



Cancer care in Northern Ireland: A decade of change

Cancer services in Northern Ireland have changed considerably over the last decade. This is a summary of a series of reports on this change, which have been produced by the NI Cancer Registry over recent years.

CHANGING SERVICES

- 1993 – Breast screening established throughout Northern Ireland
- 1994 – Northern Ireland Cancer Registry (NICR) established
- 1995 – Calman Hine Report (UK)
- 1996 – Campbell Report (NI)
- 1999 – First cancer incidence data for Northern Ireland covering 1993-1996
- 2004 – NI Cancer Network (NICaN) established
- 2006 – Cancer Centre Opened
- 2008 – Waiting times initiative
- 2009 – Development of Cancer Patient Pathway System (CaPPS)
- 2011 – Cancer framework launched

CAMPBELL REPORT

The Campbell Report (1996) resulted from the work of many clinicians, service planners and patients who worked together with the aim of improving cancer services.

Key report recommendations

- Patients be managed by multidisciplinary teams;
- Appropriate training for staff;
- Establishment of a single Cancer Centre and 4 other Cancer Units (one in each Health Board);
- Radiotherapy services to be moved to the Cancer Centre and chemotherapy to be available in each Cancer Unit;
- Review of palliative services;
- Additional investment in oncology services.



NICR AUDITS



NICR have conducted a series of audits to document changes in cancer services between 1996 and 2006. They are conducted at five-yearly intervals by reviewing clinical notes of patients registered with NICR at the time the audits were conducted.

The results are available in reports on the NICR web site:
www.qub.ac.uk/nicr

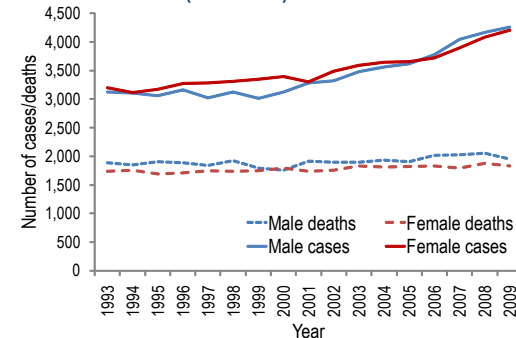
See page 6 for methods

CANCER TRENDS

In 2009 there were 4,260 male and 4,209 female cancer cases diagnosed (ex. non-melanoma skin cancer (NMSC)), and 1,955 male and 1,832 female cancer deaths.

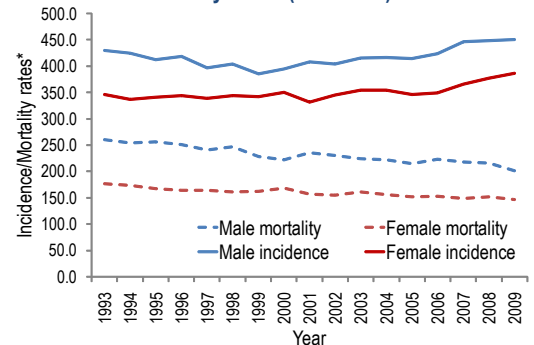
The number of cancer cases (excluding (NMSC)) increased by 74 male and 60 female cases per year since 1993. Male and female deaths each increased by 9 deaths per year in the same period of time.

Cases and Deaths (ex. NMSC)



NMSC: Non-melanoma skin cancer

Incidence and Mortality Rates (ex. NMSC)



* European age-standardised rate per 100,000 males/females

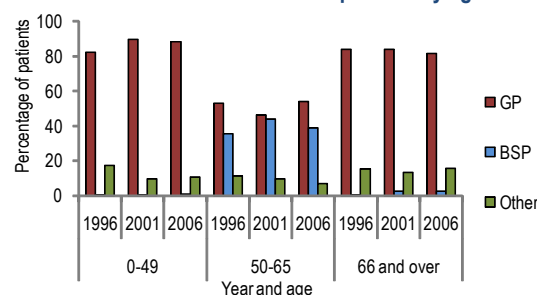
A significant proportion of the change is due to an increasing and ageing population. Age-standardised incidence rates, which exclude these factors, decreased among males between 1993 and 1999 by 1.7% per year, but increased by 1.5% per year in 1999-2009. Female incidence rates increased by 0.6% per year between 1993 and 2009. Despite the rising incidence rates, mortality rates decreased by 1.3% for males and 0.9% for females between 1993 and 2009.

BREAST SCREENING

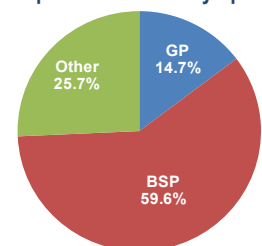
In 2006 54% of breast cancer patients of screening age (aged 50-65) were referred by GPs with 39% detected by the Breast Screening Programme (BSP). This compared with 44% detected by the BSP in 2001 and 35% in 1996. 88% of patients in 2006 aged 0-49 and 81% of patients aged 66 and over were referred by a GP.

