Diagnostic delay in lung cancer: Barriers and facilitators in delay.

Tod AM. Craven J.
Lung cancer: barriers and facilitators in diagnostic delay

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Lung cancer: barriers and facilitators in diagnostic delay

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Executive summary

This report outlines selected results of a qualitative research project conducted in South Yorkshire. This report presents results relating to factors that hinder or help people in reporting lung cancer symptoms early. Semi-structured individual and group interviews were conducted with 20 lung cancer patients, eight nurses involved in care of lung cancer patients and two lay representatives.

The study identified a range of interacting factors that influence delay in reporting symptoms of lung cancer. Many of the participants’ stories resonate with the findings of other studies on symptom reporting behaviour in other cancers. However, the results of this study indicate additional social and cultural influences on delay in reporting symptoms, for example, stoicism, health care utilization and the perceptions and attitudes of medical staff.

Participants’ stories revealed how factors interacted on an individual basis to contribute to delay in symptoms reporting. Overall, six themes emerged to explain the barriers to reporting symptoms.

- Experience of symptoms
- Knowledge
- Fear
- Blame and stigma
- Cultural
- GP and hospital services

Additional results describe the factors identified as helping to overcome delay in reporting symptoms. These were families and gender.

Delay in symptom reporting was attributed to the nature of and variation in symptoms. Additional factors were a low perception of risk and tendency to attribute symptoms incorrectly. Two new issues were identified as contributing to diagnostic delay in lung cancer. These were, first, misunderstanding from previous media campaigns that non- and ex-smokers would not get lung cancer and, second, cultural factors within the South Yorkshire communities leading to delay in symptom reporting, most notably stoical attitudes and patterns of health care utilization.

The existing level of public knowledge of lung cancer and its symptoms is clearly lacking. The study suggests that current information is further compromised by the orientation towards smoking. This confuses understanding regarding risk and reinforces blame and stigma. Social and cultural influences hindering symptom reporting are further entrenched by
media messages highlighting resource restraints in the NHS. Ways of counterbalancing these beliefs and educating the public need to be developed so that people are encouraged to report emerging symptoms of illnesses such as lung cancer.

Once people had recognised and reported symptoms further delay in diagnosis was experienced because of not being referred for investigation e.g. chest x-ray or referral to a consultant physician. The fact GPs see so few patients with lung cancer, compared to chronic lung conditions, may partly explain this. Scenarios described here indicate that some GPs were relatively unfamiliar with lung cancer symptom presentation. As a result previous negative chest x-rays were not repeated, even if conducted years earlier. Deterioration was attributed to concurrent illnesses such as asthma or arthritis. This picture indicates that current guidelines for the investigation and diagnosis of lung cancer are not always followed (Department of Health, 2005). Increased vigilance is needed amongst primary care health professionals regarding early detection and investigation of lung cancer symptoms. Education of health practitioners is required to facilitate this.

The role of pharmacists and the development of shared local protocols between primary and secondary care also have the potential to overcome some of the barriers identified here.

Finally, encouraging a responsible use of health care is sensible in a context of finite resources. However, it would seem that, for some people, this message has provoked an unwanted reticence in consulting a GP about symptoms. This indicates a need for more balanced information that gives people permission to go to their GP without fear of ridicule, being seen someone who is a time waster or squandering valuable health resources.
Lung cancer: barriers and facilitators in diagnostic delay

1. Introduction

This is the first of two reports presenting the results of a qualitative study exploring delay in diagnosing lung cancer. This first report focuses on the factors influencing delay in reporting lung cancer symptoms. The second report presents results relating to education interventions that have the potential to reduce delay in reporting symptoms and diagnosing lung cancer (Tod & Craven, 2006).

Background

Lung cancer is one of the main causes of cancer death in the western world, accounting for approximately 5% of all deaths in developed countries (Manser et al 2004). It is the second most common cancer after breast cancer. Lung cancer is the biggest cancer killer in the United Kingdom (UK) for both men and women. Over 37,000 people are diagnosed with lung cancer each year. That is equal to over 100 people a day (Macmillan Cancer Support, 2006). Mortality rates remain as high as 85 to 90% (Manser et al 2004). In the UK this means over 33000 lung cancer deaths a year (Corner et al, 2005), or 92 every day (Macmillan Cancer Support, 2006).

UK lung cancer survival rates (7%) are lower than those in Europe where the highest five-year survival rate is 16% (Cancer Research UK, 2006). For 80% of people with lung cancer their disease is inoperable because it has been diagnosed too late. This suggests that improvements to mortality could be made by reducing diagnostic delay (National Statistics, 2005; Corner et al, 2005).

The high levels of lung cancer and socio-economic disadvantage that exist in the communities of Barnsley, Rotherham and Doncaster make the issue a
priority. Nationally and locally, many cases of lung cancer are in advanced stages when reported to health services. It is known that delay in obtaining a diagnosis has an adverse impact on outcome (Corner et al, 2005). A theoretical argument has therefore emerged that reducing delay in reporting of symptoms of lung cancer may bring about early detection, treatment and, so reduce mortality and improve quality of life. Recent attempts to reduce delay have focused on process delays in health services that occur after a person has reported symptoms (NICE, 2005). However, a more prolonged delay is thought to occur between patients noticing symptoms and reporting them to a doctor (Corner et al, 2005).

Two limitations exist with regard to current research on delay in reporting symptoms of ill health. First, information is available regarding delay in reporting symptoms of other illness, for example heart disease and breast cancer (Smith et al, 2005; Tod et al, 2001; Horne et al, 2000; Johnson & King, 1995). However, little evidence exists regarding delay in reporting lung cancer symptoms. It is not possible to assume that what is known about other disease populations is transferable to lung cancer or to areas of inequality, such as South Yorkshire. Second, research has concentrated on identifying demographic or psychological characteristics of people most likely to delay. There is little understanding of social and cultural influences on delay, including lay epidemiology, myths and expectations that may influence reporting of symptoms.

Thus there is a demand for research that increases understanding of why delay occurs and what can be done to reduce it. Information of this nature can inform the development of health education messages and campaigns on lung cancer for use in the high risk communities such as South Yorkshire. This study seeks to address this need.

The study emerged from concerns raised by local clinicians. It was undertaken by researchers from School of Nursing and Midwifery at the University of Sheffield. It was conducted in partnership with Public Health at South
Yorkshire Strategic Health Authority, health professionals from Doncaster NHS Trusts, and lay representatives from North Trent Cancer Network Consumer Research Panel (Appendix 1).

**Aims of the study**

The aims of the overall study were to:

i) Identify factors influencing delay in reporting early symptoms of lung cancer and factors that would facilitate earlier reporting of symptoms.

ii) Generate data to inform the development of interventions to reduce delay e.g. an acceptable and accessible education message and the media chosen to deliver it.

This report presents the results relating to the first aim, that is, those results relating to factors that hinder or help people to report lung cancer symptoms early.
2. **Methodology and methods**

**Methodology**
An interpretivist approach was taken for the study. Research of this nature aims to explore and understand the patient experience using the views, values and perspectives of the participant and the understanding and interpretation of the researcher (Charmaz, 2003; Snape & Spencer, 2003).

**Methods and design**
Qualitative methods were used to allow in-depth exploration of participants’ experiences and views. A combination of semi-structured interviews with lung cancer patients and survivors (n = 20), and a focus group of eight lung cancer nurses and two lay representatives were conducted. Framework Analysis techniques facilitated ongoing testing and validation of emerging themes from different perspectives.

Framework Analysis is pragmatic approach to qualitative data analysis emerged from policy research. It “involves a systematic process of sifting, charting and sorting the material into key issues and themes” (Ritchie & Spencer, 1994). It also allows the integration of existing knowledge from previous research and policy into the emerging data analysis.

