Research

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Understanding diagnosis of lung cancer in primary care:

qualitative synthesis of significant event audit reports

Abstract

Background
Most lung cancers present symptomatically, but the pathway to diagnosis in primary care can be complex and is poorly understood. Significant event audit (SEA) is a quality improvement technique widely used in UK general practice.

Aim
To gain insights into the diagnostic process for lung cancer, drawn from analysis of SEA documents.

Design and setting
Qualitative analysis of SEAs from 92 general practices in the North of England Cancer Network.

Method
Participating practices were provided with a standardised electronic template and asked to undertake a significant event audit related to the most recent diagnosis of lung cancer in the practice, even if that patient had since died. Reported accounts for 132 diagnoses were analysed using a modified framework approach.

Results
Most SEAs demonstrated timely recognition and referral. Where this had taken longer, there were often reasonable explanations, including: chest X-rays reported as normal or with benign findings; patient-mediated factors, such as delay in re-presenting or declining earlier referral; and presentation complicated by comorbidity. Some opportunities for earlier referral were also found. Lessons drawn from these events included limitations of chest X-ray as a diagnostic tool, the need for vigilance in patients with existing morbidity, and the importance of 'safety-netting'.

Conclusion
Qualitative synthesis of SEAs offered considerable value in understanding circumstances surrounding the diagnostic process for lung cancer in primary care. The most common presentation was with cough or other symptoms indicative of infection, and it is by understanding more about these patients in particular that most can be gained.

Keywords
cancer; early diagnosis; lung; primary health care; qualitative research.

INTRODUCTION

Lung cancer is a significant health problem worldwide and the most common cause of cancer mortality in the UK, accounting for more than one in five cancer deaths.[1] Survival rates vary significantly between comparable countries[2] and it has been argued that this is largely due to the timing of the diagnosis.[3] Consequently, there is considerable interest in better understanding the pathway to diagnosis to develop interventions to improve outcomes.

Much of the research to date has focused largely on the patient perspective,[4–5] producing useful information about the factors that are associated with help seeking. From these studies we know that patients experience at least one new symptom before diagnosis and, although persistent, these are not interpreted as being serious at onset.[4] Some patients, such as long-term smokers and those with existing disease, take particularly long to consult, however, the primary care response to help seeking with these symptoms is poorly understood.[6]

Most lung cancers in the UK present symptomatically and patients tend to present to GPs, who are the usual source of referral to secondary care as a result of their gate-keeping role within the NHS. Many of the associated symptoms, such as cough and breathlessness, are common in primary care practice;[4] therefore, before initiating further investigation or referral, GPs must distinguish between those patients whose symptoms may be attributable to lung cancer and the much larger group of patients who have a benign, self-limiting illness. This is further complicated by patients who are long-term smokers or who have existing respiratory disease. Despite this complexity, there is a relative lack of research exploring the process to lung cancer diagnosis from a general practice perspective.

Significant event audit (SEA) is a quality improvement technique that is widely used in UK primary care practice. Developed in the mid-1990s, SEA can be applied to any aspect of health care and provides a structured, narrative analysis of the circumstances surrounding an event of interest.[7] This can be something that almost went wrong (near miss), did go wrong (adverse event), or went well (celebration). In 2004, SEA was incorporated as an education indicator in the Quality and Outcomes Framework (QOF) for the NHS;[8] despite its widespread utilisation and capacity to improve quality and safety in health care[9] however, relatively little research has been carried out into the use of it in practice.[10–11] In addition, although SEA has traditionally been used as a tool for self-reflection and improvement within practice teams,[12] using it to obtain insights into the general care process of a condition is novel. This article reports an innovative analysis of SEAs, designed to gain a better understanding of the pathway to diagnosis of lung cancer.

METHOD

Setting and practices
The study was carried out in the North of England Cancer Network. All practices

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clinical review to ensure that all sections of the template had been completed (including provision of presentation and consultation details, and reflection on the case), and that no identifiable patient data had been included. SEA reports with incomplete sections were returned to practices for revision. Following this process, anonymised versions of the SEA documents were then forwarded to the research team. Reports were completed between December 2008 and May 2009.