60% of asymptomatic breast cancer patients in 2006 were referred by the BSP, a reduction from the 81% in 2001. The majority of the rest were from "other" sources such as breast clinics

Source of referral for breast cancer patients by age

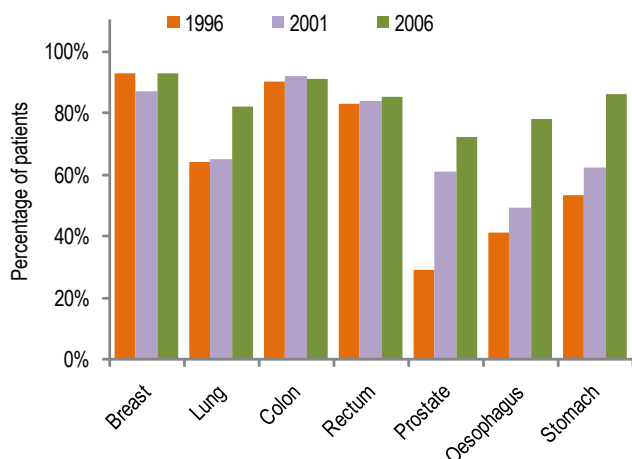


Source of referral in 2006 for breast cancer patients with no symptoms



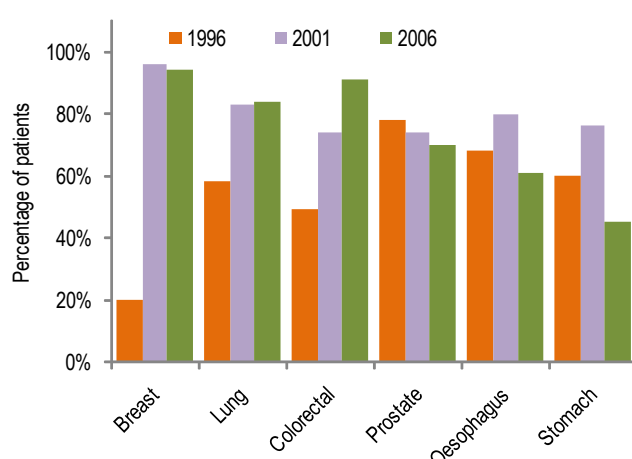
BSP : Breast Screening Programme

STAGING



The proportion of patients having a TNM stage recorded in medical notes was above 80% for breast and colorectal patients in all three years. Lung cancer patients saw an increase in this percentage between 2001 and 2006 from 65% to 82%, while there was a year on year increase in the proportion of prostate and upper GI patients that had a stage recorded.

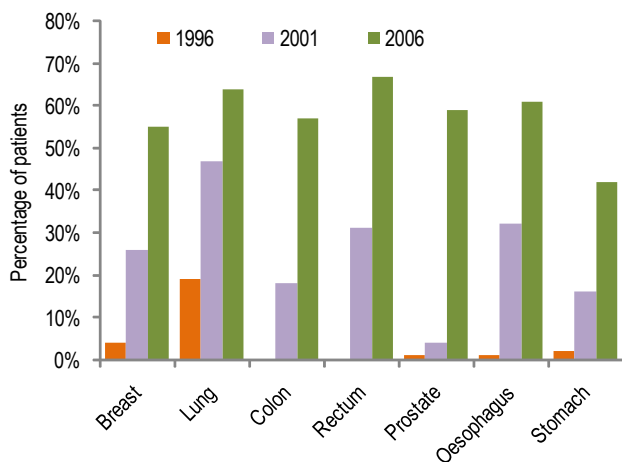
DIAGNOSIS DISCUSSED WITH PATIENT



Information provided to patients on their diagnosis was very poor among breast cancer patients in 1996, but considerable improvements were made by 2001. Lung and colorectal cancer patients also saw an increase in this proportion over the ten year period, while prostate cancer patients saw a decrease. Despite improvements between 1996 and 2001 for upper GI patients, the proportion of patients provided information on their diagnosis was lower in 2006 than in 1996. These patterns may be a reflection on how this information is recorded.

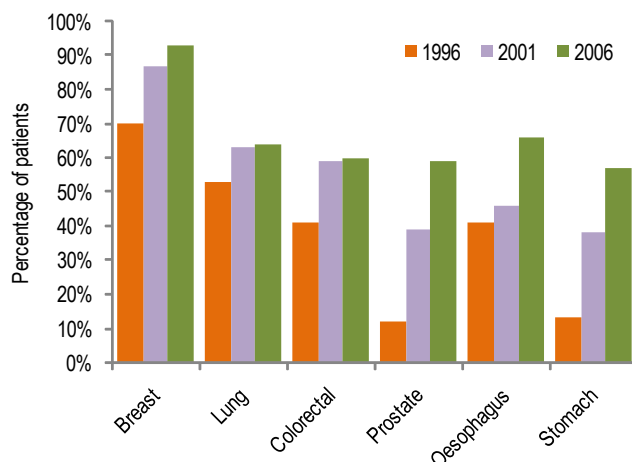
MULTIDISCIPLINARY TEAM (MDT) MEETINGS

The proportion of patients recorded as having had a MDT meeting increased year on year between 1996 and 2006, however with a maximum of 67% recorded as having had a MDT meeting (for rectal cancer patients), the situation in 2006 was still considerably lower than the ideal of 100% of patients having a MDT meeting. It is expected that the use of the CaPPS system will improve recording of MDT meetings further.