Research ethics committee and governance approval was obtained for the study.

**Sample and setting**
The study was conducted in hospital and community settings in Doncaster, South Yorkshire. Participants were recruited with through the respiratory consultant and Lung Cancer Nurse Specialists, who contacted interviewees on behalf of the researchers.
A focus group was conducted first in order to assist the theoretical sensitivity of the researchers (Table 1). Theoretical sensitivity refers to the ability of the researcher to “have insight, understand and give meaning to the data, and to detach the relevant from the irrelevant” (McCann & Clark, 2003, p8).

**Table 1. Focus group participants**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Reason for attendance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1*</td>
<td>Female</td>
<td>Lung cancer nurse specialist</td>
</tr>
<tr>
<td>2*</td>
<td>Female</td>
<td>Lung cancer nurse specialist</td>
</tr>
<tr>
<td>3*</td>
<td>Female</td>
<td>Lung cancer nurse specialist</td>
</tr>
<tr>
<td>4</td>
<td>Female</td>
<td>Staff nurse, chest clinic</td>
</tr>
<tr>
<td>5</td>
<td>Female</td>
<td>Health care assistant, outpatients department</td>
</tr>
<tr>
<td>6</td>
<td>Female</td>
<td>Lung cancer research nurse</td>
</tr>
<tr>
<td>7</td>
<td>Female</td>
<td>Staff nurse, respiratory ward</td>
</tr>
<tr>
<td>8*</td>
<td>Male</td>
<td>Lay representative, father dies from lung cancer</td>
</tr>
<tr>
<td>9*</td>
<td>Female</td>
<td>Lay representative, father in law died of lung cancer (wife of 9)</td>
</tr>
<tr>
<td>10*</td>
<td>Female</td>
<td>Lung cancer nurse specialist <em>(Only took part in second group interview)</em></td>
</tr>
</tbody>
</table>

* Denotes that the participant also took part in the second group interview at the end of the project

The patient sample for the interviews comprised 18 people diagnosed with lung cancer and under the care of consultant chest physicians and oncologists at the Doncaster NHS Hospital Trust (Table 2). Purposive sampling (Bowling, 1997; Field & Morse, 1985) was used to ensure the appropriate range of characteristics e.g. age, sex, employment, and location. In the final stages of the study, two lung cancer survivors contacted the researchers after reading about the research in the local free press (Table 2). They agreed to be interviewed for the study. Recruitment continued until theoretical saturation was reached. This is when no new categories or themes emerge from the data (Chamberlain, 1999; Strauss and Corbin, 1995) such that further interviews are unlikely to add much.
Table 2. Individual interview participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age/Gender</th>
<th>Marital status</th>
<th>Children</th>
<th>Courses of antibiotics</th>
<th>Co-morbidity</th>
<th>Risk factors</th>
<th>Smoking status</th>
<th>Employment status</th>
<th>job</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>47, Female</td>
<td>Married</td>
<td>2 adult children</td>
<td>3</td>
<td>None</td>
<td>Smoker, pub worker, Grandparents lung cancer</td>
<td>Gave up on diagnosis</td>
<td>On sick leave</td>
<td>Shop worker</td>
</tr>
<tr>
<td>2</td>
<td>81, Male</td>
<td>Widowed</td>
<td>3 adult children</td>
<td>&gt; 2</td>
<td>Industrial deafness, emphysema</td>
<td>Ex-smoker, miner, exposed to asbestos</td>
<td>Ex-smoker 25 years</td>
<td>Retired following redundancy</td>
<td>Miner</td>
</tr>
<tr>
<td>3</td>
<td>63, Female</td>
<td>Married</td>
<td>1 adult son</td>
<td>3</td>
<td>Hypertensive, hyperactive thyroid</td>
<td>Passive smoker (bingo)</td>
<td>Non-smoker</td>
<td>Retired on diagnosis</td>
<td>Cleaner</td>
</tr>
<tr>
<td>4</td>
<td>58, Male</td>
<td>Married</td>
<td>2 adult children</td>
<td>5</td>
<td>Throat cancer</td>
<td>Ex-smoker, previous throat cancer</td>
<td>Ex-smoker 21 years</td>
<td>Retired</td>
<td>Engineer, factory manager</td>
</tr>
<tr>
<td>5</td>
<td>54, Female</td>
<td>Married</td>
<td>3 adult children</td>
<td>None</td>
<td>Diabetes</td>
<td>Smoker, worked with asbestos</td>
<td>Current smoker</td>
<td>Employed</td>
<td>NHS clerk</td>
</tr>
<tr>
<td>6</td>
<td>64, Female</td>
<td>Divorced</td>
<td>2 adult children</td>
<td>2</td>
<td>Asthma Emphysema</td>
<td>Ex-smoker</td>
<td>Ex-smoker 1 year</td>
<td>Retired</td>
<td>Shop assistant</td>
</tr>
<tr>
<td>7</td>
<td>57, Male</td>
<td>Divorced (but lives with partner)</td>
<td>4 adult children</td>
<td>None</td>
<td>None</td>
<td>Ex-smoker</td>
<td>Ex-smoker 3 years</td>
<td>About to stop working</td>
<td>Publican (living above the pub)</td>
</tr>
<tr>
<td>8</td>
<td>77, Female</td>
<td>Widow</td>
<td>1 adult child</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>Non-smoker</td>
<td>Retired</td>
<td>Nursing Auxiliary</td>
</tr>
<tr>
<td>9</td>
<td>81, Male</td>
<td>Married</td>
<td>6 adult children</td>
<td>None (recently)</td>
<td>COPD</td>
<td>Ex-smoker</td>
<td>Miner worked with asbestos</td>
<td>Ex-smoker 33 years</td>
<td>Retired</td>
</tr>
<tr>
<td>10</td>
<td>59, Male</td>
<td>Married</td>
<td>3 adult children</td>
<td>3 (1 for ear infection)</td>
<td>None</td>
<td>Ex-smoker</td>
<td>Ex-smoker 7 months</td>
<td>On sick leave</td>
<td>Senior Police Officer</td>
</tr>
</tbody>
</table>