Analysis

Each SEA represents a narrative account of a specific event — in this case a new diagnosis of cancer and the context surrounding it — and, as such, a qualitative approach to analysis was employed. This was based on a modified framework approach.[14] SEA documents were read and re-read, after which a thematic coding framework was developed to identify key issues within the data. This was based around the four sections of the SEA template and on the issues raised by participating practices. At the outset of this process, a sample of reports was independently reviewed and coded by two authors as a means of validating the analytic process. Individual codes were combined into broader themes after discussion within the project team.

To better understand the factors surrounding the pathway of diagnosis and referral, an interpretative matrix was also constructed. Relevant data from each SEA were extracted and incorporated into a thematic chart as a means of identifying and interpreting common and diverse aspects related to presenting features and pathways of care. QSR Nvivo 2.0 software was used to facilitate coding and the organisation of data for analysis.

Although the methods used represent a novel approach to the analysis of these data and of SEAs (analysis is of documented narratives rather than those obtained from face-to-face interviews), document analysis is an established qualitative research technique[15] and one that is particularly suited to qualitative case studies.[16–17] Additionally, although the examination of SEAs may provide quantitative data related to some elements of the diagnostic process, caution has been exercised in the reporting of numbers as the study was designed to contextualise the events surrounding presentation and the subsequent referral pathway, rather than to quantify clinical symptoms or referral timescales. Where quantitative data have been presented, this has been done to characterise participants

Table 1. Characteristics of reported patient cases (*n* = 132)

Characteristic	*n* (%)
Sex[a]	
Male	64 (48.5)
Female	43 (32.6)
Unknown	25 (18.9)
Age at diagnosis, years	
Range	30–93
Mean (SD)	67.9 (11.1)
Status at time of SEA	
Alive	85 (64.4)
Dead	47 (35.6)
Smoking status[b]	
Smoker	52 (39.4)
Ex-smoker	22 (16.7)
Non-smoker	9 (6.8)
Unknown	49 (37.1)
Respiratory disease[b]	
COPD	22 (16.7)
Asthma	5 (3.8)
Other	4 (3.0)

COPD = chronic obstructive pulmonary disease. SD = standard deviation. SEA = significant event audit. [a]Information on patient sex was specifically requested in the SEA template but was not provided by some responding practitioners. [b]Smoking and morbidity data were not required by the template, but have been provided for those patients that were included in the practitioner's narrative of the case.

in two of the primary care trusts (PCTs) incorporated in the network (NHS South of Tyne and Wear, and NHS County Durham and Darlington) were invited to participate (*n* = 202). These organisations cover a population of more than 1 million people and include urban, rural, and semi-rural locations, as well as a range of socioeconomic settings.

Data collection

All practices in the two PCTs were contacted by the local NHS cancer leads and asked to participate in the study. They were asked to undertake at least one SEA related to the most recent diagnosis of lung cancer in the practice, even if that patient had since died. SEAs were documented on a standardised electronic template provided to all practices. This was closely based on the format recommended by the UK National Patient Safety Agency[13] and comprised four sections that required practice teams to:

- document the process of the event;
- reflect on, and understand, what happened and why it happened;
- identify the learning points (both good and bad); and
- consider changes to be made or actions to be taken.

In addition, specific prompts designed to generate a richer and more comprehensive narrative account of the circumstances involved were added to each section. Information to characterise the practice was also requested. SEA reports were returned to the relevant local lead, who undertook

and to identify longer referrals for in-depth study.

RESULTS

Completed SEAs were received from 92 (45.5%) practices. Most provided a report of one lung cancer diagnosis, although some provided two, generating accounts for a total of 132 cases. The majority of lung diagnoses (84.8%) were made in 2008–2009, with the remainder diagnosed between 2003 and 2007. Average patient age at diagnosis was 67.9 years (standard deviation [SD] 11.1), and almost two-thirds were alive at SEA completion (Table 1).

