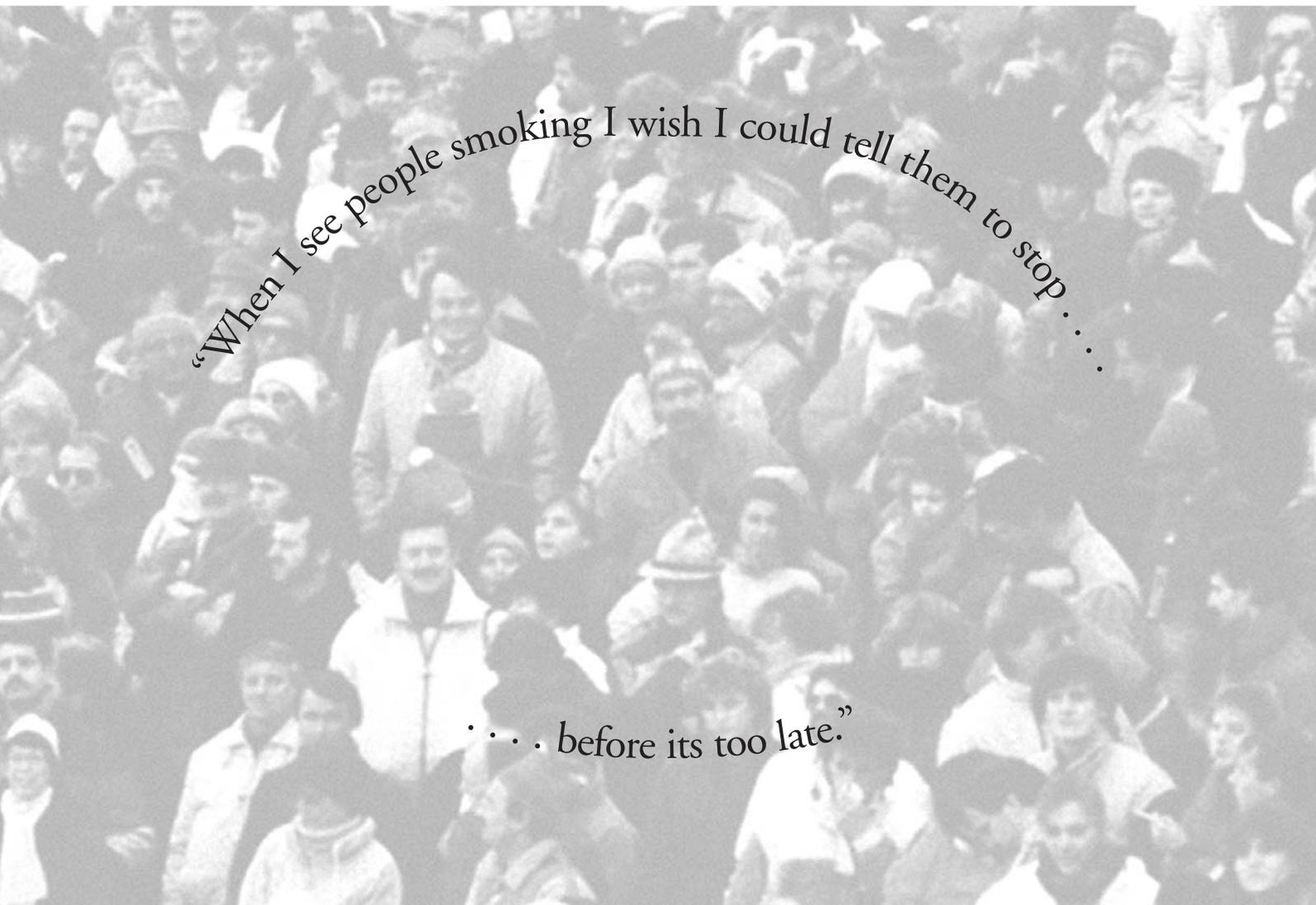




Cancer Services Audit 1996 & 2001  
**Lung**



*“When I see people smoking I wish I could tell them to stop . . .*

*. . . before its too late.”*



Queen's University  
Belfast



Cancer Services Audit 1996 & 2001  
**LUNG**

Edited by: **Anna Gavin, Deirdre Fitzpatrick and Lisa Ranaghan.**

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## FOREWORD

Cancer services in Northern Ireland have improved in recent years. Developments have spanned prevention, early detection and screening, diagnosis, management and palliative care. The Northern Ireland Cancer Registry has played an important role and made a vital contribution in monitoring this progress.

Since 1996 we have seen the establishment of five Cancer Units at Altnagelvin, Antrim, Belfast City, Craigavon, and Ulster hospitals and a regional Cancer Centre at the Belfast City Hospital working closely with the Royal Group of Hospitals. The Cancer Units are now the main focus for the delivery of services for people with the more common cancers. In addition, some services for other less common cancers are provided from Cancer Units, in conjunction with the Cancer Centre, on a shared care basis. These organisational changes have already made an impact on care.

This report on lung cancer is very welcome. It is the fourth in a series which examines in detail the pathways of care for patients with cancer here. The reports provide a fascinating insight into how care has changed over the period. They will also facilitate the ongoing work of improving services and patient care.

This work marks a significant step in the evaluation of cancer care and confirms the great value of the Registry as a public health tool. I look forward to future reports in this series and regular five yearly snapshots of the changing process of cancer care.



Dr Henrietta Campbell  
Chief Medical Officer

## ACKNOWLEDGEMENTS

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- Eastern Health and Social Services Board
- Northern Health and Social Services Board
- Regional Medical Audit Group
- Research and Development Office
- Southern Health and Social Services Board
- Western Health and Social Services Board

The quality of data in this project is a result of the work of the present and past Registry Tumour Verification Officers especially Kate Donnelly, Rosemary Ward, Elinor Johnston, Eileen Shepherd, Mary McCartney and Carmel Corr who meticulously extracted detailed information from clinical records for analysis and presentation in this report. A special word of gratitude to the Medical Records staff of all the hospitals in Northern Ireland who, in the course of the total project, pulled an estimated 10,000 charts.

We are grateful to the clinicians who commented on the detail of data to be collected, its interpretation and final presentation.

The work of the N. Ireland Cancer Registry, including the production of this report, is the result of the work of the team listed below:

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Kate Donnelly	Patricia Donnelly	Deirdre Fitzpatrick	Colin Fox
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Dr Lisa Ranaghan	Dr Jeffrey Robertson	Breige Torrains	Rosemary Ward

I wish also to record my thanks to the Management Group and Council of the Registry who guide that work.

This presentation, I feel, has been enhanced by the stories from patients who have walked the patient journey. A journey we have attempted to analyse and quantify with a view to identifying current practice so clinicians may be facilitated in improving care.



A Gavin  
Director, NICR  
2005

## PATIENT STORIES

*“I had smoked from when I was a wee girl of the age of 12, smoking butts. I then became a very heavy smoker of 40-50 cigarettes a day whenever I could afford them until my mid 50’s. I took a notion to quit, the information on the TV highlighting the harm cigarettes could do was the main reason I decided to stop. It was very hard to give up cigarettes. I thought it would give me some more years of life.*

*I was off cigarettes for at least 10 years when I developed a pain in the back of my chest and I found it hard to breathe. After about a month I went to my GP and had a chest X-ray and was referred from the local hospital to the Cancer Unit.*

*I was diagnosed with a lung cancer in the lower lobe of my left lung. After a lot of tests it was decided that I would benefit from surgery. I was in the Royal for three weeks in total and then had to have six weeks radiation therapy, I stayed up in Belvoir for that and went home at weekends as I lived a good distance from Belfast. The radiation didn’t bother me much, I was just tired. I got very good attention in all the hospitals and I am very happy with the care I received.*

*Now I feel great. It is over six years since I was diagnosed. I go to Belvoir Park Hospital for an annual check-up.*

*When I see young people smoking now I think they are foolish and wish I could tell them to stop before it’s too late.”*

~

*“I always had a cough as I was a smoker from I was 16. I also worked in a bar which was a smoky atmosphere. I was careless with the air I breathed. One day I felt a bad taste in my mouth and realised I had coughed up blood. I had read an article that lung cancer patients can be treated if they recognise their symptoms and go early for treatment.*

*I went to my GP and asked if I could have an X-ray. I had one in the local hospital but didn’t bother following up for the result until a few weeks later when I started to get a wheeze. I was afraid about getting the result. I was feeling a little bit better but knew I wasn’t completely right. The X-ray showed a shadow which needed urgent investigation.*

*I had a bronchoscopy and a biopsy which confirmed I had a cancerous growth. I also had a CT scan. I was then referred to the surgeon who indicated the tumour would have to be shrunk by chemotherapy before it could be operated on and even then the chemotherapy only works in 30% of cases. I was afraid of the chemotherapy. I lost all my hair. I wasn’t too tired. During that time I started to watch my diet and keep healthy. I felt I had to do something.*

*I was lucky, the tumour shrank and I was able to have surgery. That was six years ago. I can’t*

## Cancer Services Audit 1996 & 2001

### Lung

*believe how well I recovered. I had a recurrence last year with secondaries in my adrenal gland and kidney. I had to have the kidney, adrenal gland and part of the diaphragm removed. I feel very well now even though I have only one lung and one kidney. I had radiotherapy for the area around the diaphragm which finished about 10 months ago.*

*I have had a clear CT scan and will have further CT scans in the future. I didn't want a lot of information and I am happy with the level of information I received. I had paid the price for smoking. Smoking is a serious addiction which is very hard to stop. I stopped smoking about 50 times but each time I started again. The effects on health are not immediately obvious. I think it is about time we had smoke-free workplaces. I didn't realise what I was inflicting on other people as I smoked around them."*

~

*I started to smoke single cigarettes when I was eleven and by the age of thirteen got myself a paper round so I could afford the cigarettes. I was a smoker for about ten years and then gave up for about ten years but then went back on them again for another five years. I had been off them for six or seven years when, in my mid forties, about a year ago, I started to feel generally unwell. I had sore joints, swollen ankles, a rash and severe night sweats. Six weeks later I developed a cough and couldn't finish a sentence because of it.*

*I had various tests done including a chest X-ray which showed I had swollen glands in my lung. I was seen quite quickly by a respiratory physician and later had a CT scan and bronchoscopy. A biopsy was inconclusive. My case was discussed at a meeting of experts and a PET scan was ordered. Then I had a mediastinoscopy. This yielded some tissue which showed I had a definite malignancy. It was felt to be inoperable and I was referred to the oncologist.*

*Once I knew I was to have chemotherapy, the wait, whilst this was being organised, was difficult. Because of the chemotherapy I had a few days of nausea, pains in my joints and lost my hair. When the chemotherapy was finished I had a follow-up CT scan and could not believe I was being offered surgery. I saw this as my salvation*

*When the surgeon operated he took away my right lung but indicated that they had cleared all of the tumour and glands. I have had clear reviews and now keep myself fit by walking a lot. I notice that even though I have been keeping myself fit I get breathless on climbing stairs, so I am missing my lung.*

*You always have to have hope. I found great solace and hope from prayers offered for me. If I could go back in time and give myself some advice it would be don't start to smoke.*

## INTRODUCTION

This Report is the fourth in a series which examines in detail the pathway of care for cancer patients in Northern Ireland. Lung cancer represents a major cancer and the years 1996 and 2001 represent two points in time either side of the publication of the Campbell Report **“Cancer Services - Investing for the Future”**<sup>1</sup>.

