate support and guidance is not always readily available for GPs to make referrals	CRUK Facilitators Macmillan GPs	Staff Time	Provide a training course for GPs around the referral guidelines and make relevant support resources available to all GPs across the Thames Valley CRUK resources / materials for referral routes relating to new NICE guidelines		Reduced delay for patients in accessing tests and reaching a diagnosis Thames Valley GPs up to date with latest referral guidelines and understand what pathway to use and when

AIM 14: TO ENSURE THAT THERE ARE PATHWAYS AND SYSTEMS IN PLACE TO DEAL WITH PATIENTS WITH VAGUE/ATYPICAL SYMPTOMS THAT REQUIRE INVESTIGATION

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
Patients with vague / unspecific symptoms do not neatly fit the established tumour site specific pathways and as a result can find themselves in a cyclical referral loop back to the GP resulting in a delayed diagnosis.	Slough CCG Oxfordshire CCG	Staff Time Funding (to set up Unit)	A central referral point with a MDT assessment unit for further investigations to be established E.g. ACE programme being piloted in Slough and Oxfordshire Trusts could invite GPs to attend MDT meetings when relevant		Reduced delay for patients in reaching a diagnosis Central Referral Units will be available to GPs for non-specific cases requiring a diagnosis Patients with serious but non-specific symptoms will be referred and diagnosed earlier

AIM 15: TO ENSURE THAT EXPEDITED PATHWAYS ARE IN PLACE SO THAT PATIENTS CAN BE REFERRED FROM ONE SECONDARY CARE SPECIALTY TO ANOTHER TO ENABLE SPEEDIER DIAGNOSIS

Situation /need Audit findings	Responsibility	Inputs – e.g. Staff, time additional funding	Recommended Actions	Current Status RAG	Potential Outcomes
It is not uncommon for a test result to come back showing no abnormalities, but the patient still remains unwell or with worsening symptoms. It is usual in these instances for the patient to be sent back to the GP for re-referral on a different pathway resulting in delayed diagnosis .	CCGs	Staff Time Funding	An in house pathway to be established in each trust that allows for internal referrals to be made from specialist to specialist .		As above Secondary Care clinicians able to refer direct to another specialty if patient symptoms suggest a different pathway to their original referral

APPENDIX D

ANALYSIS BY THEMES

This appendix presents the detailed findings from the qualitative part of the SEAs; the findings from the GP SEAs and the Trust SEAs are treated separately. The GP SEAs are discussed by the underlying factors which may have led to the emergency presentation, (see figure 1 for an infographic showing the thematic map of the causal mechanisms which emerged from the data). The first underlying factor to be addressed is the tumour while the second factor is the person. The system and healthcare professionals are the third underlying factor, this is broken down into several parts. Firstly the primary care part which is subdivided into events during the consultation and then processes within the practice. The next part of the analysis covers diagnostics which encompasses the tumour, the person and the system. Analysis of secondary care follows and the last part of the system factor is the findings on the role of guidelines. The final part of the analysis section explores the findings from the qualitative elements of the Trust SEAs. The report provides a lot of detail on the comprehensive analysis which was undertaken and is designed to be dipped into and read selectively rather than read from cover to cover.

The layout of the analysis by themes is as follows:

- GP SEAs
    - Tumour factors
    - Person factors
    - System and healthcare professionals factors
        - Primary care
            - During the consultation
            - Processes in the practice
    - Diagnostics (encompasses tumour, person and system)
        - Secondary care
        - Wider cancer community (role of guidelines)
- Trust SEAs

Direct quotes from the SEAs are used throughout this part of the report; the sex, age and tumour site of the SEA case is presented in brackets after the quote or within the text when a case is referred to. The key actions taken by practices and their recommendations are provided at the end of sections where appropriate.

TUMOUR FACTORS - COMPLEXITY OF PRESENTATION

The tumour featured as a contributing factor to the diagnosis via an emergency presentation in nearly two-thirds of the SEAs. Most of the SEAs recorded some information about the site of the cancer and whether it had spread although this was not recorded systematically in many cases metastases were present, with a small number where no spread had been found. On occasion it was not clear where the primary cancer site was. Generally it was the lack of or vagueness of symptoms that were commented on. In some cases the presenting symptoms worsened rapidly and the person deteriorated very quickly. It was found that the symptoms could easily have been misattributed to other causes or an existing co-morbidity and this sometimes led to a referral to the 'wrong' specialty.

No symptoms

Key Findings:

- Sometimes no symptoms related to the cancer were experienced.
- Some cancers were found incidentally.
- Many GPs recorded when a symptom was not present.
- Some GPs expected that there would be a symptom present if the patient had cancer.

Some people had attended the GP practice prior to their diagnosis but they had not seemed to experience any symptoms related to the cancer. Three cases had had no GP contact prior to their diagnosis. On several occasions the cancer was described as being found incidentally meaning that the person had presented as an emergency but not for reasons related to the cancer, which was then subsequently diagnosed. One GP commented on how more and more cancers were being found incidentally due to the increased use of scans (M, 83, lung).

Some SEAs stated that it was not clear whether the GP had asked about certain symptoms while many GPs recorded when a symptom was not present. This information was generally gathered in one of three ways; through taking a medical history, GP examination or further investigations. Common statements were that there was no weight loss or no mass was found on examination or the GP recorded from the results of urine and blood tests if something such as blood was not present or the person was not anaemic. The lack of a symptom was sometimes reported as the patient 'denying' the symptom, implying that the symptom was perhaps present. On a few occasions the GP was able to ascertain at a later time that the symptom had been there but generally there was no way of checking the existence of an earlier symptom. There seemed to be an expectation by some GPs that in the time leading up to a cancer diagnosis, often late stage, there would be a symptom present.

> "Some cancers do present late and it can be impossible to find them earlier in their illness course." (F, 86, liver)

Vague, atypical or non-red flag symptoms

Key Findings:

- Several types of cancer were 'notorious' for having no or atypical symptoms and presenting 'late'.
- Vague symptoms meant it was difficult to know which specialty to send the 2WW referral to

There were several types of cancer which were mentioned as being 'notorious' for having no or atypical symptoms and therefore tending to present 'late'; these included cholangiocarcinoma, pancreatic cancer and ovarian cancer. One presentation was described as atypical for upper GI cancer as there had been no weight loss recorded (M, 54, stomach). Another SEA mentioned that the person had symptoms of dizziness which are common in the general population with often a benign differential making it difficult for clinicians to pick out concerning cases (M, 63, brain & CNS).

> "We would like a 2WR referral for people who are unwell but we don't know which system they are unwell with. This seems a recurrent problem in our discussions this year."
> (F, 82, brain & CNS)

Table 9 and figure 3 show the variety of symptoms which were presented by the various tumour types. The symptoms being vague meant it was often difficult to know what to do with the patient and which specialty to refer to via a two week wait, although the GP suspected that something was wrong and had accepted that the patient was not well. On one occasion it was noted that it was a GP who knew the patient well who observed the change in appearance and referred him (M, 82, bowel). Vague symptoms could also be masked by other problems such as mental health issues making the presentation even more complex.

Quick deterioration

Key Findings:

- Sometimes symptoms became worse quickly, this should set alarm bells ringing.
- A number of attendances in a short space of time could be 'considered as a red flag'.

Comments in some SEAs noted how quickly symptoms progressed or how rapidly the person's health deteriorated. For example in one case the person was described as having gone from normal ultrasound and blood test results to liver metastases and abnormal blood results in one month (F, 39, pancreas). This indicated that any presentation route other than an emergency one was unlikely to have been possible for some of the cases in this audit. In some circumstances a two week wait referral was made but the emergency presentation happened before this appointment took place. It was also noted that some people have a number of attendances for the same

> "One senior GP commented that he will always seriously consider referral if a patient presents twice for the same problem in quick succession."
> (F, 52, brain & CNS)

problem in a short space of time, and it was suggested that this could possibly be considered as a red flag symptom to be acted upon.

Symptoms suggesting an alternative diagnosis

Key Findings:

- Often symptoms presented to the GP suggested an alternative diagnosis.
- If person treated for the symptom and an improvement was seen this led to false reassurance.
- Pain could often be explained by an earlier injury.
- The cancer could be 'masked' by the alternative diagnosis.
- On reflection more could have been done to question the working diagnosis.
- GPs suggested in the SEAs that many primary care procedures were reasonable in light of the symptoms presented with.

"his admission for abdominal pain highlighted several medical issues that were unrelated to his eventual diagnosis of myeloma including a likely renal carcinoma, gallstones and an abdominal aortic aneurysm."
(M, 75, multiple myeloma)

Often the symptoms presented to the GP suggested a diagnosis that was not the cancer finally diagnosed. On a few occasions bereavement was mentioned as being either the cause of the symptoms (weight loss, depression) or the reason for the person not engaging well with primary care. Sometimes the symptoms fitted with an existing illness that the person was known to have, while on other occasions a new condition was the working diagnosis that was initially investigated and treated. In one example the person presented with rectal bleeding that was explained by piles and it was felt that the 'red' bleeding was not a symptom of the ultimate caecal cancer (F, 70, bowel). If the person's symptoms were found to respond to treatment this additionally complicated matters, giving less incentive to investigate further. Alternatively if an investigation was done and there was no cancer found then this false reassurance could impact how the symptom was then assessed by both the GPs and the person if the symptom persisted.

"Awareness of tendency to assume new symptoms/ worsening symptoms are attributable to patient's poor compliance/worsening of existing conditions instead of thoroughly investigating them and consider malignancy as a differential."
(M, 65, NHL)

Difficulties arose if there could be more than one possible diagnosis based on the presenting symptom or if the GP investigating an alternative diagnostic possibility which was not incorrect based on the information available. This was often the case for joint or bone pain where a previous injury or gout was probably the correct explanation for at least some of the pain experienced.

In all of these complex scenarios the cancer was 'masked' and it was often a new dramatic symptom or a continuing deterioration in the individual's health that led to the emergency presentation. These cases were referred due to their symptoms but this was not always through the two week wait rule and was not usually for a suspected cancer. The GPs felt that on some occasions the 'routine' referral route was appropriate as there were no red flag symptoms present.

Symptoms prompting referral to 'wrong' specialty

Key Findings:

- Co-morbidities made it difficult to ascertain which symptom was attributable to the eventual cancer.
- Symptoms sometimes prompted referral to 'wrong' specialty

A patient who presents to their GP may have compounding factors and co-morbidities which could have been responsible for the presenting or worsening symptoms. In one SEA the person was described as having multiple different symptoms including gastrointestinal, respiratory and haematological (F, 70, liver). This not only complicated the presentation but also made the choice of where to refer the person challenging for the GP. Some of the SEAs reflected on the referrals made in light of the presenting symptoms, including reference to the guidelines and what criteria have to be filled to be able to make a two week wait referral. Guidelines are discussed in more detail later on in the report (see section on Role of Guidelines). Some GPs commented that there had been symptoms presented by the person but that these were neither symptoms associated with the cancer eventually diagnosed nor red flags on the Cancer Assessment tool. In one example although the person had some bowel symptoms he was referred for upper GI as "he only fulfilled the criteria for an urgent upper GI referral" (M, 82, bowel).

Shared learnings / recommendations for GP actions to address tumour factors:

- Be aware of common conditions that can mask cancer
- Have systems in place to monitor vulnerable groups
- Introduce processes to review serious, non-specific symptoms
- Maintain high index of suspicion for cancer in people with existing long term conditions and infrequent attendees
- In the medical record code for symptoms to enable the person's narrative to be followed.
- Consistently re-assess the working diagnosis
- Practice the 'three strikes and you're in' rule
- Trust gut feeling and if in doubt speak to a colleague / consultant

PATIENT FACTORS

As seen earlier, there were very few cases (Figure 5, three SEAs) where the person was described as the only contributing factor to the diagnosis being made through an emergency presentation. On several occasions the person was described as following medical advice and engaging well with GP services. Overall the patient's behaviour was seen to contribute in some way in about a quarter of cases in this audit through mechanisms such as; poor awareness of symptoms, symptoms being experienced for a long time, symptoms being denied or concealed, difficulties providing a good medical history, declining medical advice, reluctance on the part of the person to be tested, reluctance to come to the GP practice, failing to attend appointments, being slow to re-present to primary care or go for investigations, and difficulties accessing primary care including physical barriers and communication barriers. Each of these will be discussed in turn, see also the infographic (figure 1) for how these person factor elements are in some cases at the interface between the tumour and the person or the person and the system factors. The SEAs are completed within the GP practice and have not sought the opinion of the person diagnosed with cancer or their family so this section is the GP's reflection of the role the person played.

Awareness of symptoms

Key Findings:

- Interpretation of symptoms impacts person's behaviour.
- Most people presented to primary care in the year before EP.
- Bereavement can impact symptom interpretation.

This element lies at a point between the tumour and the person factor. How someone interprets their symptoms can impact on their behaviour. Symptoms can often be vague or atypical leading to a complex presentation, which the patient then has to interpret before they decide whether to take action or not. There were only three out of 184 SEAs where the person had no contact with primary care in the year leading up to their emergency presentation. Therefore in the majority of cases the patient had acted on the symptoms they were experiencing and had presented to primary care.

Sometimes the person presenting the symptom gave a plausible reason for their symptom such as it being associated with an injury or an allergic reaction. On one occasion the GP records that the person has researched their symptoms on the internet and was concerned about malignancy (F, 64, multiple myeloma). In a couple of cases the medical record noted that there was a family history of cancer which had led to some additional concern either by the GP, the person or both. The onus of being aware of a symptom sometimes shifted to others as in some cases the person's condition was discussed with other family members (usually the spouse or grown up child); this was either because the person was not able to clearly discuss their own health or they were unwilling to engage with medical care.
Those people who were in a nursing home or had regular carers sometimes had the GP discuss their medical condition with the nursing home staff or their carer, so again moving the responsibility for awareness on to someone else.

One patient was believed to have been either unaware of their symptoms or aware but interpreting them inappropriately as they were experiencing bereavement (M, 81, pancreas). A GP noted that one patient who had presented no symptoms to primary care stated after their diagnosis that they had believed their cough to only be "a smoker's cough" (F, 46, lung).

Length of time symptoms experienced

Key Findings:

- Length of time symptoms experienced before seeking medical advice generally varied from a few days to a few months.
- Delay in presenting symptoms to primary care was not a major contributor to the emergency route to diagnosis.

Overall the GPs in the audit highlighted very few cases where the patient was considered to have delayed presenting their symptom to primary care and this did not seem to be a major contributor to being diagnosed via an emergency presentation. The length of time a symptom was experienced varied between a few days (e.g. back, limb or chest pain, incontinence, neurological events, vomiting, diarrhoea, constipation, shortness of breath, swollen limbs, difficulty passing urine, rectal bleeding, jaundice, malaena), to a few weeks (e.g. tiredness, shortness of breath, cough, muscular aches, diarrhoea, pain, dyspepsia, sores on skin, loss of appetite, abdominal pain, weakness) to a month (e.g. lump in the neck, frequency in urination, tiredness, weight loss, back or abdominal pain, bloating, constipation) to a few months or longer (e.g increasing exhaustion, weight loss, change in bowel habit, intermittent chest pain, increased shortness of breath, PR bleeding, indigestion, abdominal pain, back pain, nausea, vomiting, headaches).