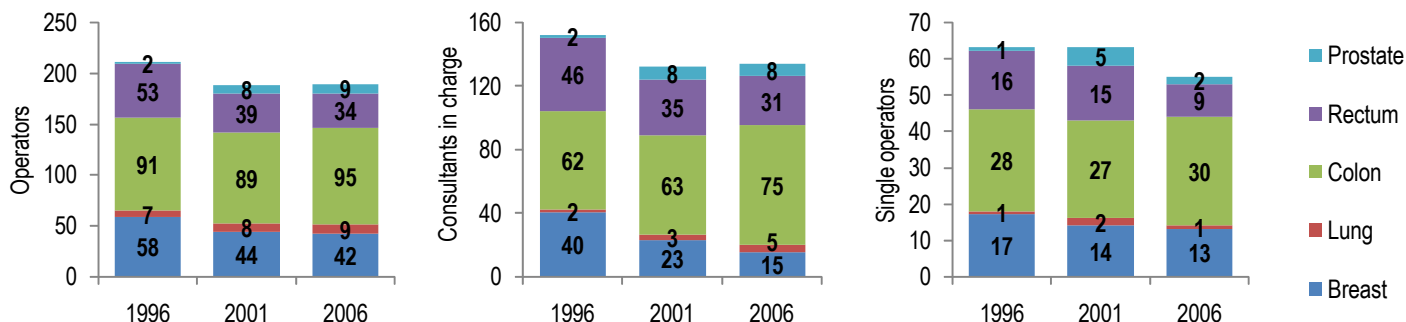


REFERRAL TO ONCOLOGY

The proportion of patients referred to oncology increased for all cancer types between 1996 and 2001. A further increase was recorded between 2001 and 2006 for breast cancer, prostate cancer and cancers of the oesophagus and stomach. 2001 levels were maintained for lung and colorectal cancers.



NUMBER OF OPERATORS AND CONSULTANTS IN CHARGE OF SURGERY

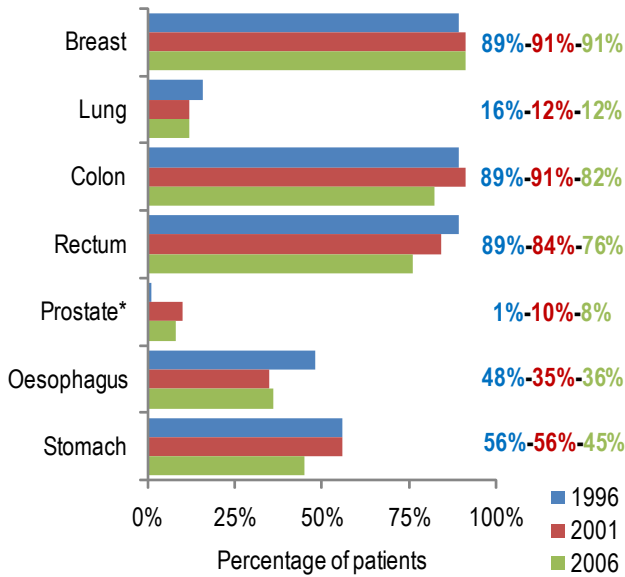


Note: Top four cancers only (breast, lung, colorectal and prostate)

The total number of operators and consultants in charge of surgery decreased for the top four cancers combined between 1996 and 2001. A decrease in the number of breast cancer consultants in charge was observed between 2001 and 2006, as was an increase in consultants in charge for colon cancer. Overall the combined total remained steady between 2001 and 2006. The number of surgeons performing a single operation for a particular cancer in a calendar year decreased slightly between 1996 and 2006, driven by reductions in single operators for breast and rectal cancer.