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

Subsequent to the publication of the Campbell Report, a Cancer Working Group in Northern Ireland produced a sub-group report on lung cancer<sup>2</sup>. This made 18 specific recommendations in relation to lung cancer services in Northern Ireland which are listed below:

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.

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### Lung

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.

In 1998, the NHS produced a document outlining Guidance on Commissioning Cancer Services: “**Improving Outcomes in Lung Cancer**”<sup>3</sup>. Key recommendations in relation to lung cancer were made for the following areas:

- Prevention.
- Access, Diagnosis and Staging.
- Multiprofessional Teams.
- Communication, Information and Support.
- Radical Treatment for Non-small cell Lung cancer.
- Radical Treatment for Small cell Lung cancer.
- Palliative Intervention and Care.

Further recommendations<sup>4, 5, 6, 7, 8, 9</sup> were made between 1996 and 2001.

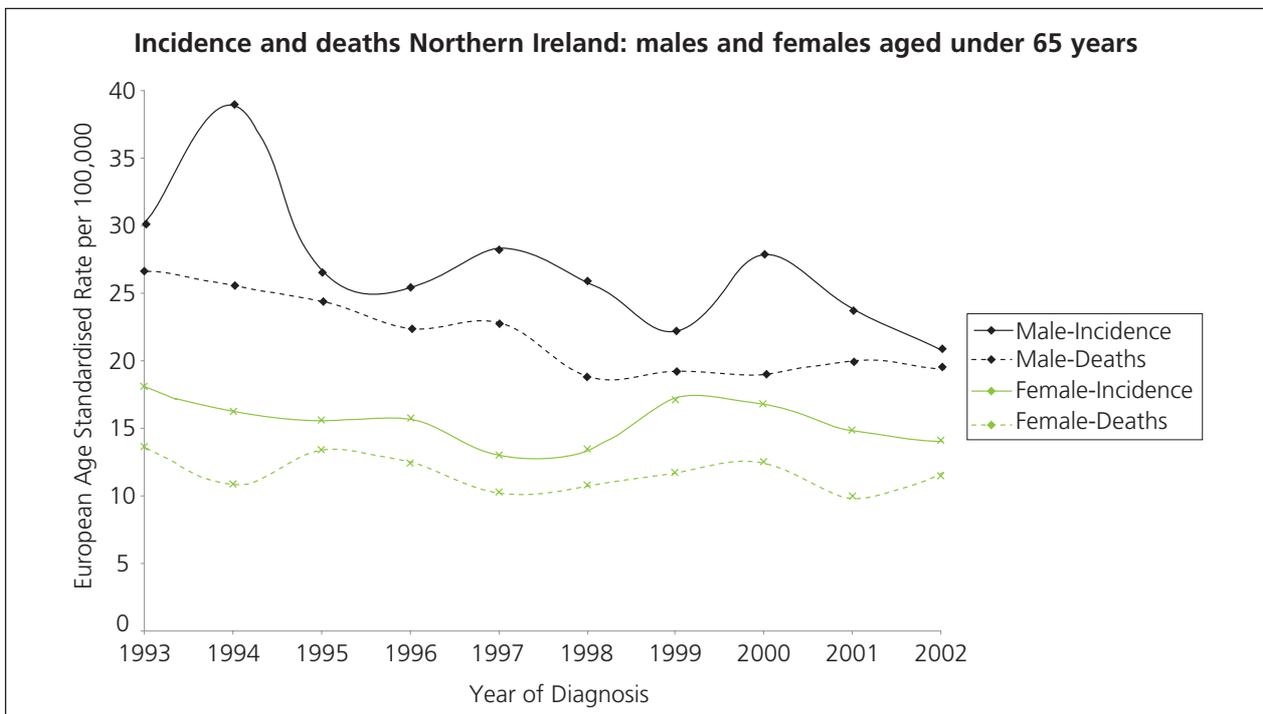
**PROJECT AIM**

This Report aims to measure changes to care for patients with lung cancer from a baseline in 1996 and to determine whether they are in keeping with the recommendations of the Campbell Report<sup>1</sup>.

**BACKGROUND**

In Northern Ireland each year 556 men and 326 women are diagnosed with cancer of the lung and 791 (505 men, 286 women) die from these cancers. Cancer of the lung accounts for 13% of cancer cases and 26% of cancer deaths in men, and 7% of cancer cases and 15% of cancer deaths in women<sup>10</sup> (annual average 1993-2001). Lung cancer is the most common cause of cancer death in men and in 2002, it overtook breast cancer to become the most common cause of cancer death in women. While deaths from lung cancer in men under 65 years have fallen significantly ( $p < 0.05$ ) between 1993 and 2002 in Northern Ireland, there has been no corresponding downward trend in women.

**Lung Cancer Trends**





## Cancer Services Audit 1996 & 2001

### Lung

#### RISK FACTORS

While lung cancer is a disease of the older age groups (half of all cases were over 70 years when diagnosed), it is still a relatively common condition in younger patients<sup>10</sup>, with 1 in 10 patients being under the age of 55 years when diagnosed. Cigarette smoking is implicated in more than 90% of cases, and although early detection would significantly improve outcome, no evidence exists to show screening can reduce lung cancer mortality<sup>7</sup>, however trials are ongoing. An individual who smokes one packet of cigarettes daily, has a 20 times increased risk of lung cancer compared to a non-smoker. The risk is proportional to the number of cigarettes per day and the number of years smoked<sup>11</sup>. 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<sup>12</sup>.

## METHODS

#### DATA COLLECTION

Registry Tumour Verification Officers (TVOs) collected data by reviewing clinical notes of cases already registered with the N. Ireland Cancer Registry. This in many cases, involved review of notes from several hospitals. Data was then entered into an electronic proforma, which had been developed with the guidance of relevant clinicians; copy available at [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)

#### EXCLUSIONS & ANALYSES

Patients were excluded if their records lacked sufficient information or if information was available only from a death certificate (DCO). After cleaning and validation, data analysis was carried out in SPSS. Statistics used to test for significance throughout the report include Chi-square. The Kaplan-Meier method was used for survival analysis.

## RESULTS

### Study patients

	Number of Patients	
	1996	2001
Total number of patients	858	884
Exclusions – Death certificate only	13	8
Exclusions – Lack of information	135	154
Total exclusions	148	162
Total reported on – Male	464 (65%)	465 (64%)
Total reported on – Female	246 (35%)	257 (36%)
Total	710 (100%)	722 (100%)
Average age at diagnosis – Male	69	69
Average age at diagnosis – Female	67	68

- The Registry identified 858 patients in 1996 and 884 in 2001 registered with lung cancer. After exclusions, 710 remained in 1996 and 722 in 2001.
- 148 patients in 1996 and 162 in 2001 were excluded, either due to lack of information or because they were death certificate only (DCO) cases.
- Almost two thirds of study patients were male.
- In 1996, 12% of study patients were over 80 years, 13% in 2001.

### Comparison of cases excluded with study patients

	All	Study Patients	Excluded
Total number of patients	1742	1432	310
Percentage female	36%	35%	39%
Percentage male	64%	65%	61%
Average age at diagnosis (years)	69	69	72
Percentage of patients dying within 1 week of diagnosis	9%	6%	24%
Percentage of patients dying within 1 month of diagnosis	26%	23%	40%
1-year observed survival (%)	22%	23%	21%

- In both years, the patients excluded were significantly older than those reported on ( $p < 0.05$  in 1996 and  $p < 0.01$  in 2001). Patients excluded were also found to have significantly lower observed survival at one year ( $p < 0.05$ ) than those included in this Report. Differences in survival were very marked at one week and one month indicating those unable to be included were very ill patients. The subset of patients in this Report therefore represent those with better prognosis. There was no statistically significant difference in the sex distribution for patients excluded/included in both years ( $p > 0.05$ ).

# Cancer Services Audit 1996 & 2001

## Lung

### Socio-economic status of patients

Deprivation Quintile	Number of Patients (%)	
	1996 (n=710)	2001 (n=722)
Quintile 1 (Least Deprived)	144 (20%)	140 (19%)
Quintile 2	113 (16%)	117 (16%)
Quintile 3	113 (16%)	133 (18%)
Quintile 4	121 (17%)	133 (18%)
Quintile 5 (Most Deprived)	219 (31%)	199 (28%)

- If a disease is not related to deprivation in the general population, it is expected that 20% of all cases of disease would fall in each quintile. Our data shows that there is no difference in the levels of lung cancer with deprivation in these populations ( $\chi^2 = 3.18, p > 0.05$ ).

This probably reflects the relatively small numbers as, in previous N. Ireland Cancer Registry reports<sup>10</sup>, a higher level of disease among most deprived groups has been shown for N.Ireland when data are combined from several years.

### Source of referral to specialist care

Source	Number of Patients (%)	
	1996 (n=710)	2001 (n=722)
GP (General Practitioner)	534 (75%)	552 (76%)
Physician	51 (7%)	56 (8%)
General surgeon	5 (<1%)	11 (1%)
Radiology	3 (<1%)	3 (<1%)
Not recorded	61 (9%)	6 (<1%)
Other *	56 (8%)	94 (13%)

- Three quarters of lung cancer cases in both years came from GP referrals, of which, about 40% were emergency admissions.
- Less than 1% of patients were direct referrals from radiology.

