N. IRELAND Cancer Registry

Monitoring care of Lung cancer patients in Northern Ireland diagnosed 2006 (with comparisons 1996 & 2001)






2006 Lung

Queen's University Belfast

Monitoring care of Lung cancer patients in Northern Ireland diagnosed 2006 (with comparisons 1996 & 2001)

Edited by: **Finian Bannon and Anna Gavin**

This report should be cited as; Bannon F, Gavin A, 2009. Monitoring care of Lung cancer patients in Northern Ireland diagnosed 2006 (with comparisons 1996 & 2001). Available at http://www.qub.ac.uk/research-centres/nicr/Research/CancerServicesAudit/

FOREWORD

This report describes the characteristics of patients with lung cancer and their care in 2006. It also makes comparisons with the care received by patients with these conditions in 1996 and 2001. The report introduces the third phase of a process, supported by local clinicians, where the care of cancer patients and their survival is documented in detail. In building on the information for patients diagnosed in 1996 and 2001, it demonstrates welcome changes in service organisation.

It is very reassuring to have evidence of improved services which reflects excellent, co-operative working of professionals and the investment in services. We are on a journey and there is still considerable room for improvement. This report provides valuable information which is essential in helping us to track our progress and identify those areas where change is still needed. This series of reports highlights the importance of the Cancer Registry as a valuable public health tool which has grown and developed significantly over the last few years and now plays a leading role in monitoring cancer care within Northern Ireland.

Dr Michael McBride
Chief Medical Officer

ACKNOWLEDGEMENTS

This report has been compiled in collaboration with the NI Cancer Network (NICaN) Lung Cancer Group. I am grateful to the clinicians who helped with determining the data items to collect, their interpretation and final presentation.

The N. Ireland Cancer Registry is funded by the Department of Health, Social Services & Public Safety Northern Ireland (DHSSPSNI) and its audit work is facilitated by grants from the Guideline and Audit Implementation Network (GAIN), previously known as the Regional Multiprofessional Audit Group (RMAG).

The quality of data in this project is a result of the work of the Registry Tumour Verification Officers, Rosemary Ward and Kate Donnelly, who meticulously extracted detailed information from clinical records for analysis and presentation in this report. Data abstraction was facilitated by Colin Fox of the Registry's IT group. The analysis of data was undertaken by Dr. Finian Bannon. A special word of gratitude to the Medical Records staff of all the hospitals in Northern Ireland who have facilitated the Registry in this work.

The work of the N. Ireland Cancer Registry including the production of this report is the result of the work of the Registry team. I wish also to record my thanks to the Management Group and Council of the Registry who guide that work.

A Gavin
Director, NICR
2009

NORTHERN IRELAND CANCER NETWORK – REGIONAL LUNG GROUP

The Northern Ireland Cancer Network (NICaN) is a managed clinical network working towards the continuous improvement in cancer care and cancer survival for the people of Northern Ireland. It aims to promote equitable provision of high quality, patient focused and clinically effective cancer services. The way in which this is being achieved is by supporting groups of health professionals, patients and voluntary sector representatives to work together in a co-ordinated way across geographical, organisational and professional boundaries.

For lung cancer, a multiprofessional multidisciplinary group meets regularly to drive forward the agenda of improving the care and outcomes for people with lung cancer. The group's remit includes being the authoritative source of expertise and guidance to planners, commissioners and providers of service, indicating resource requirements, reviewing and agreeing regionally agreed standards of care and an active consideration and support for lung cancer prevention measures.

The Regional Group which first met in June 2005 was chaired by Dr. Richard Shepherd until June 2008, and is now chaired by Dr Jonathan McAleese. The Group has played an active role in the development of the cancer service framework and progressed a number of work areas including workforce reviews, regional patient information pathways, and the creation of a lung cancer support group.

Patients and their carers have been ably represented by Mr and Mrs Colville to whom we owe a debt of gratitude.

The work of the N. Ireland Cancer Registry in producing audit figures such as in this report allow clinicians and NICaN to consider where improvements may be needed.

Network website: http://www.cancerni.net/og/lunggroup

Network contact: Lisa McWilliams, Clincial Network Co-ordinator, phone 028 9056 5860

SECTION I – INTRODUCTION, BACKGROUND & METHODS

Introduction

This Report is the second in a series which examines in detail the pathway of care for cancer patients in Northern Ireland in the years 1996, 2001, and 2006. Lung cancer represents a major cancer and this report assesses change in service provision over a 10 year period.

The Campbell Report[1] resulted from the work of many clinicians, service planners and patients. It made 14 recommendations with the aim of improving cancer services in Northern Ireland (see Appendix A).

Subsequent to the publication of the Campbell Report, a Cancer Working Group produced a sub-group report on lung cancer[2]. This made 18 specific recommendations in relation to lung cancer services in N. Ireland (see Appendix B).

The most recent cancer services audit of lung cancer patients diagnosed in N. Ireland in the years 1996 and 2001[3] noted the following improvements:

- There was evidence of earlier presentation by patients and better management of referrals by primary care.
- Waiting times had improved.
- Recording of MDT discussion had improved substantially but further improvement is necessary in this area.
- Better use of diagnostic tools has resulted in better targeting of treatment.
- Improved communications with patients and primary care was evident.
- Survival for patients having surgery improved significantly reflecting appropriate selection of patients for curative surgery.

Key issues raised at the time were that:

- 95% of patients had a history of tobacco use. Lung cancer is a disease with poor prognosis and prevention through tobacco control is the best option to improve health.
- The high proportion of emergency presentation pose difficulties for improving outcomes.
- The high level of significant co-morbidities (related to historical tobacco use) increase risk in these patients.
- Discussion of patients at multidisciplinary team meetings and the recording of this needs to be improved; this will need additional resources.
- A high proportion of patients require palliative care services.

Overall recommendations of the 1996 & 2001 report are[†]:

- Tobacco control should be a priority - smoke free workplaces in all areas should be introduced as soon as possible.
- Asbestos exposure is a significant risk factor which should be monitored.
- The work of the Northern Ireland Cancer Network (NICaN) in promoting standards for lung cancer investigation and treatment should continue.

[†] The conclusions and recommendations from this report are on pages 62.

In 2005, the NHS/NICE produced clinical guidance[4] on the diagnosis and treatment of lung cancer. Key priorities for implementation were identified as follows:

Access to services

- All patients diagnosed with lung cancer should be offered information, both verbal and written, on all aspects of their diagnosis, treatment and care. This information should be tailored to the individual requirements of the patient, and audio and videotaped formats should also be considered.
- Urgent referral for a chest X-ray should be offered when a patient presents with:
  - haemoptysis, or
  - any of the following unexplained or persistent (that is, lasting more than 3 weeks) symptoms or signs:
    - cough
    - chest/shoulder pain
    - dyspnoea (breathlessness)
    - weight loss
    - chest signs
    - hoarseness
    - finger clubbing
    - features suggestive of metastasis from a lung cancer (for example, in brain, bone, liver or skin)
    - cervical/supraclavicular lymphadenopathy.
- If a chest X-ray or chest computed tomography (CT) scan suggests lung cancer (including pleural effusion and slowly resolving consolidation), patients should be offered an urgent referral to a member of the lung cancer multidisciplinary team (MDT), usually a chest physician.

Staging

- Every cancer network should have a system of rapid access to ^{18}F-deoxyglucose positron emission tomography (FDG-PET) scanning for eligible patients.

Radical radiotherapy alone for treatment of non-small-cell lung cancer

- Patients with Stage I or II non-small-cell lung cancer (NSCLC) who are medically inoperable but suitable for radical radiotherapy should be offered the continuous hyperfractionated accelerated radiotherapy (CHART) regimen. CHART is an intensive regime of radiotherapy, which is given in a shorter period while the patient remains in hospital.

Chemotherapy for non-small-cell lung cancer

- Chemotherapy should be offered to patients with Stage III or IV NSCLC and good performance status (WHO 0, 1 or a Karnofsky score of 80–100) to improve survival, disease control and quality of life.

Palliative interventions and supportive and palliative care

- Non-drug interventions for breathlessness should be delivered by a multidisciplinary group, coordinated by a professional with an interest in breathlessness and expertise in the techniques (for example, a nurse, physiotherapist or occupational therapist). Although this support may be provided in a breathlessness clinic, patients should have access to it in all care settings.

Service organisation

- The care of all patients with a working diagnosis of lung cancer should be discussed at a lung cancer MDT meeting.
- Early diagnosis clinics should be provided where possible for the investigation of patients with suspected lung cancer, because they are associated with faster diagnosis and less patient anxiety.
- All cancer units/centres should have one or more trained lung cancer nurse specialists to see patients before and after diagnosis, to provide continuing support, and to facilitate communication between the secondary care team (including the MDT), the patient's GP, the community team and the patient. Their role includes helping patients to access advice and support whenever they need it.

In 2005, the Scottish Intercollegiate Guidelines Network produced a national clinical guideline[5] for the management of patients with lung cancer.

Among its recommendations were:

- Pathways for patients with suspected or confirmed lung cancer should be reviewed by managed clinical networks with a view to implementing fast track models for assessing these patients.
- Contrast enhanced CT scanning of the chest and abdomen is recommended in all patients with suspected lung cancer, regardless of chest X-ray results.
- Non-small cell lung cancer patients with a negative CT scan result for mediastinal adenopathy should proceed to PET.
- Patients having radical radiotherapy should be given CHART (54Gy/36F/12 days) in preference to 60Gy/30F/6W.
- Selected older patients with Stage III/IV NSCLC should be offered chemotherapy.
- Second line chemotherapy should be considered for resected NSCLC, but discussed fully given the small margin of benefit, risk of toxicity and uncertainty as to which group of patients are most likely to benefit.
- Adjuvant chemotherapy should be considered for resected NSCLC, but discussed fully given the small margin of benefit, risk of toxicity and uncertainty as to which group of patients are most likely to benefit.
- All patients with a diagnosis of lung cancer should have their treatment and management planned and directed by a multidisciplinary team.
- Follow up by clinical nurse specialists should complement conventional arrangements.
- Communication skills training should be provided across the MDT.
- Availability of appropriate information for patients and carers.

Project aim

This Report aims to measure changes to care for patients with lung cancer from 1996 and 2001 and to determine whether they are in keeping with the recommended guidance on investigation and treatment.

Background

In Northern Ireland, from 1993-2006, every year 550 men and 340 women were diagnosed with cancer of the lung, and 498 men and 297 women die annually from this cancer (Fig. 1). Cancer of the lung annually accounts for 12.6% of cancer cases and 26.6% of cancer deaths in men, and 7.6% of cancer cases and 16.8% of cancer deaths in women. Lung cancer is the most common cause of cancer death in men, and since the late 1990s it causes marginally more deaths than breast cancer - thus becoming the most common cause of cancer death in women also.

Figure 1 All patients incidence and mortality of lung cancer in N. Ireland 1993-2006

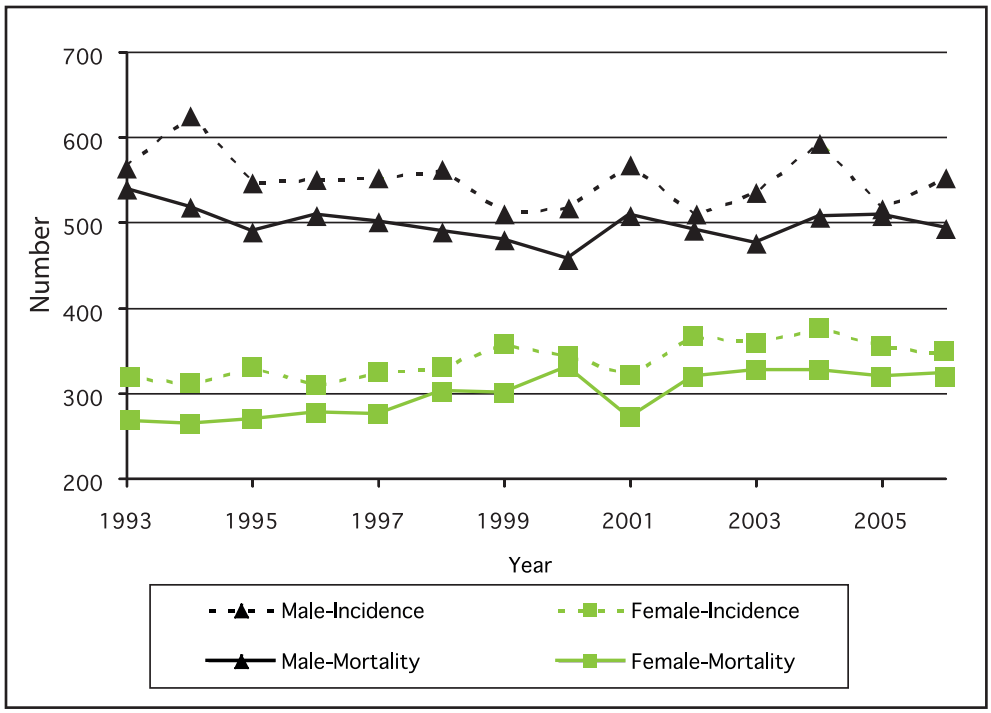
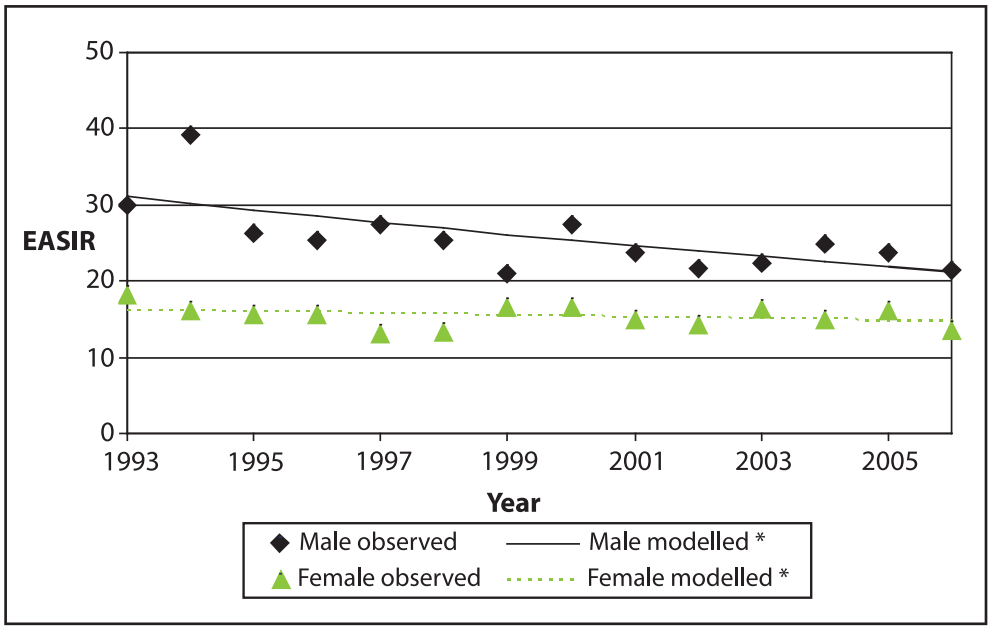


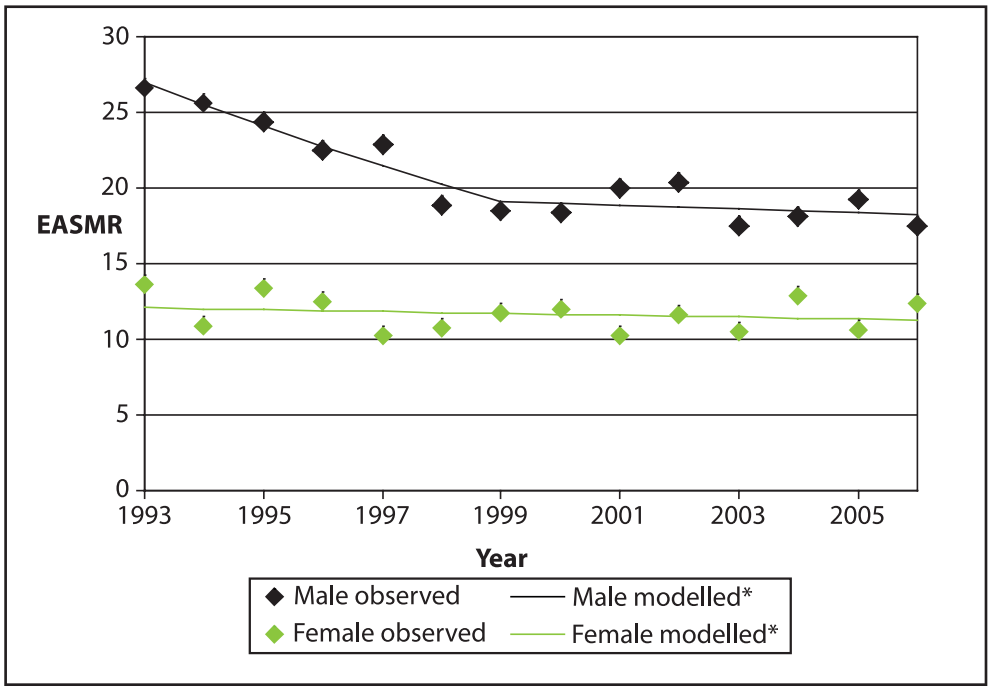
Figure 2 Patients under 65 years: European age-standardised incidence rate (EASIR, per 100,000) lung cancer in Northern Ireland 1993-2006



**the modelled trend line was fitted and tested for significance using Joinpoint[6]*

In men under 65 years of age, there has been a 3% annual decline (P<0.01; Joinpoint[6]) in age-standardised incidence over the period 1993-2006, but not in women (Fig. 2); this suggests that the risk factors for men are decreasing.