In a few SEAs, symptoms were experienced for many years and it was possible that for some of these cases chronic conditions and not the cancer were responsible for the symptoms. Often it is not known from the SEAs if the person had presented these symptoms more than a year before the EP as this data was not collected. Examples of long-term symptoms included back pain being suffered for 20 years (F, 51, lung), a history of blood in the stools for years (F, 62, bowel), several years experiencing dizziness (F, 92, pancreas), while one case recorded eight years of abdominal discomfort (F, 70, liver). A further case reported a history of 10 years of coughing but that it had only been keeping the person awake for two weeks (M, 75, lung).

Concealing / denying symptoms

Key Findings:

- People who don’t want to make a fuss sometimes minimised symptoms.
- Some people may have ignored symptoms.

For some people it was felt that they were not always honest about their symptoms and that they were minimised because the individual didn’t want to make a fuss. A possible reason for denying symptoms may be a reluctance to undergo invasive investigations. In one case where it was noted that a symptom (weight loss) was “explicitly denied” no explanation was given as to why that may have been the case (M, 36, stomach). A further example noted that the person and their family were reporting different symptoms to the GP (M, 82, bowel).

> “Diagnosis may have been confused / delayed by +ve h pylori and partial response to treatment. ....Suspect patient was somewhat stoical and not entirely honest about symptoms, family subsequently revealed to me that she had been concealing how ill she was feeling at her appointments with me.” (F, 68, stomach)

> “This man must have been aware of his testicular mass and chose to ignore it.” (M, 33, testis)

In another case the person was described as ignoring their symptoms (M, 33, testis). The GP rationalised the man’s decision not to present because he would not usually come to the surgery so would not have seen the advice available in the waiting room about testicular cancer.

Difficulty giving a good medical history

Key Findings:

- Some people found it difficult to provide a comprehensive medical history due to co-morbidities, such as mental health problems, Alzheimers and alcohol abuse.
- Problems could arise when the translator was a relative.

Apart from the person potentially concealing or denying symptoms, the difficulty of providing a good medical history during the consultation was sometimes put down to mental health problems or degenerative disorders such as Alzheimer’s. On other occasions this was attributed to lifestyle behaviours such as alcohol abuse. In one example it was believed that the presentation was masked by the person’s other social problems and that he may not have been taken seriously “due to the repetitive nature and presentation of ETOH” (M, 78, lung). In one case the person came to the consultation with many different problems and it was considered that this may have put the GP under time pressure to collect a good medical history (F, 78, bowel).

In a handful of cases a language barrier was given as the reason for the difficulty in collecting comprehensive medical details. When the person who was translating was a child (albeit an adult child) this was described by the GP as leading to the person being reluctant to disclose symptoms of an intimate nature (F, 57, cervix).

Declining medical advice / reluctance to be tested

Key Findings:

- Some people did not take responsibility for their own health.
- GPs felt that in some circumstances it was important to consider the person's wishes.
- There were a group of people who were not keen on hospital attendance or investigations.
- Alternative tests should be considered when people are reluctant to undergo specific tests.

"Patient still autonomous and if declined referral with knowledge that symptoms could suggest cancer then inevitably will be delay in diagnosis." (M, 60, oesophagus)

The medical records in some of the SEAs noted that the person went privately for some aspects of their care, this may have been in order to get an appointment sooner than they felt they could get through the NHS. However, some people were described as not fully engaging with their responsibilities over their own health or managing their conditions. This included self-discharging from hospital or not complying with health clinic instructions in terms of taking medications. In a few cases it was clear that the responsibility for health had been given to another family member, usually a spouse or child as they were the ones mainly in contact with the GP practice.

On one occasion the GP made it clear that the person was reluctant to follow the medical advice but that they were eventually persuaded to be admitted (F, 88, pancreas). In another case (F, DK, ovary) the person did not want to be admitted due to her caring responsibilities for her husband. In a further example the individual refused a biopsy or treatment after diagnosis as they were 89 years old and experiencing many co-morbidities. In this case the GP respected the person's wishes and did not put pressure on them to undergo further medical intervention (F, 89, lung). In a contrasting case the GP reflected that the sequence of events were probably not the most suitable as they followed a paternalistic medical model with much intervention rather than following the person's wishes (M, 96, bowel).

"The patient was resigned to her illness as she was elderly and in poor health. She declined any further investigation and was happy to be nursed and looked after at home, where she died peacefully surrounded by her family." (F, 90, CUP)

It was apparent from the SEAs that there were a group of people who were not keen on hospital attendance or investigations. The GPs did not know whether this was due to the fear of undergoing the procedure or fear of finding out the diagnosis. Some people were reluctant to undergo certain investigations or further assessments, in some cases this was believed to have led to a delay in the diagnosis. The GPs discussed in some SEAs how alternative tests could have been considered if the person was reluctant to undergo the initially suggested test. In one example the GP reflected that a barium swallow or a CT scan could have been offered to the person who did not want to have an OGD (M, 76, stomach). The appropriateness of trying to persuade some people to undergo diagnostic tests or hospital attendance was questioned by the GPs who felt that in some circumstances it was important to consider the wishes of the person and what was ultimately in the person's best interest.

> "This case has taught us as GPs to carefully consider a patient's condition and likely future pathway. Here, the possible clinical diagnosis was considered during an emergency admission and the patient went through investigations that were possibly not in his best interests."
> (M, 96, bowel)

Reluctance to come to the GP surgery

Key Findings:

- Some people were 'infrequent' attendees, or missed screening appointments.
- Reasons for reluctance to attend the surgery included no clear medical need and people finding GP visits stressful.

Some people were regular attendees to clinics for asthma or diabetes. No one in the sample was described as attending the GP practice unnecessarily or wasting the GP's time. The medical notes also recorded on occasion whether the person was a regular attendee at the GP practice and whether they attended their screening appointments. Some of the people were described as 'infrequent' attendees. Infrequent attendance could be down to several factors such as no clear medical need as well as a reluctance to use primary care services. Dementia was cited as a possible reason for non-attendance as well as lifestyle factors. One person was described as reluctant to attend the GP surgery as they found the experience very stressful (M, 80, stomach), another was described as leading a "reclusive life" and had not attended for seven years (M, 77, lung). One person is described as "a reluctant patient" (F, 80, lung) because she did not want to come to the surgery in fear of receiving more advice about stopping smoking. Most people did visit the GP at some point within the year of their diagnosis however one person tended to use the Out of Hours service who recommended that he attend the GP, which he did not do (M, 78, lung).

> "Patient took no responsibility for his own health. All contacts were initiated by wife or son."
> (M, 78, lung)

Failing to attend appointments

Key Findings:

- Missed appointments may be due to person’s poor health.

There were instances within the SEAs of people failing to attend appointments in both primary care and secondary care settings. Often there was no explanation for their non-attendance, this seemed to especially be the case for missed primary care consultations. For missed secondary care appointments there was some explanation put forward. In one example (F, 92, pancreas) the person had not been able to attend the two week wait appointment because they wanted to go on holiday and so the referral was returned to the practice. However, the person’s condition deteriorated so quickly that they were unable to go on holiday and presented as an emergency. So in this case it was likely that the route to diagnosis would have been an emergency one even if the appointment for the two week wait had been made. Sometimes the general health of the person made attending investigations problematic. For example in one case the person felt too unwell to attend for a chest x-ray (F, 79, lung) while another did not attend a referral due to severe depression (M, 58, bowel).

Slow to re-present or go for investigation

Key Findings:

- Some people will wait for an appointment with their preferred GP.
- Some people did not appreciate the seriousness of their condition.
- People can be falsely reassured after a normal test result.

The SEAs described how some people take a long time to re-present to primary care or to undergo an investigation which the GP had suggested. On occasions people choose not to take the first available appointment as it was not with the doctor of their choice and this may look like they have not presented in a timely manner. Some people were described as not appreciating the seriousness of their condition as they were slow to attend for further investigations such as blood tests. This could be an issue with how information was communicated by the doctor as well as how it was received by the individual and their families.

> “Safety netting was generally rather non-specific and may have contributed to the delay in the patient returning.” (F, 39, bowel)

In one case the person was described as perhaps being falsely reassured as her symptom of fatigue was put down to vitamin D deficiency. It was suggested that she may have returned sooner if this had not been the case (F, 70, bowel). In another case a normal cystoscopy was believed to have led to the person not re-attending for 4-5 months (M, 42, bowel).

Difficulty accessing primary care – physical barriers and communication barriers

Key Findings:

- Some people had home visits as they could not attend the GP practice.
- When people moved surgeries it could take up to 6 weeks to obtain their medical records.
- Communication barriers included language differences and mental health problems.

Difficulty in accessing primary care can be considered as a factor that overlaps between the person and the system. Several of the SEAs concerned cases where the person was in a care home or was unable to come to the GP practice to attend appointments; these people were generally then seen as home visits. However, their fitness to undergo certain investigations was specifically mentioned for people in nursing homes and may have impacted their route to diagnosis.

There can be difficulty in contacting the person if the address details held in the practice are incorrect. In one example the person had moved to a nursing home and the GP practice had not been informed, this led to delays in follow up (F, 90, stomach). In another example the incorrect contact details were obtained from the person this resulted in a delay in contacting them (M, 72, stomach). When the person moves, the onus is put completely on the individual to attend their new GP practice with any concerns they may have. One GP stated that it took six weeks to obtain the previous medical notes when a person registered from another practice (F, 44, lung).

Shared learnings / recommendations for GP actions to address patient factors:

- Raise patient awareness about cancer symptoms through information provided in the practice, on the practice website and opportunities during the consultation
- Implement processes to increase uptake of healthy life choices
- Consider initiatives to increase uptake of bowel screening
- Implement processes to target screening defaulters
- Establish which people find GP visits stressful, mark in medical record and if possible find individual solutions such as a designated quiet area
- Record medical history from carer's viewpoint also when appropriate
- Mark in medical record any communication barriers, address these through longer consultation slots or ensuring person is accompanied at consultations
- Be aware when person translating is a relative that sensitive symptoms may be difficult to capture
- Always ascertain and record patient's wishes in terms of medical intervention and end of life planning
- Ascertain reasons behind reluctance to be tested and try to offer alternatives where appropriate
- Establish reasons behind non attendance for patient who frequently miss appointments in primary and / or secondary care
- Ensure patient understands next steps at the end of the consultation by supplying appropriate patient information leaflets.

SYSTEM AND HEALTHCARE PROFESSIONAL FACTORS

In nearly two-thirds of the SEAs system factors featured as a contributing factor to the diagnosis via an emergency presentation. There are many parts to the underlying system and healthcare professional factor; primary care, secondary care and the wider cancer community, such as NICE who provide guidelines as to when referrals should be made. These will be considered individually.

PRIMARY CARE - DURING THE CONSULTATION

Areas which were discussed as part of the consultation included; communication with the patient, taking medical histories, performing examinations, being slow to refer or referring to the 'wrong' specialty which links to symptoms, issues around safety-netting and documenting, and the working diagnoses not being re-assessed.

Communication with the patient

Key Findings:

- Generally communication between the GP practice and the patient was good.
- Communication barriers included language problems, mental health problems, issues with memory impairment and reluctance of the patient to engage.
- GP had to rely on inaccurate information in some cases.
- Communication with the patient extended to communication with the family
- Important aspect of care especially with end of life planning.

Generally communication between the GP practice and the patient was described as good in the SEAs. In one case the patient was described as utilising the safety-netting advice and attending A&E when the pain and the vomiting worsened (M, 81, pancreas). There were however, comments describing situations where the communication could have been improved. For example one GP stated that they could have safety-netted by asking the patient to inform them if the appointment had not been received within five days so that it could be chased up (F, 75, lung).

As previously reported there were several barriers to communication described by the SEAs (see the sections on 'Difficulty giving a good medical history' and 'Difficulty accessing primary care'). Miscommunications could lead to emergency presentation which may have been avoidable; e.g. one person went to A&E after being advised they needed a chest x-ray and a two week wait referral (M, 44, mesothelioma). The GP felt that this man, who did not have English as a first language, may have misunderstood the consultation and was not familiar with how the referral system operated or how to use hospital services. Even in cases where a translator was present this could cause difficulties as mentioned earlier when relatives of the patient are the translators (F, 57, cervix).

The GP should be aware that information supplied by the patient may not always be accurate. In one case the GP commented that the patient was saying that they felt better, however, the

GP also noted that if the patient's weight had been taken it would have been possible for the GP to discuss the weight loss with the patient (M, 60, oesophagus). Communication with the patient extended to communication with the family in cases where the family were heavily involved in the health of the individual. In one case it was felt that the urgency of the situation had perhaps not been properly communicated to the family as the patient delayed going for their chest x-ray (F, 85, lung). In the same case it was noted that the patient had delayed their appointment by three days to discuss the two week wait referral as they wanted to see their own doctor face to face.

Communication was seen as an important aspect of care especially in the situations where the patient was very frail and did not wish for medical intervention. End of life planning was also mentioned in several SEAs, sometimes this was in place and the GP noted that the patient died at home peacefully surrounded by their family. However, on other occasions it was the speed of the deterioration in health and the resulting emergency presentation route that was described as being particularly traumatic for the patient and their family. This situation provided little opportunity for those involved to plan for a suitable end of a life and therefore the patient experienced a very poor quality of life leading up to their death.

> "Patients outlook and preferences for care can be a bigger influence than physical clinical pathways. Frank discussion with patients where appropriate helps delineate the patient's preference in an informed manner. Need to document clearly patient's preferences so that multiple clinicians and disciplines don't have to duplicate conversations" (F, 81, lung)

Taking medical histories

Key Findings:

- Challenges include communication problems, memory issues, mental health problems, reluctance to engage with primary care and restriction of consultation time available.
- Ability to review previous history during a home visit was limited.
- Important to review previous consultations and results for the context of the medical history.

The SEAs captured information from the medical record on patients' presenting symptoms at consultation. Often there was mention of how long the person had experienced the symptom and sometimes what the patient thought the reason for the symptom was. As discussed earlier under 'Person Factors' and 'Communication with the patient' there were several difficulties outlined with regards history taking, these were; communication problems with the patient, memory issues, mental health problems and reluctance to engage with primary care. From the GP's perspective there were particular issues with taking a good medical history within the constraints of the time available for the consultation and where the consultation took place.

It was noted by one GP that in the space of a ten minute consultation it was challenging to collect the amount of detail which was necessary (M, 42, bowel). If the consultation took place through a home visit the ability to review the previous history was limited. One SEA described how the history which the patient gave differed to that provided by their family and it would have been good to record both to see where the discrepancies were and how the patient may be questioned on some symptoms which they were perhaps denying (M, 82, bowel).

"importance of taking clear history and starting afresh when dealing with patients who attend regularly" (M, 78, prostate)

In order to make good clinical decisions, GPs felt it was really important to review previous consultations within the medical history, to add more context. The importance of a good medical history was emphasised in situations where other GPs were reviewing test results and deciding what action should be taken. In one SEA the time when good history taking was felt to be especially pertinent was when the patient presented as an emergency appointment in primary care as this was considered often a time when continuity of care might be broken (F, 39, bowel).

Examinations in primary care

Key Findings:

- Often correct examinations were performed and recorded.
- Certain examinations were sometimes not performed or not recorded.
- General opinion was to always examine the patient and note in the medical record.
- Normal examination could lead to false reassurance.