\*Includes self referrals, referrals from nursing homes and referrals from geriatric consultants.

### Mode of presentation

Mode of presentation	Number of Patients (%)	
	1996 (n=710)	2001 (n=722)
Outpatient referral	327 (46%)	317 (44%)
Medical emergency admission	239 (34%)	306 (42%)
Surgical emergency admission	18 (3%)	19 (3%)
Consultant referral*	38 (5%)	63 (9%)
Other**	29 (4%)	11 (1%)
Not recorded	59 (8%)	6 (<1%)

- In 2001, more patients were recorded as presenting as emergencies (45% vs 37% in 1996) ( $\chi^2 = 21.7, p < 0.001$ ).

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

### Risk factors

Risk factor	Percentage of patients recorded (% not recorded)	
	1996 (n=710)	2001 (n=722)
Smokers	84% (10%)	92% (3%)
Exposure to asbestos	25% (75%)	13% (87%)
Asbestosis	2% (16%)	<1% (<1%)

- Recording of smoking status improved between 1996 and 2001, so that by 2001 only 3% of patients did not have their smoking status recorded in their notes. Only 5% of patients had never smoked (3% of males and 7% of females).

- By 2001, a higher proportion of females with lung cancer were recorded as being current smokers (64%) compared with males (60%) (not shown).
- One quarter of patients in 1996 had a record of asbestos exposure. This had fallen to 13% by 2001, which may reflect a real change or a change in recording of this information.
- Less than 1% of patients were recorded as having asbestosis (2% in 1996).

### Co-morbidities (NOTE: Patients may have had more than one co-morbidity)

Co-morbidity	Percentage of patients recorded (% not recorded)	
	1996 (n=710)	2001 (n=722)
Cardiovascular disease	31% (6%)	34% (<1%)
COPD*	30% (10%)	29% (<1%)
Hypertension	16% (6%)	17% (<1%)
Other malignancy	9% (8%)	6% (<1%)
Cerebrovascular disease	7% (6%)	7% (<1%)
Diabetes	7% (5%)	9% (<1%)

\* *Chronic Obstructive Pulmonary Disease*

- There was better recording of co-morbidity in 2001.
- The rates of co-morbidities were similar in both years.
- Approximately one third of patients with lung cancer had a history of cardiovascular disease.
- COPD was present in almost 30% of patients

- About one patient in thirteen had a personal history of another malignancy. Of these malignancies 25% were skins, 15% were bladder, 12% were prostate, 7% colorectal, 6% breast, 5% lymphoma and 5% cervix.

# Cancer Services Audit 1996 & 2001

## Lung

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

Symptom/sign	Percentage of patients having the symptom recorded (% not recorded)	
	1996 (n=710)	2001 (n=722)
Cough	65% (13%)	60% (7%)
Breathlessness	52% (9%)	50% (1%)
Weight-loss	35% (18%)	37% (4%)
Pain	34% (10%)	28% (<1%)
Lethargy	25% (22%)	19% (1%)
Haemoptysis (Coughing blood)	24% (11%)	22% (1%)
Acute respiratory infection	24% (11%)	16% (<1%)
Unresolved pneumonia	10% (13%)	3% (<1%)
Pain on breathing	10% (17%)	14% (2%)
Hoarseness	9% (11%)	7% (1%)
Altered neurological status	7% (10%)	8% (<1%)
Dysphagia (Difficulty swallowing)	4% (12%)	4% (1%)
SVC* obstruction	3% (10%)	1% (1%)
Incidental/Asymptomatic	10% (3%)	10% (<1%)

\* Superior Vena Caval Obstruction – a rare complication of lung cancer.

- Symptom recording was better in 2001.
- Cough was the most common presenting symptom, occurring in 60% of patients.
- Just over one third of patients complained of weight-loss in both years.
- For those patients who were asymptomatic, more than three quarters in both years had their cancer first picked up on X-ray (not shown).
- Over a fifth of patients had haemoptysis, but fewer of these in 2001 (3%) had the symptom for longer than 6 months compared with 1996 (11%) (see below).
- One tenth of patients in both years were asymptomatic or presented as incidental findings, of whom four patients had finger clubbing.

### Patients who had experienced a symptom/sign for 6 months or more

Symptom/sign	Number of Patients with that symptom (%)	
	1996	2001
Weight-loss	62 (25%)	52 (19%)
Lethargy	29 (16%)	14 (11%)
Breathlessness	54 (15%)	50 (14%)
Unresolved pneumonia	11 (15%)	0
Cough	63 (14%)	58 (13%)
Hoarseness	7 (11%)	5 (10%)
Haemoptysis (Coughing blood)	19 (11%)	4 (3%)
Dysphagia (Difficulty swallowing)	3 (10%)	1 (4%)
Pain	22 (9%)	8 (4%)
Altered neurological status	4 (8%)	1 (2%)
Pain on breathing	4 (6%)	2 (2%)
Acute respiratory infection	2 (1%)	4 (3%)

- Fewer patients had haemoptysis and pain relating to their lung cancer for more than 6 months, possibly reflecting increased population awareness of symptoms.
- There was evidence of faster referral and diagnosis for patients with unresolved pneumonia by 2001, perhaps indicating improvements in service delivery.

## PRESENTATION

### Hospital of presentation

Hospital	Number of Patients (%)	
	1996 (n=710)	2001 (n=722)
Belfast City (BCH)*	157 (22%)	129 (18%)
Royal Victoria (RVH)*	83 (12%)	55 (8%)
Altnagelvin (AH)**	66 (9%)	83 (11%)
Ulster (UH)**	61 (9%)	77 (11%)
Antrim (ANT)**	52 (7%)	62 (9%)
Craigavon Area (CAH)**	31 (4%)	50 (7%)
Mater (MIH)	47 (7%)	49 (7%)
South Tyrone (STH)	28 (4%)	12 (2%)
Coleraine/Causeway (COL/CAU)	26 (4%)	32 (4%)
Whiteabbey (WHA)	26 (4%)	24 (3%)
Downe (DH)	25 (4%)	20 (3%)
Daisy Hill (DHH)	20 (3%)	37 (5%)
Lagan Valley (LVH)	16 (2%)	27 (4%)
Erne (ERN)	13 (2%)	22 (3%)
Ards Community (AR)***	13 (2%)	1 (<1%)
Tyrone County (TCH)	12 (2%)	16 (2%)
Mid Ulster (MUH)	11 (2%)	13 (2%)
Ulster Independent Clinic (UIC)****	4 (<1%)	0
Musgrave Park (MPH)	3 (<1%)	5 (<1%)
Banbridge (BBH)***	3 (<1%)	0
Braid Valley (BVH)	3 (<1%)	0
Armagh City (ACH)	2 (<1%)	0
Belvoir Park (BPR)	2 (<1%)	0
Moyle (MLE)	1 (<1%)	2 (<1%)
Mullinure (MULL)	1 (<1%)	0
Dalriada (DAL)	0	1 (<1%)
Lurgan (LGH)	0	1 (<1%)
Roe Valley (RV)	0	1 (<1%)
Waveney (WAV)	1 (<1%)	0
North-West Clinic (NWC)****	1 (<1%)	0
Not recorded	2 (<1%)	3 (<1%)

- In 1996, 710 patients presented to 27 hospitals, whilst in 2001, 722 patients presented to 22 hospitals.
- In 2001, 63% of patients presented to a Cancer Unit/Cancer Centre.

\* RVH/BCH work collaboratively as the Cancer Centre for lung cancer \*\* Cancer Unit \*\*\* Changed to community health facility with no in-patient facilities by 2001 \*\*\*\* The Ulster Independent Clinic and the North West Independent Clinic are private hospitals.

# Cancer Services Audit 1996 & 2001

## Lung

### Patients presenting within their own Board

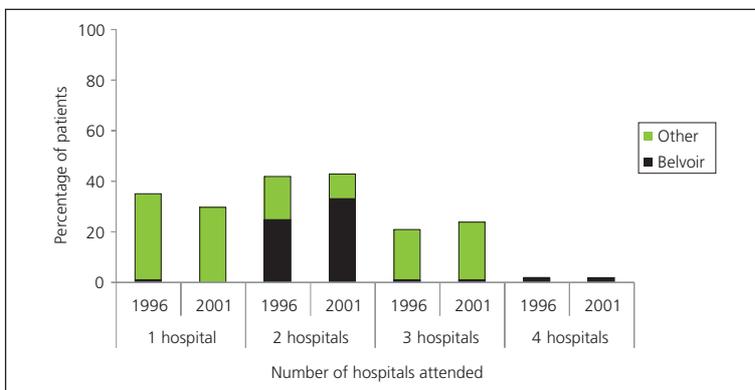
Board of residence	Number of Patients (%)	
	1996	2001
NHSSB	93 (55%)	110 (64%)
EHSSB	347 (99%)	312 (99%)
SHSSB	78 (77%)	95 (86%)
WHSSB	81 (93%)	119 (98%)

- The majority of patients (88%) presented to hospitals within their own Board of residence. This was more marked in 2001. However more than one third of patients residing in the Northern Board, presented to hospitals within the Eastern Health Board in both years.

### HOSPITALS ATTENDED

- In 2001, 31% of patients attended one hospital, 43% two hospitals, 25% three hospitals and 2% attended four hospitals for their investigations/treatment. These figures were similar to 1996.
- By 2001, 59% of patients attended Belvoir Park Hospital (Northern Ireland Radiotherapy Centre) (48% in 1996).

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



### Specialty of consultant first referred to

Source	Number of Patients (%)	
	1996 (n=710)	2001 (n=722)
Thoracic medicine	264 (37%)	368 (51%)
Thoracic surgery	26 (4%)	17 (2%)
General medicine	236 (33%)	164 (23%)
Geriatric medicine	56 (8%)	67 (9%)
Cardiology	23 (3%)	22 (3%)
ENT*	13 (2%)	5 (<1%)
Endocrinology	7 (1%)	4 (<1%)
Other	58 (8%)	71 (10%)
Not recorded	27 (4%)	4 (<1%)

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

\* Ear, nose and throat

## ECOG

Eastern Cooperative Oncology Group (ECOG) (USA) performance status<sup>13</sup> is used by doctors to assess how disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis.

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 in notes

ECOG recorded	Number of Patients (%)	
	1996 (n=710)	2001 (n=722)
Yes	28 (4%)	171 (24%)
No	682 (96%)	551 (76%)

- By 2001, a quarter of patients had an ECOG performance status recorded in their clinical notes.