Figure 3 Patients under 65 years: European age-standardised mortality rate (EASMR, per 100,000) lung cancer in Northern Ireland 1993-2006



**the modelled trend line was fitted and tested for significance using Joinpoint[6]*

In men under 65 years of age, there was a 5.6% annual decline (P<0.01; Joinpoint[6]) in age-standardised mortality over the period 1993-1999, but then levelling off till 2006; there was no decline evident in women under 65 over the period 1993-2006 (Fig. 3).

The five year relative survival for patients diagnosed with lung cancer in N. Ireland between 1997-2000 was 9.1% for men and 9.2% for women[7].

Risk factors

While, in N. Ireland from 1993-2006, lung cancer is a disease of the older age groups (54% of all cases were over 70 years when diagnosed), it is still a relatively common condition in younger patients, with 1 in 11 patients being under the age of 55 years when diagnosed. Cigarette smoking is causal in more than 90% of cases[8], and although early detection would significantly improve outcome, no evidence exists to show screening can reduce lung cancer mortality[9], however trials are ongoing. An individual who smokes without quitting successfully, has a 20 times increased risk of lung cancer compared to a never smoker[8]. The risk is proportional to the number of cigarettes per day and the number of years smoked. Other factors related causally to lung cancer are exposure to environmental tobacco smoke, asbestos, radon gas and industrial products such as arsenic, zinc, nickel, chromium and polycyclic hydrocarbons[8].

Methods

Data collection

Registry Tumour Verification Officers (TVOs) collected data by reviewing clinical notes of patients already registered with the N. Ireland Cancer Registry as diagnosed with lung cancer (topography codes C33 & C34 ICD10[†,10]; this includes carcinoids but not mesothelioma). For many patients, case notes from different hospitals were reviewed to complete their audit. Data was then entered into an electronic proforma, which had been developed with the guidance of relevant clinicians; a copy is available at www.qub.ac.uk/nicr.

Exclusions & analyses

Patients were excluded if 1) their records lacked sufficient information, 2) information was available only from a death certificate (DCO), and 3) they were diagnosed with a carcinoid. The patients included in the report generally all passed through the hospital health system, therefore the audit report audits the performance of this sector more than any other (e.g. hospice, etc.). After cleaning and validation, data analysis was carried out in STATA[11]. Analysis used to test for statistical significance throughout the report include: Chi-square, logistic regression, and Kaplan-Meier (survival analysis).

[†] ICD10: International Statistical Classification of Diseases and Related Health Problems: Tenth Revision

SECTION II – RESULTS OF LUNG CANCER AUDIT

Study patients

	Number of patients		
	1996	2001	2006
Total number of patients	860	888	895
Exclusions – Carcinoids	3	4	5
Exclusions – Death Certificate Only	13	7	10
Exclusions – Lack of information	139	161	46
Total exclusions	155	172	61
Total Reported on (% of all patients)	705 (82%)	716 (81%)	834 (93%)
Total Reported on – Male (%)	462 (65.5%)	463 (64.7%)	513 (61.5%)
Total Reported on – Female (%)	243 (34.5%)	253 (35.3%)	321 (38.5%)
Average age at diagnosis – Male	70.0	69.6	70.2
Average age at diagnosis – Female	68.2	69.2	69.7

- The Registry identified 860 patients registered with lung cancer in 1996, 888 in 2001, and 895 in 2006.
- Aggregated over all years, there was a greater proportion ($P<0.05$) of women with lung cancer under 50 years of age (5%) than men (3%).

Study patients

- After exclusions (due to lack of information, death certificate only (DCO) cases, carcinoid cases), 705 (82% of total) remained in 1996, 716 (81%) in 2001, and 834 (93%) in 2006. This may be because a greater number of lung cancer patients attended hospital for treatment in 2006.
- Overall, two thirds of the study patients were male with no significant difference between years ($P=0.21$).
- The proportion of study patients who were over 80 years of age increased ($P<0.05$) from 12% in 1996 to 16% in 2006.

Comparison of study patients with all lung cancer patients

	Study patients			All patients		
	1996	2001	2006	1996	2001	2006
Total number of patients	705	716	834	860	888	895
Percentage male	65.5%	64.6%	61.5%	63.9%	63.8%	61.7%
Percentage female	34.5%	35.4%	38.5%	36.1%	36.2%	38.3%
Average age at diagnosis (years)	69.4	69.5	70.0	69.7	70.0	70.1
Percentage of patients dying within one week of diagnosis	6.8%	6.0%	4.6%	10.7%	8.6%	6.0%
Percentage of patients dying between a week and a month after diagnosis	13.6%	16.9%	15.6%	14.1%	15.9%	15.6%
Percentage of patients dying within one month of diagnosis	20.4%	22.9%	20.1%	24.8%	24.4%	21.7%
21-month observed survival*	11.5%	12.7%	17.2%	12.6%	13.5%	17.6%

**Patients whose basis of diagnosis was a death certificate or post mortem were excluded from the observed survival estimation.*

- The proportion of all patients dying within one week of diagnosis decreased steadily from 1996 to 2006 (P<0.01, logistic regression).
- The 21-month observed survival of all lung cancer patients in N. Ireland in 2006 (17.6%) was significantly greater than for combined patients diagnosed in 1996 & 2001[†] (13.0%) (P<0.05, log rank test).
- Among the study patients, 2006 showed a significant (P<0.05) increase in the 21-month observed survival compared with 1996 and 2001 (P<0.05, log rank test).
- The patients excluded from the audit were generally older (P<0.01), with a greater probability of dying in the week after diagnosis (P<0.01).

[†] In this report, the ampersand symbol (&) when joining two years, for instance 1996 & 2001, denotes aggregation of those years' data for comparison with the remaining year, in this instance, 2006

Socio-economic residential area of patients

Deprivation Quintile	Number of patients (%)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
Quintile 1 (Least Deprived)	85 (12%)	92 (13%)	94 (11%)
Quintile 2	102 (14%)	107 (15%)	154 (19%)
Quintile 3	124 (18%)	133 (19%)	152 (18%)
Quintile 4	158 (22%)	160 (22%)	183 (22%)
Quintile 5 (Most Deprived)	236 (34%)	224 (31%)	251 (30%)

- The population of N. Ireland can be divided into five equally sized quintiles ranked by socio-economic deprivation level of area of residence. If a disease is not related to deprivation, it is expected that 20% of all cases of lung cancer would fall in each quintile The greater incidence of lung cancer incidence in socio-economically deprived areas of N. Ireland than expected is significant (P<0.01) and consistent in each year.
- In 2006, for every 1 person diagnosed with lung cancer in the least deprived community there were 2.7 diagnosed in the most deprived population quintile in N. Ireland.
- If the lung cancer rates in 2006 in the most deprived areas were reduced to the rates in the most affluent areas, then 360 fewer people would be diagnosed annually with this disease in N. Ireland.

Referral and presentation

Source of referral to specialist care

Source	Number of patients (%)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
GP (General Practitioner)	530 (75%)	549 (77%)	668 (80%)
Physician	50 (7%)	54 (8%)	52 (6%)
General Surgeon	5 (<1%)	11 (1%)	6 (<1%)
Radiology	3 (<1%)	2 (<1%)	14 (2%)
Not recorded	61 (9%)	6 (<1%)	21 (2%)
Other*	56 (8%)	94 (13%)	73 (9%)

**Includes self referrals, referrals from nursing homes, referrals from other consultants, and patients under review for other disease.*

- There was a significant increase (P<0.05) in the proportion of patients who were referred by their GP from 1996 (75%) to 2006 (80%); over the three years, 77% of lung cancer patients came from GP referrals, of which about 47% were emergency admissions.
- In 2006, 2% of patient referrals came from radiology; an increase from 1% in 1996 & 2001.

Mode of presentation

Mode of presentation	Number of patients (%)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
Outpatient	324 (46%)	314 (44%)	313 (38%)
Medical emergency admission	237 (34%)	305 (43%)	405 (49%)
Surgical emergency admission	18 (3%)	19 (3%)	15 (2%)
Consultant Referral*	38 (5%)	61 (8%)	61 (7%)
Other**	29 (4%)	11 (1%)	19 (2%)
Not recorded	59 (8%)	6 (<1%)	21 (2%)

** A 'consultant referral' is a referral between consultants, where the initial consultant visit was not related to this cancer. ** 'Other' includes patients who presented as domiciliary visits or private patients.*

- Over the three audit years, there has been an increase in the percentage of patients recorded with an emergency presentation from 34% in 1996 to 49% in 2006 (P<0.01).

Risk factors

Risk factor	Percentage of patients recorded (% not recorded)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
History of tobacco use	84% (10%)	93% (3%)	92% (1%)
Exposure to asbestos	25% (42%)	13% (52%)	14% (60%)
Asbestosis	2% (16%)	<1% (<1%)	2% (<1%)

- In 2006, 92.4% of lung cancer patients had a history of tobacco use, 6.3% of patients had never smoked (3% of males and 12% of females), and 1.2% had no record of smoking history.
- Overall, 56% of patients were current smokers.
- Recording of smoking status improved between 1996 and 2006, so that by 2006 less than 1% of patients did not have their smoking status recorded in their notes.
- One quarter of patients in 1996 had a record of asbestos exposure; this had fallen to 14% by 2006. Note this may reflect a real change or a change in recording of this information.
- Overall, 1.5% of patients were recorded as having asbestosis.
- In 2006, 3 out of the 35 never-smokers (8.6% or almost 1 in 12) with a recorded occupation had worked in high second-hand smoke exposure environment (bars, etc). An additional 17 smokers (3.2%) out of 540 with occupation recorded had a record of working in a similar environment.

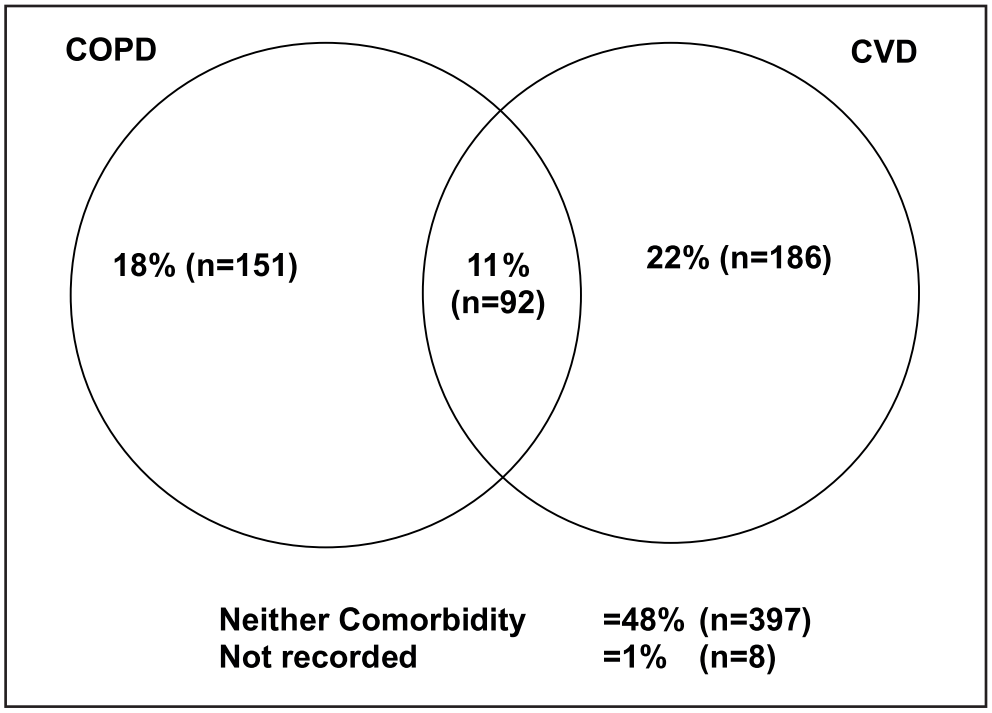
Comorbidities (NOTE: Patients may have had more than one comorbidity)

Comorbity	Percentage of patients recorded (% not recorded)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
Cardiovascular disease	31% (6%)	34% (<1%)	34% (<1%)
COPD*	30% (10%)	29% (<1%)	29% (<1%)
Hypertension	16% (7%)	17% (<1%)	31% (<1%)
Other Malignancy	9% (8%)	6% (<1%)	11% (<1%)
Cerebrovascular disease	7% (6%)	7% (<1%)	8% (<1%)
Diabetes	7% (5%)	9% (<1%)	10% (1%)

**Chronic Obstructive Pulmonary Disease*

- Recording of comorbidity improved in 2001 and 2006.
- Apart from hypertension and 'other malignancy', the rates of comorbidities were similar in all years.
- One third of patients with lung cancer had a history of cardiovascular disease.
- COPD was present in 29% of patients.
- About one patient in twelve had a personal history of another malignancy. Among the malignancies of these patients (n=188/2255) were skin (16%), bladder (14%), prostate (12%), breast (11%), colorectal (5%), larynx (4%), and cervix (4%).

Percentages (numbers) of patients in 2006 (n=834) with chronic obstructive pulmonary disease (COPD) and cardiovascular disease (CVD).



Symptoms/signs at presentation (NOTE: Patients may present with more than one symptom)

Symptom/sign	Percentage of patients having the symptom recorded		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
Cough	65%	60%	64%
Breathlessness	53%	50%	51%
Weight-loss*	36%	37%	42%
Haemoptysis (coughing blood)	25%	22%	24%
Pain**	34%	28%	22%
Lethargy**	25%	19%	18%
Acute respiratory infection**	23%	16%	15%
Incidental/asymptomatic	11%	10%	15%
Pain on breathing*	10%	14%	14%
Altered neurological status	7%	8%	9%
Hoarseness	9%	7%	9%
Dysphagia (difficulty swallowing)	4%	4%	4%
Unresolved pneumonia**	10%	3%	4%
Finger clubbing	2%	5%	3%
SVC Obstruction***	3%	<1%	2%

**Significant (P<0.05) increase between 1996-2006, ** significant (P<0.05) decrease between 1996-2006. ***Superior Vena Caval Obstruction – a rare complication of lung cancer.*

- Symptoms recorded were remarkably consistent in each year, however presentations with pain, lethargy, acute respiratory infection, and unresolved pneumonia symptoms were reduced (P<0.01) with time, while weight loss and pain on breathing symptoms increased (P<0.05).
- Cough was the most common presenting symptom, occurring in 63% of patients.
- Half of patients presented with breathlessness.
- On average, over a third of patients experienced weight loss.
- For those patients who were asymptomatic or had lung cancer picked up as an incidental finding (12% of all patients) more than 85% were first suspected of having lung cancer through radiology; in 2006, 36% were first suspected on the basis of a CT scan.
- Over a fifth of patients had haemoptysis, but fewer of them in 2001 (3%) and 2006 (1%) had the symptom for longer than 6 months compared with 1996 (11%) (see next table).

Patients who have a record of experiencing a symptom/sign for 6 months or more

(NOTE: Patients may present with more than one symptom)

Symptom/sign	Number of patients (% of all patients with that symptom)		
	1996	2001	2006
Cough*	62 (13%)	58 (14%)	106 (20%)
Weight-loss	62 (25%)	51 (19%)	91 (26%)
Breathlessness	55 (15%)	50 (14%)	72 (17%)
Lethargy	29 (17%)	14 (10%)	18 (12%)
Pain**	22 (9%)	8 (4%)	9 (5%)
Hoarseness	7 (11%)	5 (10%)	6 (8%)
Acute respiratory infection	1 (<1%)	6 (5%)	4 (3%)
Pain on breathing	4 (6%)	2 (2%)	3 (3%)
Unresolved pneumonia	10 (14%)	0	3 (8%)
Dysphagia (difficulty swallowing)	3 (10%)	1 (4%)	3 (9%)
Haemoptysis (coughing blood)**	19 (11%)	4 (3%)	2 (1%)
Altered neurological status	4 (8%)	1 (2%)	0

**Significant (P<0.05) increase between 1996-2006, ** significant (P<0.05) decrease between 1996-2006.*

- In 2001 & 2006, the recording of symptom duration had increased to 75% from 63% in 1996.
- Overall, 23.2% of patients had a recorded symptom that lasted greater than 6 months.
- From 1996 to 2006, the proportion of patients that had a record of pain, or haemoptysis for more than 6 months prior to presentation declined (P<0.05), possibly reflecting increased awareness of these alert or warning symptoms.
- In 2006, a higher proportion of patients had cough for more than 6 months compared with 2001 and 1996 (P<0.01). It is likely that this relates to the older patient profile in the 2006 audit, or better recording of symptom duration.
- Patients greater than 80 years of age and from rural areas were less likely (estimated probability of 11%) to have a record of a symptom for lung cancer for more than 6 months in comparison to rural patients less than 80 years of age (23%), whereas urban patients, irrespective of age grouping, had a probability of 24% of having a symptom for greater than 6 months. Year of audit, sex, socio-economic status, or current smoking status, of the patient did not influence the probability of having a symptom recorded for greater than 6 months.

Patients who have a record of experiencing a symptom/sign for 12 months or more

(NOTE: Patients may present with more than one symptom)

Symptom/sign	Number of patients (% of patients with that symptom)		
	1996	2001	2006
Cough*	29 (6%)	41 (10%)	73 (14%)
Breathlessness	35 (9%)	35 (10%)	51 (12%)
Weight-loss	32 (13%)	31 (12%)	39 (11%)
Pain	6 (3%)	2 (<1%)	7 (4%)
Lethargy	8 (5%)	4 (3%)	5 (3%)
Acute respiratory infection	0	1 (<1%)	3 (2%)
Hoarseness	3 (5%)	3 (6%)	3 (4%)
Pain on breathing	0	0	2 (2%)
Haemoptysis (coughing blood)**	7 (4%)	2 (1%)	1 (<1%)
Dysphagia (difficulty swallowing)	2 (6%)	1 (4%)	1 (3%)
Unresolved pneumonia	4 (6%)	0	1 (3%)
Altered neurological status	2 (4%)	0	0

**Significant (P<0.05) increase between 1996-2006, ** significant (P<0.05) decrease between 1996-2006.*

- Overall, 15% of patients had a recorded symptom that lasted greater than 12 months.
- The proportion of patients who had cough for more than 12 months prior to presentation increased from 1996 to 2006 (P<0.01).
- The proportion of patients who had haemoptysis for more than 12 months prior to presentation declined from 1996 to 2006 (P<0.05).
- None of the following patients' factors significantly affected the proportion of patients that experienced a symptom for more than 12 months: year of audit, sex, affluence of place of residence, current smoking status, urban/rural area of residence, age under or over 80 years.