Insights into the referral process for lung cancer

Patterns of presentation. Although, for many patients, initial presentation was about lung and lung-related symptoms, the nature of the presentations varied hugely (Box 1). In addition to the known tendency for smokers and for those with chronic obstructive pulmonary disease (COPD) to present with chest infection-type symptoms, presentation also occurred in the context of other illnesses. Three main presentation patterns emerged.

- Presentation with a chest symptom or symptom suggestive of malignancy. Haemoptysis, although reported, was described in only 10 of these cases. Much more common was a combination of symptoms that were initially suggestive of a chest infection, indeed almost half of the patients discussed in the SEAs presented in this way.

- Presentation with a non-chest symptom that would not generally be considered to indicate lung cancer. For some of these patients, lung cancer was an incidental finding on investigation while, for others, the presentation was simply unusual or reflected metastatic disease.

- Events in which diagnosis did not occur as a result of presentation to primary care. For these patients, diagnosis occurred in a variety of ways, including follow-up for other cancers, during work-ups (investigations) for other conditions, and on emergency admission for other causes.

GP responses to presentation. Responses described by GPs — both to initial presentation and subsequent consultations — were generally appropriate and in keeping with best practice.[18] At first presentation with new chest symptoms, patients were frequently examined, with findings recorded, antibiotics prescribed, and chest X-ray ordered. Other responses included arranging follow-up review, advising of return if there was no improvement in symptoms, or onward referral to a specialist clinic or other primary care professional (such as a physiotherapist). Most patients were seen more than once and subsequent management was determined by the nature of symptoms; many were re-examined, some had further antibiotics. Those with non-resolving symptoms were commonly sent for a chest X-ray, while patients who became more unwell were often admitted to hospital as emergencies.

Factors related to longer referral for chest symptoms or symptoms suggestive of malignancy. The time interval from initial presentation to referral or acute admission was identifiable in most of the documented accounts, and many examples of good practice were evident (Table 2). In order to better understand the factors that related to longer referrals, accounts where this took more than 1 month (≥31 days) were analysed in detail (n = 45). A timed cut-off was used rather than considering patients with or without a 2-week wait referral (that is, when the patient should be seen by a

Table 2. Accounts of events demonstrating exemplary practice

Presentation	Details of response(s) to presentation	Best practice characteristics
Patient with a history of upper respiratory tract infection, with increasing cough	Examination revealed tenderness over anterior chest wall and right chest signs. The patient was prescribed analgesia and antibiotics, and given a review appointment with the same GP to check resolution after treatment. The patient was reviewed 2 weeks later and reported pain was much better but cough persisted. Examination still showed signs in the chest. Chest X-ray was organised and carried out 2 days later. The following day, the report was faxed to the surgery. The GP contacted the patient on the same day and arranged for them to visit the surgery that same day with a family member. After this, a 2WW referral was sent.	Good 'safety-netting'; good communication between primary and secondary care; good communication between GP, patient, and patient's family.
Patient with a hoarse voice	Treatment was given by the GP. A review was arranged for 8 days later, at which time the patient was no better. The patient was referred under the 2WW to ENT for persistent hoarse voice. Chest X-ray was done as part of the work-up and showed a suspicious lesion. The patient was then referred under the 2WW to the chest clinic.	Good safety-netting; good GP follow-up.
Patient with a 1-month history of dry cough (aged 50 years, ex-miner, known diagnosis of asthma)	There were chest signs on examination, and the patient was given a course of steroids. Because of the duration of cough, a chest X-ray was arranged at that initial consultation. This showed signs of infection in the right lung. Follow-up was not recommended by the radiologist. The patient re-attended around 3 weeks later saying they still had a dry cough and did not feel quite right. Chest signs were heard corresponding to previous chest X-ray changes. The patient was given antibiotics but a repeat chest X-ray was ordered to ensure resolution of infection; this showed progressive changes and the patient was immediately referred under the 2WW to the chest clinic.	Vigilance; good safety-netting; good GP follow-up.
Patient under the care of the rheumatologists	Having noted that inflammatory markers had been rising and haemoglobin falling, the GP wrote to the rheumatology consultant. The patient did not exhibit any symptoms but the rheumatology appointment was brought forward and a chest X-ray carried out at the clinic; this showed a lung mass.	Vigilance (especially given that blood tests were secondary-care results copied to GP); good communication between primary and secondary care.
Patient (aged 72 years) with a 3-week history of productive cough (seen by GP registrar)	In view of smoking history and clinical findings, a chest X-ray was ordered. The radiologist phoned the same day to say there were significant changes in the left upper lobe, and advised that the patient be given antibiotics followed by an interval chest X-ray 4 weeks later. A week later the patient returned, was no better and so was offered immediate referral. The patient declined this, instead opting for another antibiotic. The patient was seen a week later, much improved. Patient had a repeat chest X-ray as planned 4 weeks after the original; this was slightly improved, but an urgent CT scan was advised and arranged.	Prompt, appropriate action by GP registrar in line with guidance; good communication between primary and secondary care.
Patient noted to be thin at COPD review	Seen by the nurse the month following the COPD review; weight loss was documented but the patient declined to see the GP. The patient was persuaded to see the GP around 2 weeks later, and a chest X-ray carried out that day was reported as normal. However, in view of the weight loss, patient was referred urgently to the chest clinic.	Vigilance; good follow-up.