ECOG code	Number of Patients (%)	
	1996 (n=28)	2001 (n=171)
0 (Fully active)	4 (14%)	43 (25%)
1	10 (36%)	45 (26%)
2	9 (32%)	44 (26%)
3	5 (18%)	36 (21%)
4 (Completely disabled)	0	3 (2%)

- Only 25% of lung cancer patients assessed were scored as grade 0, fully active.

When ECOG was recorded	Number of Patients (%)	
	1996 (n=28)	2001 (n=171)
Initial assessment	3 (11%)	40 (23%)
Preoperative	1 (4%)	9 (5%)
Postoperative	1 (4%)	1 (<1%)
Pre-chemotherapy	2 (7%)	50 (29%)
Post-chemotherapy	1 (4%)	0
Pre-radiotherapy	18 (64%)	68 (40%)
Not recorded	2 (7%)	3 (2%)

- In 2001, there was increased recording of ECOG status of patients, initially and pre-chemotherapy.

# Cancer Services Audit 1996 & 2001

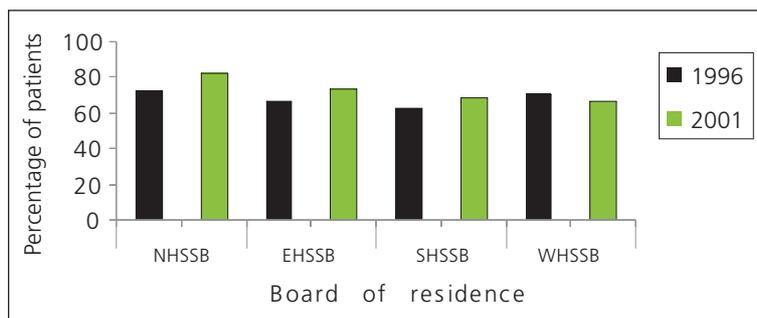
## Lung

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

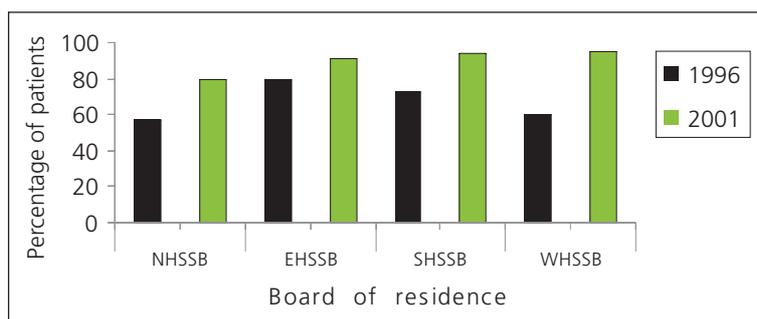
Investigation	Number of Patients (%)			
	All Patients		Surgery Patients	
	1996 (n=710)	2001 (n=722)	1996 (n=113)	2001 (n=92)
Chest X-ray	674 (95%)	691 (96%)	111 (98%)	89 (97%)
CT scan	503 (71%)	644 (89%)	107 (95%)	91 (99%)
Bronchoscopy	481 (68%)	533 (74%)	105 (93%)	84 (91%)
Mediastinoscopy	13 (2%)	42 (6%)	3 (3%)	20 (27%)

- By 2001, three-quarters of patients had a bronchoscopy and almost 90% had a CT scan.
- Almost 45% of patients had their bronchoscopy performed in Belfast City Hospital by 2001 (not shown).
- In 2001, a smaller proportion of patients had their bronchoscopy performed in the Royal Victoria (11% in 1996, 5% in 2001) and South Tyrone hospitals (5% in 1996, 0 in 2001), whilst an increase was noted in the proportion of bronchoscopies at Antrim (<1% in 1996, 13% in 2001) and Craigavon hospitals (1% in 1996, 10% in 2001(not shown). This represents service reorganisation.
- The use of mediastinoscopy increased and by 2001, was performed on 6% of all patients and 27% of surgery patients.
- The sub-group of patients who had surgery had, as expected, higher levels of CT scanning, bronchoscopy and mediastinoscopy.

### Percentage of patients having a bronchoscopy by Board of residence



### Percentage of patients having a CT scan by Board of residence



- By 2001, a higher proportion of patients in each of the Health Boards had bronchoscopies, with the exception of the Western Board, where a slight decrease was observed. However, the number of patients in the Western Board having a bronchoscopy increased (61 in 1996 to 82 in 2001).
- In 2001, the proportion of patients in the Northern Board having bronchoscopy was significantly higher than the other Boards ( $\chi^2 = 9.16$ ,  $p < 0.05$ ).
- By 2001, use of CT scanning increased substantially in all Health Boards.
- In 2001, the proportion of patients in the Northern Board having CT scans was significantly lower than the other Boards ( $\chi^2 = 25.1$ ,  $p < 0.001$ ).

### Patients having an investigation within their own Board of residence

Board of residence	Number of Patients (%)			
	Bronchoscopy		CT scan	
	1996	2001	1996	2001
NHSSB	24 (20%)	93 (65%)	18 (19%)	78 (57%)
EHSSB	231 (99%)	231 (99%)	260 (93%)	275 (96%)
SHSSB	28 (44%)	50 (66%)	44 (60%)	88 (85%)
WHSSB	54 (89%)	81 (99%)	41 (79%)	103 (89%)

- By 2001, more patients had their bronchoscopy/CT scan carried out within their Board of residence.
- However in 2001, around a third of patients in the Northern and Southern Board had their bronchoscopy carried out in the Eastern Board. Similarly, 42% of Northern Board patients, 14% of Southern Board patients and 3% of Western Board patients had their CT scan carried out in the Eastern Board.

### Investigations by age (NOTE: Patients may have had more than one type of investigation)

Investigation	Number of Patients (%)			
	79 years and under		80 years and over	
	1996 (n=623)	2001 (n=625)	1996 (n=87)	2001 (n=97)
Chest X-ray	589 (95%)	597 (96%)	85 (98%)	94 (97%)
CT scan	458 (74%)	568 (91%)	45 (52%)	76 (78%)
Bronchoscopy	448 (72%)	489 (78%)	33 (38%)	44 (45%)
Mediastinoscopy	13 (2%)	42 (7%)	0	0

- By 2001, use of bronchoscopy and CT scanning increased in both age groups.
- Those 80 years and over were as likely as younger patients to have a chest X-ray, but were less likely to have a bronchoscopy ( $\chi^2= 47.0$ ,  $p<0.001$ ) or a CT scan ( $\chi^2= 13.7$ ,  $p<0.001$ ). This may have been for clinical reasons.
- No patient aged 80 years or over had a mediastinoscopy.

### Respiratory physician assessment

Assessed by a respiratory physician	Number of Patients (%)	
	1996 (n=710)	2001 (n=722)
Yes	473 (67%)	615 (85%)
No	168 (24%)	96 (13%)
Not recorded	69 (10%)	11 (2%)

- By 2001, significantly more patients were being assessed by a respiratory physician ( $\chi^2= 80.1$ ,  $p<0.001$ ). This was observed in each Health Board.
- In 2001, there was no statistically significant difference in the proportion of patients assessed by a respiration physician by Health Board ( $p>0.05$ ).

## Cancer Services Audit 1996 & 2001 Lung

### Hospital where assessment by a respiratory physician was carried out

Hospital	Number of Patients (%)	
	1996 (n=473)	2001 (n=615)
Belfast City (BCH)*	216 (46%)	176 (29%)
Royal Victoria (RVH)*	26 (5%)	38 (6%)
Ulster (UH)**	39 (8%)	48 (8%)
Whiteabbey (WHA)	16 (3%)	17 (3%)
Lagan Valley (LVH)	12 (2%)	23 (4%)
Mater (MIH)	5 (1%)	38 (6%)
Altnagelvin (AH)**	98 (21%)	103 (17%)
Erne (ERN)	1 (<1%)	18 (3%)
Craigavon Area (CAH)**	0	55 (9%)
South Tyrone (STH)	24 (5%)	7 (1%)
Coleraine/Causeway (COL/CAU)	6 (1%)	29 (5%)
Antrim (ANT)**	3 (<1%)	51 (8%)
Other	11 (2%)	12 (2%)
Not recorded	16 (3%)	0

- In 1996, 46% of patients had their assessment carried out in Belfast City Hospital. This decreased to 29% in 2001.
- In 2001, there were a higher proportion of patients assessed by a respiratory physician in Antrim, Craigavon, Coleraine/Causeway and Mater hospitals than in 1996. The proportion of patients assessed in Altnagelvin and South Tyrone hospitals decreased during the same period, although the numbers actually increased in Altnagelvin.

\* RVH/BCH work collaboratively as the Cancer Centre for lung cancer \*\* Cancer Unit

### 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 of diagnosis	Number of Patients (%)			
	All Patients		Surgery Patients	
	1996 (n=710)	2001 (n=722)	1996 (n=113)	2001 (n=92)
Histopathology	332 (47%)	350 (48%)	97 (86%)	82 (89%)
Cytology	204 (29%)	224 (31%)	14 (12%)	9 (10%)
CT scan	71 (10%)	98 (14%)	1 (<1%)	1 (1%)
X-ray	59 (8%)	16 (2%)	1 (<1%)	0
Bronchoscopy	8 (1%)	13 (2%)	0	0
Clinical opinion	26 (4%)	18 (2%)	0	0
Other*	10 (1%)	3 (<1%)	0	0

\* 'Other' includes endoscopy, MRI Scan and Ultrasound.

- Over three quarters of patients in both years had a histologically/cytologically confirmed diagnosis of lung cancer. Almost all surgery patients had a microscopically confirmed diagnosis of lung cancer.