In many of the SEAs the examinations performed were recorded and on reflection it was felt that the GP followed the correct procedure. However, there were cases where the lack of certain examinations was noted or there were no examinations performed at all. In one case it was suggested that a neurological examination should have taken place when the patient described themselves as feeling 'spacey' (F, 63, lung). In another case it was felt that if a rectal examination had been done then the GP would have been alerted to a prostate problem and a two week referral would have happened at the first presentation (M, 65, prostate). Other SEAs suggested, in hindsight, the examination that should have been performed and recorded in the light of the symptoms which the patient presented with. For example, dark urine and low posterior chest pain should have led to an abdominal examination but this had not been performed (M, 63, bowel). In another SEA the GP questioned whether it was the patient's high BMI that led to them not being examined appropriately (F, 51, liver). The general sentiment seemed to be that the GP should always examine the patient if they had suspicions. One SEA noted that weight should be monitored even if the person has a high BMI (M, 66, lung).

It is possible that some examinations took place but were not recorded; the GPs stated in the SEAs that they should have been noted on the medical record to ensure continuity of care.

Physical examinations reporting normal results could have the same false reassurance effect of a normal result from an investigation. In one case the GP commented that it was important to re-examine patients if the symptoms were ongoing and not to rely on the examinations of other health professionals.

Referrals

Key Findings:

- Referral to 'wrong specialty' can lead to patient being discharged back to primary care.
- Sometimes multi specialty referral led to lack of ownership of the patient.
- Sometimes unclear which specialty to refer to, due to the non-specific nature of the symptoms and trying to follow the guideline criteria.
- Back pain was a difficult symptom to decide whether to refer for investigation or not.
- Referral made was sometimes appropriate based on symptoms recorded.
- Opportunity for earlier or speedier referral had been missed in some cases.
- Some patients refused referral while others self-referred to A&E.
- Local targets may have influenced referral patterns.

The route to diagnosis is influenced by individual GP's referral practice, ie, where, when and why some patients are referred or not, to whom they are referred and through what route. Variation and difficulty were noted in each of these areas in the SEAs.

During the time leading up to emergency presentation some patients had already had referrals in to secondary care. Referral destinations included departments such as physiotherapy where the patient continued to be seen, or the referral led to nothing being found and the patient discharged back to primary care (M, 78, pancreas). There were a handful of SEAs where the emergency visit happened before the referral appointment or investigation date had been reached. Sometimes a referral to another department such as physiotherapy led to advice to primary care regarding the patient's condition. In one example it was only after the physiotherapist mentioned drop that a referral was made to neurology (M, 28, brain & CNS). In this case, although the physiotherapist and the optician had suggested the problem may be neurological, the GP continued at first with orthopaedics thus delaying the eventual diagnosis. In a contrasting case, the GP stated that it was secondary care that had not followed up appropriately as the patient's condition deteriorated and the GP was requesting that an urgent OGD be performed (F, 27, oesophagus). One SEA outlined how the patient had multi-specialty input and this meant that no one was looking at them holistically (M, 78, lung).

> "Delays can arise then a 2WR referral results in a 'negative' diagnosis for cancer and the patient is referred back to the GP. Often the patient and the GP are falsely reassured that there is 'no cancer (anywhere).'' (M, 54, multiple myeloma)

One of the common themes regarding referral was the problem with not always knowing who the best specialty to refer to was due to the non-specific nature of the symptoms and the criteria in the guidelines. This meant that on occasion a referral was delayed or did not happen at all as the GP sometimes did more tests to try to establish what the underlying problem might be. It was mentioned on more than one occasion that it would have been useful to have a 2WW referral destination for patients with vague non-red flag symptoms but that give the GP cause for concern rather than force them into a specialty where the symptoms did not fit or wait for an emergency situation to arise. The issue of being able to order certain diagnostic tests such as colonoscopy or CT imaging was mentioned as one way to help with knowing which specialty to refer someone to, which might speed up the referral process. In another SEA the GP stated that they were unclear where someone with effusions should be referred to and at the time of completing the SEA they were still waiting for advice from the chest clinic (M, 44, mesothelioma).

> "we will now refer SVC obstruction via 2 week rule to respiratory and they can sort it out"
> (F, 75, lung)

The symptom of back pain was mentioned on several occasions as being a difficult symptom to decide whether to refer or not, especially in circumstances where there was a good explanation as to the potential cause of the back pain. As back pain was such a common symptom in primary care it was acknowledged that not everyone with back pain could be referred or have MRIs performed. Sometimes it was the appearance of a red flag symptom that prompted the referral, whether that was the emergency referral to A&E or an urgent referral that was then superseded by an emergency presentation. On occasion, referrals were made without a red flag symptom being present.

On reflection in some of the SEAs the GP noted that the referral made was appropriate. In one case the GP noted that a referral was made when many GPs would probably not have referred based on the patient's age and normal test results (F, 39, pancreas). Some of the GPs defended that there had been no referral as there were no symptoms present which would warrant a referral under the criteria which existed at the time and there was some acknowledgement that even in retrospect some cases were difficult to diagnose. For example one GP stated how it was difficult to know when to refer elderly patients with low grade anaemia as it may be nutritional (M, 93, bowel).

In another example the patients age meant they did not meet the criteria for two week wait referral (F, 32, bowel). There was some discussion in one SEA on how to refer urgently when the specific criteria were not met (M, 57, lung). An alternative referral pathway was suggested in one SEA which was to the geriatric day unit which offered swift appointments (F, 71, pleura).

In some SEAs on reflection an earlier or speedier referral did seem to have been missed and this could have avoided an emergency presentation. Some SEAs stated that red flag symptoms had been missed when the case was examined through the SEA process. For example someone

> "Beware of processing an "urgent" but not 2WR referral, what does this mean? This patient still had not received an appointment 5 weeks after the urgent referral was made and a telephone call at this stage still showed no appointment was in the pipe line."
> (M, 77, bladder)

with a seven month history of PR bleeding was referred as routine rather than urgent (F, 39, bowel). On another occasion a two week wait referral was 'missed' as the results from one of the investigations had not been seen by the referring GP (M, 77, bladder). A further case found that there had been a 3 day delay by the GP practice in faxing the two week wait referral (M, 72, stomach).

The SEAs mentioned symptoms brought to the attention of the GP by the patient's family and that these may be in addition to what the patient presents with or they may contrast with the patient account. In one case it was believed that the referral could have happened earlier if the symptoms reported by the family were acted upon as they fulfilled the criteria for a two week wait referral (M, 82, bowel). There were patients who refused referrals which led to the eventual diagnosis being made through an emergency route. In contrast some of the SEAs described how patients self-referred to A&E when their symptoms became very severe. One case described how the patient opted to go privately rather than wait for an NHS referral (F, 39, pancreas).

In one case the GP reflected on why they may not have done a two week wait referral for the patient whose working diagnosis was gallstones but had a possible abdominal mass. The GP suggested that a possible reason for doing in-house investigations and avoiding referral was that the practice was already over their target for referrals and that the CCG was monitoring their referral patterns (M, 82, bowel).

Safety-netting and documenting in the medical record

Key Key Findings:

- On occasion good safety-netting had been used well or appropriately.
- Safety-netting was more challenging when main contact was carer or family member.
- Safety-netting sometimes identified as being poor or absent may have contributed to the patient being slow to return to the GP if a symptom continued or worsened.
- Some cases with no record of an examination being performed or no working diagnosis led to difficulties making future comparisons and following the patient's narrative.
- Occasionally safety-netting recorded but not followed up by the next doctor the patient saw.
- Follow up was a key factor; following up results or ensuring that the patient returned for a follow up visit.

Many of the SEAs outlined instances where good safety-netting had been used well or appropriately and been recorded in the medical notes, this included recording negative history as well as examination results, advice regarding what to do if things did not improve and picking up when the patient had not attended for an appointment. For example, in one SEA a telephone referral was made to the Transient Ischemic Attack (TIA) clinic and the patient was told if there was worsening neurology then they should attend A&E (M, 79, lung). In another example the GP commented that the patient followed the safety-netting advice and did attend A&E when their symptoms worsened (M, 81, pancreas). In one SEA the GP described how the concern regarding cancer and the reason for the chest x-ray were discussed with the patient and that this was documented in the notes (F, 76, pancreas).

Sometimes safety-netting was identified as being difficult especially if the patient was reluctant to engage with primary care or if the patient had carers or family members taking responsibility for their health. In one example the GP commented that safety-netting was in place but it was reliant on the daughter contacting the surgery if their parent was no better and sometimes there seemed to be long gaps for this to happen (M, 82, bowel).

> "Seen Jan 2013 by GP with epigastric pain and vomiting, no further investigations done at this time, given a PPI, "safety netted" was documented but unclear what this was."
> (F, 70, liver)

There were however, cases where safety-netting was identified as having been poor or absent. This may have contributed to the patient being slow to return to the GP if a symptom continued or worsened and the patient was unclear about when they should return. In some cases there was no record of an examination being done and therefore no result in the medical record which future examinations could be compared to. It was also mentioned on occasion that no 'working diagnosis' had been recorded and that this would have been useful for subsequent doctors reviewing the patient. In one SEA the GP commented that the record from the Out of Hours consultation did not contain any mention of safety-netting (M, 44, mesothelioma). In another SEA the GP recorded the safety-netting around anaemia follow up as being inadequate as the request for repeat bloods was unclear as both a normal or abnormal result would have needed to be followed up (F, 72, ovary). This was felt to be particularly important in this case as it was possible that other clinicians would be checking the results. It was also considered important that results were noted and accessible on the GP record. In one case the letter indicating the abnormal scan had not been seen by the next doctor who saw the patient; the GP commented that it should have been downloaded onto the patient record and then flagged or coded as abnormal (M, 42, bowel).

Follow up was a key factor mentioned on several occasions, whether this was following up someone's results or ensuring that the patient returned for a follow up visit. There were several occasions where mention was made of safety-netting being recorded but not followed up by the next doctor who saw the patient. One case described how the district nurse had not done the requested blood test but the GP had failed to notice this and had not followed up (F, 83, bowel). In another case the patient had had several urine samples taken some of which had shown blood and one had not, three different doctors were involved in the consultations and were not all aware of all the tests which had been done, this led to a delay in making a two week wait referral (M, 77, bladder).

On one occasion safety-netting was done but the next GP who saw the patient did not spot what was recorded and so did not ask about relevant issues (F, 62, bowel). On another occasion the GP described how the patient was seen by seven different GPs over 18 months and how sometimes safety-netting was documented but not followed up by subsequent doctors (M, 75, multiple myeloma). The use of problem titles in the medical record was commented on by one GP where they described that for six face to face consultations there were only two records with problem titles and these were different to each other, this made following the patient's narrative very difficult for other doctors and may have resulted in less than adequate care (F, 78, bowel). In a further example the safety-netting advice was given in an answer phone message; on reflection this was not felt to be appropriate (M, 80, stomach).

Reassessing working diagnosis

Key Findings:

- Some cases with hindsight would have had the same route and outcome.
- 'Nondescript worry' should be considered a clinical sign.
- Cancer diagnosis masked by other conditions.
- Missing weight loss as a symptom could impact on the working diagnosis.
- Minimal contact with the patient made re-assessing the working diagnosis challenging.
- Sometimes lack of key symptom meant working diagnosis not re-assessed.
- More education needed re current NICE guidelines.
- Much overlap in symptoms and signs of some cancers.

It was clearly easier to see when something may have been missed in hindsight but several GPs commented that they remembered the case and that they had had concerns during the time leading up to diagnosis. Under the theme of re-assessing the working diagnosis, one GP noted that non-specific clinical concern should raise the index of suspicion. In contrast with some cases it was accepted that even with the cancer diagnosis it was difficult to spot any occasion retrospectively when something could have been done differently. In one example the symptoms were described as not having been at a level where cancer would be considered, especially as the person was relatively young (F, 40, bowel).

Many GPs commented in the SEAs that the examinations done, the investigations undertaken and the treatments that were tried were reasonable in light of the symptoms presented with. Although an alternative diagnosis was plausible some GPs occasionally commented that on reflection more could have been done to question the working diagnosis. Sometimes the alternative diagnosis was connected with lifestyle factors or mental health issues that could often make collecting a good medical history challenging.

The issue of the diagnosis being masked by other possible conditions was a theme of many of the SEAs. The impression was that there were opportunities for GPs to ask about red flag symptoms that had been missed as the focus was on another condition, often mental health problems or stress. As discussed previously, for some SEAs it was felt that there were multiple diagnoses and it was this complexity of the presentation which meant that some of the symptoms of the cancer may have been missed as they were being attributed to another cause. In one case where the patient was a long term migraine sufferer it was commented that the change in headache symptoms did not seem to have the importance attached to it that it should have done (F, 52, brain &CNS).

Weight loss was mentioned in many SEAs and not appreciating this as a symptom may have impacted on the working diagnosis. Some SEAs discussed how this could be addressed, and noted it may mean both increase in work load for the nurses if they were the ones to record and monitor the weight and extra responsibility to inform the GPs when weight loss had been detected. There was also the issue of sensitivity for the patient regarding having their weight regularly measured.

> “Multiple co-morbidities provide a ‘smoke screen’ for the emerging lung cancer” (F, 81, lung)

A feature of several SEAs was the circumstances leading to symptoms being missed either because the GP did not ask about them or the person had little contact with the GP practice thus making opportunities to re-assess the working diagnosis limited. One scenario was in patients who are on long term medications but did not visit the GP practice very often (M, 90, lung). Another situation was missing the opportunity to ask heavy smokers about lung cancer symptoms when they presented for other reasons. It was also felt there were some missed opportunities for those people who had multiple pathologies but were not regularly reviewed. Additionally if the person with multiple pathologies had seen many different GPs then there was the issue of lack of continuity of care, which may mean an opportunity for earlier diagnosis was missed.

If key symptoms were not reported by the patient it was believed to impact on the actions taken in primary care and the working diagnosis of cancer not having been made sooner. For example one GP commented that there was no jaundice in the patient, which was unusual for pancreatic cancer (F, 39, pancreas). Some GPs commented in the SEAs that there was no documentation regarding symptoms that GPs asked the patient about, but which they were not experiencing. It was felt to be important to document that a symptom had been asked about.

> “This case is a salutary reminder to think about bony metastases in patients with persistent non-mechanical pain.” (M, 87, thyroid)

It was also considered to be important that if the patient was to be reviewed that the GP who was documenting this in the notes was very clear about what their concerns were and what format the review should take. Follow up was mentioned on several occasions with one case highlighting that the patient’s anaemia had not been properly followed up (F, 72, ovary). There were certain combinations of symptoms that prompted GPs to reflect that cancer should be considered in these cases in line with current guidelines. It was not always the case that this was done in each SEA which led to the reflection that some more education was needed to remind the practice staff of the guidelines. There was also some discussion in the SEAs regarding the considerable overlap in the symptoms and signs for some cancers, e.g. ovarian cancer and gastrointestinal cancers. This is nicely demonstrated in table 9 and figure 3 earlier which show all the symptoms which were presented for each cancer type and indicates that most people presented with many symptoms leading up to their diagnosis of cancer. This shows the possibility that some were symptoms of the final cancer diagnosed while other symptoms were perhaps for other conditions. This will

> “It would appear that GP3 was considering Osteoporosis as a cause for the fracture and pain. No documentation of taking into account the advice from radiology who recommended MRI Spine.” (F, 64, multiple myeloma)

always make re-assessing the working diagnosis a challenge in both primary and secondary care. GPs commented that the new symptoms presented by the patient may not always have been considered in light of the past medical history and other new symptoms which could have meant the holistic view of the person was missed. It was acknowledged that some conditions such as hyponatraemia were difficult to deal with as there were no guidelines on what level to investigate at and there was a long list of possible diagnoses.

