Delay in diagnosis and treatment of lung cancer

PhD thesis
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The Research Unit and Department of General Practice
Faculty of Health Sciences
University of Aarhus
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Preface
This thesis is based on the following articles


Motivation

After acquiring my certification as a specialist in general medicine in 1999 I took a three month locum post at the Department of Oncology, Aarhus University Hospital. I ended by staying for two years followed by a six-month appointment at the Department of Haematology. During my years working with cancer patients I met several patients who had experienced a delay in diagnosis and treatment. Some of these patients, and some of their relatives, felt a great bitterness about this delay, especially patients whose physician, most often the GP, had failed to suspect cancer. Their bitterness was caused by the thought that the cancer might have been cured if it been had been discovered earlier.

As a future GP I listened to these stories with interest and regret because they sometimes left the impression that GPs in general were very poor at diagnosing cancer. I was aware that patients with negative experiences had a greater need to tell their stories, and more often did so, than patients with positive experiences and that some of the cases might look quite differently from the perspective of the GP. But still some stories remained which made it clear that the GPs and the Danish health care system in general could do better.

During my employment at the Department of Oncology I talked to Professor Frede Olesen from the Research Unit for General Practice about making a research study on diagnostic delay in cancer at the Research Unit, and as he had been interested in this research topic for many years, we agreed that I should make this study.

Acknowledgement

First of all I want to thank Frede Olesen for being such an inspiring supervisor. He has had major influence of the project from the beginning to the end. Next, I want to thank my other supervisors, Torben Palshof and Ronald Dahl, for inspiration and guidance throughout the project. I also want to thank Anders Bonde Jensen who was involved in the birth of the project and gave invaluable advice on the preparation of the protocol for the project.

Many people have been involved in the project, and it had been impossible to do it without their help. I am really grateful to all of them.

I would like to thank Hans Svanholm, The Department of Pathology, Randers Hospital and Ulrik Baandrup and Jane Hjort, The Department of Pathology, Aarhus University Hospital for searching the pathology registers.

Twice a week, during the periods of inclusion, I participated in the morning conferences at the outpatient clinic of The Department of Respiratory Diseases, Aarhus University Hospital, a clinic specialised in diagnosing lung cancer. I would like to thank nurses and secretaries at the clinic for always being so cooperative and Consultant Torben Riis Rasmussen for helping me whenever he could – he even lent me his office when I needed a computer.

I thank nurses Marianne Lyngsoe and Marianne Eriksen from the Department of Oncology, who took care of the practical implementation of the project at the department, and Janette Kortsen, Karen Kirk, Bente Ølund and the other nurses at the outpatient clinic who informed the patients fulfilling the inclusion criteria. I am convinced that the low dropout rate is due to their efforts.

I am grateful to Consultant Hans Pilegaard from the Department of Thoracic Surgery, Aarhus University Hospital, and the nurses at section T3 who helped to inform the patients after lung resection. Especially I want to thank Secretary Lene Svarre who helped me find the patients who were eligible for inclusion in the study. She was very helpful whenever I called, which I often did.
I thank Consultant Jens Frandsen and nurses Tove Olesen and Gitte Aagaard at the outpatient clinic diagnosing lung cancer under The Department of Medicine, Randers Hospital. They were always very helpful.

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Finally I thank my family for their support, especially my children, Victor and Amanda, who, especially during the writing phase, had to take over a larger part of the domestic duties and did so without (too much) complaining.

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### Abbreviations

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<th>Full Form</th>
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<tr>
<td>DLCG</td>
<td>Danish Lung Cancer Group</td>
</tr>
<tr>
<td>DLCR</td>
<td>Danish Lung Cancer Register</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>IQR</td>
<td>Inter-quartile range</td>
</tr>
<tr>
<td>NSCLC</td>
<td>Non-small cell lung cancer</td>
</tr>
<tr>
<td>SCLC</td>
<td>Small cell lung cancer</td>
</tr>
<tr>
<td>OR</td>
<td>Odds ratio</td>
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General introduction
1.1. Lung cancer

1.1.1. Incidence and aetiology

Lung cancer is the most common cancer among men and the third most common cancer among women in Denmark, skin cancer excluded. In 2001 there were 3653 new cases of lung cancer in Denmark: 2068 men (57%) and 1585 women (43%) (1). The median age was 69 years for men and 67 years for women (2). The Danish incidence of lung cancer has been rising since the 1940s and until today were it has reached 87 per 100 000 for men and 52 per 100 000 for women (1). For men it peaked during 1982-1986 when it reached 105 per 100 000, after which it started to level off. For women the incidence has been somewhat lower, but it has been steadily increasing and it is expected that the gender difference will narrow further and will have disappeared by 2020 (3).

The change in incidence of lung cancer reflects the changing smoking habits in men and women in Denmark during the 20th century. Smoking remains the main cause of lung cancer, accounting for 70-80% of cases in men and 50-60% among women (4). Among other important risk factors are industrial exposure to asbestos, nickel, chromium and cadmium and exposure to natural and man-made radon (4-5).

1.1.2. Histology and staging of lung cancer

Histologically, lung cancer is divided into small cell lung cancer (SCLC), and non-small cell lung cancer (NSCLC). SCLC, accounting for about 15% of the cases (6), is characterised by a propensity for early hematogenous dissemination, rapid progression and poor prognosis. NSCLC is a collective name for squamous cell carcinoma, adenocarcinoma, large-cell carcinoma and some more rare subtypes.

Patients are staged according to the International System for Staging Lung Cancer (7), which is based on the TNM System Classification (see Table 1.1). T describes size and extension of the primary tumour, N describes the regional lymph node involvement and M denotes the present or absence of distant metastases. TNM can be based on clinical diagnostic examinations (cTNM) or based on surgical-pathologic material (pTNM). Frequencies of the different stages of lung cancer is based on cTNM are shown in Table 1.2. SCLC is primary divided into limited disease and advanced disease. Limited disease is defined as disease confined to one hemi-thorax that can be encompassed within one radiotherapy port and absence of a malignant effusion. Approximately one third of patients diagnosed with SCLC will present with limited disease (8).

1.1.3. Treatment

The treatment of lung cancer depends on histology, the stage of the disease and the patient’s general condition. SCLC is characterised by high sensitivity to multiple chemotherapeutic agents and radiotherapy. Chemotherapy is the treatment of choice to which about 80-95% of the patients respond, and even very ill patients may benefit from the treatment. About 50% of the patients obtain complete remission, but death from recurrent disease within two years of diagnosis is seen in 80-98% of the cases (8). A small group of patients with stage IA disease may receive surgery followed by chemotherapy.

NSCLC has low sensitivity to chemotherapy and radiotherapy, and until 2000, treatment in Denmark only included surgery in patients with stage I and II and in some patients with stage IIIA. For the remaining patients, i.e. about 70%, there was no standardized treatment. Since 2000, palliative chemotherapy has been standard treatment for patients with good performance status in
### Table 1.1. Staging of lung cancer according to the International System for Staging Lung Cancer

<table>
<thead>
<tr>
<th>Stage</th>
<th>T=N=M</th>
<th>TNM Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 0</td>
<td></td>
<td>Carcinoma in situ</td>
</tr>
<tr>
<td>Stage IA</td>
<td>T1 N0 M0</td>
<td>Malignant cells but no tumour</td>
</tr>
<tr>
<td>Stage IB</td>
<td>T2 N0 M0</td>
<td>Carcinoma in situ</td>
</tr>
<tr>
<td>Stage IIA</td>
<td>T1 N1 M0</td>
<td>Tumour &lt; 3 cm</td>
</tr>
<tr>
<td>Stage IIB</td>
<td>T2 N1 M0</td>
<td>Tumour &gt; 3 cm or atelectasis</td>
</tr>
<tr>
<td></td>
<td>T3 N0 M0</td>
<td>Invasion of chest wall, diaphragm, mediastinal pleura, parietal pericardium or main bronchus &lt; 2 cm from carina</td>
</tr>
<tr>
<td>Stage IIIA</td>
<td>T3 N1 M0</td>
<td>Invasion of heart, great vessels, trachea, esophagus, vertebral body, carina or malignant pleural effusion</td>
</tr>
<tr>
<td></td>
<td>T1 N2 M0</td>
<td>Metastasis to ipsilateral peribronchial or hilar lymph nodes</td>
</tr>
<tr>
<td></td>
<td>T2 N2 M0</td>
<td>Metastasis to ipsilateral mediastinal or subcarinal lymph nodes</td>
</tr>
<tr>
<td></td>
<td>T3 N2 M0</td>
<td>Metastasis to contralateral mediastinal or hilar lymph nodes or supraclavicular lymph nodes</td>
</tr>
<tr>
<td>Stage IIIB</td>
<td>T4 N0 M0</td>
<td>No lymph node metastasis</td>
</tr>
<tr>
<td></td>
<td>T4 N1 M0</td>
<td>Metastasis to ipsilateral peribronchial or hilar lymph nodes</td>
</tr>
<tr>
<td></td>
<td>T4 N2 M0</td>
<td>Metastasis to ipsilateral mediastinal or subcarinal lymph nodes</td>
</tr>
<tr>
<td></td>
<td>T1 N3 M0</td>
<td>Metastasis to contralateral mediastinal or hilar lymph nodes or supraclavicular lymph nodes</td>
</tr>
<tr>
<td></td>
<td>T2 N3 M0</td>
<td>No distant metastasis</td>
</tr>
<tr>
<td></td>
<td>T3 N3 M0</td>
<td>Distant metastasis present</td>
</tr>
<tr>
<td>Stage IV</td>
<td>Any T Any N M1</td>
<td>Distant metastasis present</td>
</tr>
</tbody>
</table>

### Table 1.2. Frequencies of the different stages of lung cancer in Denmark 2004 based on cTMN (7).

<table>
<thead>
<tr>
<th>Stage</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 0</td>
<td>1 %</td>
</tr>
<tr>
<td>Stage IA</td>
<td>7 %</td>
</tr>
<tr>
<td>Stage IB</td>
<td>13 %</td>
</tr>
<tr>
<td>Stage IIA</td>
<td>0 %</td>
</tr>
<tr>
<td>Stage IIB</td>
<td>6 %</td>
</tr>
<tr>
<td>Stage IIIA</td>
<td>8 %</td>
</tr>
<tr>
<td>Stage IIIB</td>
<td>19 %</td>
</tr>
<tr>
<td>Stage IV</td>
<td>46 %</td>
</tr>
</tbody>
</table>
### Table 1.3. Five-year survival rate (%) dependent on stage

<table>
<thead>
<tr>
<th>Clinical stage</th>
<th>Surgical-pathologic stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>IA</td>
<td>61</td>
</tr>
<tr>
<td>IB</td>
<td>38</td>
</tr>
<tr>
<td>IIA</td>
<td>34</td>
</tr>
<tr>
<td>IIB</td>
<td>24</td>
</tr>
<tr>
<td>IIIA</td>
<td>13</td>
</tr>
<tr>
<td>IIIB</td>
<td>5</td>
</tr>
<tr>
<td>IV</td>
<td>1</td>
</tr>
</tbody>
</table>

Modified from CF Mountain (7)

### Table 1.4

#### Symptoms that should raise suspicion of lung cancer

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dyspnoea</strong></td>
<td>Lung cancer can produce atelectasis, pleural effusion or more rarely diaphragmatic paralysis due to infiltration of tumour into the phrenic nerve. Patients with new dyspnoea should be referred to a chest x-ray. Stridor of unknown cause should be investigated with laryngobronchoscopy even when the chest x-ray is normal.</td>
</tr>
<tr>
<td><strong>Hoarseness</strong></td>
<td>Patients with hoarseness for more than three or four weeks should be seen by an otologist because the hoarseness could be due to tumour infiltration into the phrenic nerve.</td>
</tr>
<tr>
<td><strong>Haemoptysis</strong></td>
<td>First time haemoptysis should lead to a chest x-ray. Haemoptysis is frequently seen in patients with chronic bronchitis but also in patients with lung cancer. Haemoptysis for more than a week in patients at high risk for lung cancer (smokers, &gt; 50 years old) should lead to bronchoscopy even when the chest x-ray is normal.</td>
</tr>
<tr>
<td><strong>Systemic symptoms</strong></td>
<td>If the patient has non-organ related symptoms a chest x-ray should be considered especially if the patient is smoking or ex-smoker.</td>
</tr>
<tr>
<td><strong>Oedema of head and neck</strong></td>
<td>Tumour infiltration in the vena cava superior can cause swelling of the head and neck, and the patient should be acutely admitted.</td>
</tr>
<tr>
<td><strong>Cough</strong></td>
<td>Cough for more than six weeks in patients with no earlier history of lung diseases and a change in the cough in patients with known bronchitis should lead to referral for chest x-ray</td>
</tr>
<tr>
<td><strong>Thoracic pain</strong></td>
<td>Tumour infiltration in the chest wall can produce thoracic pain and persistent pain should lead to chest x-ray in patients at high risk of lung cancer. Pain in the upper part of the chest with radiation to shoulder and arm can be seen with tumour infiltration into ribs and brachial plexus (Pancoast tumour)</td>
</tr>
<tr>
<td><strong>Bone pain</strong></td>
<td>Bone metastases are common in lung cancer and bone pain of unknown cause should therefore also indicate to chest x-ray.</td>
</tr>
</tbody>
</table>

Modified from DLCG, Reference program 2001 (17).
stage IIIB and IV, and some patients with stage IIIA. Patients with stage I and II who are found unsuitable for surgery, e.g. due to reduced lung function, are now offered curative intended (stereotactic) radiotherapy. The five-year survival rate for patients treated with radiotherapy has improved with the new techniques but is still inferior to the five-year survival rate for patient receiving surgery (9). Since 2005 patients with stage IB, IIA and III B have received postoperative chemotherapy.

1.1.4. Prognosis

In 1989 a project called EUROCARE was set up to measure and explain European differences in cancer survival (10). It showed that lung cancer survival varied more than two-fold across Europe with Denmark, England, Scotland and Poland having the poorest performance (11). The status in 2002 on the survival of lung cancer patients in Denmark showed a five-year relative survival rate of only 7% (12), and lung cancer is the most common cause of cancer death in both women and men (13). It seems that Danish patients had the same survival as patients in the other Nordic countries in the 1950s and 60s, but had foregone the improvement in prognosis seen in these other Nordic countries in recent decades (14)(Fig 1.1). The inferiority in survival has primarily been explained by patients in Denmark having more advanced disease at the time of diagnose (14), but comparison with Sweden also indicates that Denmark lags behind in treatment capacity (15).

The prognosis of lung cancer is highly dependent on the stage of the disease (5). Table 1.3 shows the five-year survival rate according to cTNM staging and pTNM staging. The difference in survival rate between these two systems reflects that surgical-pathologic findings often produce more accurate results showing a more advanced stage of the disease (7).

In 1992, the lack of improvement in prognosis inspired the formation of the Danish Lung Cancer Group (DLCG), the purpose of which was to establish guidelines for investigation and treatment of lung cancer and to found the Danish Lung Cancer Register (DLCR), the purpose of which is to improve and harmonise quality in health care of lung cancer patients in Denmark. The DLCR started registration of diagnostic investigations, treatment and survival of patient with lung cancer in January 2000. Every year since 2001, a report has been published with data from departments diagnosing and treating lung cancer. The latest reports on survival show an increase in the one-year survival especially for women. The five-year survival have increased to nearly 10%, but is still inferior to the other Nordic countries (3).

1.1.5. Diagnosing lung cancer

Denmark has a tax-financed public health system providing free care in general practice and at hospitals. About 98% of the Danes are registered with their own general practitioners (GP) who act as so-called gatekeepers (16). The GP examines the patient and, if indicated, refers the patient to hospital or to an examination at an outpatient clinic.

Even though lung cancer is one of the most common cancers in Denmark a GP sees only about one new case of lung cancer per year. The core symptoms, cough and dyspnoe are, on the other hand, very common in general practice. The high prevalence of lung cancer symptoms and the low incidence of lung cancer in general practice invites suspicion that symptoms are often misinterpreted and the diagnosis often delayed. The Reference Program 2001 from the DLCG contains a list of symptoms that should raise such suspicion of lung cancer (17)(Table 1.4).

GPs can organize simple investigations like blood tests and chest x-ray. If diagnostic difficulty remains or these investigations are abnormal, the GP can refer the patient to a hospital ward or an
Figure 1.1. Relative five-year survival in the Nordic countries for men (top) and women (bottom), 1958-1987.
♦: Denmark; ■: Finland; ▲: Norway; ●: Sweden. RSR: relative survival rate.

examination at an outpatient clinic. The larger hospitals have outpatient clinics specialised in diagnosing lung cancer.

1.1.6. Screening

The close association between prognosis for lung cancer and the stage of the disease at the time of diagnosis has triggered much interest in the possibilities offered by lung cancer screening. Four randomized controlled trials on such screening were conducted with chest x-ray and/or sputum cytology in the USA and Czechoslovakia in high-risk populations (male smokers). None of the trials showed a reduction in overall mortality (18-20).

Low-radiation-dose computed tomography (low-dose CT) has been deployed in trials in some medical centres in the USA and Japan, but none of the trials were randomized. They shown that 60-93% of the lung cancers detected by low-dose CT screening were in stage I (21;22), which is markedly better than the current state in Denmark where 20% of all newly diagnosed lung cancers are stage I. But CT screening suffers from major limitations, especially a high rate of nodule detection: up to 20% of the participants are test positive, which produces a high number of follow-up CT scans, invasive procedures for benign lesions, and detection and treatment of slowly growing clinically unimportant tumours. There also is a small risk of cancer associated with multiple follow-up CT scans.

A Danish screening trial planned by a group under the DLCG was launched on 1 October 2004 at Gentofte Hospital. This European collaborative trial includes 4000 people at high risk (age 50-65 years, smoking history of at least 20 packets years) and patients are randomised into annual low-dose CT scan for five years or no scanning (23). All included patients are offered participation in a smoking cessation programme. The main object of the project is to analyse the impact on survival of an annual CT scan together with a smoking cessation programme compared with a smoking cessation programme alone (24). It is unlikely that a general screening for lung cancer will be introduced in Denmark before the results of the Danish study and similar studies from other countries are available.