2WW = 2-week wait. COPD = chronic obstructive pulmonary disease. CT = computer tomography. ENT = Ear nose and throat.

specialist within 2 weeks of referral by a GP) as not all of the patients had symptoms that might indicate urgent referral. In addition, using type of referral would not provide the appropriate context from which to consider referral delay, as it does not take account of time from initial presentation.

Three main themes emerged from analysis of these accounts; they related to issues with the initial chest X-ray report, patient-mediated factors, and complex presentations.

Box 2. Examples of complexity in the process of referral

Comorbidity

A patient (aged 78 years) presented with cough. Antibiotics were given and a follow-up arranged. The patient attended secondary care three times per week for renal dialysis; four unsuccessful attempts were made by the practice to contact the patient by telephone (patient was assumed to be unreachable because of the dialysis sessions). The patient was eventually admitted to hospital. The GP and community matron were both involved; in addition, the patient was seen at accident and emergency and discharged. On the first emergency admission with breathlessness, a chest X-ray showed fluid overload due to a valvular heart condition. The GP is still unclear as to how a diagnosis was eventually reached.

A healthcare assistant noted that the patient (aged 74 years) was coughing a lot. As the patient had been on an ACEi, initially it was thought that the cough was caused by this. The ACEi was changed to an ARB, to which the patient had a reaction. The patient also had numerous consultations with other symptoms (including numbness in arm, dizziness, shingles-type pain, leg cramps). In addition, a previous CT scan from general medicine showed incidental findings (40 weeks before abnormal chest X-ray). Diagnosis was eventually made on a chest X-ray carried out at a general medicine outpatient appointment; this showed dense left hilum, could be vascular or tumour, and referral to a chest physician was advised (35 weeks after initial consultation).

Plausible alternative diagnosis

A patient (aged 69 years) presented with a shoulder pain and a swollen arm that was red and sore. As the patient had been given the pneumococcal vaccine the day before, this was diagnosed as an adverse reaction. The patient next presented 13 weeks after the initial consultation complaining of back pain for which they had consulted seven times in the previous year. An MRI scan was carried out as there was concern about nerve root signs; this showed an aortic aneurysm and the patient was referred to the vascular surgeons. The patient next attended almost another month later with continuing shoulder pain and pain over the scapula on coughing. As the patient was a heavy smoker, they were sent for a chest X-ray, which showed a mass; an urgent referral was made. The patient's back pain was not related to the cancer diagnosis.

A patient (aged 63 years) presented with shoulder pain, which had occurred after press-ups and was thought to be due to soft-tissue injury. The patient thought the pain was due to injury, but at the third consultation had also complained of tiredness and weight loss. On the fourth consultation with non-resolving shoulder pain, an urgent chest X-ray was arranged.