Shared learnings / recommendations for GP actions to address events during the consultation:

- Ensure all staff know how to access translation services
- Mark in medical record any communication barriers, address these through longer consultation slots or ensuring person is accompanied at consultations
- Record medical history from carer's viewpoint also when appropriate
- Always ascertain and record people's wishes in terms of medical intervention and end of life planning
- A detailed medical record is necessary in order to be able to follow the patient's narrative
- Review patient's history before consultation, especially for home visits
- Use risk profiling tools
- Enquire about red flag symptoms during history taking
- Use READ codes rather than free text
- Ensure all consulting rooms have weighing scales and regularly weigh patients where there is clinical concern
- If weight is being monitored set alerts on the patient record
- When there is clinical suspicion, do the examination, ie rectal exam, neurological exam
- Advise patients and record in notes that they should return if symptoms persist, especially if they have had a 'normal' examination or test result
- Ensure that patients understand that 2WW referral is to rule out cancer, provide 2WW referral leaflet (Cancer Research UK 2016)
- Note in the medical record whether patient attended referral appointment and outcome
- Keep 2WW log for co-ordinating attendance and follow up
- When referring a patient on the 2WW pathway GPs to clearly state their concerns, provide more detail when symptoms don't fit a specific referral criteria
- GPs advised to question downgraded 2WWs, expressing concerns about the patient and reasons for referral

PRIMARY CARE - PROCESSES IN THE PRACTICE

SEAs noted various processes which took place in practices that could impact on the route to diagnosis: including lack of responsibility for the patient, lack of vigilance for vulnerable people, continuity of care, and poor communication within the practice.

Responsibility for the patient

Key Findings:

- Some positive comments about the care that GP practices took of patients during the time leading up to diagnosis.
- Sometimes a lack of 'ownership' and responsibility towards the patient.
- Home visits sometimes rushed and consulting GP only has a summary output of the medical notes.
- Potential conflict in terms of person's wishes and best medical care.

In some SEAs there were very positive comments about patient care provided by the GP during the time leading up to diagnosis. Sometimes examples were given of the persistent attitude of the GP or how favours were called in to get investigations performed (F, 27, oesophagus). However, on reflection there were cases when there was a sense of there being a lack of 'ownership' and responsibility towards the patient. For example, one GP noted that the patient's GP did not "take it back with any vigour" when the patient was referred back from the geriatrician, further describing the GP's work up as "stopping at first base" (M, 75, bowel).

> "At his previous practice there appeared to be no ownership of the patient or sense of urgency of referral" (M, 28, brain and CNS)

In one of the SEAs there was some discussion about home visits and how they are for the most vulnerable patients but that they are often rushed and the attending doctor only takes a summary output of the medical notes compared with in the surgery where during a consultation the GP could look through the whole medical record (M, 82, bowel). It was felt that in this particular case the ability to see the trends in blood tests would have been helpful to refer the person quicker. In another case the GP stated that it was difficult to assess the patient's health as symptom discussion may have happened at 'routine nurse reviews', implying that these were not recorded on the medical record (F, 51, lung).

> "He was admitted to cardiology via the cardiac and stroke receiving unit and IHD excluded, abnormal inflammatory markers and GP f/u advised. 9 further consultations with GPs occurred before these were repeated" (M, 61, pancreas)

There was a potential conflict in terms of responsibility when the GP had to take into account the patient's wishes but also give them the best medical care they could. A further conflict was seen when the patient seemed reluctant to engage with primary care and take responsibility for their own health leaving the GP to question how much responsibility then reasonably fell to the GP practice. There was some discussion regarding this in several SEAs with one doctor commenting "Appropriate attempts were made to help manage the patient." (F, 86, skin). Offering smoking cessation advice was mentioned and discussed in several SEAs. In one SEA there was some debate as to whether quit smoking advice should be given at every opportunity especially as some patients had made it clear that they did not wish to receive this advice and there was a fear that this may put them off consulting (F, 84, lung).

Lack of vigilance for high risk groups

Key Findings:

- Groups identified as high risk included those with extensive co-morbidities, previous cancer diagnoses, mental health problems, alcohol issues, infrequent attendees and those reluctant to engage, those with high BMI and the elderly.
- Communication issues with patients recognised as having a potentially higher risk of delayed cancer diagnosis.
- Some groups, such as smokers, were 'high risk' patients but not always considered as such during their consultations.

Groups which were identified as high risk or vulnerable included those with already extensive co-morbidities especially COPD, previous cancer diagnoses and mental health problems, also those with alcohol issues and those who seemed reluctant to engage with primary care or who were infrequent attendees. People with a high BMI and the elderly were also considered as groups who could be high risk. When there were communication issues due to either language barriers or for example dementia these people were recognised as being potentially at higher risk of having their cancer diagnosis delayed. The SEAs commented on how vigilance for high risk groups by the GPs was necessary at all stages along the pathway in terms of what diagnosis was originally considered, the tests which were ordered and the follow up which was undertaken. Taking a holistic approach was especially relevant for high risk groups as it may be that their lifestyle or co-morbidities were key factors to considering a cancer diagnosis as the possible cause for their symptoms.

Some groups such as smokers were identified as being especially 'high-risk' patients and that this status was not always considered during their consultations leading up to diagnosis and it was suggested that some GPs had not been vigilant enough. It was also suggested that smokers with chest symptoms should be referred sooner rather than later but that not all patients with COPD could be referred on two week wait. A chest x-ray was not always requested for smokers; some GPs stated that it was an appropriate approach no matter what symptoms were presented and would have prompted an earlier diagnosis while others cited how there could be the risk of false reassurance from normal chest x-rays and a symptom should be present to justify a test.

"From what I can see this patient did not fulfil criteria for urgent referral – there was no mention of jaundice or weight loss, and no abdominal mass on first presentation. Her only risk factor was that she smoked." (F, 39, pancreas)

When discussing high risk patients there was mention about the use of various diagnostic tools, which in some cases the GP felt would have been useful to help diagnose the patient (F, 45, lung). The threshold of when to send someone for an investigation was discussed in several SEAs especially regarding chest x-rays for smokers or ex-smokers. It was acknowledged in one SEA that the practice did well at sending smokers or ex-smokers for an x-ray if they had a cough but that they did not have the same degree of urgency to send for x-ray if the symptom for this group was weight loss and that in this particular case the lack of chest x-ray may have extended the time to diagnosis (M, 64, lung).

Continuity of care

Key Findings:

- Continuity of care desirable but sometimes difficult to achieve.
- Continuity of care threatened when patient changed practices.
- Good record keeping and documentation meant continuity of care was less of an issue.

"Great continuity of care, the patient was well cared for throughout and was extremely pleased with the medical care she received." (F, 72, bowel)

"He was seen by several nurses & doctors although they could have seen the computer record they may not have had the same sense of symptoms persisting & progressing as if he had been seen by the same staff each time" (M, 28, brain & CNS)

Continuity of care was mentioned on several occasions as being something which was desirable but sometimes difficult to achieve due to the working patterns of the GPs, including part time working, GPs being on study days, off ill or on holiday, and the appointment system at the practice allowing for urgent same day cases to be seen. In some of the SEAs the fact that there had been good continuity of care was commented upon by the GP. Continuity of care was particularly difficult if the person changed practices and there was a delay in receiving the previous medical notes. In one case, there was a delay in the new practice receiving the medical notes from the previous practice which meant that important background information, such as the results of previous blood tests, was missing when the patient first consulted (M, 80, bowel). It was noted that seeing many different health professionals may have been the reason for there being less follow through of questioning what was happening (M, 61, pancreas).

In another example the patient was seen five times over six weeks plus one phone consultation all with different GPs, this resulted in a lack of continuity of care and no follow up was arranged at any of the consultations (F, 32, bowel). It was acknowledged that there could be delays if there was a discrepancy between the GP requesting the result and the GP who followed up the result. If there was good record keeping and communication between the GPs this was felt to be less of an issue. A few practices who did not have personalised lists questioned whether that would lead to an improvement, while one practice which had changed to a personalised list system felt that both the GPs and the patients were happier (M, 82, bowel).

Communication within the practice

Key Findings:

- Communication within the practice includes the role of administrative staff, record keeping and GPs discussing cases with each other.
- Not always clear if the examination had not been performed or it had not been recorded.
- Other health professionals were seen in the primary care setting during the time leading up to diagnosis and needed to be communicated with.
- Discharge summaries from the Out of Hours service sometimes needed better follow up.

Communication within the practice included the role of administrative staff, record keeping and GPs discussing cases with each other. There were instances of good communication such as doctors in the practice discussing vulnerable patients (F, 85, lung). However, some SEAs highlighted how poor communication within the GP practice could have led to the emergency diagnosis as actions were either delayed or the best clinical decision was not reached. In one example it was the receptionists who were designated as not taking ownership of tasks to request appointments, which could lead to it taking up to two weeks for patients to be contacted (M, 82, bowel). In this particular practice the system has been rectified so that contact is made within 48 hours and usually on the same day. In another practice there was still an outstanding problem with the way blood forms were pulled off the system meaning that requests remained active; this led to the wrong blood tests being performed on the patient and a potential delay in diagnosis (F, 67, ovary).

Sometimes the record keeping was commented on e.g it was noted that some examinations had not been recorded so was not clear if the examination had not been performed or had been done but not been recorded, this was mentioned several times for weight loss. There were also comments in the SEAs about the lack of documentation regarding discussion of test results with the patient. One GP commented that it was difficult to assess what had happened as there was a lack of documentation (F, 64, multiple myeloma). It was stated on several occasions how important it was to document the discussions which were had with the patient and the family regarding end of life care and possible future medical intervention. When this did not happen there was the possibility of the person experiencing an emergency presentation and invasive tests, which in one case the GP felt was not in the best interest of the patient (M, 96, bowel).

Communication within the practice extended to include other health professionals who were seen in primary care settings during the time leading up to diagnosis. In one case the nurse taking a blood test noted and acted on the severity of the person's condition was spotted (F, 74, CUP). In another case it was demonstrated that there was good communication between the professionals involved and that this facilitated quality and timely patient care (F, 67, kidney). For people who were resident in care homes there was some expectation by the GPs that the staff at the home would notice continuing symptoms and flag these up with the medical team but, this was not always felt to happen as well as it could.

> "Doctors are reminded of the importance of documentation of thorough examination."
> (M, 70, mesothelioma)

The use of the Out of Hours (OOH) service was mentioned in a few SEAs with some reflection on how the discharge summaries from this service were followed up (M, 78, lung). This was particularly relevant in this case as the patient used the OOH service more than they visited the GP and it was felt this may have contributed to his eventual route to diagnosis. In one case the GP reflected that if there had been better communication with the midwife then the diagnosis might have been made sooner as the midwife was the first health professional the patient reported their the breast lump to (F, DK, breast).

Shared learnings / recommendations for GP actions to address processes within the practice:

- Identify high risk patients in the medical records
- Consider annual health checks / blood tests for patients who are considered high risk such as smokers, those with extensive co-morbidities or a previous cancer diagnosis.
- Ensure patients on long term medications are seen at least once a year
- GPs to take blood taking equipment to home visits, to use when necessary
- Consider implementing a list system
- Patients attending frequently over a short period of time should see the same GP
- Train reception staff to recognise people who are unwell and need same day attention
- Reception staff to ask patients if they are returning with the same symptom to see the same GP if possible
- Ensure patient's contact details are up to date, especially when someone moves into a nursing home.
- Implement systems to ensure that patients records are transferred speedily between GP practices when someone changes their GP practice.
- Create opportunities to discuss difficult cases either in routine meetings or coffee-break sessions
- Ensure consistent practice of recording examinations in the medical notes
- Record communication with other health professionals in the patient record
- Ensure GP actions from other health professionals and discharge summaries are recorded and acted upon

DIAGNOSTIC TESTS

Diagnostic test use depends on three underlying factors; patient symptoms, GP assessment and decision to investigate, and what tests the GP can request directly. Many of the SEAs made reference to investigative tests and the impact that they had on the route to diagnosis. The tests that were ordered were often defended as having been the most appropriate test in the circumstances but there were occasions when a different test or a different interpretation of the results might have led to a quicker diagnosis or avoidance of an emergency presentation. There were many contradictions surrounding diagnostic testing, for example which was the most appropriate test, who should be ordering the investigation, how reliable are the results and can the reliance on diagnostic tests lead to delays as well as speedier diagnoses.

Comments in the SEAs regarding diagnostics fell into several areas; the availability of the test to GPs, the adequacy of the test, how long it took for the test to be done, how the results were received in primary care and how these results were interpreted.

Availability of the test

Key Findings:

- Not all GPs can send their patients for all the tests that they may want to have undertaken.
- Some GPs do not want more access to tests.
- Many cancers were diagnosed through CT scans but not all GPs could access these and some cancers were not identifiable on CT scans.
- GPs suggested alternative ways of accessing tests such as sending the patient to physiotherapy.

The route to diagnosis can be influenced by the availability of a diagnostic test. A GP must decide whether to test first or refer directly to secondary care. A GP would usually make this decision partly based on which tests were directly available to them when making the decision of how to respond to a symptom. There was some discussion within some of the SEAs on whether this was ideal or not. Some preferred to have a greater choice of tests while others commented that the specialist who could order the investigation was best placed to interpret the results. One GP questioned whether they should be doing cancer markers as these are not normally undertaken in primary care (F, 39, pancreas).

"We do NOT, in general, feel that direct GP access to CT scans would be particularly helpful as we are not in a position to interpret or manage the findings." (F, 40, bowel)

"We could manage patients better if we had access to urgent USS" (Male, 63, bowel)

Many of the cancers diagnosed through an emergency presentation in this sample were found through a CT scan though some cancers were noted as not being visible on the CT scan

"We are at the beck and call of the radiologist about when we can do CTs – GPs in our area are not allowed to request them without discussion with a consultant radiologist." (M, 75, lung)

even at the time of emergency presentation. In order for their patient to have a CT scan, which they could not refer to directly, one GP said they use the 2WW referral path to another specialty such as the gastroenterologist or colorectal teams (F, 69, disseminated malignancy). In another case the patient went themselves to A&E because the GP practice was not able to offer her an urgent ultrasound scan (F, 67, ovary). One GP questioned whether a GP should ever send someone directly for a sigmoidoscopy (M, 54, multiple myeloma).

There were some conditions such as back pain where it was felt that imaging investigation should have been considered. However, according to some GPs it was necessary to refer to the physiotherapists first, this could lead to a longer time to diagnosis.

"Access to urgent diagnostics would improve patient care, reassure Dr and Pt alike and potentially reduce A+E attendance." (F, 67, ovary)

Appropriateness / adequacy of the test

Key Findings:

- The test requested has to fit the person's symptoms or be prompted by lifestyle factors, i.e. a chest x-ray for a smoker.
- The appropriateness of specific tests such as the PSA and CA125 were questioned.