1.1.7. Attitudes towards lung cancer

The poor prognosis and the limited treatment options for lung cancer patients earlier made some doctors express the attitude that lung cancer never can be diagnosed too late. This defeatist attitude has been believed to be a reason for delay in diagnosis and treatment of lung cancer (25;26). The National Cancer Plan, 2000, from the Danish National Board of Health also states that “… a lack of knowledge of cancer diseases and their treatment has resulted in lack of attention and in many cases a defeatist attitude among the health care staff towards detection and treatment of cancer patients"(27)(translated by the researcher). Studies from the USA and Canada have shown that knowledge and beliefs about prognosis and treatment of NSCLC vary widely both between physician specialties and within each speciality, which may give rise to concern, as doctors’ beliefs about the efficacy of treatment are strongly associated with their treatment recommendations (28;29). We found no previous Danish studies examining this issue.
1.2. Delay

1.2.1. Definition

Delay in treatment of cancer has been an issue of scientific concern since the early twentieth century. The modern approach to the issue of delay was introduced by Pack and Gallo in 1938 who defined “undue patient delay” in a somewhat arbitrary way as “three months or more elapsed time between discovery of symptoms and a visit to a physician” (30). Physician delay was defined as failure either to reach a diagnosis or to make proper referral within one month of the first visit. The paper by Pack and Gallo was followed by a number of studies reporting percentages of patients who delayed three months or more from discovery of symptom until consulting a physician (31;32). This definition did not take into account the great difference between different cancer diseases and the great variation in presenting symptoms. A Norwegian study therefore used a subjective evaluation of how long the patient had delayed physician contact based on individual characteristics for each cancer type and each patient (33), but a subjective evaluation hampers comparison of the results with those of other studies. Other researchers have used the term avoidable (or retrospective) delay (31;34), but there is not always a clear distinction between avoidable and unavoidable delay.

There is still no standardized definition of delay in the diagnosis and treatment of cancer, but in recent years most studies have used an operational definition of delay counting the whole period from the first symptom until diagnosis or treatment initiation. Delay has been subdivided into patient delay and doctor (physician/provider) delay, where the former is defined as time from discovery of the first symptom and until the first contact with a medical provider and the latter is defined as time from the first provider consultation until diagnosis or treatment (32;35;36). Doctor delay has further been subdivided into, first doctor delay or GP delay and second doctor delay or

![Figure 1.2. Subdivisions of delay.](image-url)
hospital delay (25;37-41). This subdivision provides important information, but does not answer the question whether the cause of the delay is lack of suspicion of cancer or long waiting times for consecutive investigations or both. An answer to this question requires a distinction between genuine doctor delay due to lack of investigation of cancer-related symptoms and system delay due to waiting times for investigation of cancer-related symptoms and administration. A model for division of delay is shown in Figure 1.2.

1.2.2. Delay in diagnosis and treatment of lung cancer

A number of studies have explored delay in the diagnosis and treatment of lung cancer with the aim of describing the length of the delay or of exploring the impact of delay on stage and survival. Table 5 shows a list of previous studies of delay performed over the last 20 years (25;37-40;42-55). It should be noticed that many of these studies only included patients with NSCLC or patients attending specific departments or hospitals. Only three studies, all Swedish, were population-based. Two of them used the same population (44;46), which included 39 patients, and the last study only included patients with NSCLC who received treatment (52). Three other studies, a Spanish (53), a Turkish (54) and a Finnish study (55), included patients from district hospitals, but whether they included all lung cancer patients in the district or not remains unclear.

Table 6 shows the findings of different delay subgroups. Three studies from Table 5 are not included in Table 6. One used percentages of patients having different intervals of delay (49). Another study calculated the difference in delay between patients in stage I and II with patients in stage III and IV (48) and the last study, which was based on a questionnaire for discharged patients, only made crude delay estimations (40).

No studies looking at the impact of delay in diagnosis and treatment on survival from lung cancer, except for one study (48), found any significant association between long delay and survival (36;37;49-53). This does not imply that the length of the delay is not important to survival. The doubling times for lung tumours vary widely both between and within the different histological subtypes (56). A rapidly progressing tumour produces severe symptoms and signs that may influence the speed of the medical decision process and thus shorten the delay. The opposite may be the case for a slowly growing, non-aggressive tumour with an inborn, good prognosis. This is consistent with the association between advanced cancer, poor prognosis and short delay found in some studies (49;52). A British study examining the impact of delay on treatment in lung cancer patients awaiting radiotherapy with curative intent showed that six out of 29 patients (21%) became incurable while they were on the waiting list (45). This indicates that delay is associated with prognosis, also when adjustment is made for the nature and inborn prognosis of the cancer.

Besides increased risk of progression of the disease, delay also causes psychological distress in the patients and this distress is shown to correlate positively with the length of delay (57).

1.3. Aim

Lung cancer is one of the most common cancer diseases in Denmark and the most common cause of cancer death. The prognosis is very poor and has not improved much over the years. The five year survival rate in Denmark is inferior to that of the other Nordic countries, which can partly be explained by the fact that patients in Denmark have more advanced disease at the time of diagnosis. The reason for this is not known and we lack knowledge of the exact types of delay that may help explain this discrepancy. One explanation offered has been that of a presumed defeatist attitude towards diagnosis and treatment of lung cancer among the health care staff, especially GPs.
Earlier studies of delay in the diagnosis and treatment of lung cancer have mainly studied selected groups of lung cancer patients, and they have mainly focused on assessments of delay or the impact of delay on stage and prognosis.

The aims of this ph.d.-thesis were:

- To examine if a defeatist attitude towards diagnosis and treatment of lung cancer was common among Danish GPs
- To make a population-based assessment of delay in diagnosis and treatment of lung cancer
- To distinguish between delay due to lack of suspicion of lung cancer and delay due to waiting times and administration related to investigations and treatment of lung cancer
- To identify areas that could be candidates for improvement in both primary and secondary health care
### Table 1.5. Studies of delay in diagnosis of lung cancer from the last 20 years.

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<th>Author (publication year)</th>
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<th>Number of patients</th>
<th>Year of inclusion</th>
<th>Patient group</th>
<th>Data source</th>
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<td>1993</td>
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References


Chapter 1. General introduction


Chapter 1. General introduction


16


Chapter 2

General introduction of methods
Chapter 2. General introduction of methods

2.1. The questionnaire

The aim of the questionnaire was primarily to reveal whether a defeatist attitude towards diagnosis and treatment of lung cancer was common among Danish GPs and secondly to obtain the GPs opinion about the diagnostic organisation.

2.1.1. Making the questionnaire

No validated questionnaire measuring GPs’ attitudes towards diagnosing lung cancer and the organisation of the diagnostic procedures was available, so a questionnaire with ad hoc questions was accordingly designed on the basis of a literature review. To ensure that the questionnaire covered important issues in the diagnostic process, two focus group interviews were conducted. Each interview was attended by six physicians: four GPs, a respiratory physician, and a thoracic surgeon or an oncologist.

The questionnaire was pilot tested among five GPs with research experience. The questionnaire was revised and a new pilot test performed among 30 randomly selected GPs of whom 14 answered and commented on the questionnaire. After a new revision the final questionnaire designed (See appendix A). The questions probed whether the GPs had a defeatist attitude towards diagnosing lung cancer, how they perceived the possibilities for improving prevention, how they evaluated the organisation of the diagnostic process and what the actually did when they had a patient in whom they suspected lung cancer. The questions were formed as statements to which the responder could answer on a Lickert scale: “totally agree”, “somewhat agree”, “somewhat disagree” and “totally disagree”. There was also a possibility for a “don’t know” answer.

2.1.2. Sampling the GPs and data collection

In order to obtain a representative sample and to obtain acceptable statistical confidence intervals we chose to send the questionnaire to one third of all Danish GPs. The Department of Registration in the Danish Medical Association (DADL) randomly selected 1201 Danish GPs. For each GP, information about address of consultation, sex, age and year of graduation was listed. In September 2002 the questionnaire was sent by mail to 1186 GPs. Fifteen GPs were excluded due to participation in focus group interviews or pilot testing. Five weeks later a reminder was sent to 492 GPs (42 %) not yet having returned the questionnaire. Data from the questionnaires were scanned by the computer program TELEform and gathered in a database.

2.1.3. Statistics

The statistical software program Stata 8.0 was used for data analysis. Answers were dichotomised into “agree” and “not-agree”, and “don’t know” answers were coded as missing. Logistic regression was used in order to analyze differences in answers in relation to gender, age, and whether the GP worked alone or with other GPs. Two sided t-test and $\chi^2$-test were used for drop-out analysis.

2.2. The case study

The aim of the case study was to analyse delay in diagnosis and treatment in lung cancer and to detect its possible causes, distinguishing between delay due to lack of suspicion of cancer and delay due to waiting times related to investigations and treatment.
2.2.1. Criteria of inclusion

We chose to include consecutive patients with newly diagnosed lung cancer living in the county of Aarhus. The focus of our interest was the processes for diagnosing lung cancer in the county, and we therefore excluded patients investigated outside the county and, for practical reasons, non-Danish speaking patients, too. The lung cancer had to be histologically or cytologically verified to be sure that we obtained a well-defined group of patients. Verification should be done between 1 April and 31 May or between 1 September and 31 December 2003.

2.2.2. Identifying the patients

Malignant diagnoses established on the bases of biopsies from lungs, bronchia, mediastinum, and lymph nodes in mediastinum were searched fortnightly in the two pathology registers in the county, which are located at the Departments of Pathology, Aarhus University Hospital and at the Department of Pathology at Randers Hospital. These registers use histological diagnoses and it is therefore not possible to differentiate patients with lung cancer from other cancer patients. A search was therefore performed covering frequent biopsy locations in lung cancer patients. The so-called “Green System”, which is a national hospital computer register that obtains information about hospital admissions in Denmark, was used to identify patients on the list meeting the inclusion criteria, and to locate the hospital and department diagnosing or treating the patient.

The search in the pathology register did not identify patients diagnosed e.g. by biopsies from liver, skin, or bones, or by cytology from pleural effusion. Patients meeting the inclusion criteria but untraceable via the pathology registers (approximately 10%) were included in the following manner: The researcher a) participated twice weekly in a daily conference at the outpatient clinic diagnosing lung cancer at the Department of Respiratory Diseases, Aarhus University Hospital; b) phoned the nurses at the outpatient clinic diagnosing lung cancer at the Department of Medicine, Randers Hospital on a weekly basis, c) contacted the secretary responsible for summoning patients to surgery for lung cancer at the Department of Thoracic Surgery, Aarhus University Hospital, every second week; d) regularly looked through the list of new patients referred to chemotherapy or radiation therapy at the outpatient clinic at the Department of Oncology, Aarhus University Hospital; e) looked through the list of patients discussed at a two times weekly joint conference for lung cancer in the county.

The Department of Medicine at Silkeborg Hospital, which also diagnoses lung cancer, could not find the time to participate in this part of the study.

2.2.3. Information of the patients

When the patients were identified, their clinical pathway was followed until treatment initiation or decision not to treat. Patients receiving chemotherapy were informed about the study and invited to participate by the nurses at the Department of Oncology. Patients receiving radiotherapy were mainly informed and invited to participate by the researcher. Patients receiving surgery at the Department of Thoracic Surgery were asked by the nurses if the researcher was allowed to contact them later by phone in order to disseminate information about the study and invite them to join. Patients who did not receive surgery, chemotherapy or radiotherapy were asked by mail for permission for the researcher to contact them on the phone.

The patients could accept full participation in the study, including an interview, or they could accept participation and decline the interview.
2.2.4. Patient interviews

After the literature search, a guide was made for a semi-structured patient interview. Pilot interviews were made with four patients. These interviews were taped and transcribed. The interview guide was revised and the final guide was made (see appendix B). Patients participating in the study were first asked to tell what had happened in the period between the recognition of the first symptoms of the lung cancer and until treatment was initiated or the decision of no treatment was taken. After this narrative, the interviewer asked additional questions to be sure that all issues on the check list had been covered. The interviews were taped and half of them were transcribed. Before the interview, a review was made of the patient’s medical hospital records and all dates of investigations were written into a calendar that was used as a time line if the patient had problems remembering what had happened.

When the patient had accepted the invitation to join the study, a time for an interview was scheduled. Patients receiving chemotherapy or radiotherapy were interviewed at the Department of Oncology on the day of treatment. Most of the patients receiving surgery were interviewed at home, but three of them preferred to be interviewed at the researcher’s office and one at the Department of Surgery. Patients who did not receive treatment were interviewed at home. The length of the interview ranged from 15 to 90 minutes. Most of the interviews lasted between 30 and 40 minutes.

2.2.5. GP interviews

A questionnaire was designed for telephone interview with the patients’ GPs and a single pilot interview was conducted. The purpose of the interviews was to obtain the facts about the first presentation of lung cancer-related symptoms, type of symptoms, the GP’s considerations and actions, and date and type of investigations.

The GPs were contacted during the time of their telephone consultations and asked if they would participate in the study. In most cases a new time for the interview was scheduled. If the patient was included post mortem, a letter was sent to the GP before they were contacted on the phone. This letter contained information about the study and a copy of the permission from the Danish National Board of Health to include patients in the study who had died shortly after the diagnosis was made.

The interviews lasted about 10 minutes and were taped.

2.2.6. Handling data

Based on the information obtained from the hospital journal, the patient interview and the telephone interview with the GP, a review of delay from the first symptom until treatment initiation or decision not to treat was made for each patient. On the basis of these reviews, the author of this dissertation estimated the different types of delay and discussed them with the principal supervisor (FO). Disagreement on the estimations was confined to a few cases, which were reviewed and discussed until consensus was obtained. Definitions used for estimation of delay are shown in Box 2.1.

Quantitative data collected through interviews and reviews of journals were gathered in an Access database and transferred to Stata.

2.2.7. Statistics

All statistical calculations were made in Stata 8.0. Non-parametric test were used. The Mann-Whitney test was used to test for significant differences between the median in two independent
groups, the Kruskal-Wallis test to test for significant differences between more than two independent groups, and the Wilcoxon matched pair test was used to test for significant differences in median between paired groups. A non-parametric test for trend by Cuzik and Altman was also used (1).
### Box 2.1. Definitions

- **Patient delay**: Time intervals from first symptom until treatment, when the patient had not yet consulted the health care system or had delayed investigation or treatment.

- **Doctor delay**: Time elapsed without investigation of cancer-related symptoms and signs.

- **System delay**: Time elapsed due to waiting times related to investigation of cancer-related symptoms and administration.

- **Treatment delay**: The time from referral to treatment by the diagnosing department until treatment initiation. Strictly speaking, it is a subcategory of system delay.

- **Primary health care**: General practice, specialist practices outside the hospitals, and outpatient clinic contacts. The hospital only makes the investigations and leaves the responsibility for follow-up to the GP.

- **Secondary health care**: Hospital admissions and outpatient clinic contacts. The hospital is responsible for follow-up.

- **Delay in primary health care**: The time from the patient’s presentation of the first symptoms or signs that could be related to the lung cancer until referral to hospital.

- **Delay in secondary health care**: The time from referral to hospital until start of treatment.

- **The date of first symptom**: The date of the first symptom or sign that can be related to the lung cancer given by the patient or the date written in the medical records. Dates are chosen as approximate dates. For example, if the record only says June, the 15 of June is chosen as the date of first symptom. If it says in the beginning of June, the first of June is chosen, and if it says late June, the first of July is chosen. If it is told that the patient has been coughing for 2 months, the date 2 months before the date written into the record is chosen. If there is disagreement between the information from the different sources, the information given by the GP is used as a rule.

- **First contact with the health care system**: The date at which the patient for the first time presents symptoms or signs that can be related to the lung cancer. Visits out-of-hours are not included. If the cancer is found by chance, we entered the date when an investigation raised suspicion of cancer.

- **Start of treatment**: Start of treatment with the aim of lowering the number of tumour cells.

- **Distinction between primary and secondary care**: If the patient is referred to investigation at an outpatient clinic at the hospital and the hospital chose to refer the patient to further investigations, the date of the referral to further investigation is the first day of delay in secondary health care.
References

Chapter 4

Patient, doctor and system delay in diagnose and treatment of lung cancer

Marianne Bjerager, Torben Palshof, Ronald Dahl, Peter Vedsted & Frede Olesen

(Submitted)
4.1. Abstract

**Background:** Delay of diagnosis and treatment of lung cancer is a well-known problem and previous studies have shown that there is room for improvements in both primary and secondary health care. The aim of the present study was to analyse delay in diagnose and treatment for a group of lung cancer patients and to detect possible reasons for delay. We wanted to divide delay into delay due to lack of suspicion of cancer and waiting times related delay due to investigations and treatment.

**Methods:** A population-based systematic review of the time from first symptom until treatment initiation or decision not to treat for 92 consecutive lung cancer patients. The reviews were based on the patient’s medical hospital records, patient interviews and telephone interviews with the patient’s general practitioner (GP).

**Results:** Median delay from first presentation to the health care system until treatment initiation exceeded three months. System delay was nearly six-fold longer than doctor delay. Delay in primary health care was associated with the type of first symptom. Chest x-rays raising no suspicion of cancer were an important reason for delay, causing prolonged delay – often for months.

**Conclusion:** Increased focus on system delay is necessary if we want to shorten the time for diagnosis and treatment of lung cancer patients. It is important that GPs (and other physicians) are aware of the low sensitivity of chest x-rays when diagnosing lung cancer.
Chapter 4. Patient, doctor and system delay in diagnosis and treatment of lung cancer.

4.2. Introduction

Lung cancer is a common cancer disease with an unfavourable prognosis. It is the most common cause of cancer death in Denmark among both men and women (1). Its prognosis depend much on the stage of the disease at the time of diagnosis (2). Delay of diagnosis and treatment is found to be a problem in many studies (3-9). Besides hampering timely treatment, diagnostic delay also causes extra psychological distress in the patients (10). For both biological and psychological reasons, a short diagnostic delay is therefore recommended.

Some studies have quantified the delay, e.g. in patient delay, delay in general practice, and delay at the hospital (11-14), and they show room for improvements both in primary and secondary health care. The absence of knowledge of the precise nature and causes of this delay hampers any attempt at proposing areas of improvement. The aim of the present study was to analyse delay in diagnosis and treatment of a group of lung cancer patients and to detect its possible causes, distinguishing between causes attributable to lack of suspicion of cancer and causes rooted in waiting times related to investigations and treatment.

4.3. Material and methods

The study took place in the Danish County of Aarhus (680 000 inhabitants), where about 400 new cases of lung cancer are diagnosed per year. Three hospital departments diagnose lung cancer in the county: The Department of Respiratory Diseases at Aarhus University Hospital, the Department of Medicine at Randers Hospital and the Department of Medicine at Silkeborg Hospital. Surgical treatment is performed at the Department of Thoracic Surgery and radiotherapy and chemotherapy at the Department of Oncology both placed at the Aarhus University Hospital. All histological and cytological tests performed in the county are registered in two pathology registers, one at the Department of Pathology at Aarhus University Hospital and one at the Department of Pathology at Randers Hospital.

