

**Monitoring care of female
breast cancer patients in
Northern Ireland diagnosed 2006
(with comparisons to 1996 & 2001)**



2006 Breast



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

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This report should be cited as: Donnelly D and Gavin A. Monitoring care of female breast cancer patients in Northern Ireland diagnosed 2006 (with comparisons to 1996 & 2001). N. Ireland Cancer Registry 2010. Available at <http://www.qub.ac.uk/nicr>

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Foreword

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

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



Dr. Michael McBride
Chief Medical Officer
2010

Acknowledgements

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

The Northern Ireland Cancer Registry is funded by the Public Health Agency and its audit work is facilitated by grants from the Guideline and Audit Implementation Network (GAIN), previously known as the Regional Multiprofessional Audit Group (RMAG).

The quality of data in this project is the result of the work of the Registry Tumour Verification Officers, Bernadette Anderson, Eamon O'Callaghan and Gavin Kennedy, who meticulously extracted detailed information from clinical records for analysis and presentation in this report. Data abstraction was facilitated by Colin Fox of the Registry's IT group while cleaning of the collected data was undertaken by Dr. Denise Catney. The analysis of data was undertaken by Dr. David Donnelly. I am grateful to the Northern Ireland Statistics and Research Agency for the secondment of Dr. Donnelly to the Registry. A special word of gratitude is due to the Medical Records staff of all the hospitals in Northern Ireland who have facilitated the Registry in this work and the clinicians who provided comments on the contents of the report, in particular Mr. Stephen Kirk, Mr. Robert Kennedy and Dr. Seamus McAleer.

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



Anna Gavin
Director, NICR
2010

SECTION I – INTRODUCTION, BACKGROUND & METHODS

Introduction

This report is the sixth in a series which examines in detail the pathway of care for cancer patients in Northern Ireland. Breast cancer represents the leading cancer among women after non-melanoma skin cancer and this report assesses change in service provision and outcome over a 10-year period.

The changes in service provision are driven by recommendations and guidance developed by several working groups and public bodies. The key documents providing guidance for the optimum treatment and care of breast cancer patients are:

- The Campbell Report (1996) which 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.¹
- Subsequent to the publication of the Campbell Report, a Cancer Working Group in Northern Ireland produced a subgroup report (1996) on breast cancer which made 16 specific recommendations on the future of breast cancer services in Northern Ireland.²
- In 1997 the NHS produced a document outlining guidance on commissioning cancer services: “Improving Outcomes in Breast Cancer”. This was later updated in 2002 by the National Institute for Health and Clinical Excellence (NICE) with five key recommendations.³
- The British Association of Surgical Oncologists (BASO) produced a report “Guidelines for Surgeons in the Management of Symptomatic Breast Disease in the United Kingdom” (1995). The document included nine recommendations.⁴ The guidelines were updated in 2009.⁵
- The referral guidelines for suspected cancer published by NICE had 15 recommendations (4 general and 11 specific) regarding urgent referral of breast cancer. These were published in 2005.⁶

A summary of the key recommendations from these documents are contained in appendix A.

Aim

The primary aim of this report is to measure changes to care for women with breast cancer from 1996 to 2006 and to determine whether they are in keeping with the recommended guidance on investigation and treatment.

Background

Anatomy

The breasts are a collection of connective tissue, glandular tissue and fat. Each breast contains 15 to 20 lobes which are made up of smaller parts called lobules where milk is produced. The lobes are connected to the nipple by tubes known as ducts. Fat fills the spaces between the lobes and ducts.

Breast tissue is drained by lymphatic vessels that lead to one of three sets of lymph nodes: axillary, internal mammary and supraclavicular. These form part of the lymphatic system that traps bacteria, cancer cells and harmful substances and connects to most other parts of the body.⁷

Breast cancer

The breast is made up of millions of cells that are constantly being renewed and replaced. Breast cancers, like all cancers, arise as a result of changes in the regulation of cell growth and behaviour. It develops either when a single cell begins to multiply out of control creating new, unnecessary cells or when old cells do not die at the end of their natural lifespan.^{7,8} Collectively these form masses known as tumours which can have one of four behaviours:

- **Malignant tumour:** A cancerous tumour that can invade and destroy nearby tissue and spread to other parts of the body.
- **In situ tumour:** An early cancer that has not spread to neighbouring tissue.
- **Uncertain tumour:** A tumour, which at the time of diagnosis, cannot be classified as either benign or malignant.
- **Benign tumour:** A tumour that neither invades nor destroys the tissue in which it originates, nor spreads to distant sites in the body.

In situ breast tumours are rarely life threatening. They are generally not considered to be breast cancer; however malignant tumours require careful management and treatment.

Breast cancer usually starts in a cell lining a duct or lobule; however cancer can develop in most parts of the breast. As the cancer grows, some cells may eventually break away and spread to other parts of the body through the lymphatic system.

Breast cancer occurs primarily among females, although a small number of males also develop the disease (an average of 5 per year in Northern Ireland between 2000 and 2007).

Risk factors

Reproductive history is related to the risk of developing breast cancer. An early menarche (first period), late menopause, late first birth or nulliparity (never giving birth) all increase the risk of getting breast cancer, while the use of breast-feeding can have a protective effect.⁹ Exposure to oestrogen through Hormone Replacement Therapy can increase breast cancer risk.¹⁰

There is some evidence that obesity in post-menopausal women contributes to an increased risk,¹¹ while 4-5 hours of exercise per week may have a protective effect against breast cancer although the evidence in this regard is not conclusive.¹² Alcohol consumption is also related to breast cancer, with women who do not drink having a lower risk of developing the disease compared to those who do. The greater the amount of alcohol consumed per week, the greater the risk of breast cancer.¹³

Personal histories of breast cancer can also increase the risk of developing a second breast cancer.¹⁴ Additionally a significant family history, such as having a mother diagnosed with breast cancer before the age of 40 or having two or more close relatives on the same side diagnosed with breast cancer may result in an increased risk of developing the disease.¹⁵ Approximately 5% of breast cancers are inherited via faulty genes, usually BRCA1 or BRCA2, the presence of which can significantly increase the life time risk of developing breast cancer. The presence of these faulty genes can be detected and are accompanied by a strong family history of the disease.¹⁶

Symptoms

Lumps in the breast are the most common symptom of breast cancer although the majority of such lumps are not cancerous. Other symptoms include blood discharge from the nipple, nipple tenderness, swelling in the area of the armpit or a change in the shape or appearance of the breast or nipple.¹⁷

Screening

Screening for breast cancer can result in detection of the disease earlier than would normally have occurred by presentation of symptoms. The most common form of breast cancer screening is in the form of a mammogram, which is a picture of the breast that is taken using x-rays. Although not 100% sensitive, mammograms can reveal breast cancer before the lump in the breast becomes apparent.

Screening using mammograms with a three yearly population based call and recall for women aged 50-65 has been in place in all parts of Northern Ireland since 1993, and is due to be extended to women aged up to 69. In Northern Ireland 76% of women aged 50-65 who are invited to attend take advantage of this service.¹⁸

Diagnosis

In the event that either symptoms or the result of a mammogram suggest the presence of cancer further investigations are carried out to determine whether cancer is genuinely present or the symptoms/screening results are caused by something else. These investigations can be broken into two types:

- **Imaging procedures** such as diagnostic mammograms, chest x-rays, ultrasounds of the breast, magnetic resonance imaging (MRI) and CT scans.
- **Biopsies** in which tissue is removed from the breast and tested for the presence of cancer. A variety of types of biopsy exist including fine needle aspiration (FNA), core biopsies and excision biopsies. The first two use needles to extract tissue and cells while an excision biopsy is a surgical procedure in which the entire lump is removed.

Further investigations, such as ultrasounds of the abdomen and scans of brain and bone, may be carried out to determine whether the cancer has spread beyond the breast.

If the patient is consequently diagnosed with cancer further information about the type and stage (see appendix B) of the cancer is required for the accurate planning of treatment.

Treatment

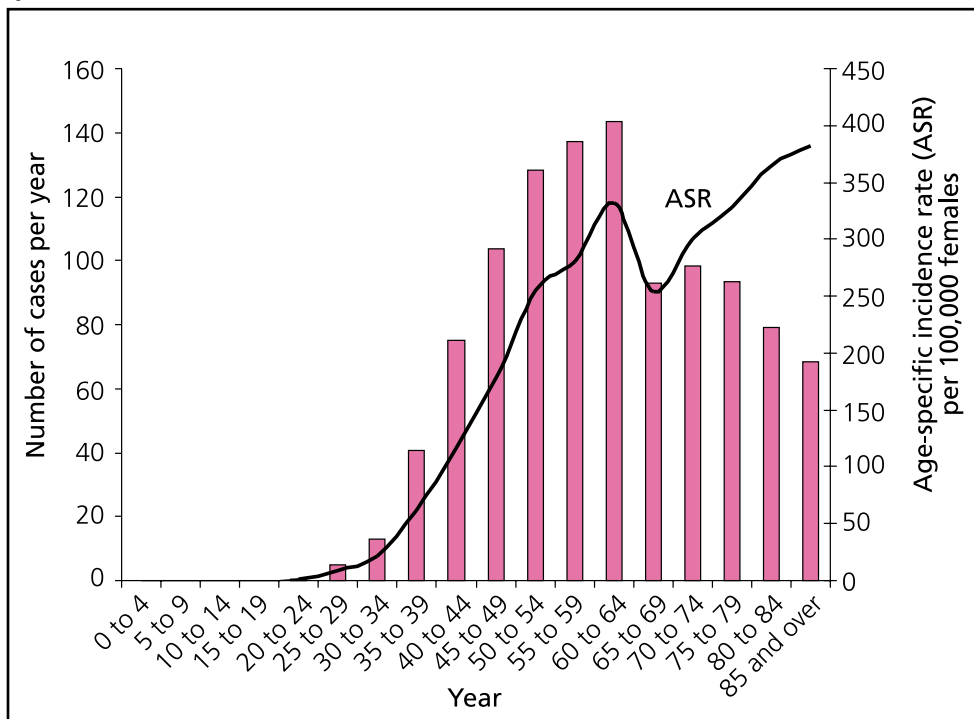
There are several treatment options for women with breast cancer, with a combination of the different types frequently used to combat the disease.

- **Surgery.** An operational procedure conducted to remove cancerous tissue or control its spread. There are several types of surgery. An operation to remove the cancer but not the breast is breast-conserving surgery also called wide local excision or lumpectomy. Sometimes an excision biopsy (or local excision) serves as a lumpectomy because the surgeon removes the whole lump. A mastectomy however is an operation to remove the whole breast with a quadrantectomy, segmental mastectomy or partial mastectomy used whenever only part of the breast needs removed. In most cases, the surgeon also removes lymph nodes under the arm. This procedure is called an axillary lymph node dissection. It shows whether cancer cells have entered the lymphatic system.
- **Radiotherapy.** The application of radiation to either destroy or reduce the size of malignant tumours. This can be applied before or after surgery with application depending upon the size of the tumour among other factors.
- **Chemotherapy.** Treatment of cancer through the use of drugs to kill cancer cells. The drugs are administered either orally or via injection.
- **Hormone therapy.** The treatment of cancer through the addition, removal or blockage of hormones. The most common form of hormone therapy is administration of the drug Tamoxifen although Anastrozole is becoming increasingly popular.

Overview of breast cancer in Northern Ireland

Breast cancer was the second most common female cancer diagnosed in Northern Ireland during 2003-2007 after non-melanoma skin cancer with an average of 1,079 cases each year. It made up 22.3% of all female cancers with an annual average of 122.3 cases diagnosed per 100,000 women in the general population. The risk of developing the disease before the age of 75 was high at 8.6% which corresponds to a 1 in 12 chance of developing the disease. However this risk is considerably lower at younger ages with the odds of developing the disease before the age of 40 only 1 in 216, while before the age of 50 the odds are 1 in 52 and before the age of 60 the odds are 1 in 22. Half of the females diagnosed with breast cancer in 2003-2007 were diagnosed with the disease before the age of 61 making the age distribution of patients slightly younger than for most cancers. The number of cases in 2003-2007 was greatest in the 60-64 age group, although age-specific rates were highest among those aged 85 and over. (Fig. 1)

Figure 1: Age distribution of patients diagnosed with breast cancer in Northern Ireland: Number and age-specific rates: 2003-2007 combined

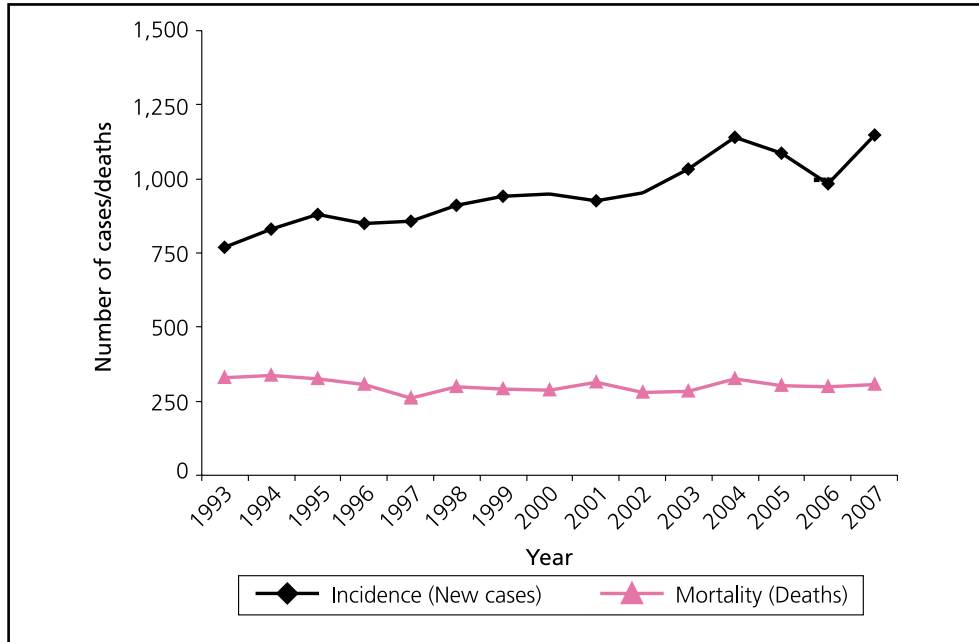


During 2003-2007 there were on average 302 deaths per year in Northern Ireland as a result of breast cancer. It was the second most common cause of cancer death in women after lung cancer (16.6% of all female deaths as a result of cancer). The odds of a female resident in Northern Ireland dying from the disease before the age of 75, assuming the absence of other causes of death was 1 in 49. The median age at death was 71 years.