Symptoms suggestive of a different malignancy

A patient (aged 75 years) presented with persistent laryngeal discomfort and variable hoarseness, and was referred to ENT. At the ENT clinic, a laryngoscopy was carried out and was normal (approximately 8–12 weeks after initial consult). Symptoms persisted and the patient was re-referred to the ENT clinic approximately 1 year after initial consult; again, no abnormality was found. The patient was then referred to the chest clinic and was seen around 3 months later, when lung cancer was diagnosed.

ACEi = angiotensin converting enzyme inhibitor. ARB = angiotensin receptor blocker. CT = computer tomography. ENT = Ear, nose and throat. MRI = magnetic resonance imaging.

Initial chest X-ray reported as normal or consistent with benign disease. For many patients, the chest X-ray was reported as normal or as showing no change from previous films. For others, it showed infection, inflammatory changes, or was inconclusive. In one unusual case, the radiologist advised referral to the breast clinic as the mass seen was thought to represent a breast tumour. In many of these cases, the chest X-ray was repeated, commonly as part of the ongoing primary care diagnostic process but, in some instances, at the suggestion of the radiologist.

Patient-mediated factors. There were several accounts in which patient factors had a substantial bearing on referral time. These included waiting several weeks after the first consultation before re-presenting with ongoing symptoms, declining referral when it was first offered or recommended by the GP, failing to attend an appointment at the chest clinic or for a chest X-ray, declining to see the GP when recommended by the nurse, and declining hospital admission.

Complexity of presentation. A number of the accounts described complex cases for which it would have been challenging to reach an earlier diagnosis. This complexity was often related to comorbidity, a plausible alternative diagnosis, or symptoms suggestive of a different malignancy (Box 2).

Opportunities for earlier diagnosis of lung cancer involving chest symptoms. Detailed analysis of the accounts highlighted some cases in which opportunities for earlier diagnosis may have been missed. As far as could be determined from the data, nine such cases were described; although these relate to only a small number of the patients who presented with chest symptoms or symptoms suggestive of malignancy, they afford particular opportunities for learning nonetheless (Box 3). The cases illustrated several key issues, most notably around the need for vigilant care.

Factors related to longer time to referral for non-chest symptoms. Of the accounts relating to patients who presented with symptoms that were not chest or malignancy related, five waited longer than 1 month before being referred. All had reasonable explanations for the longer referral interval (Box 4).

Box 3. Potential missed opportunities for earlier diagnosis

Patient 1
62-year-old smoker with a 1-week history of cough, which was initially treated as a viral infection. Subsequent presentation 4 months later. Patient had seven consultations with various chest symptoms before being referred 63 weeks after first presentation.

Patient 2
Patient with two consultations, 3 weeks apart, for upper respiratory tract infection symptoms. Next presented 6 weeks later with shortness of breath, at which point a chest X-ray was carried out.

Patient 3
Increasing shortness of breath in a 63-year-old patient with known asbestos exposure. Chest X-ray ordered 2 months after initial consultation.

Patient 4
66-year-old patient with known COPD was seen five times over a 5-month period with exacerbations. Sent for chest X-ray after complaining of weight loss.

Patient 5
59-year-old non-smoker with 3-week history of cough was given antibiotics at initial presentation. Next presented 2 months later, still coughing, and was sent for urgent chest X-ray.

Patient 6
64-year-old patient with known COPD, well known to the respiratory team, presented with increasing shortness of breath, cough, wheeze, and leg weakness. A specialist respiratory nurse was also involved. Referral was made when symptoms worsened, by which time patient had superior vena cava obstruction.

Patient 7
59-year-old patient with a 2-month history of persistent cough with yellow phlegm was prescribed antibiotics. Chest X-ray was arranged at next presentation 2 months later.

Patient 8
82-year-old patient presented with a chesty cough with purulent sputum. Next presented 4 weeks later with similar symptoms, then again 3 weeks later. Chest X-ray was arranged at fourth consultation.

Patient 9
Patient presented with new onset of wheezing, and was seen several times with chest symptoms before chest X-ray was ordered. Patient factors also relevant as had a fear of investigations and hospitals.