We identified and included all patients living in the County of Aarhus with newly diagnosed lung cancer histologically verified between 1 April and 31 May, or between 1 September and 31 December 2003. Non-Danish speaking patients and patients diagnosed outside the county were excluded.

The pathology registers were searched for malignant diagnoses from biopsies from lungs, bronchia, mediastinum, and lymph nodes in mediastinum. Patients diagnosed by biopsies from other organs were identified by searching the lists of patients discussed at two weekly joint clinical conferences on lung cancer in the county. To further optimise inclusion, we contacted the departments of oncology and thoracic surgery and two of three departments in the county that diagnosed lung cancer during the periods of inclusion. The last department could not find time for this complementation of the primary inclusion.

Patients were informed about the study after treatment initiation at the Department of Oncology, after operation at the Department of Thoracic Surgery or by letter sent to their home addresses if there were no treatment to offer. Patients who died shortly after the diagnosis were included post mortem by permission of the Danish National Board of Health.

A systematic review of delay was made for each patient starting with the first symptom until treatment initiation or, if the patient received no surgery, chemotherapy or radiotherapy, until decision not to treat. These reviews were based on the patients’ medical hospital records, interviews with the patients and telephone interviews with the patients’ GP. When the patient accepted participation, a time for an interview was scheduled, either at the hospital or at the patient’s home.
Following this interview, the patient’s GP was contacted and asked for a telephone interview. The interviews were taped and selected interviews were transcribed.

4.3.1. Definitions

We divided the time from first symptom until start of treatment into three main parts (Fig. 1.2):

Patient delay: Time intervals from first symptom until treatment, when the patient had not yet consulted the health care system or had delayed investigation or treatment.

Delay in primary health care: The time from the patient’s first presentation of symptoms or signs caused by the lung cancer until referral to hospital.

Delay in secondary health care: The time from referral to secondary care until start of treatment.

Primary care: General practice, specialist practices outside the hospitals, and outpatient clinic contacts. The hospital only makes the investigations and leaves the responsibility for follow-up to the GP.

Secondary care: Hospital admissions and outpatient clinic contacts. The hospital is responsible for follow up.

The health care system delay was subdivided into:

Doctor delay: Time elapsed without investigation of cancer-related symptoms and signs.

System delay: Time elapsed due to waiting times related to investigation of cancer-related symptoms and administration.

Treatment delay: The time from referral to treatment by the diagnosing department until treatment initiation. Strictly speaking it is a subcategory of system delay, but in this paper treatment delay is analysed separately.

4.3.2. Estimations of delay

The different types of delays were estimated by M.B. and F.O. In the few cases where estimators disagreed, the cases were discussed until consensus was achieved. Calculation of medians, inter-quartile range (IQR) and p-values were made in Stata 8.0.

4.4. Results

We identified 132 lung cancer patients through the pathology registers. Another 14 patients were identified by contacting the departments. In all, four patients were excluded: two because part of the diagnostic process was located outside the county and two because they did not speak Danish. Thus 142 patients were included in this study. Eighteen patients were not informed about the study for different reasons (see Fig. 4.1). Twenty-seven patients were included post mortem. We asked 97 patients to participate of whom 65 patients agreed. A total of 92 patients participated in the study. For one patient, included post mortem, it was not possible to estimate delay of diagnosis and treatment. Analysis of delay was therefore carried out for 91 patients. Fifty-two patients and 86 of the patients GPs were interviewed.

There was no statistically significant difference between participating patients and non-participating patients according to age and sex. Among the former more received chemotherapy (Table 4.1). All the patients who died shortly after the diagnosis where included in the study, but in the following months several of the non-participating patients died. A year after diagnosis 50.0% of the included patients and 42.0% of the non-participating patients were still alive.
Chapter 4. Patient, doctor and system delay in diagnosis and treatment of lung cancer.

4.4.1. Delay
Half of the patients experienced a delay exceeding four months from first symptom until treatment initiation or decision not to treat (Table 4.2). Delay in secondary health care was significantly longer than delay in primary health care (p=0.001, Wilcoxon), and system delay, including treatment delay, was significantly longer than doctor delay (p<0.001, Wilcoxon). Most of the latter occurred in primary health care (p<0.001, Wilcoxon) and its distribution was highly skewed: doctor delay ranged from nil in 31 patients (34%) to more than three months in 12 patients (13%).

Lung cancer was found by chance in eight cases, but exclusion of these patients had no significant effect on results. There were no significant differences in types of delay between the 26 patients included post-mortem and the rest of the 91 patients.

4.4.2. Types of debut
For 65 patients (71%) the presenting symptoms were lung-related, i.e., coughing, dyspnoea, haemoptysis, or thoracic pain. Fourteen patients (15%) had non-typical symptoms like arthralgia, muscle pain, pain in back or shoulder, or vague symptoms such as fatigue. Four patients (4%) had
Chapter 4. Patient, doctor and system delay in diagnosis and treatment of lung cancer.

Table 4.1. Characteristics of participating and non-participating patients.

<table>
<thead>
<tr>
<th></th>
<th>Participated</th>
<th></th>
<th></th>
<th>p-value†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes (n=92)</td>
<td>No (n=50)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age in years – mean</td>
<td>65.4 (63.3 – 67.5)</td>
<td>68.3 (65.6 – 71.0)</td>
<td>0.105</td>
<td></td>
</tr>
<tr>
<td>(95% confidence intervals)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Woman (%)</td>
<td>38.0</td>
<td>38.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Operation</td>
<td>32.6</td>
<td>36.1</td>
<td>0.867</td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>34.8</td>
<td>17.0</td>
<td>0.029</td>
<td></td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>21.7</td>
<td>31.9</td>
<td>0.193</td>
<td></td>
</tr>
<tr>
<td>No treatment</td>
<td>10.9</td>
<td>14.9</td>
<td>0.495</td>
<td></td>
</tr>
<tr>
<td>Mortality (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Died within:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-2 months</td>
<td>26.09</td>
<td>6.0</td>
<td>0.004</td>
<td></td>
</tr>
<tr>
<td>3-5 months</td>
<td>11.96</td>
<td>30.0</td>
<td>0.008</td>
<td></td>
</tr>
<tr>
<td>6-8 months</td>
<td>7.61</td>
<td>18.0</td>
<td>0.061</td>
<td></td>
</tr>
<tr>
<td>9-11 months</td>
<td>4.35</td>
<td>4.0</td>
<td>0.922</td>
<td></td>
</tr>
<tr>
<td>12-14 months</td>
<td>10.87</td>
<td>10.0</td>
<td>0.872</td>
<td></td>
</tr>
</tbody>
</table>

† Mann-Whitney (except mean age where t-test is used)

symptoms related to brain metastases and in eight patients (9%) the lung cancer was found by chance during investigation for another disease.

Patients with non-typical symptoms experienced longer delay in primary health care than the rest of the patients (p=0.006, Mann-Whitney) (Table 4.3). This was due to longer doctor delay (p=0.002, Mann-Whitney). There was no significant difference in system delay in primary health care between patients with and patients without these presenting symptoms (p=0.801, Mann-Whitney).

4.4.3. Chest x-ray with suspicion of cancer

All patients had a chest x-ray. In 70 patients (77%), the first chest x-ray raised suspicion of cancer. For four patients (4%) the radiologist suggested a control x-ray within two to four weeks after the first chest x-ray. The remaining 17 patients (18%) had at least one chest x-ray taken that missed the diagnosis. These patients experienced an average delay of 97 days from the chest x-ray that raised no suspicion of cancer until the next x-ray or a CT scan; and this significantly increased the delay in primary health care for these patients (p<0.001, Mann-Whitney) (Table 4.4). There were no significant differences of delay in secondary health care between patients with and patients without an initial chest x-ray raising suspicion of cancer. (p=0.170, Mann-Whitney).

4.5. Discussion

4.5.1. Principal findings

There was a three-month median delay from first contact to the health care system until treatment initiation or decision not to treat. System delay, including that of treatment, was nearly six times as
long as doctor delay. Some patients experienced a considerable, up to one-year-long doctor delay, but its median duration was 13 days and it mainly occurred in primary care.

Delay in primary health care was associated with the type of first symptom. It was longest for patients with non-typical symptoms because of a longer doctor delay. Chest x-ray raising no suspicion of cancer was an important reason, often prolonging the delay for several months.

### 4.5.2. Strengths and weaknesses in the study

This study is based on 91 patients on whom we have very detailed information. The study population was consecutive and included all lung cancer patients in the county. Patients dying shortly after the diagnosis were also included, so all kinds of patients with histologically verified lung cancer were represented. This serves to strengthen the general nature of the results, but also made data collection more complex, which may have increased the number of dropouts. More dropouts than participating patients died within one year, indicating that the dropouts had more advanced diseases. This could be ascribed to a longer delay in this group of patients, in which case we might have underestimated the median delay, or it could be ascribed to a shorter delay due to more aggressive nature of their tumours, in which case we overestimated the median delay. However, we found no significant differences in any types of delay between the patients included post-mortem and the rest of the participating patients.

### Table 4.2. Delay in days from first symptom until treatment or decision not to treat for 91 patients with lung cancer.

<table>
<thead>
<tr>
<th>Type of delay</th>
<th>n†</th>
<th>Median</th>
<th>Mean</th>
<th>IQR‡</th>
<th>Min-max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient delay</td>
<td>74</td>
<td>24</td>
<td>52</td>
<td>6-61</td>
<td>0-365</td>
</tr>
<tr>
<td>Before first presentation</td>
<td>74</td>
<td>24</td>
<td>50</td>
<td>6-60</td>
<td>0-365</td>
</tr>
<tr>
<td>After first presentation</td>
<td>88</td>
<td>0</td>
<td>2</td>
<td>0-0</td>
<td>0-60</td>
</tr>
<tr>
<td>Primary health care</td>
<td>87</td>
<td>29</td>
<td>52</td>
<td>10-63</td>
<td>0-416</td>
</tr>
<tr>
<td>Doctor delay</td>
<td>87</td>
<td>8</td>
<td>36</td>
<td>0-36</td>
<td>0-368</td>
</tr>
<tr>
<td>System delay</td>
<td>88</td>
<td>13</td>
<td>16</td>
<td>2-24</td>
<td>0-69</td>
</tr>
<tr>
<td>Secondary health care</td>
<td>90</td>
<td>58</td>
<td>67</td>
<td>42-70</td>
<td>8-199</td>
</tr>
<tr>
<td>Doctor delay</td>
<td>90</td>
<td>0</td>
<td>4</td>
<td>0-0</td>
<td>0-71</td>
</tr>
<tr>
<td>System delay</td>
<td>91</td>
<td>37</td>
<td>48</td>
<td>28-57</td>
<td>4-173</td>
</tr>
<tr>
<td>Treatment delay</td>
<td>91</td>
<td>15</td>
<td>17</td>
<td>7-25</td>
<td>0-50</td>
</tr>
<tr>
<td>Total health care delay</td>
<td>88</td>
<td>94</td>
<td>125</td>
<td>68-147</td>
<td>8-724</td>
</tr>
<tr>
<td>Total delay</td>
<td>74</td>
<td>127</td>
<td>173</td>
<td>93-228</td>
<td>20-724</td>
</tr>
</tbody>
</table>

| Total doctor delay#      | 87   | 13     | 40    | 0-65   | 0-368   |
| Total system delay*      | 88   | 75     | 78    | 60-92  | 8-198   |

† n= number of valid estimations within each type of delay among 91 patients – see text for further explanations
‡ IQR= Inter-quartile range
# Doctor delay in both primary and secondary health care
* System delay in both primary and secondary health care – incl. treatment delay
4.5.3. Results in relation to other studies

Most other studies of delay in diagnosis and treatment have examined selected subgroups of lung cancer patients and they have used different definitions of delay. These discrepancies should be considered when comparing the length of delays in different studies.

Four studies explored patient delay: a British study analysing patients attending 10 centres for radiotherapy (12), a Swedish study of patients referred to a department of respiratory medicine (13), a Turkish study of patients referred to two centres of oncology (14), and a Finish study including patients referred to a university hospital (15). These four studies found a median patient delay of 14-30 days and our results fall in the middle of this range.

Four studies estimated delay in primary care: the Swedish and the British studies found a delay comparable to our findings (median 33 days and 28 days) (12;13), but the British study counted delay from first presentation until first attendance to hospital instead of referral to hospital. The Finish study found a shorter delay in primary care (median 16 days) than the present study (15) and so did another British study of patients with non-small cell lung cancer who had an operation (mean 32 days) (11).

Four studies have estimated delay in secondary care as time from referral until treatment and they all found shorter delay (mean 58 days (11), median 48 days (7;9), and median 41 days (15)) than our study. The Finish study and a Swedish study, including patients with non-small cell lung cancer who received treatment (9), both estimated the time from first attendance to hospital until treatments which, of course, gave a shorter delay.

Nearly 20% of the patients in our study had a chest x-ray that did not trigger investigation for lung cancer. A Dutch and an English study found that about 24% of the patients had lesions visible on chest radiographs taken before the radiograph diagnosing the cancer (16;17). The Dutch study found that another four percent of the patients had no abnormalities on their chest radiograph.

4.5.4. Implication and further research

This study shows that system delay is the key problem in delay in diagnosing lung cancer, and increased focus on this issue is mandatory to a shortening of the time for diagnosis and treatment of such patients.

Chest x-ray is the most important tool for GPs for diagnosing lung cancer. It is a low-costs and low-risk tool, but also one with a low sensitivity (16;17). It is important that GPs (and other physicians) are aware of the poor sensitivity of chest x-rays when diagnosing lung cancer.

Further research is needed on how to optimise clinical pathways, both for patients who are referred to the hospital with suspicion of lung cancer and for those with other clinical presentations. Chest x-ray is still a first choice of investigation upon suspicion of lung cancer, at least in primary care, but we need to examine whether other investigations are cost-effective and more sensitive.
Table 4.3. Delay in primary health care in relation to first symptom. N = 87 patients where delay in primary health care could be estimated.

<table>
<thead>
<tr>
<th>Symptom of debut</th>
<th>N</th>
<th>Doctor delay</th>
<th>System delay</th>
<th>Total delay</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Median</td>
<td>IQR‡</td>
<td>Median</td>
</tr>
<tr>
<td>Lung symptoms</td>
<td>62</td>
<td>8</td>
<td>0-35</td>
<td>14</td>
</tr>
<tr>
<td>Non-typical symptoms</td>
<td>13</td>
<td>98</td>
<td>13-136</td>
<td>14</td>
</tr>
<tr>
<td>Brain metastases</td>
<td>4</td>
<td>9</td>
<td>12-19</td>
<td>9</td>
</tr>
<tr>
<td>Lung cancer found by chance</td>
<td>8</td>
<td>0</td>
<td>0-0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>8</td>
<td>0-36</td>
<td>13</td>
</tr>
</tbody>
</table>

† n= Number of valid estimations.
‡ IQR= Inter-quartile range

Table 4.4. Delay in days according to result of first chest x-ray. Number of patients=91.

<table>
<thead>
<tr>
<th>Result of first chest x-ray</th>
<th>N</th>
<th>Primary health care</th>
<th>Secondary health care</th>
<th>Total delay</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Median</td>
<td>IQR‡</td>
<td>Median</td>
</tr>
<tr>
<td>True positive x-ray</td>
<td>70</td>
<td>22</td>
<td>8-40</td>
<td>57</td>
</tr>
<tr>
<td>X-ray with suspicion – new x-ray recommended</td>
<td>4</td>
<td>63</td>
<td>29-92</td>
<td>65</td>
</tr>
<tr>
<td>False negative x-ray</td>
<td>17</td>
<td>135</td>
<td>42-201</td>
<td>63</td>
</tr>
<tr>
<td>Total</td>
<td>91</td>
<td>29</td>
<td>10-63</td>
<td>58</td>
</tr>
</tbody>
</table>

‡ IQR= Inter-quartile range
Chapter 4. Patient, doctor and system delay in diagnosis and treatment of lung cancer.

References


Chapter 6

Delay in diagnose and treatment of lung cancer in Danish secondary health care

Marianne Bjerager, Torben Palshof, Ronald Dahl & Frede Olesen

(Prepared for publication)
6.1. Abstract

**Background:** In Denmark treatment initiation within 42 days of referral to investigation of suspected lung cancer has been a goal, but obtaining this goal is met with little success. This study aims to analyse delay in diagnosis and treatment of lung cancer in Danish secondary health care.

**Methods:** A population-based systematic review of delay from referral to secondary health care until treatment initiation or decision not to treat for 92 patients with lung cancer. The review is based on examination of medical hospital records, interviews with the patients and the patients’ general practitioners (GPs).

**Results:** Median delay in secondary health care was nearly two months and was associated with type of treatment. Patients receiving treatment with curative intent experienced the longest delay, partly due to more investigations needed to verify and stage the disease before referral to surgery or radical radiotherapy. Besides blood tests, patients had a median of five investigations performed for verification and staging purposes. As expected, the delay increased with number of investigations performed. A quarter of the patients had at least one investigation repeated and for every sixth an investigation was cancelled. Every tenth patient was initially investigated in outpatient clinics not specialised in diagnosing cancer and they experienced a more than two-fold longer median delay in secondary health care than the rest of the patients.

**Conclusion:** Improvement of the organisation of clinical diagnostic pathways is essential to reach the goal of shorter delays in the diagnosis of lung cancer in secondary health care. Greater attention to waiting times in normal outpatient clinic settings is also needed as diagnostic assessment for patients with uncharacteristic symptoms can end up with a malignant diagnosis.

6.1. Introduction

Lung cancer is a common cancer disease, and in Denmark it is the most common cause of cancer death for both men and women (1). The five year-survival in Denmark is about 10%, which is inferior to that of the other Nordic countries (2). Patients in Denmark have been shown to have more advanced disease at the time of diagnosis than patients in Finland and Norway (3). The prognosis of lung cancer is highly dependent on the stage of the disease at the time of diagnosis (4), and as psychological distress correlates positively with total delay (5), a short diagnostic delay is recommended for both biological and psychological reasons.

The Danish Lung Cancer Register and the Danish National Indicator Project oversee the quality of diagnosis and treatment of lung cancer in Denmark. One of their goals is to secure that the time elapsed between the hospital’s receipt of the referral to lung cancer investigation and until treatment initiation is below 42 days. This goal is only achieved for 30% of the patients receiving surgery and for 60% of the patients receiving chemotherapy or radiotherapy (6).

The aim of the present study was to analyse delay in diagnosis and treatment of lung cancer in secondary health care in order to identify possible areas of improvement.