In the SEAs GPs felt that the test had to be appropriate to the symptoms which were presented but that certain combinations of symptoms or certain lifestyle factors should always prompt specific tests. In one SEA the GP stated that the patient should have had a chest x-ray when they were first diagnosed with COPD and they felt that this was the main reason why the diagnosis was delayed as a lung lesion could have been identified earlier (M, 71, lung). One GP commented that they could have offered a chest x-ray but the symptoms were gastrointestinal in nature so implying that that would not have been appropriate (F, 69, disseminated malignancy). However, in another example the GP suggested that as the person was a smoker a chest x-ray would have been appropriate although the main symptom was abdominal pain (M, 72, mesothelioma). Several SEAs commented that a chest x-ray should have been prompted for a smoker or ex-smoker without specific respiratory symptoms and this could have led to a cancer diagnosis. However the ability to find lung cancer in smokers through a chest x-ray was also questioned by one GP who cited a study showing that 20-25% of lung cancer patients have had a normal chest x-ray preceding diagnosis (M, 49, lung).

Some GPs suggested that certain tests are not appropriate to diagnose certain cancers. In one case the GP stated that ultrasound was "not a good diagnostic test for cancer of the pancreas" (F, 39, pancreas). Another GP, when reflecting generally on diagnostics, questioned the use of the CA125 marker to indicate ovarian cancer as it was not believed to be a sensitive test (F, 92, pancreas). Although some tests were discouraged, such as the ESR, in one case it was felt that it would have been useful to acknowledge the raised ESR as an indicator that "something was going on" (F, 69, disseminated malignancy). The use of PSA testing was also questioned and whether it should be routinely performed with some GPs supporting it while other GPs did not. In one case it was found that local guidelines and NICE guidelines differed regarding what should be done regarding PSA monitoring (M, 77, prostate). In one example a PSA test was believed would have led to an earlier diagnosis and avoided the unplanned emergency presentation but the GP suggested that the person was then likely to have undergone aggressive cancer treatment instead which may also have affected his quality of life (M, 73, prostate).

In one case the GP stated that an ultrasound would have been the best test but considering how ill the patient was it was more appropriate to admit the person urgently (M, 82, pancreas). Some GPs commented on the tests which they thought should have been carried out in secondary care and how on one occasion "The process was flawed" when the appropriate investigation was not booked by the hospital (F, 75, lung).

Timing of the test

Key Findings:

- GPs questioned how long a wait was acceptable for certain tests to be undertaken.
- Some GPs commented that appointments for some tests in secondary care took too long.

On the whole tests were performed within what was considered a reasonable amount of time by the GPs completing the SEAs. Some of the SEAs questioned whether a particular test could have been done sooner and how long a wait should be acceptable for certain tests to be undertaken. However, there was more than one occasion where the GP felt strongly that there were delays within secondary care in the test being done and reported (F, 75, lung; M, 77, bladder), and in another case there were problems with obtaining the biopsy result and the interpretation of the scan from secondary care (F, 70, liver). In contrast, early investigations and continuity of care were believed to be the reasons why one GP had early knowledge of a serious pathology despite an unusual emergency presentation leading to the final diagnosis (F, 69, disseminated malignancy).

"Following the upper GI endoscopy, the patient had been waiting almost another 4 weeks and still had not received an appointment for an ultrasound scan. Given that this patient was referred on a 2-week wait basis to exclude a cancer, surely more urgency and priority should have been placed in arranging this, especially as the endoscopy was normal?" (F, 89, liver)

Receiving results

Key Findings:

- Who filed the test results impacted on appropriate action being taken.
- The patient was informed about test results in various ways, including by phone, by letter and at the next consultation.

"It also goes against the concept of the clinician requesting a test being responsible for following up the result." (M, 42, bowel)

How the results of tests were dealt with in the GP practice was mentioned on several occasions. Best practice was often cited as the requesting clinician filing the results or the duty doctor looking at the results and the medical record to ensure appropriate actions are taken. An area of concern was highlighted in cases where the doctor who filed the results of the test was not the requesting doctor (F, 45, lung). In one SEA the GP commented that there was an incident where the GP practice had not received the results from previous tests and they had not been followed up (F, 79, lung). On other occasions the GPs felt that it took too long to get the results from a test. In one case this was believed to have led to a delay in referral compounded by communication problems with the patient who spoke little English and there was no interpreter (F, 52, lung). Usually the test results were relayed to the patient promptly however, on one occasion the GP notes that the patient wanted to specifically discuss the results with their own GP so there was a 3 day wait before the patient received the result (F, 85, lung). In another case the diagnosis was felt to be delayed because the result of the test was sent to the patient by post rather than by calling the patient directly (F, 80, bowel and bladder).

Interpretation of results

Key Findings:

- On occasions there had been false reassurance of a normal test result.
- Normal results should prompt further action when symptoms remain unexplained rather than simply filing as 'normal, no action'.
- Even normal results may show a change over time which should be noted.
- Abnormal results could lead to diagnosis of another condition, which could mask the cancer.
- It was important to provide detailed information from the medical history and the suspected diagnosis when a test was requested or discussed with secondary care.
- Abnormal results should always prompt an action.

Results can usually be classified into one of three groups; falling within a normal range, abnormal, or indeterminate. One of the most frequent comments in the SEAs regarding diagnostics was to not be falsely reassured by a negative result from an investigation or screening test. In one case the GP described how five days before the diagnosis of lung cancer the patient had a normal chest x-ray (M, 83, lung). Chest x-ray was mentioned on several occasions but was certainly not the only test cited where the results could lead to false reassurance. In one case the patient had undergone bowel screening and after an initial positive result had done two further tests which were negative so the overall test was considered negative; the patient shortly thereafter was diagnosed with bowel cancer and died from his cancer (M, 62, bowel). In another case a colonoscopy did not show bowel cancer but the GP suggested that the patient's symptoms of weight loss, new onset back pain, abdominal pain and abnormal bowel habit should have prompted further investigations as they were indicative of there being a cancer present (M,78, pancreas).

"Should have been followed up regardless as if abnormal needed treatment and if normal needed further investigation". (F, 72, ovary)

It was sometimes the case that a 'normal' test result should have been acted upon but was coded as 'normal, no action' and thus potentially missing an opportunity to diagnose by prompting other investigations to be undertaken. Some consideration was given in one of the SEAs about tracking the test results for an individual because although they fell within the normal range they could have shown that a change was happening (M, 54, multiple myeloma). It was acknowledged that this could be a time consuming exercise.

An abnormal test result could also lead to a diagnosis which then masked the cancer, as the alternative diagnosis was treated and focussed on in primary care. In one case the patient was treated for diverticulitis as the results from the tests indicated that this was the cause for the patient's symptoms (F, 72, bowel). In another case the patient was treated for vitamin D deficiency but this turned out not to be the cause of the fatigue that the patient presented to the GP (F, 70, bowel).

GPs were strongly guided by the reports they received from secondary care on the investigations their patients had undergone. One GP requested that more clear follow up thoughts be included in these reports and that any anomalies of chest x-rays should be discussed with a radiologist (F, 62, bowel). In one case it was felt that if the information on the chest x-ray request had been different then the results from the radiologist may have been reported with more concern and a CT scan would have been offered more quickly which could have led to an earlier diagnosis (M, 75, lung).

On another occasion the GP stated that the responsibility for not following up an abnormal blood test result lay with both the GP and A&E (M, 61, pancreas). There was a question raised as to when an abnormal chest x-ray should be repeated as the guidance stated that it should happen following appropriate treatment. However, on some occasions it was felt that perhaps rather than repeating tests it would be better to refer someone. Some SEAs indicated that the person had been neither retested nor referred and it was this scenario which led to the ultimate emergency presentation. In one example it was the apparent "relative good health" which deferred the GP from making the further enquiries about the abnormal tests (M, 72, mesothelioma).

There was also some reflection on whether further investigations should have been undertaken if the results from the test remained unresolved or were inconclusive. It was generally agreed by the GPs that unresolved test results and symptoms should continue to be investigated until an explanation was found. The medical record on some SEAs did not imply that this had happened, amongst others, there were examples for anaemia, constipation and urine retention not being fully investigated to find the underlying cause.

When considering the test results, some SEAs made mention of advice from others such as the radiologist, the medical registrar or a biochemist. In one case the advice given by the biochemist was questioned and it was felt that a referral should have been made despite the advice given (M, 75, lung).

Shared learnings / recommendations for GP actions to address issues with diagnostic testing:

- Agree within the GP practice protocols for requesting certain tests and undertake training sessions to understand the use of and limitations of common diagnostic tests for cancer such as the PSA and CA125
- Where possible make provision within the practice for same day testing for investigations such as urgent blood tests and ECGs
- Discuss with colleagues if patient’s symptoms do not fit protocol but there is clinical suspicion
- Ensure ongoing communication with the CCG with regards access to tests
- Use diagnostics in parallel with a 2WW referral where appropriate
- Ensure patients know how and when they will receive results
- Provide as much detail as possible on the test request form including if GP is suspicious of cancer
- Monitor that results have been obtained for tests ordered
- Have system in place to decide who has responsibility for receiving and acting on test results in the GP practice
- Record in the medical notes that patient informed of abnormal results
- Ensure abnormal results are followed up and re-assess working diagnosis if clinical picture no longer fits
- GP requesting test to note in medical record action required if test is normal
- Put system in place for tracking normal test results over time
- Re-assess working diagnosis if symptoms persist despite normal test results
- Unresolved test results should be followed up if symptoms persist

SECONDARY CARE

The system as a contributing factor to the cancer diagnosis via an emergency presentation featured in nearly two-thirds of the SEAs. This could have been any part of the system including primary care, secondary care and the wider cancer community incorporating organisations such as NICE who construct the guidelines relating to cancer referrals. This part of the report considers findings from the GP SEAs and the role of secondary care, the next part of the report discusses the role of guidelines. The role of secondary care was centred on five themes:

- investigations and diagnostic tests which were discussed in the preceding part of the report;
- issues concerning taking responsibility for the patient;
- communication with primary care and within secondary care;
- considering the complexity of the patient's presentation and taking a holistic approach;
- referrals and pathways within secondary care.

The final part of the analysis section of the report addresses the same five themes from the perspective of the Trust SEAs.

Responsibility

Key Findings:

- Issues of responsibility were present when the patient moved between primary and secondary care.
- Confusion over who was responsible for patient with regards to safety netting/chasing results, once a patient had been referred to secondary care.
- Discharge back to primary care – questions over how responsibility was handed back to the GP.
- A&E did not always provide an action plan to GPs.
- GPs perceived varying levels of care provided by secondary care.
- On occasion it was appropriate for primary and secondary care to share the responsibility for the patient.

The theme of responsibility split into two main areas within the GP SEAs. There were issues of where responsibility lay when the patient was moving between primary and secondary care and, secondly the perceived responsibility, from the perspective of the GP, that lay with secondary care when the patient was in their care.

"ENT should have followed this up, however never did, and was discharged from their care."
(M, 67, tonsil)

In one case the GP commented that it was usual practice for hospital colleagues to ask them to arrange for follow up with their patients, however, there was no system in place to ensure that patients were keeping appointments in secondary care and that the individual GP would need to follow that up (M, 42, bowel).

The transfer of responsibility from secondary care to primary care when the patient was discharged was discussed in some SEAs. The importance of arranging appropriate follow up was noted as being the responsibility of the GP. One problem which was highlighted was that subsequent blood tests may need to be compared with hospital blood tests but these may only be available in the discharge letter and not electronically (M, 82, pancreas). In another case the GP commented that the discharge letter from the hospital made no mention of the patient's raised LFTs and so there was no trigger for the GP to investigate further (M, 76, kidney). In a further case the patient was sent back to the GP as she did not attend her appointments in the breast clinic, there were extraordinary circumstances in this case, so the GP questioned whether the breast clinic needed to review its policy (F, DK, breast). The GP suggested that secondary care needed to monitor their own clinics and decide when it was safe to discharge someone who had missed a biopsy.

There were some comments from primary care regarding how those in secondary care took responsibility for the patient once they were in the hospital system. On occasions the comments were very positive and implied that in-patient treatment was appropriate and successful in reaching a diagnosis. However, there were several critical comments e.g. in one SEA the review in secondary care was described as "very basic and not very thorough" with the GP having to admit the patient acutely the following day (F, 79, liver).

"This patient's CT scan was arranged by the hospital and should they therefore have followed up and investigated potential causes of vertebral collapse?" (M, 75, multiple myeloma)

On one occasion the person under consultant review repeatedly needed antibiotics issued by the GP, so the GP questioned who had responsibility for following up the patient (M, 90, lung). In a further case which questioned shared responsibility, someone had blood tests done in A&E and they were not followed up, this was felt to be the responsibility of both the GP and A&E (M, 61, pancreas). In a similar case the GP questioned whether the abnormal blood test results should be followed up by the GP or was it reasonable for the GP to assume that the surgeon had adequately diagnosed abdominal issues (M, 76, kidney). In this case it was felt that a routine review would have brought the abnormal result to the GPs attention and more investigations could have been organised perhaps leading to speedier diagnosis.

"A+E being dismissive? – attended A+E at least 4 times over the year and usually well investigated, but 23/02/2014 the tone of letter is irritated. Bloods not done – 2 weeks later is admitted with metastatic cancer. Difficult when seen patient many times and for maybe what they deem not appropriate, but vulnerable. Patient who was likely not to really understand the GP system?" (F, DK, breast)

A further case demonstrated neither primary care nor secondary care taking appropriate responsibility. A patient had symptoms, which warranted a digital rectal examination, but this was not performed in five opportunities in primary care and two opportunities in secondary care (F, 32, bowel).

Communication

Key Findings:

- There are examples of good and poor communication between primary and secondary care.
- There should be promotion of the usefulness of seeking advice from secondary care.
- When patient is referred as much information as possible should be provided by the GP.
- Secondary care should provide as much information as is appropriate when discharging the patient or providing test results.
- Recording of information across the primary-secondary interface (including the private sector) can be problematic. Reports of missing information, or information not received in a timely manner.
- From the GP's perspective the patient should be told of their cancer diagnosis in secondary care.

There were instances of good as well as poor communication highlighted between secondary care and primary care, this included verbal communications as well as written communications (e.g. referring GPs requesting investigations and referrals and secondary care providing results and discharge summaries). One GP described how the practice had a good telephone and email communication system with the local consultants (M, 78, kidney). Another GP described how a discussion took place with radiology colleagues and this ensured that the ultrasound scan was done on an urgent basis which demonstrated good use of resources and team-working (M, 81, pancreas). Seeking advice from secondary care was mentioned in a few SEAs, one GP commented that if the advice offered did not resolve the clinical concern then be prepared to ask for further discussion or a second opinion (M, 32, bowel). Another GP reflected that it may have been better practice to contact a specialist within secondary care to ask for advice in certain circumstances (F, 81, breast), while in one case the GP felt restricted in that they were only able to request a CT scan after discussion with a radiologist (M, 75, lung).

The communication of patient information was discussed by some of the GPs. The consensus was that when a patient was referred or advice was sought then as much detail about the medical history should be given and if the GP had a concern regarding cancer this should be clearly stated. On one occasion it was felt that this could have been done better by the GP and may have led to the result of the diagnostic test being reported differently by the radiologist (M, 75, lung).