### Table 2: Individual interview participants (continued)

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age/Gender</th>
<th>Marital status</th>
<th>Children</th>
<th>Courses of antibiotics</th>
<th>Co-morbidity</th>
<th>Risk factors</th>
<th>Smoking status</th>
<th>Employment status</th>
<th>job</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>72, Female</td>
<td>Married</td>
<td>2 adult children</td>
<td>3</td>
<td>Hypertension, raised cholesterol, osteoporosis</td>
<td>Ex-smoker, father died of lung cancer</td>
<td>Ex-smoker, gave up on reporting symptoms</td>
<td>Retired</td>
<td>Nursery nurse and shop assistant</td>
</tr>
<tr>
<td>12</td>
<td>68, Male</td>
<td>Widowed</td>
<td>1 adult child</td>
<td>2</td>
<td>None</td>
<td>Worked with asbestos</td>
<td>Non-smoker</td>
<td>Retired</td>
<td>Fitter in a power station</td>
</tr>
<tr>
<td>13</td>
<td>64, Male</td>
<td>Married</td>
<td>3 adult children</td>
<td>3</td>
<td>Bronchitis</td>
<td>Ex-smoker</td>
<td>Ex-smoker, 25 years</td>
<td>Retired on diagnosis</td>
<td>Decorator, then security guard</td>
</tr>
<tr>
<td>14</td>
<td>51, Male</td>
<td>Divorced (but living with fiancé)</td>
<td>2 adult children</td>
<td>None</td>
<td>None</td>
<td>Smoker</td>
<td>Stopped for 17yrs, started again 2yrs ago</td>
<td>On sick leave</td>
<td>Production Manager</td>
</tr>
<tr>
<td>15</td>
<td>68, Male</td>
<td>Married</td>
<td>2 adult children</td>
<td>3</td>
<td>Arthritis</td>
<td>Smoker, toxic work environment, ? asbestos ?</td>
<td>Current smoker</td>
<td>Retired after redundancy</td>
<td>Railway vehicle builder</td>
</tr>
<tr>
<td>16</td>
<td>67, Male</td>
<td>Married</td>
<td>2 adult children</td>
<td>At least one</td>
<td>Liver disease, diabetes Ex-smoker, passive smoker</td>
<td>Ex-smoker, 25 years</td>
<td>Ex-smoker, 25 years</td>
<td>Retired</td>
<td>RAF officer</td>
</tr>
<tr>
<td>17</td>
<td>63, Female</td>
<td>Married</td>
<td>3 adult children</td>
<td>None</td>
<td>Chronic asthma</td>
<td>Smoker, father dies of lung cancer, bowel cancer</td>
<td>Current smoker</td>
<td>Housewife</td>
<td>Housewife</td>
</tr>
<tr>
<td>18</td>
<td>69, Male</td>
<td>Married</td>
<td>4 adult children</td>
<td>None</td>
<td>Bronchitis</td>
<td>Smoker</td>
<td>Smoker for 55 years</td>
<td>Retired</td>
<td>British rail</td>
</tr>
<tr>
<td>19</td>
<td>65, Female</td>
<td>Married</td>
<td>3 adult children</td>
<td>1</td>
<td>Colonic polyps</td>
<td>Ex-smoker</td>
<td>Ex-smoker, gave up on diagnosis</td>
<td>Retired</td>
<td>NHS clerk</td>
</tr>
<tr>
<td>20</td>
<td>65, Male</td>
<td>Married</td>
<td>2 adult children</td>
<td>None</td>
<td>Stroke 5 years previously</td>
<td>Ex-smoker</td>
<td>Ex-smoker, 33 years</td>
<td>Retired</td>
<td>Television engineer</td>
</tr>
</tbody>
</table>
The original 18 patients were included if:

- They had been diagnosed with lung cancer in the last six months. This meant that they could remember their decision-making regarding reporting of symptoms.
- They were under the care of a consultant oncologist and/or respiratory physician.
- In the opinion of their Consultant, the interview would not cause unnecessary distress or inconvenience.
- They agreed to take part and had signed a form to indicate informed consent.

At the end of the project, another group interview was held with five members of the initial focus group plus an additional Nurse Specialist (Table 1). This final group interview, and the two individual interviews with lung cancer survivors, allowed for verification of the themes identified and for testing our interpretation of the data.
**Table 3. Literature informing the thematic framework**

<table>
<thead>
<tr>
<th>Authors / Reference</th>
<th>Purpose</th>
<th>Design / Methods</th>
<th>Key Findings</th>
</tr>
</thead>
</table>
| **Breast Cancer**   | To investigate the association between delay and type of breast cancer (BC), emotional response to BC, perceived risk of BC, role of talking to others about symptoms. | Questionnaire survey and interview study of 85 woman attending Breast Clinic. Australia | • Delay associated with type of symptom, initial distress on getting symptom.  
• Perceived risk of BC, role of talking to others about symptoms unrelated to delay.  
• Those with breast lump reported earlier.  
• More research needed. Predictors of delay included:  
• Inability to identify BC symptoms  
• Negative attitudes towards medical help seeking and ones ability to seek help (age 35-54)  
• Negative beliefs about consequences of BC (over 65)  
• Further research required.  
Likelihood of delay higher in those:  
• With lower income and education  
• Who are black or Latino  
• Who report preference to self care  
• Who are fatalistic about BC  
• Who have a perceived lack of health care access and poor utilization.  
• Who have partner/employer constraints  
• Who lack knowledge of BC symptoms. |
| Meechan et al (2005) | | | |
| **Grunfeld et al (2003)** | To examine perceptions of BC symptoms and test association between delay and age/beliefs | General population postal survey of 546 women UK | |
| Facione et al (2002) | To test the association between BC delay and use of self care, fatalistic beliefs, prejudice about care delivery and social role constraints | Survey of 699 asymptomatic women from community settings. United States | |
| **Lung Cancer Delay** | To examine perceptions and experience of stigma in lung cancer patients | Qualitative interview study of 45 patients with lung cancer UK | • Stigma commonly experienced, especially by smokers  
• Non / ex-smokers felt unjustly blamed  
• Smokers blame other causes e.g. pollution  
• Stigma and blame impacted on interaction with friends, family and doctor e.g. concealing illness  
• Media adds to stigma and adds to fear.  
• Belief that diagnosis and access to health care is affected by stigma, especially by smokers. |
## Table 3. Literature informing the thematic framework (continued)

<table>
<thead>
<tr>
<th>Authors / Reference</th>
<th>Purpose</th>
<th>Design / Methods</th>
<th>Key Findings</th>
</tr>
</thead>
</table>
| Corner et al (2005) | To explore the pathway to diagnosis in lung cancer and test assumption that late diagnosis of lung cancer is due to the symptoms being silent. | Qualitative interviews of 22 men and women with lung cancer, triangulated with case note review UK | • 30 different symptoms were reported  
• Chest symptoms and fatigue were most common  
• Patients had symptoms 4 to 24 months prior to reporting.  
• Symptoms identified as a change in health but not seen as serious, leading to self management.  
• A median of 7 months elapsed between symptom onset and the trigger to report. Little contact with GP in this time.  
• More research required. |
| Delay - all cancers | To investigate patients experiences of recognising symptoms of cancer and seeking help | Synthesis of 32 qualitative research articles into symptom experience in 20 different cancers and help-seeking. | • Only study on lung cancer (Chapple et al, 2004)  
• Similarities identified between different cancers  
• Key concepts were recognition and interpretation of symptoms and fear of consultation (embarrassment, cancer, death).  
• Gender and sanctioning of help-seeking prompted consultation. |
| Coronary Heart Disease | To identify barriers to use of health services in angina | Qualitative study with individual interviews of 14 angina patients, 9 GPs, and group five group interviews of general population and one of GPs UK | • Complex interrelation of factors led to delay in reporting new angina symptoms to the GP  
• This led to a delay in diagnosis  
• Delay factors fell into six categories: structural, personal, social and cultural, experience and expectations, diagnostic confusion and knowledge and awareness. |
**Data collection and analysis**

The interviews were guided by an interview schedule devised from related literature and ongoing analysis. The schedule comprised open and closed questions on knowledge, expectation and experience of lung cancer symptoms, decision-making regarding reporting, and views on health education messages. The individual interviews were tape-recorded and field notes taken. Informed consent to take part and have the discussion audio taped was obtained prior to participation.

The group interviews were conducted by a facilitator with a second researcher acting as a scribe and taking notes. Tapes and notes were transcribed and made anonymous. Transcripts were exported into a computer software database (*qsr NVIVO*) for data management and coding.

The transcripts were analysed using the Framework Analysis techniques of familiarisation, developing a thematic framework, indexing, charting, and mapping and interpretation. Constant comparison was conducted between the data collected from patients, survivors, nurses and lay members to test the interpretation. An initial thematic framework was drawn up. The dataset was re-coded using this framework. Additional codes were incorporated at this stage (Appendix 3). The thematic framework was then synthesised with key research findings from studies on delay in diagnosis in lung cancer, breast cancer and coronary heart disease (Table 3). A new condensed thematic framework was then generated and verified by applying it to the dataset, recoding and comparing. The final thematic framework was then developed (Table 4).