Hospital of presentation

Hospital	Number of patients (% of total)		
	1996 (n=705)	2001 (n=715)	2006 (n=834)
Belfast City Hospital* (BCH)	157 (22%)	127 (18%)	119 (14%)
Royal Victoria Hospital* (RVH)	82 (12%)	54 (8%)	80 (10%)
Mater Infirmorum Hospital (MIH)	46 (7%)	49 (7%)	63 (8%)
Musgrave Park Hospital (MPH)	3 (<1%)	5 (<1%)	1 (<1%)
Belvoir Park Hospital**** (BPR)	2 (<1%)	0	0
TOTAL BELFAST TRUST	**290 (41%)**	**235 (33%)**	**263 (32%)**
The Ulster Hospital** (UH)	61 (9%)	77 (11%)	116 (14%)
Lagan Valley Hospital (LVH)	16 (2%)	27 (4%)	26 (3%)
Downe Hospital (DH)	24 (3%)	20 (3%)	24 (3%)
Ards Hospital*** (AR)	13 (2%)	1 (<1%)	0
TOTAL SOUTH-EASTERN TRUST	**114 (16%)**	**125 (17%)**	**166 (20%)**
TOTAL EHSSB	**404 (57%)**	**360 (50%)**	**429 (51%)**
Antrim Hospital** (ANT)	51 (7%)	62 (9%)	69 (8%)
Causeway (Coleraine) Hospital (COL)	26 (4%)	32 (4%)	43 (5%)
Whiteabbey Hospital (WHA)	26 (4%)	24 (3%)	22 (3%)
Mid-Ulster Hospital (MUH)	11 (2%)	12 (2%)	9 (1%)
Braid Valley Hospital (BVH)	3 (<1%)	0	0
Dalriada Hospital (DAL)	0	1 (<1%)	0
Moyle Hospital (MLE)	1 (<1%)	2 (<1%)	0
Waveney Hospital (WAV)	1 (<1%)	0	0
TOTAL NHSSB/NORTHERN TRUST	**119 (17%)**	**133 (19%)**	**143 (17%)**
Craigavon Area Hospital** (CAH)	31 (4%)	50 (7%)	65 (8%)
Daisy Hill Hospital (DHH)	20 (3%)	37 (5%)	47 (6%)
South Tyrone Hospital (STH)	28 (4%)	12 (2%)	7 (<1%)
Armagh Community Hospital (ACH)	2 (<1%)	0	1 (<1%)
Banbridge Hospital (BBH)	3 (<1%)	0	0
Lurgan Hospital (LGH)	0	1 (<1%)	0
Mullinure (MULL)	1 (<1%)	0	0
TOTAL SHSSB/SOUTHERN TRUST	**85 (12%)**	**100 (14%)**	**120 (14%)**
Altnagelvin Hospital** (AH)	65 (9%)	82 (11%)	91 (11%)
Erne Hospital (ERN)	13 (2%)	21 (3%)	30 (4%)
Tyrone County Hospital (TCH)	12 (2%)	16 (2%)	14 (2%)
Roe Valley (RV)	0	1 (<1%)	0
TOTAL WHSSB/WESTERN TRUST	**90 (13%)**	**120 (17%)**	**135 (16%)**
Ulster Independent Clinic (UIC)	4 (<1%)	0	3 (<1%)
North-West Independent Clinic (NWC)	1 (<1%)	0	0
TOTAL PRIVATE HOSPITALS	**5 (<1%)**	**0**	**3 (<1%)**
Not recorded	**2 (<1%)**	**2 (<1%)**	**4 (<1%)**

** RVH/BCH work collaboratively as the Cancer Centre for lung cancer in 2006 ** Cancer Unit *** Changed to community health facility with no in-patient facilities by 2001****BPR provided the regional radiotherapy/oncology service until 17/3/2006 when the role was taken over by the BCH Cancer Centre.*

- In 1996, 705 patients presented to 27 hospitals; in 2001, 715 patients presented to 22 hospitals, and in 2006, 834 patients presented to 19 hospitals.
- Around 64% of patients presented to a Cancer Unit or the Cancer Centre in Belfast irrespective of the year of audit.
- From 1996 to 2001 & 2006, there was a significant (P<0.01) decline in the proportion of patients presenting in the EHSSB from 57% to 51%, respectively.

Patients recorded as presenting within their own Board of residence

Board of residence	Number of patients (% of patients resident in that board)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
NHSSB	114 (68%)	133 (77%)	140 (81%)
EHSSB	342 (97%)	309 (98%)	396 (99%)
SHSSB	78 (78%)	94 (85%)	118 (93%)
WHSSB	81 (94%)	117 (98%)	131 (97%)

- In 2006, overall 94% of patients in the Northern Ireland presented in their own Health Board, an increase (P<0.01) from 87% in 1996; however, in the Northern Board in 2006 only 81% of patients presented there, and 17% of its patients presented in the Eastern Board.
- In 2006, patients for the SHSSB and NHSSB were more likely (P<0.05) to present within their own Health Board of residence than they were in 1996.

Hospitals ever attended (Note: patients may be counted more than once)

Hospital ever attended	Number of patients (% of all patients)		
	1996 (n=705)	2001 (n=715)	2006 (n=834)
Belfast City Hospital* (BCH)	272 (39%)	256 (36%)	548 (66%)
Belvoir Park Hospital** (BPR)	337 (48%)	421 (59%)	3 (<1%)
Royal Victoria Hospital* (RVH)	184 (26%)	149 (21%)	307 (37%)
Mater Infirmorum Hospital (MIH)	46 (7%)	50 (7%)	63 (8%)
Musgrave Park Hospital (MPH)	6 (<1%)	6 (<1%)	1 (<1%)
TOTAL BELFAST TRUST	**536 (76%)**	**561 (78%)**	**652 (78%)**
The Ulster Hospital*** (UH)	75 (11%)	79 (11%)	117 (14%)
Lagan Valley Hospital (LVH)	16 (2%)	38 (5%)	45 (5%)
Downe Hospital (DH)	24 (3%)	20 (3%)	26 (3%)
Ards Hospital**** (AR)	17 (2%)	1 (<1%)	0
TOTAL SOUTH-EASTERN TRUST	**118 (17%)**	**130 (18%)**	**170 (20%)**
TOTAL EHSSB	**574 (81%)**	**591 (83%)**	**697 (84%)**
Antrim Hospital*** (ANT)	56 (8%)	79 (11%)	96 (12%)
Causeway (Coleraine) Hospital (COL)	26 (4%)	32 (4%)	43 (5%)
Whiteabbey Hospital (WHA)	27 (4%)	26 (4%)	25 (3%)
Mid-Ulster Hospital (MUH)	11 (2%)	12 (2%)	10 (1%)
Braid Valley Hospital (BVH)	4 (<1%)	0	0
Dalriada Hospital (DAL)	0	1 (<1%)	0
Moyle Hospital (MLE)	1 (<1%)	2 (<1%)	0
Waveney Hospital (WAV)	1 (<1%)	0	0
TOTAL NHSSB/NORTHERN TRUST	**122 (17%)**	**135 (19%)**	**147 (18%)**
Craigavon Area Hospital*** (CAH)	54 (8%)	66 (9%)	80 (10%)
Daisy Hill Hospital (DHH)	20 (3%)	37 (5%)	47 (6%)
South Tyrone Hospital (STH)	39 (6%)	13 (2%)	7 (<1%)
Armagh Community Hospital (ACH)	3 (<1%)	0	1 (<1%)
Banbridge Hospital (BBH)	3 (<1%)	0	0
Lurgan Hospital (LGH)	0	1 (<1%)	0
Mullinure (MULL)	1 (<1%)	0	0
TOTAL SHSSB/SOUTHERN TRUST	**86 (12%)**	**100 (14%)**	**122 (15%)**
Altnagelvin Hospital*** (AH)	131 (19%)	113 (16%)	105 (13%)
Erne Hospital (ERN)	13 (2%)	21 (3%)	31 (4%)
Tyrone County Hospital (TCH)	13 (2%)	16 (2%)	18 (2%)
Roe Valley (RV)	0	4 (<1%)	0
TOTAL WHSSB/WESTERN TRUST	**146 (21%)**	**143 (20%)**	**138 (17%)**
Ulster Independent Clinic (UIC)	5 (<1%)	0	4 (<1%)
North-West Independent Clinic (NWC)	1 (<1%)	0	0
TOTAL PRIVATE HOSPITALS	**6 (<1%)**	**0**	**4 (<1%)**

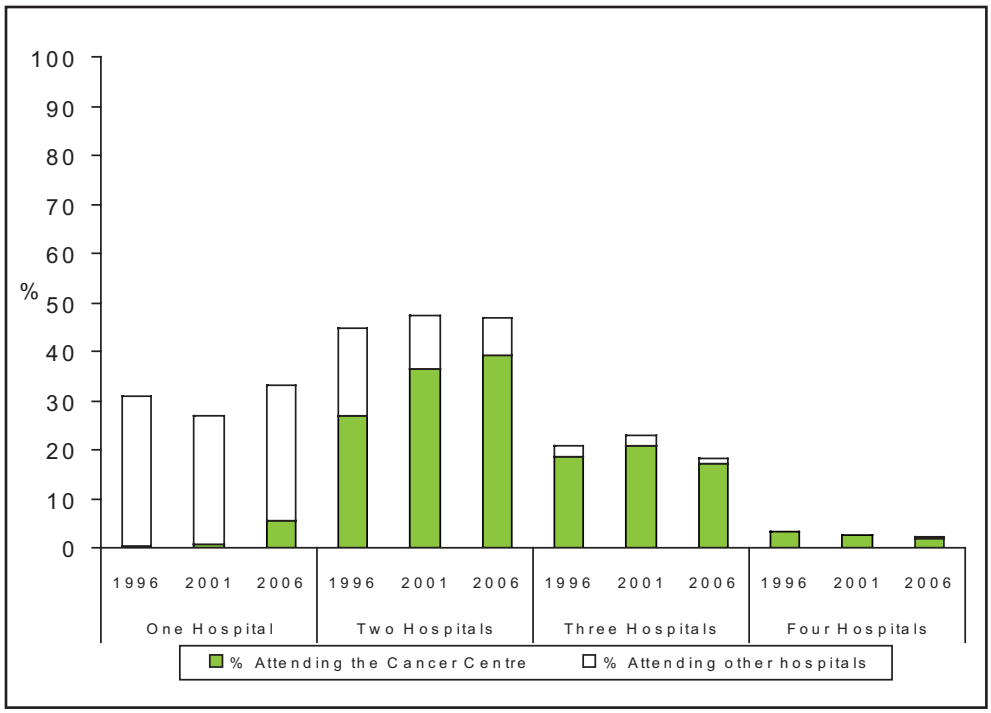
** RVH/BCH work collaboratively as the Cancer Centre for lung cancer in 2006; surgery patients were assigned to hospital where surgeon was based, generally the RVH, but sometimes these operations actually took place in BCH **BPR provided the regional radiotherapy/oncology service until 17/3/2006 when the role was taken over by the BCH Cancer Centre. ***Cancer Unit **** Changed to community health facility with no in-patient facilities by 2001.*

- In 2006, 88% of lung cancer patients had attended a hospital in the EHSSB and 66% had attended the Belfast City Hospital site.

Hospitals attended

- In 2006, 33% of patients attended one hospital, 47% two hospitals, 18% three hospitals and 2% attended four hospitals for their investigations/treatment; this pattern was broadly similar in 1996 and 2001.
- For 2001 & 2006, 62% of patients attended the Cancer Centre which was a significantly greater (P<0.01) proportion than in 1996 (49%). (Note: In 2006, patients considered to have attended the Cancer Centre were those patients who attended Belvoir Park Hospital or who received surgery, chemotherapy, radiotherapy in either Belfast City Hospital or the Royal Victoria Hospital; for 1996 and 2001, only patients who attended Belvoir Park Hospital were considered to have attended the Cancer Centre).

Percentage of patients attending one, two, three or four hospitals



- One patient in 2001 attended a fifth hospital, which was the Royal Victoria Hospital.
- 67% of patients in 2006 attended more than one hospital for their investigation and treatments; this underlines the need for good communication.

The Health and Social Care Trusts to which patients diagnosed in 2006 were transferred after their Trust of presentation*

Source	Number of patients diagnosed in 2006 (% of patients who transferred from Trust of presentation)				
Trust of presentation	Trust of the second hospital				
	Belfast	Northern	South Eastern	Southern	Western
Belfast	135 (94%)	3 (2%)	4 (3%)	2 (1%)	0
Northern	84 (76%)	25 (23%)	0	0	1 (<1%)
South Eastern	110 (90%)	0	12 (10%)	0	0
Southern	67 (87%)	0	0	9 (12%)	1 (1%)
Western	84 (86%)	0	0	0	14 (14%)
Total	480 (87%)	28 (5%)	16 (3%)	11 (2%)	16 (3%)
Trust of presentation	Trust of the third hospital				
	Belfast	Northern	South Eastern	Southern	Western
Belfast	20 (91%)	1 (5%)	0	0	1 (5%)
Northern	36 (95%)	2 (5%)	0	0	0
South Eastern	38 (86%)	0	6 (14%)	0	0
Southern	25 (86%)	0	0	4 (14%)	0
Western	32 (94%)	0	0	0	2 (6%)
Total	151 (90%)	3 (2%)	6 (4%)	4 (2%)	3 (2%)
Trust of presentation	Trust of the fourth hospital				
	Belfast	Northern	South Eastern	Southern	Western
Belfast	0	–	–	–	–
Northern	1 (100%)	–	–	–	–
South Eastern	10 (100%)	–	–	–	–
Southern	2 (100%)	–	–	–	–
Western	4 (100%)	–	–	–	–
Total	17 (100%)	–	–	–	–

**The patient pathway above is derived by listing all the hospitals that a patient is known to have attended through hospitals of presentation, investigations and treatment, and ranking them according to the earliest known date of attendance. If the date of a hospital is unknown (1.5% of cases) then it is assumed they were the last hospital attended. This definition, therefore, doesn't take account of patients who, for instance, may return to their local or hospital of presentation between their 2nd and 3rd transfer above.*

- 87% of patients who attended a second hospital did so in the Belfast Trust, for the third and fourth hospital this rose to 90% and 100%, respectively. Patients that didn't transfer to Belfast generally attended a further hospital in their Trust of presentation.

Specialty of consultant for first referral (or allocated if not referred e.g. emergency)

Source	Number of patients (% of Total)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
Respiratory medicine	262 (37%)	365 (51%)	452 (54%)
Thoracic surgery	26 (4%)	15 (2%)	5 (<1%)
General medicine	233 (33%)	163 (23%)	257 (31%)
Geriatric medicine	56 (8%)	67 (9%)	27 (3%)
Cardiology	23 (3%)	22 (3%)	11 (1%)
ENT*	13 (2%)	5 (<1%)	4 (<1%)
Endocrinology	7 (<1%)	4 (<1%)	0
Other	58 (8%)	71 (10%)	57 (7%)
Not recorded	27 (4%)	4 (<1%)	21 (3%)

** Ear, nose and throat*

- By 2001 & 2006, over half of patients were referred directly to a respiratory specialist, an improvement from 1996.

ECOG status

Eastern Cooperative Oncology Group (ECOG) (USA) performance status[12] is used by doctors to assess how disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis.

Grade ECOG

Grade	ECOG
0	Fully active, able to carry out all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry out any selfcare. Totally confined to bed or chair

ECOG recorded	Number of patients (%)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
Yes	28 (4%)	169 (24%)	437 (52%)
No	677 (96%)	547 (76%)	397 (48%)

- By 2006, over half of the patients had an ECOG performance status recorded in their clinical notes an improvement from 4% in 1996.

ECOG Status	Number of patients (% of total)		
	1996 (n=28)	2001 (n=169)	2006 (n=437)
0 (Fully active)	4 (14%)	42 (25%)	76 (17%)
1	10 (36%)	44 (26%)	141 (32%)
2	9 (32%)	44 (26%)	117 (27%)
3	5 (18%)	36 (21%)	82 (19%)
4 (Completely disabled)	0	3 (2%)	21 (5%)

- Of those with an ECOG status recorded, on average only 19% of lung cancer patients were considered fully active.

When ECOG was first recorded*	Number of patients (%)		
	1996 (n=28)	2001 (n=169)	2006 (n=437)
Initial Assessment	2 (7%)	39 (23%)	232 (53%)
Preoperative	1 (4%)	9 (5%)	14 (3%)
Postoperative	1 (4%)	1 (<1%)	1 (<1%)
Pre-chemotherapy	2 (7%)	49 (29%)	95 (22%)
Post-chemotherapy	1 (4%)	0	0
Pre-radiotherapy	18 (64%)	68 (40%)	94 (21%)
No time recorded	3 (10%)	3 (2%)	1 (<1%)

** Generally for this audit, ECOG status was recorded only once at the earliest time in the pathway that it was recorded.*

- In 2006, there was a large increase in the recording of ECOG status of patients at initial assessment. The number of patients assessed both for pre-chemotherapy and pre-radiotherapy increased in 2006, though their percentage share of those assessed declined due to the large increase in patients receiving an initial assessment.