Trends

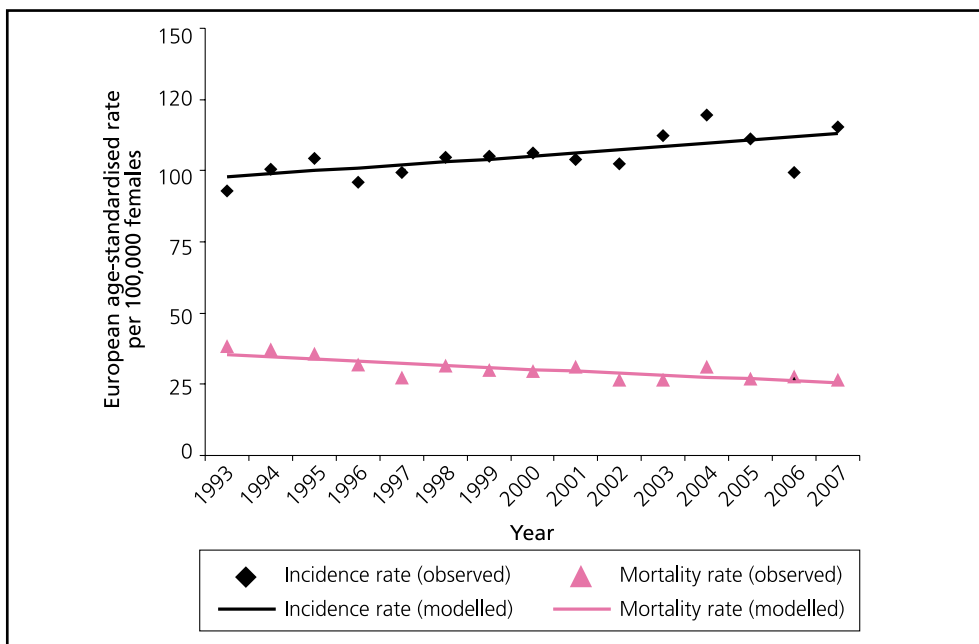
In Northern Ireland the number of women diagnosed with breast cancer increased by an average of 22.8 cases per year with the ageing and growth of the population likely to be a major factor in this increase. Despite this the number of deaths decreased by an average of 1.4 deaths per year reflecting improvements in survival through earlier detection of the disease and improved treatment and care. (Fig. 2, appendix C)

Figure 2: Incidence and mortality of breast cancer in Northern Ireland: 1993-2007



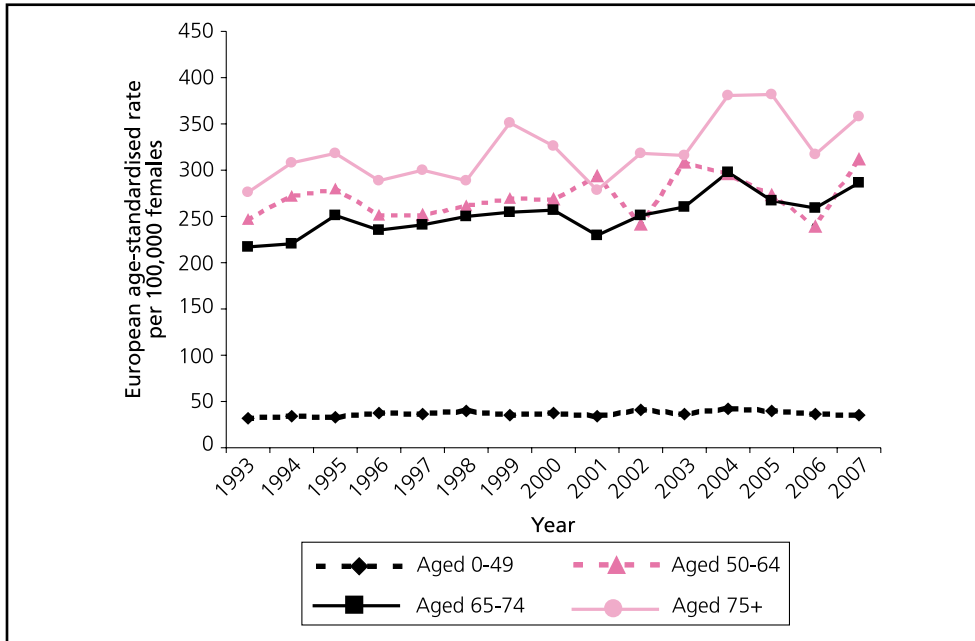
To remove the effect of demographic change from analysis of trends European age-standardised rates (EASR) are analysed. Incidence rates of female breast cancer increased steadily by an average of 1.0% ($p=0.005$) each year between 1993 and 2007. Mortality rates however decreased consistently and significantly throughout the period by 2.3% ($p<0.001$) each year. (Fig. 3, appendix C)

Figure 3: European age-standardised incidence and mortality rates of breast cancer in Northern Ireland: 1993-2007



The increase in incidence rates was driven by the 65-74 and 75 and over age groups, both of which demonstrated a significant increase of 1.5% in rates each year between 1993 and 2007. The 0-49 and 50-64 age groups also had increases in incidence rates; however these were not statistically significant. (Fig. 4)

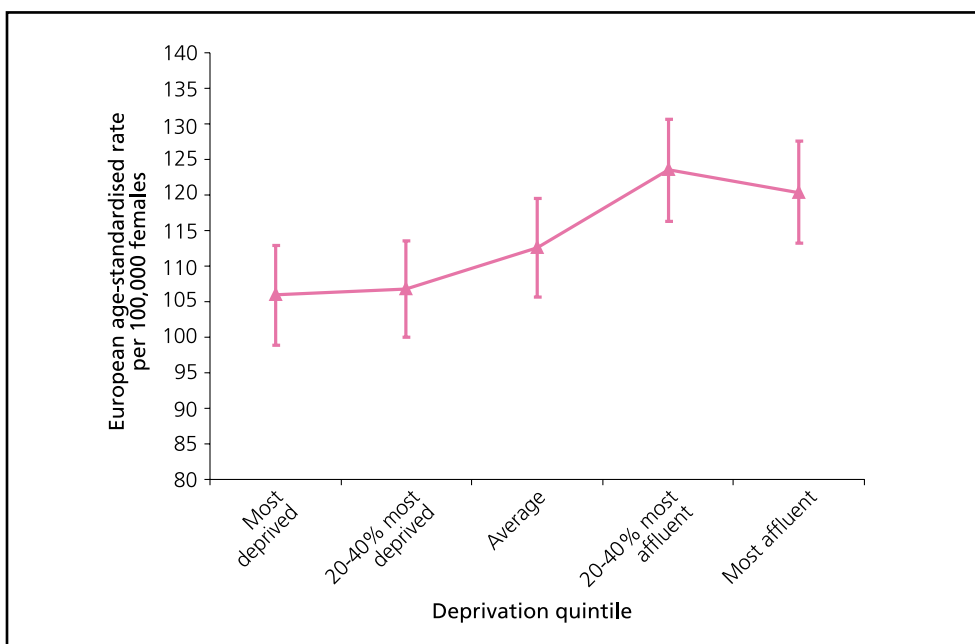
Figure 4: European age-standardised incidence rates of breast cancer in Northern Ireland by age at diagnosis: 1993-2007



Socio-economic factors

In Northern Ireland incidence rates (EASRs) of breast cancer among the 20% of the population living in the least deprived areas were 13.6% (p=0.046) higher than among the 20% of the population living in the most deprived areas (Fig. 5). This is a fairly common pattern found in most developed countries including Republic of Ireland²¹ and the rest of the UK.²²

Figure 5: European age-standardised incidence rates of breast cancer in Northern Ireland by deprivation quintile: 2003-2007

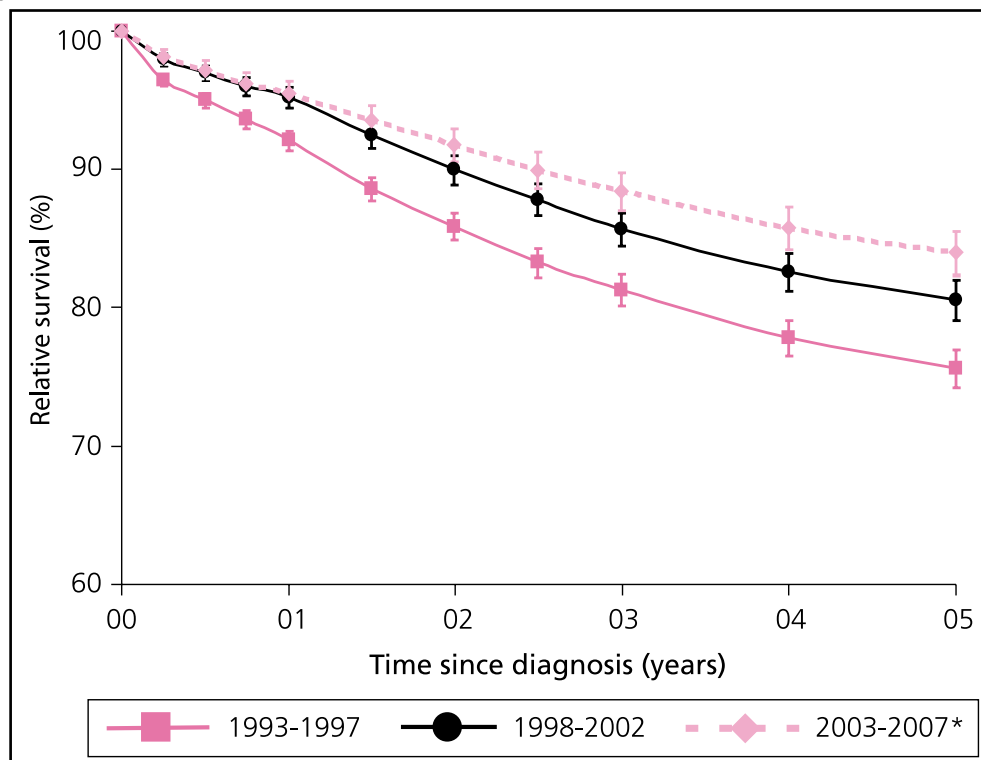


Survival

Survival from breast cancer in Northern Ireland compares favourably with other countries, with relative survival (which excludes deaths from causes other than cancer) for patients diagnosed during 2003-2007 95.5% after one year and 83.4% after five years. (Fig. 6)

Five-year relative survival from breast cancer has improved considerably over the last decade with a 4.9% improvement for patients diagnosed in 1998-2002 (80.5%) compared to patients diagnosed in 1993-1997 (75.6%) with a further 3.5% improvement by 2003-2007 (83.4%). (Fig. 6)

Figure 6: Relative survival from breast cancer in Northern Ireland by period of diagnosis: 1993-2007



*Estimates using period analysis²³

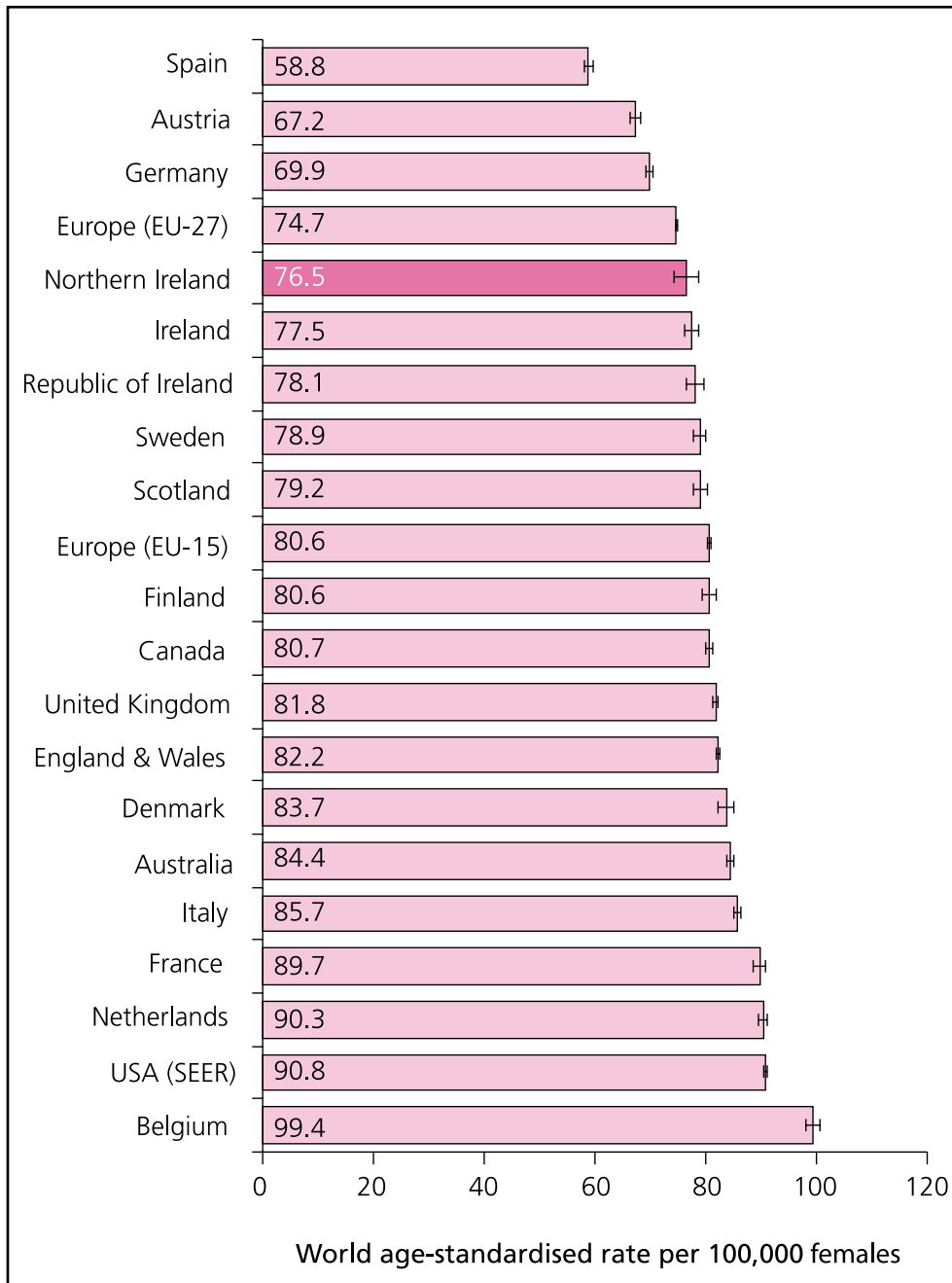
Age is a significant factor in breast cancer survival with five-year relative survival for females aged 45-54 diagnosed during 2003-2007 being 11.4% higher than those aged 75 and over (89.2% vs. 77.8%). Relative survival from breast cancer also decreases significantly with increasing stage at diagnosis. Specifically five-year relative survival for patients diagnosed with breast cancer at Stage I in 2003-2007 was 99.8% compared to 62.1% for Stage III and 13.8% for Stage IV.

International comparisons

Incidence rates of breast cancer in Northern Ireland during 1998-2000 were some of the lowest in Western Europe being 5.1% lower than in the European Union (15 countries) and 6.5% lower than in UK. They were also lower than rates in USA, Canada and Australia. However when newer members of the European Union are included, which are mostly from Eastern Europe, incidence rates of breast cancer in Northern Ireland were 2.4% higher than in the European Union (27 countries). (Fig. 7)

With regards to survival of breast cancer patients, five-year (age-standardised) relative survival for breast cancer patients diagnosed in 1995-1999 in Northern Ireland was similar to the European average and to that in England, Wales and Scotland. (Fig. 8)

Figure 7: International comparisons of world age-standardised incidence rates for female breast cancer: 1998-2000



Source: IARC²⁴

Note: Ireland refers to Republic of Ireland and Northern Ireland combined, while United Kingdom is the combined political entity of England, Wales, Scotland and Northern Ireland.

Figure 8: European comparisons of five-year age-standardised relative survival for female breast cancer patients: 1995-1999



Source: EUROCARE-4²⁵

Study methods

Study aim

This study aims to document the presentation, treatment, care and outcomes of female breast cancers diagnosed in Northern Ireland in 2006 and compare that with similar data from 1996 and 2001.

Data collection

Registry Tumour Verification Officers (TVO's) collected data by reviewing clinical notes of patients with a new primary breast 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. The study was conducted on female malignant breast cancers only (ICD10²⁶: C50) and excludes the 104 in situ tumours (ICD10: D05) diagnosed in 2006, which have an excellent prognosis. After cleaning and validation data analysis was carried out using SPSS.

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). While this is fairly straightforward, random fluctuations in values mean that caution needs to be exercised when comparing either two proportions or the overall distribution of factors between two sets of patients. Statistical tests exist for both scenarios and are utilised in this report to identify those differences that are statistically significant. Statistical decisions with regard to differences in proportions are based upon the assumption that any differences are normally distributed about zero, while the chi-square test is used to test for differences between the distribution of patient or tumour characteristics of two different cohorts. In both cases a 95% confidence level is applied.

Details on both the normal distribution with its use in testing for differences in proportions and on the chi-square test for differences between distributions can be found in numerous statistical texts.^{e.g.27}

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 2007, thus restricting survival analysis to two 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). In this report the Kaplan-Meier method has been used to calculate the observed survival with the Mantel-Cox log-rank test used to test for differences in survival between patient groups. A detailed explanation of these techniques can be found in texts on survival analysis.^{e.g. 28}

SECTION II – RESULTS FROM BREAST CANCER AUDIT

Study patients

Patients	1996	2001	2006
Total number of breast cancer patients	912	1,012	1,088
Exclusions - Insitu breast cancer	63	85	104
Total number of malignant breast cancer patients	849	927	984
Exclusions - Death certificate only	5	1	2
Exclusions - Insufficient information	80	45	31
Total exclusions	85	46	33
Total reported on (% of malignant breast cancer patients)	764 (90.0%)	881 (95.0%)	951 (96.6%)
Average age at diagnosis	61	60	62
Median age at diagnosis	60	59	61

- NICR identified 849 female patients registered with malignant breast cancer (ICD10: C50) in 1996, 927 in 2001 and 984 in 2006, with the increase in numbers due to the growth and ageing of the population along with changing lifestyle factors.
- Cases identified via death certificates only were excluded as were cases where insufficient information existed to complete the audit. These exclusions include those patients who were registered after the initial extraction of data from the NICR system for audit purposes. However the study patients will accurately represent the patients who received treatment within the hospital system as these patients are flagged by multiple information sources.
- After exclusions 764 patients remained in 1996, 881 in 2001 and 951 in 2006.
- The median age at diagnosis for study patients was 60 years in 1996, 59 years in 2001 and 61 years in 2006. This was the same as the median age at diagnosis before exclusions for insufficient information were made.
- Among the study patients there was no significant difference in the levels of breast cancer by area-based deprivation for any audit year. This probably reflects the relatively small numbers as five years worth of aggregated data is usually required to detect such differences within the Northern Ireland population (see background).