One GP commented that because they had not made it clear that bowel cancer was suspected the surgeons did not investigate appropriately (M, 59, bowel). In another case the GP commented that there was no indication from the radiologist that the fluid in the fissure was significant (F, 45, lung). There was also discussion regarding the communication with radiology with one case wanting more detailed information from them (F, 45, lung) while in another case they warn against just relying on the advice of the radiologist (F, 63, lung).

In a further case the GP commented that on reflection it would have been good for the primary and secondary care teams to have discussed how they could have worked together better (M, 60, bowel). Another practice also commented on how they had written urgent letters to try to get an investigation for their patient but had had no response resulting in a delay in diagnosis and worried and frustrated GPs (F, 27, oesophagus). On one SEA there was a comment that receiving the results of the CT scan had been delayed but that the family were aware of the presumed diagnosis and that the treatment was likely to be palliative (F, 87, oesophagus).

"If worried, be prepared to push back on secondary care or request further advice" (M, 32, bowel)

When the medical record was reviewed as part of the SEA process some GPs commented on how there was sometimes little information from a particular specialist who the patient was seeing outside of primary care, this included private consultations as well as documentation from A&E visits. It was felt that effective communication with these specialists would be useful and appropriate and if there was information missing it could impact clinical decisions taken in primary care. For example in one SEA the GP noted that several letters were not received from secondary care until after the diagnosis (F, 52, breast). In another case it was noted that for oesophageal dysplasia the full biopsy results were often not shared with primary care (F, 62, oesophagus). In one case it seems that the patient was not informed of their diagnosis, which had been incidental, in secondary care. The histology report was sent to the GP who then informed the patient of their cancer diagnosis (M, 17, neuroendocrine). In another example there was no documentation in the medical record to show whether the patient had been informed of the possible diagnosis by anyone, either primary or secondary care (F, 32, bowel). In a further case the patient was informed of their diagnosis by secondary care but had not understood that the prognosis was not life shortening and came to see the GP being very upset and considering life was not worth living (M, 77, prostate).

"The patient's first attendance at A&E results in a diagnosis of potential Hepatitis A, without it being clear why this was diagnosed as no discharge paperwork was received. Should there have been discharge paperwork, it would have potentially increased communication between primary and secondary care, allowing more rapid diagnosis." (F, 74, CUP)

"Some pathways are already different 2 years down the line, some are in evolution, but themes of handover and communication seem to persist!" (F, 86, bowel)

Complexity of presentation – taking a holistic approach

Key Findings:

- Re-assessing the working diagnosis was also relevant in secondary care and out of hours when the presentation was complex.

The mechanism of re-assessing the working diagnosis and the benefit of taking a holistic approach has already been discussed from the perspective of the practitioners in primary care. However, the GP SEAs also commented on how other health professionals, whether in secondary care or out of hours, responded to symptoms. For example in one case it was felt by the practice GPs that the symptom of drowsiness should have triggered an admission by an Out of Hours doctor (F, 52, brain & CNS). In another case the hospital was criticised for not making further investigations of the patient's rapidly progressing anaemia (F, 27, oesophagus).

> "Difficulty lies within liaison with and follow up within secondary care, seen as separate issues, not addressing single cause, and reminded to think of bigger picture when presented with several new symptoms." (F, 52, breast)

Referrals / pathways in secondary care

Key Findings:

- Multiple referrals to different secondary care specialties can lead to unclear patient responsibility and delay.
- A&E not always acting thoroughly on abnormal results.
- Speed of referral can be delayed (e.g. due to choose and book issues, or 2WWs being 'bounced back')
- Some GPs rely on gut instinct that something is wrong to push for referral.

In the GP SEAs there was a record of any contact the patient had had with secondary care leading up to the emergency presentation. In some SEAs there were also details about the patient's experiences post the emergency presentation such as the investigations they had, the teams they had contact with, their prognosis and their treatment.

In some cases there was a lot of contact between the patient and secondary care due to multiple referrals or previous A&E attendances before the emergency presentation. For example, in one situation the person was referred to gynaecology after a reassuring gastroenterology review, gynaecology then suggested redirecting the referral to gastroenterology. The GP commented that there was no clear documentation in the notes or the medical record of safety-netting having taken place in either primary or secondary care (F, 62, oesophagus). One SEA described how the person had two hospital admissions before the diagnosis and on both occasions was discharged the same day with no investigation having taken place (F, 52, breast). In another example the patient was described as having a chest x-ray which had changes but these were not followed up or commented on in the discharge summary (M, 78, lung). A further example described how A&E did not act upon the abnormal LFT results and that there was no clear plan of action in the notes received from A&E (F, 39, pancreas). One case in particular went in to a lot of detail regarding a patient referred under a two week wait system who had missed opportunities to diagnose their cancer; this meant that ultimately the cancer was diagnosed through an emergency presentation leaving little chance to arrange advanced care planning or consider the patient's wishes about place of death (F, 89, liver).

The care provided by secondary care was not always felt to be of the highest standards. In one case the care by the GPs was felt to be good overall as the GPs chased referrals and re-referred into hospital when the management of the patient was felt to be inadequate (F, 52, breast). In another case the GP practice wrote a letter of complaint as they felt the radiology department had been deficient in their care (F, 75, lung). In a further case there was a six month delay in seeing a gynaecologist after an ovarian cyst had been found which according to the GP SEA was due to communication problems within secondary care (F, DK, ovary).

The speed of referral being inappropriate was commented on in several SEAs. One case identified that the 'choose and book system' was not fit for purpose as the telephone number to call was never answered (F, 72, ovary). In another case it was the hospital which downgraded the two week wait referral to a routine referral; this was communicated to the referring clinician but was not documented and the GP completing the SEA stated that it was not challenged either and should have been (F, 70, liver). There was on occasion a sense from the GPs that they had to convince secondary care that their patient should be seen. The expression 'spider sense' was used more than once to describe the GP intuitively knowing there was something wrong but the diagnosis not being obvious.

"There was a 'sense' of some serious cause being missed, yet no real evidence for it – "GP spider sense"! This can make it difficult to convince secondary care colleagues to take the patient's symptoms very seriously – "nothing to hang it on"." (F, 40, bowel)

In some SEAs it was difficult to be clear who had referred to A&E whether it was the GP or the patient had self-referred, this information had not been explicitly requested. There was also sometimes detail of investigations undertaken in secondary care after emergency presentation and which investigation confirmed the diagnosis. CT and MRI scans and x-rays seemed to be the most commonly mentioned investigations but there were also colonoscopies and ultrasound scans which led to a diagnosis of cancer; some patients had had biopsies to confirm the diagnosis while for some it was recorded that they were not able to have a biopsy because they were either too frail or refusing further medical intervention. If the finding had been believed to have been incidental the GPs often commented on this. In one case the GP commented that the referral from the hospital specialist to the oncologist took eight weeks, which was felt to not be timely for an urgent referral (F, 52, small intestine). In a further example it was considered that the transfer of care from the acute admission team to the oncology department was poor as was the timing of the oncology appointments (M, 86, bowel).

THE ROLE OF GUIDELINES

The role of guidelines was mentioned in many of the SEAs. How the GP responded to the symptoms presented was in large part determined by the guidelines advising when someone should be referred, to whom and with what level of urgency. Guidelines were also used when considering which diagnostic tests should be ordered, but this was also heavily influenced by what was available to each individual GP practice as this was not consistent across the area. There were several elements to the role of guidelines including; symptoms do not always meet the 2WW criteria, there are varying levels of GP awareness of the criteria, some cancers are not represented in the guidelines and there is some clarity lacking as to the interpretation of some guidelines.

Symptoms not meeting criteria

Key Findings:

- Symptoms don't always meet requirements for 2WW referral, but warrant timely investigation.
- Some patients were admitted to A&E whilst waiting for a 2WW appointment.
- Sometimes symptoms fulfil criteria for the 'wrong' specialty.
- Some GPs 'found ways around the system'.
- Guidelines can sometimes be unhelpful and irrelevant.
- There can be missed opportunities for referral under 2WW.

Whether symptoms fulfilled the criteria for the two week wait referral pathway was one of the most common themes within the SEAs. Some people had been referred appropriately under the two week wait rule based on their symptoms. These cases did not lead to a cancer diagnosis because either the specialty referred to turned out to be inappropriate or the emergency presentation happened before the referral appointment. There was more than one example of symptoms fulfilling the criteria for the 'wrong specialty' amongst the SEAs. In one example the GP described how the patient fulfilled the criteria for two separate two week wait pathways as well as an urgent rheumatology referral but that none of these picked up the patient's cancer (F, 63, lung). Table 9 and figure 3 earlier illustrate for each cancer site how many different symptoms are presented at primary care. Overlaps in symptoms seem to occur across many of the sites, especially between upper GI and lower GI symptoms as well as gynaecological and haematological cancers exhibiting many gastrointestinal symptoms. Also lung cancer often presented with neurological symptoms as well as respiratory symptoms, which could have been as a result of metastases or other conditions.

> "...this would have been appropriate for a 2week rule referral to a nondistinct cancer referral path."
> (F, 75, lung)

It was stated on some SEAs that all the correct protocols and the 2005 NICE suspected cancer guidelines were followed, with extracts from the guidelines sometimes included on the SEA.

For example in one case the GP commented that the acute admission to the surgeons was appropriate as the patient had acute bowel obstruction (M, 80, bowel). Following the guidelines did not always mean that the patients were referred. Often, on reflection the reason given for the patient not being referred was that the guideline was followed and the individual did not fulfil the criteria for a particular pathway. This meant that the GP was given little option as to what to do, leading in some circumstances to frustrated and anxious GPs. However, some GPs suggested that they could have 'found ways around the system' by for example referring on the two week wait form and attaching a letter with their concerns (M, 76, stomach; F, 78, bowel), or sending the patient for geriatric review (F, 75, lung), alternatively discussing with the radiologist if the symptoms did not fit a particular two week wait pathway (F, 72, ovary). Another suggestion for getting a CT scan conducted for disseminated malignancy which had symptoms not fulfilling a single NICE protocol was to refer on the two week wait pathway to either gastroenterology or the colorectal team (F, 69, disseminated malignancy). As a result of the experience in the GP practice one GP commented on the SEA that they would no longer seek to investigate a SVC obstruction but would instead refer it to a specialty under the two week wait pathway (F, 75, lung).

"In April 2013, the patient had three appointments where malignancy was suspected but the site was unknown so a two week referral was delayed." (M, 78, bladder)

There were cases where it was clearly stated that the guidelines were "completely unhelpful / irrelevant" (F, 40, bowel) as the case was complex or unusual and it was important for the GP to depend upon their clinical instinct or "spider sense". Some GPs did question whether they could have been able to refer under the two week wait rules but often this seemed to be only with the knowledge of hindsight and an acceptance that even in retrospect some cases were difficult to diagnose. In one example the GP acknowledged that the symptom of 'diarrhoea' could have been the first symptom of the colorectal cancer but that it was reasonable to attribute this to gastroenteritis as it was only present for a few days and would not have qualified as a criteria leading to a two week wait referral (M, 87, bowel). In another case the GP stated that an opportunity had been missed because the NICE guidelines states that new COPD patients should have a chest x-ray, however in this case that would have only occurred one month before the patient died (F, 66, lung). In a contrasting case the guideline not being followed was believed to have been an important factor in the delay of the cancer diagnosis (M, 71, lung).

"This patient was aged only 40, and thus cancer is a priori unlikely compared to much older patients. Do younger patients 'miss out' as they often do not meet criteria for cancer investigations in national and local guidelines?" (F, 40, bowel)

Awareness of criteria

Key Findings:

- Some GPs lacked awareness of criteria for some 2WW referrals.
- Occasionally there were differences between NICE guidelines and local guidelines.

On reflection there were occasions where it was felt that the opportunity to refer under the two-week wait pathway had been missed. In one case the GP commented that twice the patient asked to be referred and this was declined, it was not clear from the SEA why their request had been declined (M, 61, pancreas). In another case the GP stated that there should have been a two week wait referral after the abnormal chest x-ray result (M, 87, lung). In a further case the patient was sent for an urgent endoscopy and not put through the two week wait system, although endoscopies were taking place in under two weeks it was felt after discussion that a two week wait referral would have been appropriate (M, 67, oesophagus).

There was an example in one of the SEAs where scrutiny of the guidelines led the GPs discussing the case to realise that the patient's symptoms of dyspepsia and weight loss should have resulted in a two week wait referral which had not happened (M, 36, stomach). There was an admitted confusion in another case where the guideline for referral for people over 50 with microscopic haematuria had believed to have needed two out of three positive samples having excluded urine infection when the actual guideline stated that unexplained microscopic haematuria should be referred after one episode (M, 77, bladder). This case was made more complex by many different health professionals being seen with assumptions being made about what was happening to the patient. This case highlighted the need for good record keeping as well as all the clinicians being aware of the criteria for referring under the two week wait rule.

> "The reason for the delay in diagnosis was not really acceptable in this case as due to additional change of bowel habit documented ... she should have been referred on two-week wait at this point as she was aged over 55 with change in bowel habit lasting greater than 6 weeks." (F, 62, bowel)

The 'new' versus the 'old' guidelines were mentioned in a few of the SEAs and how the clinicians' knowledge in the GP practice would need to be refreshed. In one SEA the GP noted that there had been a change in the guidelines for colorectal cancer with regards the haemoglobin levels and that now levels of less than 11 in women and 12 in men should prompt a referral (F, 92, pancreas). On a few occasions the difference between local and NICE guidelines was mentioned. For example with regards unexplained altered bowel habit for more than six weeks the NICE guideline was for patients over 60 while the local guideline was for those over 55 to prompt a two week wait referral (F, 70, bowel).

Cancers without guidelines

Key Findings:

- No guidelines available for some cancers (e.g. multiple myeloma).

For some cancers there were no clinical guidelines available at the time of diagnosis. For example one GP commented that there were no guidelines available for multiple myeloma but a guideline was expected in February 2016 (M, 75, multiple myeloma). The GP went on to state that there was some guidance published by the British Committee for Standards in Haematology but that it was 99 pages long and aimed towards secondary care and the technical aspects of managing myeloma.

Interpretation of criteria

Key Findings:

- Lack of clarity around interpretation of guidelines.
- Clinical decision support tools were used to aid referral decisions but occasionally identified patient as only at low risk.

In some cases the criteria specified in the guidelines was queried by GPs. For example one GP commented that a 'change in bowel habit' rather than specifying 'diarrhoea' should warrant a referral (M, 82, bowel). However, another GP commented that 'a change in bowel habit' would warrant referral under the two week wait referral guidelines issued by NICE (F, 70, bowel). There would seem to be some confusion regarding the interpretation of the guidelines. All the SEAs refer to diagnoses which happened under the previous 2005 NICE guidelines. These guidelines state that for 'change in bowel habit' it had to be to looser stools or more frequency for at least six weeks. In the new 2015 NICE guidelines the 'change in bowel habit' is less prescriptive so the change can be to constipation as well as looser stools.

How symptoms are described in the guidelines was questioned by several GPs with one questioning "How long is persistent??" (F, 64, multiple myeloma). For some symptoms the GPs seemed unsure what was the best action to take, for example in one case the GP questioned whether a patient with clinical pleural effusion should be admitted or treated with antibiotics and tests started (M, 59, lung). In another case the lack of red flag symptoms meant that the normal pathway for chronic cough without red flags was followed which led to a delayed referral while all the other options were worked through (M, 75, lung).