6.2. Materials and methods

The study took place in the County of Aarhus, Denmark (680 000 inhabitants) where about 400 new cases of lung cancer are diagnosed per year. Three hospital departments diagnose lung cancer in the county: The Department of Respiratory Diseases at Aarhus University Hospital, the Department of Medicine at Randers Hospital and the Department of Medicine at Silkeborg Hospital. Surgical treatment is performed at the Department of Thoracic Surgery and radiotherapy and chemotherapy at the Department of Oncology both placed at the Aarhus University Hospital. All histological and cytological tests performed in the county are registered in two pathology registers, one at the Department of Pathology at Aarhus University Hospital and one at the Department of Pathology at Randers Hospital.

We identified and included all patients living in the County of Aarhus with newly diagnosed lung cancer histologically verified between 1 April and 31 May, or between 1 September and 31 December 2003. Non-Danish speaking patients and patients diagnosed outside the county were excluded.

The pathology registers were searched for malignant diagnoses from biopsies from lungs, bronchia, mediastinum, and lymph nodes in mediastinum. Patients diagnosed by biopsies from other organs were identified by searching the lists of patients discussed at two weekly joint clinical conferences on lung cancer in the county. To further optimise inclusion, we contacted the departments of oncology and thoracic surgery and two of three departments in the county that diagnosed lung cancer during the periods of inclusion. The last department could not find time for participation of this part of primary inclusion.

Patients were informed about the study after treatment initiation at the Department of Oncology, after operation at the Department of Thoracic Surgery or by letter sent to their home addresses if there were no treatment to offer. Patients who died shortly after the diagnosis were included post mortem by permission of the Danish National Board of Health.

A systematic review of delay was made for each patient starting with the first symptom until treatment initiation or, if the patient received no surgery, chemotherapy or radiotherapy, until decision not to treat. These reviews were based on the patients’ medical hospital records, interviews with the patients and telephone interviews with the patients’ GP. When the patient accepted participation, a time for an interview was scheduled, either at the hospital or at the patient’s home.
Following this interview, the patient’s GP was contacted and asked for a telephone interview. The interviews were taped and selected interviews were transcribed.

Calculation of medians, inter-quartile range (IQR) and p-values were made in Stata 8.0.

6.2.1. Definitions

*Secondary care*: Hospital admissions and outpatient clinic contacts where the hospital is responsible for follow up.

*Delay in secondary care*: The time from referral to secondary care until treatment initiation.

*Treatment delay*: The time from referral to treatment by the diagnostic department until treatment initiation.

6.3. Results

We identified 132 lung cancer patients through the pathology registers. Another 14 patients were identified by contacting the departments. In all, four patients were excluded: two because part of the diagnostic process was located outside the county and two because they did not speak Danish. Thus 142 patients were included. Eighteen were not informed about the study for different reasons (see Figure 4.1). Twenty-seven patients were included post mortem. We asked 97 patients to participate and 65 patients agreed. A total of 92 patients participated in the study. Fifty-two patients and 86 of the patients’ GPs were interviewed.

There was no statistically significant difference between participating patients and non-participating patients according to age, sex and treatment. However, among the former more received chemotherapy (Table 4.1). In the months following several of the non-participating patients died. One year after diagnosis, 50.0% of the included patients and 42.0% of the non-participating patients were still alive.

Table 6.1. Total median delay in secondary health care and the median number of investigations in relation to entrance into secondary health care.

<table>
<thead>
<tr>
<th>Entrance in secondary care</th>
<th>n</th>
<th>%</th>
<th>Median delay in days (IQR)</th>
<th>Median number of investigations*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosing department or outpatient clinic</td>
<td>71</td>
<td>78</td>
<td>33 (25-50)</td>
<td>5</td>
</tr>
<tr>
<td>Another department</td>
<td>8</td>
<td>10</td>
<td>54 (41-93)</td>
<td>5</td>
</tr>
<tr>
<td>Another medical outpatient clinic</td>
<td>5</td>
<td>5</td>
<td>140 (134-167)</td>
<td>7</td>
</tr>
<tr>
<td>Found by chance</td>
<td>6</td>
<td>7</td>
<td>66 (49-77)</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>90</td>
<td>100</td>
<td>37 (28-57)</td>
<td>5</td>
</tr>
</tbody>
</table>

* Investigations, besides blood tests, made in secondary health care in order to verify and stage lung cancer.
† Information was missing for one patient referred to the diagnosing department and one patient referred to another department.
6.3.1. Entrance into secondary health care

Fifty-four of the patients (58.7%) were referred from their GP with a chest x-ray showing suspicion of cancer. They were all referred directly to the diagnosing outpatient clinic or hospital ward. Another 18 patients were referred directly with suspicion of cancer, but without a chest x-ray. In total 72 patients (78.3%) were referred directly. The length of the delay in secondary care was affected by the way of entrance into secondary health care (p<0.001, Kruskal-Wallis) (Table 6.1). The differences in delay between secondary health care facilities shown in Table 2 could not be explained by differences in the number of investigations made per patient in order to verify and stage the disease (blood tests excluded) (p=0.079, Kruskal-Wallis).

Patients referred to outpatient clinics due to benign diagnosis experienced a substantial delay due to waiting times for their first consultation. For six patients the lung cancer was found by chance during investigation and treatment of another disease, and for five of them the initial investigations were made in outpatient clinics not specialised in diagnosing cancer. This meant longer waiting times for investigations and, especially, longer time before the physicians took action in relation to the findings of malignancy. Examples are shown in Box 6.1. A total of 10 patients (10.9%) were initially investigated in outpatient clinics not specialised in diagnosing cancer. Their median delay in secondary health care was 138 days (IQR 84-165 days) compared with 55 days (IQR 41-69 days) for the rest of the patients (p<0.001, Mann-Whitney). Four of these ten patients received surgery.

6.3.2. Delay and type of treatment

The median delay in secondary health care was 58 days (IQR 42-70 days) and the median treatment delay was 15 days (IQR 7-25 days). Patients receiving surgery or radical radiotherapy experienced a longer total delay in secondary health care than the rest of the patients (p<0.001, Mann-Whitney) (Table 6.2.), even though they had a shorter treatment delay (p=0.002, Mann-Whitney). Half of the patients receiving treatment with a curative intent experienced a delay exceeding two months in secondary health care.

| Table 6.2. Delay in days in relation to type of treatment. IQR in brackets. |
|-------------------------------------------------|----------|-----------------|------------------------------|-----------------|
| Treatment                                      | n  %    | Delay from     | Treatment delay | Total delay in secondary |
|                                                |         | referral to     |                              | care            |
|                                                |         | secondary care  |                              |                 |
|                                                |         | until referral  |                              |                 |
|                                                |         | to treatment    |                              |                 |
| None                                           | 10 11  | 30 (21-40)      | 0 (0-8)*                    | 39 (28-49)      |
| Surgery/relative radiotherapy                   | 33 37  | 53 (36-64)      | 10 (7-13)                   | 62 (53-79)      |
| Chemotherapy/Palliative radiotherapy           | 47 49  | 30 (23-50)      | 23 (16-27)                  | 56 (41-70)      |
| Total                                          | 90† 100| 37 (28-58)      | 15 (7-25)                   | 58 (42-70)      |

* Also includes time elapsed between referral to treatment and decision not to treat anyway

**Box 6.1. Delay in cases where the lung cancer was found by chance**

<table>
<thead>
<tr>
<th><strong>Patient C:</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Woman, 58 years old, smoker. No lung-related symptoms.</td>
<td></td>
</tr>
<tr>
<td>The find of lung cancer: she is acutely admitted to a Department of Surgery due to pyelonephritis. A CT scan shows a tumour just above the left adrenal gland and she is discharged with an appointment for a control CT scan after a month and a time for information about the result of the scan 17 days later.</td>
<td></td>
</tr>
<tr>
<td>The control scan shows, besides the tumour of the adrenal gland, suspicion of a right sided lung tumour. Follow-up: the patient is informed about the result of the CT scan at a planned consultation 17 days later at the outpatient clinic. She is referred to a thoracic CT scan which is carried out 14 days later. After further 11 days she is referred to an outpatient clinic specialised in diagnosing lung cancer. The patient is informed by letter. Five days after the referral she is seen at the outpatient clinic diagnosing lung cancer. At that time the patient has been feeling ill for some days and complains about thoracic pain. Two days later she is admitted due to suspicion of development of a lung abscess.</td>
<td></td>
</tr>
<tr>
<td>Delay between the tumour was found by chance and first visit at the outpatient clinic diagnosing lung cancer: 40 days. Total delay in secondary care: 97 days.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Patient D:</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Woman, 73 years old, never-smoker. No lung-related symptoms.</td>
<td></td>
</tr>
<tr>
<td>The find of lung cancer: She is admitted due to diarrhoea that declines during admission. A chest radiography is first interpreted as being normal but three days later, just after the patient is discharged, the department receives a description of the chest radiography with suspicion of cancer. Follow-up: The same day a referral to a CT scan is made and the patient is informed by letter. The thoracic CT scan, made 24 days later, shows a left sided lung tumour. After further 12 days she is referred to an outpatient clinic specialised in diagnosing lung cancer. The patient is informed by letter.</td>
<td></td>
</tr>
<tr>
<td>Delay between the tumour was found by chance and first visit at the outpatient clinic diagnosing lung cancer: 47 days. Total delay in secondary care: 84 days.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Patient E:</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Man, 75 years old, smoker. The patient has diabetes, peripheral neuropathy and coronary heart disease. The find of lung cancer: At a visit at the diabetes outpatient clinic he complains about persistent cough. The cough is interpreted as being an adverse effect to treatment with an ACE inhibitor and the treatment is therefore ended. He is referred to a chest x-ray under the diagnosis of heart failure. The chest x-ray is done seven days later and shows a tumour in the left lung. Follow-up: Seven days later the patient is seen at a new control at the diabetes outpatient clinic. The cough has declined after treatment with ACE-inhibitor has ended. The description of the chest radiography is first seen by the physician after the patient has left the outpatient clinic. The patient gets a new appointment a week later. He is then informed about the result of the chest x-ray and a referral to the outpatient clinic diagnosing lung cancer is made.</td>
<td></td>
</tr>
<tr>
<td>Delay between the tumour was found by chance and first visit at the outpatient clinic diagnosing lung cancer: 28 days. Total delay in secondary care: 50 days.</td>
<td></td>
</tr>
</tbody>
</table>
6.3.3. Number of investigations

The median delay before referral to treatment generally increased with the number of investigations made in order to verify the diagnosis and the stage of the disease (Table 6.3) (p<0.001, non-parametric test for trend). In the group of patients who had most investigations, many investigations were performed over a short period of time during the admission in order to verify the diagnosis in four patients with unknown diagnosis and advanced disease.

Besides blood tests, the patients went through 1-12 investigations in order to verify and stage the disease (e.g. x-ray, CT scan, bronchoscopy, mediastinoscopy and needle aspirations). Patients referred to surgery or radical radiotherapy had a median five investigations (IQR 5-7) and the rest of the patients had a median of four investigations (IQR 3-6) (p=0.027, Mann-Whitney).

Patients who had six or more investigations experienced a median delay of nearly two months before they were referred to treatment and a quarter of them had a delay of more than three months.

Table 6.3. Delay in days in secondary health care until referral to treatment vs. number of investigations (besides blood tests) performed in order to verify and stage the lung cancer

<table>
<thead>
<tr>
<th>Number of investigations</th>
<th>n</th>
<th>Median</th>
<th>Mean</th>
<th>IQR</th>
<th>Min-max</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>17</td>
<td>27</td>
<td>27</td>
<td>20-30</td>
<td>4-64</td>
</tr>
<tr>
<td>4</td>
<td>18</td>
<td>30</td>
<td>43</td>
<td>23-42</td>
<td>11-167</td>
</tr>
<tr>
<td>5</td>
<td>19</td>
<td>39</td>
<td>46</td>
<td>31-53</td>
<td>19-134</td>
</tr>
<tr>
<td>6-7</td>
<td>22</td>
<td>57</td>
<td>64</td>
<td>37-91</td>
<td>28-140</td>
</tr>
<tr>
<td>8-12</td>
<td>14</td>
<td>53</td>
<td>72</td>
<td>30-98</td>
<td>21-195</td>
</tr>
<tr>
<td>Total</td>
<td>90*</td>
<td>37</td>
<td>50</td>
<td>28-57</td>
<td>4-195</td>
</tr>
</tbody>
</table>

* For two patients information was missing about number of investigations in secondary health care.

6.3.4. Organisation of the diagnostic process

Twenty-three patients (25.0%) had at least one investigation repeated: in three patients due to an insufficient initial CT scan, in 11 patients due to inconclusive biopsies, in three patients because the initial CT scan had become too old and in four patients the bronchoscopy was repeated in connection with the mediastinoscopy. One patient had several investigations repeated due to inconclusive biopsies and both a CT scan and a mediastinoscopy that had become too old.

Thirteen patients (14.1%) showed up for a planned investigation that got cancelled, either because a planned fine needle aspiration could not be executed due to lack of visibility of the tumour on x-ray or ultrasound, because the patients’ condition did not allow the investigation, or because a CT scan was missing.

The high number of investigations made the organisation of the diagnostic process important. Box 6.2 shows examples of patients experiencing prolonged delay due to inappropriate organisation of the diagnostic investigations.

Box 6.2. Cases with delay due to the diagnostic organization

**Patient A:**
Man, 37 years old, heavy smoker. His is acutely admitted due to haemoptysis, weight loss of 10 kilos and a chest x-ray showing a large left sided tumour.

Three days later a thoracic CT scan shows a large tumour in mediastinum with close relation to the heart. Biopsies from a bronchoscopy made the same day contain squamous carcinoma cells. After the bronchoscopy he is discharged and informed that he will be called in for information of the results of the investigations and for a mediastinoscopy.

15 days later, when he is admitted again, he is informed about the diagnosis of lung cancer. The mediastinoscopy, which is made at another hospital, is carried out two days later. Biopsies from mediastinal lymph nodes are without malignancy.

After the investigation he develops high fever and treatment with antibiotics is initiated. Four days later he develops atrial fibrillation.

At the joint clinical conference two days later it is concluded that the CT scan shows pericardial involvement which excludes resection of the tumour. The mediastinoscopy was therefore without consequence.

The patient is referred to chemotherapy which is initiated 22 days after referral.

Total delay in secondary health care: 52 days.

**Patient B:**
Man, 71 years old, former smoker. Several earlier admissions due to pneumonia and chronic lung disease. After treatment of pneumonia his GP refers him is to a control chest x-ray that shows suspicion of a right sided lung tumour. The patient is referred to an outpatient clinic diagnosing lung cancer at the university hospital but the referral is redirected to the local hospital where he is admitted 22 days later.

A thoracic CT scan the day after shows suspicion of a tumour in the right lung but no enlarged lymph nodes. Seven days later a bronchoscopy shows nothing abnormal. Cytology is without tumour cells. A fine needle aspiration is therefore made five days later. The patient is discharged with the promise that he will be summoned for information of the results of the needle aspiration. The aspiration is without tumour cells and a letter is send to the patient that summons him to a new needle aspiration a week after the first aspiration. The patient does not receive the letter on time and therefore miss the appointment. He gets a new appointment a week later. The second needle aspiration is also without tumour cells and a third needle aspiration is made after further a week.

Six days later a joint clinical conference concludes the patient can be treated with stereotactic radiation therapy if mediastinoscopy does not reveal metastatic lymph nodes.

Three day later (35 days after he was referred to the first needle aspiration) the patient is informed about the diagnosis of lung cancer and that a mediastinoscopy is planned 14 days later. Biopsies from lymph nodes are without tumour cells and 11 days after the investigation the patient is referred to treatment.

Stereotactic radiation therapy is initiated 37 days after referral.

Total delay in secondary health care: 129 days.

6.4. Discussion

6.4.1. Principal findings

The median delay in secondary health care was nearly two months. The length of the delay was associated with the clinical pathway. Every tenth patient was initially investigated in outpatient clinics not specialised in diagnosing cancer and their median delay was more than twice as long as that of those who were referred to a specialist lung cancer facility.
Patients receiving surgery or radical radiotherapy experienced a longer delay before referral to treatment than the rest of the patients, partly because more investigations were performed to verify and stage their disease before referral to treatment with a curative intent. Besides blood tests, the patients had a median of five investigations for verification and staging purposes. A quarter of the patients had at least one investigation repeated and every sixth had an investigation cancelled. As expected, the delay rose with the number of investigations performed. For patients who had more than six investigations, the median delay before referral to treatment was nearly two months.

6.4.2. Strengths and weaknesses in the study

This study was based on 92 patients on whom we have detailed information. The study was population-based and, as patients dying shortly after the diagnosis were also included, all kinds of patients with histologically verified lung cancer were represented. This serves to strengthen the general nature of the results, but also made the data collection more complex, which may have increased the number of dropouts. More dropouts than participating patients died within a year, which indicates that the dropouts had more advanced diseases. The excess mortality among dropouts could be attributed to a longer delay, in which case we would have underestimated the median delay, or it could be attributed to a shorter delay because their tumours were more aggressive, in which case we would have overestimated the median delay. However, we found no differences in any type of delay between patients included post-mortem and the rest of the participating patients. We accordingly have little reason to believe that our date is fraught by either overrepresentation or underrepresentation.

6.4.3. Results in relation to other studies

We found a two month median delay in secondary health care which is comparable to findings in two recent studies from Sweden and Finland (7;8), if we take into account that these studies used first hospital consultation as initial cut point.

Previous studies of delay in secondary health care have primarily estimated length of delay. Three studies though, have listed some reasons for delay among the group of patients with the longest delay: long waiting times, tumour that was first thought to be benign, treatment of comorbidity, patients wanting time for reflection, and delay due to transferring of patients and information between hospitals(8-10).

Delay in secondary health care is mainly rooted in waiting times for consecutive investigations and inadequate organisation of the diagnostic process. A British pilot study showed that it is possible to shorten the period until first treatment by four weeks by organising a centralised two-stop diagnostic pathway for patients suspected of having lung cancer (11). But before entering an organised fast-track diagnostic pathway, the patients needs a chest x-ray diagnosis of lung cancer or symptoms strongly indicative of lung cancer. The Danish Indicator Project estimates delay from the day the hospital receive the referral until investigation for lung cancer. Some patients may therefore experience a substantial delay in secondary health care even though the goal of treatment within 42 days after referral to investigation for lung cancer had been obtained.