Referral and presentation

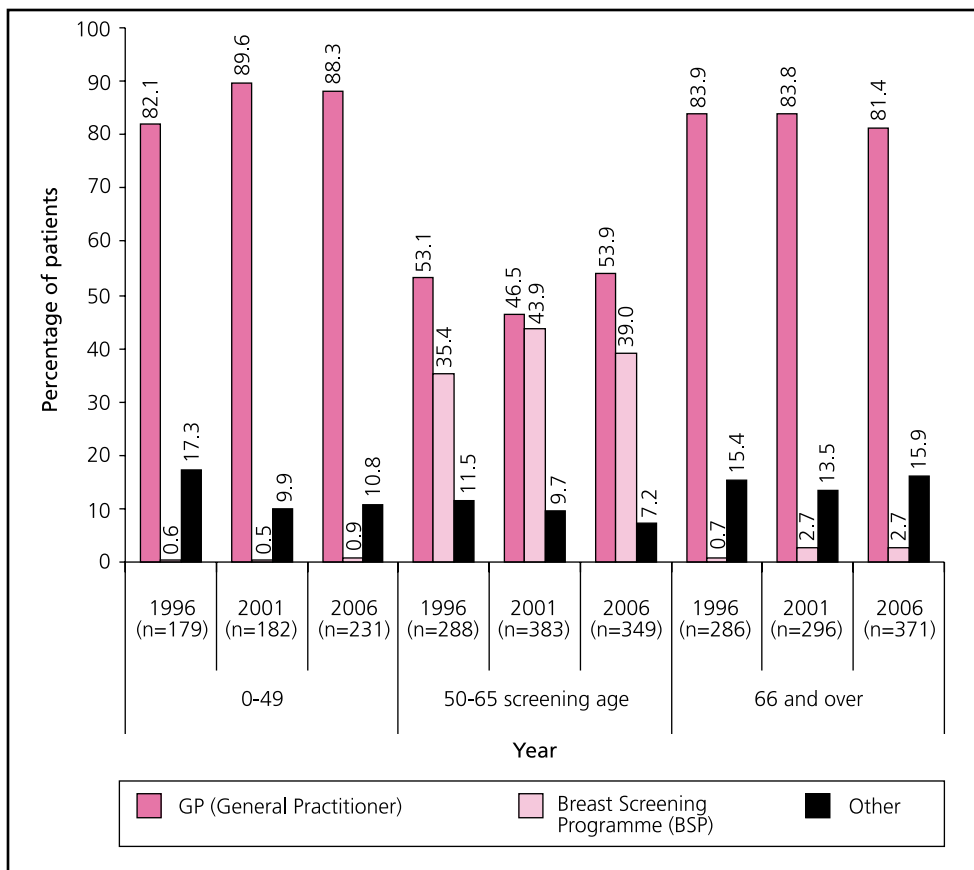
Source of referral to specialist care

Source of referral	1996 (n=764)	2001 (n=881)	2006 (n=951)
GP (General Practitioner)	541 (70.8%)	594 (67.4%)	694 (73.0%)
Breast Screening Programme (BSP)	106 (13.9%)	180 (20.4%)	148 (15.6%)
Action Cancer	15 (2.0%)	26 (3.0%)	19 (2.0%)
Other*	51 (6.7%)	60 (6.8%)	85 (8.9%)
Not recorded	51 (6.7%)	21 (2.4%)	5 (0.5%)

* "Other" includes referrals from consultants, family planning clinics, breast clinics and accident & emergency.

- Almost three quarters of patients diagnosed in 2006 came from GP referrals. This is an increase on the proportion referred from a GP in 2001 ($p=0.009$).
- The number of referrals from the Breast Screening Programme (BSP) decreased between 2001 and 2006 from 20% to 16% ($p=0.007$). This was after a considerable increase in referrals from the BSP between 1996 and 2001.
- The recording of source of referral in patient notes has consistently improved since 1996.

Source of referral for patients by age at presentation



*Other includes "other" from the previous table plus Action Cancer and not recorded.

Note: Excludes unknown age at presentation

- In 2006 54% of patients within the screening age (i.e. aged 50-65) were referred by GPs with 39% detected by the Breast Screening Programme. This compared with 44% detected by the Breast Screening Programme in 2001 and 35% in 1996. Changes from 2001 to 2006 in the percentage of women aged 50-65 referred from the Breast Screening Programme were not statistically significant.
- 88% of patients in 2006 aged 0-49 and 81% of patients aged 66 and over were referred by their GP.

Family history of breast cancer (any relative)

	1996 (n=764)	2001 (n=881)	2006 (n=951)
Yes	195 (25.5%)	247 (28.0%)	315 (33.1%)
No/not recorded	569 (74.5%)	634 (72.0%)	636 (66.9%)

Family history of breast cancer (first degree relative)

	1996 (n=764)	2001 (n=881)	2006 (n=951)
Yes	124 (16.2%)	129 (14.6%)	180 (18.9%)
No/not recorded	640 (83.8%)	752 (85.4%)	771 (81.1%)

Family history of other cancer

	1996 (n=764)	2001 (n=881)	2006 (n=951)
Yes	82 (10.7%)	195 (22.1%)	264 (33.8%)
No/not recorded	682 (89.3%)	686 (77.9%)	517 (66.2%)

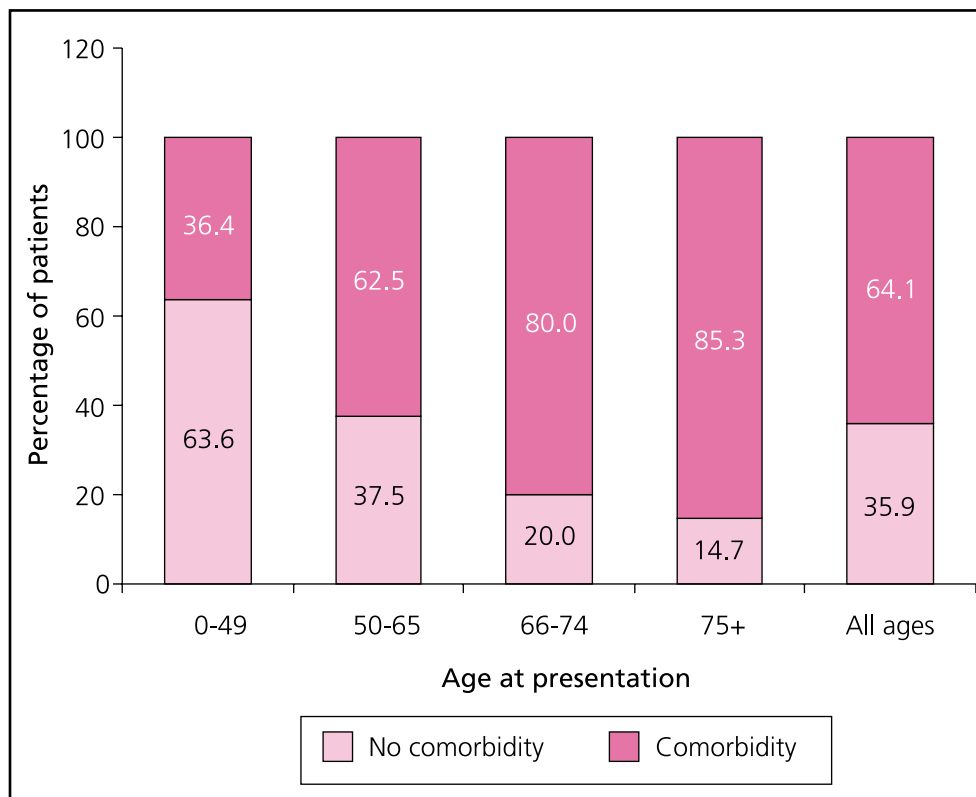
- Recording of family history of any cancer in the family improved by 2006.
- One third of breast cancer patients had a positive family history of breast cancer in 2006 with 19% having a record of a first degree relative with a history of breast cancer.

Comorbidities

Comorbidity	1996 (n=764)	2001 (n=881)	2006 (n=951)
Hypertension	164 (21.5%)	226 (25.7%)	324 (34.1%)
History of breast disease (benign)	128 (16.8%)	174 (19.8%)	172 (18.1%)
Arthritis	100 (13.1%)	153 (17.4%)	176 (18.5%)
COPD - Chronic Obstructive Pulmonary Disease	58 (7.6%)	86 (9.8%)	38 (4.0%)
Ischaemic Heart Disease	114 (14.9%)	86 (9.8%)	87 (9.1%)
Cerebrovascular Disease	25 (3.3%)	46 (5.2%)	18 (1.9%)
Diabetes	40 (5.2%)	45 (5.1%)	71 (7.5%)
Osteoporosis	10 (1.3%)	33 (3.7%)	60 (6.3%)
Psychiatric Disorder	25 (3.3%)	20 (2.3%)	30 (3.2%)
Dementia	12 (1.6%)	19 (2.2%)	24 (2.5%)
Alzheimers	1 (0.1%)	5 (0.6%)	11 (1.2%)
History of breast cancer	3 (0.4%)	4 (0.5%)	17 (1.8%)
Parkinson's Disease	6 (0.8%)	4 (0.5%)	6 (0.6%)
Other malignancy	32 (4.2%)	40 (4.5%)	79 (8.3%)
No comorbidity recorded	322 (42.1%)	323 (36.7%)	341 (35.9%)

- Approximately two thirds of women with breast cancer had a comorbidity recorded in 2006. One third of patients were recorded with hypertension while almost one fifth had a history of benign breast disease and 2% had a history of breast cancer.
- Between 2001 and 2006 there was an increase in recording of hypertension (26% vs. 34%, $p<0.001$), diabetes (5% vs. 8%, $p=0.038$), osteoporosis (4% vs. 6%, $p=0.013$), history of breast cancer (0.5% vs. 2%, $p=0.007$) and history of other malignancy (4% vs. 8%, $p=0.001$). There was however a decrease in recorded COPD (10% vs. 4%, $p<0.001$) and cerebrovascular disease (5% vs. 2%, $p<0.001$). The change in COPD may however be an artifact of changes in guidance as to how COPD is recorded.
- The proportion of patients with no comorbidity recorded was similar in 2001 and 2006.

Presence of comorbidity by age at presentation: 2006



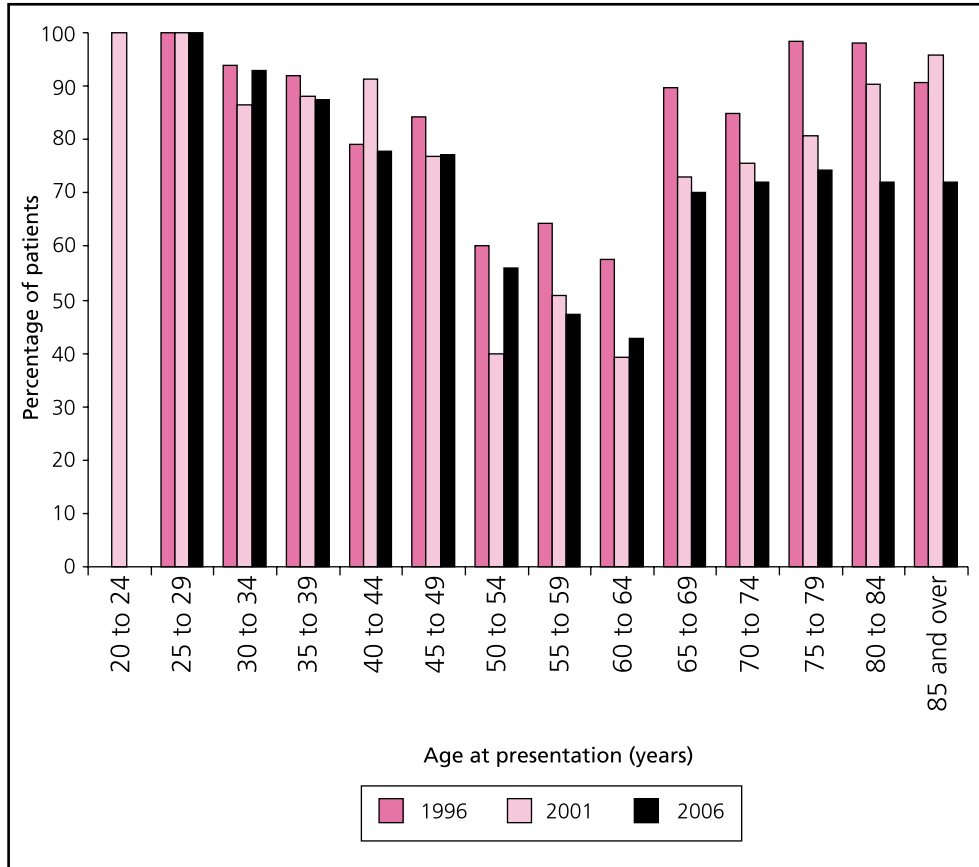
- The likelihood of breast cancer patients having a comorbidity increased with increasing age. In 2006 36% of patients aged 0 to 49 had a comorbidity compared to 85% of those aged 75 and over.

Symptoms

Symptom	1996 (n=764)	2001 (n=881)	2006 (n=951)
Breast/axillary lump	600 (78.5%)	576 (65.4%)	625 (65.7%)
Breast pain	120 (15.7%)	163 (18.5%)	165 (17.4%)
Nipple discharge/abnormality	100 (13.1%)	123 (14.0%)	125 (13.1%)
Abscess	12 (1.6%)	20 (2.3%)	15 (1.6%)
Deformity	46 (6.0%)	69 (7.8%)	56 (5.9%)
Skin changes	125 (16.4%)	164 (18.6%)	103 (10.8%)
Presented with secondary symptoms	36 (4.7%)	10 (1.1%)	15 (1.6%)
Weight loss	31 (4.1%)	38 (4.3%)	22 (2.3%)
Other	163 (21.3%)	137 (15.6%)	123 (12.9%)
Asymptomatic	92 (12.0%)	193 (21.9%)	225 (23.7%)

- Two thirds of patients presented with a breast/axillary lump in 2006. The percentage presenting with this symptom fell between 1996 and 2001 from 78% to 65% ($p < 0.001$) but remained steady between 2001 and 2006.
- The percentage of patients presenting with skin changes fell between 2001 and 2006 from 19% to 11% ($p < 0.001$) while weight loss as a symptom decreased from 4% to 2% ($p = 0.016$). The proportion of patients who were asymptomatic was similar between 2001 and 2006.

Percentage of patients presenting with breast/axillary lumps as a percentage of total patients in each age group



- Among women aged 50-64 diagnosed in 2006, the proportion presenting with breast/axillary lumps was less than for other age groups and most likely reflects early detection of tumours by the Breast Screening Programme before a lump is palpable.

Source of referral for asymptomatic patients

Source of referral	1996 (n=92)	2001 (n=193)	2006 (n=225)
GP (General Practitioner)	5 (5.4%)	8 (4.1%)	33 (14.7%)
Breast Screening Programme (BSP)	77 (83.7%)	157 (81.3%)	134 (59.6%)
Action Cancer	5 (5.4%)	12 (6.2%)	7 (3.1%)
Other	5 (5.4%)	16 (8.3%)	51 (22.7%)

- 60% of asymptomatic patients in 2006 were referred by the Breast Screening Programme, a reduction from the 81% in 2001 ($p < 0.001$). The majority of the rest were from "other" sources such as breast clinics.

Symptoms and duration

Symptom		1 month or less	2-5 months	6-11 months	12 or more months	Not recorded	Total
Breast/axillary lump	1996	266 (44.3%)	87 (14.5%)	25 (4.2%)	56 (9.3%)	166 (27.7%)	600
	2001	342 (59.4%)	80 (13.9%)	29 (5.0%)	31 (5.4%)	94 (16.3%)	576
	2006	336 (53.8%)	120 (19.2%)	24 (3.8%)	29 (4.6%)	116 (18.6%)	625
Breast pain	1996	41 (34.2%)	23 (19.2%)	7 (5.8%)	13 (10.8%)	36 (30.0%)	120
	2001	59 (36.2%)	16 (9.8%)	3 (1.8%)	6 (3.7%)	79 (48.5%)	163
	2006	65 (39.4%)	35 (21.2%)	4 (2.4%)	6 (3.6%)	55 (33.3%)	165
Nipple discharge/ abnormality	1996	17 (17.0%)	11 (11.0%)	9 (9.0%)	7 (7.0%)	56 (56.0%)	100
	2001	35 (28.5%)	13 (10.6%)	3 (2.4%)	10 (8.1%)	62 (50.4%)	123
	2006	42 (33.6%)	28 (22.4%)	12 (9.6%)	11 (8.8%)	32 (25.6%)	125
Weight loss	1996	6 (19.4%)	7 (22.6%)	1 (3.2%)	2 (6.5%)	15 (48.4%)	31
	2001	5 (13.2%)	4 (10.5%)	7 (18.4%)	6 (15.8%)	16 (42.1%)	38
	2006	1 (4.5%)	4 (18.2%)	0 (0%)	6 (27.3%)	11 (50.0%)	22

- 54% of patients in 2006 who presented with a breast/axillary lump reported its presence for less than one month. This is a slight decrease on the 59% in 2001 ($p=0.050$).
- Approximately 5% of 2006 patients with a breast/axillary lump had the symptom for more than one year while 18% of those with nipple discharge/abnormality had this symptom for more than six months.
- There was a 45% reduction in the number of women who had a lump and a 54% reduction in the number of women who had breast pain for more than one year between 1996 and 2001 with this reduction maintained until 2006.