The criteria of “trustworthiness” were used for verification of the accuracy and appropriateness of the data analysis (Tod 2003; Lincoln & Guba, 1985) (Appendix 2). All the interviews were conducted by the authors.
Table 4. Lung Cancer Delay: Thematic Framework

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category (Code)</th>
</tr>
</thead>
</table>
| 1. Experience of symptoms | • Symptom variation  
|                        |   • Nature of symptoms  
|                        |     • Symptom type  
|                        |     • Minor symptoms  
|                        |     • No lump  
|                        |   • Attribution  
|                        |     • Minimize seriousness  
|                        |     • Other explanation e.g. age, gender  
|                        |     • Diagnostic decoys e.g. infection, other chronic condition  
|                        |   • Recognition  
|                        |     • Low perceived risk of LC  
|                        |     • More risk of other cancers  
| 2. Knowledge          | • No knowledge  
|                        |   • Symptoms  
|                        |   • Treatments  
|                        | • Wrong knowledge  
|                        |   • Mismatch between expectations and experience  
|                        |   • Misunderstanding of health education (e.g. increased fear in smokers or reduced awareness in non/ex smokers)  
|                        | • No survivors (Don’t know survivors to learn about symptoms from)  
| 3. Fear (of)           | • Death (Believe nothing can be done)  
|                        | • Cancer (Treatment or suffering)  
|                        | • Consultation  
|                        |   • Previous bad experiences  
|                        |   • Being seen as a time waster, neurotic or stupid  
|                        | • Embarrassment (e.g. examination)  
|                        | • Blame or stigma |
Table 4. Lung Cancer Delay: Thematic Framework (continued)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category (Code)</th>
</tr>
</thead>
</table>
| 4. Blame and stigma       | • Smokers blamed  
• Smokers undeserving  
• Resisting blame (e.g. blaming other things e.g. pollution)  
• Stigma (of being thought a smoker even if not) |
| 5. Cultural               | • Fatalism  
• Stoicism  
• Age (expectation of illness at a certain age)  
• Gender  
  • Health care utilization  
  • Men don’t talk  
  • Women put family first  
• Class (see doctors as more intelligent) |
| 6. GP and hospital services| • Perceived quality  
• Process delays  
  • Lost notes  
  • Not being referred  
  • No repeat X-Ray  
  • Treated for infection / asthma |
| 7. Facilitators           | • Gender (women can talk)  
• Family sanctioning help seeking  
• Family taking action on patient’s behalf |
Table 5. *Individual interview: symptoms and delay*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Symptom profile</th>
<th>Delay from symptom to reporting</th>
<th>Delay from symptom to diagnosis</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Breathless, loss of appetite, voice problems</td>
<td>2 weeks</td>
<td>One month</td>
<td>In-operative</td>
</tr>
<tr>
<td>2</td>
<td>Shoulder pain, breathless</td>
<td>48 months</td>
<td>48 months</td>
<td>In-operative, mesothelioma</td>
</tr>
<tr>
<td>3</td>
<td>Chest pain, arm pain, engorged veins (chest/face), facial rash and swelling, palpitations</td>
<td>4 months</td>
<td>24 months</td>
<td>In-operative</td>
</tr>
<tr>
<td>4</td>
<td>Cough, recurrent chest infections</td>
<td>48 months</td>
<td>60 months</td>
<td>In-operative</td>
</tr>
<tr>
<td>5</td>
<td>Slight breathlessness on exertion</td>
<td>None, picked up on x-ray at diabetic check up</td>
<td>None</td>
<td>Operable</td>
</tr>
<tr>
<td>6</td>
<td>Haemoptysis</td>
<td>None (chest x-rays came back clear)</td>
<td>6 months</td>
<td>In-operative</td>
</tr>
<tr>
<td>7</td>
<td>Collapse</td>
<td>None, picked up on CXR at A&amp;E</td>
<td>None</td>
<td>Operable</td>
</tr>
<tr>
<td>8</td>
<td>No related symptoms. Pain in left buttock</td>
<td>None, picked up on CXR at OPD</td>
<td>None</td>
<td>In-operative</td>
</tr>
<tr>
<td>9</td>
<td>Breathless (COPD) for 6 years</td>
<td>None. Picked up on CXR during hospital admission for pneumonia</td>
<td>None/? 6 years</td>
<td>In-operative</td>
</tr>
<tr>
<td>10</td>
<td>Pains down right side of trunk, tiredness, breathless.</td>
<td>None</td>
<td>3 months</td>
<td>In-operative</td>
</tr>
<tr>
<td>11</td>
<td>Cough, squeaky voice, difficulty swallowing</td>
<td>4 months</td>
<td>9 months</td>
<td>In-operative</td>
</tr>
<tr>
<td>12</td>
<td>Discomfort in left hand side of body</td>
<td>None</td>
<td>3 months</td>
<td>In-operative, mesothelioma</td>
</tr>
<tr>
<td>13</td>
<td>Irritable persistent cough, breathlessness, haemoptysis</td>
<td>2 months</td>
<td>4 months</td>
<td>In-operative</td>
</tr>
<tr>
<td>14</td>
<td>Collapse</td>
<td>None, picked up on CXR through A&amp;E</td>
<td>None</td>
<td>In-operative</td>
</tr>
<tr>
<td>15</td>
<td>Pins &amp; Needles in arm &amp; chest. Loss of power in hand. Gruff voice for about 9 months</td>
<td>9 month delay in reporting voice disturbance, no delay with other symptoms</td>
<td>3 months</td>
<td>In-operative</td>
</tr>
<tr>
<td>Participant</td>
<td>Symptom profile</td>
<td>Delay from symptom to reporting</td>
<td>Delay from symptom to diagnosis</td>
<td>Outcome</td>
</tr>
<tr>
<td>------------</td>
<td>----------------------------------------------------------------------------------</td>
<td>---------------------------------</td>
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<td>-----------------------</td>
</tr>
<tr>
<td>16</td>
<td>Blackout; loss of speech, loss of movement on right side of body. Fitting.</td>
<td>None-picked up on CXR through A&amp;E</td>
<td>None</td>
<td>In-operable</td>
</tr>
<tr>
<td>17</td>
<td>Stomach pain, anaemic, diagnosed with bowel cancer</td>
<td>None. Diagnosed from routine chest x-ray following bowel cancer surgery</td>
<td>None</td>
<td>In-operable</td>
</tr>
<tr>
<td>18</td>
<td>Increasing cough</td>
<td>None</td>
<td>None (GP referred for CXR straight away)</td>
<td>Operable</td>
</tr>
<tr>
<td>19</td>
<td>Irritable persistent cough</td>
<td>1 month</td>
<td>3 months</td>
<td>Operable cancer, 18 month survival</td>
</tr>
<tr>
<td>20</td>
<td>Fatigue, slight cough, reduced energy and activity</td>
<td>None</td>
<td>3 months</td>
<td>Operable cancer, 18 month survival</td>
</tr>
</tbody>
</table>
3. Results

The study identified a range of interacting factors that influence delay in reporting symptoms of lung cancer (Table 4). Many of the participants’ stories resonate with the findings of studies on symptom reporting behaviour in other cancers (Table 3). However, the results of this study indicate additional social and cultural influences on delay in reporting symptoms, for example, stoicism, health care utilization and the perceptions and attitudes of medical staff.

Participants’ stories revealed how factors interacted on an individual basis to contribute to delay in symptom reporting. Overall, six themes emerged to explain the barriers to reporting symptoms.

- Experience of symptoms
- Knowledge
- Fear
- Blame and stigma
- Cultural
- GP and hospital services

The results are presented here using the above themes as headings. Additional results describe the factors identified as helping to overcome delay in reporting symptoms. These were families and gender.