Investigations

Investigations recorded in notes (NOTE: Patients may have had more than one type of investigation)

Investigation	Number of patients (%)		
All Patients	1996 (n=705)	2001 (n=716)	2006 (n=834)
Chest X-ray	669 (94%)	685 (95%)	763 (91%)
CT scan	498 (70%)	638 (89%)	787 (94%)
Bronchoscopy	477 (67%)	528 (73%)	574 (68%)
PET scan	-	-	238 (28%)
Mediastinoscopy	13 (1%)	41 (5%)	29 (3%)
Surgery patients	1996 (n=110)	2001 (n=89)	2006 (n=104)
Chest X-ray	108 (98%)	86 (96%)	95 (91%)
CT scan	104 (94%)	88 (98%)	100 (96%)
Bronchoscopy	102 (92%)	82 (92%)	84 (80%)
PET scan	-	-	97 (93%)
Mediastinoscopy	3 (2%)	20 (22%)	19 (18%)

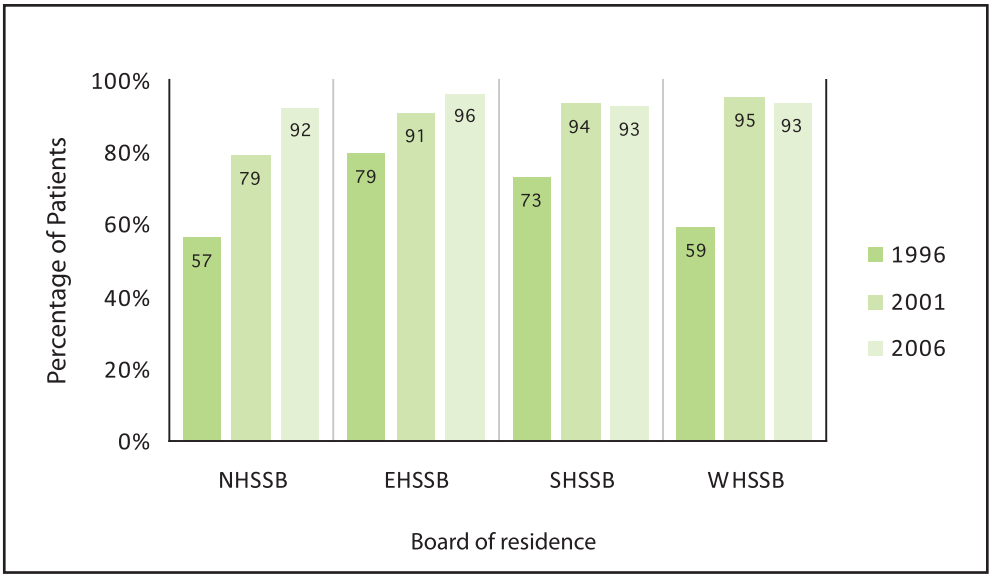
- In 2006, 94% of patients had a CT scan, and 68% had bronchoscopy.
- 28% of all patients had a PET scan in 2006. The NICE 2005 guidelines[4] recommend that "every cancer network should have a system of rapid access to ^{18}F-deoxyglucose positron emission tomography (FDG-PET) scanning for eligible patients."
- In 2006, 33% of patients had their bronchoscopy performed in Belfast City Hospital, 12% in Altnagelvin Hospital, 12% in the Ulster Hospital, 10% in Antrim Hospital, 9% in Craigavon Area Hospital, and 6% in the Royal Victoria Hospital (not shown).
- By 2001 & 2006, a smaller proportion of patients had their bronchoscopy performed in the Royal Victoria (11% in 1996, 6% in 2001 & 2006) and South Tyrone hospitals (5% in 1996, 0 in 2001 & 2006), whilst an increase was noted in the proportion of bronchoscopies at Antrim (<1% in 1996, 11% in 2001 & 2006) and Craigavon hospitals (<1% in 1996, 9% in 2001 & 2006) (not shown). This represents service reorganisation.
- In 2006, patients who had surgery were more likely to have CT scans (96%), bronchoscopies (80%), and PET scans (93%).

Timing of first CT scan and first Bronchoscopy

Investigation combination	Number of patients (%)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
CT scan before bronchoscopy	126 (18%)	228 (32%)	365 (44%)
Bronchoscopy before CT scan	159 (23%)	205 (29%)	122 (15%)
No CT scan/bronchoscopy combination	329 (47%)	229 (32%)	270 (32%)
CT scan or bronchoscopy timing unrecorded	91 (13%)	54 (8%)	77 (9%)

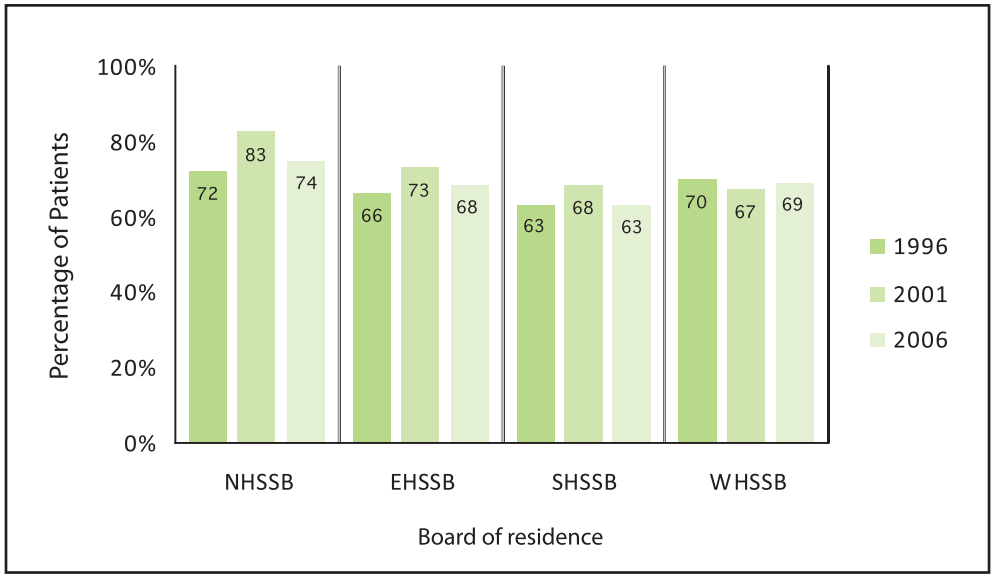
- Of those patients who received a bronchoscopy (n=574), 64% (365/574) were recorded as having had their CT scan first.

Percentage of patients having a CT scan by Board of residence



- By 2001 & 2006, the use of CT scanning had increased substantially in all Health Boards.
- In 2001, the proportion of patients in the Northern Board having CT scans was significantly lower (79%) than the other Boards (92%) (P<0.01), but this gap had closed in 2006.

Percentage of patients having a bronchoscopy by Board of Residence



- In 2006, the numbers of patients having a bronchoscopy increased in all Boards except the Northern Board. However, the proportion of patients receiving a bronchoscopy in 2006 has declined from 2001 in all Boards, except the Western Board, most possibly due to the greater number of elderly patients included in the 2006 audit data.
- Taking all years combined, the proportion of patients in the Northern Board having bronchoscopy (76%) was significantly higher than the other Boards (68%) (P<0.01).
- In 2006, the NHSSB had the highest percentage of their patients having a bronchoscopy (74%), whereas the SHSSB had the lowest (63%).

Age classification of patients who had a bronchoscopy

Age groups at diagnosis	Number of patients (% of all patients in that age group)		
	1996 (n=477)	2001 (n=528)	2006 (n=574)
0-54	43 (75%)	53 (79%)	53 (77%)
55-64	117 (79%)	122 (81%)	151 (80%)
65-74	218 (70%)	212 (75%)	205 (69%)
75+	99 (51%)	141 (63%)	165 (58%)

- The proportion of those aged 75 and over who had bronchoscopy was lower than for younger age groups – this most likely reflects the clinical status of patients.
- In 2006, there has been a reduction in the proportion of patients over 65 years of age that have had a bronchoscopy; this may partly reflect the greater age of patients in the 2006 audit.

Investigations by age (Note: Patients may have had more than one investigation)

Audit year	Number of patients (% of patients in that age group)				
	Aged less than 65 years				
	Chest X-ray	CT scan	Bronchoscopy	Mediastinoscopy	PET scan
1996 (n=205)	193 (94%)	157 (77%)	160 (78%)	6 (3%)	–*
2001 (n=216)	207 (96%)	205 (95%)	175 (81%)	20 (9%)	–
2006 (n=256)	234 (91%)	246 (96%)	204 (80%)	16 (6%)	89 (35%)
	Between 65 and 80 years				
	Chest X-ray	CT scan	Bronchoscopy	Mediastinoscopy	PET scan
1996 (n=413)	391 (95%)	296 (72%)	284 (69%)	7 (2%)	–
2001 (n=403)	384 (95%)	357 (89%)	309 (77%)	21 (5%)	–
2006 (n=444)	406 (91%)	420 (95%)	302 (68%)	13 (3%)	133 (30%)
	80 years and older				
	Chest X-ray	CT scan	Bronchoscopy	Mediastinoscopy	PET scan
1996 (n=87)	85 (98%)	45 (52%)	33 (38%)	0	–
2001 (n=97)	94 (97%)	76 (78%)	44 (45%)	0	–
2006 (n=134)	123 (92%)	121 (90%)	68 (51%)	0	16 (12%)

**PET scans were not available in N. Ireland in 1996 and 2001*

- By 2006, CT scanning increased in all age groups from previous years (P<0.01); chest x-rays declined in all age groups, perhaps some were substituted by a CT scan.
- Patients 80 years and over were as likely as younger patients to have a chest X-ray, but were less likely to have a bronchoscopy (P<0.01) or a CT scan (P<0.01); this may have been for clinical reasons.
- No patient aged 80 years or over had a mediastinoscopy.
- There has been a steady increase since 1996 in the proportion of patients 80 year old and over receiving a CT scan (P<0.01).
- In 2006, 32% of patients less than 80 years of age had a PET scan compared to 12% for patients 80 years and over.

Patients having an investigation within their own Board of residence
(Note: see pages 29 and 30 for investigations by Board of residence)

Board of residence	Number of patients (% of all patients that received the investigation within that Board)					
	Bronchoscopy			CT Scan		
	1996	2001	2006	1996	2001	2006
NHSSB	34 (28%)	106 (74%)	102 (79%)	20 (21%)	92 (67%)	129 (81%)
EHSSB	229 (98%)	229 (99%)	271 (99%)	258 (92%)	273 (95%)	371 (96%)
SHSSB	28 (44%)	49 (65%)	74 (92%)	44 (60%)	87 (84%)	107 (90%)
WHSSB	53 (88%)	79 (98%)	88 (94%)	40 (78%)	100 (88%)	117 (92%)

- By 2006, a majority of patients had their bronchoscopy or CT scan carried out within their Board of residence.
- In 2006, 17% of NHSSB lung cancer patients had a bronchoscopy in the Eastern Board; it was only 5% and 3% for the Southern and Western Board respectively.

Respiratory physician assessment

Patients assessed by respiratory physician	Number of patients assessed (% of total)		
All patients			
	1996 (n=705)	2001 (n=716)	2006 (n=834)
Assessed by respiratory physician	496 (67%)	610 (85%)	732 (88%)
Surgery patients			
	1996 (n=110)	2001 (n=89)	2006 (n=104)
Assessed by respiratory physician	82 (75%)	84 (94%)	99 (95%)

- By 2001 and 2006, significantly more patients were recorded as being assessed by a respiratory physician ($P<0.001$); this was observed in each Health Board (not shown).
- In 2001 and 2006, the percentage of surgery patients being assessed by a respiratory surgeon rose to 95% ($P<0.01$).

Hospital where assessment by a respiratory physician was carried out

Hospital	Number of patients (% of total patients seen by a respiratory physician)		
	1996 (n=469)	2001 (n=610)	2006 (n=732)
Belfast City Hospital* (BCH)	215 (46%)	174 (29%)	131 (18%)
Royal Victoria Hospital* (RVH)	25 (5%)	38 (6%)	75 (10%)
Mater Infirmorium Hospital (MIH)	5 (1%)	38 (6%)	52 (7%)
TOTAL BELFAST TRUST	**245 (52%)**	**250 (41%)**	**258 (35%)**
The Ulster Hospital** (UH)	39 (8%)	48 (8%)	90 (12%)
Lagan Valley Hospital (LVH)	12 (3%)	23 (4%)	17 (2%)
Downe Hospital (DH)	5 (1%)	1 (<1%)	12 (2%)
Ards Hospital*** (AR)	5 (1%)	0	0
TOTAL SOUTH-EASTERN TRUST	**61 (13%)**	**72 (12%)**	**119 (16%)**
TOTAL EHSSB	**306 (65%)**	**322 (53%)**	**377 (51%)**
Antrim Hospital** (ANT)	3 (<1%)	50 (8%)	69 (9%)
Causeway (Coleraine) Hospital (COL)	6 (1%)	29 (5%)	39 (5%)
Whiteabbey Hospital (WHA)	16 (3%)	17 (3%)	16 (2%)
Mid-Ulster Hospital (MUH)	0	5 (<1%)	2 (<1%)
Moyle Hospital (MLE)	0	1 (<1%)	0
TOTAL NHSSB/NORTHERN TRUST	**25 (5%)**	**102 (17%)**	**126 (17%)**
Craigavon Area Hospital** (CAH)	0	55 (9%)	63 (9%)
Daisy Hill Hospital (DHH)	0	3 (<1%)	39 (5%)
South Tyrone Hospital (STH)	24 (5%)	7 (1%)	6 (<1%)
TOTAL SHSSB/SOUTHERN TRUST	**24 (5%)**	**65 (10%)**	**108 (15%)**
Altnagelvin Hospital** (AH)	96 (20%)	102 (17%)	94 (13%)
Erne Hospital (ERN)	1 (<1%)	17 (3%)	17 (2%)
Tyrone County Hospital (TCH)	0	1 (<1%)	3 (<1%)
Roe Valley (RV)	0	1 (<1%)	0
TOTAL WHSSB/WESTERN TRUST	**97 (21%)**	**121 (20%)**	**114 (16%)**
Ulster Independent Clinic (UIC)	1 (<1%)	0	3 (<1%)
TOTAL PRIVATE HOSPITALS	**1 (<1%)**	**0**	**3 (<1%)**
Not recorded	16 (3%)	0	4 (<1%)

RVH/BCH work collaboratively as the Cancer Centre for lung cancer ** Cancer Unit * RVH/BCH work collaboratively as the Cancer Centre for lung cancer in 2006 ** Cancer Unit * Changed to community health facility with no in-patient facilities by 2001.*

- Between 2001 and 2006, more patients were assessed by a respiratory physician in Ulster, Royal Victoria, Causeway, Mater Infirmorum, and Antrim hospitals, but with decreased numbers in Belfast City and Altnagelvin.

Method of Diagnosis

In agreement with national and international guidelines, NICR uses a hierarchy when deciding the certainty of a cancer diagnosis. Microscopic verification (MV) (histology/cytology) is generally most reliable. However, if this is not possible, results of imaging procedures such as CT scan or chest X-ray, which for some patients is the only way of confirming a diagnosis, is accepted. In the absence of any microscopic or visual confirmation of the lung cancer, the Registry accepts the opinion of a clinician (CO) that the patient has cancer.

Method	Number of patients (%)					
	All patients			Surgery Patients		
	1996 (n=705)	2001 (n=716)	2006 (n=834)	1996 (n=110)	2001 (n=89)	2006 (n=104)
Histopathology	333 (47%)	349 (48%)	398 (47%)	97 (86%)	82 (89%)	96 (88%)
Cytology	201 (28%)	223 (31%)	237 (28%)	14 (12%)	9 (10%)	13 (12%)
CT scan	71 (10%)	98 (14%)	150 (18%)	1 (<1%)	1 (1%)	0
X-ray	59 (8%)	16 (2%)	15 (2%)	1 (<1%)	0	0
Bronchoscopy	8 (1%)	13 (2%)	14 (2%)	0	0	0
Clinical opinion	26 (4%)	18 (3%)	10 (1%)	0	0	0
Other*	10 (2%)	3 (<1%)	15 (2%)	0	0	0

** 'Other' includes endoscopy, MRI scan, PET scan, ultrasound scan, post-mortem.*

- Over three quarters of patients in all years had a histologically/cytologically confirmed diagnosis of lung cancer, and almost all surgery patients had a microscopically confirmed diagnosis of lung cancer, 100% in 2006.
- The proportion of patients diagnosed by clinical opinion alone, although small, declined from 1996 to 2006 ($P<0.01$).

Histopathology and staging

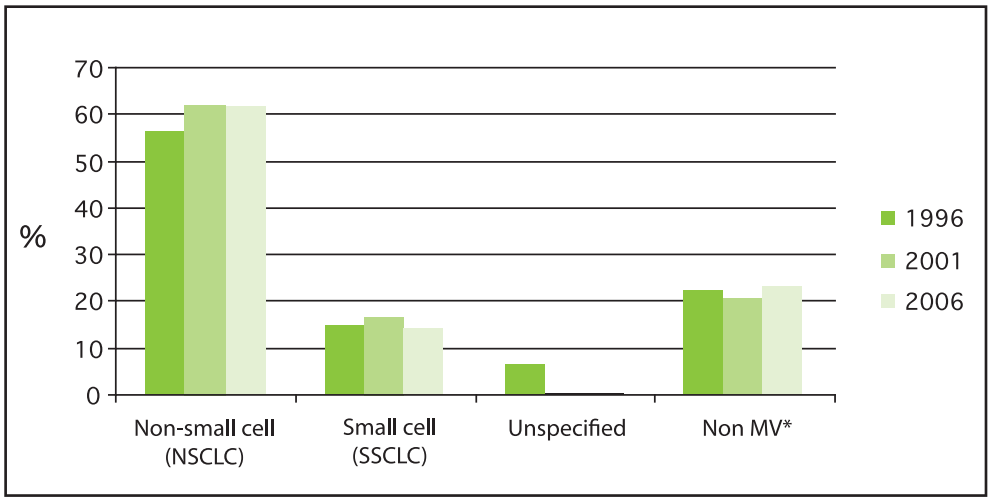
Histopathological Type

Sub type*	Number of patients		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
Non-small cell (NSCLC)	396 (56%)	443 (62%)	515 (61%)
Small cell (SCLC)	106 (15%)	121 (17%)	120 (14%)
Non MV**	158 (22%)	148 (21%)	196 (23%)
Unspecified	45 (6%)	4 (<1%)	3 (<1%)

** Note carcinoid of the lung are excluded from this audit ** 'Non MV'= non-microscopically verified; these tumours have the same morphology codes as 'unspecified', but their basis of diagnosis was not histology or cytology.*

- There was better histopathological subtyping in 2001 & 2006 compared with 1996, with fewer cases unspecified.
- As expected, non-small cell lung cancer was the most common histological type.
- In 2006, of those microscopically verified, 81.0% were non-small cell, 18.5% small cell, and less than 0.5% unspecified.