Location of presentation

- There was a decrease of 5% in the proportion of breast cancer patients presenting to the Breast Screening Programme (BSP) between 2001 and 2006 ($p=0.007$).
- The number of patients presenting to each cancer unit remained steady between 2001 and 2006 except for Altnagelvin hospital, which had almost twice as many patients presenting in 2006 compared to 2001. This is due to reductions in patient presentation at Erne and Tyrone County hospitals between the two years.
- The proportion of patients presenting to the Ulster Independent Clinic increased from 2% to 10% ($p<0.001$) between 2001 and 2006 representing a fivefold increase in the number of patients presenting at private hospitals.

Location of presentation

Patients can present either at a hospital or the Breast Screening Programme.

Trust	Location	1996 (n=764)	2001 (n=881)	2006 (n=951)
Belfast HSCT	Belfast City Hospital*	56 (7.3%)	223 (25.3%)	235 (24.7%)
	Royal Victoria Hospital	136 (17.8%)	1 (0.1%)	1 (0.1%)
	Mater Infirmorum Hospital	12 (1.6%)	6 (0.7%)	0 (0%)
	Musgrave Park Hospital	0 (0%)	1 (0.1%)	0 (0%)
	Belvoir Park Hospital	0 (0%)	0 (0%)	1 (0.1%)
	Total	204 (26.7%)	231 (26.2%)	237 (24.9%)
Northern HSCT	Antrim Hospital*	22 (2.9%)	120 (13.6%)	119 (12.5%)
	Causeway (Coleraine) Hospital	36 (4.7%)	2 (0.2%)	6 (0.6%)
	Whiteabbey Hospital	5 (0.7%)	0 (0%)	0 (0%)
	Mid-Ulster Hospital	4 (0.5%)	2 (0.2%)	0 (0%)
	Braid Valley Hospital	0 (0%)	1 (0.1%)	0 (0%)
	Moyle Hospital	1 (0.1%)	0 (0%)	1 (0.1%)
	Massereene Hospital	50 (6.5%)	0 (0%)	0 (0%)
	Total	118 (15.4%)	125 (14.2%)	126 (13.2%)
South-Eastern HSCT	Ulster Hospital*	96 (12.6%)	112 (12.7%)	119 (12.5%)
	Lagan Valley Hospital	21 (2.7%)	4 (0.5%)	0 (0%)
	Downe Hospital	11 (1.4%)	3 (0.3%)	0 (0%)
	Ards Hospital	1 (0.1%)	0 (0%)	0 (0%)
	Bangor Community Hospital	3 (0.4%)	0 (0%)	0 (0%)
	Total	132 (17.3%)	119 (13.5%)	119 (12.5%)
Southern HSCT	Craigavon Area Hospital*	49 (6.4%)	107 (12.1%)	118 (12.4%)
	Daisy Hill Hospital	34 (4.5%)	2 (0.2%)	0 (0%)
	South Tyrone Hospital	5 (0.7%)	0 (0%)	0 (0%)
	Armagh Community Hospital	1 (0.1%)	0 (0%)	0 (0%)
	Banbridge Hospital	0 (0%)	1 (0.1%)	0 (0%)
	Total	89 (11.6%)	110 (12.5%)	118 (12.4%)
Western HSCT	Altnagelvin Hospital*	58 (7.6%)	56 (6.4%)	103 (10.8%)
	Erne Hospital	15 (2.0%)	17 (1.9%)	2 (0.2%)
	Tyrone County Hospital	15 (2.0%)	13 (1.5%)	0 (0%)
	Total	88 (11.5%)	86 (9.8%)	105 (11.0%)
Private Hospitals	Ulster Independent Clinic	7 (0.9%)	20 (2.3%)	96 (10.1%)
Breast Screening Programme		106 (13.9%)	180 (20.4%)	148 (15.6%)
Not recorded		20 (2.6%)	10 (1.1%)	2 (0.2%)

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients audited in this report were thus treated under the old Health and Social Services Board (HSSB) structure. Under that structure both the Belfast HSCT and South-Eastern HSCT were part of Belfast HSSB while the Northern, Southern and Western HSCTs were the same as the Northern, Southern and Western HSSBs respectively.
*Cancer Unit.

Trust and hospital first seen at

Trust	Hospital	1996 (n=764)	2001 (n=881)	2006 (n=951)
Belfast HSCT	Belfast City Hospital*	58 (7.6%)	251 (28.5%)	260 (27.3%)
	Royal Victoria Hospital	170 (22.3%)	1 (0.1%)	1 (0.1%)
	Mater Infirmorum Hospital	12 (1.6%)	6 (0.7%)	0 (0%)
	Musgrave Park Hospital	0 (0%)	1 (0.1%)	0 (0%)
	Belvoir Park Hospital	0 (0%)	0 (0%)	1 (0.1%)
	Total	240 (31.4%)	259 (29.4%)	262 (27.5%)
Northern HSCT	Antrim Hospital*	30 (3.9%)	160 (18.2%)	132 (13.9%)
	Causeway (Coleraine) Hospital	37 (4.8%)	2 (0.2%)	7 (0.7%)
	Whiteabbey Hospital	5 (0.7%)	0 (0%)	0 (0%)
	Mid-Ulster Hospital	4 (0.5%)	2 (0.2%)	0 (0%)
	Braid Valley Hospital	0 (0%)	1 (0.1%)	0 (0%)
	Moyle Hospital	1 (0.1%)	0 (0%)	1 (0.1%)
	Massereene Hospital	68 (8.9%)	0 (0%)	0 (0%)
	Total	145 (19.0%)	165 (18.7%)	140 (14.7%)
South-Eastern HSCT	Ulster Hospital*	100 (13.1%)	157 (17.8%)	140 (14.7%)
	Lagan Valley Hospital	21 (2.7%)	5 (0.6%)	0 (0%)
	Downe Hospital	11 (1.4%)	3 (0.3%)	0 (0%)
	Ards Hospital	1 (0.1%)	0 (0%)	0 (0%)
	Bangor Community Hospital	3 (0.4%)	0 (0%)	0 (0%)
	Total	136 (17.8%)	165 (18.7%)	140 (14.7%)
Southern HSCT	Craigavon Area Hospital*	78 (10.2%)	136 (15.4%)	159 (16.7%)
	Daisy Hill Hospital	35 (4.6%)	2 (0.2%)	0 (0%)
	South Tyrone Hospital	5 (0.7%)	0 (0%)	0 (0%)
	Armagh Community Hospital	1 (0.1%)	1 (0.1%)	0 (0%)
	Banbridge Hospital	0 (0%)	1 (0.1%)	0 (0%)
	Lurgan Hospital	0 (0%)	0 (0%)	1 (0.1%)
	Total	119 (15.6%)	140 (15.9%)	160 (16.8%)
Western HSCT	Altnagelvin Hospital*	66 (8.6%)	88 (10.0%)	148 (15.6%)
	Erne Hospital	15 (2.0%)	17 (1.9%)	2 (0.2%)
	Tyrone County Hospital	15 (2.0%)	13 (1.5%)	0 (0%)
	Total	96 (12.6%)	118 (13.4%)	150 (15.8%)
Private Hospitals	Ulster Independent Clinic	8 (1.0%)	24 (2.7%)	97 (10.2%)
Not recorded		20 (2.6%)	10 (1.1%)	2 (0.2%)

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients audited in this report were thus treated under the old Health and Social Services Board (HSSB) structure. Under that structure both the Belfast HSCT and South-Eastern HSCT were part of Belfast HSSB while the Northern, Southern and Western HSCTs were the same as the Northern, Southern and Western HSSBs respectively.

*Cancer Unit.

- There was a 4.0% decrease in the proportion of breast cancer patients first seen at hospitals in the Northern and South-Eastern Trusts between 2001 and 2006 (p=0.021).
- There is good evidence that by 2001 breast cancer services were centralized in each Trust area, although this was less apparent in the Western Trust. There has been further concentration of services in 2006 with 98% of Health Service patients (i.e. excluding private patients) first seen at one of five cancer units.

Trust of hospital first seen at by Trust area of residence

Trust area of residence		Trust of hospital first seen at (% patients in Trust area of residence)							
		Belfast HSCT	Northern HSCT	South-Eastern HSCT	Southern HSCT	Western HSCT	Private Hospitals	Not recorded	Total patients
Belfast HSCT	1996	142 (72.4%)	0 (0%)	45 (23.0%)	0 (0%)	0 (0%)	4 (2.0%)	5 (2.6%)	196
	2001	120 (60.3%)	0 (0%)	66 (33.2%)	0 (0%)	0 (0%)	8 (4.0%)	5 (2.5%)	199
	2006	122 (68.2%)	0 (0%)	39 (21.8%)	1 (0.6%)	0 (0%)	17 (9.5%)	0 (0%)	179
Northern HSCT	1996	41 (21.4%)	144 (75.0%)	0 (0%)	2 (1.0%)	0 (0%)	2 (1.0%)	3 (1.6%)	192
	2001	37 (17.5%)	164 (77.4%)	2 (0.9%)	3 (1.4%)	1 (0.5%)	2 (0.9%)	3 (1.4%)	212
	2006	57 (22.4%)	135 (53.1%)	8 (3.1%)	5 (2.0%)	20 (7.9%)	28 (11.0%)	1 (0.4%)	254
South-Eastern HSCT	1996	44 (31.2%)	1 (0.7%)	86 (61.0%)	0 (0%)	0 (0%)	2 (1.4%)	8 (5.7%)	141
	2001	82 (42.7%)	0 (0%)	94 (49.0%)	4 (2.1%)	0 (0%)	11 (5.7%)	1 (0.5%)	192
	2006	64 (33.5%)	1 (0.5%)	90 (47.1%)	5 (2.6%)	0 (0%)	30 (15.7%)	1 (0.5%)	191
Southern HSCT	1996	12 (8.9%)	0 (0%)	4 (3.0%)	116 (85.9%)	1 (0.7%)	0 (0%)	2 (1.5%)	135
	2001	20 (12.3%)	0 (0%)	3 (1.9%)	132 (81.5%)	4 (2.5%)	3 (1.9%)	0 (0%)	162
	2006	18 (9.4%)	3 (1.6%)	3 (1.6%)	148 (77.1%)	3 (1.6%)	17 (8.9%)	0 (0%)	192
Western HSCT	1996	1 (1.0%)	0 (0%)	1 (1.0%)	1 (1.0%)	95 (95.0%)	0 (0%)	2 (2.0%)	100
	2001	0 (0%)	1 (0.9%)	0 (0%)	1 (0.9%)	113 (97.4%)	0 (0%)	1 (0.9%)	116
	2006	1 (0.7%)	1 (0.7%)	0 (0%)	1 (0.7%)	127 (94.1%)	5 (3.7%)	0 (0%)	135

- Over 94% of patients resident in the Western HSCT were first seen at a hospital within that Trust. The overlap between Trust of residence and Trust of hospital first seen at was smaller for the other four Trusts.

- The proportion of patients first seen at a hospital within their own Trust decreased considerably between 2001 and 2006 for the Northern Trust. This is due to an increase in Northern Trust residents first seen at Belfast City Hospital (22%) and at private hospitals (11%).
- 16% of South-Eastern Trust residents were first seen at a private hospital in 2006, while 34% were first seen at a hospital in the Belfast Trust. However 22% of Belfast Trust residents were first seen at a hospital in the South-Eastern Trust.

Diagnosis

Investigations

Investigation	All patients			Surgery patients		
	1996 (n=764)	2001 (n=881)	2006 (n=951)	1996 (n=677)	2001 (n=804)	2006 (n=862)
Mammography	655 (85.7%)	823 (93.4%)	868 (91.3%)	610 (90.1%)	778 (96.8%)	817 (94.8%)
Fine Needle Aspiration (FNA)	653 (85.5%)	748 (84.9%)	865 (91.0%)	584 (86.3%)	693 (86.2%)	796 (92.3%)
Core biopsy	54 (7.1%)	370 (42.0%)	479 (50.4%)	51 (7.5%)	351 (43.7%)	432 (50.1%)
Excision biopsy	179 (23.4%)	54 (6.1%)	25 (2.6%)	179 (26.4%)	54 (6.7%)	25 (2.9%)
Ultrasound - Breast	207 (27.1%)	627 (71.2%)	739 (77.7%)	199 (29.4%)	592 (73.6%)	699 (81.1%)
Chest X-Ray	375 (49.1%)	520 (59.0%)	591 (62.1%)	321 (47.4%)	488 (60.7%)	549 (63.7%)
Ultrasound - Abdomen	212 (27.7%)	425 (48.2%)	413 (43.4%)	188 (27.8%)	398 (49.5%)	379 (44.0%)
CT Scan	18 (2.4%)	45 (5.1%)	209 (22.0%)	15 (2.2%)	32 (4.0%)	174 (20.2%)
Brain Scan	19 (2.5%)	15 (1.7%)	34 (3.6%)	12 (1.8%)	9 (1.1%)	27 (3.1%)
Bone Scan	165 (21.6%)	356 (40.4%)	421 (44.3%)	146 (21.6%)	331 (41.2%)	393 (45.6%)
Other*	56 (7.3%)	45 (5.1%)	119 (12.5%)	43 (6.4%)	36 (4.5%)	102 (11.8%)

Note: Patients may have more than one type of investigation.

* Other includes MRI scans, X-Rays and Ultrasounds of other parts of the body.

- The use of different methods of investigation has changed significantly over time. While mammography use remained at a similar level between 2001 and 2006 the proportion of patients receiving other pre-operative investigation techniques has increased between the two years. Specifically:
 - Fine needle aspiration has increased from 85% to 91% ($p < 0.001$) for all patients and from 86% to 92% ($p < 0.001$) for surgery patients.
 - Core biopsy has increased from 42% to 50% ($p < 0.001$) for all patients and from 44% to 50% ($p < 0.001$) for surgery patients, while excision biopsies have declined.
 - Ultrasound of the breast has increased from 71% to 78% ($p = 0.001$) for all patients and from 74% to 81% for surgery patients ($p < 0.001$).
- Between 2001 and 2006 the use of CT scans to detect metastatic disease increased considerably from 5% to 22% for all patients ($p < 0.001$) with a similar change for surgery patients. The use of brain scans also increased slightly, however the use of ultrasound of the abdomen declined, possibly as a result of demand on radiology services.
- "Other" investigative techniques increased considerably between 2001 and 2006. This included an increased use of magnetic resonance imaging (MRI).

Cancer site

Site	1996 (n=764)	2001 (n=881)	2006 (n=951)
Nipple	4 (0.5%)	15 (1.7%)	24 (2.5%)
Central Portion	118 (15.4%)	114 (12.9%)	59 (6.2%)
Upper Inner Quadrant	68 (8.9%)	96 (10.9%)	132 (13.9%)
Lower Inner Quadrant	30 (3.9%)	52 (5.9%)	57 (6.0%)
Upper Outer Quadrant	357 (46.7%)	317 (36.0%)	369 (38.8%)
Lower Outer Quadrant	59 (7.7%)	65 (7.4%)	75 (7.9%)
Axillary Tail	3 (0.4%)	1 (0.1%)	4 (0.4%)
Overlapping Lesion	4 (0.5%)	7 (0.8%)	22 (2.3%)
Not specified	121 (15.8%)	214 (24.3%)	209 (22.0%)

- The most common location of breast cancer was the upper outer quadrant in all three years.
- 22% of patients in 2006 did not have a specific cancer site recorded. While this is similar to the proportion in 2001 it is higher than the 16% without a site recorded in 1996 (p=0.001).

Laterality

Side of tumour	2006 (n=951)
Left	501 (52.7%)
Right	446 (46.9%)
Both	2 (0.2%)
Not recorded	2 (0.2%)

- Laterality (i.e. side of tumour) was recorded in the audit for the first time in 2006, with a high level of completeness (>99%).
- While it would be reasonable to expect equal numbers of patients with the left or right breast affected by cancer, incidence of cancer in the left breast was slightly higher than in the right during 2006 (p=0.013). This is in keeping with recent research findings.²⁹
- Only two patients in 2006 had cancer in both breasts at diagnosis.

Histopathological type

Type	1996 (n=764)	2001 (n=881)	2006 (n=951)
Adenocarcinoma	14 (1.8%)	0 (0%)	0 (0%)
Carcinoma	130 (17.0%)	80 (9.1%)	76 (8.0%)
Infiltrating ductal	465 (60.9%)	663 (75.3%)	756 (79.5%)
Infiltrating lobular	89 (11.6%)	96 (10.9%)	99 (10.4%)
Paget's disease of breast	5 (0.7%)	23 (2.6%)	10 (1.1%)
Other	3 (0.4%)	7 (0.8%)	6 (0.6%)
Malignancy (not otherwise specified)	58 (7.6%)	12 (1.4%)	4 (0.4%)

- The majority of breast cancers in all three years were infiltrating ductal carcinomas. While the proportion of breast cancer patients with this histopathological type appears to be increasing this is likely due to better classification with the number of cancers with an unspecified type decreasing.