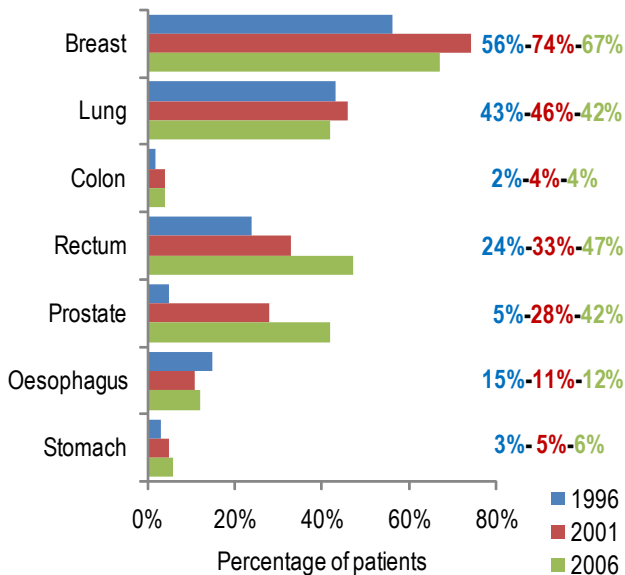
TREATMENT

Surgery

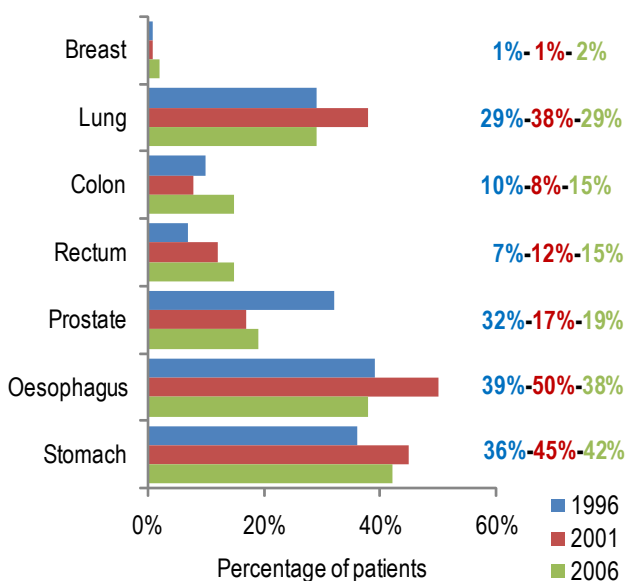


* Radical prostatectomy only

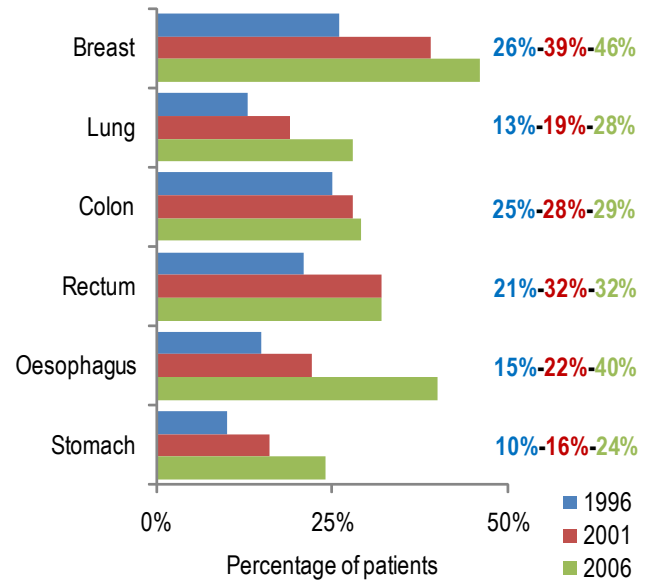
Radiotherapy



No tumour directed treatment

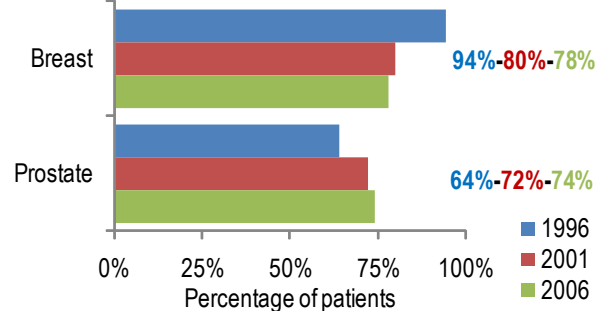


Chemotherapy



* Prostate cancer excluded as these patients rarely receive chemotherapy

Hormone therapy



* Hormone therapy given to breast and prostate cancer patients only

The proportion of cancer patients receiving tumour directed surgery over the decade saw some notable changes:

- Lung cancer surgery decreased between 1996 and 2001
- There was an increase in radical prostatectomy from 1% of prostate cancer patients in 1996 to 8% in 2006.
- The proportion of colorectal and upper GI cancer patients receiving surgery decreased between 1996 and 2006.

Reductions in lung and upper GI cancer operations likely reflect better patient selection.

Chemotherapy use increased for all cancer sites between 1996 and 2006, except prostate cancer for which this treatment is rarely used. The increase was greatest for breast cancer (26% to 46%), lung cancer (13% to 28%), oesophageal cancer (15% to 40%) and stomach cancer (10% to 24%).

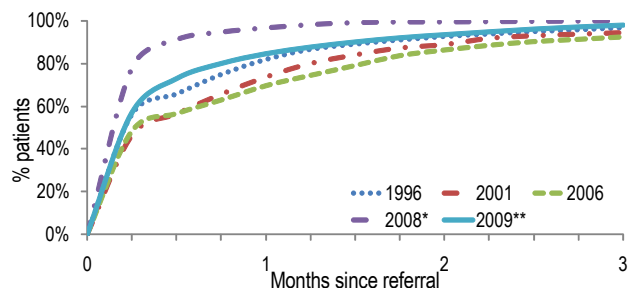
Radiotherapy levels changed little over time for lung, colon and upper GI patients. However there was a marked increase in the proportion of prostate cancer patients receiving radiotherapy (5% in 1996 compared to 42% in 2006). The proportion of rectal cancer patients receiving radiotherapy also increased between 1996 (24%) and 2001 (33%), with another increase in 2006 (47%). Radiotherapy use also increased among breast cancer patients between 1996 and 2001; although a small decrease occurred in 2006.

There was an increase from 64% to 74% in the proportion of prostate cancer patients receiving hormone therapy over the decade. Among breast cancer patients hormone therapy use in 1996 was already very high (94%), but decreased to 80% in 2001, a level maintained in 2006.

Decreases in the proportion of prostate cancer patients who had no tumour directed treatment recorded occurred between 1996 and 2001, with this reduction maintained in 2006. There was little change between 1996 and 2006 in this proportion for both lung and breast cancer patients, despite an increase in 2001 for lung cancer. However over the decade colorectal and upper GI cancer saw an increase in the proportion of patients who had no treatment recorded in their hospital notes.