Histological classification of lung cancer



** 'Non MV'= Non-microscopically verified*

Staging (see also Appendix C)

Recording of stage in the clinical notes had improved by 2006, with 71% of patients having stage recorded compared to only 9% in 1996. By 2006, 88% of patients undergoing surgery had a stage recorded in their notes, up from 26% in 1996.

When stage was not recorded and there was sufficient information available in the clinical notes, Registry TVOs were able to assign a stage group (Registry-assigned stage). The AJCC staging classification[13] was applied.

TNM Stage (recorded in notes or Registry-assigned)

Stage	Number of patients (%)					
	All patients			Surgery patients		
	1996 (n=705)	2001 (n=716)	2006 (n=834)	1996 (n=110)	2001 (n=89)	2006 (n=104)
Stage I	68 (9%)	95 (13%)	109 (13%)	45 (41%)	37 (42%)	45 (43%)
Stage II	35 (5%)	39 (5%)	45 (5%)	15 (14%)	19 (21%)	22 (21%)
Stage IIIA	34 (5%)	45 (6%)	51 (6%)	11 (10%)	12 (13%)	11 (11%)
Stage IIIB	84 (12%)	40 (6%)	83 (10%)	10 (9%)	5 (6%)	8 (8%)
Stage IV	232 (33%)	250 (35%)	396 (48%)	16 (14%)	5 (6%)	14 (13%)
Staging not possible*	252 (36%)	247 (35%)	150 (18%)	13 (12%)	11 (12%)	4 (4%)

**Staging for these patients was not possible due to a lack of information in the notes*

- In 1996 & 2001, around one third of patients did not have sufficient information in their notes for a stage to be determined; in 2006, this proportion declined to less than one fifth (18%).
- In 1996 & 2001, approximately one third of patients presented with Stage IV disease in both years (accounting for 52% of those staged), whereas in 2006, 48% of patients were Stage IV making up 58% of staged patients.
- In 2006, 96% of patients undergoing surgery were staged.
- By 2001 & 2006, the percentage of Stage II surgery patients increased (P=0.10), indicating perhaps improved pre-operative staging practice allowing better selection of patients in whom cure is possible.

Patients with insufficient data for TNM Staging by Board of residence

Board of residence	Number of unstaged patients (% patients resident in that Board)		
	1996	2001	2006
NHSSB	62 (37%)	67 (39%)	26 (15%)
EHSSB	118 (34%)	102 (32%)	85 (21%)
SHSSB	40 (40%)	42 (38%)	21 (17%)
WHSSB	32 (37%)	36 (30%)	18 (13%)
All unstaged patients in N. Ireland	252	247	150

- The percentage of patients for whom it was not possible to determine stage decreased between 2001 and 2006 in all Boards (P<0.01).
- In 2006, fewer patients in the EHSSB were staged than in any other Board.

Patients with insufficient data for TNM Staging by age

Age groups in years	Number of unstaged patients (% of all patients in age group)		
	1996	2001	2006
0-54	9 (16%)	12 (18%)	7 (10%)
55-64	48 (32%)	42 (28%)	23 (12%)
65-74	104 (34%)	97 (35%)	49 (17%)
75+	91 (48%)	96 (43%)	71 (25%)
All unstaged patients	252	247	150

- In 2006, the proportion of patients who were unstaged increased with age from 10% in the 0-54 age group to 25% in the 75+ age group (P<0.01); this pattern was similar in other years.

Patients with insufficient data for TNM Staging by sex

Sex	Number of unstaged patients (% of patients of that sex)		
	1996	2001	2006
Female	83 (34%)	94 (37%)	54 (17%)
Male	169 (37%)	153 (33%)	96 (19%)
All unstaged patients	252 (36%)	247 (34%)	150 (18%)

- There was no difference in the proportion of unstaged patients between males and females (P=0.66) in any of the audit years.

Patients with insufficient data for TNM staging for various patient pathways

Pathways	Number of unstaged patients (% of patients receiving that referral or treatment)		
	1996	2001	2006
Referred for oncology	113 (30%)	148 (33%)	64 (12%)
Radiotherapy	90 (30%)	100 (31%)	46 (13%)
Chemotherapy	29 (32%)	46 (34%)	31 (13%)

- By 2006, the number of unstaged patients referred to oncology or receiving radiotherapy or chemotherapy declined from 1996 & 2001 (P<0.01).

Multidisciplinary Team Meetings

The effective management of lung cancer patients requires input from a range of experts. Multidisciplinary team meetings (MDTs) involve a group of healthcare professionals meeting to discuss the diagnosis and treatment of patients. The NICE guidelines[4] state: "The care of all patients with a working diagnosis of lung cancer should be discussed at a lung cancer MDT meeting." As there are a range of potential treatments that could be carried out, multidisciplinary discussions are of great importance. With respect to MDTs it should be noted that discussions among healthcare professionals, regarding the diagnosis and treatment of patients, may have taken place but may not have been recorded in the patient notes.

Multidisciplinary team meetings recorded in the notes by Board of residence

Board of residence	Number of patients having a MDT recorded in their notes (% all patients in that Board)		
	1996	2001	2006
NHSSB	20 (12%)	73 (42%)	110 (64%)
EHSSB	98 (28%)	146 (46%)	239 (59%)
SHSSB	15 (15%)	45 (41%)	62 (48%)
WHSSB	2 (2%)	74 (61%)	126 (93%)
N. Ireland	135 (19%)	338 (47%)	537 (64%)

- Recording in the clinical notes that discussion at an MDT had taken place improved substantially from 19% in 1996 to 64% in 2006.
- The greatest improvement was noted for residents of the Western Board which reached a 93% rate in 2006.

Multidisciplinary team meetings of surgery patients recorded in the notes by Board of residence

Board of residence	Number of patients having a MDT recorded in their notes (% all surgery patients in that Board)		
	1996 (n=110)	2001 (n=89)	2006 (n=104)
NHSSB	11 (44%)	15 (75%)	16 (84%)
EHSSB	27 (47%)	39 (89%)	42 (89%)
SHSSB	5 (33%)	9 (69%)	9 (53%)
WHSSB	1 (8%)	10 (83%)	21 (100%)
N. Ireland	44 (40%)	73 (82%)	88 (85%)

- In 2006, the proportion of recorded MDT meetings in the notes was higher for surgery patients (85%) than all patients (64%-see previous table).
- In 2006, all surgery patients in the WHSSB received an MDT.
- In 2006, MDT meeting were less likely to be recorded for surgery patients in the SHSSB compared to 2001.

Multidisciplinary team meetings recorded in the notes by stage

Stage of disease	Number of patients having a MDT recorded in their notes (% all patients with that stage)		
	1996	2001	2006
Stage I	34 (50%)	63 (66%)	81 (74%)
Stage II	10 (29%)	28 (72%)	36 (80%)
Stage IIIA	11 (32%)	29 (64%)	43 (84%)
Stage IIIB	12 (14%)	23 (58%)	71 (86%)
Stage IV	24 (10%)	84 (34%)	235 (59%)
Not recorded	44 (17%)	111 (45%)	71 (47%)
Total	135 (19%)	338 (47%)	537 (64%)

- In 2006, 80% of patients staged I, II, or III had an MDT recorded compared with 56% of patients with Stage IV or unrecorded stage ($P<0.01$).

Multidisciplinary team meetings recorded in the notes by age

Age groups	Number of patients having a MDT recorded in their notes (% all patients in that age category)		
	1996	2001	2006
0-54	13 (23%)	42 (63%)	45 (66%)
55-64	32 (22%)	81 (54%)	129 (68%)
65-74	67 (22%)	126 (45%)	200 (68%)
75 years or older	23 (12%)	89 (40%)	163 (58%)
All patients	135 (19%)	338 (47%)	537 (64%)

- By 2006, patients less than 75 years old were more likely to have an MDT (68%) than patients greater than 75 years old (58%) (P<0.01).

Treatment plan recorded in the notes by Board of residence

Board of residence	Number of patients having a treatment plan recorded in their notes (%)		
	1996	2001	2006
NHSSB	5 (2%)	57 (32%)	104 (60%)
EHSSB	48 (13%)	128 (40%)	224 (56%)
SHSSB	7 (7%)	40 (36%)	54 (42%)
WHSSB	2 (2%)	73 (61%)	124 (91%)
N. Ireland	62 (8%)	298 (41%)	506 (60%)

- Recording in the clinical notes of the treatment plan also improved from 1996 to 2006, but by 2006, 40% of patients did not have a treatment plan recorded.
- The greatest improvement and the highest proportion of patients with a record of treatment occurred in the Western Board.
- Not all patients discussed at an MDT had a treatment plan recorded in their notes but all, except one in 2001, with a treatment plan had been discussed at an MDT.

Surgery and oncology

Surgical procedures (see Appendix C for management of lung cancer)

For the purposes of this Report, surgery is classified as thoracotomy (1996, n =101; 2001, n=89; 2006, n =98) and/or excisions which include lobectomy, pneumonectomy and segmentectomy (1996, n=88; 2001, n=77; 2006, n=100). Pleural aspiration, mediastinoscopy and endobronchial therapy were not included and are classified as other procedures.

Surgery	Number of patients (%)					
	All audit patients			Patients 70 years or older		
	1996 (n=705)	2001 (n=716)	2006 (n=834)	1996 (n=364)	2001 (n=369)	2006 (n=448)
Yes	110 (16%)	89 (12%)	104 (12%)	33 (9%)	35 (9%)	41 (9%)
No	441 (63%)	623 (87%)	710 (85%)	247 (68%)	332 (90%)	394 (88%)
Not recorded	154 (22%)	4 (<1%)	20 (2%)	84 (23%)	2 (<1%)	13 (3%)

- In both 2001 & 2006, 12% of lung cancer patients had surgical treatment – a reduction from 16% in 1996.
- By 2006, 100% of patients receiving surgery had non-small cell lung cancer (90% in 1996).
- Of those patients not undergoing a surgical procedure, 48 (8%) patients in 1996, 42 (7%) in 2001 and 37 (5%) in 2006 died within one week of being diagnosed; there was a significant decline from 1996 to 2006 (P<0.01).
- There was no change between 1996 and 2006 in the proportion of patients greater than 70 years old (9%) who received surgery.

Procedure intent of surgery as recorded in notes

Procedure intent	Number of surgery patients (%)		
	1996 (n=110)	2001 (n=89)	2006 (n=104)
Curative	67 (61%)	72 (81%)	93 (89%)
Diagnostic	12 (11%)	13 (15%)	9 (9%)
Palliative	7 (6%)	2 (2%)	1 (<1%)
Staging	4 (4%)	0	0
Not recorded	20 (18%)	2 (2%)	1 (<1%)

- By 2001 & 2006, there was significantly better recording of surgical intent.
- The proportion of surgery patients receiving surgery with recorded curative intent has steadily increased from 61% in 1996 to 89% in 2006 (P<0.01).

Other recorded procedures for lung cancer

Other procedures	Number of patients (%)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
Pleural aspiration	45 (6%)	11 (2%)	7 (<1%)
Mediastinoscopy	13 (2%)	41 (6%)	29 (3%)
Endobronchial therapy	1 (<1%)	5 (<1%)	4 (<1%)

- From 1996 to 2006, there has been a continual decline in the number of patients with a record of having had pleural aspiration to less than 1% (P<0.01).
- On average 4% of patients had a mediastinoscopy, while less than 1% received endobronchial therapy.

Number of surgeons and procedures performed

Number of procedures	Number of surgeons (% of procedures)		
	1996	2001	2006
40 or more procedures	0	1 (45%)	0
21 - 40 procedures	3 (79%)	1 (34%)	1 (27%)
11 - 20 procedures	0	1 (14%)	4 (63%)
6 - 10 procedures	1 (8%)	0	1 (6%)
2 - 5 procedures	1 (4%)	1 (2%)	1 (3%)
1 procedure	1 (<1%)	2 (2%)	1 (<1%)
Surgeon's name not available	(8%)	(3%)	(<1%)
Total surgeons	7	8	9
Total consultant surgeons	2	3	5
Total procedures	109*	89	104

**One patient received their surgery in Dublin*

- The proportion of patients who were operated on by a surgeon doing more that 20 operations declined from 79% in 1996 & 2001 to 27% in 2006.
- The largest number of operations performed by a single surgeon was 32 in 1996, 40 in 2001, and 28 in 2006.
- Three surgeons performed surgery in all three years, 1996, 2001 and 2006.

Oncology treatment for lung cancer

Treatment	Number of patients (%)					
	Chemotherapy			Radiotherapy		
	1996 (n=705)	2001 (n=716)	2006 (n=834)	1996 (n=705)	2001 (n=716)	2006 (n=834)
Yes	91 (13%)	136 (19%)	235 (28%)	304 (43%)	327 (46%)	352 (42%)
No	503 (71%)	576 (80%)	501 (60%)	342 (49%)	387 (54%)	392 (47%)
Not recorded	111 (16%)	4 (<1%)	98 (12%)	59 (8%)	2 (<1%)	90 (11%)

- The use of chemotherapy increased (P<0.01) from 13% in 1996 to 28% in 2006, however there was no significant change in radiotherapy remaining at around 44%.
- In 2006, 36 out of 54 (67%) of patients with recorded non-small cell lung cancer (NSCLC), Stage I or II disease, and who had no surgery, received radiotherapy.
- In 2006, 60 out of 101 (59%) of patients with recorded Stage III or IV disease, NSCLC, and who had good performance status (0 or 1 ECOG[12] status), received chemotherapy. One of the key priorities in the NICE guidelines for lung cancer[4] states: "Chemotherapy should be offered to patients with Stage III or IV NSCLC and good performance status (WHO [World Health Organization] 0, 1 or a Karnofsky score of 80–100) to improve survival, disease control and quality of life."

Chemotherapy, radiotherapy & surgery combined treatment modalities for lung cancer patients as recorded in notes

Treatment	Number of patients (%)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
Surgery alone	53 (7%)	58 (8%)	49 (6%)
Chemotherapy alone	22 (3%)	44 (6%)	66 (8%)
Radiotherapy alone	130 (18%)	227 (32%)	194 (23%)
Combination chemo & radio	33 (5%)	76 (11%)	129 (15%)
Combination chemo & surgery	2 (<1%)	10 (1%)	26 (3%)
Combination radio & surgery	28 (4%)	15 (2%)	7 (<1%)
Combination chemo, radio & surgery	8 (1%)	5 (<1%)	9 (1%)
No chemo, radio, or surgery treatment	206 (29%)	273 (38%)	241 (29%)
Not recorded*	223 (32%)	8 (1%)	113 (14%)

**Of the 'Not recorded' 126/223 (57%) in 1996 did get some definite treatment, i.e. at least either chemotherapy, radiotherapy, or surgery was recorded but not all three; this was 5/8 (63%) in 2001 and 30/115 (29%) in 2006*

- Almost a third of all patients had a record of not receiving chemotherapy, radiotherapy or surgery.
- The increase in the number of patients (14%) with unrecorded information in 2006, after a decline to 1% in 2001, may be due to the greater number of older patients in the 2006 audit.
- The number of patients having no chemotherapy, radiotherapy, or surgery appeared to peak in 2001; it is likely however that these patients had some palliative treatment or care.

Patients who had no active treatment recorded (Note: Categories are not mutually exclusive)

Patient factors	Number of patients (% of patients with no active treatment)		
	1996 (n=206)	2001 (n=273)	2006 (n=241)
Stage IV	71 (34%)	111 (41%)	134 (56%)
Aged over 80 years at diagnosis	41 (20%)	60 (22%)	58 (24%)
Died within 2 weeks of diagnosis	49 (24%)	89 (33%)	48 (20%)

- Of those patients who did not receive any active treatment, the proportion of them with Stage IV cancers has been increasing from 34% 1996 to 56% in 2006, possibly reflecting better staging.
- There is no statistically significant trend over time in the proportion over 80 years old (22% on average) that did not receive treatment.
- The proportion of patients that did not receive treatment and died within 2 weeks varied among the years at around 26% average.

Timelines in the patient pathway

Summary timeline

Timeline	Referral to first seen at hospital			First seen to diagnosis		
	1996 (n=705)	2001 (n=716)	2006 (n=834)	1996 (n=705)	2001 (n=716)	2006 (n=834)
	Patients					
Duration not recorded (% of total)	160 (23%)	19 (3%)	58 (7%)	90 (13%)	6 (<1%)	23 (3%)
Days since start point	**% patients seen**			**% patients diagnosed**		
Day 1	51%	50%	57%	15%	6%	8%
Day 14	84%	82%	83%	66%	60%	62%
Day 31	93%	93%	95%	80%	79%	78%
Day 62	97%	98%	99%	88%	88%	88%

- There was better recording of timelines in 2001 and 2006.
- In all years, approximately 4/5 of patients were seen within 2 weeks of referral to hospital and approximately 2/3 were diagnosed within two weeks of being seen with no change over time for either measure.
- Of those patients who were diagnosed on the same day as referral (Day 1), 62% were emergency admissions in 1996, 27% in 2001, and 54% in 2006.