**HISTOPATHOLOGY**

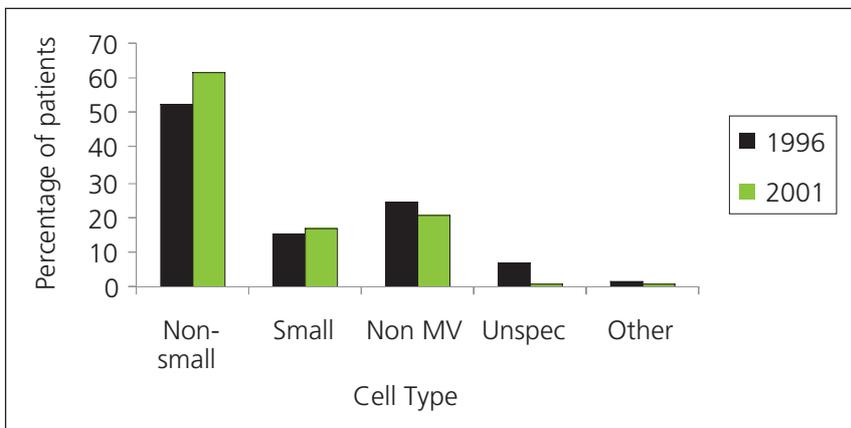
**Histopathological Type**

Sub type	Number of Patients (%)	
	1996 (n=710)	2001 (n=722)
Non-small (NSCLC)	375 (53%)	444 (61%)
Small (SCLC)	106 (15%)	120 (17%)
Unspecified	46 (7%)	5 (<1%)
Other*	9 (1%)	4 (<1%)
Non MV**	174 (24%)	149 (21%)

\*'Other' includes carcinoid and mucinoid  
\*\* Non MV – Non Microscopically Verified

- There was better histopathological sub-typing in 2001 compared with 1996, with fewer cases unspecified.
- As expected, non-small cell lung cancer was the most common histological type.
- In 2001, of those histologically verified, 77% were non-small cell, 21% small cell, 1% unspecified and less than 1% other. The corresponding cell types for 1996 were 70% non-small cell, 20% small cell, 9% unspecified and 2% other.

**Histological classification of lung cancer**



**STAGING** (see also Appendix B)

- Recording of stage in the clinical notes, had improved by 2001, with 23% of patients having stage recorded compared to only 9% in 1996.
- By 2001, 59% of patients undergoing surgery had a stage recorded in their notes.

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 was applied<sup>14</sup>.

## Cancer Services Audit 1996 & 2001 Lung

### TNM Stage (recorded in notes or Registry-assigned)

Stage	Number of Patients (%)			
	All Patients		Surgery Patients	
	1996 (n=710)	2001 (n=722)	1996 (n=113)	2001 (n=92)
Stage I	63 (9%)	94 (13%)	45 (40%)	38 (41%)
Stage II	34 (5%)	38 (5%)	15 (13%)	21 (23%)
Stage IIIA	37 (5%)	42 (6%)	14 (12%)	11 (12%)
Stage IIIB	82 (12%)	35 (5%)	9 (8%)	5 (5%)
Stage IV	226 (32%)	249 (35%)	16 (14%)	5 (5%)
Staging not possible*	268 (38%)	264 (37%)	14 (12%)	12 (13%)

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

- Overall, one third of patients did not have sufficient information in their notes for a stage to be determined.
- Approximately one third of patients presented with Stage IV disease in both years (accounting for 51% in 1996 and 54% in 2001 of those staged).
- 87% of patients undergoing surgery were or could be staged by 2001.
- By 2001, the percentage of surgery patients found to have advanced stage disease decreased, while the percentage of Stage II increased, indicating better pre-operative staging practice allowing selection of patients in whom cure is possible.

### Patients with insufficient data for TNM Staging

Area of residence	Number of Patients	
	Total unstaged in each area (%)	
	1996	2001
NHSSB	65 (38%)	72 (41%)
EHSSB	125 (36%)	109 (34%)
SHSSB	43 (43%)	43 (39%)
WHSSB	35 (40%)	40 (33%)
N. Ireland	268 (38%)	264 (37%)

- The percentage of patients for whom it was not possible to determine stage decreased between 1996 and 2001 for all Board patients, except for those residing in the Northern Board. The greatest improvement was noted for patients of the Western Board.

### MULTIDISCIPLINARY TEAM MEETINGS

The effective management of lung cancer patients requires input from a range of experts. Multidisciplinary team meetings (MDMs) involve a group of healthcare professionals meeting to discuss the diagnosis and treatment of patients. As there are a range of potential treatments that could be carried out, multidisciplinary discussions are of great importance. With respect to MDMs 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

Area of residence	Number of Patients having a MDM recorded in their notes (%)	
	1996	2001
NHSSB	22 (13%)	74 (43%)
EHSSB	97 (28%)	148 (47%)
SHSSB	16 (16%)	45 (41%)
WHSSB	2 (2%)	75 (62%)
N. Ireland	137 (19%)	342 (47%)

- Recording in the clinical notes that discussion at a MDM had taken place improved substantially from 19% in 1996 to 47% in 2001.
- The greatest improvement was noted for residents of the Western Board.

#### Multidisciplinary treatment plan recorded in the notes by Board

Area of residence	Number of Patients having a MD treatment plan recorded in their notes (%)	
	1996	2001
NHSSB	5 (3%)	57 (33%)
EHSSB	47 (13%)	130 (41%)
SHSSB	8 (8%)	40 (36%)
WHSSB	2 (2%)	74 (61%)
N. Ireland	62 (9%)	301 (42%)

- Recording in the clinical notes of the multidisciplinary treatment plan also improved, but by 2001, 58% of patients did not have one recorded.
- The greatest improvement was noted for residents of the Western Board.
- Not all patients discussed at a MDM had a treatment plan recorded in their notes but all with a treatment plan had been discussed at a MDM.

## Cancer Services Audit 1996 & 2001

### Lung

#### SURGICAL PROCEDURES (see Appendix B p.33 for management of lung cancer)

For the purposes of this Report, surgery is classified as thoracotomy (n<sub>1996</sub>=113, n<sub>2001</sub>=92) and/or excisions which include lobectomy, pneumonectomy and segmentectomy (n<sub>1996</sub>=91, n<sub>2001</sub>=80). Pleural aspiration, mediastinoscopy and endobronchial therapy were not included and are classified as other procedures.

Surgery	Number of Patients (%)			
	All Patients		Patients 80 years and older	
	1996 (n=710)	2001 (n=722)	1996 (n=87)	2001 (n=97)
Yes	113 (16%)	92 (13%)	1 (1%)	2 (2%)
No	443 (62%)	626 (87%)	64 (74%)	94 (97%)
Not recorded	154 (22%)	4 (<1%)	22 (25%)	1 (<1%)

- There was a reduction in the number of surgical procedures performed between 1996 and 2001 from 16% to 13%, perhaps reflecting improved initial staging.
- By 2001, 94% of patients receiving surgery had non-small cell lung cancer (87% in 1996).
- Of those patients not undergoing a surgical procedure, 61 patients in 1996 and 42 in 2001 died within one week of being diagnosed, 13 patients in 1996 and 18 in 2001 were offered surgery but declined, and 35 patients in 1996 and 12 in 2001 were recorded as being unfit for surgery.
- In 1996, 35 Stage I/II patients did not have surgery, three of which were offered surgery but declined, with a further 8 patients recorded as being unfit. In 2001, 74 Stage I/II patients did not have surgery, two of which were offered surgery but declined, with a further 7 patients recorded as being unfit.

#### Procedure intent as recorded in notes

Procedure intent	Number of Surgery Patients (%)	
	1996 (n=113)	2001 (n=92)
Curative	70 (62%)	75 (82%)
Diagnostic	12 (11%)	13 (14%)
Palliative	7 (6%)	2 (2%)
Staging	4 (4%)	0
Not recorded	20 (18%)	2 (2%)

- By 2001, there was significantly better recording of surgical intent, with more curative intent recorded ( $\chi^2=19.8$ , p<0.001).

#### Other recorded procedures for lung cancer

Other procedures	Number of Patients (%)	
	1996 (n=710)	2001 (n=722)
Pleural aspiration	41 (6%)	11 (1%)
Mediastinoscopy	13 (2%)	42 (6%)
Endobronchial therapy	1 (<1%)	5 (1%)

- By 2001, only a small proportion of patients had endobronchial therapy, while mediastinoscopy rates increased to 6%.

### Oncology treatment for lung cancer

Treatment	Number of Patients (%)			
	Chemotherapy		Radiotherapy	
	1996 (n=710)	2001 (n=722)	1996 (n=710)	2001 (n=722)
Yes	88 (12%)	137 (19%)	295 (42%)	329 (46%)
No	510 (72%)	581 (80%)	351 (49%)	391 (54%)
Not recorded	112 (16%)	4 (<1%)	64 (9%)	2 (<1%)

- Just under half of patients had radiotherapy in 2001, whilst less than one fifth had chemotherapy.
- By 2001, use of chemotherapy and radiotherapy had increased.

### Treatment modalities for lung cancer patients as recorded in notes

Treatment	Number of Patients (%)	
	1996 (n=710)	2001 (n=722)
Surgery alone	58 (8%)	62 (9%)
Chemotherapy alone	23 (3%)	44 (6%)
Radiotherapy alone	131 (18%)	228 (32%)
Combination chemo & radio	33 (5%)	77 (11%)
Combination chemo & surgery	2 (<1%)	10 (1%)
Combination radio & surgery	28 (4%)	15 (2%)
Combination chemo, radio & surgery	8 (1%)	5 (<1%)
None of the above treatments	206 (29%)	273 (38%)
Not recorded	221 (31%)	8 (1%)

*chemo - chemotherapy, radio - radiotherapy*

- In 2001, there was better recording of treatment, with only 1% of patients not having their treatment recorded compared with 31% in 1996.
- In 2001, 38% of patients did not have surgery, chemotherapy or radiotherapy, compared with 29% in 1996. However, these patients are likely to have treatment related to palliative care.

### Patients who had no active treatment recorded

Patient factors	Number of Patients (%)	
	1996 (n=206)	2001 (n=273)
Stage IV	74 (36%)	111 (41%)
Aged over 80 years at diagnosis	41 (20%)	60 (22%)
Died within 2 weeks of diagnosis	49 (24%)	88 (32%)
Patient recorded as declining treatment	12 (6%)	38 (14%)
Patient recorded as being unfit for treatment	26 (13%)	28 (10%)

*Note: Categories are not mutually exclusive*

- Of those patients who did not receive any treatment regime, 36% in 1996 and 41% in 2001, presented with late Stage IV disease.
- Approximately one fifth of patients in both years, were aged over 80 at the time of diagnosis.
- 14% of patients declined further treatment.