Experience of symptoms

The symptoms described by the participants indicated that experience of these created barriers in reporting the symptoms. The nature of and variation in the symptoms appeared to influence attribution and decision making regarding symptom reporting.

Symptom variation and type

There was a huge variation in symptoms experienced by participants which meant no clear symptom profile emerged for lung cancer (Table 5).
“I think everybody’s body is different. What symptoms might show for me…. for somebody else it might be a pain in the shoulder. It’s very difficult to say, “Well, you know, look for this, this and this” (Patient 19)

A feature of the variation was that symptoms ranged from the severe and acute to the more nebulous and systemic.

“I’ve always been active and …. I just seemed to plummet. Every day was an effort to get up. Every day was … walking was too much of an effort” (Patient 3)

“Persistent cough, losing weight, loss of appetite” (Patient 4)

“Every now and again slight breathless, but I walk about 6 to 7 miles every day going from place to place. I run up and down two flights of stairs all day going upstairs, downstairs” (Patient 5).

“He didn’t seem as fit as he was and you couldn’t have put your finger on anything, but just didn’t seem as fit as he had been” (Wife of patient 16).

Many described symptoms that were quite minor and unspecific, for example a reduced activity, rather than extreme symptoms

“I noticed I were getting a bit short of breath and I went off my food” (Patient 1).

“His enthusiasm for doing his DIY wasn’t as great as it had been.” (Patient 16)

Often, when symptoms started as minor or vague, they only triggered action once they got severe. This could mean months of delay

“I developed a cough, which sometimes was quite severe. I nearly cough unconscious sometimes. But in the early days there was a very little cough. I coughed occasionally, but the cough didn’t really give me a clue” (Patient 12).

A marked contrast was drawn between lung cancer and other cancers with a clear, defined symptom profile, for example breast and testicular cancer. These cancers also had the added benefit of being detected through physical self-examination. No such clarity was experienced with lung cancer.

“I mean with breast cancer you check yourself regular for lumps and bumps and things like that…. But it’s what symptoms to look for, ain’t it? That’s the thing. I mean I didn’t have any at all until my lung filled up
with fluid. I mean if that hadn’t have happened to me, today I would still be no wiser because I didn’t have any pain” (Patient 1).

“You do get more publicity for breast cancer and testicular cancer with men. You know, you get more publicity. You see it in the papers and on the television, but I’ve never heard anything about checking for lung cancer or that type of thing” (Patient 12).

One factor to emerge resonates strongly with the findings of Smith et al (2005) regarding symptom recognition. Two issues related to recognition of symptoms emerged. First, participants did not see themselves at risk of lung cancer so wouldn’t have thought of symptoms in that context.

“The last thing on my mind would have been cancer…. I suppose I always thought “Well, I smoke. It is a risk what you take, all smokers take, you know,” but you never think it’s going to happen to you” (Patient 1).

“Well, I smoked, but I didn’t think I’d be at risk, no” (Patient 11).

A second and related issue was that people saw themselves as more at risk of other cancers.

“You’re more likely to think of yourself getting breast cancer than lung cancer, even as a smoker I think because you hear more of breast cancer. That was always a fear for me to get breast cancer” (Patient 1).

Participants indicated that no common pattern of symptoms was experienced. This variation in the nature and severity of symptoms, added to the inability to conduct a physical examination and misperceptions regarding risk contributed to participants delaying in reporting their symptoms and obtaining a diagnosis.

**Attribution**
The nature and variation in symptoms contributed to a tendency to attribute symptoms to other things. Two strategies were used to do this. First, people minimized the seriousness of symptoms by finding other explanations for the symptoms. Many examples of this were given when symptoms were not severe or were vague in nature.

“I didn’t have a day when I weren’t busy, you see…. my husband said to me, “I'm not surprised you’re bloody tired! You never stop!” But that’s just what I thought it was” (Patient 1).
“I put it down to putting weight on and smoking too much” (Patient 5).

“I’d got this irritating cough and …. where I were working they’d just put air conditioning in and going and I put it down to that, didn’t I” (Patient 12)

Some people interpreted their symptoms as part of the natural process of aging.

“Obviously a younger man might have detected that more because when you get older you don’t run like you used to do anyway without getting short of breath. That’s part of the way you develop into old age I’m afraid (Patient 12).

“It was just getting older, you know?” (Patient 16)

A second attribution strategy was to use diagnostic decoys. That is to ascribe symptoms to other acute and chronic conditions. The most common acute event was that of a cold or chest infection.

“I started bringing a bit of blood up and I just … I assumed … I thought, “Oh, I’ve strained myself with coughing” (Patient 12).

“We went to Hong Kong to see my son, who’s out there working…. we came back I had a cough, which lasted about 5 weeks or so and we both thought “Well, it might an Asian flu.” It could have been anything, but mine went…. But my wife’s continued” (Husband of Patient 11).

Chronic conditions such as lung diseases like asthma and arthritis were also used to explain and accommodate symptoms. Sometimes the use of diagnostic decoys was reinforced by doctors after people had reported symptoms

“I just put it down to … well, possibly a bit of asthma or something like that. I was just getting older, you know”(Patient 16).

“The doctor examined me and came up with a theory … well I say theory, I don’t know. He’s a doctor. That is was arthritis which apparently you can get really bad pains with arthritis” (Patient 3).

The tendency to find alternative explanations or use diagnostic decoys was exaggerated when people did not smoke.

“So you just put it down to the weather, your age, physical exertion, nothing new. I mean all of your friends said to me, “But he doesn’t smoke” (Wife of Patient 16).

In some cases symptoms got worse over time but alternative explanations were retained and symptoms not reported. This was more likely when participants had had a clear x-ray in the past, even if the x-ray had been years previously.
“The x-rays came back and said they thought it could be cleared up with antibiotics, well you tend to sort of believe an x-ray, don’t you? So we would have carried on believing had he have not have had all that blood that night” (Wife of Patient 13).

Knowledge
Lack of information
The experience and interpretation of symptoms occurred within an environment where little knowledge of lung cancer existed. Information and awareness about lung cancer symptoms was poor.

“I don’t think I had any real knowledge of what the symptoms are and I don’t think I do now. I mean what are the symptoms? Breathlessness, a cough”? (Patient 16).

Information tended to focus on other cancers. Where lung cancer information was available it was smoking related.

“There’s an awful lot of publicity about breast cancer, about testicular cancer, about prostate cancer, but the only publicity around lung cancer is …. If you smoke, you get lung cancer. If you don’t smoke you’re going to be all right” (Patient 19).

In addition, participants did not know that treatments for lung cancer existed. As a result people were not motivated to report symptoms as they thought that nothing could be done for lung cancer.

“To be honest I mean you just think, “Oh cancer, that’s it,” you know. “How long have you got?”” (Patient 19)

This meant that early reporting and detection were not viewed as useful. Many people only realised after diagnosis, that:

“The earlier you catch it, the easier it is [to treat]” (Patient 13).

One factor that may have contributed to poor knowledge of lung cancer symptoms and treatment was the fact that none of the 18 patient participants knew survivors of lung cancer.

“I know loads with breast cancer, but not lung cancer” (Patient 5).
**Misinformation**

Against this backdrop of lack of knowledge, there were examples where misinformation appeared to influence a delay in reporting symptoms. These examples fell into two categories.

First, people experienced a mismatch between their expectations of lung cancer symptoms and their experience. Some had no idea what to expect. However, where expectations did exist, participants expected lung cancer symptoms to be severe and extreme. When their experience conflicted with this expectation there were examples of people attributing symptoms to other more minor ailments.