6.4.4 Implication and further research

More research is needed to get detailed insight into the reasons for the observed system-related delay and to test methods that can enhance speed in the clinical pathways, especially where many necessary investigations are anticipated. Greater focus on the long waiting times in normal
outpatient clinic settings is also needed in order to avoid unnecessary protraction of diagnostic procedures and the concomitant risk that what began as general symptoms ends up as malignant disease. In order to reduce the number of investigations needed, and thereby reduce delay, more research is necessary to develop more effective diagnostic tests.

References


Chapter 7

General discussion of methods
7.1. The questionnaire

7.1.1 Reliability and validity

All the dimensions in the questionnaire, except the questions about using the word cancer in referrals, were related to the primary object: did the GPs have a nihilistic attitude towards diagnosis and treatment of lung cancer.

The validity of a questionnaire expresses the ability of the questionnaire to measure the issues you really want to measure (1). We primarily wanted to measure whether the GPs had a defeatist attitude towards diagnosing lung cancer, and secondly how they looked at possibilities for improving prevention, how they evaluated the organisation of the diagnostic process, and what they actually did when they had a patient where they suspected lung cancer.

The reliability of a questionnaire expresses the ability to receive precise answers. This implies that the meaning of the questions is stable over a time span (intra-observer reliability) and is the same for all the receivers of the questionnaire (inter-observer reliability) and that the researcher who interprets and reports the data agrees with this meaning (2-3).

The two pilot tests were made in order to optimise the reliability and the validity of the questionnaire. When analysing the collected data further evaluation of the questions was made and three questions with more than 10% of missing or “don’t know” answers were excluded from further analysis.

Most of the questions were about the GPs’ opinion of different issues. Very specific and concrete questions are preferable if a high reliability and validity is wanted (4), but questions about opinions can be very difficult to make specific and concrete. If the questions do not interest the respondent, considerations may be necessary before answering the questions. This may lead to the use of satisficing strategies where the respondent copes with the cognitive demand of answering by giving an answer that is satisfactory (a box on the questionnaire is filled in) but not optimal (5;6). This may result in a high number of “don’t know”-answers. This was not a problem in this study were two-thirds of the questions using the Lickert scale had less than five percent of “don’t know”-answers; only in three questions the number of “don’t know”- answers exceeded 10%. Another result of satisficing is social desirability bias (5) where the respondents chose socially desirable answers. In the light of the debate about the national cancer plan, a non-defeatist attitude and a clinical practice consistent with DLCG’s guidelines probably would be considered most social desirable in this case. If social desirability is more marked among women or among older GPs we might have overestimated the differences in attitude among men and women, and in clinical practice among younger and older GPs, but we have no data to answer this question.

7.1.2. Non-responders

The questionnaire was send to 1186 GPs in Denmark and 848 of them (71.5%) answered. The GPs were randomly selected but among the receivers of the questionnaire the non-responders might have been a selected group. The non-responders were older and a larger percentage was men. A general assumption might be that GPs with a defeatist attitude towards lung cancer would be less likely to participate in a questionnaire about the issue than other GPs. This would result in an underestimation of the number of GPs with a defeatist attitude. There were more men among the non-responders and as men more often expressed a defeatist attitude this also contributed to an underestimation of delay. On the other hand, the average age was higher among non-respondents, and older GPs expressed higher attention to lung cancer in the clinical practice.
7.1.3. Evaluation of the questionnaire

The answers in all the dimensions supported the conclusion that a nihilistic attitude towards lung cancer is not common among Danish GPs. Secondly it revealed that half of the GPs were dissatisfied with waiting times and that many of them had problems using the word cancer in referrals to investigations. There are limitations in a questionnaire study like this one especially because of the possibility of a split between given answers and clinical practice. But the number of respondents gave acceptable statistical limits and together with the consistency between answers in the different dimensions it supports the assumption that we produced valid conclusions.

7.2. The case study

7.2.1. Selection of patients

We chose to include all patients living in the County of Aarhus diagnosed with histological verified lung cancer during the two periods of inclusion. Thereby we included all kinds of patients diagnosed with lung cancer independent of clinical pathway and received treatment. Together with the permission of including patients dying shortly after the diagnosis post mortem, it opposed selection bias in sampling.

In order to identify patients as soon as possible after the diagnosis was made we used the pathology registers in the county. Unfortunately, however, the register search only found 90% of the patients fulfilling our inclusion criteria. It was therefore necessary to use several different sources of information in order to identify the remaining 10% of the patients.

According to the Danish Cancer Register about 450 patients are diagnosed with lung cancer in the County of Aarhus every year (7;8) and just above 80% have a histologically verified diagnosis (9). The estimates from 2003 are not available yet; a linkage of data from the Danish Register of Causes of Death is awaited. If we assume that the numbers have not changed much we would expect to find about 180 patients (80% of 450 divided with two) during the six months we included patients. We only found 146 patients of which four were excluded. On the other hand, our findings correspond well to the number of patients registered in the Danish Lung Cancer Register in 2003, where a total of 313 patients were registered; of whom about 10% were not histologically verified (90% of 313 divided with two gives 140 patients) (10).

The method used for identification of patients made it easier to find patients diagnosed by biopsies from primary tumour, patients diagnosed at departments specialised in lung cancer and patients receiving treatment. Among the patients we failed to identify we therefore expect a higher number of patients with metastatic disease, patients admitted due to other diseases than lung cancer and patients receiving no treatment. Whether the inclusion of these patients would have changed the estimations of delay we cannot say, but we expect that the patients were older, had more comorbidity and more advanced disease meaning that this selection bias would tend to underestimate the prehospital delay in our results.

7.2.2. Period of inclusion

Patient identification, information and obtaining accept of participation was complex and turned out to be very time consuming. In order to catch up with the continuously included patients we divided the period of inclusion into two. This made it possible to finish the data collection for the patients included in the first period before starting inclusion of patients in the second period.
### 7.2.3. Drop-outs

Among the 142 patients who fulfilled the criteria of inclusion, 92 patients (64.8%) participated in the study and 27 of them were included post mortem. Many of the patients were very ill at the time of diagnosis. To be diagnosed with a cancer, which has such a poor prognosis as lung cancer, also causes great psychological distress and some patients did not have the energy to take in the information of the study and to decide whether they wanted to participate or not. A part of the patients used that explanation for their decline of participation, and it is likely that this also explains a number of other drop-outs among patients never responding the request for participation. This assumption is supported by the fact that the non-participating patients had a higher mean age and that more of them died within a year indicating that they were more affected by their disease.

Table 7.1 shows the distribution of non-participating patients, participating patients included by acceptation, and patients included post mortem in relation to treatment. The different fractions of the three patient groups among the different types of treatment may reflect different issues. As shown in Table 7.2, a higher fraction of patients who received no treatment or were treated with radiotherapy died within six months compared to patients receiving chemotherapy or surgery. The difference in number of drop-outs between patients receiving surgery and patients receiving chemotherapy may reflect the fact that the researcher was a known face at the Department of

### Table 7.1. Distribution of non-participators, participators accepting participation, and participators included post mortem, in relation to treatment.

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Participators</th>
<th>Non-participators*</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Acceptation</td>
<td>Post mortem</td>
<td></td>
</tr>
<tr>
<td>Operation</td>
<td>25 (53.2)</td>
<td>5 (10.6)</td>
<td>17 (36.2)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>26 (68.4)</td>
<td>4 (10.5)</td>
<td>8 (21.1)</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>11 (32.4)</td>
<td>8 (23.5)</td>
<td>15 (44.1)</td>
</tr>
<tr>
<td>None</td>
<td>3 (15.0)</td>
<td>10 (50.0)</td>
<td>7 (35.0)</td>
</tr>
<tr>
<td>Total</td>
<td>65 (46.8)</td>
<td>27 (19.4)</td>
<td>47 (33.8)</td>
</tr>
</tbody>
</table>

* Information about treatment was missing for three of the non-participating patients.

### Table 7.2. Fraction of patients, dieing within six months, in relation to treatment.

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Died within six months</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Operation</td>
<td>7 (14.9)</td>
<td>40 (85.1)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>10 (26.3)</td>
<td>28 (73.7)</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>20 (58.8)</td>
<td>14 (41.2)</td>
</tr>
<tr>
<td>None</td>
<td>15 (75.0)</td>
<td>5 (25.0)</td>
</tr>
<tr>
<td>Total</td>
<td>52 (37.4)</td>
<td>87 (62.6)</td>
</tr>
</tbody>
</table>

* Information about treatment was missing for three of the non-participating patients.
Oncology and visited the department regularly in connection with patient interviews, as where the researcher was an unknown face at the Department of Thoracic Surgery and only visited the department a few times during the project. This lack of familiarity with the study probably caused some of the logistic problems with patients who received surgery. Some patients were discharged from the department without being informed about the study or they were informed but not asked whether they accepted the researcher contacting them or not. In retrospect we realised that this might have been prevented if we had connected one of the department’s nurses as a local consultant (11).

7.2.4. Interviews

Among the 92 participating patients 27 were included post mortem and an interview was therefore not possible. Six patients did not want to participate in an interview and six patients died or became too ill between acceptance of participation and the planned interview. In all 53 patients (57.6%) were interviewed. The group of most ill patients was not interviewed which could lead to information bias in the data collected from patient interviews. This risk for bias was minimized as we got information from medical hospital records for all participating patients and from all but six of the patients’ GPs. For five of these six patients lung cancer was found at the hospital during investigation and treatment of another disease.

The interviews with patients and GPs were retrospective which may have lead to recall bias. Some GPs, who had a patient with an inappropriate diagnostic process in general practice, might have tried to make the diagnostic course look better than it actually did. Recall bias was opposed by triangulating the data when possible and by making the GPs cite their medical records during telephone interviews.

7.2.5. Estimation of delay

Based on the collected data a detailed review was made of the delay from first symptom till treatment initiation for each patient (examples are shown in appendix D). Based on these reviews an estimation of the different subtypes of delay was made by the researcher and the principal supervisor. Assessment of patient delay was only made for 74 (80.4%) of the 92 participating patients. A valid date of first symptom can be difficult to determine. For 12 patients not interviewed neither the medical hospital records nor the GP interviews could provide information about time of first symptom. Six of the interviewed patients stated that symptoms had come so gradually that it was impossible to state a date or a month for the first symptom. The definition of date of first symptom used in estimation of patient delay is shown in Box 2.1.

An audit where agreement about estimations of delay was obtained between GPs, hospital physicians and the researcher might have made the estimations more valid, but it would have been time consuming and more difficult to arrange. However, there were only few disagreements about the estimations of delay between the researcher and the principal supervisor. Cases with disagreement were discussed until agreement was achieved.

7.2.6. Generalisation of results

The National Audit Report 2004 from the Danish National Indicator Project contains a comparison of the counties in Denmark concerning the percentages of patients for whom the goal have been fulfilled, i.e., less than six weeks’ delay from receipt at the hospital of the referral to lung cancer investigation and till treatment initiation. This comparison shows that the percentage of patients in
the County of Aarhus fulfilling the goal is a little lower than the average in Denmark for patients receiving surgery (20% against 29%) and a little higher than the average for patients receiving chemotherapy or radiotherapy (64% against 57%) (12).

The report shows great variation in delay in diagnosis and treatment of lung cancer in Denmark reflecting different organisations of the diagnostic process at different hospitals. This study included patients diagnosed mainly at the three hospitals in the county having departments specialised in lung cancer diagnosis. For two of the three departments the diagnostic organisation was highly specialised and mainly performed in outpatient clinics, but having differences in waiting times for CT scans. At the last hospital the majority of investigations were performed during admission. This diversity in organisation of lung cancer diagnosis within the county makes the qualitative results (reasons of delay) of the study more representative. It is not possible to conclude whether the quantitative results (assessments of delay) found in the study are representative for the whole Danish population, but data from the Danish National Indicator Project and Cancer Plan II from the Danish National Board of Health support this assumption.

The conclusions of this study cannot be transferred to health care systems different from the Danish system. But studies from other countries and commentaries from medical journals show that countries like Sweden and especially England have similar problems (13-17). We therefore assume that our results can pinpoint areas that should be focus for local investigations and possible quality improvements in any health care service. We also assume that our method with dividing delay into genuine doctor delay and system delay can add new dimensions to analysis of delay.

7.2.7. Evaluation of the method used in the case study

We wanted to include all newly diagnosed lung cancer patients in the county and thereby avoid selection bias in sampling. We furthermore wanted to triangulate the data collection in order to minimize information bias by obtaining the patients’, the GPs’ and the hospitals’ perspective of what had happened. It was important to include the patients shortly after treatment initiation both because it made it easier for the patients to remember what had happened, but also because the poor prognosis of lung cancer resulted in 25% of the included patients died within three months after the diagnosis was made. All this made the data collection complex and it is likely that the number of drop-outs could have been minimized had the data collection been less complex. If we had made a retrospective study only based on medical reviews the problems with dropouts could have been avoided, but we would also have lost important information about diagnostic process and reasons for delay obtained from interviews with patients and GPs.

A study based on 92 patients of course has its limitations. The strength of this study is the population-based selection of patients, the triangulation of data when possible, and the detailed data collected, making a detailed analysis of the reasons for delay possible. More detailed information about reasons for delay could have been obtained from qualitative in-depth interviews with patients and physicians and more valid assessments of length of delay could have been obtained including a larger number of patients. This study, though, did identify areas of improvement in the diagnostic process for lung cancer and separated genuine doctor delay from delay due to waiting times and administration.
Chapter 7. General discussion of methods

References


Chapter 8

General discussion of results
8.1. GPs attitude

The questionnaire showed no defeatist attitude against diagnosing and treatment of lung cancer among Danish GPs, despite the lack of evidence for correlation between delay and survival. The GPs believed that it is possible to improve lung cancer prevention, and more than four out of five GPs described themselves as active in the diagnostic process for lung cancer. There was a widespread dissatisfaction among GPs regarding waiting times, especially for patients with non-typical symptoms. The data from the DLCR shows great variation in waiting times among the Danish counties both in primary and secondary health care(1). There is no association, though, between the length of delay in primary care found in the register and the percentages of GPs in the county that are dissatisfied with the waiting times. But the data in the register is collected from hospital departments and its data about delay in primary health care are less valid than the rest of the data.

Men more often stated a defeatist attitude. Whether this is due to a real difference in attitude among men and women or just a difference in social desirability bias in their responses to the questionnaire cannot be concluded from this study. Neither can it be concluded whether older GPs are more careful about diagnosing lung cancer or they just stated so. The possible difference in diagnostic practice could be explained by the fact that older and more experienced GPs have seen more patients with lung cancer including patients with non-typical presenting symptoms. They might have missed the diagnosis earlier and have therefore become more careful in controlling patients at risk.

A departmental order from 2001 (1) states that patients referred to investigation under suspicion of cancer shall be examined within two weeks. But more than one out of four GPs was reluctant to use the word cancer in referrals to hospitals or for investigations. They did not want to worry the patient and were afraid of loosing reliability if they used the word cancer in referrals too frequently and therefore reserved the use of the word cancer to patients where the suspicion of cancer was strong. Instead the case study showed that GPs indirectly expressed suspicion of cancer by using phrases like “smoker during many years, now persistent cough”. There is a big grey zone between symptoms not related to cancer and symptoms often related to cancer. This can make it difficult for the GPs to determine an exact cut point in severity of symptoms that can justify the words “suspected cancer” in referrals to diagnostic investigations.

The case study revealed no defeatist attitude among GPs either. The median doctor delay in primary care was about a week and long doctor delay in primary care was in most cases due to diagnostic difficulties caused by false negative chest x-rays or non-typical symptoms.

8.2. Assessment of delay

There was a four-month median delay from first symptom till treatment initiation or decision not to treat. Within the health care system the median delay was three months. Comparison with other studies is shown in Table 1.6.

In all studies estimating both mean and median delay, mean delay was the longest and often twice as long as median delay indicating that a group of patients experienced very long delay.

8.2.1. Patient delay

The median patient delay was 3 weeks. This study only included an assessment of the length of patient delay, as the study focused on delay in the health care system. Further analysis of patient
Chapter 8. General discussion of results

delay based on data gathered from the patient interviews, made in relation to this study, will be carried out later.

8.2.2. Delay in primary health care

The median delay in primary care was nearly one month. Results from five other studies assessing delay in primary care are shown in Table 1.6. None of these studies analysed reasons for delay nor differentiated between genuine doctor delay and delay due to waiting times. Few studies looked at reasons for diagnostic delay in primary care for lung cancer patients. A small Dutch study including 20 lung cancer patients from an audit analysed the GPs diagnostic style when confronted with ambiguous symptoms. The study concluded that some GPs had a biased diagnostic style characterized by little alertness for detail, less careful observations, and overinterpretation of facts supporting the initial hypotheses, and that this diagnostic style increased the risk of missing the diagnosis (2).

Another Dutch study including patients with head and neck cancers found that patients, who are not referred or followed-up after the first consultation in primary care (which was half of the patients in the study), are at risk of increased doctor delay. Several factors are related to delay in returning to the GP: type of symptoms, not being familiar with the symptoms of the cancer, not being suspicious that the symptoms might indicate cancer and generally not being inclined to seek support when facing a problem (3). The risk of being labelled as “hypochondriac” or “time-waster” has shown to be a reason for patient delay in qualitative studies. In some cases of early presentation, doctors made benign diagnoses, which reinforced the patient’s fear of being a time-waster and made the patient postpone seeing the GP again (4).

We found that patients with non-typical symptoms experienced considerable longer delay in primary care compared to patients with lung-related symptoms. Due to the size of the study we made no distinction between the different lung-related symptoms. An Italian study has analysed the association between presenting symptoms and delay in referral to specialist evaluation, found that infections and bloody sputum were the only lung-related symptoms that were capable of speeding up referral. Cough, dyspnoea, and systemic symptoms such as weakness, anorexia, and fatigue were the most neglected symptoms being associated with prolongation of delay in referral (5).

A false negative chest x-ray is known to cause delay in primary care (6), but we found no other studies looking at the impact of a false negative chest x-ray on delay in primary care. There seems to be a need for much more attention to the needed clinical consequences of the limitations of chest x-ray.

8.2.3. Delay in secondary health care

The nearly two-month median delay in secondary health care does not differ much from a Swedish and a Finish study both estimating delay from first consultation at the hospital (7;8). Waiting times for consecutive diagnostic investigations and treatment are a problem and cause delay in secondary health care (8-12).

Three studies have looked at reasons for delay among the included patients experiencing the longest delay (8;9;13). Long waiting times, treatment of comorbidities, observation of lesions thought to be benign, and patients wanting time for reflection were all reasons mentioned to cause delay in secondary health care.
8.3. Doctor delay and system delay

The median system delay was more than five times as long as the median doctor delay. Doctor delay was primarily placed in primary health care. Important reasons for doctor delay in primary care were a false negative chest x-ray, non-typical symptoms, co-morbidity, and lack of follow-up appointments. In secondary care the main reason was chest x-rays or biopsies with no suspicion of malignancy leading to a decision of a wait and see strategy.