TNM¹⁹ Stage

Stage	All patients			Surgery patients		
	1996 (n=764)	2001 (n=881)	2006 (n=951)	1996 (n=677)	2001 (n=804)	2006 (n=862)
Stage I	259 (33.9%)	305 (34.6%)	265 (27.9%)	249 (36.8%)	305 (37.9%)	264 (30.6%)
Stage IIA	198 (25.9%)	214 (24.3%)	266 (28.0%)	194 (28.7%)	214 (26.6%)	265 (30.7%)
Stage IIB	129 (16.9%)	155 (17.6%)	118 (12.4%)	127 (18.8%)	154 (19.2%)	118 (13.7%)
Stage IIIA	44 (5.8%)	30 (3.4%)	84 (8.8%)	43 (6.4%)	29 (3.6%)	84 (9.7%)
Stage IIIB	14 (1.8%)	26 (3.0%)	20 (2.1%)	11 (1.6%)	23 (2.9%)	19 (2.2%)
Stage IIIC	1 (0.1%)	0 (0%)	66 (6.9%)	1 (0.1%)	0 (0%)	66 (7.7%)
Stage IV	62 (8.1%)	39 (4.4%)	67 (7.0%)	29 (4.3%)	16 (2.0%)	31 (3.6%)
Unknown*	57 (7.5%)	112 (12.7%)	65 (6.8%)	23 (3.4%)	63 (7.8%)	15 (1.7%)

* Stage not recorded in patient notes.

- 7% of patients in 2006 did not have a stage recorded in patient notes, a significant change on the 13% in 2001 ($p < 0.001$) but a similar result to that in 1996.
- In general, patients diagnosed in 2006 were diagnosed at a later stage than in 2001. Notably:
 - The proportion of Stage I or II patients in 2006 was 68% compared to 76% in 2001 ($p < 0.001$).
 - The proportion of Stage III patients in 2006 was 18% compared to 6% in 2001 ($p < 0.001$).
 - The proportion of Stage IV patients in 2006 was 7% compared to 4% in 2001 ($p = 0.016$).
 - While some of the increase in later stages may be a result of stage shift due to better investigation or a result of better recording of stage, this cannot entirely explain the increase in late diagnosis. A similar pattern was present for surgery patients.
- Diagnosis at Stage IIIC in 2006 has greatly increased compared to previous years. This however has been identified as better classification and coding of the number of nodes with metastases.
- Of the patients diagnosed at Stage I or Stage II in 2006 only 2 did not receive surgery. One of these patients initially refused treatment while the other was unfit for surgery as a result of comorbidities.

Nottingham Prognostic Index - Surgery patients

The Nottingham Prognostic Index (NPI) is a clinical indicator which gives a measure of the likelihood of survival from breast cancer. It is based upon histological grade, tumour size and number of nodes involved. It is used as an alternative to TNM¹⁹ to determine stage for treatment and outcome monitoring, however TNM¹⁹ is more commonly used for international comparisons. (see Appendix B for further information)

NPI	1996 (n=677)	2001 (n=804)	2006 (n=862)
Good (<3.4)	237 (35.0%)	286 (35.6%)	232 (26.9%)
Moderate (3.4-5.4)	259 (38.3%)	313 (38.9%)	412 (47.8%)
Poor (>5.4)	87 (12.9%)	130 (16.2%)	201 (23.3%)
Not possible	94 (13.9%)	75 (9.3%)	17 (2.0%)

- Levels of NPI recording were very good. The level of recording of NPI increased between 1996 and 2001 (p=0.006) and again between 2001 and 2006 (p<0.001).
- The NPI for surgery patients was generally poorer in 2006 than in 2001. In particular
 - The proportion of patients with good NPI (i.e. less than 3.4) in 2006 was 27% compared to 36% in 2001 (p<0.001).
 - The proportion of patients with moderate NPI (i.e. between 3.4 and 5.4) in 2006 was 48% compared to 39% in 2001 (p<0.001).
 - The proportion of patients with poor NPI (i.e. greater than 5.4) in 2006 was 23% compared to 16% in 2001 (p=0.016).
 - This change may be due to more precise recording of information, particularly in tumour size which in 2006 was recorded to the nearest millimetre compared to the nearest centimetre in 2001 and 1996. Additionally the number of nodes examined between each year has increased, possibly resulting in more affected nodes being detected by pathologists.

Patients with insufficient information for TNM staging or NPI recorded in patient notes

Trust of hospital first seen at	Patients (%within Trust with no TNM stage information recorded in patient notes)			Surgery patients (%within Trust with no NPI information recorded in patient notes)		
	1996	2001	2006	1996	2001	2006
Belfast HSCT	19 (7.9%)	42 (16.2%)	22 (8.4%)	26 (12.0%)	26 (11.1%)	4 (1.7%)
Northern HSCT	10 (6.9%)	6 (3.6%)	8 (5.7%)	7 (5.5%)	4 (2.5%)	2 (1.6%)
South-Eastern HSCT	13 (9.6%)	31 (18.8%)	14 (10.0%)	17 (15.2%)	19 (13.2%)	1 (0.8%)
Southern HSCT	7 (5.9%)	12 (8.6%)	12 (7.5%)	19 (17.6%)	13 (10.0%)	3 (2.1%)
Western HSCT	2 (2.1%)	13 (11.0%)	3 (2.0%)	22 (23.9%)	10 (8.8%)	5 (3.6%)
Private hospitals	0 (0%)	0 (0%)	4 (4.1%)	1 (12.5%)	1 (4.3%)	2 (2.1%)
Not recorded	6 (30.0%)	8 (80.0%)	2 (100.0%)	2 (16.7%)	2 (100.0%)	0 (0.0%)

- The proportion of patients without a TNM stage recorded in patient notes was highest for those who were first seen at a hospital in the South-Eastern Trust and lowest for those in the Western Trust.
- While not a requirement for the treatment of patients, NPI recording increased in all Trusts between 2001 and 2006.

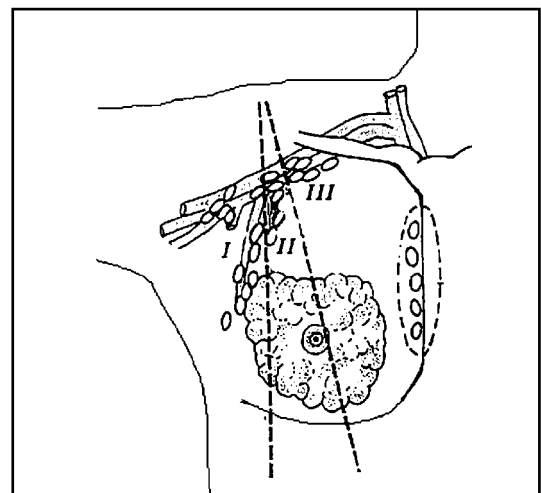
Patients with insufficient information for TNM staging or NPI recorded in patient notes

Age at presentation	Patients (%within age group with no TNM stage information recorded in patient notes)			Surgery patients (%within age group with no NPI information recorded in patient notes)		
	1996	2001	2006	1996	2001	2006
0-49	5 (2.8%)	12 (6.6%)	4 (1.7%)	21 (12.1%)	15 (8.4%)	3 (1.3%)
50-65	6 (2.1%)	23 (6.0%)	4 (1.1%)	33 (11.9%)	37 (9.8%)	8 (2.3%)
66-74	9 (6.9%)	14 (10.0%)	11 (6.9%)	15 (13.2%)	11 (8.7%)	4 (2.9%)
75 and over	35 (22.4%)	58 (37.2%)	46 (21.8%)	23 (22.8%)	10 (9.3%)	2 (1.3%)
Not recorded	2 (18.2%)	5 (25.0%)	0 (0%)	2 (20.0%)	2 (14.3%)	0 (0%)

- The proportion of patients without a TNM stage recorded in patient notes increased with increasing age with 22% of patients aged 75 and over and diagnosed in 2006 not having a TNM stage recorded compared to 2% of those aged 0 to 49.
- In 1996 the lack of recording of NPI was higher among those aged 75 and over. By 2001 recording of NPI was unrelated to age, a pattern maintained in 2006.

Levels of axillary clearance - Surgery patients only

Breast tissue is drained by lymphatic vessels that lead to one of 3 sets of lymph nodes: axillary (located in the armpit), internal mammary (located along each side of the breast bone) and supraclavicular (located above the collar bone). When breast cancer spreads, the axillary nodes are frequently involved. The axillary nodes are divided into 3 levels (I, II & III) according to their position in relation to the pectoralis minor muscle. The level I axillary nodes, also referred to as low-axillary, are usually involved before level II or III. NICE guidelines³ issued in 2002 indicate that sentinel node biopsy can be used as an alternative to axillary clearance (see section 3.5, appendix A).



Levels of axillary clearance	1996 (n=677)	2001 (n=804)	2006 (n=862)
I	135 (19.9%)	43 (5.3%)	27 (3.1%)
II	311 (45.9%)	162 (20.1%)	66 (7.7%)
III	108 (16.0%)	490 (60.9%)	529 (61.4%)
Sentinel node checked*	-	-	183 (21.2%)
Not recorded	123 (18.2%)	109 (13.6%)	57 (6.6%)

* Procedure only came into effect after 2002.

- Between 1996 and 2001, there was a large increase in the proportion of patients who had more extensive axillary surgery to level III nodes (16% vs. 61%, p<0.001).
- By 2006 examination of the sentinel node as an alternative to axillary clearance had been introduced in Altnagelvin and Ulster hospitals, although there is some evidence to suggest that both procedures were in use as sentinel biopsies were introduced.

Lymph nodes examined - Surgery patients

BASO guidelines for surgeons⁴ indicate that at least 4 lymph nodes should be examined, however updated NICE guidance issued in 2002³ indicated that this may not be necessary in the event of examination of the sentinel node.

Lymph nodes examined	1996 (n=677)	2001 (n=804)	2006			
			Sentinel node checked – Negative (n=128)	Sentinel node checked – Positive (n=55)	Sentinel node not checked (n=679)	All surgery patients (n=862)
None	63 (9.3%)	11 (1.4%)	0 (0%)	0 (0%)	6 (0.9%)	6 (0.7%)
1-3 nodes	37 (5.5%)	2 (0.2%)	68 (53.1%)	0 (0%)	2 (0.3%)	70 (8.1%)
4-5 nodes	59 (8.7%)	8 (1.0%)	11 (8.6%)	2 (3.6%)	2 (0.3%)	15 (1.7%)
6-11 nodes	309 (45.6%)	180 (22.4%)	20 (15.6%)	6 (10.9%)	69 (10.2%)	95 (11.0%)
12-20 nodes	180 (26.6%)	426 (53.0%)	16 (12.5%)	28 (50.9%)	345 (50.8%)	389 (45.1%)
21+ nodes	26 (3.8%)	158 (19.7%)	11 (8.6%)	19 (34.5%)	246 (36.2%)	276 (32.0%)
Not recorded	3 (0.4%)	19 (2.4%)	2 (1.6%)	0 (0%)	9 (1.3%)	11 (1.3%)

- 21% of surgery patients diagnosed in 2006 had the sentinel node examined. This practice occurred in Altnagelvin and Ulster hospitals.
- Excluding patients in 2006 who had examination of the sentinel node, 1% had less than 4 nodes examined and 87% had more than 12 nodes examined.
- Excluding those who had a sentinel node biopsy, there was an increase in the proportion of patients having 12 or more lymph nodes examined between 2001 and 2006 (73% vs. 87%, $p < 0.001$).
- All surgery patients diagnosed in 2006 who had the sentinel node examined with a positive result went on to have four or more lymph nodes examined.

Oestrogen Receptor Status

Oestrogen Receptor (ER) Status is a good predictive factor for response to hormonal therapy such as Tamoxifen and Anastrozole which improves overall survival especially in postmenopausal women. A test on a sample of tumour cells will reveal if the cancer has oestrogen receptors i.e. if it is oestrogen positive or negative. If a tumour is oestrogen receptor positive, then drugs such as Tamoxifen and Anastrozole can be used to block the receptor on the tumour cell and prevent the growth of the cancer.

Oestrogen Receptor Status	1996 (n=764)	2001 (n=881)	2006 (n=951)
Positive	43 (5.6%)	596 (67.7%)	734 (77.2%)
Negative	126 (16.5%)	199 (22.6%)	194 (20.4%)
Not recorded	595 (77.9%)	86 (9.8%)	23 (2.4%)

- There was an increase in the number of patients who, by 2006, had an ER status recorded (98%).
- 79% of patients with ER status recorded were oestrogen receptor positive in 2006, an increase on the 75% who were positive in 2001 ($p=0.042$).

HER2 Status

HER2 Status	2006 (n=951)
Positive	161 (16.9%)
Negative	690 (72.6%)
Not recorded	100 (10.5%)

- In 2006 90% of patients had HER2 status recorded, with 17% recorded as positive.

Multidisciplinary Team Meetings

The effective management of breast cancer patients requires input from a range of experts. Multidisciplinary team meetings (MDTs) involve a group of healthcare professionals meeting to discuss the diagnosis and treatment of patients. As there are a range of potential treatments that could be carried out, multidisciplinary discussions are of great importance. With respect to MDTs it should be noted that discussions among healthcare professionals, regarding the diagnosis and treatment of patients, may have taken place but may not have been recorded in the patient notes.

Multidisciplinary team meeting	1996 (n=764)	2001 (n=881)	2006 (n=951)
Yes	30 (3.9%)	230 (26.1%)	527 (55.4%)
No	734 (96.1%)	651 (73.9%)	424 (44.6%)

- Recording in the clinical notes that discussion at a MDT had taken place improved from 26% in 2001 to 55% in 2006 ($p<0.001$).

Multidisciplinary Team Meetings by Trust of residence and hospital first seen at

Trust of residence	Patients (% MDT within Trust)		
	1996	2001	2006
Belfast HSCT	12 (6.1%)	75 (37.7%)	77 (43.0%)
Northern HSCT	10 (5.2%)	36 (17.0%)	92 (36.2%)
South-Eastern HSCT	6 (4.3%)	75 (39.1%)	104 (54.5%)
Southern HSCT	1 (0.7%)	33 (20.4%)	124 (64.6%)
Western HSCT	1 (1.0%)	11 (9.5%)	130 (96.3%)

Trust of hospital first seen at	Patients (% MDT within Trust)		
	1996	2001	2006
Belfast HSCT	11 (4.6%)	85 (32.8%)	81 (30.9%)
Northern HSCT	10 (6.9%)	23 (13.9%)	43 (30.7%)
South-Eastern HSCT	7 (5.1%)	79 (47.9%)	104 (74.3%)
Southern HSCT	1 (0.8%)	29 (20.7%)	115 (71.9%)
Western HSCT	1 (1.0%)	11 (9.3%)	148 (98.7%)
Private hospitals	0 (0%)	3 (12.5%)	36 (37.1%)
Not recorded	0 (0%)	0 (0%)	0 (0%)

- Recording that an MDT had taken place was highest for patients resident in the Western Trust (96%) and lowest for those resident in the Northern Trust (36%).
- Recording that an MDT had taken place was also highest for patients who were first seen at a hospital in the Western Trust (99%) and lowest for patients who were first seen at a hospital in the Northern (31%) and Belfast (31%) Trusts.

Treatment

Treatment for breast cancer patients

Treatment type	1996 (n=764)	2001 (n=881)	2006 (n=951)
Surgery	677 (88.6%)	804 (91.3%)	862 (90.6%)
Chemotherapy	196 (25.7%)	344 (39.0%)	434 (45.6%)
Radiotherapy	431 (56.4%)	648 (73.6%)	637 (67.0%)
Hormone therapy	719 (94.1%)	703 (79.8%)	746 (78.4%)
Herceptin*	-	-	94 (9.9%)
No treatment	6 (0.8%)	9 (1.0%)	18 (1.9%)

Note: Patients may receive more than one type of treatment.

* Herceptin receipt collected in 2006 only.

- 91% of patients diagnosed in 2006 with breast cancer had surgery, a similar proportion to both 2001 and 1996.
- Use of chemotherapy increased between 1996 and 2001 ($p < 0.001$) and again between 2001 and 2006 ($p = 0.004$) so that in 2006 46% of patients received this type of treatment.
- Radiotherapy use increased between 1996 and 2001 from 56% to 74% ($p < 0.001$) however it decreased again in 2006 to 67% ($p = 0.002$).
- Hormone therapy use was very high in 1996 with 94% of patients receiving this treatment type. By 2001 this had declined to 80% ($p < 0.001$), a level maintained in 2006.
- 10% of patients in 2006 received herceptin as a treatment.