“I thought probably it was an infection. I didn’t think it was anything very serious really because I didn’t feel ill”. (Patient 12)

“It wasn’t like a bronchial cough or anything like that. It was just a niggly cough that he’d got. I mean I have bronchitis and it was nothing like that. It was more niggly, weren’t it”? (Wife of Patient 13)

The most common reported expectation of lung cancer symptoms was weight loss and a severe cough. However, in opposition to their expectation, weight loss was the last symptom to emerge, occurring after participant’s diagnosis. In addition, those that had a cough described it as “niggly” rather than severe.

“I would have expected to start losing weight as a first symptom and expected a cough, but I haven’t had a cough. I don’t cough”. (Patient 5).

Two participants (13 and 16) revealed another scenario where misinformation created a barrier to reporting lung cancer symptoms. Both these men had given up smoking over twenty years ago, on the birth of their first child. This was motivated by a desire to protect the health of their child and to be healthy themselves and provide for their child’s future. Their decision was influenced by a believe, derived from health education messages, that if they gave up smoking their lungs would be clear and they would not risk of lung cancer would be nil.

“I packed up smoking and then after ten years you hear stories, you know, “well, it’s all cleared out your system and everything” and I thought, I’m
never going to get lung cancer or any other one come to that. I’m not smoking” (Patient 13).

This belief that they were not at risk of lung cancer meant that as symptoms emerged, and got worse, they continued to ignore them or explain them away as something else.

“I mean I gave up 25 years ago so you almost forgot that you ever were a smoker” (Patient 16). “If he’d been a smoker and he was getting breathless and he ... his irritating cough had got worse it would be different.... we might well have said, “Hang on, you’d better get this looked at,” I think everybody associates lung cancer with smoking and if you don’t smoke they assume you’re not at risk”. (Wife of Patient 16).

An additional issue to emerge from the experiences of these two participants was the lack of awareness of the risks of second hand smoke. Both men thought their risk of lung cancer was nil after stopping smoking. This was despite working and socializing in smoky atmospheres. It was only after diagnosis that they realised the lung cancer risk from passive smoking.

“But he worked in a smoky atmosphere and .... I think most people think, “Oh I don’t smoke. I’m safe,” and that’s not true.... But the message that comes across is that it’s the cancer of the smoker, so if you’re not a smoker you can sit back and think, “Well, I’m not going to get that” (Wife of Patient 16)

**Fear**

The experiences of fear in this study mirror the findings in other studies (Table 3). Once symptoms had developed to stage where people were concerned, there was still a tendency to delay in reporting them out of fear of death and a cancer diagnosis.

“They are frightened aren’t they, you know, of the outcome”. (Patient 6).

If symptoms were not reported, they obtained a reprieve in being told bad news. The delay and denial that resulted was illustrated by the wife of one man, who had been trying to convince him to go to the doctor:

“I says, “I’m not mentioning it no more. You’re old enough. It’s your own decision you not going [to the GP],” and he admitted he were frightened” (Patient 15).
One aspect contributing to fear of a cancer diagnosis was fear of the examination and any interventions. The expectation was that these would be invasive, unpleasant or embarrassing.

“I was actually frightened about going ... about having things shoved in my mouth and round the back of me and whatever” (Patient 15).

Fear of a medical consultation was referred to where people had previous bad experiences of health care.

“I went through all these tests [for a claim to the war department for a war pension] after the way I was treated during the tests it was as if I was cheating and I lost any confidence I had for doctors” (Patient 2).

Finally, there was a reported fear of being seen as a time waster by the health service, primarily the GP.

“Doctors are very busy people. We’re always being told, “Don’t waste the doctor’s time....” (Patient 16).

**Blame and stigma**

As with other studies on lung cancer (Chapple et al, 2004) the results revealed a prevailing expectation that people with lung cancer would experience blame and stigma. The experience of the participants of this study mirrors those of Chapple et al (2004).

Blame was manifest in a number of ways. First, people expected smokers to be blamed and held responsible for developing lung cancer. This was reinforced by the tone of stop smoking education campaigns and the way smokers had been treated by health professionals in the past.

“Whenever you see warnings about cancer, there’s always a cigarette there. I don’t think I’ve seen a warning where there hasn’t been a cigarette and I think that’s wrong” (Patient 13).

“I’ve got a friend who has a hacking cough because she smokes and I’m always saying to her, “you ought to get that looked at.” She said, “I’m not going to the doctor because the minute they find out I’m a smoker I get in trouble”. So you don’t go because you don’t want to be ticked off” (Wife of patient 16).

Some participants who smoked did see themselves at fault. Others blamed environmental factors e.g. polluted work environments.
“All smokers know that they’re at risk, ....I think because I’m a smoker and I know the risks that I’m running that if I come into problems it’d take me a lot, lot longer to go and find out what was wrong with me” (Patient 5).

I’ve always said what with the welding fumes, burning fumes at work oxyacetylene burners for me to go into.... the amount of fumes and muck that comes off it ....about six weeks ago they were burning wagons up at the other side of the railway line.....so smoking, obviously smoking didn’t help. That bugger didn’t help any either” (Patient 15).

Because of the blame, there was a perception that smokers would be stigmatised and seen as undeserving of health care. This perception created a sense of being ostracised and added to delay in symptom reporting.

“I mean it’s all been focused on smoking and I’m not denying that that is what probably caused my cancer and other people’s cancer, but, ....I don’t know, by dictatorial ways or pressing people, making you feel ostracised, doesn’t work”! (Patient 19).

Even those who were non- or ex-smokers delayed in reporting symptoms because of an expectation they would be stigmatized as a smoker and blamed for their illness. This expectation was reinforced by experience. Health professionals assumed that they were smokers and kept asking about smoking status.

“They keep asking have I smoked? Have I drunk? It’s mainly have I smoked ... anytime? I says, “No.” The only thing I have is gone into a bingo where there’s been smoke” (Patient 3).

**Culture**

There were a number of cultural issues cited in relation to delay in lung cancer symptom reporting in the South Yorkshire communities. Amongst these were the prevailing cultural beliefs mentioned above. These were that lung cancer was always fatal and that people would develop certain symptoms as they grew older.

An additional cultural influence was the great value placed on stoicism, not complaining and “putting a brave face on things”.

“He was out with some friends and I picked him up and he said he’d blacked out and I said, “You did what?” He said, “I blacked out.” I said,
“Well I think you ought to get checked out at the hospital.” “Oh there’s nothing wrong with me. You fuss” (Patient 16).

The stoicism contributed to delay in symptom reporting in participants from older generations and those who had worked in traditional industries such as coal mining, steel and at the railway plant.

“I think people of our generation, you put up … if you’ve got any aches or pains you didn’t go to the doctors every two minutes. Like you get the younger ones now, as soon as they’re not feeling very well they’re straight to the doctor. Well we were never brought up like that, you know, unless ... it had to be something really seriously wrong to make you go which is same as me. The pair of us have very rarely been to the doctor, very rare all our working lives”. (Patient 15)

Stoical tendencies were also explained by gender, with a greater expectation placed on men not to complain or go to the doctors.

“Men don’t like to know generally. They don’t like to fuss. Going to the doctors is fussy. It’s a sign of weakness.... They don’t want to know. Men don’t look after their health. I mean I could nag you from now until Monday and you wouldn’t have gone” [to the GP] (Wife of Patient 16).

Lifelong patterns of health care utilization within the communities contributed to delay in symptom reporting. Participants from the traditional working class communities tended not to use Primary Care services because they could remember pre-NHS health care, where people had to pay to see a doctor.

“I think we were told, “Oh you don’t go unless it’s something serious” (Wife of Patient 15).