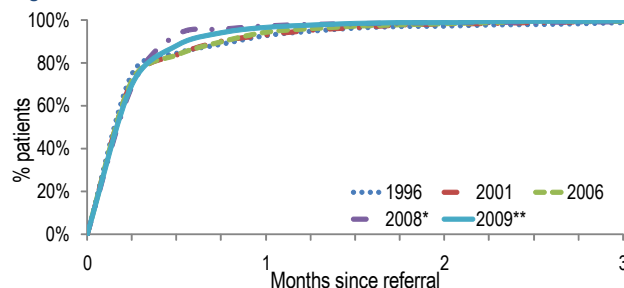
TIMELINES – REFERRAL TO FIRST SEEN

Colorectal



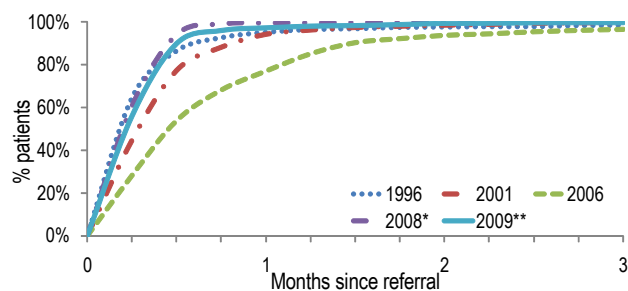
| | 1996 | 2001 | 2006 | 2008* | 2009** |
|---------|------|------|------|-------|--------|
| 32 days | 82% | 73% | 69% | 96% | 84% |
| 64 days | 93% | 89% | 86% | 99% | 93% |

Lung



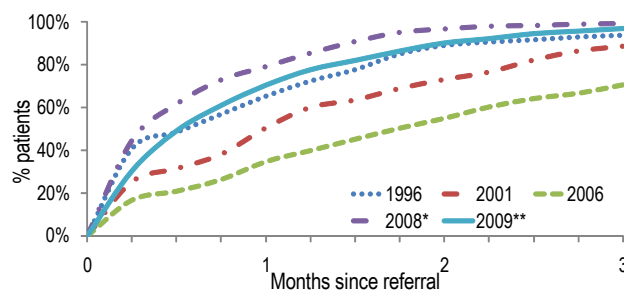
| | 1996 | 2001 | 2006 | 2008* | 2009** |
|---------|------|------|------|-------|--------|
| 32 days | 93% | 93% | 95% | 97% | 97% |
| 64 days | 97% | 98% | 99% | 99% | 99% |

Breast



| | 1996 | 2001 | 2006 | 2008* | 2009** |
|---------|------|------|------|-------|--------|
| 32 days | 95% | 94% | 77% | 99% | 97% |
| 64 days | 98% | 98% | 94% | 100% | 99% |

Prostate

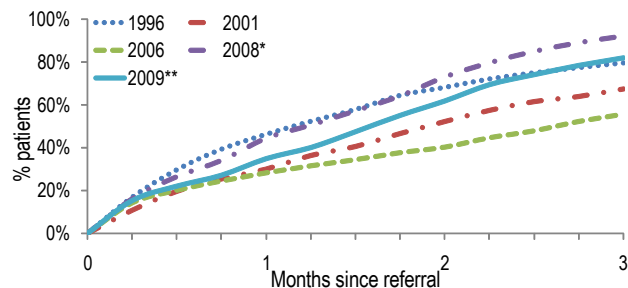


| | 1996 | 2001 | 2006 | 2008* | 2009** |
|---------|------|------|------|-------|--------|
| 32 days | 65% | 50% | 35% | 79% | 70% |
| 64 days | 89% | 73% | 55% | 97% | 90% |

All but a handful of lung cancer patients were first seen within 64 days of referral during 1996-2009. However for colorectal, breast and prostate cancer patients time between referral and first being seen increased between 1996 and 2006. After this point waiting time targets were introduced and the average time between referral and first being seen decreased in 2008. However a slight increase occurred in 2009 for colorectal and prostate cancer patients.

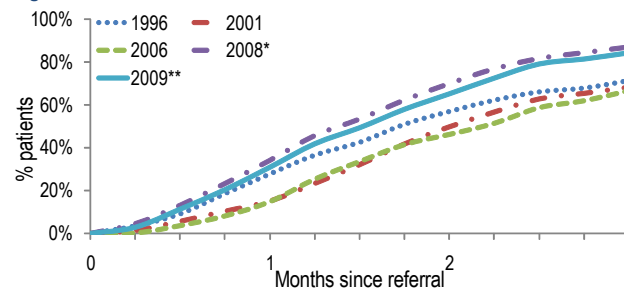
TIMELINES – REFERRAL TO FIRST TREATMENT

Colorectal



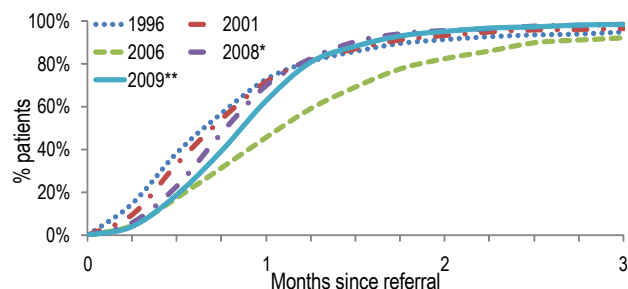
| | 1996 | 2001 | 2006 | 2008* | 2009** |
|---------|------|------|------|-------|--------|
| 32 days | 46% | 30% | 28% | 44% | 35% |
| 64 days | 68% | 52% | 40% | 73% | 62% |