Treatment combinations for breast cancer patients

Treatment combinations	1996 (n=764)	2001 (n=881)	2006 (n=951)
Surgery alone	14 (1.8%)	26 (3.0%)	27 (2.8%)
Chemotherapy alone	1 (0.1%)	1 (0.1%)	0 (0%)
Radiotherapy alone	0 (0%)	2 (0.2%)	3 (0.3%)
Hormone therapy alone	61 (8.0%)	53 (6.0%)	52 (5.5%)
Surgery and chemotherapy	5 (0.7%)	7 (0.8%)	31 (3.3%)
Surgery and radiotherapy	7 (0.9%)	28 (3.2%)	34 (3.6%)
Surgery and hormone therapy	195 (25.5%)	116 (13.2%)	119 (12.5%)
Chemotherapy and radiotherapy	2 (0.3%)	3 (0.3%)	2 (0.2%)
Chemotherapy and hormone therapy	4 (0.5%)	1 (0.1%)	4 (0.4%)
Radiotherapy and hormone therapy	10 (1.3%)	3 (0.3%)	9 (0.9%)
Surgery, chemotherapy and radiotherapy	10 (1.3%)	102 (11.6%)	90 (9.5%)
Surgery, chemotherapy and hormone therapy	47 (6.2%)	20 (2.3%)	63 (6.6%)
Surgery, radiotherapy and hormone therapy	275 (36.0%)	300 (34.1%)	255 (26.8%)
Chemotherapy, radiotherapy and hormone therapy	3 (0.4%)	5 (0.6%)	1 (0.1%)
Surgery, chemotherapy, radiotherapy and hormone therapy	124 (16.2%)	205 (23.3%)	243 (25.6%)
No treatment	6 (0.8%)	9 (1.0%)	18 (1.9%)

- The most common treatment combinations in all three years was the combination of surgery, radiotherapy and hormone therapy or all four types of treatment combined.
- By 2006, there was a small increase in the number of patients having the combination of surgery and chemotherapy ($p < 0.001$) and combined surgery, chemotherapy and hormone therapy ($p < 0.001$), while there was a reduction in combined use of surgery, radiotherapy and hormone therapy ($p = 0.001$).
- Less than 2% of patients in all three years did not have surgery, chemotherapy, radiotherapy or hormone therapy.

Main surgery for breast cancer

Surgery includes mastectomy and the breast conserving procedures: partial mastectomy (including quadrantectomy and segmental mastectomy), wide local excision, excision biopsy (including lumpectomy) and other procedures not specified. The tables below report on the main operation a patient receives. A patient may have received more than one type (e.g. a patient may have received a mastectomy after an excision biopsy). This differs from the table in the 1996-2001 audit report which reported on the first operation received which may not always be the main operation received.

Surgery type	Patients (% of surgery patients)		
	1996 (n=677)	2001 (n=804)	2006 (n=862)
Mastectomy	350 (51.7%)	410 (51.0%)	500 (58.0%)
Partial mastectomy	51 (7.5%)	200 (24.9%)	218 (25.3%)
Wide local excision	180 (26.6%)	173 (21.5%)	138 (16.0%)
Excision biopsy	36 (5.3%)	17 (2.1%)	3 (0.3%)
Other	39 (5.8%)	4 (0.5%)	2 (0.2%)
Not recorded	21 (3.1%)	0 (0%)	1 (0.1%)

- 22% more patients had a mastectomy as their main operation in 2006 compared to 2001. This was also an increase in the proportion of all breast cancer surgery patients receiving a mastectomy (51% vs. 58%, $p = 0.005$).

Mastectomy by age at presentation

Age at presentation	Patients (% of all patients within age group)		
	1996	2001	2006
0-49	100 (55.9%)	96 (52.7%)	130 (56.3%)
50-65 (screening age)	141 (49.0%)	170 (44.4%)	187 (53.6%)
66-74	56 (43.1%)	63 (45.0%)	71 (44.4%)
75 and over	47 (30.1%)	72 (46.2%)	112 (53.1%)
Unknown	7 (63.6%)	9 (45.0%)	0 (0%)
Total	351 (45.9%)	410 (46.5%)	500 (52.6%)

- 44% of patients aged 66-74 had a mastectomy in 2006, slightly lower than the 53-56% among other age groups ($p = 0.004$).
- The proportion of patients aged 50-65 receiving a mastectomy increased between 2001 and 2006 from 44% to 54% ($p = 0.013$). Between 1996 and 2006 the proportion of patients aged 75 and over undergoing a mastectomy also increased, from 30% to 53% ($p < 0.001$).

Mastectomy by stage

Stage	Patients (% of all patients within stage group)		
	1996	2001	2006
Stage I	98 (37.8%)	96 (31.5%)	93 (35.1%)
Stage II	188 (57.5%)	222 (60.2%)	236 (61.5%)
Stage III	43 (72.9%)	44 (78.6%)	140 (82.4%)
Stage IV	12 (19.4%)	13 (33.3%)	22 (32.8%)
Unknown	10 (17.5%)	35 (31.3%)	9 (13.8%)
Total	351 (45.9%)	410 (46.5%)	500 (52.6%)

- More patients with Stage III disease had a mastectomy in all three years compared to other stages. This reflects patient selection for the procedure depending upon disease severity, although stage is not directly used as criteria for selection of a patient for a mastectomy.

Mastectomy by cancer site

Cancer site	Patients (% of all patients within site group)		
	1996	2001	2006
Nipple	2 (50.0%)	10 (66.7%)	18 (75.0%)
Central Portion	86 (72.9%)	91 (79.8%)	44 (74.6%)
Upper Inner Quadrant	33 (48.5%)	35 (36.5%)	64 (48.5%)
Lower Inner Quadrant	19 (63.3%)	16 (30.8%)	36 (63.2%)
Upper Outer Quadrant	134 (37.5%)	128 (40.4%)	180 (48.8%)
Lower Outer Quadrant	24 (40.7%)	36 (55.4%)	41 (54.7%)
Axillary Tail	2 (66.7%)	0 (0%)	0 (0%)
Overlapping Lesion	1 (25.0%)	6 (85.7%)	8 (36.4%)
Not specified	50 (41.3%)	88 (41.1%)	109 (52.2%)
Total	351 (45.9%)	410 (46.5%)	500 (52.6%)

- More patients with cancer of the nipple or central portion of the breast had a mastectomy compared to use of the procedure overall ($p=0.029$).

Primary reconstruction (mastectomy patients only)

Trust of surgery	Mastectomy patients (% within Trust of surgery)			Trust of residence	Mastectomy patients (% within Trust)
	1996	2001	2006		2006
Belfast HSCT	3 (2.5%)	12 (11.0%)	27 (16.7%)	Belfast HSCT	16 (15.7%)
Northern HSCT	2 (3.3%)	4 (4.9%)	7 (8.6%)	Northern HSCT	22 (15.7%)
South-Eastern HSCT	4 (7.3%)	21 (23.9%)	31 (31.3%)	South-Eastern HSCT	20 (21.1%)
Southern HSCT	0 (0%)	0 (0%)	2 (3.1%)	Southern HSCT	16 (16.7%)
Western HSCT	0 (0%)	3 (5.5%)	3 (4.3%)	Western HSCT	4 (6.0%)
Private hospitals	0 (0%)	0 (0%)	7 (30.4%)		
Other/Not recorded*	0 (0%)	0 (0%)	1 (100.0%)		
Northern Ireland	9 (2.6%)	40 (9.8%)	78 (15.6%)	Northern Ireland	78 (15.6%)

* Includes outside of Northern Ireland

- There were twice as many women having a primary reconstruction in 2006 compared to 2001, with 16% of women who had a mastectomy having had primary reconstruction in 2006.
- Almost one third of patients having a mastectomy in the South-Eastern Trust or in a private hospital in 2006 had primary reconstruction. However only a handful of patients having a mastectomy in the Northern, Southern or Western Trusts had primary reconstruction.
- Only 6% of patients resident in the Western Trust who had a mastectomy received primary reconstruction. The proportion of mastectomy patients resident in the other Trusts who received primary reconstruction was similar to the Northern Ireland average of 16%.

Trust and hospital of surgery

- In 1996, 677 patients had at least one surgical procedure, carried out in one of 20 hospitals, while in 2001, 804 patients had procedures in 13 hospitals and in 2006 there were 862 patients operated on in 10 hospitals.
- Excluding private hospitals, 86% of surgery patients in 2006 were operated on within a cancer unit.
- In 2006 Belfast and Western Trusts had only one hospital performing breast cancer operations, while the remaining Trusts had two hospitals. However it should be noted that for patient convenience operations on patients from any of the five Trusts are occasionally performed in hospitals belonging to another Trust.
- The proportion of patients having operations was redistributed across hospitals in Northern Ireland between 2001 and 2006. There were:
 - Increases in Belfast City Hospital, Daisy Hill Hospital and Altnagelvin Hospitals.
 - Decreases in Antrim Hospital, Lagan Valley Hospital and Craigavon Area Hospital.
 - No operations performed in Erne and Tyrone County Hospital in 2006.

Trust and hospital of surgery

Trust	Hospital	Patients (% of surgery patients)			2006 hospital first seen at
		1996 (n=677)	2001 (n=804)	2006 (n=862)	
Belfast HSCT	Belfast City Hospital*	46 (6.8%)	192 (23.9%)	246 (28.5%)	260 (27.3%)
	Royal Victoria Hospital	164 (24.2%)	0 (0%)	0 (0%)	1 (0.1%)
	Mater Infirmorum Hospital	8 (1.2%)	1 (0.1%)	0 (0%)	0 (0%)
	Total	218 (32.2%)	193 (24.0%)	246 (28.5%)	262 (27.5%) [¶]
Northern HSCT	Antrim Hospital*	81 (12.0%)	106 (13.2%)	77 (8.9%)	132 (13.9%)
	Causeway (Coleraine) Hospital	36 (5.3%)	47 (5.8%)	51 (5.9%)	7 (0.7%)
	Whiteabbey Hospital	4 (0.6%)	0 (0%)	0 (0%)	0 (0%)
	Mid-Ulster Hospital	8 (1.2%)	0 (0%)	0 (0%)	0 (0%)
	Total	129 (19.1%)	153 (19.0%)	128 (14.8%)	140 (14.7%) [†]
South-Eastern HSCT	Ulster Hospital*	82 (12.1%)	147 (18.3%)	152 (17.6%)	140 (14.7%)
	Lagan Valley Hospital	19 (2.8%)	47 (5.8%)	23 (2.7%)	0 (0%)
	Downe Hospital	9 (1.3%)	0 (0%)	0 (0%)	0 (0%)
	Ards Hospital	4 (0.6%)	0 (0%)	0 (0%)	0 (0%)
	Total	114 (16.8%)	194 (24.1%)	175 (20.3%)	140 (14.7%)
Southern HSCT	Craigavon Area Hospital*	72 (10.6%)	112 (13.9%)	86 (10.0%)	159 (16.7%)
	Daisy Hill Hospital	34 (5.0%)	11 (1.4%)	37 (4.3%)	0 (0%)
	South Tyrone Hospital	2 (0.3%)	0 (0%)	0 (0%)	0 (0%)
	Armagh Community Hospital	0 (0%)	2 (0.2%)	0 (0%)	0 (0%)
	Total	108 (16.0%)	125 (15.5%)	123 (14.3%)	160 (16.8%) ^Δ
Western HSCT	Altnagelvin Hospital*	65 (9.6%)	84 (10.4%)	144 (16.7%)	148 (15.6%)
	Erne Hospital	15 (2.2%)	17 (2.1%)	0 (0%)	2 (0.2%)
	Tyrone County Hospital	13 (1.9%)	11 (1.4%)	0 (0%)	0 (0%)
	Roe Valley Hospital	2 (0.3%)	0 (0%)	0 (0%)	0 (0%)
	Total	95 (14.0%)	112 (13.9%)	144 (16.7%)	150 (15.8%)
Private Hospitals	Ulster Independent Clinic	11 (1.6%)	26 (3.2%)	42 (4.9%)	97 (10.2%)
	North-West Independent Clinic	1 (0.1%)	0 (0%)	2 (0.2%)	0 (0%)
	Total	12 (1.8%)	26 (3.2%)	44 (5.1%)	97 (10.2%)
Other**/Not recorded		1 (0.1%)	1 (0.1%)	2 (0.2%)	2 (0.2%)

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients audited in this report were thus treated under the old Health and Social Services Board (HSSB) structure. Under that structure both the Belfast HSCT and South-Eastern HSCT were part of Belfast HSSB while the Northern, Southern and Western HSCTs were the same as the Northern, Southern and Western HSSBs respectively.

Note: The table indicates the hospital where a patients' main operation was performed and does not refer to the hospital that either the patient is allocated to for treatment or that the surgeon performing the operation is employed by.

* Cancer unit. **Other includes outside of NI.

¶ Includes 1 patient first seen at Belvoir Park Hospital; † Includes 1 patient first seen at Moyle Hospital; Δ Includes 1 patient first seen at Lurgan Hospital.

Where patients had their surgery

Trust area of residence		Trust of surgery							Total patients
		Belfast HSCT	Northern HSCT	South-Eastern HSCT	Southern HSCT	Western HSCT	Private Hospitals	Other/ Not recorded	
Belfast HSCT	1996	126 (73.3%)	0 (0%)	39 (22.7%)	0 (0%)	0 (0%)	6 (3.5%)	1 (0.6%)	172
	2001	96 (57.8%)	0 (0%)	60 (36.1%)	0 (0%)	0 (0%)	10 (6.0%)	0 (0%)	166
	2006	116 (69.9%)	0 (0%)	42 (25.3%)	0 (0%)	1 (0.6%)	6 (3.6%)	1 (0.6%)	166
Northern HSCT	1996	38 (22.4%)	128 (75.3%)	0 (0%)	1 (0.6%)	0 (0%)	3 (1.8%)	0 (0%)	170
	2001	33 (16.7%)	152 (76.8%)	8 (4.0%)	1 (0.5%)	1 (0.5%)	3 (1.5%)	0 (0%)	198
	2006	58 (25.0%)	123 (53.0%)	14 (6.0%)	3 (1.3%)	21 (9.1%)	12 (5.2%)	1 (0.4%)	232
South-Eastern HSCT	1996	40 (35.1%)	1 (0.9%)	69 (60.5%)	0 (0%)	2 (1.8%)	2 (1.8%)	0 (0%)	114
	2001	50 (27.9%)	0 (0%)	115 (64.2%)	2 (1.1%)	0 (0%)	12 (6.7%)	0 (0%)	179
	2006	45 (26.8%)	1 (0.6%)	100 (59.5%)	4 (2.4%)	1 (0.6%)	17 (10.1%)	0 (0%)	168
Southern HSCT	1996	13 (10.4%)	0 (0%)	5 (4.0%)	106 (84.8%)	1 (0.8%)	0 (0%)	0 (0%)	125
	2001	13 (8.7%)	0 (0%)	10 (6.7%)	121 (81.2%)	4 (2.7%)	1 (0.7%)	0 (0%)	149
	2006	24 (14.0%)	4 (2.3%)	18 (10.5%)	115 (66.9%)	3 (1.7%)	8 (4.7%)	0 (0%)	172
Western HSCT	1996	1 (1.0%)	0 (0%)	1 (1.0%)	1 (1.0%)	92 (95.8%)	1 (1.0%)	0 (0%)	96
	2001	1 (0.9%)	1 (0.9%)	1 (0.9%)	1 (0.9%)	107 (95.5%)	0 (0%)	1 (0.9%)	112
	2006	3 (2.4%)	0 (0%)	1 (0.8%)	1 (0.8%)	118 (95.2%)	1 (0.8%)	0 (0%)	124

- The majority of patients were operated on within their Trust of residence in all three years.
- Between 2001 and 2006 there was a shift in breast cancer surgery patients out of the Northern Trust with almost one quarter of all patients resident in the Northern Trust in 2006 operated on in the Belfast Trust, with a further 9% operated on in the Western Trust and 5% operated on in private hospitals.
- In addition there was an increase between 2001 and 2006 in the proportion of patients resident in the Southern Trust who were operated on in either the Belfast Trust, the South-Eastern Trust or in a private hospital.
- There was also considerable overlap between the Belfast and South-Eastern Trusts reflecting the old Health Board structure.

Surgeon case volumes - Number of patients receiving main operation

Number of patients	Number of surgeons (% of patients)		
	1996	2001	2006
41 or more patients	7 (59.4%)	9 (64.3%)	10 (70.0%)
21-40 patients	2 (9.7%)	5 (16.0%)	6 (19.5%)
11-20 patients	5 (10.0%)	6 (11.4%)	2 (3.2%)
6-10 patients	7 (7.8%)	3 (3.2%)	2 (1.6%)
2-5 patients	20 (9.3%)	7 (2.4%)	9 (3.0%)
1 patient	17 (2.5%)	14 (1.7%)	13 (1.5%)
Surgeon not recorded	- (1.2%)	- (0.9%)	- (1.2%)
Total surgeons*	58	44	42
Consultants in charge	40	23	15
Total patients	677	804	862

Note: Patients may have more than one operation. Patients are assigned to the surgeon/consultant responsible for their main operation.

* Includes surgeons in training.

- By 2001, 89% of breast surgery was performed by surgeons with high case volumes (21 or more procedures per year), an increase from the 80% in 2001 ($p < 0.001$) reflecting increasing specialisation in breast cancer within the region, as recommended in the Campbell Report.
- 2% of the surgery workload in 2006 was conducted by surgeons who only operated on one patient, while 2 surgeons operated on 21% of all breast cancer surgery patients (181 patients).
- The number of consultants in charge decreased by over half between 1996 and 2006 reflecting increased specialization.