Summary timeline for CT/bronchoscopy

Timeline	Referral for CT scan			Referral for Bronchoscopy		
	1996 (n=498)	2001 (n=638)	2006 (n=787)	1996 (n=477)	2001 (n=528)	2006 (n=574)
	Patients					
Duration not recorded (% of total)	130 (26%)	19 (3%)	63 (8%)	108 (23%)	16 (3%)	47 (8%)
Days since referral	**% patients having CT scan**			**% patients having bronchoscopy**		
Day 1	6%	7%	11%	3%	1%	1%
Day 14	46%	53%	63%	50%	49%	44%
Day 31	70%	75%	83%	72%	77%	77%
Day 62	86%	89%	93%	87%	90%	92%

- There was better recording of the timing of investigation in 2001 & 2006 compared with 1996.
- Between 1996 and 2006, the patients' waiting time from referral to CT scan improved (P<0.01); 10% more patients had had a CT within 2 weeks from referral in 2006 compared with 2001.
- Between the years, the proportion of patients whose time interval from referral to bronchoscopy was under two weeks declined (P=0.09); this may reflect the increase in the proportion of patients having either a CT or PET scan before bronchoscopy from 18% in 1996 to 44% in 2006 (not shown).

Summary timeline for CT scans by Board of residence

Timeline	Time from referral to CT scan in 2006			
	NHSSB (n=159)	EHSSB (n=384)	SHSSB (n=118)	WHSSB (n=126)
	Patients			
Duration not recorded (% of total)	13 (8%)	30 (8%)	9 (8%)	11 (9%)
Days since referral	**% patients with CT scan carried out**			
Day 1	8%	14%	8%	30%
Day 14	53%	62%	64%	81%
Day 31	80%	81%	87%	89%
Day 62	93%	92%	93%	95%

- The time interval for patients from referral to CT scan differed between the Boards (P<0.01); patients resident in the WHSSB had the shortest time interval from referral to CT scan with 81% of patients who had a CT scan having them no longer than 2 weeks after referral, in contrast to the NHSSB at 53%.

Summary timeline for bronchoscopy by Board of residence

Timeline	Time from referral to bronchoscopy in 2006			
	NHSSB (n=128)	EHSSB (n=273)	SHSSB (n=80)	WHSSB (n=93)
	Patients			
Duration not recorded (% of total)	12 (9%)	23 (8%)	6 (8%)	6 (6%)
Days since referral	**% patients with bronchoscopy carried out**			
Day 1	3%	0%	0%	0%
Day 14	43%	38%	47%	57%
Day 31	78%	76%	81%	79%
Day 62	97%	90%	93%	94%

- The patient waiting times from referral to bronchoscopy did not differ between the Boards (P>0.05).

Summary timeline for onward referral

Timeline	Referral to first seen by a respiratory physician			Diagnosis to first seen by a thoracic surgeon		
	1996 (n=469)	2001 (n=610)	2006 (n=732)	1996 (n=238)	2001 (n=193)	2006 (n=166)
	Patients					
Duration not recorded (% of total)	117 (25%)	17 (3%)	53 (7%)	57 (24%)	14 (7%)	5 (3%)
Days since start point	**% patients seen by a respiratory physician**			**% patients seen by a thoracic surgeon**		
Day 1	11%	15%	23%	43%	42%	35%
Day 14	63%	66%	69%	61%	55%	40%
Day 31	82%	86%	90%	73%	72%	57%
Day 62	91%	95%	97%	92%	88%	81%

- From 1996 to 2006, there has been a steady reduction in the waiting time for patients between referral and first seen by a respiratory physician (P<0.01).
- From 1996 to 2006, there has been a steady increase in the waiting time for patients in the interval between referral and first seen by a thoracic surgeon (P<0.01).

Summary timeline for referral to respiratory physician by Board of residence

Timeline	Referral to first seen by a respiratory physician in 2006			
	NHSSB (n=154)	EHSSB (n=351)	SHSSB (n=115)	WHSSB (n=112)
	Patients			
Duration not recorded (% of total)	13 (8%)	26 (7%)	8 (7%)	6 (5%)
Day since referral	% patients who have seen respiratory physician			
Day 1	21%	26%	27%	48%
Day 14	62%	67%	72%	83%
Day 31	89%	87%	92%	97%
Day 62	99%	95%	97%	100%

- In 2006, there were significant differences (P<0.01) between Boards in the patient waiting time between referral to first seen by a respiratory physician; patients in the WHSSB saw their respiratory physician soonest—83% within two weeks.

Summary timeline for thoracic surgeon by Board of residence

Timeline	Diagnosis to first seen by a thoracic surgeon in 2006			
	NHSSB (n=36)	EHSSB (n=81)	SHSSB (n=22)	WHSSB (n=27)
	Patients			
Duration not recorded (% of total)	0	2 (2%)	0	3 (11%)
Day since referral	% patients assessed by thoracic surgeon			
Day 1	28%	33%	36%	54%
Day 14	33%	39%	36%	58%
Day 31	53%	57%	59%	63%
Day 62	83%	77%	86%	83%

- In 2006, patients in the WHSSB appeared to have the shortest intervals between diagnosis and first assessment by a thoracic surgeon, however there were no statistical differences between Boards possibly due to small numbers in the analysis.

Information and after care

Information recorded in notes

Information	Number of patients (% of all patients)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
Diagnosis discussed with patient	407 (58%)	595 (83%)	697 (84%)
Diagnosis not discussed with patient	61 (9%)	77 (11%)	46 (6%)
Treatment plan discussed with patient	398 (56%)	589 (82%)	699 (84%)
Referred to oncology centre	373 (53%)	449 (63%)	534 (64%)
Entered for clinical trial	19 (3%)	5 (<1%)	8 (<1%)

- By 2001 & 2006, 83% of patients had information on discussion of diagnosis, and treatment plan recorded in their notes–an improvement from 58% in 1996 (P<0.01).
- The number of patients referred to the oncology centre increased from 53% in 1996 to 63% in 2001 & 2006.
- Few patients were being entered into clinical trials (3% in 1996 and less than 1% in 2001 & 2006). This may reflect availability of suitable trials.
- About 8% of patients had a record that their diagnosis was not discussed with them, and a higher proportion (64%) of these were female in 2006, than in 1996 & 2001 at 43%.
- Of those patients who did not have their diagnosis discussed with them, 37% were aged over 80 years and 64% had significant co-morbidities (chronic obstructive pulmonary disease, cardiovascular disease, cerebrovascular disease, or hypertension). The proportion of these patients who died within 2 weeks of diagnosis were, 26% in 1996, 42% in 2001, and 15% in 2006.

Follow-up care details

This relates to information recorded in the discharge letter from hospital to GP.

After care recorded (Note: patients may have had more than one type of referral).

After Care	Number of patients (% of all patients)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
GP	167 (24%)	584 (82%)	655 (79%)
Community Nurse	40 (6%)	118 (16%)	252 (30%)
Macmillan nurse	98 (14%)	286 (40%)	305 (37%)
Hospice	65 (9%)	124 (17%)	226 (27%)
Marie Curie nurse	14 (2%)	19 (3%)	22 (3%)
Palliative care specialist	31 (4%)	192 (27%)	242 (29%)
Psychologist referral	6 (<1%)	14 (2%)	23 (3%)
Info on support groups/education supplied	2 (<1%)	13 (2%)	22 (3%)
No onward referral recorded	443 (63%)	106 (15%)	147 (18%)

- In 2006, 27% of patients were referred to a hospice, a significant (P<0.01) increase of 10% since 2001.
- By 2001 & 2006, the recording of referral to after care had improved, with only 16% of patients having no onward referral recorded in their notes (63% in 1996).
- In 2001 & 2006, there was increased recording of referrals to all services noted above, most notably Macmillan nurses, hospices and palliative care specialists.
- In 2001 & 2006, 3% of patients had a referral to a Marie Curie nurse recorded in their notes, 2% to a psychologist, and only 2% of patients in 2001 & 2006 recorded as having been given information on support groups. Provision of information on support groups etc. was poorly recorded in the notes. The NHS/NICE guidelines in 2005[4] state "All patients diagnosed with lung cancer should be offered information, both verbal and written, on all aspects of their diagnosis, treatment and care. This information should be tailored to the individual requirements of the patient, and audio and videotaped formats should also be considered." It should be noted that referral to these specialists could also take place via the GP and would not then be recorded in the letter to the GP.
- The percentage of patients recorded as receiving some form of palliative care increased from 38% in 1996 to 85% 2006.
- NHS/NICE guidelines 2005[4] suggest that "All cancer units/centres should have one or more trained lung cancer nurse specialists to see patients before and after diagnosis, to provide continuing support, and to facilitate communication between the secondary care team (including the MDT), the patient's GP, the community team and the patient. Their role includes helping patients to access advice and support whenever they need it". Lung cancer nurse specialists were not recorded in this audit; however, there was very little evidence of their presence from the notes from 1996 to 2006.

Information in GP letter

Information	Number of patients (%)		
	1996 (n=705)	2001 (n=716)	2006 (n=834)
Diagnosis discussed with patient	281 (40%)	462 (65%)	580 (70%)
Diagnosis not discussed with patient	116 (16%)	182 (25%)	30 (4%)
Diagnosis discussed with family	238 (34%)	336 (47%)	476 (57%)
Prognostic information	317 (45%)	276 (39%)	326 (39%)
Management plan	540 (77%)	659 (92%)	801 (96%)

- From 1996 to 2001 & 2006, an increasing proportion of GP letters contained a record that diagnosis was discussed with patients, and their family (P<0.01). The percentage of patients with whom diagnosis was positively not discussed has declined sharply to 4% in 2006 (P<0.01).
- Fewer patients (39%) in 2001 & 2006 had their prognosis recorded in their information to the GP than in 1996 (45%) (P<0.01).
- In 2006, 96% of patients in 2006 had a management plan recorded.

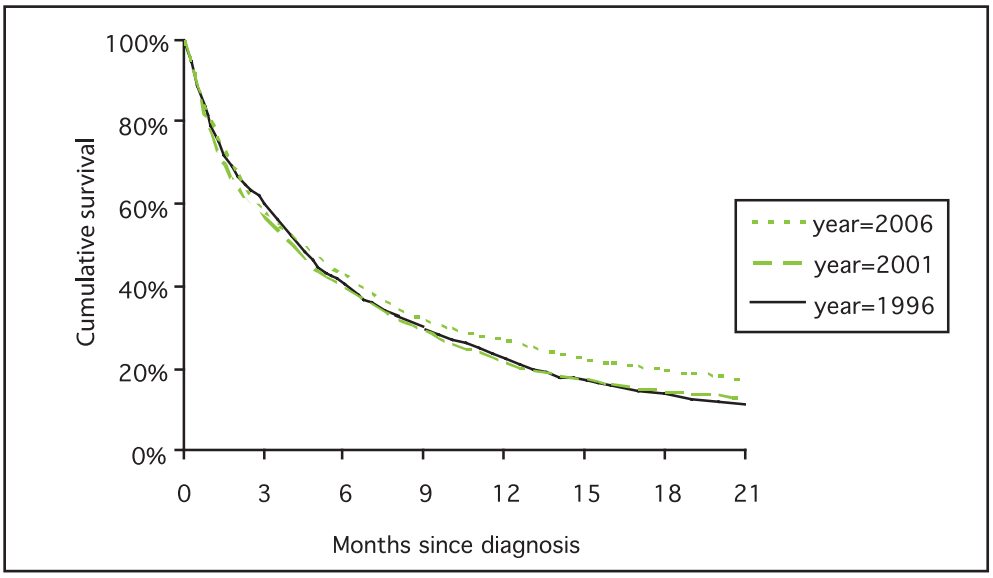
Patient outcomes

Survival analysis was performed on patients diagnosed in 1996, 2001, and 2006, with sub-group analysis for surgery patients, cell type and stage of disease.

Percentage of patients alive at various times after diagnosis

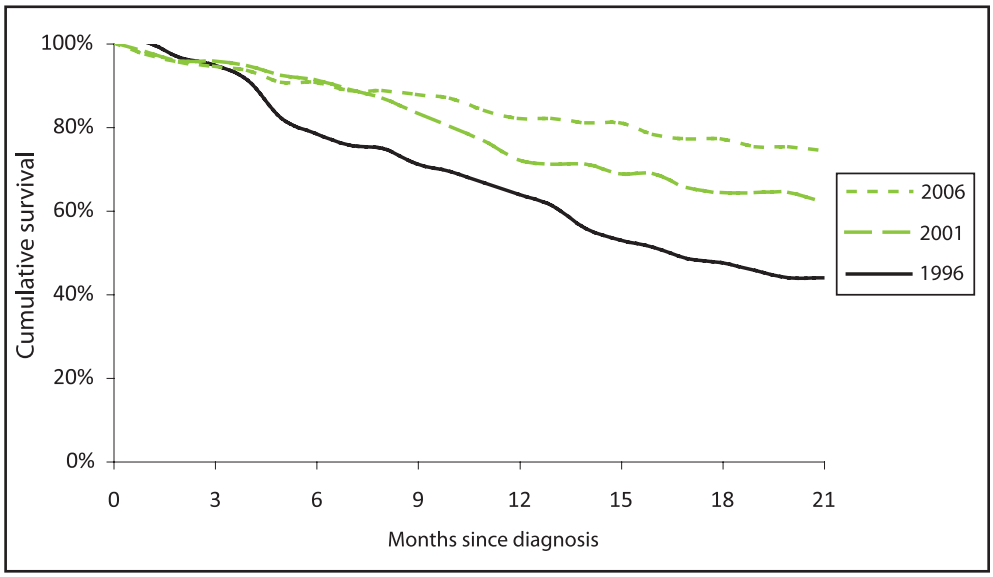
Time	All patients			Surgery only patients		
	1996 (n=705)	2001 (n=716)	2006 (n=834)	1996 (n=110)	2001 (n=89)	2006 (n=104)
30 days	80%	77%	80%	100%	98%	97%
60 days	67%	64%	67%	96%	96%	95%
6 months	41%	40%	43%	78%	91%	90%
12 months	23%	22%	27%	64%	72%	82%
21 months	11%	13%	17%	44%	62%	74%

Lung cancer observed survival by year (all patients)



- The observed survival of all study patients was significantly (P=0.017) different between the years; the 21-month observed survival of patients was 17% in 2006, 13% in 2001, and 11% in 1996.
- When the observed survival was calculated for all lung cancer patients in N. Ireland for 1996, 2001, and 2006, a similar pattern occurred (P=0.051).

Lung cancer observed survival by year for surgery patients



- For those patients who had surgery, survival was significantly different (P<0.01) between years; the 21-month observed survival was 44% in 1996, 64% in 2001, and 74% in 2006.

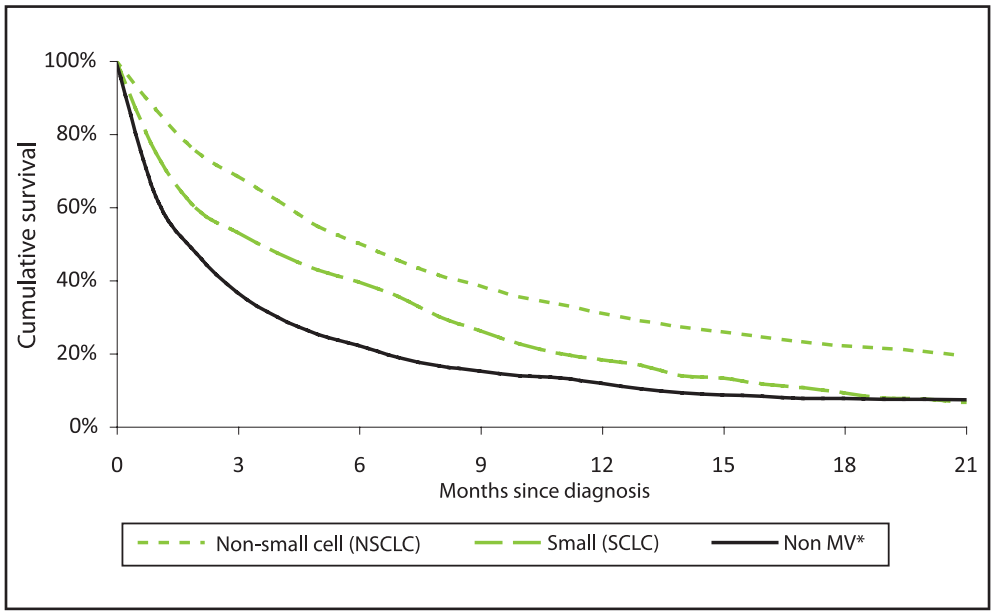
Percentage of patients alive at various times after diagnosis by cell type

Time	Non-small (n=1354)	Small (n=347)	Non-MV* (n=502)	Unspecified (n=52)
30 days	86%	75%	63%	77%
60 days	75%	59%	47%	62%
6 months	50%	39%	22%	21%
12 months	31%	18%	12%	8%
21 months	19%	6%	7%	2%

**Non MV=non-microscopically verified*

- As expected, there was a highly significant difference in the overall survival of patients by cell type (P<0.001), and of the three major groupings, the non-microscopically verified patients had the poorest overall observed survival (12% at 12 months and 7% at 21 months).
- Patients with non-small cell type lung cancer had the best survival (31% at 12 months and 19% at 21 months).