Lung



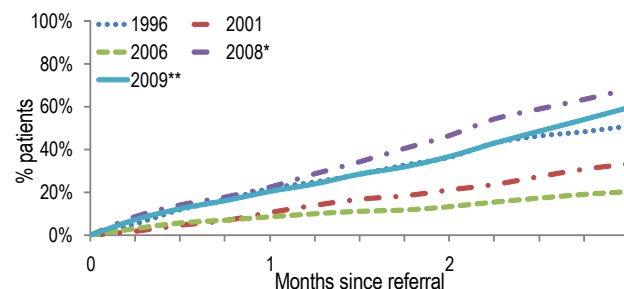
| | 1996 | 2001 | 2006 | 2008* | 2009** |
|---------|------|------|------|-------|--------|
| 32 days | 28% | 15% | 15% | 34% | 31% |
| 64 days | 57% | 50% | 46% | 70% | 65% |

Breast



| | 1996 | 2001 | 2006 | 2008* | 2009** |
|---------|------|------|------|-------|--------|
| 32 days | 73% | 72% | 46% | 70% | 63% |
| 64 days | 92% | 93% | 82% | 96% | 95% |

Prostate



| | 1996 | 2001 | 2006 | 2008* | 2009** |
|---------|------|------|------|-------|--------|
| 32 days | 22% | 11% | 9% | 22% | 20% |
| 64 days | 36% | 21% | 13% | 47% | 37% |

Time between referral and first treatment increased for all four of the most common cancers between 1996 and 2006. A considerable improvement then occurred between 2006 and 2008; however this improvement was not maintained in 2009, with time between referral and first treatment increasing marginally for all four cancers. Despite this increase the situation in 2009 was still considerably better than that in 2006.

* 2008 data extracted from Cancer Waiting Times dataset; ** 2009 data extracted from Cancer Patient Pathway System (CaPPS)

Note: Analysis excludes patients with unknown timelines and does not adjust for patients cancelling appointments

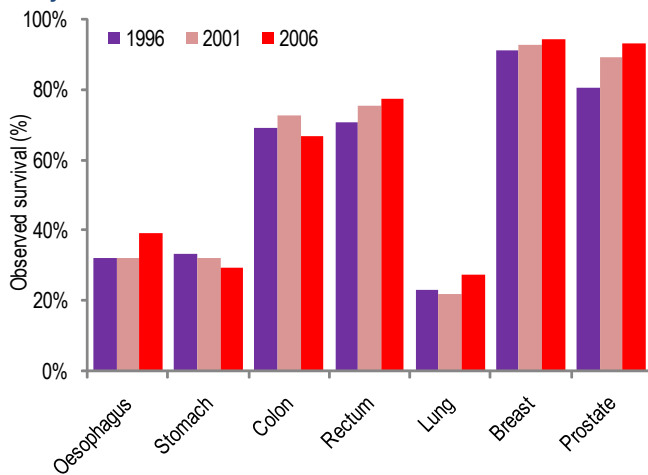
PATIENT SURVIVAL

| | 1 month | | | 3 months | | | 6 months | | |
|------------|---------|------|------|----------|------|------|----------|------|------|
| | 1996 | 2001 | 2006 | 1996 | 2001 | 2006 | 1996 | 2001 | 2006 |
| Oesophagus | 91% | 90% | 92% | 68% | 70% | 78% | 51% | 49% | 56% |
| Stomach | 77% | 76% | 82% | 58% | 57% | 66% | 48% | 44% | 51% |
| Colon | 90% | 91% | 92% | 85% | 84% | 80% | 78% | 78% | 74% |
| Rectum | 95% | 96% | 95% | 89% | 88% | 90% | 83% | 82% | 85% |
| Lung | 80% | 77% | 80% | 61% | 57% | 58% | 41% | 40% | 43% |
| Breast | 98% | 99% | 99% | 97% | 98% | 98% | 94% | 96% | 97% |
| Prostate | 96% | 99% | 99% | 92% | 97% | 97% | 88% | 94% | 96% |