COPD = chronic obstructive pulmonary disease.

Lessons learned in the diagnosis of lung cancer

The ways in which GPs described the circumstances surrounding these events indicated that they had learned from reflecting on, and discussing, the case — even if the process from initial patient presentation to referral had been ideal. Areas of learning highlighted by practices related to:

- presentation and diagnosis;
- system issues and the primary–secondary care interface;
- patient factors;
- practitioner issues; and
- the role of guidelines.

Presentation and diagnosis. Lessons learned around presentation and diagnosis of lung cancer centred on the: complexity associated with atypical symptoms; need for vigilance, even when symptoms seem straightforward; and usefulness and limitations of chest X-ray as a diagnostic tool:

'... [the case] reminded all team members that cancer can have few general symptoms until disease is advanced, that patients may underplay symptoms, and that a simple, brief examination can reveal significant findings and is always worth doing even it if does not appear to be indicated.' (LN-153A)

'Always be aware of changes in patients with chronic chest disease and have a high suspicion for further investigation. Don't assume it is simply the underlying problem.' (LO-008B)

'Chest X-rays are non invasive, cheap and easily arranged and we will continue to use them readily to pursue clinical suspicions.' (LN-080A)

Practitioners considered the importance of chest X-ray in patients with prolonged symptoms, even if examination suggested infection, as well as the appropriate time for referral for chest X-ray in such patients. The question was also raised as to whether chest X-ray should be routinely used in the assessment for possible COPD, and whether patients with abnormal chest X-ray should be referred under the 2-week wait as a precaution.

System issues and the primary–secondary care interface. Many of the comments in this area focused on communication and record keeping, either between members of the

Box 4. Cases of longer time to referral for non-chest symptoms

Patient 1
Presented with epigastric pain; referral was made to gastroenterology after an ultrasound showed liver metastases.

Patient 2
Presented with neck pain and nausea. An ultrasound arranged by gastroenterology showed a pelvic mass and ovarian cancer was eventually diagnosed. A CT scan performed during work-up showed lung cancer, which appears to have been an incidental finding.

Patient 3
Presented with painful left arm. Pain was initially thought to be musculoskeletal so the patient was referred to physiotherapy 1 day after initial consultation. The physiotherapist suggested referral to orthopaedics some weeks later. Diagnosis was eventually non-small cell cancer invading the brachial plexus.

Patient 4
Presented with left arm and neck pain. Patient was referred to physiotherapy, although had normal investigations following an episode of haemoptysis within the previous year.

Patient 5
Presented with diarrhoea. Hyponatraemia was found during investigations for diarrhoea, but the initial chest X-ray was inconclusive.

CT = computer tomography.

primary care team, between primary and secondary care, or between primary care and other providers such as Macmillan nurses:

'It was acknowledged that communication between clinicians is vitally important in the current climate of general practice as patients may not always be able to consult with the same GP on every occasion. Good documentation [is] *paramount to ensure other clinicians have enough information to make further clinical decisions.'* (LN-168A)

In the main, the SEA accounts described examples of good team working and communication, but there were some instances of apparent lack of adequate communication at the primary–secondary care interface. This included the non-reporting of X-rays and a failure to provide practices with test results, or discharge or follow-up arrangements:

'Poor communication from secondary to primary care. This [the details of the case] *should have been noted and the information requested from the hospital rather than relying on patients accounts.'* (LN-034A)

Patient factors. There was recognition among practitioners that co-existing disease could mask symptoms of malignancy:

'We reflected on other cases of lung cancer when delays in diagnosis had been present. Major causes of delay included delay in patient presentation and confusion of symptoms with co-existing illness such as COPD.' (LN-036A)

As such, the possibility of a serious cause should be considered in patients with an existing respiratory condition (for example, asthma or COPD) or another disease. Similarly, the importance of having a high index of suspicion in patients who are smokers was also identified. Allied to this, was acknowledgement of a continuing need for patient education around smoking cessation and cancer symptoms in general:

'We, as a team, felt that what is important is the patient education regarding these unspecific symptoms such as weight loss, "not entirely well", tired all the time... [These] *should be the points to advertise in surgeries, local/national papers.'* (LN-179A)

Practitioner issues. Practitioners described the importance of, and need for, safety-netting: the inclusion of a back-up process for dealing with an alternative outcome to the initial working diagnosis.[19] Some practitioners used the term explicitly in their narratives, commenting on its importance as part of the consultation. The concept was also discussed more implicitly in relation to various aspects of diagnosis and management, including history taking and examination, follow-up (both of non-resolving symptoms and of negative test results), and ensuring continuity across consultations:

'We are all agreed that safety-netting is an important part of the consultation. The natural history of the symptoms and information provided need to be clearly recorded. Routinely asking all patients to return for a check up following an infection, however, is not felt to be beneficial.' (LN-081A)

'Clinical awareness and examination are essential to get an early diagnosis.' (LN-088A)

The role of guidelines. As part of the SEA

process, GPs had often reviewed the role, content, and use within the practice of existing local and national guidelines, as well as the referral pathways involved in the documented cases:

'[The] *2-week rule lung cancer referral guidelines were discussed and indications/ criteria for referral were reinforced.'* (LN-187B)

'*We discussed the problems of using TWR* [2-week rule] *referrals for unclear CXR* [chest X-ray] *pathology as too many inappropriate urgent referrals just clogs the system.'* (LN-026A)

In many instances, the lessons learned related to the fact that guidelines had been followed. In others, however, they related to guidelines being inappropriate given the associated circumstances, including symptoms at initial presentation not meeting the criteria for referral, the patient presenting elsewhere (such as accident and emergency), the patient already being under specialist care, or the patient not wanting to be referred:

'*While the 2WW guidelines might have indicated a need for more rapid referral, in this case the patient and family were quite clear that active intervention was not wanted … As a result the referral pathway was negotiated with the patient, who retained control of that process and ongoing treatment. Although there is pressure to comply with guidelines it is important to remain patient centred.'* (LN-018A)

DISCUSSION
Summary
This study analysed multiple SEA reports to draw inferences about the process of diagnosis of lung cancer in primary care. Most accounts demonstrated appropriate recognition and referral; where delays occurred, there were often plausible explanations. It was found that, in many cases, the diagnostic process was complicated by comorbidity. Lessons learned by practices related to the presentation and diagnosis of cancer, system issues and the primary–secondary care interface, patient factors, practitioner issues, and the role of guidelines.

Strengths and limitations
This appears to be the first time that SEA has been used as a source of data for research. In this study, a large number of reports on a single subject, lung cancer diagnosis, were obtained in a standardised format, and

with clinical review of their quality prior to inclusion. One of the particular strengths of the data generated by this study is that, in addition to details relating to the process of care prior to diagnosis being provided, GPs' reflections on the circumstances surrounding this, including lessons learned as a result of the cases discussed, were obtained.

A qualitative methodology was applied to a non-representative group of patient reports and, as such, absolute generalisability of these results should be cautioned against. Participating practices may have been more engaged with cancer care and so could represent better than average practice, however this likelihood applies to any research undertaken. Similarly, although practices were asked to report on their most recent lung cancer diagnosis to guard against self-selection of the 'best' cases, it was not possible to confirm that this was always done.

The index consultation related to the diagnosis of cancer was not always easy to identify, particularly in patients who consulted relatively frequently. It was clear from some reports that the GPs may have found it difficult to identify the initial presentation and, in some cases, they provided details on all consultations in the year prior to diagnosis. In such instances, the index consultation was determined by the researchers. It was concluded that the best option was to use the first relevant consultation but, in so doing, it is possible that a somewhat rigid approach may have been taken, which may have resulted in an overestimation of the time to referral in some cases.

One month (31 days) was used as the cut-off for considering 'longer' times to referral; although a relatively arbitrary time point, this is a reasonable interval for the fairly typical pattern of presentation and referral (from the data) to take place. This pattern featured: chest-related presentation, followed by initial treatment, followed by review if no improvement, followed by chest X-ray and report, followed by referral.