In addition, those who worked in heavy industry had a tradition of accessing health care at work from the “pit doctor” or “railway doctor”.

“If you were sick....and you work at Thorne on the railways, you would have come into Doncaster into the medical centre and seen the doctor who were there once a day. We had a doctor come in and so we had all this first class health stuff like, yeh..... Not your own doctor, but the railway doctor” (Patient 15).

Finally issues related to class and education created a disincentive to obtaining a diagnosis. For example, one woman described how she felt less educated than the GP and was therefore reluctant to report symptoms or to insist on being
referred for investigation when she didn’t respond to antibiotics. She preferred to trust the GP’s knowledge and felt unable to be assertive.

“I’m not learned. Because I’m not learned. If I were a bit more learned I would have said straight up front, but ... he’s a doctor, he should know.... you rely on them. If you ... if you haven’t been to college or anything, it’s difficult” (Patient 3).

Media messages interacted with cultural tendencies to reinforce the belief that you shouldn’t go to the doctor unless a problem was extreme.

“You don’t want to waste the doctor’s time because the message is you don’t need a doctor for 95% of things that are wrong with you. You know, you phone NHS Direct, you talk to a pharmacist, so if you go to a pharmacist and you say, “I’ve got this niggling cough,” and he gives you cough medicine” (Patient 16).

**GP and hospital services**

A number of issues were raised regarding the perceived quality of NHS services. As indicated above, some people were put off reporting symptoms if they doubted the quality of care because of a previous bad experience. This was seen to contribute to a delay in diagnosis. However, having some diagnostic delay explained by poor service quality encountered after symptoms had been diagnosed. Many examples were related to breakdowns or faults in the health care process:

**Poor communication and co-ordination:**

“I don’t want to keep just sitting here and somebody pissing down my back and trying to tell me it’s raining.... Alright, I mean I realise these guys are very busy people and they’ve got a lot on their plate, but I do feel that they’ve treated me a bit like a mushroom in some places [kept in the dark]. I’m sure there needs to be better co-ordination in the medical profession as well. As I say, they’re very busy people, but it doesn’t help me, does it? (Patient 12)

**Lack of continuity in services:**

“He did say that there was a shortage of specialists in that field and so therefore they were borrowing someone from a different Trust. So, of course, there’s that many different people involved and everybody else thought somebody else was doing something” (Patient 12).

“I think that the service you get from your GP is abysmal .... You see in the old days ... when I used to go to the doctors in 1980 you used to be able to see a doctor when you wanted to see a doctor. You used to be able to see your
doctor ... the same doctor.... I go and see any Tom, Dick and Harry now and all the locums they can find. I've seen every single doctor down there and I don't think they read your notes because they haven't got a clue who you are” (Patient 10).

**Not being referred:**
Despite persistent symptoms some GPs did not refer patients for further chest x-rays or for review by a consultant physician. In some cases, this occurred even if symptoms worsened or infections were not responding to antibiotics (Tables 4 and 5)

“I thought he would have sent me for something down to have a look what was wrong down there, but he never did” (Patient 3).

As with the patients, diagnostic decoys appeared to exist for GPs. Some continued to treat for concurrent conditions such as chest infection and asthma. For example, one man who eventually became concerned his symptoms were due to lung cancer was treated for asthma after a clear x-ray. His GP was then reluctant to repeat his chest x-ray.

“And I saw him and I said, “I think I’ve got lung cancer.” He said, there’s lots of things that this could be,” and he said, “I think you’ve got asthma” He rang me and said, “Your chest x-ray’s all clear. Pick up a prescription for some asthma spray and I’ll see you in four weeks’ time,” and .... I thought, “Well, that’s good,” you know, “It looks as if my lung cancer’s not lung cancer and it’s actually asthma” (Patient 4).

**Facilitators in overcoming diagnostic delay**
The few factors that emerged as facilitators in reducing delay in obtaining a lung cancer diagnosis fell into two themes, gender and families.

With reference to gender, there was a perception that women are more comfortable talking about their health and bodies. As a result they may be more willing to go to a doctor or discuss symptoms. This contrasts with men.

“I think men still ignore their health. Because they always like their head in the sand anyway. Men don’t like to know generally” (Wife of Patient 16).

Families were key facilitators in overcoming delay in symptom reporting.
“Most of this picking up early signs, it relies on somebody else to do it because doing it on your own you think, “Well there’s nothing wrong with me”” (Wife of patient 16).

They were often the first to notice symptoms.

“I thought there was a little alarm bell ringing in my head a week or two earlier”. (Husband of Patient 11)

Family members also legitimized and encouraged reporting.

“Now I went to the doctors, didn’t I? You [his wife] said, “Look go to the doctors and get it looked at…. There’s something wrong somewhere like.” So off I went” (Patient 15).

“My daughter’s a school teacher and she said to me, “Dad, you’ve not got asthma.” She said, “I’ve seen … kids with asthma. They don’t cough.” (Patient 4)

There were cases where the family member made them an appointment or coerced the person into reporting their symptoms.

‘My daughter says, “you’re coughing a lot aren’t you”? I says “I am lately”. she says “I’ve phoned the doctor up anyway and you’re booked in for Thursday, half -past nine”. I said “I can’t go Thursday, I’m playing golf”. She said, “You’re going to the doctors”! (Patient 18).

There were also examples of how relatives arbitrated for the patient if symptoms were not being investigated.

“My daughter-in-law got onto him on the phone. “You’d better come and see my father-in-law who’s pretty bad.”” (Patient 2)

“He [the participants son] said “No, we’re not waiting 3 month”. I mean it’s a good job really. He said “No…. we want it sorting out”” (Patient 6).
4. Discussion

The results of this study indicate that a number of interrelated factors conspire to delay diagnosis in lung cancer. The importance of these are now discussed in relation to first, delay in symptom reporting and second, health professionals and health services.

Delay in symptom reporting

The results regarding delay in symptom reporting reflect and reinforce those of previous studies, summarized in Table 3.

Delay in reporting symptoms was associated with the type of symptoms, their variation and lack of knowledge of these. Difficulty in recognizing and interpreting symptoms of lung cancer were complicated by the fact that many symptoms were not severe or specific. Even where a change in health was detected it was not seen as serious. People would then tend to self manage symptoms, e.g. going to the pharmacist for cough medicine. The nebulous, systemic and minor nature of symptoms, were contrary to expectations, which added to delay in symptom reporting. Additional factors that were identified here and which mirror previous studies include:

- A tendency to attribute symptoms to other causes and illnesses.
- A perception that participants were not at risk of lung cancers, even smokers.
- Once symptoms were severe enough to prompt alarm, underlying fatalistic beliefs regarding lung cancer induced denial and delay.
- Expectations of stigma and blame regarding smoking and lung cancer, sometimes reinforced by previous experiences of negative attitudes from health professionals.
- Fear of embarrassment because of health consultations.
- Lack of knowledge of treatments for lung cancer reinforced fatalistic beliefs.
The study builds on this previous knowledge by identifying a number of new issues contributing to diagnostic delay in lung cancer. First, the absence of a tangible symptom e.g. a lump was a barrier to detecting and reporting symptoms earlier. Unlike breast or testicular cancer there was no symptom that would have been detected through physical self examination.

Second, misunderstanding from previous media campaigns strengthened a belief that non- and ex-smokers would not get lung cancer. This created a lack of vigilance regarding symptoms and fostered the tendency to attribute symptoms to erroneous causes. Third, cultural factors within the South Yorkshire communities, contributed to delay in symptom reporting, most notably stoical attitudes and patterns of health care utilization.