Previous studies of doctor delay in the diagnostic process for lung cancer also define waiting times as doctor delay and therefore it has not been possible to compare the estimations of doctor delay found in this study with other studies.

In many cases the physician’s diagnostic decisions affected the length of system delay. The GPs have the ability to make urgent referrals to chest x-ray or hospital admissions but they also have the role as gatekeepers which make it necessary to reserve urgent referrals to selected patients. One way to minimize system delay is to refer to more than one investigation at a time. Waiting for the result of one investigation before ordering the next is a way to avoid unnecessary investigations, but it also increases the length of system delay.

8.4. Areas of improvement

8.4.1. Improvements in primary health care

Suspicion of lung cancer is the first step in the diagnostic process. This is, in most cases, not the problem if the patient has lung-related symptoms. Patients with non-typical symptoms on the other hand, often give diagnostic problems. Patients with lung cancer are not frequent in general practice. Lung cancer patients presenting with non-typical symptoms are less frequent, but many of their symptoms are frequent among non-cancer patients. It is important, however, that all GPs are aware that presenting symptoms of lung cancer can be, e.g. shoulder pain, finger clubbing, and more diffuse musculoskeletal symptoms.

If malignancy is not suspected it is important to consider the degree of follow-up. Delay can be avoided if the GP makes a clear contract about follow-up. If no follow-up is found necessary the GP should at least make it clear for the patient when he/she ought to return.

Reducing waiting times for chest x-ray is essential if we want to reduce system delay in primary health care. One third of the patients referred to a non-acute chest x-ray waited more than 2 weeks for the investigation – and every sixth of them waited another week or more before they were informed about the result of the investigation. In the County of Vejle, Denmark, the problem has been solved by a scheduled hours at two hospitals in the county with open access for patients referred to chest x-rays.

Due to the high cost and the high radiation dose, GPs in Denmark are not allowed to refer patients to a chest CT scan. Chest x-ray is therefore the central investigation in general practice when lung cancer is suspected. A normal chest x-ray reduces the risk of cancer but it does not exclude it. Besides raising the awareness among GPs of the low sensitivity of chest x-ray it is outside the scope of this project to conclude how delay due to false negative chest x-ray is avoided. A way forward might be to open for referrals to CT scan after a negative chest x-ray in cases where the GP gives specific reasons.
8.4.2. Improvements in secondary health care

Delay in secondary health care can be reduced either by reducing the number of investigations made in order to verify and stage the disease or by reducing waiting times for investigations. A great deal of research is done in order to develop new more sensitive and less invasive diagnostic investigations (14-16). On the other hand, treatment of lung cancer is becoming more differentiated and individualized in order to improve the prognosis and thus it is important to make the necessary investigations to determine the stage and histology correct. We need critical research to evaluate the added value of each extra investigation and of different pre-treatment strategies when balanced against extra waiting time.

That it is possible to reduce system delay considerably is shown in a recent British pilot study. Eighty-eight patients at three District General Hospitals all suspected of having lung cancer were randomised either to local investigation in a conventional chest clinic setting or to a centralised two-stop pathway at a Central Hospital. A four-week improvement in time to first treatment was obtained for patients in the central arm (17).

The Cancer Plan II, prepared for the Danish National Board of Health in 2005, contains a series of professional recommendations of how to improve cancer treatment in Denmark and make it comparable to the best international results. In relation to lung cancer the organisation of a diagnostic fast track in the County of Vejle has provided basis for the recommendations. This highly organised fast track makes it possible to investigate and initiate treatment within 42 days for more than 60% of the patients receiving surgery and more than 70% of the patients treated with chemotherapy or radiotherapy. The average results for Denmark are 29% and 57%, respectively.

An important tool in reducing delay in the County of Vejle has been to schedule most of the investigations before the patient’s first visit at the outpatient clinic and then cancel investigations not needed. The CT scan is scheduled to day one, which leads to a 10% estimated CT scans that could have been avoided had the scan been scheduled later. On the other hand, the early CT scan makes it possible to finish the diagnostic process at day two for patients with CT scans not showing malignancy.

A reduction of system delay is needed and so is research in methods to organize the clinical work so system delay can be reduced.
References


Chapter 9

Conclusion
9.1. Conclusions

A defeatist attitude among Danish GPs was not found to be a reason for diagnostic delay in lung cancer neither in the questionnaire study nor in the case study. More than every fourth of the GPs were reluctant to use the word cancer in referrals to investigations and admissions, either because they did not want to worry the patients or because they were afraid of losing reliability if they used the word too frequently. This may lead to a fast track strategy for diagnostic assessment that is not well-functioning, and which might need to be reconstructed. This need is further stressed by the fact that many patients have non-typical symptoms or symptoms frequently related to non-malignant diseases, thus cancer is only one among many diagnostic possibilities. This makes the GP use descriptive terms such as “smoker for many years” instead of “suspected cancer” when referring to further investigations.

Half of the patients experienced more than four months’ delay from first symptom until treatment initiation or decision not to treat. Within the health care system the median delay was three months. The vast majority of delay was system delay due to waiting times for investigations of cancer-related symptoms, waiting times for treatment, and administration. Median delay in secondary health care was twice as long as median delay in primary health care.

Doctor delay was primarily placed in primary health care where a group of patients experienced very long delay. The main reasons for this delay were chest x-rays with no suspicion of cancer, non-typical presenting symptoms, comorbidity, and lack of explicit follow-up appointments. We need more detailed insight into the relative weigh of these components. Our study supports a change in chest x-ray strategy towards open access clinics in order to diminish waiting times.

Nearly 20% of the patients had a chest x-ray raising no suspicion of lung cancer. The impact of a false negative chest x-ray on delay was considerable, resulting in a six-fold longer delay in primary health care. The health care system needs to develop strategies in order to diminish the impact of a false negative chest x-ray. This should at least consist of a raised awareness of this risk of missing the diagnosis, but it might for instance also include conditioned open access to chest CT scans.

The combination of long waiting times and many investigations necessary to verify and stage the disease, especially for patients referred to treatment with curative intent, led to a nearly two month median delay in secondary health care. A quarter of the patients had at least one investigation repeated and every sixth of the patients had an investigation cancelled. One tenth of the patients were initially investigated in a normal outpatient clinic setting and they experienced a delay before referral to treatment that was twice as long as patients diagnosed under admission or in lung cancer specialised outpatient clinics. More research is needed to get detailed insight in reasons for the observed system-related delay and to test methods that can enhance speed in the clinical pathways, especially when many needed investigations can be anticipated.
Chapter 10

Perspective and further research
10.1. Perspective and further research

The main finding of this thesis has been the very long system delay. There is a need for a broad-perspective research on health services efforts to find ways to reduce this part of the delay. This will especially demand more research in how to optimise clinical pathways, both for patients referred to diagnostic investigations due to suspicion of lung cancer and for those with other clinical presentations, especially patients with non-typical symptoms where cancer is only one among several possible diagnoses. Scheduled hours at radiology departments with open access for patients referred to chest x-rays may be a way to minimize system delay in primary health care, and in secondary health care system delay can be reduced by establishing fast tracks for diagnostic assessment. The latter will require an obvious suspicion of cancer, but fast tracks may also be needed for patients with nontypical symptoms where cancer is one among many diagnostic possibilities. How do we ensure that patients not diagnosed by fast track pathways do not experience unacceptable diagnostic delay?

This study shows a need for more attention to the limitations of chest x-rays as a diagnostic tool in diagnosing lung cancer. A way forward may be conditional open access to GP referral to chest CT provided that specific requirements are fulfilled, but more research is needed on this issue.

In order to reduce diagnostic delay in primary health care more research is needed on how to motivate GPs to undertake an earlier reassessment of the diagnosis of the patients who are not diagnosed upon their first consultation. This will, among other things, require that the GPs become aware of the low sensitivity of chest x-rays and the non-typical, e.g. musculoskeletal, symptoms presented by some patients.

Another research question is how to avoid the delay occurring when patients who received no diagnosis upon their first consultation have to contact the GP again. Which patients need an exact follow-up appointment and which patients can do with information about when to return if symptoms persist or become worse? And how do we secure that these patients really do return when needed?

The questionnaire study showed that more than every fourth practitioner was reluctant to use the word cancer in referrals to hospitals or for investigations. This was especially a problem if there was no strong suspicion of cancer. It is important to reach consensus about the usage of the word cancer among GPs and physicians taking care of triage in the secondary health care system.

This thesis has not dealt with patient delay, but it is evident from the literature that we know too little about this topic, especially about patient’s perception of and coping with symptoms, their decision to see a doctor and the doctor-patient interaction when symptoms are presented.
Chapter 11

English summary
11.1 Background

Lung cancer is a common cancer disease in Denmark and the most common cause of cancer death among both men and women. The five-year survival rate is about 10% which is inferior to the other Nordic countries. The prognosis for lung cancer strongly depends on the stage of the disease at the time of diagnosis. Previous studies have shown that patients in Denmark have more advanced disease at the time of diagnosis compared to patients in Finland and Norway. Several possible explanations have been suggested: longer patient delay in Denmark, lack of diagnostic capacity and less tendency among Danish GPs to refer to further diagnostic investigations due to suspicion of lung cancer. The latter may be caused by a defeatist attitude against diagnosis and treatment of lung cancer due to the poor prognosis.

11.2 Aim

The study consisted of two parts:

- A questionnaire study among Danish GPs primarily aiming to reveal whether a defeatist attitude towards diagnosis and treatment of lung cancer was common or not. The secondary aim was to obtain the GPs opinion about the diagnostic organisation.

- A case study among patients with newly diagnosed lung cancer for whom a review was made of delay from the first symptom until treatment initiation or decision not to treat. The aim was to analyse reasons for delay in diagnosis and treatment of lung cancer, to distinguish between genuine doctor delay and delay due to waiting times and administration (system delay), and to identify areas for improvements.

11.3. Methods

*The questionnaire*

A questionnaire was prepared containing questions about whether the GPs had a defeatist attitude towards diagnosing lung cancer, how they looked on possibilities for improving prevention, how they evaluated the organisation of the diagnostic process, and what they actually did when they had a patient under suspicion of lung cancer. The questionnaire was sent to nearly 1200 randomly selected GPs in Denmark.

*The case study*

The patients were primarily identified by searching the pathology registers at Randers Hospital and Aarhus University Hospital. Patients diagnosed by biopsies from metastases were identified by contact with departments that diagnose and treat the disease. The patients should be newly diagnosed with lung cancer, be living in and diagnosed in the County of Aarhus, and the cancer should be histologically verified between 1 April and 31 May 2003 or 1 September and 31 December 2003.

Patients dying shortly after the diagnosis were included post mortem. The remaining patients were invited to participate after treatment initiation at the Department of Oncology or after surgery at the Department of Thoracic Surgery at Aarhus University Hospital. If no treatment were offered they were informed by mail.

For each of the participating patients a detailed review of delay was made starting with time of first symptom until treatment initiation or decision not to treat. These reviews were based on medical hospital records and interviews with patients and GPs.

Based on the reviews an estimation of delay was made for each patient. Delay was divided in patient delay, delay in primary health care, and delay in secondary health care. Delay within the
health care system was further subdivided into doctor delay and system delay. Doctor delay was
defined as: time elapsed without investigation of cancer-related symptoms and signs. System delay
was defined as: time elapsed due to waiting times related to investigation of cancer-related
symptoms and administration.

11.4. Results

*The questionnaire:* In total 848 GPs (71%) answered the questionnaire. Twelve percent agreed with
the statement that the prognosis for lung cancer is so unfavourable that you really do not need to be
in a hurry about diagnosing the disease, and 22 % agreed in the statement that diagnostic delay
rarely means anything for the prognosis. About half of the GPs were dissatisfied with the length of
the diagnostic delay for patients with lung cancer, but the percentage of GPs who were dissatisfied
varied a lot among the different counties. Every fourth of the GPs were reluctant to use the word
cancer in referrals to diagnostic investigations.

*The case study:* Among the 142 patients fulfilling the criteria of inclusion, 92 patients participated
in the study (64.8%). Half of the patients experienced more than three months’ delay within the
health care system before treatment initiation. The median patient delay was 24 days, the median
delay in primary health care was 29 days and in secondary health care the median delay was 58
days. The median system delay was nearly six times as long as the median doctor delay (75 days
and 13 days, respectively). Nearly 20% of the patients had a chest x-ray raising no suspicion of
cancer and in primary health care this resulted in a six-fold longer delay. Other important reasons
for delay were non-typical symptoms, lack of follow-up appointments, comorbidity, and diagnostic
investigations in outpatient clinic settings not specialised in diagnosing lung cancer.

11.5. Conclusion

This thesis proved no defeatist attitude among Danish GPs. Delay in diagnosis and treatment of
lung cancer was predominantly system delay, and focus on waiting times is essential if we want to
reduce delay. More research is needed on how we best optimise clinical pathways, both for patients
referred to diagnostic investigations due to suspicion of lung cancer and for those with other clinical
presentations. Chest x-rays raising no suspicion of cancer was an important reason for delay
especially in primary health care. It is important that GPs become more aware of the low sensitivity
of chest x-ray and that some patients present with non-typical symptoms.
Chapter 12

Dansk resumé
12. Baggrund

Lungecancer er en hyppig cancersygdom i Danmark og den hyppigste årsag til cancerdød hos både mænd og kvinder. 5-årsoverlevelsen i Danmark er omkring 10%, hvilket er lavere end i de øvrige nordiske lande. Prognosen for lungecancer er stærkt afhængig af sygdomsstadie på diagnosetidspunktet og undersøgelsler har vist at danske patienter har mere udbredt sygdom på diagnosetidspunktet end patienter i Finland og Norge. Af mulig forklaring herpå har været nævnt: At danske patienter venter længe med at søge læge, at der på grund af manglede udrednings kapacitet er længere ventetider i Danmark og at danske praktiserende læger er mere tilbageholdende med at henvise patienterne til udredning. Som forklaring på sidstnævnte har været anført en nihilistisk holdning til udredning og behandling af lungecancer blandt praktiserende læger på grund af den dårlige prognose.

12.2. Formål

Projektet bestod af to dele:

- En spørgeskemaundersøgelse blandt praktiserende læger i Danmark med det primære formål at afdække om der fandtes en nihilistisk holdning til udredning af lungecancer og det sekundære formål at undersøge lægernes vurdering af organiseringen af udredningen.
- Et casestudie med gennemgang af forløbet fra første symptom til behandlingsstart, eller beslutning om ikke at handle, for en række patienter med nydiagnosticeret lungecancer. Formål med studiet var at analyse årsager til delay i diagnostik og behandling af lungecancer, at skelne mellem egentligt lægedelay og delay på grund af ventetider og administration (systemdelay) og at identificere områder, hvor der er muligheder for forbedringer.

12.3. Metode

Spørgeskemaundersøgelsen: Der blev udarbejdet et spørgeskema omhandlende mulighederne for at forbedre den forebyggende indsats, holdninger til lungecancerudredning, meninger om ventetider i udredningen og om lægernes kliniske praksis. Spørgeskemaet blev sendt til knap 1200 tilfældigt udvalgte danske praktiserende læger.


Patienter der døde umiddelbart efter at diagnosen var stillet blev inkluderet post mortem. De øvrige patienter blev informeret om projektet efter behandlingsstart på Onkologisk afdeling eller efter operation på Thoraxkirurgisk afdeling, Aarhus Universitetshospital, eller per brev hvis de ikke modtog behandling.

For hver af de deltagende patienter blev der udarbejdet en detaljeret beskrivelse af hændelsesforløbet fra første symptom til behandlingsstart eller til beslutning om ikke at handle. Beskrivelserne baserede sig på gennemgang af sygehusjournaler, patientinterviews og telefoninterviews med patienternes praktiserende læge.

På baggrund af forløbsbeskrivelserne blev udarbejdet en opgørelse af delay for hver patient. Delay blev inddelt i patientdelay, delay i primærsektoren og delay i sekundærsektoren. Delay i sundhedsvæsenet blev yderligere underopdelt i lægedelay og systemdelay. Lægedelay blev
defineret som: Tidsintervaller hvor der ikke foregår nogen udredning af cancerrelaterede symptomer. Systemdelay blev defineret som: Tidsintervaller relateret til ventetider på undersøgelser af cancerrelaterede symptomer og administration.

12.4. Resultater

Spørgeskemaundersøgelsen: I alt 848 (71%) læger besvarede spørgeskemaet. Tolv procent var enige i, at lungecancer havde en så dårlig prognose, at det reelt ingen hast havde med at få stillet diagnosen og 22 % var enige i, at forlænget udredningstid sjældent ville betyde noget for prognosen. Ca. halvdelen mente, at udredningstiden for patienter med lungecancer var for lang. Der var dog stor variation fra amt til amt.

Casestudiet: Af de 142 patienter der opfyldte inklusionskriterierne deltog 92 patienter (64,8%). Halvdelen af patienterne oplevede mere end tre måneders delay i sundhedsvæsnet inden de kom i behandling. Medianværdien for patientdelay var 24 dage, for primærsektoren 29 dage og for sekundærsektoren 58 dage. Mediane systemdelay var næsten seks gange det mediane lægedelay (75 dage og 13 dage henholdsvis). Knap 20 % af patienterne fik taget et røntgen af thorax der ikke gav mistanke om malignitet. I primærsektoren havde patienter med falsk negativt røntgen af thorax seks gange så langt delay som de øvrige patienter. Andre væsentlige årsager til delay var atypiske debutsymptomer, manglende aftaler om opfølgning i primærsektoren, komorbiditet og udredning i ikke cancer-specialiseret ambulant regi på sygehuset.

12.5. Konklusion

Appendix A
Sådan udfylder du spørgeskemaet

Sæt et kryds i firkanten ud for det svar, du synes, passer bedst. Sæt krydser inden i firkanterne. Det gør ikke noget, at du kommer lidt ud over firkanten.

Rigtigt: 
Forkert: 

Under enkelte spørgsmål bliver du bedt om at skrive tal. Skriv så tydeligt som muligt og helst så de ligner nedenstående eksempler.

1 2 3 4 5 6 7 8 9 0

Hvis du kommer til at **lave en fejl**, kan du blot sætte **et minus** ud for den forkerte markering og derefter udfyde den rigtige firkant.

Er der spørgsmål, hvor du har svært ved at finde en svarmulighed, der passer præcist, skal du vælge den, der umiddelbart passer bedst.