## Cancer Services Audit 1996 & 2001 Lung

### Frequency of lung cancer surgery carried out by surgeon

Procedures	Number of Surgeons (% of procedures)	
	1996	2001
41 or more procedures	0	1 (51%)
21 – 40 procedures	3 (78%)	1 (36%)
11 – 20 procedures	0	1 (13%)
6 – 10 procedures	1 (8%)	0
2 – 5 procedures	1 (3%)	0
1 procedure	2* (2%)	0
Surgeon's name not available	(9%)	0
Total surgeons	7	3
Total procedures	113	92

\* One of these was performed in Dublin

- Almost 90% of patients in 1996 and 2001 were operated on by a surgeon who performed at least 21 lung cancer operations per year. The largest number of operations performed by a single surgeon was 32 in 1996 and 47 in 2001.
- Three surgeons performed surgery in both years.

### TIMELINES/WAITING TIMES

#### Summary timeline for all patients

Time	Number of Patients (%)			
	Referral - First Seen at Hospital		First Seen - Diagnosis*	
	1996 (n=710)	2001 (n=722)	1996 (n=710)	2001 (n=722)
Same day	281 (40%)	351 (49%)	91 (13%)	41 (6%)
1 – 14 days	178 (25%)	227 (31%)	319 (45%)	389 (54%)
15 – 42 days	69 (10%)	96 (13%)	110 (16%)	163 (23%)
43 – 84 days	14 (2%)	23 (3%)	42 (6%)	61 (8%)
More than 84 days	8 (1%)	5 (<1%)	57 (8%)	61 (8%)
Minus values**	0	0	1 (<1%)	1 (<1%)
Not recorded	160 (23%)	20 (3%)	90 (13%)	6 (<1%)

\*For almost 80% of patients, date of diagnosis equals date of histological/cytological confirmation

\*\* Minus values – diagnosis made prior to hospital visit

- Between 1996 and 2001 the percentage of patients seen within 2 weeks of referral increased from 65% to 80%.
- Slightly more people in 2001 had their diagnosis made within 2 weeks of being first seen (60% vs 58% in 1996).
- Fewer patients in 2001 had their diagnosis made on the day they were first seen at hospital. However of the 91 patients in 1996 diagnosed on the day they were first seen at hospital, 62% presented as an emergency (27% in 2001).

### Summary timeline for all patients

Time	Number of Patients (%)			
	Referral – CT scan		Referral – Bronchoscopy	
	1996 (n=503)	2001 (n=644)	1996 (n=481)	2001 (n=533)
Same day	9 (2%)	21 (3%)	5 (1%)	4 (<1%)
1 – 14 days	151 (30%)	281 (44%)	174 (36%)	251 (47%)
15 – 42 days	123 (25%)	186 (29%)	117 (24%)	180 (33%)
43 – 84 days	44 (9%)	69 (11%)	40 (8%)	45 (8%)
More than 84 days	33 (7%)	40 (6%)	31 (6%)	35 (6%)
Minus values*	12 (2%)	27 (4%)	6 (1%)	1 (<1%)
Not recorded	131 (26%)	20 (3%)	108 (23%)	17 (3%)

\* Minus values – investigation was carried out prior to referral

- There was better recording of information on timing of investigation in 2001 compared with 1996.
- Between 1996 and 2001 the percentage of patients having a CT scan within 2 weeks of referral, increased from 34% to 51%.
- Similarly, more patients in 2001 (48%) had a bronchoscopy within 2 weeks of referral, compared to 1996 (38%).
- 17% of patients waited over 6 weeks for a CT scan, while 14% waited over 6 weeks for a bronchoscopy in both years.

### Summary timeline for all patients

Time	Number of Patients (%)					
	Referral - First seen by a respiratory physician		Diagnosis - First seen by a thoracic surgeon		First seen by a thoracic surgeon - Surgery	
	1996 (n=473)	2001 (n=615)	1996 (n=241)	2001 (n=197)	1996 (n=113)	2001 (n=92)
Same day	35 (7%)	90 (15%)	4 (2%)	11 (6%)	5 (4%)	4 (4%)
1 – 14 days	185 (39%)	304 (49%)	32 (13%)	23 (12%)	46 (41%)	34 (37%)
15 – 42 days	85 (18%)	147 (24%)	39 (16%)	47 (24%)	19 (17%)	32 (35%)
43 – 84 days	32 (7%)	34 (5%)	26 (11%)	21 (11%)	16 (14%)	14 (15%)
More than 84 days	16 (3%)	22 (4%)	6 (3%)	14 (7%)	7 (6%)	5 (5%)
Minus values*	4 (<1%)	0	76 (32%)	67 (34%)	0	0
Not recorded	116 (25%)	18 (3%)	58 (24%)	14 (7%)	20 (18%)	3 (3%)

\* Minus values – patients had a histologically/cytologically confirmed diagnosis but may have had an earlier clinical diagnosis

- By 2001, 64% of patients were seen within 2 weeks of referral to a respiratory physician, compared to 47% in 1996.
- Similarly, more patients in 2001 (51%) were seen by a thoracic surgeon within 2 weeks of diagnosis, compared to 1996 (46%) .
- In 2001, 41% of patients had their surgery within 2 weeks of being seen by a thoracic surgeon, compared to 45% in 1996.

## Cancer Services Audit 1996 & 2001 Lung

### Information recorded in notes

Information	Number of Patients (%)	
	1996 (n=710)	2001 (n=722)
Diagnosis discussed with patient	411 (58%)	601 (83%)
Diagnosis not discussed with patient	61 (9%)	77 (11%)
Treatment plan discussed with patient	402 (57%)	595 (82%)
Referred to oncology centre	374 (53%)	452 (63%)
Entered for clinical trial	19 (3%)	5 (<1%)

- By 2001, over 80% of patients had information on discussion of diagnosis and treatment plan recorded in their notes, an improvement from 1996.
- The number of patients referred to oncology increased from 53% to 63%.
- Few patients were being entered into clinical trials (3% in 1996 and less than 1% in 2001). This may reflect availability of suitable trials.
- About one in ten patients had a record that their diagnosis was not discussed with them, and was similar for both males and females. This increased to 25% when information included in the GP letter was considered (see later).
- Of those patients who did not have their diagnosis discussed with them in 2001, 44% were aged over 80 years, 47% died within two weeks of diagnosis, while 38% had significant co-morbidities. (Note: these were not mutually exclusive categories).

### 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 referral).

After Care	Number of Patients (%)	
	1996 (n=710)	2001 (n=722)
GP	169 (24%)	589 (82%)
Community nurse	41 (6%)	119 (17%)
Macmillan nurse	99 (14%)	287 (40%)
Hospice	65 (9%)	124 (17%)
Marie Curie nurse	14 (2%)	19 (3%)
Palliative care specialist	31 (4%)	193 (27%)
Psychologist referral	6 (<1%)	14 (2%)
Info on support groups/education supplied	2 (<1%)	14 (2%)
No onward referral recorded	438 (61%)	107 (15%)

- By 2001 the recording of referral to after care had improved, with only 15% of patients having no onward referral recorded in their notes (61% in 1996).
- In 2001, there was increased recording of referrals to all services noted above, most notably Macmillan nurses, Hospices and Palliative care specialists.
- Few patients were referred to a Marie Curie nurse or a psychologist (3% and 2% respectively in 2001), with only 2% of patients in 2001 recorded as having been given information on support groups. It is 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.
- Provision of information on support groups etc. was poorly recorded in the notes.
- The percentage of patients referred for some form of palliative care increased from 25% in 1996 to 54% in 2001, reflecting increased availability of this service and the poor prognosis of lung cancer.

#### Information in GP letter

Information	Number of Patients (%)	
	1996 (n=710)	2001 (n=722)
Diagnosis discussed with patient	283 (40%)	466 (65%)
Diagnosis not discussed with patient	118 (17%)	183 (25%)
Diagnosis discussed with family	240 (34%)	340 (47%)
Prognostic information	320 (44%)	276 (38%)
Management plan	544 (77%)	665 (92%)

- Fewer patients in 2001 had their prognosis recorded in their information to the GP.
- More patients in 2001 had recorded in their information to the GP that their diagnosis had been discussed with themselves or their family.
- More than 90% of patients in 2001 had a management plan recorded.

#### PATIENT OUTCOMES

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

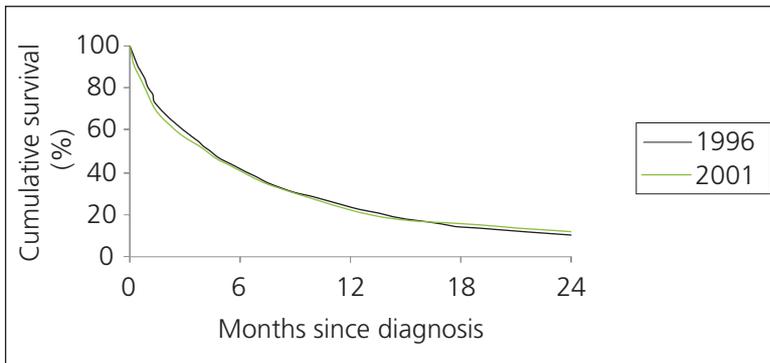
#### Percentage of patients alive at various times after diagnosis

Time	Surgery only patients		Non-surgery patients		All patients	
	1996	2001	1996	2001	1996	2001
30 days	99%	97%	76%	74%	80%	77%
60 days	96%	95%	62%	60%	67%	64%
6 months	79%	90%	34%	33%	42%	40%
1 year	64%	72%	15%	15%	23%	22%
2 years	42%	55%	5%	5%	11%	11%
Total patients	113	92	597	630	710	722

# Cancer Services Audit 1996 & 2001

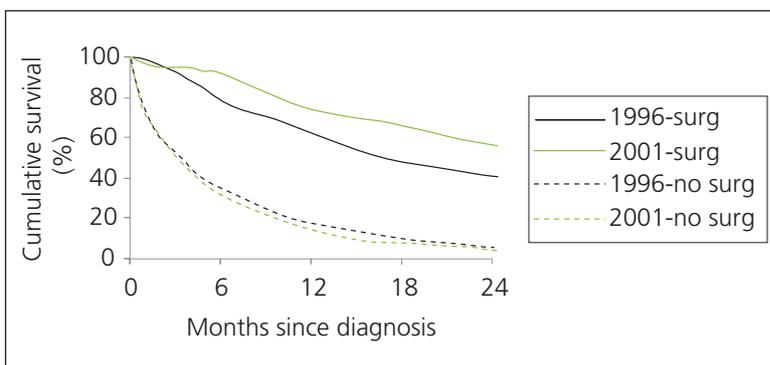
## Lung

### Lung cancer observed survival by year (all patients)



- Survival from lung cancer is poor, with observed one-year survival at 22% and two-year survival at 11%.
- There was no significant difference in the overall survival of patients in 1996 compared with 2001 ( $p>0.05$ ).