The findings highlight challenges in addressing delay in lung cancer symptom reporting. The importance of finding a way of educating the public is emphasised. The existing level of education is clearly lacking. There is less information, and therefore knowledge, about lung cancer than other cancers e.g. breast and testicular cancer. The study suggests that current information is further compromised by the orientation towards smoking. This confuses understanding regarding risk and reinforces blame and stigma. Many participants recommended removing smoking from education on lung cancer. Family members emerged as major facilitators to symptom referral. This role needs to be acknowledged and fostered in education of the public. Finally, emphasis is given to the importance of considering cultural and social influences on symptom reporting. The results suggest that social and cultural factors promote an underlying attitude that primary care services should not be accessed unless for more extreme cases. This is further entrenched by media messages highlighting resource restraints in the NHS. Ways of counterbalancing these beliefs need to be developed so that people are encouraged to report emerging symptoms of illnesses such as lung cancer.
Health professionals and health services.

One participant summed up the context within which diagnostic delay occurs in primary care.

“I suppose the thing is with a GP, they would only ever see a few people with that condition in their whole working life”. (Patient 12).

Once people had recognised and reported symptoms a number of issues were identified that conspired to further delay diagnosis. Key amongst these was not being referred for investigation by chest x-ray or to a consultant physician. The fact GPs see so few patients with lung cancer, compared to chronic lung conditions, may partly explain this. It would seem from the scenarios described here, that some GPs were relatively unfamiliar with lung cancer symptom presentation. As a result previous negative chest x-rays were not repeated, even if conducted years previously. Participants were not re x-rayed, despite persisting and worsening symptoms. Deterioration was attributed to concurrent illnesses such as asthma or arthritis. This picture indicates that current guidelines for the investigation and diagnosis of lung cancer are not always followed (Department of Health, 2005). Increased vigilance is needed amongst primary care health professionals regarding early detection and investigation of lung cancer symptoms.

Education of health practitioners is required to raise awareness of the nature and variation of lung cancer symptoms. This will facilitate vigilance. In addition, increased awareness is required amongst primary care practitioners of a number of points raised in the existing NICE guidelines. These are that:

- Chest x-ray is a mandatory first line of treatment,
- BUT the chest x-ray is “an insensitive method”
- Therefore if symptoms persist, patients should be referred for a repeat x-ray or physician assessment, despite an earlier negative x-ray.

The protocol recommends that where there is a low suspicion of lung cancer a GP should continue to observe and manage the patient. Little information is
available about what this means in practice, for example, what time should elapse between repeat chest x-rays.

The problems in communication and co-ordination of services highlight the importance of better collaboration regarding lung cancer investigation and diagnosis. For examples, workable shared local protocols between primary and secondary care. The dependence of some people on work place health services indicate that occupational health services should be actively encouraged to participate in developing and implementing local protocols.

Pharmacists constitute additional partners in local initiatives to reduce diagnostic delay in lung cancer. Lack of information, stoicism and health service utilisation patterns mean people are self managing symptoms and buying symptom remedies from chemists. Pharmacists can therefore play a key role in addressing these barriers to symptom reporting by providing information, monitoring use of shop bought remedies, and by recommending people consult their GP.

A point of concern was that people felt news and education within the media discourage people from using health services unless absolutely necessary. Encouraging responsible use of health care is sensible in a context of finite resources. However, it would seem that, for some people, this message has had provoked an unwanted reticence in consulting a GP about symptoms. This indicates a need for more balanced information that gives people permission to go to their GP without fear of ridicule, being seen as a time waster or as squandering valuable health resources.

**Conclusion**

This qualitative study has identified a number of factors influencing diagnostic delay in lung cancer. In part, the results reinforce those of previous studies regarding delay in symptom reporting. However, additional social and cultural influences were identified as contributing to delay. Additional factors related to the quality of health services, awareness of health professionals of the nature
and variation of lung cancer symptoms, and knowledge of patient referral criteria. These issues could be addressed through education of the public and those working in the health services. The recommendation is to develop educational strategies and interventions to reduce delay in lung cancer diagnosis.
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Appendix 1. Research Team and Steering Group

Research team

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Project team

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Appendix 2.  Trustworthiness

The following strategies were used to verify the confirmability, dependability, transferability and credibility of the results.

<table>
<thead>
<tr>
<th>CRITERIA</th>
<th>EXPLANATION</th>
<th>TECHNIQUES USED TO MEET THE CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Credibility</td>
<td>The “truth value” or the level of credibility of the results for the participants.</td>
<td>• Transcripts checked against tapes and field notes</td>
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<td>• Random interviews observed and discussed with second researcher.</td>
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<td>Transferability</td>
<td>The extent to which the results can be transferred and applied to other populations and contexts.</td>
<td>• Peer debriefing between researchers.</td>
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<td></td>
<td></td>
<td>• Ongoing discussions regarding interpretation of data.</td>
</tr>
<tr>
<td>Dependability</td>
<td>The extent to which the results would be repeated if the study was to be replicated.</td>
<td>• Testing emerging interpretations in subsequent interviews.</td>
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<td></td>
<td></td>
<td>• Sample triangulation, patients, survivors, nurses, lay members</td>
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<tr>
<td>Confirmability</td>
<td>The extent to which the results are derived from the participants and not due to bias or misinterpretation by the researcher.</td>
<td>• Reflection and feedback within the interview.</td>
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<td>• Maintaining a study journal and field notes.</td>
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<td>• Self-reflection by the researcher to maintain awareness of risk of bias.</td>
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<td>• Comparing and integrating previous literature in the later stages of analysis.</td>
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Compiled with reference to Tod (2003) and Lincoln and Guba (1985)
Appendix 3. Initial codes and themes

1. **Experience of symptoms**
   - *Symptom variation*
     - Breathless
     - loss of appetite
     - voice disturbance
     - shoulder pain
     - cough
     - dizziness
     - haemoptysis
     - difficulty swallowing
     - discomfort on side of torso
     - pins and needles
     - arm paralysis
     - chest pain
     - collapse
     - sight disturbance
     - fatigue
     - arm pain
     - rash, skin discomfort
     - facial swelling
     - palpitations
     - engorged veins
     - weight loss
     - reduced activity and mobility
   - *Nature of symptoms*
     - symptom type
       - severe
       - mild
     - no lump
     - Persisting
   - *Attribution*
     - Minimize seriousness
     - Other explanation e.g. age
     - Diagnostic decoys e.g. infection
     - Negative investigations
   - *Recognition*
     - Perceived risk
     - More risk other cancers
     - Thought it was cancer

2. **Knowledge**
   - *No knowledge*
     - Symptoms
     - Treatments
   - *Wrong knowledge*
     - /Mismatch expectations and experience
     - Misunderstanding e.g. health education messages
   - *No survivors*
   - *Myths*
3. Fear
   - Death
   - Cancer
   - Consultation
     - Previous bad experiences
     - Seen as time waster
     - Embarrassment
   - Blame and stigma

4. Blame and stigma
   - Smokers blamed
   - Smokers undeserving
   - Resisting blame
   - Stigma

5. Culture
   - Fatalism
   - Stoicism
   - Age/health expectations
   - Gender
     - Health care use
     - Men don’t talk
     - Women put family first
   - Class
   - Health care utilization

6. GP and hospital services
   - Perceived quality
   - Process delays
     - Lost notes
     - Not referring
     - No repeat x ray
     - Treated for infection or asthma
     - Not visiting
     - Negative xray
     - X-ray results not picked up
     - Appointments
   - Doctors believing tests and training not patient

7. Facilitators
   - Family
     - Noticing symptoms
     - Sanctioning help seeking
     - Taking action
   - Gender
   - Finding information
   - Persisting
   - Knowing your body
   - Opportunistic screening

8. Health education ideas

9. Health service ideas