Hvis du har spørgsmål eller kommentarer, er du meget velkommen til at kontakte Forskningsenheden for Almen Medicin, Vennelyst Boulevard 6, 8000 Århus C ved:

Læge  
Marianne Bjerager  
Tlf.: 89 42 60 19  
Fax: 86 12 47 88  
E-mail: mb@alm.au.dk

**Mange tak for hjælpen!**

Skemaet indsendes snarest muligt i vedlagte portofrie svarkuvert
Demografiske data:

1. Køn
   □ Kvinde
   □ Mand

2. Fødselsår

3. Kandidatår

4. Antal år i praksis

5. Praksistype: (Sæt evt. 2 krydser)
   □ Solopraksis
   □ Samarbejdspraksis
   □ Kompagniskab

6. Min praksis ligger i: ____________________________ Amt/Kbh/Frb. kommune

7. Hvis jeg har mistanke om at en patient har lungecancer, henviser jeg dem normalt til den følgende afdeling:
   □ Medicinsk afdeling
   □ Lungemedicinsk afdeling
   □ Andet (ikke røntgen) ____________________________

8. By (som sygehuset er beliggende i): ____________________________
## Meninger om forebyggelse

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(Sæt kun et kryds pr. spørgsmål)

9. Den indsats, der foregår i sundhedsvæsenet generelt mht. at forebygge lungecancer, bør intensiveres.

10. Den indsats, der foregår i almen praksis mht. forebyggelse af lungecancer, bør intensiveres.

11. Jeg kan intensivere det forebyggende arbejde i min praksis.

## Meninger om diagnostisk indsats

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12. Sundhedsvæsenet i mit amt bør fokusere mere på tidlig diagnostik af lungecancer.

13. Storpygere (>15 cigaretter dagl.) over 50 år bør få taget rutinemæssig røntgen af thorax hvert andet år.

14. Lungecancer har en så dårlig prognose, at det reelt ingen hast har med at få stillet diagnosen.

Kampagner om vigtigheden af tidlig lægekontakt ved symptomer på lungecancer vil skabe uhensigtsmæssig sygdomsangst i befolkningen.
16. Øget fokus på tidlig lægekontakt ved symptomer, vil næppe føre til tidligere diagnostik af lungecancer.  
   - Helt enig  - Delvis enig  - Delvis uenig  - Helt uenig  - Ved Ikke

17. Patenter med symptomer på lungecancer ventrer ofte uhensigtsmæssigt længe med at gå til læge.  
   - Helt enig  - Delvis enig  - Delvis uenig  - Helt uenig  - Ved Ikke

18. Jeg vil generelt karakterisere mig selv som meget aktiv, når det gælder udredning af lungecancer.  
   - Helt enig  - Delvis enig  - Delvis uenig  - Helt uenig  - Ved Ikke

19. Jeg synes, praktiserende læger skal have mulighed for selv at ordinere CT-scanning når indiceret (fortsat mistanke trods normalt røntgen af thorax).  
   - Helt enig  - Delvis enig  - Delvis uenig  - Helt uenig  - Ved Ikke

### Meninger om ventetider og koordinering

20. For patienter med ukarakteristiske symptomer er den samlede udredningstid (fra påbegyndt udredning til endelig diagnose) for lang.  
   - Helt enig  - Delvis enig  - Delvis uenig  - Helt uenig  - Ved Ikke

   - Helt enig  - Delvis enig  - Delvis uenig  - Helt uenig  - Ved Ikke

22. Ventetiden, fra hospitalet overtager ansvaret for patientens udredning til de starter behandling, er for lang.  
   - Helt enig  - Delvis enig  - Delvis uenig  - Helt uenig  - Ved Ikke
### 23. Forlænget udredningstid betyder sjældent noget for prognosen for lungecancerpatienter.

<table>
<thead>
<tr>
<th>Helt enig</th>
<th>Delvis enig</th>
<th>Delvis uenig</th>
<th>Helt uenig</th>
<th>Ved Ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 24. Når jeg har henvist en patient til udredning for mulig lungecancer på sygehuset, forløber udredningen efter min mening hurtigt og uden problemer.

<table>
<thead>
<tr>
<th>Helt enig</th>
<th>Delvis enig</th>
<th>Delvis uenig</th>
<th>Helt uenig</th>
<th>Ved Ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
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</tr>
</tbody>
</table>

### 25. Patienterne oplever forløbet af udredningen, som styres fra min praksis, som passende hurtig.

<table>
<thead>
<tr>
<th>Helt enig</th>
<th>Delvis enig</th>
<th>Delvis uenig</th>
<th>Helt uenig</th>
<th>Ved Ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

### 26. Patienterne oplever forløbet af udredningen, som sygehuset foretager, som passende hurtig.

<table>
<thead>
<tr>
<th>Helt enig</th>
<th>Delvis enig</th>
<th>Delvis uenig</th>
<th>Helt uenig</th>
<th>Ved Ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Handlinger

#### 27. Mistanken om cancer skal være stor, før jeg bruger ordet cancer/kræft i en henvisning.

<table>
<thead>
<tr>
<th>Helt enig</th>
<th>Delvis enig</th>
<th>Delvis uenig</th>
<th>Helt uenig</th>
<th>Ved Ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### 28. Jeg vil nødigt miste troværdighed ved for ofte at bruge ordet cancer i mine henvisninger.

<table>
<thead>
<tr>
<th>Helt enig</th>
<th>Delvis enig</th>
<th>Delvis uenig</th>
<th>Helt uenig</th>
<th>Ved Ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### 29. Jeg undlader ofte at nævne ordet cancer/kræft i henvisningspapirer for at undgå at gøre min patient bekymret.

<table>
<thead>
<tr>
<th>Helt enig</th>
<th>Delvis enig</th>
<th>Delvis uenig</th>
<th>Helt uenig</th>
<th>Ved Ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### 30. Patienter over 40 år uden fokale klager, men med almene symptomer, fx. træthed og nedsat appetit, henviser jeg til røntgen af thorax, hvis de er storbygere (>15 cigaretter dagl.).

<table>
<thead>
<tr>
<th>Helt enig</th>
<th>Delvis enig</th>
<th>Delvis uenig</th>
<th>Helt uenig</th>
<th>Ved Ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helt enig</td>
<td>Delvis enig</td>
<td>Delvis uenig</td>
<td>Helt uenig</td>
</tr>
<tr>
<td>---</td>
<td>-----------</td>
<td>-------------</td>
<td>--------------</td>
<td>------------</td>
</tr>
<tr>
<td>31.</td>
<td>Storrygere (&gt;15 cigaretter dagl.) over 40 år som øvrigt er raske, får i min praksis altid taget kontrolrøntgen af thorax efter en behandling for pneumoni.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>32.</td>
<td>En klinisk sikker lunginfektion hos en patient over 40 år, der ellers ikke har lungesygdom, får mig normalt til at aftale en kontrolkonsultation.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>33.</td>
<td>Ved længervarende knoglesmerter af ukendt genese hos en person over 40 år tager jeg altid røntgen af thorax.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>34.</td>
<td>En 60-årig storryger med kronisk bronkitis og hæmoptyse i over en uge vil jeg altid henvise til bronkoskopi, også selv om røntgen af thorax er normalt.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>35.</td>
<td>Hos en tidligere lungerask ryger over 40 år med hoste gennem 6 uger vil jeg altid tage røntgen af thorax.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
  1. Ja, flere gange
  2. Ja, en enkelt gang
  3. Nej, aldrig
Man arbejder for tiden på at forbedre mulighederne for at diagnosticere lungecancer tidligere efter symptomdebut, end det sker idag.

### Hvad mener du, at man især bør fokusere på?

<table>
<thead>
<tr>
<th></th>
<th>Helt enig</th>
<th>Delvis enig</th>
<th>Delvis uenig</th>
<th>Helt uenig</th>
<th>Ved Ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td>37.</td>
<td>At få patienterne til at komme tidligere ved symptomer.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>38.</td>
<td>At øge de praktiserende lægers opmærksomhed på symptomer på lungecancer generelt.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>39.</td>
<td>At reducere ventetiderne på de udredningsundersøgelser, der ordineres i praksis.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>40.</td>
<td>At reducere udredningstiden fra sygehuset overtager udredningsansvaret, til den endelige diagnose foreligger</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>41.</td>
<td>Andet.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Kommentarer:

__________________________
__________________________
__________________________
__________________________
__________________________
__________________________
__________________________

Forbeholdt kodning
Appendix B
**Patientinterview – åbne spørgsmål.**

Prøv at fortælle mig, hvordan det gik til, da du fik stillet diagnosen.

Prøv at fortæl lidt om hvordan symptomer startede.

Hvilke tanker gjorde du dig om de symptomer du havde?

Var du bekymret?

Snakkede du med nogen om det?

Var der noget, der – måske ubevidst – fik dig til at udskyde lægebesøget?

Var der nogen, der skubbede på?

Hvad fik dig til at gå til læge?

Hvad fortalte du lægen om dine symptomer?

Hvilke forklaringer gav din læge dig?

Kan du beskrive forløbet hos din egen læge?

Kan du beskrive forløbet hos speciallæge/fys./kiropraktor?

Kan du beskrive forløbet på sygehuset, frem til du kom i behandling?

Hvordan oplevede du den ventetid, der har været mellem de forskellige undersøgelser?

Hvornår tænkte du første gang på, at det kunne være kræft?

Hvornår fik du første gang at vide, at man troede, det kunne være kræft?

Hvordan oplevede du at få beskeden?
# Checkliste til patientinterview

Dato:

<table>
<thead>
<tr>
<th>Patientnr.</th>
<th></th>
</tr>
</thead>
</table>
| Har der været symptomer forud for at diagnosen blev stillet? | □ Ja
          | Nej |
| Ved symptomer: |        |

## Første symptom

| Hvad var det første, du mærkede til din sygdom? | Manglende appetit
| - gerne flere svar | Hoste/ændret hoste
| | Åndenød
| | Blodigt opspyt
| | Hæshed
| | Vedvarende ell. gentagende infektioner
| | Vægttab
| | Træthed
| | Smertesmeverv (thorax)
| | Knogle
| | Andet ___________________________
| | ____________________________________

| Hvornår bemærkede du det/de første symptomer?
Dato - så præcist som muligt | Vage symptomer (på at du ikke var rask)
| | ___________________________
| | Sikre symptomer (på at du var syg)
| | ___________________________

| Hvornår besluttede du, at du ville søge læge? | ___________________________
| | |

| Da du havde besluttet at du ville gå til læge, bestilte du så tid med det samme? | Ja
| | Nej
| | Ved ikke |
### Appendix B

<table>
<thead>
<tr>
<th><strong>Hvor udtalte var generne, da du valgte at søge læge første gang?</strong></th>
<th><strong>Meget lette (ikke påvirkning af funktionsevnen)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Lette (påvirkning af funktionsevnen - men følte sig ikke syg)</td>
</tr>
<tr>
<td></td>
<td>Middel (følte sig syg, men kunne passe sit arbejde/ var ikke sengeliggende)</td>
</tr>
<tr>
<td></td>
<td>Udtalte (Var sengeliggende, sygemeldt)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Hvad troede du, var den mest sandsynlige årsagen til generne, på det tidspunkt hvor du søgte læge første gang?</strong></th>
<th><strong>Havde ikke tænkt på hvad årsagen var</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Kæft</td>
</tr>
<tr>
<td></td>
<td>Andet</td>
</tr>
<tr>
<td></td>
<td>Infektion</td>
</tr>
<tr>
<td></td>
<td>Forværring i kronisk lungelidelse</td>
</tr>
<tr>
<td></td>
<td>Forværring af anden kronisk sygdom</td>
</tr>
<tr>
<td></td>
<td>Stress</td>
</tr>
<tr>
<td></td>
<td>Muskel- eller knoglelidelse</td>
</tr>
<tr>
<td></td>
<td>Andet</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Hvad fik dig til at søge læge?</strong></th>
<th><strong>Smerter</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Evt. flere krydser</strong></td>
<td><strong>Bekymring for om det var noget alvorligt</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Pres fra familie/venner</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Manglende evne til at passe jobbet/klare dagligdagen</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Havde aftale med lægen i forvejen</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Ønsket om at få behandling - jeg troede ikke det var noget alvorligt jeg fejlede.</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Andet</strong></td>
</tr>
</tbody>
</table>

### Generelle helbredsstatus

<table>
<thead>
<tr>
<th><strong>Har du tidligere fået at vide, at du lider af en af en lungesygdom?</strong></th>
<th><strong>Nej</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Ja</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Lider du af en anden sygdom, hvis symptomer ligner de symptomer du har haft i aktuelle sygdomsforløb?</strong></th>
<th><strong>Nej</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Ja</strong></td>
</tr>
</tbody>
</table>
### Delaytendens

<table>
<thead>
<tr>
<th>Hvis du ser bagud i tid, synes du så at du søgte læge på det rette tidspunkt</th>
<th>Ja</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nej, jeg synes jeg burde være gået til læge før</td>
</tr>
<tr>
<td></td>
<td>Ved ikke</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Når du er syg, har du så en tendens til at udskyde lægebesøg?</th>
<th>Ja, altid</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ja, af og til</td>
</tr>
<tr>
<td></td>
<td>Det er sket enkelte gange</td>
</tr>
<tr>
<td></td>
<td>Nej, aldrig</td>
</tr>
<tr>
<td></td>
<td>Ved ikke</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Da du fik symptomer - Udskød du rent faktisk lægebesøget den her gang?</th>
<th>Nej</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ja, et par dage</td>
</tr>
<tr>
<td></td>
<td>Ja, over en uge</td>
</tr>
<tr>
<td></td>
<td>Ja, over en måned</td>
</tr>
<tr>
<td></td>
<td>Ja, over tre måneder</td>
</tr>
<tr>
<td></td>
<td>Ved ikke</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hvad var årsagen til, at du udskød lægebesøget?</th>
<th>Jeg troede, at symptomerne ville forsvinde af sig selv</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Jeg troede ikke at det var alvorligt</td>
</tr>
<tr>
<td></td>
<td>Jeg var bange</td>
</tr>
<tr>
<td></td>
<td>Jeg havde ikke tid</td>
</tr>
<tr>
<td></td>
<td>Pga.____________________________</td>
</tr>
<tr>
<td></td>
<td>Andet___________________________</td>
</tr>
</tbody>
</table>

### Forholdet til den praktiserende læge

<table>
<thead>
<tr>
<th>Føler du generelt, at din læge tager dig alvorligt, når du kommer til ham/hende med et problem?</th>
<th>Altid</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Oftest</td>
</tr>
<tr>
<td></td>
<td>Sjældent</td>
</tr>
<tr>
<td></td>
<td>Ved ikke</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Følte du, at din læge tog dig alvorligt, da du kom til ham/hende i forbindelse med aktuelle sygdom?</th>
<th>Ja</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Delvis</td>
</tr>
<tr>
<td></td>
<td>Nej</td>
</tr>
<tr>
<td></td>
<td>Ved ikke</td>
</tr>
</tbody>
</table>
### Forløbet hos den praktiserende læge

| Hvornår gik du til lægen første gang? Dato. | Henvisning til udredning for kræft Andet:  
C. Beroligelse  
D. Ny tid til kontrol  
E. Recept på penicillin ell. andet medicin  
F. Henvisning til speciallæge  
G. Blodprøver  
H. Henvisning til røntgen  
I. Ambulant sygehus henvisning  
J. Henvisning til indlæggelse  
K. Andet: ____________________________  
L. Husker ikke |
|----------------------------------------|----------------------------------|

<table>
<thead>
<tr>
<th>Hvad var resultatet af første lægebesøg? Evt. flere krydser</th>
<th>Tror du, din læge tænkte: “Det her kan være (lunge)kræft”?</th>
</tr>
</thead>
</table>
| Henvisning til udredning for kræft Andet:  
C. Beroligelse  
D. Ny tid til kontrol  
E. Recept på penicillin ell. andet medicin  
F. Henvisning til speciallæge  
G. Blodprøver  
H. Henvisning til røntgen  
I. Ambulant sygehus henvisning  
J. Henvisning til indlæggelse  
K. Andet: ____________________________  
L. Husker ikke |
| Tror du, din læge tænkte: “Det her kan være (lunge)kræft”? |
| Tror du, din læge tænkte: “Det her kan være (lunge)kræft”? | Ja  
Måske  
Nej  
Ved ikke |

<table>
<thead>
<tr>
<th>Dato for henvisning til røntgen/ lungemedicinsk afd. eller indlæggelse?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dato for røntgen/1. ambulante undersøgelse/ indlæggelse</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hvad skete der i tiden mellem 1. lægekontakt og henvisning til røntgen/medicinsk afdeling? Dato og begivenhed.</th>
</tr>
</thead>
</table>
| 1. ____________________________  
2. ____________________________  
3. ____________________________  
4. ____________________________ |

<table>
<thead>
<tr>
<th>Måtte du på noget tidspunkt selv presse på, for at få tingene til at ske hurtigere?</th>
</tr>
</thead>
</table>
| Måtte du på noget tidspunkt selv presse på, for at få tingene til at ske hurtigere? | Ja, flere gange  
Ja, en enkelt gang  
Nej  
Ved ikke |
## Forløbet på sygehuset

<table>
<thead>
<tr>
<th>Spørgsmål</th>
<th>Ja</th>
<th>Ja, delvis</th>
<th>Nej</th>
<th>Ved ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td>Første gang du blev henvist til røntgen/sygehuset, og fik tid</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Spørgsmål</th>
<th>Tilfredsstillende kort</th>
<th>Acceptabel</th>
<th>Uacceptabel lang</th>
<th>Ved ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hvordan har du oplevet den ventetid, der har været mellem de undersøgelser du har fået lavet?</td>
<td>Evt. årsag til vurderingen</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Spørgsmål</th>
<th>Tilfredsstillende kort</th>
<th>Acceptabel</th>
<th>Uacceptabel lang</th>
<th>Ved ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hvordan har du oplevet den ventetid, der har været på at komme i behandling</td>
<td>Evt. årsag til vurderingen</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Mistanke om kræft