Seen by a breast care nurse during diagnosis/treatment

Seen by a breast care nurse	1996 (n=764)	2001 (n=881)	2006 (n=951)
Yes	298 (39.0%)	596 (67.7%)	692 (72.8%)
No/Not recorded	466 (61.0%)	285 (32.3%)	259 (27.2%)

- By 2006 73% of patients were seen by a breast care nurse at least once during their diagnosis and/or treatment, an increase on the 39% in 1996 ($p < 0.001$).

Patients receiving hormonal therapy

Hormone drugs	1996 (n=764)	2001 (n=881)	2006 (n=951)
Tamoxifen	696 (91.1%)	673 (76.4%)	457 (48.1%)
Anastrozole	3 (0.4%)	25 (2.8%)	271 (28.5%)
Goserilin	2 (0.3%)	0 (0%)	3 (0.3%)
Other	18 (2.3%)	5 (0.6%)	15 (1.6%)
None recorded	45 (5.9%)	178 (20.2%)	205 (21.6%)

- Although the total number of patients receiving hormonal therapy was similar in 2001 and 2006, the type of drug received changed considerably between the two years due to a ten fold increase in the use of Anastrozole.

Tamoxifen or Anastrozole prescription and ER status of patients

Tamoxifen/ Anastrozole prescribed	1996		2001		2006	
	ER status		ER status		ER status	
	Positive	Negative	Positive	Negative	Positive	Negative
Yes	37 (86.0%)	114 (90.5%)	578 (97.0%)	53 (26.6%)	705 (96.0%)	10 (5.2%)
No	6 (14.0%)	12 (9.5%)	18 (3.0%)	146 (73.4%)	29 (4.0%)	184 (94.8%)
Patients*	43	126	596	199	734	194

* Excludes patients with unknown ER status (see diagnostic section).

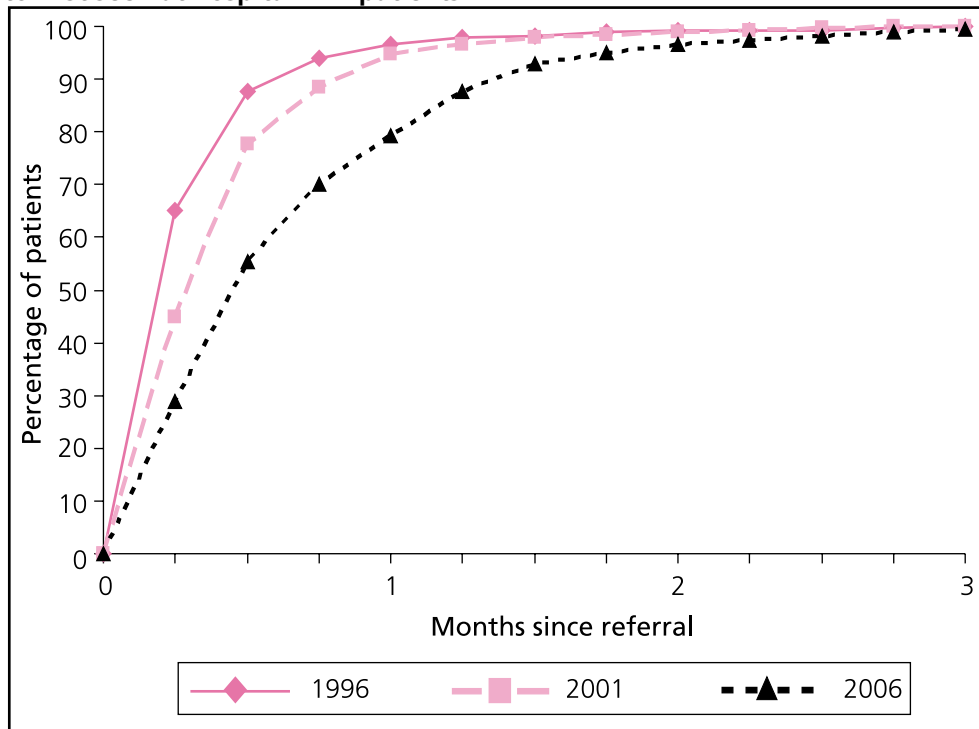
- By 2006, the prescription of Tamoxifen or Anastrozole was rarely given to patients who were ER negative.
- 96% of patients who were ER positive in 2006 received Tamoxifen or Anastrozole, similar to the 97% in 2001.

Timelines

Referral to first seen at hospital - All patients by age

Time (days)	1996 (n=764)			2001 (n=881)			2006 (n=951)		
	Under 60	60 and over	Total	Under 60	60 and over	Total	Under 60	60 and over	Total
Not recorded	88 (23.1%)	77 (20.1%)	165 (21.6%)	33 (7.3%)	26 (6.0%)	59 (6.7%)	26 (5.8%)	23 (4.6%)	49 (5.2%)
Percentage of patients with timeline recorded									
Day 1	44 (15.0%)	59 (19.3%)	103 (17.2%)	27 (6.5%)	21 (5.2%)	48 (5.8%)	42 (9.9%)	52 (10.9%)	94 (10.4%)
Day 14	232 (79.2%)	253 (82.7%)	485 (81.0%)	279 (66.7%)	291 (72.0%)	570 (69.3%)	187 (44.2%)	237 (49.5%)	424 (47.0%)
Day 31	277 (94.5%)	294 (96.1%)	571 (95.3%)	394 (94.3%)	380 (94.1%)	774 (94.2%)	304 (71.9%)	392 (81.8%)	696 (77.2%)
Day 62	286 (97.6%)	300 (98.0%)	586 (97.8%)	413 (98.8%)	398 (98.5%)	811 (98.7%)	389 (92.0%)	458 (95.6%)	847 (93.9%)

Referral to first seen at hospital - All patients

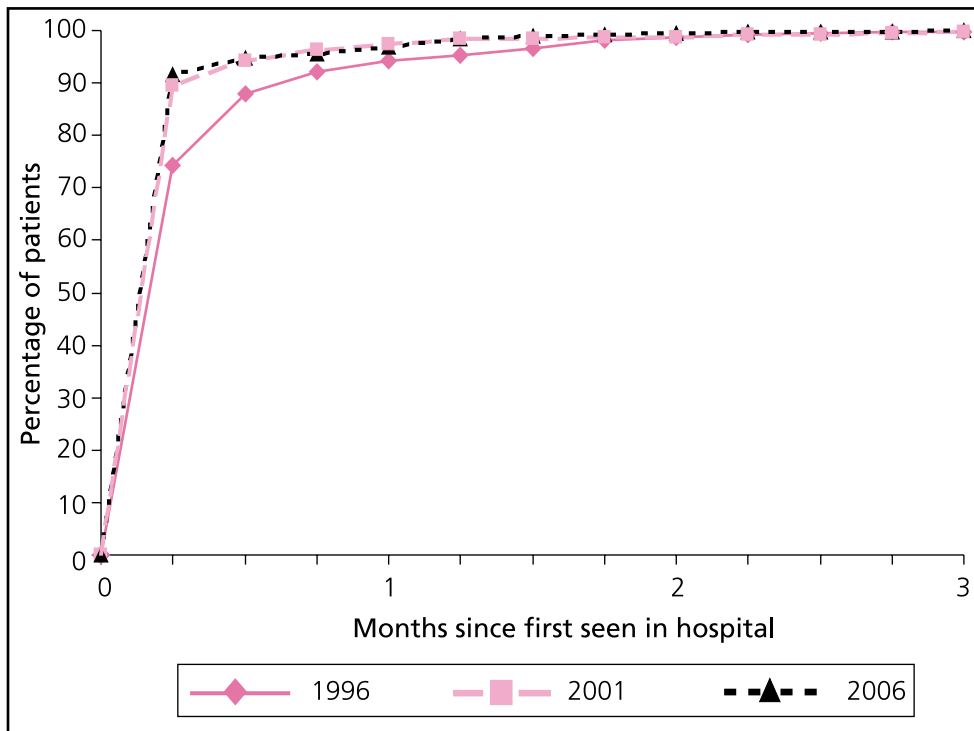


- In 2006 47% of patients were first seen at hospital within 14 days of referral. This was a considerable reduction on the 69% in 2001 ($p < 0.001$) and the 81% in 1996 ($p < 0.001$). This was accompanied by an increase in the proportion of patients waiting more than 31 days, from 6% in 2001 to 23% in 2006 ($p < 0.001$).
- For those aged 60 and over in 2006 50% were seen within 14 days of referral. This was also a decrease on the proportions seen within this period in 1996 and 2001 ($p < 0.001$).
- In 2006 younger people had longer to wait between referral and first being seen in hospital than those aged 60 and over ($\chi^2 = 30.4$, $p < 0.001$).

First seen at hospital to diagnosis - All patients by age

Time (days)	1996 (n=764)			2001 (n=881)			2006 (n=951)		
	Under 60	60 and over	Total	Under 60	60 and over	Total	Under 60	60 and over	Total
Not recorded	7 (1.8%)	4 (1.0%)	11 (1.4%)	11 (2.4%)	9 (2.1%)	20 (2.3%)	0 (0%)	0 (0%)	0 (0%)
Percentage of patients with timeline recorded									
Day 1	200 (53.5%)	221 (58.3%)	421 (55.9%)	361 (82.0%)	339 (80.5%)	700 (81.3%)	354 (78.8%)	423 (84.3%)	777 (81.7%)
Day 14	304 (81.3%)	326 (86.0%)	630 (83.7%)	411 (93.4%)	393 (93.3%)	804 (93.4%)	407 (90.6%)	483 (96.2%)	890 (93.6%)
Day 31	334 (89.3%)	365 (96.3%)	699 (92.8%)	429 (97.5%)	407 (96.7%)	836 (97.1%)	423 (94.2%)	492 (98.0%)	915 (96.2%)
Day 62	358 (95.7%)	374 (98.7%)	732 (97.2%)	433 (98.4%)	412 (97.9%)	845 (98.1%)	441 (98.2%)	497 (99.0%)	938 (98.6%)

First seen at hospital to diagnosis - All patients

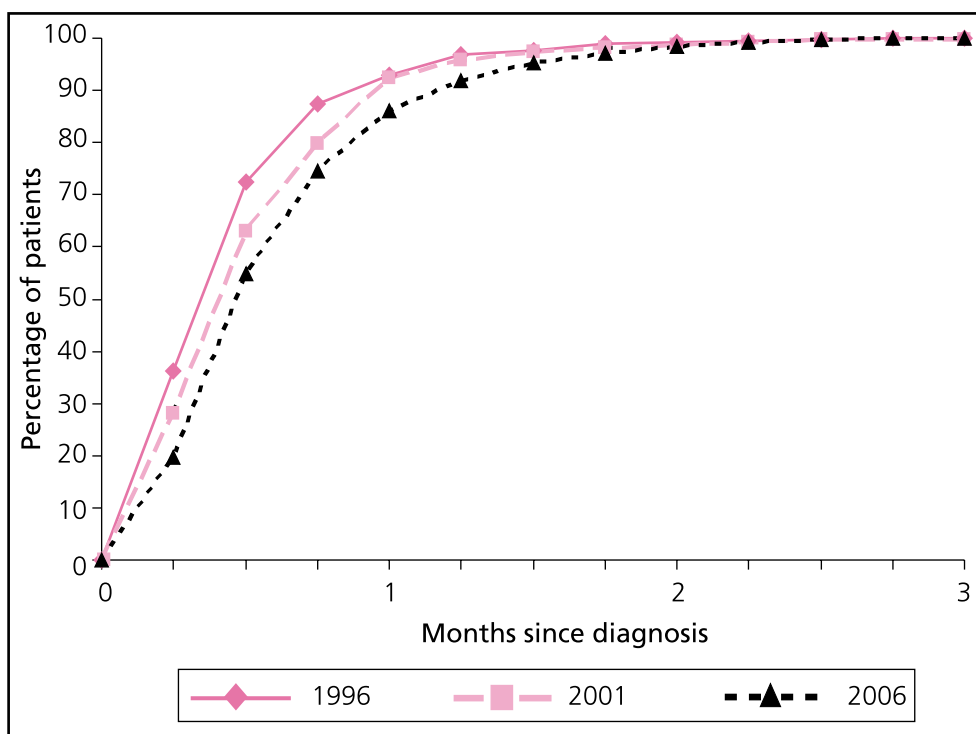


- 94% of patients in 2006 were diagnosed within 14 days of first being seen at hospital. This was similar to the proportion in 2001.
- Only 1% of patients waited more than 62 days to be diagnosed in 2006.
- For those aged 60 and over 96% were diagnosed within 14 days. This was slightly higher than the 91% of those aged under 60 (p<0.001).

Diagnosis to surgery – surgery patients by age

Time (days)	1996 (n=677)			2001 (n=804)			2006 (n=862)		
	Under 60	60 and over	Total	Under 60	60 and over	Total	Under 60	60 and over	Total
Not recorded	9 (2.4%)	14 (4.6%)	23 (3.4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (0.2%)	1 (0.1%)
Percentage of patients with timeline recorded									
Day 1	35 (9.7%)	54 (18.5%)	89 (13.6%)	20 (4.5%)	21 (5.8%)	41 (5.1%)	21 (4.8%)	7 (1.7%)	28 (3.2%)
Day 14	205 (56.6%)	190 (65.1%)	395 (60.4%)	236 (53.3%)	204 (56.5%)	440 (54.7%)	187 (42.4%)	198 (47.1%)	385 (44.7%)
Day 31	323 (89.2%)	261 (89.4%)	584 (89.3%)	396 (89.4%)	328 (90.9%)	724 (90.0%)	356 (80.7%)	363 (86.4%)	719 (83.5%)
Day 62	346 (95.6%)	277 (94.9%)	623 (95.3%)	422 (95.3%)	351 (97.2%)	773 (96.1%)	417 (94.6%)	406 (96.7%)	823 (95.6%)

Diagnosis to surgery – Surgery patients



- 45% of surgery patients in 2006 had their surgery within 14 days of diagnosis. There was no significant difference in this proportion for those aged under 60 and over 60 years.
- 16% of surgery patients diagnosed in 2006 waited more than 31 days. This proportion was lower for those aged 60 and over (14%) compared to those aged under 60 (19%) (p=0.029).
- The proportion of patients receiving surgery within 14 days of diagnosis fell from 55% to 45% between 2001 and 2006 (p<0.001), however the proportion receiving surgery more than 62 days after diagnosis was similar in the two years.

Information and follow up care

Information recorded in notes

Information recorded in notes	1996 (n=764)	2001 (n=881)	2006 (n=951)
Diagnosis discussed with patient	156 (20.4%)	842 (95.6%)	891 (93.7%)
Treatment plan discussed with patient	159 (20.8%)	841 (95.5%)	850 (89.4%)
Record of information given	22 (2.9%)	324 (36.8%)	176 (18.5%)
Consultation taped	0 (0%)	2 (0.2%)	3 (0.3%)
Referred to oncology centre	534 (69.9%)	768 (87.2%)	883 (92.8%)
Entered into clinical trial	29 (3.8%)	133 (15.1%)	5 (0.5%)

- In 2006 almost all patients had a record of a discussion on their diagnosis and treatment plan recorded in the notes. There was a slight decrease in recording of a discussion of the treatment plan compared to 2001 ($p < 0.001$).
- The number of patients referred to an oncology centre increased from 87% in 2001 to 93% in 2006 ($p < 0.001$).
- Entry into clinical trials fell from 15% of all patients in 2001 to only 5 patients in 2006. This may reflect availability of clinical trials.

After care details

Further care after treatment	1996 (n=764)	2001 (n=881)	2006 (n=951)
GP	239 (31.3%)	861 (97.7%)	912 (95.9%)
Community Nurse	169 (22.1%)	382 (43.4%)	278 (29.2%)
McMillan Nurse	27 (3.5%)	25 (2.8%)	32 (3.4%)
Hospice	28 (3.7%)	19 (2.2%)	18 (1.9%)
Marie Curie Nurse	10 (1.3%)	4 (0.5%)	4 (0.4%)
Palliative Care Specialist	14 (1.8%)	25 (2.8%)	39 (4.1%)
Psychologist	12 (1.6%)	20 (2.3%)	15 (1.6%)
Breast Care Nurse	75 (9.8%)	227 (25.8%)	51 (5.4%)
Information on support groups/education supplied	68 (8.9%)	130 (14.8%)	30 (3.2%)
Review Plan	572 (74.9%)	826 (93.8%)	859 (90.3%)
Other	44 (5.8%)	200 (22.7%)	129 (13.6%)
No onward referral recorded	125 (16.4%)	12 (1.4%)	12 (1.3%)

- In 2006 almost all patients (96%) were referred to GP for after care, although this was a slight reduction on 2001 levels (98%) ($p = 0.027$).
- The proportion of patients recorded in patients charts as having been referred to community nurses and breast care nurses decreased between 2001 and 2006 ($p < 0.001$).
- Total after care referrals to Macmillan nurses, hospices, Marie Curie nurses, palliative care specialists and psychologists remained steady in all years.

- There was a large decrease in the availability of information on support groups recorded between 2001 and 2006.
- The absolute number of patients for whom a review plan was in place in 2006 was greater than in 2001 although it represented a smaller proportion of all patients (94% vs. 90%, $p=0.007$).