### Lung cancer observed survival by year and by surgery



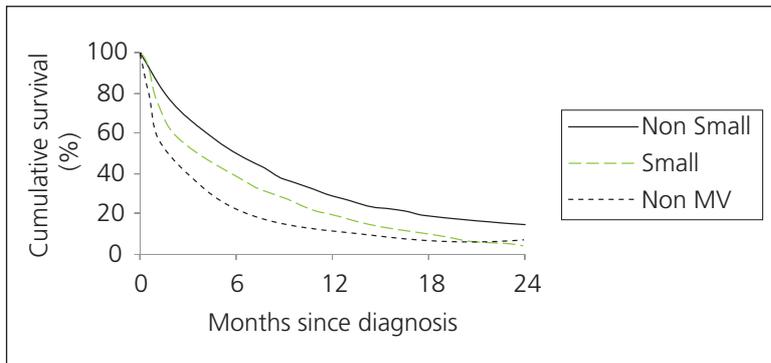
- For those patients who had surgery, survival was significantly better in 2001 than in 1996 ( $p<0.01$ ), with two-year survival of 55% (2001), reflecting enhanced selection of patients for curative-intent surgery.
- As noted earlier the percentage of surgery patients who had late Stage IV disease fell from 14% to 5%, while those with earlier Stage I or Stage II disease increased from 53% to 64%.

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

Time	Non-Small	Small	Non-MV*	Unspecified	Other**
30 days	86%	76%	77%	88%	61%
60 days	75%	59%	65%	85%	47%
6 months	50%	38%	22%	72%	22%
1 year	28%	19%	4%	56%	11%
2 years	15%	4%	0	-	5%
Total patients	819	226	52	13	322

\*Non-MV= non microscopically verified \*\*Other included carcinoid and mucinoid

**Lung cancer observed survival for all patients by cell type**



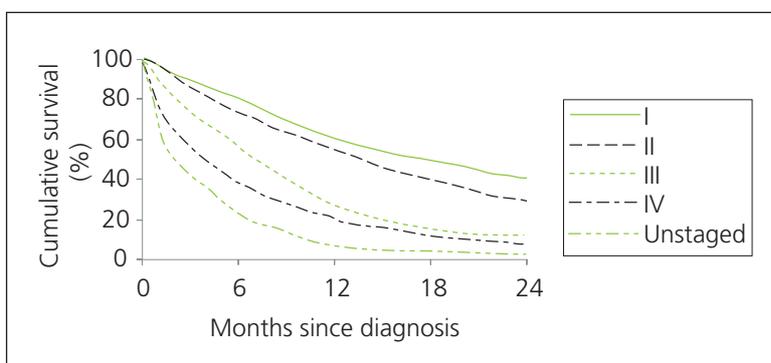
- As expected, there was a highly significant difference in the overall survival of patients by cell type ( $p < 0.001$ ), with the non-microscopically verified patients having the poorest overall observed survival (11% at one-year and 5% at two years).
- Patients with non-small cell type lung cancer had the best survival (28% at one-year and 15% at two years).

*Non-MV= non microscopically verified*

**Percentage of patients alive at various times after diagnosis by stage**

Time	Stage I	Stage II	Stage III	Stage IV	Unstaged
30 days	98%	95%	90%	68%	76%
60 days	93%	90%	82%	49%	63%
6 months	80%	73%	55%	22%	37%
1 year	61%	54%	27%	7%	19%
2 years	41%	29%	11%	2%	7%
Total patients	157	72	196	475	532

**Lung cancer observed survival for all patients by stage**



- As expected, there was a highly significant difference in the overall survival of patients by stage ( $p < 0.001$ ), with late Stage IV disease patients having the poorest overall observed survival, 2% at two years, compared to 41% at two years for Stage I patients.

## **LUNG CANCER SUMMARY**

### **RISK FACTORS**

- Only 5% of patients had never smoked.
- Between 13% (2001) and 25% (1996) of patients had a recorded history of asbestos exposure.

### **PRESENTATION**

- Three quarters of all diagnosed lung cancer cases in both years came from GP referrals, with less than 1% direct referrals from radiology.
- 710 patients presented to 27 hospitals in 1996 and 722 patients presented to 22 hospitals in 2001, almost 40% of these were emergencies.
- In 2001, 63% of patients presented to a Cancer Unit/Cancer Centre.
- As expected, the majority of patients presented to hospitals within their own Health Board of residence.
- The most common presenting symptom was a cough (60%).
- Over one fifth of patients had haemoptysis, but fewer of these in 2001 (3%) had the symptom for longer than 6 months compared with 1996 (11%).
- One tenth of patients in both years were asymptomatic or presented as incidental findings, of whom four patients had finger clubbing.
- There was evidence of faster referral and diagnosis for patients with unresolved pneumonia by 2001, perhaps indicating improvements in service delivery.
- Chronic Obstructive Pulmonary Disease was present in almost 30% of patients, while about one third of patients had a history of cardiovascular disease.
- One patient in thirteen had a personal history of another malignancy.

### **INVESTIGATIONS AND ASSESSMENT**

- Between 1996 and 2001 there was an increased recording of use of bronchoscopy (68% to 74%) and CT scan (71% to 89%).
- The sub-group of patients who had surgery had, as expected, higher levels of CT scanning (99%), bronchoscopy (91%) and mediastinoscopy (27%).
- In 2001, a higher proportion of Northern Board residents had bronchoscopy whilst fewer had CT scan investigations compared with other Board residents.
- By 2001, more patients had their investigations carried out within their Health Board of residence.
- In both years, those over 80 years were significantly less likely to receive a bronchoscopy or CT scan. This may have been for clinical reasons.
- By 2001 more patients were assessed by a respiratory physician (85% vs 67% in 1996). There was no variation in this service by Board of residence.
- The proportion of patients who had their ECOG performance status recorded increased from 4% in 1996 to 24% in 2001.

#### STAGING

- It was possible to determine stage in over 60% of cases in both years - 87% of surgery patients by 2001.
- The percentage of patients for whom it was not possible to determine stage decreased between 1996 and 2001 in all Boards between the two years, with the exception of the Northern Board, where slightly more patients were unstaged.
- By 2001, the percentage of surgery patients found to have advanced stage disease decreased, while the percentage of Stage II patients increased, indicating better pre-operative staging practice allowing selection of patients in whom cure is possible.
- Approximately one third of patients presented with Stage IV disease in both years (accounting for 51% in 1996 and 54% in 2001 of those staged).

#### HISTOLOGY

- About three quarters of lung cancer patients had a histological/cytological diagnosis in both years. For those having surgery, this rose to almost 100%.
- As expected, the majority of lung cancers in both years were non-small cell (61% in 2001).

#### RECORDING OF MULTIDISCIPLINARY TEAM MEETINGS

- Recording in the clinical notes that discussion at a MDM had taken place improved from 19% in 1996 to 47% in 2001.
- Recording in the clinical notes of the multidisciplinary treatment plan also improved, but by 2001, 58% of patients did not have one recorded.

#### SURGERY AND ONCOLOGY

- In 1996, 113 surgical procedures were carried out by 7 surgeons (includes one in Dublin), while in 2001, 92 operations were performed by 3 surgeons.
- By 2001, almost 90% of lung surgery was performed by surgeons with high case volume (21 or more procedures per year).
- The largest number of operations performed by a single surgeon was 32 in 1996 and 47 in 2001.
- In 1996, 2% of the surgery workload was performed by surgeons who were recorded as operating on one patient in that year, by 2001, all were operated on by high volume operators.
- The percentage of patients referred to oncology increased from 53% to 63% with attendances at Belvoir Park Hospital (Northern Ireland Radiotherapy Centre) increasing from 48% of lung cancer patients in 1996 to 59% by 2001.
- Overall use of chemotherapy increased from 12% to 19%. This trend was also seen for radiotherapy (42% to 46%).
- In 2001, 38% of patients did not have a record of having had surgery, chemotherapy or radiotherapy treatment (29% in 1996). Of these 41% were late Stage IV disease and 32% died within two weeks of diagnosis.
- By 2001, only a small proportion of patients (1%) had endobronchial therapy while mediastinoscopy rates increased to 6%.

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### TIMELINES/WAITING TIMES

- Between 1996 and 2001 the percentage of patients seen within 2 weeks of referral increased from 65% to 80%.
- Slightly more people in 2001 had their diagnosis made within 2 weeks of being first seen (60% vs 58% in 1996).
- Between 1996 and 2001 the percentage of patients having a CT scan within 2 weeks of referral, increased from 34% to 51%.
- Similarly, more patients in 2001 (48%) had a bronchoscopy within 2 weeks of referral, compared to (38%) 1996.
- Between 1996 and 2001 the percentage of patients seen by a respiratory physician within 2 weeks of referral increased from 47% to 64%.
- In 2001, more patients saw a thoracic surgeon within two weeks of their diagnosis (51% compared with 46% in 1996).
- In 2001, 41% of patients had their surgery within 2 weeks of being seen by a thoracic surgeon (45% in 1996).

### ONWARD REFERRAL/CLINICAL TRIALS

- The percentage of patients referred for some form of palliative care increased from 25% in 1996 to 54% in 2001, reflecting increased availability of this service and the poor prognosis of lung cancer.
- By 2001 the proportion of patients entered into a clinical trial had fallen from 3% in 1996 to less than 1%.