<table>
<thead>
<tr>
<th>Spørgsmål</th>
<th>Nej, slet ikke</th>
<th>Måske ubevidst</th>
<th>Tanket har strejfet mig</th>
<th>Ja, tanken kom undervejs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hvornår tror du, din læge/ speciallægen/de på sygehuset fik mæssen, om at det kunne være kræft for første gang?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Spørgsmål</th>
<th>Jeg nævnte selv ordet kræft for lægen</th>
<th>Egen læge</th>
<th>Speciallæge</th>
<th>Røntgenlæge</th>
<th>Sygehuslæge - ambulant - indlæggelse</th>
<th>Andet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hvem fortalte dig, at du blev undersøgt for kræft?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Spørgsmål</th>
<th>Jeg nævnte selv ordet kræft for lægen</th>
<th>Egen læge</th>
<th>Speciallæge</th>
<th>Røntgenlæge</th>
<th>Sygehuslæge - ambulant - indlæggelse</th>
<th>Andet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hvem fortalte dig, at du blev undersøgt for kræft?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Tilfredshed

| Hvordan er din tilfredshed - alt i alt - med forløbet hos den praktiserende læge? | Meget tilfredsstillende
| Tilfredsstillende
| Ikke helt tilfredsstillende
| Meget utilfredsstillende
| Ved ikke
| Ikke relevant |
| --- | --- |
| Hvordan er din tilfredshed - alt i alt - med forløbet hos speciallægen/speciallægerne? | Meget tilfredsstillende
| Tilfredsstillende
| Ikke helt tilfredsstillende
| Meget utilfredsstillende
| Ved ikke
| Ikke relevant |
| Hvordan er din tilfredshed - alt i alt - med forløbet på hospitalet? | Meget tilfredsstillende
| Tilfredsstillende
| Ikke helt tilfredsstillende
| Meget utilfredsstillende
| Ved ikke |

## Familiestatus

| Familiestatus | Bor alene
| Bor med ægtefælle/samlever/børn
| Andet (fx plejehjem)
| Ikke besvaret |

## Erhvervsmæssige stilling
<table>
<thead>
<tr>
<th>Erhverv</th>
<th>Selbstændig erhvervsdrivende Funktionær eller tjenestemand Faglært arbejder Specialarbejder eller ikke-faglært arbejder Andet Ikke i erhverv</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ikke i erhverv</td>
<td>Husmoder Folkepensionist Fortidspensionist På efterløn Arbejdsløs På bistand Andet</td>
</tr>
</tbody>
</table>

### Skoleuddannelse

<table>
<thead>
<tr>
<th>Hvilken skoleuddannelse har du?</th>
<th>Er studerende 7 eller færre års skolegang 8-9 års skolegang 10 års skolegang Studenter- , HF- eller HH-eksamen Andet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erhvervsuddannelse</td>
<td>Ingen Faglig uddannelse Kort videregående uddannelse (under 3 år) Mellemlang videregående uddannelse Lang videregående uddannelse (over 4år) Anden</td>
</tr>
<tr>
<td>Egen læge</td>
<td></td>
</tr>
</tbody>
</table>

---

**Appendix B**
Patientinformation og Samtykkeerklæring til et videnskabeligt projekt

Forsinkelse i udredningsprocessen for lungekræftpatienter

Forskningsenheden for Almen Medicin
Aarhus Universitet
Vil du deltage i et videnskabeligt projekt om, hvorledes lungekræftpatienter får stillet diagnosen?
I det følgende er beskrevet, hvad projektet går ud på, og hvad den indebærer for dig. Først når du er informeret af en læge eller sygeplejerske og har læst det følgende, skal du afgøre, om du vil deltage i projektet.

Dette projekt foregår i et samarbejde mellem læger på Forskningsenheden for Almen Medicin på Aarhus Universitet og læger på Onkologisk afdeling og Lungemedicinsk afdeling, Århus Kommunehospital.

Det er planlagt, at projektet skal omfatte i alt ca. 100 patienter.

Baggrund og formål med projektet

Formålet med dette projektet er at få et indtryk af, hvor i forløbet der opstår forsinkelser, hvor hyppigt forsinkelser opstår, og hvad grunden hertil er. Resultaterne af projektet vil blive brugt til at finde områder, hvor det er muligt at sætte ind med forbedringer.

Projektets betydning for dig selv og andre
Du vil ikke selv få gavn af at deltage i projektet, men projektet kan give ny viden, der kan være med til at forbedre forløbet fra det første symptom til endelig diagnose for fremtidige kræftpatienter.

Sådan foregår projektet
For at få din oplevelse af forløbet vil vi gerne lave et interview med dig. Interviewet tager fra 30 minutter til 1 time og vil blive optaget på bånd.


Din praktiserende læge vil ikke få oplysninger om, hvad du har sagt i forbindelse med interviewet.
Registrering af oplysninger / tavshedspligt
Alle oplysninger indsamles på Forskningsenheden for Almen Medicin og registreres på EDB under et kodenummer. Alle data vil blive behandlet fortroligt, og din identitet vil ikke fremgå, når forløbsbeskrivelserne senere bliver forelagt et panel af læger til vurdering.
Båndoptagelserne af interviewene vil kun blive hørt af den person, der interviewede dig, og båndoptagelserne vil blive slettet, når projektet er afsluttet. Citater fra interviewene vil blive brugt i forbindelse med fremlæggelse af projektet, men kun i anonym form.

Økonomi
Center for Evaluering og Medicinsk Teknologi Vurdering, der hører under Sundhedsstyrelsen, støtter projektet og betaler løn til lægen, der står for projektet.

Det er frivilligt at deltage i projektet
Det er naturligvis frivilligt, om du vil deltage i projektet. Du har krav på betænkningstid, inden du beslutter dig. Vælger du at deltage, kan du i øvrigt når som helst og uden begrundelse tilbagekalde dit samtykke, uden at det vil påvirke din nuværende eller fremtidige behandling, ligesom det ikke vil påvirke din behandling, hvis du vælger ikke at deltage.

Har du spørgsmål til projektet?
Hvis du har spørgsmål vedrørende projektet, er du naturligvis velkommen til at kontakte undertegnede på telefon 8942 6019, per brev eller på email: mb@alm.au.dk

Med venlig hilsen
Projektansvarlig læge
Marianne Bjerager
Forskningsenheden for Almen Medicin
Aarhus Universitet
Samtykkeerklæring
Jeg bekræfter hermed, at jeg efter at have modtaget information, såvel mundtligt som skriftligt, indvilger i at deltage i det beskrevne projekt.
Jeg er informeret om, at det er frivilligt at deltage, og at jeg når som helst kan trække mit tilsagn om deltagelse tilbage, uden at dette vil påvirke min nuværende eller fremtidige behandling og kontrol på afdelingen.

Udfyldes af patienten

<table>
<thead>
<tr>
<th>Jeg ønsker at deltage i hele projektet.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Dato</td>
<td>underskrift</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>navn (blokbogstaver)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Jeg ønsker kun at deltage i dele af projektet. Jeg ønsker ikke:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ At deltage i et interview</td>
</tr>
<tr>
<td>□ At interviewet optages på bånd</td>
</tr>
<tr>
<td>□ At der foretages telefoninterview med min praktiserende læge</td>
</tr>
<tr>
<td>□ At der hentes oplysninger fra min journal hos min praktiserende læge</td>
</tr>
<tr>
<td>Dato</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

Udfyldes af informerende læge/sygeplejerske

<table>
<thead>
<tr>
<th>Dato</th>
<th>navn (blokbogstaver)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>underskrift</td>
</tr>
</tbody>
</table>
Appendix C
## Guide til telefoninterview med praktiserende læger

<table>
<thead>
<tr>
<th>Læge nr.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patientnr.</td>
<td></td>
</tr>
<tr>
<td>Dato for interview</td>
<td></td>
</tr>
</tbody>
</table>

### Spørgsmål om det aktuelle forløb

- **Hvornår henvendte patienten sig første gang med symptomer, der set i bakspejlet kunne skyldes lungecancer?**

- **Hvilke symptomer kom patienten med?**
  - Manglende appetit
  - Vedvarende hoste/ændret hoste
  - Andenød
  - Blodigt opspyt
  - Hæshed
  - Vedvarende ell. gentagende infektioner
  - Vægttab
  - Træthed
  - Smerter:
    - Brystetkassen (thorax)
    - Knogle
    - Andet

- **Gav patienten udtryk for hvad han/hun troede var årsag til symptomerne?**
  - Nej
  - Ja, kræft
  - Ja, andet:
    - Infektion
    - Forværring i kronisk lungelidelse
    - Forværring af anden kronisk sygdom
    - Psykisk betinget fx stress
    - Muskel ell. knoglelidelse
    - Andet

  - Ved ikke
<table>
<thead>
<tr>
<th>Afhandling C</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hvad var din diagnose, efter at patienten havde henvendt sig første gang (med symptomer, der senere viste sig at skyldes lungecancer)?</strong></td>
</tr>
<tr>
<td>□ Havde ikke sat diagnose på</td>
</tr>
</tbody>
</table>

- □ Kræft
- □ Ikke-malignlidelse:
  - □ Infektion
  - □ Forværring i kronisk lungelidelse
  - □ Forværring af anden kronisk sygdom
  - □ Stress
  - □ Muskel- eller knoglelidelse
  - □ Andet____________________
  - □ Ved ikke

| **Hvad var resultatet af den første undersøgelse?** |
| □ Henvisning til udredning for lungecancer |
| □ Henvisning til udredning for obs.cancer |
| □ Andet |

- □ Beroligelse
- □ Ny tid til kontrol
- □ Recept på penicillin ell. andet medicin
- □ Henvisning til speciallæge
- □ Blodprøver
- □ Henvisning til røntgen
- □ Ambulant sygehus henvisning
- □ Henvisning til indlæggelse
- □ Andet____________
- □ Ved ikke

| **Ved henvisninger til speciallæger ell. undersøgelser, der ikke har været mhp mistanke om lungecancer** |
| Brug ekstra skema. |

| **Blev ordene kræft, cancer eller malign lidelse brugt i henvisningerne** |
| □ Ja |
| □ Nej |
| □ Ved ikke |

| **Hvis der ikke var mistanke om cancer i starten - hvornår fik du første gang tanken, at det kunne være cancer?** |
| □ Der var mistanke om cancer fra starten |
| □ Jeg havde ikke på noget tidspunkt mistanke om at det var cancer. |
| □ ________________________________
| ________________________________

---

**Note:**
- Forværring i kronisk lungelidelse
- Forværring af anden kronisk sygdom
- Stress
- Muskel- eller knoglelidelse
- Andet

---

**Brug ekstra skema:**
- Beroligelse
- Ny tid til kontrol
- Recept på penicillin ell. andet medicin
- Henvisning til speciallæge
- Blodprøver
- Henvisning til røntgen
- Ambulant sygehus henvisning
- Henvisning til indlæggelse
- Andet
<table>
<thead>
<tr>
<th>Spørgsmål</th>
<th>Nej</th>
<th>Ja</th>
<th>Ved ikke</th>
<th>Ja</th>
<th>Nej</th>
<th>Kendte ikke patientens rygevaner</th>
<th>Ved ikke</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gav du over for patienten udtryk for at du mistænkte cancer?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indgik patientens rygevaner i de diagnostiske overvejelser?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hvordan har du oplevet ventetiden på de undersøgelser du har henvist patienten til i udredningsforløbet?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Har patienten selv været aktiv i udredningsprocesse (fx selv foreslået undersøgelser eller bedt om henvisninger)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Har patientens netværk været aktivt i udredningsprocessen (fx foreslået undersøgelser eller givet udtryk for at de ønskede at patienten blev henvist videre)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Generelle spørgsmål om patienten**

På en skala fra 1-5, hvor 5 er det bedste, hvordan vil du

- vurdere din patients evne til at fremstille sine symptomer?  
  1 2 3 4 5 Ved ikke

- vurdere dit forhold til patienten?  
  1 2 3 4 5 Ved ikke

- vurdere dit kendskab til patienten?  
  1 2 3 4 5 Ved ikke

- vurdere styrken af patientens netværk  
  1 2 3 4 5 Ved ikke

Lider patienten af en kronisk lungesygdom?  
  Nej
  Ja: __________________________
| **Lider patienten af anden sygdom, hvis symptomer ligner de symptomer der har været i det aktuelle sygdomsforløb?** | ☐ Nej  
☐ Ja |
|---|---|
| **Hvor længe har du været læge for patienten?** | ☐ 10 år eller mere  
☐ 5 år eller mere  
☐ 3 år eller mere  
☐ 1 år eller mere  
☐ ½ år eller mere  
☐ Under ½ år  
☐ Jeg er ikke patientens faste læge |
| **Hvor mange gange har du set patienten i året op til diagnosen blev stillet? (Besøg og konsultation)** | ☐ Mindst 5 gange  
☐ 3 - 4 gange  
☐ 2 gange  
☐ 1 gang  
☐ Har kun set patienten i forbindelse med udredningen for lungecancer  
☐ Har ikke set patienten  
☐ Ved ikke |
Appendix D
Patient nr. 28                   Mand – 60 år                          Rygerstatus: 30 – 80 cigaretter dgl. i 40 år.
Tidligere: Rask.

<table>
<thead>
<tr>
<th>Dato</th>
<th>Antal dage</th>
<th>Hændelse</th>
<th>Problem</th>
<th>Ansvarlig sektor</th>
</tr>
</thead>
<tbody>
<tr>
<td>xx.xx.xx</td>
<td></td>
<td><strong>Symptomdebut:</strong> Vedvarende hoste, og efterhånden også åndenød.</td>
<td>Patienten venter alt for længe med at gå til læge. ”Det med læger og medicin det er ikke lige mig”.</td>
<td>Patient</td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>365 (p)</td>
<td><strong>I. lægekontakt:</strong> Kommer pga. hosten. Egen læge overvejer cancer. Henv. rtg. af thorax: ”Langvarig hoste, ryger, kontrol udbedes”.</td>
<td></td>
<td>Primær sektor</td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>16 (s)</td>
<td><strong>Rtg. af thorax:</strong> Øget fylde i ve. hilus, hvor man ikke kan udelukke malignitetssuspekt proces.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>7 (s)</td>
<td>Egen læge: Svar på rtg af thorax. Henv. til udredning.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>14 (s)</td>
<td>I. besøg på lungemed.dagafsnit</td>
<td></td>
<td>Sekundær sektor</td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>1 (s)</td>
<td>CT thorax: Stor proces i mediastinum omskedende hø. hovedbronchus. Lavattenuerede leverforandringer. Adskillige forstørrede glandler.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>4 (s)</td>
<td>UL lever: Ingen metastasesuspekte forandringer.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>4 (s)</td>
<td><strong>Bronkoskopi:</strong> Stor tumor der okkluderer hø. hovedbronkus, involverer karina og muligvis også øverste mm. af ve. hovedbronkus. Der afstås fra mediastinoskopi, da pt’en er inoperabel. <strong>Biopsier viser panocellulært carcinom.</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>7 (s)</td>
<td>Info om diagnose og behandling. <strong>Henvises til onkologisk afd.</strong> samt til GFR (undersøgelse af nyrefunktionen).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Appendix D

<table>
<thead>
<tr>
<th>x</th>
<th>xx.xx.xx</th>
<th>10 (b)</th>
<th>GFR.</th>
</tr>
</thead>
<tbody>
<tr>
<td>x</td>
<td>xx.xx.xx</td>
<td>7 (b)</td>
<td>1. samtale onkologisk afdeling.</td>
</tr>
<tr>
<td>x</td>
<td>xx.xx.xx</td>
<td>4 (b)</td>
<td><strong>Opstart kemoterapi.</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Delay i dage</th>
<th>I alt</th>
<th>Patient</th>
<th>Læge</th>
<th>System</th>
<th>Behandling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primær sektor</td>
<td>23</td>
<td>0</td>
<td>0</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>Sekundær sektor</td>
<td>51</td>
<td>0</td>
<td>0</td>
<td>30</td>
<td>21</td>
</tr>
<tr>
<td>Sundhedssektoren i alt</td>
<td>439</td>
<td>0</td>
<td>53</td>
<td>21</td>
<td></td>
</tr>
</tbody>
</table>

**Forklaring:**

De tre kolonner længst til venstre:
- **pt:** Oplysninger fra patientinterview
- **jo:** Oplysninger fra hospitalsjournaler
- **el:** Oplysninger fra egen læge

Kolonnen ”antal dage”:
- **(p):** Patientdelay
- **(s):** Systemdelay
- **(b):** Behandlingsdelay
<table>
<thead>
<tr>
<th>Dato</th>
<th>Antal dage</th>
<th>Hændelse</th>
<th>Problem</th>
<th>Ansvarlig sektor</th>
</tr>
</thead>
<tbody>
<tr>
<td>xx.xx.xx</td>
<td></td>
<td><strong>Symptomdebut:</strong> Åndenød og hoste.</td>
<td></td>
<td>Patient</td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>3 (s)</td>
<td><strong>Røntgen af thorax:</strong> Obs. for c. pulm sin. apikalt i ve. overlap med metastase til ve. lungehilus.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>3 (s)</td>
<td>2. lægekontakt: Får svar på rtg. af thorax. Henvises til udredning for lungecancer.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>4 (s)</td>
<td>1. besøg på lungemed.dagafsnit</td>
<td></td>
<td>Sekundær sektor</td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>12 (s)</td>
<td>CT thorax: Tumorproces apikalt i ve. overlap. Ingen patologiske glandler.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>6 (s)</td>
<td>Finnålsaspiration fra ventre lunge: ”Atlektase/retention. Repræsentativt?”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>3 (s)</td>
<td>Bronkomediastinoskopi: Intet malignt.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>6 (s)</td>
<td><strong>Grovnålsbiopsi venstre lunge:</strong> NSCLC -formentlig adenokarcinom.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>4 (s)</td>
<td>Lunekekonference: Bør tilbydes radikal fjernelse af infiltratet. Svar på grovnål mangler dog.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>xx.xx.xx</td>
<td>1 (s)</td>
<td>Info om diagnose og behandling. <strong>Henvises til operation.</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Forklaring:

De tre kolonner længst til venstre:
- **pt**: Oplysninger fra patientinterview
- **jo**: Oplysninger fra hospitalsjournaler
- **el**: Oplysninger fra egen læge

Kolommen ”antal dage”:
- (p): Patientdelay
- (s): Systemdelay
- (b): Behandlingsdelay

---

**Delay** | I alt | Patient | Læge | System | Behandling
---|---|---|---|---|---
Patient | 6 | 6 | | | |
Primær sektor | 6 | 0 | 0 | 6 | |
Sekundær sektor | 44 | 0 | 0 | 36 | 8 |
I alt | 56 | 6 | 0 | 42 | 8 |
Sundhedssektoren i alt | | | | 50 | |

---

**Indlægges.**

**Opereres**
References
References


Holstedahl KA. Diagnosis of Cancer in General Practice. A Study of Delay Problems and Warning Signals of Cancer, with Implications for Public Cancer Information and for Cancer diagnostic Strategies in General Practice. ISM skrifter, Nr. 16 ed. Universitetet i Tromsø, Institutt for Samfunnsmedisin; 1990.