GPs did not only use guidelines to help with their decision making; they also used other available cancer diagnosis tools which have been developed. One GP mentioned that if they had put the patient's symptoms into the Macmillan cancer diagnosis toolbox which they have on their computer then at no time would the person's risk have been more than 1.5% which the GP stated would have been falsely reassuring (M, 75, lung). Another GP also commented on the use of the Shared Primary Care Cancer Risk Assessment Tools and questioned whether it needed modification as their patient with chest pain would have only received a low percentage risk score (F, 45, lung).

Shared learnings / recommendations for GP actions to address the role of guidelines:

- Ensure all clinical staff including locums have ready access to cancer referral guidelines and 2WW forms during consultations
- Retain a high index of clinical suspicion and do not always wait for patients to fulfil the two week wait criteria before referring
- More GP education needed around the referral guidelines
- Note within the practice differences between the NICE and any local guidelines
- Seek advice from secondary care where there are no guidelines available or clarity is needed for guideline criteria

TRUST ANALYSIS BY THEMES

When discussing the patient's route from emergency presentation to diagnosis of cancer and treatment, the Trust SEAs referred to the appropriateness of events along the pathway. Although 35 is a limited number of SEAs from which to draw conclusions, there did appear to be, five themes identified which captured important elements occurring within secondary care. These five themes were:

- investigations and diagnostic tests;
- responsibility for the patient;
- communication with the patient, with primary care and within secondary care;
- complexity of the symptoms - whether cancer had been the first working diagnosis considered before and after EP;
- pathways within secondary care to diagnosis and treatment.

Although these themes are intertwined and overlap, each of these themes will be explored in turn.

Investigations

Key Findings:

- The audit found that there were cases where both primary and secondary care had seen the patient in the year before the EP and as a result had ordered tests and investigations. Analysis of this information found variation in the number of investigations occurring before and after EP. Some tests before EP could have happened sooner..
- Some pre-EP test results should have prompted further investigation.
- Generally timing of tests after EP was appropriate.
- Delays in testing either due to capacity issues or patient's poor health.
- On a few occasions the test after EP was considered inappropriate.
- Some cancers were found incidentally while testing for another condition.

The Trust SEA was able to capture investigations which took place in the 12 months prior to the emergency investigation which secondary care were aware of as well as recording the investigations which had been ordered since the emergency presentation. The GP SEAs indicated that primary care is strongly guided by the reports provided by secondary care regarding investigations.

Pre-emergency presentation investigations

Amongst the Trust SEAs there was great variation in the number of investigations that had taken place prior to the emergency presentation. Some patients had had no investigations at all while some had had up to four investigations in the 12 months leading up to the EP. However, there was not always consistency between the GP SEA and the Trust SEA with investigations being recorded in one but not the other.

For the time leading up to the emergency presentation there were two key points made. Firstly, questions as to whether an investigation should have happened sooner and secondly, whether as a result of a test, further investigations should have taken place.

Investigations should have happened sooner

Only occasionally did the Trust SEA question why the patient had not been sent earlier for an investigation, usually because the Trust did not have the whole medical history of the patient and so were not able to comment on the events leading up to the emergency presentation. When they did comment in this area it was regarding whether people who smoke and have COPD should receive routine chest x-rays. Another comment concerned the suggestion that the GP should have requested the x-ray at the same time as referring the patient on two week wait (F, 52, lung).

> "Each specialty has expressed concern in the number of events and hospital contacts that were made in the lead up to the final diagnosis of metastatic lung cancer .... earlier CXR imaging would have been expected to lead to an earlier diagnosis of a malignant process." (F, 51, lung)

In one case where the patient had prostate cancer a comment was made that there had been several occasions where there was contact with urology but no PSA test had been undertaken (M, 88, prostate).

Within the Trust SEAs there was some questioning whether the ability of the GP to access imaging might have been useful (M, 88, prostate); the general consensus being that once the person is in secondary care the access to tests is quick and easy whereas from the primary care setting the access can be slow and, for some tests in some regions, prohibited

Further investigations should have happened after previous results

Often the hospital where the patient presented as an emergency does not have details about previous investigations which have taken place in other secondary care settings or privately. Secondary care does not tend to have access to the patient's medical records from primary care. Usually in the Trust SEA there could only be speculation as to why a previous abnormal result had not been followed up in primary care (F, 85, lung). There was one occasion where it was recorded that the urgent OGD that had been requested during a previous admission had not been sent to the patient and therefore had not happened (F, 27, oesophagus).

> "The report for the lumbar spine MRI was not available for 2 months having been done at a private hospital under the NHS" (F, 50, ovary)

Post-emergency presentation investigations

The Trust SEAs captured which investigations had taken place after emergency presentation and who had ordered the test. There was great variation in the number and type of tests performed after EP. All Trust SEAs documented at least two tests while one patient had nine tests undertaken. The most common tests were CT scans, x-rays, ultrasounds, biopsies and blood tests. Usually these were requested by the emergency department team, but they may have also been requested by specialties such as the gastroenterology or respiratory teams. Two main elements of relevance were the timing of the investigation and the appropriateness of the investigation.

Timing of the test

Generally the timing of the test was felt to be appropriate and led to the cancer diagnosis within a short space of time. Most delays were considered minor (usually a few days) and of no or little clinical significance. However, on occasion there had been longer delays that were considered avoidable. The reasons for delays, were either assigned to there being problems with capacity to perform the test, such as outpatient biopsies or PET scans, or the patient was not considered physically fit enough to endure the test. On a few occasions biopsies were either delayed or not performed at all due to the patient being too frail or in pain (F, 37, bowel). On one occasion the decision to wait three months for a repeat scan was questioned as the patient was by then inoperable whereas they may had been fit enough for surgery if the repeat scan had been performed at one month or six weeks (M, 79, lung). The Trust SEA suggested that the window of opportunity is usually quite small and should be considered when planning the length of time between interval scans

Appropriateness of the test

Generally the tests performed after the emergency presentation were considered to be the right tests but some investigations which were undertaken were not deemed appropriate. In one example the Trust SEA questioned whether the patient should have had a biopsy as they were not considered fit enough to have chemotherapy (M, 73, bowel). In another example the patient was considered to have been discharged too early before all the tests were performed and the CT scan was planned as an outpatient when it should have been performed as an inpatient (F, 51, liver). On a further occasion the MRI test had to be cancelled because the patient had a pacemaker and therefore the test was inappropriate (M, 87, thyroid).

> "Patient presenting as an emergency with symptoms of obstruction and AXR showing obstruction should have an inpatient CT .... Outpatient barium enema is an outdated test and should not be requested." (F, 50, bowel)

There were examples amongst the Trust SEAs where the cancer had been an incidental finding and the original reason for the emergency presentation had been prompted by another clinical concern but that when the cancer was identified the further testing was then appropriate (F, 52, small intestine).

Responsibility for the patient

Key Findings:

- The issue of responsibility mainly occurred when the patient moved between primary and secondary care.
- Generally, Trusts considered team working in secondary care was very good.
- The Acute Oncology Service, Acute Nurse Practitioners and Clinical Nurse Specialists all played important roles in taking responsibility for the patient.
- Pre-diagnostic phase was an important time to be clear about who had responsibility for the patient.
- Comparison of matched GP and Trust SEAs showed discrepancies in information held and perceived responsibility.
- Shared responsibility between primary and secondary care would have benefitted some patients.
- Responsibility in the community post treatment should also be considered.

The second theme was around the idea of ownership of a patient and who has responsibility at various stages in the patient's journey after they have presented as an emergency. Responsibility for the patient also extended to include the patient themselves and community support in some situations. It would seem to be the time when the patient moves between primary and secondary care where there is most likelihood of the aspect of responsibility being an issue.

Trusts' responsibility

Effective team working in secondary care was often put forward in a very positive light leading to a timely diagnosis once cancer was suspected. As outlined earlier many different teams were often involved after someone had presented as an emergency, with many tests being undertaken and decisions needing to be made. All the patients described in the Trust SEAs had been discussed in an MDT meeting to help make the most appropriate decision regarding further investigations or treatment. There was an example when one specialty overruled the oncologist as it was felt that the patient was not well enough for surgery (M, 33, testis). In another case although the patient had initially been deemed too ill for treatment, an improvement in health meant that they were referred back to acute oncology for palliative treatment (F, 85, lung).

"Pathway from Gynae MDT to treatment worked well but AOS should have been involved to help coordinate and expedite decision process"
(F, 67, ovary)

The acute oncology service (AOS) was outlined as playing an important role in ensuring that the patient always had someone who had responsibility for them. In one case it was felt that there was a role for the AOS to be available during the weekend so as to avoid gaps in the service as it would have meant the patient could have been referred to them on admission (F, 69, disseminated malignancy). In another case a comment was made about the issue of ownership between AOS and the upper GI MDT with neither team taking the necessary ownership (F, 39, pancreas). The involvement of AOS earlier in the process was felt to have been beneficial to expedite the diagnostic pathway when the patient presented with warning signs and symptoms (F, 67, ovary). The support of Advanced Nurse Practitioners (ANP) and Clinical Nurse Specialists (CNS) at an early stage was also put forward as benefitting the patient. One Trust SEA commented that there had been no input from CNS while another SEA commented on there being no contact with oncology or the palliative care team whilst the person was an inpatient (M, 86, liver).

However, team working was not always cited as effective. On one occasion the Trust SEA described how the normal results received should have prompted a specialty clinic to investigate further (F, 51, lung). One SEA questions who has responsibility when describing that an ultrasound which was requested to happen in four weeks took three months to happen (F, 50, ovary). Continuity of care was also commented on in describing a case in which a junior doctor commented on an enlarged irregular prostate but this was not acted upon (M, 88, prostate). In a further example which concerned junior doctors completing discharge summaries, a review at a multi disciplinary meeting was mentioned which did not actually happen. It was felt that the discharge summaries should be signed off by more senior doctors as they were ultimately their responsibility (F, 51, lung).

"DRs need to engage and discuss this case – it should be highlighted and the people responsible should be made aware of the gravity of the situation" (F, 27, oesophagus)

On reviewing the patients' journeys it was sometimes found that they had had many occasions when they had already had contact with secondary care before the emergency presentation and also had seen many different GPs in primary care (M, 75, multiple myeloma); there were potential missed opportunities to have investigated further or taken a different pathway (M, 61, pancreas). In one example where the patient re-presented to A&E with the same symptoms it was felt that the scan should have happened sooner and the A&E team should have been alert to the possibility of cancer (F, 51, liver). In another case the GP SEA suggested that A&E should have acted on abnormal liver function test (LFT) results; the Trust SEA did not comment on this for this patient (F, 39, pancreas).

There was much less clarity about patient 'ownership' in the 'pre-cancer diagnosis' stage. One Trust SEA described how in - house referrals to Cancer MDTs would reduce time and the potential for the patient to get lost in the system after they were referred back to the GP when nothing abnormal had been found within a particular specialty but the symptoms remained (M, 79, lung). Another suggestion was for the 'cancer of unknown primary' MDT to be involved early on in the care and diagnostic work up if cancer was strongly suspected (M, 52, liver).

"There is no one looking out for these patients with pre-cancer diagnosis – these scans should be followed up by maybe the surgeon or CNS – and clinic appointment made earlier – or GP involved to help discuss and support the patient" (F, 51, liver)

GPs' responsibility

The responsibility for the patient at the time when they move between primary and secondary care would seem to be the area where there was most discussion about where responsibility lies. From one of the GP SEA's there was an example where the GP had outlined that they believed the hospital team should have retained responsibility for the patient instead of discharging them, the GP does not seem to have taken back the responsibility at this point on this occasion (M, 67, tonsil). One of the Trust SEAs questioned whether there were any actions taken in primary care after an abnormal chest x-ray two weeks before the emergency presentation (F, 85, lung). In a few examples the Trust suggested that the GP should have referred the patient under the two week wait rule (F, 50, bowel; F, 67, ovary) but in one case the GP stated that the NICE guidelines were followed and did not fit with a two week wait referral (F, 67, ovary). There were a few occasions where the Trust SEA suggested that the GP should have followed up test results either because they were normal so another cause needed to be proposed or they were abnormal so further investigation was warranted (M, 61, pancreas; F, 37, bowel). It was not clear in these cases what, if any, recommendations were given with the test results which the GP received.

In one example the different perspectives and information in primary care versus in secondary care became very clear. In this case the Trust SEA suggested that the GP should have acted sooner to refer the patient to secondary care as they had a long history of illness and symptoms. However, the GP SEA had no record of any symptoms being presented except for the consultation which happened the day before the emergency presentation. The GP SEA questioned why the hospital took so long to do the necessary investigations after the emergency presentation while the Trust SEA stated that all the appropriate investigations were performed (M, 52, bowel). It may sometimes be difficult to know where responsibility lies when the possible 'owners' of the patient are not fully aware of all the information relevant to the patient.

> "There was no delay in reaching the most likely diagnosis of malignancy at least from the moment of the hospital admission. There was a discrepancy between the GPs clinical examination of the abdomen and the findings on admission"
> (M, 61, pancreas)

On occasions the responsibility was felt to be shared between both the GP and the Trust especially in situations where high risk individuals were involved such as smokers with COPD and the consensus was that primary and secondary care should be constantly considering lung cancer in these cases. In one example the Trust SEA acknowledged that the person should have been seen and treated sooner but that their social issues made it difficult for them to engage with medical help at both primary and secondary levels (M, 51, upper GI).

Patient and community responsibility

Transferring responsibility to the patient only was seen as an inappropriate course of action by the GPs. In one example the patient was sent letters by two separate clinics about an incidental finding and that they should go to see their GP to get a referral. This did not happen and there was no follow up by the clinics and no direct transfer of responsibility from secondary to primary care. There was no information available to know whether the patient received the letters and if they did why they did not act on them (F, 50, ovary).

One Trust SEA outlined how there was a need for increased education in the community so that people were aware of symptoms and when they should present them to a GP (M, 67, tonsil). Responsibility for the patient in the community was also considered in some SEAs. In one example the Trust SEA outlined that the patient had stated that they had not felt well supported in the community since their diagnosis (F, 67, ovary).

> "Patient was in hospital for nearly 3 weeks. If appropriate support services in the community had been more readily accessible he could have got home sooner. Improving this of course is an on-going focus of effort throughout the Trust" (M, 62, lung)

Communication

Key Findings:

- Communication with the patient was particularly important during the pre-diagnostic phase.
- Not all patients had a date for when they were informed of their cancer diagnosis.
- There were barriers to communication such as language differences and social issues.
- Examples of both good and poor communication with the patient's GP practice.
- Perceptions of communication between primary and secondary care did not always coincide between the matching GP and Trust SEAs.
- Both GPs and Trusts felt written and verbal communication needed improving between primary and secondary care.
- Within secondary care there were occasions where the medical record could not be found.
- Previous test results from the same hospital, other hospitals and the private sector were not always available.

There are many elements to communication, including verbal communication with other practitioners in either the primary or secondary care setting as well as communication with the patient and their family or carers. Another element to communication was written documentation including the medical record, discharge summaries and requests for investigations. There were instances where communication with the patient, with primary care and within secondary care worked well and this was highlighted in the Trust SEA. However, when communication did not happen well this was cited as a possible cause for delays and a worse patient experience.