Comparison with existing literature
The symptom(s) with which patients presented were consistent with those reported by patients with newly diagnosed lung cancer, as described elsewhere.[4–5] Patients diagnosed with lung cancer often have prolonged intervals before presenting to a GP; in one such study, half of the participants had unrecognised symptoms for more than 14 weeks before initial presentation.[5] Less is known however, about the primary care response to such symptoms; this study provides some insights

into this aspect of the diagnostic process.

In a recent Delphi study[20] designed to obtain clinical consensus about safety-netting in children with acute illness, the authors derived four key recommendations. These related to:

- communicating the existence of uncertainty so that the patient is empowered to re-consult if necessary;
- outlining exactly what to look out for (that is, specific clinical features);
- giving guidance on how exactly to seek further help if needed; and
- including information on what to expect about the likely time course of the illness.

Although these recommendations were generated in relation to safety-netting for children, they could be applied elsewhere. Some commonality has been found between the themes raised in that study and this study's findings, particularly in relation to how and when to seek further help, and the expected time course.

Implications for practice

Chest symptoms are common in general practice and extremely common among smokers, who have a much higher risk of lung cancer than other population groups. It is within this context that GPs have to decide who to treat, who to investigate, and who to refer. Almost half of the patients in this study presented with symptoms suggestive of chest infection.

In patients who already have known chest disease, it can be difficult to differentiate new and potentially malignant symptoms from those related to the known disease. Consequently, it is important to have appropriate 'safety netting', that is, the inclusion of a back-up process so that when a working diagnosis and provisional management plan are made, there is also an attempt to make provision for, and to deal with, alternative outcomes.[19] Such follow-up plans should be put in place regardless of whether patients are presenting with their first recent infective episode or have attended several times.

The use of safety-netting language was prevalent throughout the SEA narratives and is a very helpful way to consider how patients with common, but potentially significant, symptoms are dealt with, both within the consultation and subsequently; in particular, at which point GPs should make the distinction between a prescriptive approach (*make an appointment for 2 weeks' time, cancel if you're better*) and a promissory one

(*come back if it doesn't get better*). There is a need to avoid causing unnecessary anxiety to patients, but practitioners must, at the same time, ensure patients are not being inappropriately reassured, which could result in delays in diagnosis and treatment. Given its significance in clinical practice, safety-netting should be considered in future iterations of existing guidelines or in the development of new referral pathways.

Two, sometimes related, problems were evident from the cases described in this study: the cough suggestive of infection that does not resolve, and the chest X-ray that is reported as normal or with a benign explanation for changes. For patients with infective symptoms, taking account of the recent history of presentations is key even if the patient presents the symptoms as pertaining to separate episodes of illness. Related to that is the role of GPs in maintaining an overview of the patient's presentations and symptoms, both in primary care and where specialist teams are involved.

The literature on the incidence of normal chest X-rays in symptomatic lung cancer is limited, but the majority of GPs in this present study mentioned chest X-ray in their accounts of diagnosis. In 87 of the 132 cases, chest X-rays were reported as having been arranged as part of the primary care investigation of the patient's symptoms; for 23 of these patients, the GP stated that this was reported as normal or suggestive of infection or other morbidity. Specific attention should be paid to these issues in terms of further research into their relationship with lung cancer presentation, and in relation to developing guidelines for primary care.

Although this was a study of primary care practice for patients with lung cancer, a number of patient-mediated factors were also identified. The findings indicate that practitioners should ensure patients understand the plan for follow-up if their symptoms do not get better, and that the process to diagnosis for any given condition may involve more than one visit to their GP. There is also scope for educating those patients at particular risk of developing lung cancer (such as smokers and those with relevant occupational exposures) to encourage earlier presentation with ongoing and new chest symptoms.

Further research is needed to better describe the diagnostic pathway for lung cancer following patient presentation; in particular, to determine the timing of investigations for those with a higher risk of lung cancer. In addition, work is needed to further develop the methodology used for this study.

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