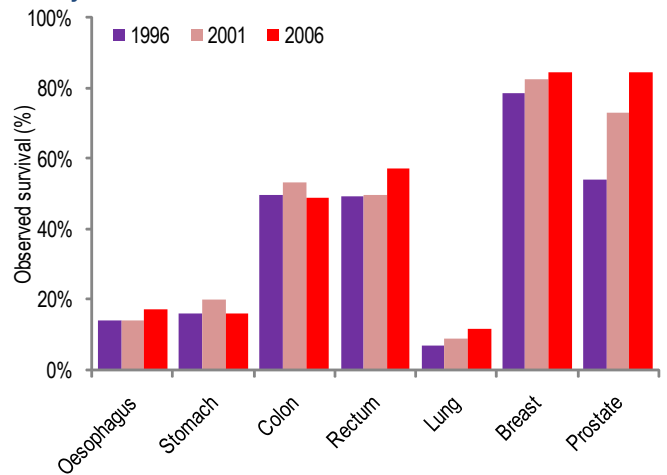
| | 1 year | | | 2 years | | | 3 years | | |
|------------|--------|------|------|---------|------|------|---------|------|------|
| | 1996 | 2001 | 2006 | 1996 | 2001 | 2006 | 1996 | 2001 | 2006 |
| Oesophagus | 32% | 32% | 39% | 22% | 18% | 24% | 14% | 14% | 17% |
| Stomach | 33% | 32% | 29% | 21% | 26% | 21% | 16% | 20% | 16% |
| Colon | 69% | 72% | 66% | 57% | 61% | 56% | 50% | 53% | 49% |
| Rectum | 71% | 75% | 77% | 58% | 61% | 67% | 49% | 50% | 57% |
| Lung | 23% | 22% | 27% | 10% | 11% | 16% | 7% | 9% | 12% |
| Breast | 91% | 93% | 94% | 84% | 88% | 89% | 79% | 82% | 84% |
| Prostate | 80% | 89% | 93% | 66% | 81% | 89% | 54% | 73% | 85% |

Note: This table gives observed survival, thus patients may have died from causes unrelated to their cancer

One-year

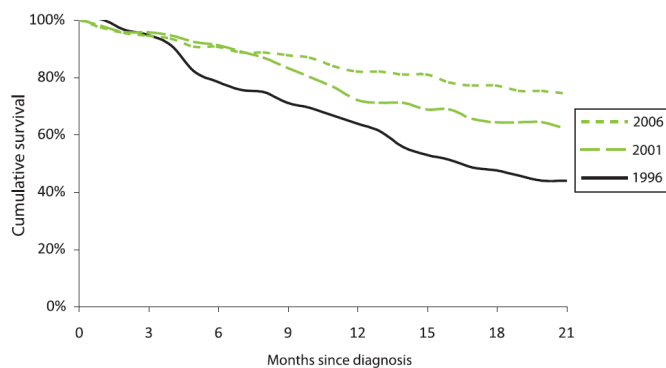


Three-year



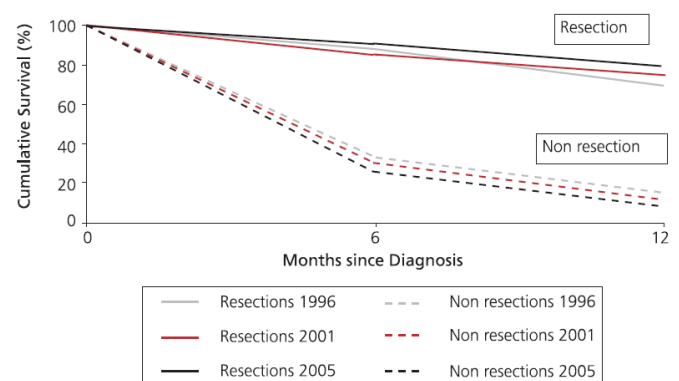
Between 2001 and 2006 survival from oesophageal cancer improved significantly, in particular one-year survival increased from 32% to 39%. Survival from cancer of the rectum also improved over the 1996 to 2006 period, although the improvements between 2001 and 2006 were not significant due to little change in survival up to one-year. Lung cancer survival was similar for patients diagnosed in 1996 and 2001, however patients diagnosed in 2006 had slightly better survival prospects with one year survival of 27% and three-year survival of 12% compared to 23% and 7% respectively in 1996. Breast cancer exhibited continuous improvement over the decade, as did prostate cancer. The latter however is mostly due to the increase in number and type of prostate cancers diagnosed as a result of the increase in use of PSA testing, which can identify non aggressive tumours earlier, increasing survival times, but having a minimal impact on mortality. Both stomach and colon cancers showed no significant improvements in survival over the decade.

SURVIVAL OF LUNG CANCER SURGERY PATIENTS



For those lung cancer patients who had surgery, survival was significantly different between years; the 21-month observed survival was 44% in 1996, 64% in 2001, and 74% in 2006. This likely reflects better patient selection for this treatment type.

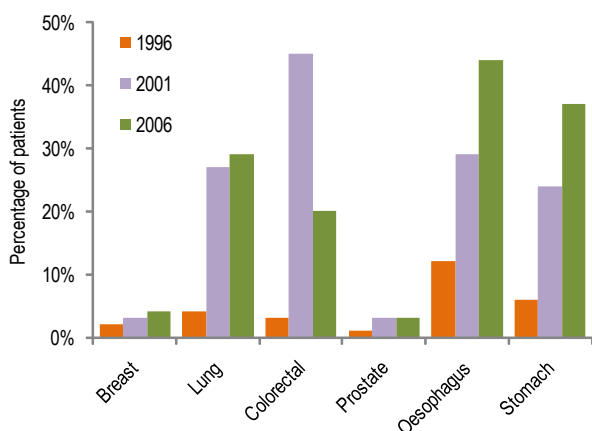
SURVIVAL OF OESOPHAGEAL RESECTION PATIENTS



Survival for oesophageal resection patients was significantly better than non surgery patients, with a significant improvement in observed survival for resection patients over the decade. In particular one-year survival increased from 69% to 79% between 1996 and 2005, while five-year survival increased from 10% in 1996 to 23% in 2001. There was no significant difference in survival of resection patients between 2001 and 2005.