Communication with the patient

Closely linked to the theme of responsibility was the notion that the patient needed to have an identified key worker who could 'own' the patient and be the point of contact for the patient and family (and also GP) to be able to discuss concerns and worries. Many of the Trusts had a system in place but it would seem that this was not always used (F, 69, disseminated malignancy). Communication was deemed particularly necessary with the patient in the pre-diagnostic phase when many tests were being performed and many different teams were involved in the patient's care. It was felt important that if there were delays with clinic appointments that the patient and the GP were informed (M, 88, prostate).

> "Patient should have been seen and treated sooner however had social issues which made clinic attendance etc.. difficult" (M, 51, upper GI)

In the majority of the Trust SEAs a date was given as to when the patient was informed of the diagnosis, in four of the 35 cases it was not clear if or when the patient was told. Sometimes the patient was told of the potential diagnosis before a procedure and then this was confirmed later.

Communication with the patient was particularly important if the patient had decided not to undergo treatment or further investigations (M, 62, lung). Trusts noted that to enable patients to feel supported there was a need to improve communication with them (F, 67, ovary). Communication with the patient was not always easy and it could be that there were barriers such as language or social issues which made good communicating a challenge (M, 51, upper GI).

Communication with primary care

The patient's notes in secondary care could demonstrate whether there had been communication with the GP or not. Both instances were found in the sample, for example in one case there had been regular updates (M, 33, testis) while in another case there was no evidence that the GP had been made aware of the involvement of the oncologists (F, 85, lung). It was also felt that improved communication was needed with the GP so that the GP would refer what the Trust considered to be appropriate cases (F, 67, ovary). Close interaction between the primary care team and acute oncology was recommended. One suggestion was for there to be telephone advice lines so that the GP could access the Acute Oncology teams if they suspected malignancy in one of their patients. This had the added advantage of AOS then being able to track the patient they had given advice about (M, 79, lung).

> "It is concerning that the discharge summary does not record / highlight the abnormal liver function tests. There is no reference to these being monitored in the future and the GP would have been unaware of these results"
> (M, 86, liver)

For the 30 Trust SEAs which had a corresponding GP SEA it was possible to consider the communication between primary and secondary care from both perspectives. The comments about communication did not always coincide, with examples of one group believing that communication went well while the other group felt communication had been poor. In one example the GP SEA described how the communication between the specialty and them was inadequate while the Trust SEA felt the communication was good because the GP was informed within 24 hours of the cancer diagnosis (M, 67, tonsil).

In the GP SEAs there were often comments about the reports and discharge summaries which were received from secondary care and how on occasion these were not very comprehensive and often lacked a clear plan of action for the GP. One Trust SEA described how a discharge summary mentioned a chest x-ray which was not performed and that this may have falsely reassured the GP (F, 51, lung). From both Trust and GP SEAs there was a need identified for better communication between primary and secondary care, especially in the cases where the patient had longstanding unexplained symptoms (M, 61, pancreas).

Generally, A&E does not have access to the patient's primary care medical record. If the patient has been referred to A&E by the GP there would be some information accompanying the patient at the time of their arrival in A&E. However, this information was not always felt to be accurate enough to inform the clinician who was seeing the patient (M, 61, pancreas). If the patient self refers there was no information available beyond what the patient or the carer themselves supplies. When a patient arrived in A&E it was felt that it was not usually possible to contact the GP to discuss the case so some access to community records was considered beneficial especially in cases where the patient kept presenting with similar symptoms (F, 27, oesophagus). It was suggested the computer system may be able to flag these cases to help arouse suspicion and prompt appropriate investigations.

Communication within secondary care

When communication between teams went well it was highlighted as showing that this led to effective team working and fewer delays. For some patients the notes demonstrated that there had been discussion between the oncologist and the specialty but in one example this had not been ratified by the MDT (M, 33, testis). All patients had been discussed during at least one MDT meeting with one or more specialties, more specialties were involved if the case was complex and in several cases the palliative care team were also involved in these discussions.

As stated earlier, communication could be both verbally and in writing. In the Trust SEAs there were occasions where the medical records of the patient had not been found and therefore some aspects of the patient's care were difficult to comment on. When investigations had been performed in other secondary care settings, NHS or private, the hospital where the patient presented as an emergency did not always have access to these results, this could potentially impact the path to presentation or mean that the patient had to undergo unnecessary repeat tests (M, 88, prostate). Even when the investigation had happened in the same hospital there was not always guarantees that the results would be available. In one case the blood tests taken at the previous A&E attendance were not recorded in the clinical notes (F, 37, bowel). In another case it was likely that the ward staff did not see the report which advised further investigation as the patient was discharged on the same day as the test (F, 50, bowel).

"During his acute admission he gave a history of having had a colonoscopy in another hospital. No further information could be found on that, so no comment can be made" (M, 52, bowel)

Information not shared properly either between teams or within teams in secondary care had the potential to impact on the patient's care. For example there was a case where the patient had been in A&E two days before the emergency presentation with the same symptoms and this had not been flagged and therefore contributed to inaccurate patient management (F, 51, liver). The role of the Acute Oncology Service was mentioned as being a key one to aid communication both with the patient and with other teams within secondary care to expedite the diagnostic process (F, 52, lung).

Complexity of symptoms – taking a holistic approach

Key Findings:

- Opportunities for re-assessing the working diagnosis exist in both primary and secondary care.
- After EP when symptoms suggested cancer then the pathway was appropriate.
- When cancer was 'masked' by other conditions delays could occur.

The complexity of the presentation of the symptoms by the patient may have had some bearing on the pathway which was taken leading to the eventual emergency presentation as discussed earlier in the analysis of the GP SEAs. However, even after emergency presentation there were still cases where the symptoms did not immediately suggest cancer and other specialities were involved in the patient's care. Having a working diagnosis and being able to consider alternative diagnoses was relevant both before and after the emergency presentation. Both of these were discussed in the Trust SEAs.

Considering alternative diagnoses before EP

The Trust SEA occasionally commented on what they considered would have been appropriate action within primary care based on the information they had on the patient. In one example the Trust suggested the patient could have had more aggressive management if they had been referred earlier based on the patient having had three courses of antibiotics and an abnormal chest x-ray. However, upon examining the GP SEA it becomes apparent that the patient had mental health issues and had refused repeat x-rays (M, 62, lung). In another case the Trust SEA suggested that the GP may have assigned the patient's deterioration and symptoms to their existing COPD diagnosis and did not perhaps consider the emerging lung cancer as a potential cause (M, 70, mesothelioma).

> "Patients attending for a number of day case related surgical procedures over a period of time may be better served by occasional senior outpatient clinical review. This would enable assessment of any potentially changing clinical scenario."
> (M, 88, prostate)

The Trust SEAs commented on occasions where the cancer diagnosis could have been considered during previous contacts with secondary care. In one example where the patient had had several outpatient appointments it was noted that no PSA test was performed which could have indicated the underlying malignancy (M, 88, prostate). Sometimes it was only with hindsight that earlier symptoms which brought the patient into secondary care were recognised as being due to the malignancy (F, 37, bowel).

Considering alternative diagnoses within secondary care after EP

Patients in this audit presented in A&E for two different reasons: either the severity of the symptom of the cancer had led to an emergency presentation or they had a symptom for another condition and the malignancy which was subsequently diagnosed could be considered as an incidental finding. Both examples were found within the sample of Trust SEAs.

When there was a clear indication that the symptom leading to EP was due to cancer then the pathway to diagnosis was clearer and the appropriate tests were ordered and acted upon which usually involved several teams (M, 61, pancreas). However, delays could occur if the cancer was not immediately suspected. One of the reasons for this lack of suspicion could be if the patient had known co-morbidities and the symptoms were originally assigned to that (M, 57, lung). Another reason could be that the patient was young and therefore cancer was not readily suspected (F, 27, oesophagus). A third reason was if the symptoms suggested an alternative diagnosis as was the case in one example where DVT was diagnosed due to the symptoms of chest pain, shortness of breath and possible calf swelling (M, 61, pancreas).

In the cases where the cancer was found incidentally it was considered important that the finding was acted on promptly so that appropriate treatment could be started (F, 52, small intestine). Incidental findings were not necessarily early stage disease for example in one case the patient had had a urinary infection and the renal ultrasound showed the liver metastases from a stage IV colorectal cancer (M, 73, bowel). In another example of an incidental finding the patient's testicular mass was picked up on clerking and had not been the original reason for the emergency presentation, this again was a stage IV cancer (M, 33, testis).

There was awareness in the Trusts that cancer symptoms are not always obvious. Suggestions were made in the Trust SEAs as to the importance of educating junior doctors on the different ways in which cancer presents itself (M, 55, lung). On reflection it was felt there were cases where cancer should have been suspected more readily due to various factors such as the age of the patient and the symptoms (F, 51, liver) or the risk factors such as smoking leading to a lower threshold for investigation (F, 51, lung). It was noted that groups such as smokers with COPD are at high risk of lung cancer and that while they are being investigated the possibility of lung cancer should not be overlooked through attributing symptoms to the already known diagnosis of COPD (M, 79, lung).

> "An AOS outpatient clinic whereby there would be time to follow up these patients that present to A&E to see if their symptoms have resolved" (M, 55, lung)

Pathways

Key Findings:

- Many patients had previous secondary care contact before the EP so there were some potential opportunities for sooner diagnosis.
- Generally a clear pathway existed from EP to diagnosis.
- Delays on the pathway included capacity to perform a test, delay in receiving results, patient's frailty, MDT issues and patient's co-morbidities.
- Most patients had contact with oncology but this was not always timely.
- Most patients received palliative care..

There was discussion of the pathway for the patient after the emergency presentation which led to the diagnosis but there was also some discussion of the potential earlier referral times and the potential missed opportunities when the patient had been in secondary care in the 12 months before the EP. There seemed to be a general consensus that "early referral to appropriate team makes all the difference in a patient pathway." (M, 67, tonsil)

Pathways prior to Emergency Presentation

There were occasions when the patient had had previous contact with secondary care, either through an A&E visit, an outpatient appointment, an inpatient episode or an investigation. These may have occurred before the symptoms leading to the cancer were present. The previous secondary care contact was not always with the specialty where the eventual cancer was diagnosed so would not necessarily have always provided the opportunity for earlier diagnosis. However, it was felt that on occasion the opportunity to do an investigation was missed (F, 51, lung) or a more holistic approach could have been taken and the working diagnosis questioned if not all symptoms were explained. The completed Trust SEAs tended to be on patients diagnosed between 2012 and 2014 when it was usual practice for patients to be referred back to primary care from individual specialties. It is generally now the case in England that referrals will happen between specialties within secondary care if it is deemed to be appropriate

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> "Was there indication for referral by GP to Lung 2WW? Did the background COPD obscure the incidence of Lung Cancer or effect the decision making process?" (M, 79, lung)

Usually the opinion was that it was best that the patient was referred into the correct specialty through a two week wait pathway as they were then seen by the appropriate medics (F, 67, ovary). Some of the Trust SEAs suggested that the GP could have used the 2WW pathway sooner based on the symptoms which the patient presented with and the medical history the Trust had available to them (F, 50, bowel). However, this was not always the case and in one example the Trust SEA stated that the patient was seen more quickly through the EP route than they would have been through the 2WW route implying that the patient had been referred by the most appropriate path for their symptoms (M, 67, tonsil).

There were cases where the patient had had contact with the relevant specialty and had been discharged back to the GP with the comment that nothing had been found (M, 67, tonsil). On another occasion the previous admission had not led to the appropriate test being performed although it had been requested it was suggested that more robust pathways were needed for these cases (F, 85, lung). In one case the patient had had some investigations performed through the private sector but there was no access to the notes, this was commented on as being a matter of concern in the Trust SEA (M, 88, prostate).

Pathways since Emergency Presentation

For some patients the pathway was considered complex from emergency presentation to diagnosis and treatment. The patient may have presented as an emergency for symptoms unrelated to the cancer and the finding was an incidental one. The Trust SEAs often described the pathway in terms of its appropriateness and timeliness of the different stages leading to a cancer diagnosis. The importance of a definite cancer diagnosis was stressed as being paramount to leading to referral to the correct oncology team. The pathway was generally considered appropriate once the person had presented at A&E and cancer was suspected with the involvement of lots of teams, including acute oncology and at least one MDT meeting and many tests being undertaken. This was generally the case with the cancer sites in the sample including cases where the primary site could not be properly identified. However, not all sites were considered as having clear pathways, for example it was questioned whether some of the rarer sites such as metastatic germ cell tumours had a clear pathway (M, 33, testis).

The Trust SEAs stressed how important it was for the patient to have access to supporting services, which was only possible once they were on the "correct pathway" (M, 55, lung). It was suggested that it would be beneficial for patients to have a point of contact during the diagnostic phase of a cancer journey to help facilitate referrals and provide a faster pathway (F, 69, disseminated malignancy). This role could have been fulfilled by either a clinical nurse specialist or someone from the AOS team; when this had happened the lack of input was commented on (M, 88, prostate).

There were times when the pathway within secondary care was inappropriate and therefore it took longer than it should have done; this could have been for several reasons. There may have been problems with capacity to perform a test, there may have been delays receiving the results, the patient may have been too ill to undergo a test or start treatment or there may have been issues concerning discussing the patient at the multi disciplinary team meeting.

> "There is a requirement for 'fast-track' biopsies in patients who are discharged with a possible cancer diagnosis. There should also be a clear route from this fast-track to referral to the appropriate MDT" (F, 69, disseminated malignancy)

The pathway between diagnosis and treatment was considered as too long due to the use of outpatient appointment slots; e.g. the PET scan pathway was highlighted as one area which needed improvement (F, 51, liver). In another example the time to ultrasound was considered as being too long (F, 50, ovary). In one trust it was suggested that the pathway from A&E and blood tests to getting the biopsy performed should be smoother (F, 39, pancreas). In one case it was suggested that getting the results from pathology and the time to receive radiology reports led to potential delays in being able to move forward with the patient's plan (M, 67, tonsil).

Sometimes it was the patient's condition which led to a delay on the pathway to diagnosis or treatment. On one occasion the patient was unable to undergo a procedure as it was too painful to lie in the correct position (F, 37, bowel). There were problems highlighted with MDT function, with examples given of patients not being discussed if the correct surgeon was not present; this was felt to be unacceptable in terms of the timing patients care (F, 51, liver). Alongside the diagnosis of cancer some patients also had other long term co-morbidities or new conditions diagnosed with potential impact on the pathway which they took and the timing of their treatment (M, 65, kidney).

Most patients had contact with the oncology service but this was not always considered to be as timely as it could have been. In one case the delay in seeing the oncologist led to a long time between surgery and chemotherapy (F, 52, small intestine). Some Trust SEAs mentioned that a system or process had changed and improved since the patient was in secondary care. In one example the Trust SEA stated that the procedure at the time the SEA was referring to would now be followed up due to the Fleischner Criteria (M, 57, lung). However, in one case the patient was described as having chemotherapy as an inpatient which was a service which was no longer available; the Trust described this as a "backward step" (F, 67, ovary).

Four fifths of the sample were not suitable for treatment with curative intent and either received palliative treatment or best supportive care. In many cases the patient was discussed by a palliative MDT but this was not always the case. In one case the patient had to delay the start of further treatment as there had been problems with the wound healing after initial surgery (M, 68, bowel). In another case the pathway was felt to have been delayed as the patient had social issues which made clinic attendance difficult (M, 51, upper GI).

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