Lung cancer observed survival for all patients by cell type



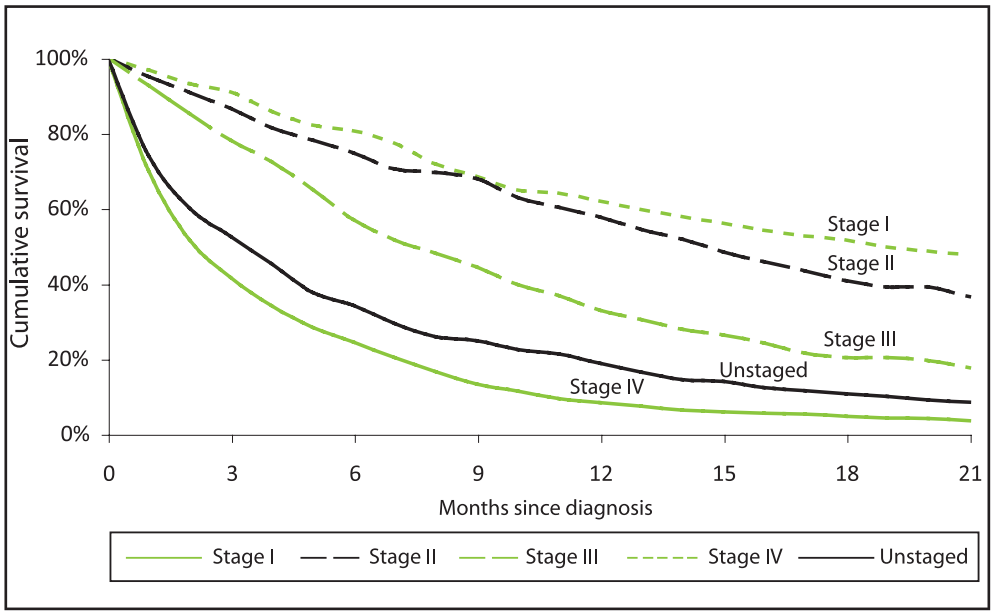
**Non MV=non-microscopically verified*

Percentage of patients alive at various times after diagnosis by stage

Time	I (n=272)	II (n=119)	III (n=337)	IV (n=878)	Unstaged (n=649)
30 days	97%	95%	93%	70%	74%
60 days	93%	91%	85%	51%	60%
6 months	81%	75%	57%	24%	34%
12 months	62%	58%	33%	8%	19%
21 months	47%	36%	18%	3%	8%

- As expected, there was a highly significant difference in the overall survival of patients by stage (P<0.01), with late Stage IV disease patients having the poorest overall survival, 3% at 21 months, compared with 47% for Stage I patients.

Lung cancer observed survival for all patients by stage



Percentage of patients alive at various times after diagnosis by Board of residence in 2006

Time	NHSSB (n=172)	EHSSB (n=400)	SHSSB (n=127)	WHSSB (n=135)
30 days	81%	81%	76%	81%
60 days	68%	68%	62%	69%
6 months	44%	43%	42%	44%
12 months	28%	27%	24%	29%
21 months	13%	18%	17%	20%

- There was no significant difference (P=0.81) between the survival of cancer patients by Board of residence.

SECTION III – LUNG CANCER SUMMARY

RISK FACTORS

- Two thirds of the study patients were male.
- Aggregated over all years, there was a greater proportion of women with lung cancer under 50 years of age (5%) than men (3%).
- If the lung cancer rates in 2006 in the most deprived areas were reduced to the rates in the most affluent areas, then 360 fewer people would be diagnosed annually with this disease in N. Ireland.
- In 2006, 92.4% of lung cancer patients had a history of tobacco use, 6.3% of patients had never smoked and 1.2% had no record of smoking history.
- In 2006, 3 out of the 35 never-smokers (8.6% or nearly 1 in 12) with a recorded occupation had worked in high second-hand smoke exposure environment (bars, etc).
- One quarter of patients in 1996 had a record of asbestos exposure; this had fallen to 14% by 2006.

PRESENTATION

- In 2006, 80% of lung cancer patients came from GP referrals, and 2% from radiology.
- From 1996 to 2006, there has been an increase in the percentage of patients recorded with an emergency presentation from 34% to 49%.
- Overall, 1.5% of patients were recorded as having asbestosis.
- One third of patients with lung cancer had a history of cardiovascular disease, and COPD was present in 29% of patients.
- About one patient in twelve had a personal history of another malignancy.
- Cough was the most common presenting symptom, occurring in 63% of patients.
- Over a fifth of patients had haemoptysis, but fewer of them in 2001 (3%) and 2006 (1%) had the symptom for longer than 6 months compared with 1996 (11%).
- 23% had symptoms over 6 months, 15% had symptoms more than 12 months with little change over time for either measure.
- From 1996 to 2006, the proportion of patients that had pain or haemoptysis for more than 6 months prior to presentation declined, possibly reflecting increased awareness of these symptoms. The proportion of patients with a recorded cough for more than 6 months increased in 2006).
- Rural patients greater than 80 years of age were less likely to have a record of a symptom for lung cancer for more than 6 months in comparison to younger rural patients and urban patients of any age.
- In 1996, 705 patients presented to 27 hospitals, in 2001, 715 patients presented to 22 hospitals, and in 2006, 834 patients presented to 19 hospitals.
- In 2006, 64% of patients presented to a Cancer Unit or the Cancer Centre in Belfast.

INVESTIGATIONS AND ASSESSMENT

- 87% of patients who attended a second hospital did so in the Belfast Trust, for the third and fourth hospital this rose to 90% and 100%, respectively.
- 67% of patients in 2006 attended more than one hospital for their investigation and treatments.
- By 2001 & 2006, over half of patients were referred directly to a respiratory specialist.
- Of those patients with a recorded ECOG in 2006 (52%), only 17% of lung cancer patients were considered fully active.
- In 2006, 94% had a CT scan, 68% of patients had a bronchoscopy, and 28% received a PET scan.
- In 2006, patients who had surgery were more likely to have CT scans (96%), bronchoscopies (80%), and PET scans (93%).
- The use of mediastinoscopy was performed on 4.5% of all patients and 20% of surgery patients by 2001 & 2006.
- Of those patients who received a bronchoscopy, 64% were recorded as having had their CT scan first.
- By 2001 & 2006, the use of CT scanning increased substantially in all Health Boards.
- In 2001 & 2006, 28% of patients undergoing a bronchoscopy were aged 75 and over, an increase from 21% in 1996 (not shown).
- Patients aged 80 years and over were as likely as younger patients to have a chest X-ray, but were less likely to have a bronchoscopy or a CT scan. There has been a steady increase since 1996 in the proportion of patients aged 80 years and over receiving a CT scan.
- By 2006, a majority of patients had their bronchoscopy or CT scan carried out within their Board of residence.
- By 2006, 88% of all patients and 95% of surgery patients were recorded as being assessed by a respiratory physician.

STAGING

- In 1996 & 2001, around one third of patients did not have sufficient information in their notes for a stage to be determined; in 2006, this proportion declined to less than one fifth (18%).
- In 2006, 96% of patients undergoing surgery were staged.
- By 2001 & 2006, the percentage of Stage II surgery patients increased (P=0.10), indicating perhaps improved pre-operative staging practice allowing better selection of patients in whom cure is possible.
- In 2006, patients who received radiotherapy were more likely to be staged (87%).
- In 2006, 88% of patients that were referred to an oncologist were staged.

HISTOLOGY

- Over three quarters of patients had a histologically/cytologically confirmed diagnosis of lung cancer, and almost all surgery patients had a microscopically confirmed diagnosis of lung cancer, 100% in 2006.
- In 2006, of those histologically verified, 81.0% were non-small cell, 18.5% small cell, and less than 0.5% unspecified.

RECORDING OF MULTIDISCIPLINARY TEAM MEETINGS

- Recording in the clinical notes that discussion at an MDT had taken place improved substantially from 19% in 1996 to 64% in 2006.
- The greatest improvement was noted for residents of the Western Board which reached a 93% rate in 2006 for all patients, 100% for surgery patients.
- In 2006, the level of recorded MDT meetings in the notes was higher for surgery patients (84%) than all patients combined (64%).
- In 2006, 80% of patients staged I, II, or III had an MDT compared with 56% of patients with Stage IV or unrecorded stage.
- Recording in the clinical notes of the treatment plan also improved from 1996 to 2006, but by 2006, 40% of patients did not have a treatment plan in their notes.

SURGERY AND ONCOLOGY

- In 2001 & 2006, 12% of lung cancer patients had surgical treatment – a reduction from 16% in 1996.
- By 2006, 100% of patients receiving surgery had non-small cell lung cancer (90% in 1996).
- The proportion of surgery patients having surgery with curative intent has steadily increased from 61% in 1996 to 89% in 2006.
- The largest number of operations performed by a single surgeon was 32 in 1996, 40 in 2001, and 28 in 2006.
- The proportion of patients who were operated on by a surgeon doing more that 20 operations declined from 79% in 1996&2001 to 27% in 2006.
- The percentage of patients receiving chemotherapy increased from 13% in 1996 to 28% in 2006.
- There was no change from 1996 to 2006 in the percentage receiving radiotherapy remaining at around 44%.
- In 2006, 36 out of 54 (67%) of patients with recorded non-small cell cancer (NSCLC), Stage I or II disease, and who had no surgery, received radiotherapy.
- In 2006, 60 out of 100 (59%) of patients with recorded Stage III or IV disease, NSCLC, and who had good performance status (0 or 1 ECOG[12] status), received chemotherapy. One of the key priorities in the NICE guidelines for lung cancer[4] states: "Chemotherapy should be offered to patients with Stage III or IV NSCLC and good performance status (WHO [World Health Organisation] 0, 1 or a Karnofsky score of 80–100) to improve survival, disease control and quality of life."
- By 2006, 29% of patients had a positive record of no treatment (surgery, chemotherapy, radiotherapy); of these 56% were Stage IV disease, 24% were greater than 80 years old, and 20% died within two weeks of their operation.
- In 2006, 33% of patients attended one hospital, 47% two hospitals, 18% three hospitals and 2% attended four hospitals for their investigations/treatment
- In 2001 & 2006, 62% of patients attended the Cancer Centre (situated in Belvoir Park Hospital in 2001 and 1996) an increase from 49% in 1996.

TIMELINES

- In all years, approximately 4/5 of patients were seen within 2 weeks of referral to hospital and approximately 2/3 were diagnosed within two weeks of being seen with no change over time for either measure.
- Between 1996 and 2006, patients' waiting time from referral to CT scan improved; 10% more patients had had a CT within 2 weeks from referral in 2006 compared with 2001.
- Between the years, patients' time interval from referral to bronchoscopy under two weeks became longer; this may reflect the increase in the proportion of patients having either a CT or PET scan before bronchoscopy from 18% in 1996 to 44% in 2006.
- The time interval for patients from referral to CT scan differed between the Boards; patients resident in the WHSSB had the shortest time interval from referral to CT scan with 81% of patients who had a CT scan having them no longer than 2 weeks after referral, in contrast to the NHSSB at 53%.
- From 1996 to 2006, there has been a steady reduction in the waiting time for patients between referral and first seen by a respiratory physician.
- From 1996 to 2006, there has been a steady increase in the waiting time for patients between referral and first seen by a thoracic surgeon.
- In 2006, there were significant differences between Boards in the patient waiting time between referral to first seen by a respiratory physician; patients in the WHSSB saw their respiratory physician soonest — 83% within two weeks.

ONWARD REFERRAL/CLINICAL TRIALS

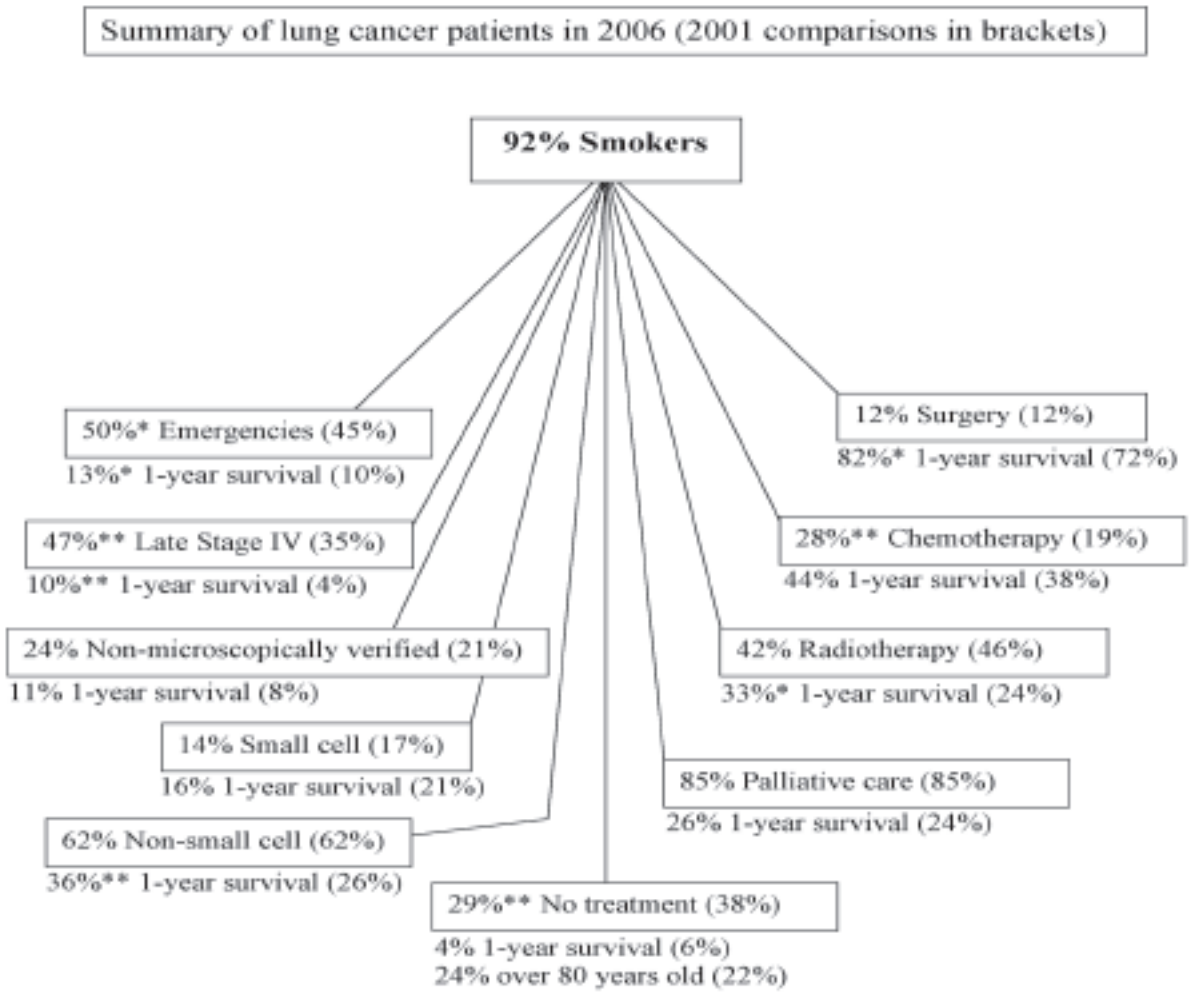
- By 2001 & 2006, the recording of referral to after care had improved, with only 16% of patients having no onward referral recorded in their notes (63% in 1996).
- In 2006, 27% of patients were referred to a hospice–a significant increase (10%) since 2001.
- The percentage of patients recorded as receiving some form of palliative care increased from 38% in 1996 to 85% 2006.
- The number of patients referred to the oncology centre increased from 53% in 1996 to 63% in 2001 & 2006.
- Few patients were entered into clinical trials (3% in 1996 and less than 1% in 2001 & 2006).

COMMUNICATION

- By 2001 & 2006, 83% of patients had information on discussion of diagnosis and treatment plan recorded in their notes, an improvement from 1996.
- About 8% of patients had a record that their diagnosis was not discussed with them, and a higher proportion (64%) of these were female in 2006, than in 1996 & 2001 at 43%.
- From 1996 to 2001 & 2006, an increasing proportion of GP letters contained evidence that diagnosis was discussed with patients, and their family. The percentage of patients of whom there was no evidence that diagnosis was discussed has declined sharply to 4% in 2006.
- Fewer patients (39%) in 2001 & 2006 had their prognosis recorded in their information to the GP than in 1996 (45%).
- In 2006, 96% of patients in 2006 had a management plan recorded.

OUTCOMES

- The observed survival of all study patients improved between 1996, 2001 and 2006; the 21-month observed survival of patients was 17% in 2006, 13% in 2001, and 11% in 1996; a similar pattern in 21-month observed survival occurred when all lung cancer patients in N. Ireland of these years were likewise analysed.
- For those patients who had surgery, survival was significantly different between years; the 21-month observed survival was 74% in 2006, 62% in 2001, and 44% in 1996.
- As expected, there was a highly significant difference in the overall survival of patients by cell type ($P<0.001$), and of the three major groupings, the non-microscopically verified patients had the poorest overall observed survival (12% at one-year and 7% at 21-months).
- There was a highly significant difference in the overall survival of patients by stage, with late Stage IV disease patients having the poorest overall survival, 3% at 21-months, compared with 47% for Stage I patients.
- The survival, followed up for one year, improved in 2006 from 2001 for the following subgroups of patients: 1) presented as an emergency, 2) had Stage IV disease, 3) had non-small cell tumour type, 4) had surgery, and 5) had radiotherapy.



*Note: patient may be included in more than one category; * an asterisk over the 2006 figure indicates that the proportion or 1-year survival curve is significantly different at the 5% level than 2001; **significantly different at the 1% level.*

The following factors contribute to the overall poor survival for lung cancer patients in 2006:

- Half of patients presented as emergencies; they have a 13% 1-year survival.
- Nearly a half (47%) of patients are Stage IV disease at presentation, a 1-year observed survival for these patients is only 10%.
- A quarter of patients do not have a microscopic verification of their diagnosis. For this subgroup their 1-year survival is 11%.
- 14% of patients present with small cell tumours, a subgroup with poorer survival than the average at 16% for 1-year survival; in contrast, 62% of patients presented with non-small cell tumours, and the 1-year observed survival was 36%.
- By comparison, patients who had surgery had a 82% 1-year survival.
- 92% of these lung cancer patients smoked tobacco. Tobacco is a major risk factor in the development of lung cancer.

Lung cancer is a disease with poor prognosis and every effort should be made to reduce levels of tobacco use in our society.

The survival, followed up for one year, improved in 2006 from 2001 for the following subgroups of patients: 1) presented as an emergency, 2) had Stage IV disease, 3) had non-small cell tumour type, 4) had surgery, 5) had radiotherapy.