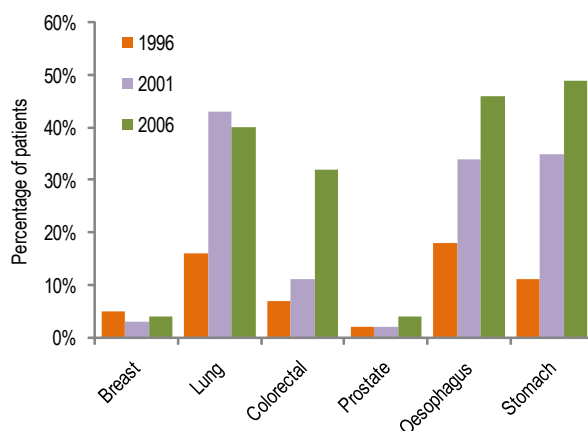
REFERRAL TO PALLIATIVE CARE SPECIALIST

The proportion of patients referred to a palliative care specialist after their treatment has ended increased between 1996 and 2001 for lung, colorectal and upper GI cancer patients. Between 2001 and 2006 there were further increases for upper GI patients, however a decrease was recorded for colorectal cancer patients. The proportion of breast and prostate cancer patients referred to a palliative care specialist within a year of diagnosis remained low for all three years.



REFERRAL TO MACMILLAN/MARIE CURIE NURSE

Referrals to a Macmillan/Marie Curie nurse within one year of diagnosis occurred for less than 20% of lung and upper GI cancer patients and for less than 10% of breast, colorectal and prostate cancer patients in 1996. By 2001 there had been significant increases in the proportion of lung and upper GI patients referred, while by 2006 there were also increases among colorectal cancer patients.



METHODS

Study aim

The various cancer audits, upon which this report is based, aimed to document the presentation, treatment, care and outcomes of lung, colorectal, prostate and female breast cancers diagnosed in Northern Ireland in 2006 and compare the result with similar data from 1996 and 2001. An earlier, similar exercise was conducted for upper GI cancers, with data collected for patients diagnosed in 2005 and compared with similar data from 1996 and 2001. In this report any reference for upper GI cancers to 2006 actually refers to 2005.

Data collection

In each audit Registry Tumour Verification Officers (TVO's) collected data by reviewing clinical notes of patients with a new primary cancer already registered with the Northern Ireland Cancer Registry. Data was then entered into an electronic proforma, which had been developed with the guidance of relevant clinicians.

Exclusions and data analysis

Patients were excluded if their records lacked sufficient information or if information was available only from a death certificate (DCO) or post mortem. Patients were identified using version 10 of the International Classification of Diseases (ICD10) as follows:

- Oesophageal cancer: C15-C16.0 (i.e. Gastro-oesophageal junction is included with oesophagus instead of stomach)
- Stomach cancer: C16.1-C16.9
- Colon cancer: C18-C19 (i.e. Colon cancer includes rectosigmoid junction)
- Rectal cancer: C20 (Note, data on cancer of the anus (C21) was also collected, and contributes to the colorectal cancer total)
- Lung cancer: C33-C34
- Female breast cancer: C50
- Prostate cancer: C61

The majority of analysis is through the derivation of the number of patients falling into particular categories relating to their demographics and process of care, with these numbers frequently presented as a percentage of all patients or a particular sub group of patients (e.g. surgery patients). Random fluctuations in values mean that caution needs to be exercised when comparing proportions. Statistical decisions with regard to differences in proportions are based upon the assumption that any differences are normally distributed about zero, with a 95% confidence level applied.

Patient survival is one of the best indicators as to the efficiency of diagnostic and treatment methods in a geographic area and is widely used by cancer registries as a broad indicator as to the effectiveness of health services in the treatment of cancer. There are several different measures of survival, the most fundamental, and perhaps of most relevance to patients, is observed survival, which is the probability that a patient with cancer will be alive at the end of a particular length of time as measured from the date of diagnosis. The length of time for which survival can be measured is restricted to the amount of follow up data available on a patient. In this report follow up of all audit patients was available to the end of 2009 (an update from published audits which may cause slight variations in values compared to the previously published results), thus restricting survival analysis to three years for patients diagnosed in 2006. Observed survival for cancer patients is independent of the cause of death and thus includes death from causes other than cancer, some of which may be related to cancer or its cause (e.g. other smoking related illnesses) or may even be completely unconnected to the disease (e.g. accidental death).

FURTHER INFORMATION

Further data from the Northern Ireland Cancer Registry is available from the Registry web site: www.qub.ac.uk/nicr, and

NI Cancer Registry
Centre for Public Health
Mulhouse Building
Grosvenor Road
Belfast, BT12 6BJ

Phone: +44 (0)2890 63 2573
e-mail: nicr@qub.ac.uk

ACKNOWLEDGEMENTS

The NI Cancer Registry is funded by the Public Health Agency, with audit work funded by the Guideline and Audit Implementation Network (GAIN).