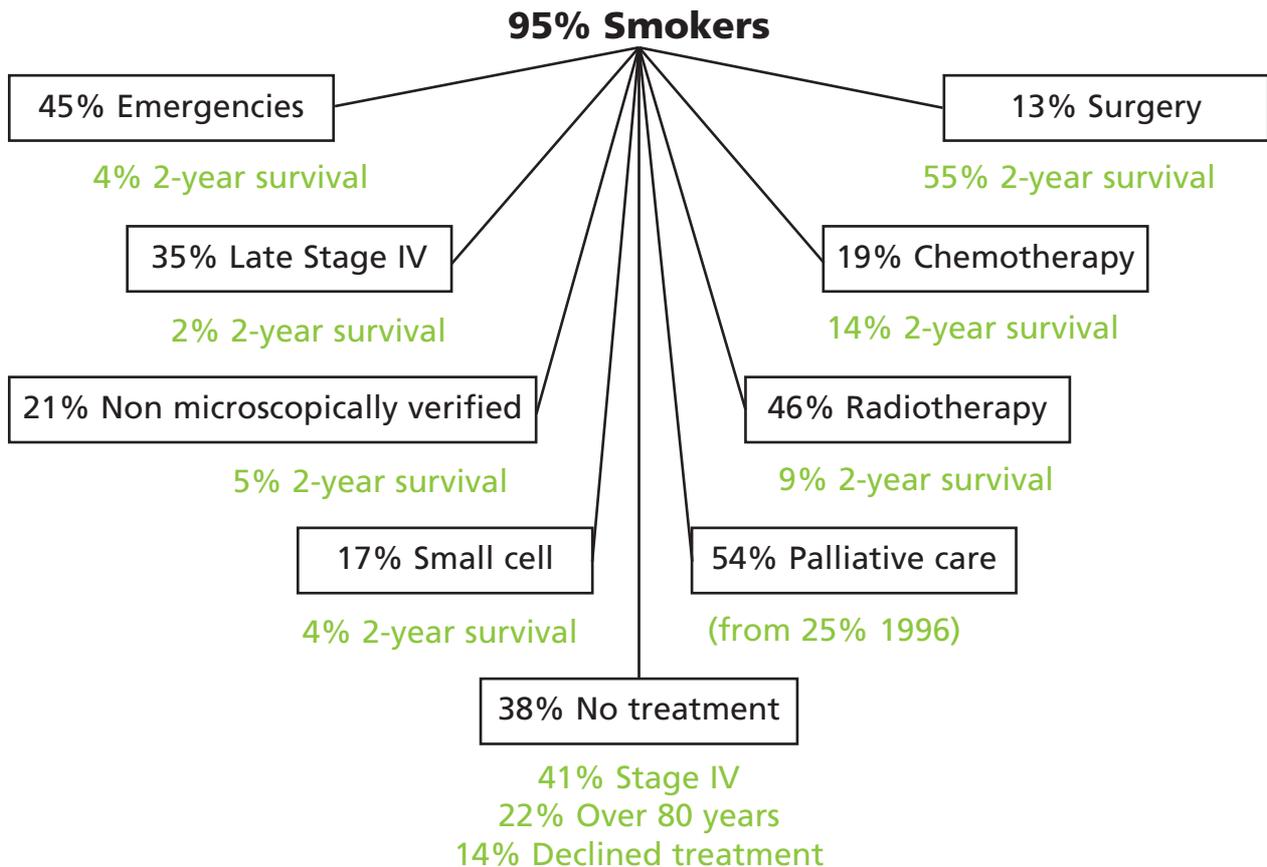
### COMMUNICATION

- By 2001, over 80% of patients had discussion of diagnosis and treatment plan recorded in the notes, an improvement from 1996 (57%).
- Overall, information to the GP has greatly improved from 1996 to 2001, especially patient and family awareness of diagnosis.
- More than 90% of patients in 2001 had a management plan recorded in their GP letter.
- Fewer patients in 2001 had their prognosis recorded in their information to the GP (38% vs 44% in 1996).

### OUTCOMES

- Survival from lung cancer is poor with observed two year survival at 11% in both years, with no significant difference in the overall survival of patients in 1996 and 2001 ( $p>0.05$ ).
- Patients receiving surgery had significantly better survival in 2001 than in 1996 ( $p<0.01$ ), with observed two year survival of 55% in 2001. This reflects appropriate selection of patients for curative surgery.
- As expected, there was a highly significant difference in the overall survival of patients by stage of disease ( $p<0.001$ ), with 41% of Stage I patients alive at two years, and as expected, Stage IV disease having the poorest survival (2% at two-years).
- As expected, there was a highly significant difference in the overall survival of patients by cell type ( $p<0.001$ ), with the non-microscopically verified patients having the poorest overall observed survival (11% at one-year and 5% at two-years).
- Patients with non-small cell type lung cancer had the best survival (28% at one-year and 15% at two-years).

## Lung Cancer Patients (2001 Summary)



Note: patients may be included in more than one category.

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

- Almost half (45%) of patients present as emergencies; they have a 4% 2-year survival.
- Over a third (35%) of patients are late Stage IV disease at presentation, a 2-year observed survival for these patients is only 2%.
- A fifth of patients do not have a microscopic verification of their diagnosis, for this subgroup their 2-year survival is 5%.
- 17% of patients present with small cell tumours, a subgroup with poorer survival than the average at 4% for 2-year survival.
- By comparison, the subgroup of patients diagnosed 2001 who were fit to have surgery had a 55% 2-year survival.
- 95% of these lung cancer patients smoked tobacco. Tobacco is a major risk factor in the development of lung cancer.

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

## **CONCLUSION, KEY ISSUES AND RECOMMENDATIONS**

By 2001, the following improvements were apparent:

- There was evidence of earlier presentation by patients and better management of referrals by primary care.
- Waiting times had improved.
- Recording of MDM 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**

- 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 service organisers.
- 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.

### **RECOMMENDATIONS**

- 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.

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## **APPENDIX A**

### **Campbell Report<sup>1</sup>: Recommendations regarding Cancer Services in N. Ireland, 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

### STAGING 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<sup>14</sup> is shown in Table 1.

#### 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 is 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.

#### 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

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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.

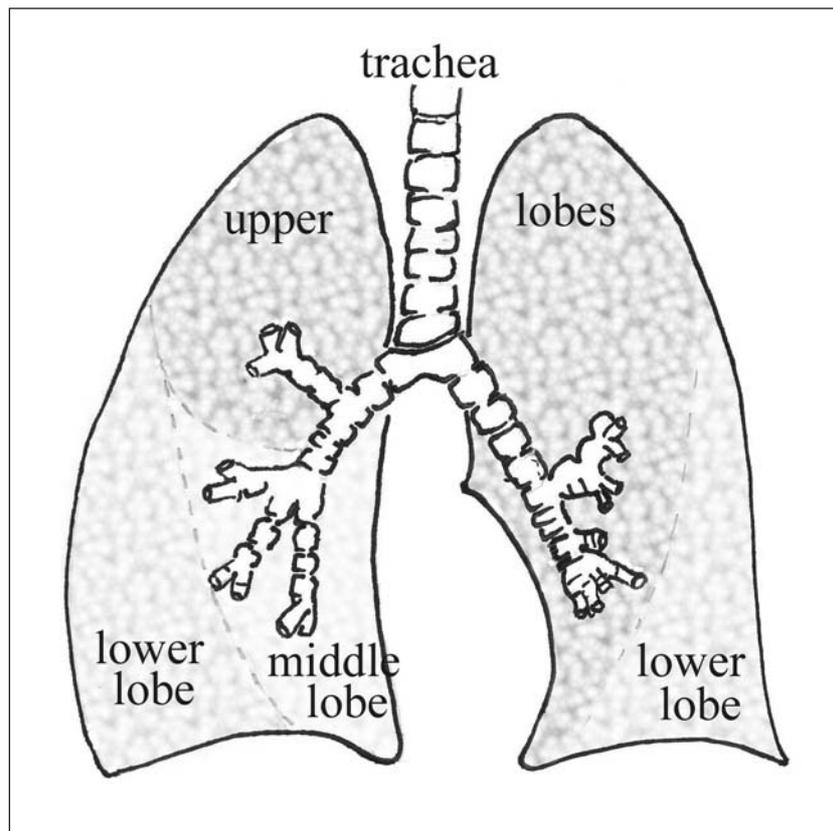


Table 1 TNM classification of Lung cancer<sup>14</sup>

		<i>Tumour</i>	
<b>T0</b>	{	<b>T0</b>	no evidence of primary tumour
<b>T1</b>	{	<b>T1</b>	tumour 3cm or less surrounded by lung or visceral pleura, without involvement of main bronchus
<b>T2</b>	{	<b>T2</b>	tumour with any of the following features of size or extent <ul style="list-style-type: none"> <li>• More than 3cm</li> <li>• Involves main bronchus, 2cm or more distal to the carina</li> <li>• Invades visceral pleura</li> <li>• Atelectasis or obstructive pneumonitis but not involving whole lung</li> </ul>
<b>T3</b>	{	<b>T3</b>	tumour of any size that directly invades <ul style="list-style-type: none"> <li>• chest wall, diaphragm, mediastinal pleura, parietal pericardium,</li> <li>• tumour in main bronchus within 2cm of but not involving the carina</li> <li>• Atelectasis or obstructive pneumonitis involving entire lung</li> </ul>
<b>T4</b>	{	<b>T4</b>	tumour of any size that directly invades <ul style="list-style-type: none"> <li>• mediastinum, heart, great vessels, trachea, oesophagus, vertebral body, carina</li> <li>• separate tumour nodules in same lobe</li> <li>• tumour with a malignant pleural effusion</li> </ul>
<i>Nodes</i>			
<b>NX</b>	{	<b>NX</b>	regional nodes not assessed
<b>N0</b>	{	<b>N0</b>	no regional nodes involved
<b>N1</b>	{	<b>N1</b>	metastases to ipsilateral peribronchial and/or ipsilateral hilar nodes, and intrapulmonary nodes
<b>N2</b>	{	<b>N2</b>	metastases to ipsilateral mediastinal and/or subcarinal nodes
<b>N3</b>	{	<b>N3</b>	metastases to contralateral mediastinal, contralateral hilar, ipsilateral or contralateral scalene or supraclavicular nodes
<i>Metastases</i>			
<b>MX</b>	{	<b>M0</b>	distant metastases cannot be assessed
<b>M0</b>	{	<b>M0</b>	no distant metastases
<b>M1</b>	{	<b>M1</b>	distant metastases (includes separate tumour nodules in a different lobe)

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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
<b>IA</b>	T1	N0	M0
<b>IB</b>	T2	N0	M0
<b>IIA</b>	T1	N1	M0
<b>IIB</b>	T2	N1	M0
	T3	N0	M0
<b>IIIA</b>	T1	N2	M0
	T2	N2	M0
	T3	N1	M0
	T3	N2	M0
<b>IIIB</b>	any T	N3	M0
	T4	any N	M0
<b>IV</b>	any T	any N	M1