CONCLUSIONS, KEY ISSUES AND RECOMMENDATIONS

Conclusions

- There have been major changes in cancer services for lung cancer patients in N. Ireland between 1996 & 2006 with:
  - Evidence that patients are presenting earlier and reduced waiting times for investigation and treatments.
  - Better recording of patient performance status (ECOG) and staging.
  - Enhanced use of more complex imaging e.g. CT Scan, PET Scan, mediastinoscopy.
  - Two thirds of patients discussed at MDT.
  - There was increased referral to respiratory physicians and palliative care, and more patients having chemotherapy.
  - There was also increased equity of service provision by geographical area.

  However,
  - In 2006, 81% of patients still presented with serious symptoms (cough, pain, breathlessness, haemoptysis)
  - 48% patients had late Stage IV disease and a further 18% remained unstaged, pointing to the need to further promote earlier diagnosis.
  - One third of patients were unsuitable for any of surgery, radiotherapy or chemotherapy.
  - Survival, although it has improved, is very poor; this highlights the need to prevent lung cancer by addressing smoking.

Although outcomes are poor, survival for all patients improved at one year. Survival for surgery patients which had improved remarkably between 1996 and 2001 largely due to improved patient selection had improved further. The survival improved in 2006 from 2001 for the following subgroups of patients: 1) presented as an emergency, 2) had Stage IV disease, 3) had non-small cell tumour type, 4) had surgery, 5) had radiotherapy. This improved survival is a testament to all the hard work of the dedicated staff who treat lung cancer patients in N. Ireland.

Good communication should be a priority between professionals as patients attend different units during the course of their treatment. Lung cancer nurses and the new cancer patient pathway IT system will play important roles in this.

Key issues

- There are issues for the service – 67% of patients attended more than one hospital with almost a fifth attending three or more hospitals highlighting the need for good communication.
- There is a worrying trend of increasing lung cancer cases in younger women, 5% of female lung cancer cases occurred in those under 50 years compared with 3% of male cases.
- Lung cancer highlights the contribution of tobacco to the health differences between the most and least affluent in our community; if the lung cancer rates in 2006 in the most deprived areas were reduced to the rates in the most affluent areas, then 360 fewer people would be diagnosed annually with this disease in N. Ireland. This represents over 40% of all lung cancers.
- One in 12 (n=35) of the never smokers who had lung cancer had worked in the hospitality industry.

Recommendations

- Enhanced efforts should be made to reduce tobacco use in our society especially among young women and those from deprived areas.
- The efforts and dedication of all staff who treat lung cancer patients should be acknowledged and the reforms of cancer services continue.
- Health care providers and patients should be alerted to the significance of serious symptoms among smokers and increase efforts towards earlier diagnosis of lung cancer.
- Lung cancer services should be re-audited in another 5 years.

REFERENCES

1. Cancer services: investing for the future (Campbell Report). Working group report. Northern Ireland: Department of Health and Social Services, 1996.

2. Cancer services: investing for the future. Working Group sub-group reports. Northern Ireland: Department of Health and Social Services, 1996.

3. Gavin A, Fitzpatrick D, Ranaghan L. Cancer Services Audit 1996 & 2001 - Lung. Audit report. Belfast: Northern Ireland Cancer Registry, 2005. Available at: http://www.qub.ac.uk/research-centres/nicr/Publications/.

4. Lung cancer: the diagnosis and treatment of lung cancer. Clinical guideline 24. London: National Institute for Clinical Excellence, 2005. Available at: www.nice.org.uk/CG024NICEguideline.

5. Management of patients with lung cancer. Clinical guideline 80. Scottish Intercollegiate Guidelines Network, 2005. Available at: www.sign.ac.uk.

6. Kim HJ, Fay MP, Feuer EJ, Midthune DN. Permutation tests for joinpoint regression with applications to cancer rates. *Stat Med* 2000; 19:335-51.

7. Donnelly DW, Gavin AT. Survival of cancer patients in Northern Ireland:1993-2004. Belfast: Northern Ireland Cancer Registry, 2007.

8. Alberg AJ, Ford JG, Samet JM. Epidemiology of lung cancer: ACCP evidence-based clinical practice guidelines (2nd edition). *Chest* 2007; 132:29S-55S.

9. Field JK, Duffy SW. Lung cancer screening: the way forward. *Br J Cancer* 2008;99:557-62.

10. *International statistical classification of diseases and related health problems.* 10th revision ed. Geneva: World Health Organisation, 1992.

11. StataCorp. *Stata statistical software:* release 9, 2005.

12. Eastern Cooperative Oncology Group (ECOG) Performance Status. Available at: http://ecog.dfci.harvard.edu/general/perf_stat.html, 2008.

13. *Cancer Staging Handbook.* 6th ed. Chicago: American Joint Committee on Cancer, 2002.

APPENDICES

APPENDIX A: Summary of recommendations of the 'Campbell Report', that is, Cancer Services:* Investing for the Future[1]*, 1996.

1. The management of patients with cancer should be undertaken by appropriately trained, organ and disease specific medical specialists.

2. All patients with cancer should be managed by multidisciplinary, multiprofessional specialist cancer teams.

3. A Cancer Forum should be established involving all key interests in the delivery of cancer services.

4. Cancer Units should, in conjunction with local GPs and other providers, develop an effective communication strategy.

5. Northern Ireland should have one Cancer Centre, which in addition to its regional role, should act as a Cancer Unit to its local catchment population of around half a million.

6. There should be four other Cancer Units, one in each Board area, each serving a population of around a quarter of a million.

7. Radiotherapy services, together with chemotherapy services, should be moved as soon as possible to the Belfast City Hospital and become an integral part of the regional Cancer Centre.

8. Each Cancer Unit should develop a chemotherapy service. This service should be staffed by designated specialist nurses and pharmacists, and should be overseen by the non-surgical oncologist attached to the unit, with back-up from a haematologist.

9. There should be a minimum target of 13 consultants in non-surgical oncology for Northern Ireland by 2005.

10. Any new appointments of trained cancer specialists should be to Cancer Units or to the Cancer Centre.

11. Guidelines should be drawn up and agreed for the appropriate investigation and management of patients presenting to non-Cancer Unit hospitals who turn out to have cancer.

12. The Cancer Centre and Cancer Units should each develop a specialist multiprofessional palliative care team.

13. There should be a comprehensive review of palliative care services in Northern Ireland.

14. The Northern Ireland Cancer Registry should be adequately resourced.

The above recommendations outlined the change that was necessary to improve cancer care.

APPENDIX B: Summary of recommendations of the Report of the Lung Cancer sub-group in* Cancer Services – Investing for the Future – Cancer Working Group Sub-Group Reports[2]*, 1996.

1. There is an urgent need for more resources to be devoted to smoking cessation and smoking prevention programmes, particularly in the primary care setting.

2. All health care professionals should be aware of the nature and relevance of suspicious symptoms in smokers.

3. Health promotion campaigns should include a warning to smokers about the extra significance that suspicious symptoms may have for them.

4. Optimal communication between hospital and primary care teams should be mandatory at all stages of disease.

5. Locally agreed guidelines should be developed for the referral of patients to a respiratory physician/ Cancer Unit.

6. Cancer Units (and the Cancer Centre) should seek to meet the performance targets set out in the Working Group Report.

7. A Cancer Unit for lung cancer should be established in each of the Area Boards.

8. The designated Cancer Centre for lung cancer should comprise the multidisciplinary team of surgeons, respiratory physicians and subsite specialised non-surgical oncologists, who currently provide the service for lung cancer, together with the supporting infrastructure.

9. Joint educational activities for general practitioners, hospitals, doctors and nurses should be developed locally to encourage an integrated and multi-professional approach to the management of lung cancer at all stages.

10. Clinical guidelines should be established and agreed between purchasers (General Practitioners and Boards) and providers and between the various clinicians involved in the management of lung cancer.

11. These guidelines should be reviewed on a regular basis and a mechanism put in place to ensure the continuation of a nationally co-ordinated approach to lung cancer.

12. Purchasers should make arrangements for immediate appointment of a third thoracic surgery consultant (accompanied by an increase in the number of operation sessions to 12 per week) to allow the current workload to be managed within clinically acceptable waiting times.

13. Purchasers should assess the need for the future appointment of a fourth thoracic surgeon to cater for the expected increase in surgical workload subsequent to the predicted rise in the number of patients with lung cancer and reorganisation of cancer services.

14. Each Cancer Centre and Unit should have a multidisciplinary palliative care team whose remit and members are defined by the Palliative Care Sub-Group.

15. The Cancer Centre should, additionally, have radiologists, surgeons and clinical oncologists whose expertise will address the less common emergencies in patients with lung cancer, such as SVC obstruction and spinal cord compression.

16. Facilities should exist to allow joint respiratory physician/palliative care physician/oncologist clinics.

17. Where appropriate, more patients with lung cancer should be entered into clinical trials (an adequate infrastructure must be provided to facilitate this).

18. Purchasers should continue to monitor patterns of service use, equity and access issues, costs, outcomes and the changing epidemiology of lung cancer.

APPENDIX C: Staging and Management of Lung cancer

Accurate staging is essential for the planning of appropriate treatment and for the comparison of the outcomes of such treatment (surgical and non-surgical). Lung cancer staging should be as detailed and methodical as possible in order to permit appropriate decision making regarding optimum therapy. The TNM system can be used for most histological types of lung cancer, but is primarily used for non-small cell tumours which constitute 80% of lung tumours. For small cell lung cancers it is not generally used as it does not predict well for survival. These small cell tumours are usually categorized as limited or extensive stage. The TNM classification of lung carcinoma[13] is shown in Table 1 (below).

Clinical staging

Clinical staging is based on the assessment of the extent of disease following non-invasive or minimally invasive assessments including physical examination, imaging using chest X-ray, CT scanning, positron emission tomography (PET) scanning, and laboratory tests. The size of the primary tumour (T) can be assessed by imaging. CT scanning of chest, including the liver and adrenal glands, is routinely performed to look for evidence of involvement of the lymph nodes and to detect distant metastases. Bronchoscopy is usually performed at this stage to establish a histological or cytological diagnosis, and it also yields additional staging information such as whether or not the tumour involves the main bronchus and/or the carina. This information is also important in deciding which type of surgery is most appropriate. For peripherally situated tumours, bronchoscopy is less likely to yield a diagnosis but a CT-guided biopsy may provide histological confirmation. More recently PET scanning is proving a valuable tool for evaluating lymph node involvement and distant metastatic disease. Mediastinoscopy with biopsy of CT or PET positive mediastinal lymph nodes is generally performed if the result will alter treatment decisions.

Pathological staging

Pathological staging adds significant information to this process. It is only possible following operative resection of the tumour and mediastinal lymph nodes, so for patients who are not suitable surgical candidates it is not undertaken, and clinical staging only is possible. Intraoperative staging enables direct inspection of the lung, pleura and diaphragm and allows dissection or complete excision of the mediastinal lymph nodes.

Evaluation of distant metastases

This process starts with a careful history and clinical examination. CT scanning of the chest should include the adrenal glands and virtually all of the liver and should be routinely performed in all patients. Patients who have physical signs, laboratory abnormalities or symptoms suggestive of metastatic disease should undergo additional appropriate investigations such as bone/brain scans to evaluate suspect areas.

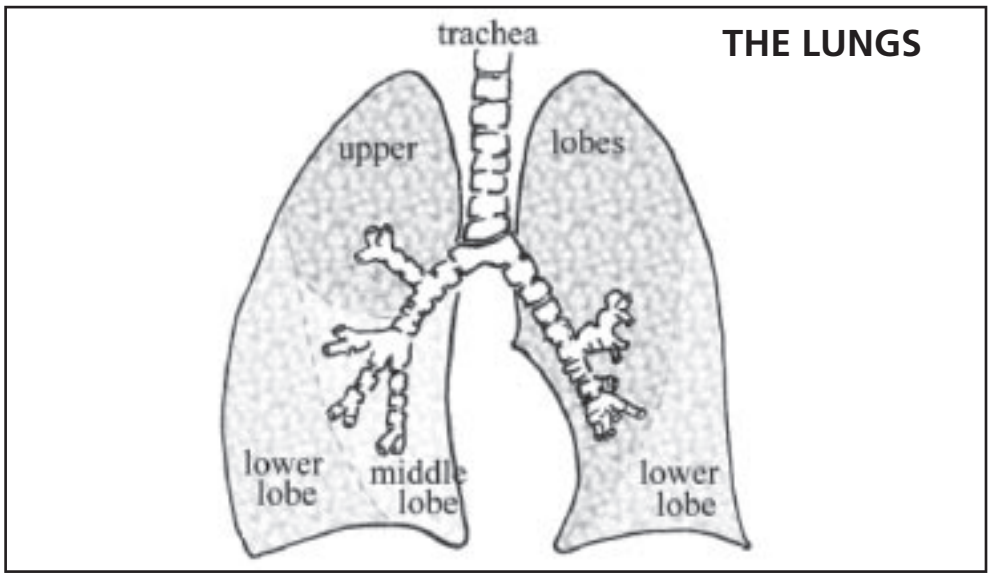


Table 1 TNM classification of lung cancer[13]

Tumour	**TX**	• Primary tumour cannot be assessed, or tumour proven by the presence of malignant cells in sputum or bronchial washings but not visualized by imaging or bronchoscopy
	T0	• no evidence of primary tumour
	T1	• tumour 3cm or less in greatest extension, surrounded by lung or visceral pleura, without bronchoscopic evidence of invasion more proximal than the lobar bronchus (i.e. not in the main bronchus)
	T2	• tumour with any of the following features of size or extent: more than 3cm in greatest dimension; involves main bronchus, 2 cm or more distal to the carina; invades visceral pleura; associated with atelectasis or obstructive pneumonitis that extends to the hilar region but does not involve the entire lung
	T3	• tumour of any size that directly invades any of the following : chest wall (including superior sulcus tumours), diaphragm, mediastinal pleura, parietal pericardium; or tumour in main bronchus less than 2cm distal to the carina, but without involvement of the carina; or associated atelectasis or obstructive pneumonitis involving entire lung
	T4	• tumour of any size that directly invades any of the following: mediastinum, heart, great vessels, trachea, oesophagus, vertebral body, carina; or separate tumour nodules in same lobe; or tumour with a malignant pleural effusion
Nodes	**NX**	• regional lymph nodes cannot be assessed
	N0	• no regional lymph node metastasis
	N1	• metastases to ipsilateral peribronchial and/or ipsilateral hilar nodes, and intrapulmonary nodes including involvement by direct extension of the primary tumour
	N2	• metastases to ipsilateral mediastinal and/or subcarinal lymph nodes
	N3	• metastases to contralateral mediastinal, contralateral hilar, ipsilateral or contralateral scalene or supraclavicular lymph nodes
Metastases	**MX**	• distant metastases cannot be assessed
	M0	• no distant metastases
	M1	• distant metastases present (includes separate tumour nodules in a different lobe [ipsilateral or contralateral])

In order to facilitate survival analysis the assigned TNM profile is condensed into a stage group category of which there are 7 (stages IA, IB, IIA, IIB, IIIA, IIIB & IV) (Table 2).

Example:

- 2cm tumour in right midzone on chest X-ray. Bronchoscopy shows tumour extending into right main bronchus. Therefore **T** = T2.
- CT scan shows enlarged mediastinal glands. Mediastinoscopy confirms ipsilateral mediastinal nodes involved therefore **N** = N2.
- clinically/radiologically there is no evidence of distant metastases and is therefore **M** = M0.

TNM profile is **cT2 pN2 cM0** (p = determined pathologically, c = clinically determined). This TNM profile is assigned to stage group IIIA.

Table 2 Stage Group Lung Cancer

Stage	T	N	M
IA	T1	N0	M0
IB	T2	N0	M0
IIA	T1	N1	M0
IIB	T2	N1	M0
	T3	N0	M0
IIIA	T1	N2	M0
	T2	N2	M0
	T3	N1	M0
	T3	N2	M0
IIIB	any T	N3	M0
	T4	any N	M0
IV	any T	any N	M1

Management

The management of patients with lung cancer should be discussed in a multidisciplinary meeting between a chest physician, thoracic surgeon and an oncologist. Management depends firstly on the stage of the cancer at diagnosis. Clinical Stage I and II lung tumours are usually considered to be operable, but fitness for the type of surgery necessary to achieve cure is a vital consideration. This will involve careful assessment of the patient's lung function in order to determine the volume of lung tissue that can be safely removed. It also enables decisions regarding which, if any, type of surgical resection is appropriate. Cardiovascular fitness is also taken into consideration as pre-existing coronary artery disease increases the postoperative morbidity. Age and overall health status and in particular documentation of significant recent weight loss or co-morbidities, will be taken into consideration when deciding the most appropriate treatment. Perioperative morbidity increases with advancing age, however, age alone should not be a contraindication to surgical resection. Some surgery patients may also be treated with chemotherapy and radiotherapy.

In non-small cell lung cancer (NCSLC), where surgery is not an option, or the patient cannot have surgery, due to poor fitness or another condition, radiotherapy is used to treat the patient; if the aim is cure then it is called radical radiotherapy. Clinicians will also advise some patients with Stage III lung cancer have radical radiotherapy in preference to surgery, for example, when the tumour is small but has spread locally into the chest wall or diaphragm.

Radiotherapy is also used to palliate or alleviate symptoms, particularly chest pain and coughing, but also pain in the bones where the cancer has spread. Chemotherapy before surgery or after radiotherapy has been shown to increase selected patients' survival. Chemotherapy can increase survival for people with advanced NSCLC, even if they are not likely to be cured of their cancer.

Chemotherapy is the main treatment for small cell lung cancer because this type of cancer responds very well to chemotherapy, but also because the tumour can spread to other parts of the body at an early stage. These patients may also be prescribed radiotherapy for symptom control.

CDS N111926

N. Ireland Cancer Registry
Centre for Public Health Research
Mulhouse Building
Grosvenor Road
Belfast BT12 6BJ

T: (44) 028 9063 2573
F: (44) 028 9024 8017
E: nicr@qub.ac.uk
W: www.qub.ac.uk/nicr

ISBN 9780853899495