Information in GP letter

Information in GP letter	1996 (n=764)	2001 (n=881)	2006 (n=951)
Diagnosis	696 (91.1%)	865 (98.2%)	776 (81.6%)
Patient unaware of diagnosis	192 (25.1%)	29 (3.3%)	20 (2.1%)
Family aware of diagnosis	199 (26.0%)	403 (45.7%)	250 (26.3%)
Proposed systematic treatment including toxicity	78 (10.2%)	366 (41.5%)	352 (37.0%)
Prognostic information	186 (24.3%)	352 (40.0%)	318 (33.4%)
Follow up plan details	633 (82.9%)	839 (95.2%)	836 (87.9%)
None recorded	41 (5.4%)	11 (1.2%)	55 (5.8%)

- Overall, information to the GP has worsened between 2001 and 2006 especially information on diagnosis and family awareness of diagnosis ($p<0.001$), with 18% of patients in 2006 not having information on diagnosis in their GP letter.
- Of the 20 patients diagnosed in 2006 who were unaware of their diagnosis 15 were aged 80 or over, with the remaining 5 aged between 65 and 79.

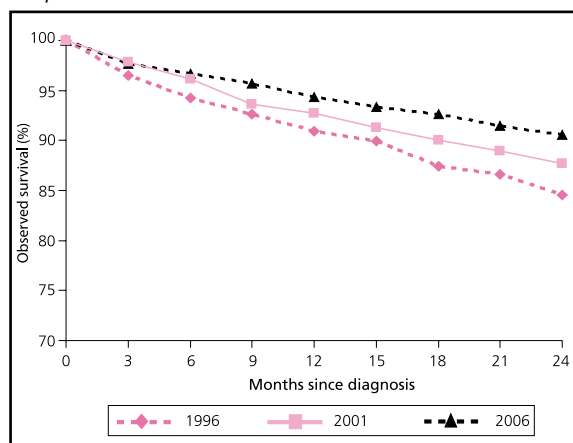
Patient outcomes

Observed survival (percentage of patients alive)

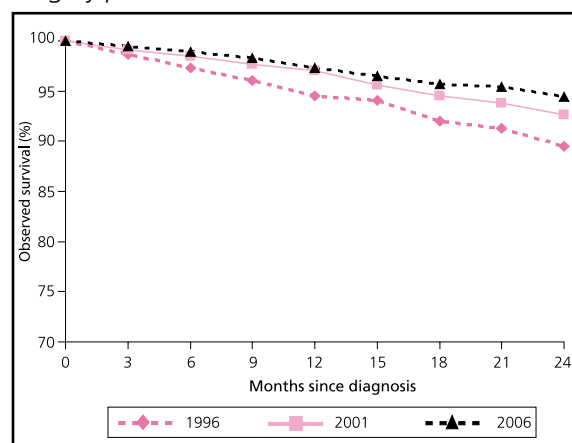
Months since diagnosis	All patients			Surgery patients		
	1996	2001	2006	1996	2001	2006
6 months	94.2%	96.1%	96.6%	97.3%	98.5%	99.0%
12 months	91.0%	92.7%	94.3%	94.5%	97.0%	97.3%
18 months	87.4%	90.0%	92.6%	92.0%	94.5%	95.7%
24 months	84.5%	87.7%	90.6%	89.5%	92.7%	94.5%

Observed survival (percentage of patients alive) by year

All patients



Surgery patients



- Survival for breast cancer patients diagnosed in 2006 was excellent with observed survival (which includes deaths from other causes) 94.3% after one year and 90.6% after two years.
- Observed survival was higher in 2006 than in 2001 ($p=0.034$) as was survival in 2001 compared to 1996 ($p=0.001$), highlighting continuous improvements in early detection and treatment of breast cancer.
- For patients receiving surgery in 2006 97.3% were alive one year after diagnosis while 94.5% were alive after two years.
- Survival for breast cancer patients who received surgery improved between 1996 and 2001, however changes between 2001 and 2006 were not statistically significant.

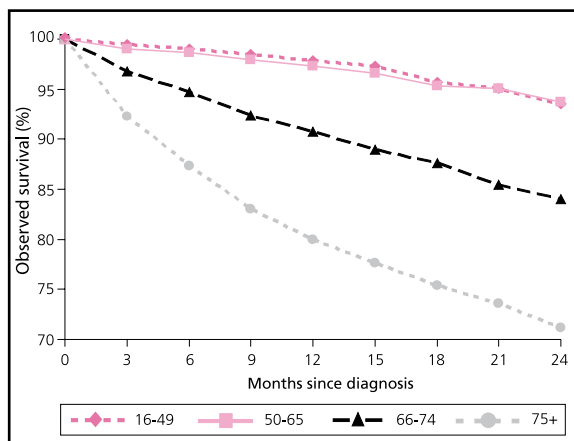
Survival by age: 1996, 2001 & 2006 combined

Months since diagnosis	Observed survival (percentage of patients alive)				Relative survival (percentage of patients who did not die from breast cancer)*			
	16 - 49	50 - 65	66 - 74	75+	16 - 49	50 - 65	66 - 74	75+
6 months	99.0%	98.6%	94.7%	87.4%	99.1%	98.9%	95.6%	90.8%
12 months	97.8%	97.3%	90.7%	80.0%	98.0%	97.8%	92.5%	86.3%
18 months	95.7%	95.3%	87.6%	75.4%	95.9%	96.2%	90.2%	84.6%
24 months	93.5%	93.7%	84.0%	71.2%	93.8%	94.8%	87.5%	83.1%

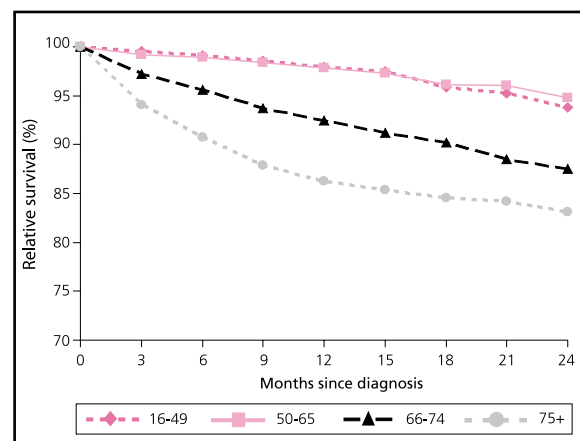
* i.e. observed survival with deaths from causes unrelated to the patients breast cancer excluded.

Survival by age: 1996, 2001 & 2006 combined

Observed survival (percentage of patients alive)



Relative survival (percentage of patients who did not die from breast cancer)

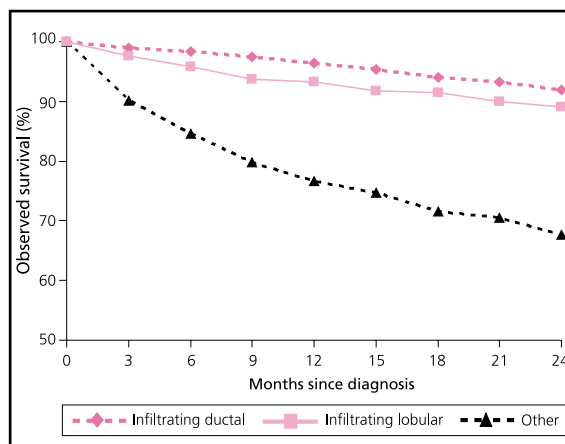


- Observed survival for breast cancer patients was similar for those aged 16 to 49 and 50 to 65 (screening age).
- However after age 65 observed survival decreased with increasing age ($p < 0.001$). In particular two-year observed survival was 71.2% for those aged 75 and over compared to 93.7% for those aged 50 to 65.
- Differences in survival by age are partially removed when deaths from causes unrelated to the patient's breast cancer are removed from the observed survival figures (i.e. relative survival). This illustrates that at least some of the age inequalities in survival are due to a higher frequency of other diseases among older people.

Observed survival (percentage of patients alive) by cell type: 1996, 2001 & 2006 combined

Months since diagnosis	Infiltrating ductal	Infiltrating lobular	Other
6 months	98.3%	95.8%	84.5%
12 months	96.4%	93.3%	76.6%
18 months	94.1%	91.4%	71.6%
24 months	91.9%	89.0%	67.6%

Observed survival (percentage of patients alive) by cell type: 1996, 2001 & 2006 combined

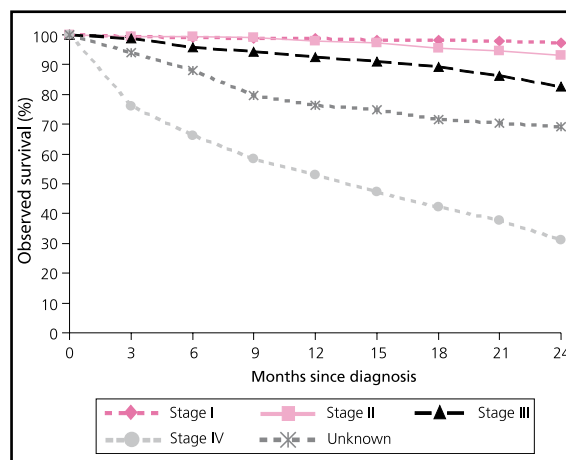


- Survival from infiltrating ductal breast cancer was slightly higher than that for infiltrating lobular breast cancer ($p=0.013$). In particular two-year observed survival from infiltrating ductal breast cancer was 91.9% compared to 89.0% for infiltrating lobular breast cancer. This is contrary to published literature³⁰ which indicates that survival from infiltrating lobular breast cancer is slightly higher than for infiltrating ductal breast cancer. The difference reported here is due to a higher proportion of older people and those diagnosed at Stage III and IV with infiltrating lobular breast cancer compared to infiltrating ductal breast cancer.
- Survival from other forms of breast cancer (mostly of an unspecified type) was lower than that for infiltrating lobular or ductal breast cancer ($p<0.001$).

Observed survival (percentage of patients alive) by stage: 1996, 2001 & 2006 combined

Months since diagnosis	Stage I	Stage II	Stage III	Stage IV	Unknown stage
6 months	99.2%	99.4%	95.8%	66.1%	87.9%
12 months	98.8%	98.0%	92.6%	53.0%	76.3%
18 months	98.2%	95.5%	89.2%	42.1%	71.5%
24 months	97.3%	93.3%	82.7%	31.3%	69.3%

Observed survival (percentage of patients alive) by stage: 1996, 2001 & 2006 combined



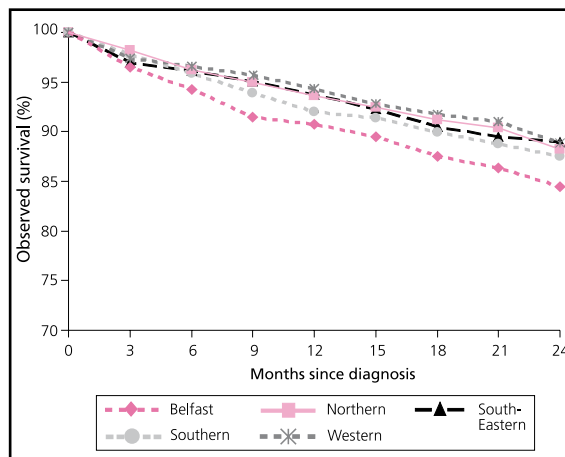
- In general survival for breast cancer patients worsened with increasing stage. In particular two-year observed survival was 31.3% for Stage IV patients compared to 82.7% for Stage III patients, 93.3% for Stage II patients and 97.3% for Stage I patients.
- Survival for patients who could not be assigned a stage was between that of Stage III and Stage IV.

Observed survival (percentage of patients alive) by Trust of residence: 1996, 2001 & 2006 combined

Months since diagnosis	Belfast	Northern	South-Eastern	Southern	Western
6 months	94.2%	96.2%	96.2%	95.9%	96.6%
12 months	90.8%	93.6%	93.7%	92.0%	94.3%
18 months	87.5%	91.2%	90.5%	89.9%	91.8%
24 months	84.5%	88.3%	88.9%	87.5%	88.9%
Age-standardised*					
24 months	82.4%	85.9%	85.5%	84.1%	84.9%

* Using standard populations of Corazziari et al.³¹

Observed survival (percentage of patients alive) by Trust of residence: 1996, 2001 & 2006 combined



- Using all three years data combined observed survival for patients resident in the Belfast Trust area was significantly lower than that in the Northern ($p=0.014$), South-Eastern ($p=0.035$) and Western Trusts ($p=0.011$).
- The lower survival in Belfast was caused by a higher proportion of breast cancer patients being aged 65 and over (47.6% in Belfast compared to 38.4% in NI as a whole). When age-standardised the difference in survival between Belfast and the next lowest Trust (Southern HSCT) is thus halved and differences by Trust are no longer statistically significant.
- There was no significant difference in observed survival from breast cancer between residents of the other four Health and Social Care Trusts.

SECTION III – BREAST CANCER SUMMARY

Study patients

- The number of women diagnosed with malignant breast cancer increased by 16% between 1996 and 2006 with 984 patients diagnosed in 2006.

Referral and presentation

- Almost three quarters of patients diagnosed in 2006 came from GP referrals.
- The number of referrals from the Breast Screening Programme (BSP) decreased between 2001 and 2006 from 20% to 16%. This was after a considerable increase in referrals from BSP between 1996 and 2001.
- In 2006 54% of patients within the screening age (i.e. aged 50-65) were referred by GPs with 39% detected by the Breast Screening Programme.
- One third of breast cancer patients had a positive family history of breast cancer in 2006 with 19% having a record of a first degree relative with a history of breast cancer.
- Approximately two thirds of women with breast cancer had a comorbidity recorded in 2006. This however depended upon age with 36% of patients aged 0 to 49 having a comorbidity compared to 85% of those aged 75 and over.
- One third of patients were recorded with hypertension while almost one fifth had a history of benign breast disease and 2% had a history of breast cancer.
- Two thirds of patients presented with a breast/axillary lump in 2006.
- Among women aged 50-64 diagnosed in 2006, the proportion presenting with breast/axillary lumps was less than for other age groups and most likely reflects early detection of tumours by the Breast Screening Programme before a lump is palpable.
- 54% of patients in 2006 who presented with a breast/axillary lump reported its presence for less than one month.
- Approximately 5% of 2006 patients with a breast/axillary lump had the symptom for more than one year while 18% of those with nipple discharge/abnormality had this symptom for more than six months.
- The proportion of patients presenting to private hospitals increased from 2% to 10% between 2001 and 2006 representing a fivefold increase.
- There is good evidence that by 2001 breast cancer services were centralized in each Trust area.

Diagnosis

- Mammography use remained at a similar level between 2001 and 2006.
- The most common location of breast cancer was the upper outer quadrant in all three years.
- Incidence of cancer in the left breast was slightly higher than in the right breast during 2006.
- The majority of breast cancers in all three years were infiltrating ductal carcinomas.
- 7% of patients in 2006 did not have a stage recorded in the patient notes.
- In general patients diagnosed in 2006 were diagnosed at a later stage than in 2001 which may reflect stage shift due to diagnostic differences.
- The NPI was generally poorer in 2006 than in 2001. In particular the proportion of patients with good NPI in 2006 was 27% compared to 36% in 2001, while the proportion of patients with poor NPI in 2006 was 23% compared to 16% in 2001. This change may be due to more precise recording of information.
- By 2006 examination of the sentinel node as an alternative to axillary clearance had been introduced in Altnagelvin and Ulster hospitals.

- 21% of surgery patients had the sentinel node examined in 2006.
- Excluding patients in 2006 who had examination of the sentinel node, 1% had less than 4 nodes examined and 87% had more than 12 nodes examined, an increase between 2001 and 2006 (73% vs. 87%).
- All surgery patients diagnosed in 2006 who had the sentinel node examined with a positive result went on to have four or more lymph nodes examined.
- There was an increase in the number of patients who, by 2006, had an ER status recorded (98%).
- 79% of patients with ER status recorded were oestrogen receptor positive in 2006, an increase on the 75% who were positive in 2001.
- In 2006 90% of patients had HER2 status recorded, with 17% recorded as positive.
- Recording in the clinical notes that discussion at a Multidisciplinary Team Meeting (MDT) had taken place improved from 26% in 2001 to 55% in 2006.
- Recording that an MDT had taken place was highest for patients resident in the Western Trust (96%) and lowest for those resident in the Northern Trust (36%).

Treatment

- 91% of patients diagnosed in 2006 with breast cancer had surgery, a similar proportion to both 2001 and 1996.
- Use of chemotherapy increased between 1996 and 2001 and again between 2001 and 2006 so that in 2006 46% of patients received this type of treatment.
- Radiotherapy use increased from 56% to 74% between 1996 and 2001 however it decreased again in 2006 to 67%.
- Hormone therapy use was very high in 1996 with 94% of patients receiving this treatment type. By 2001 this had declined to 80%, a level maintained in 2006.
- 10% of patients in 2006 received herceptin as a treatment.
- The most common treatment combinations in all three years were combined surgery, radiotherapy and hormone therapy or these three with chemotherapy.
- Less than 2% of patients in all three years did not have any of surgery, chemotherapy, radiotherapy or hormone therapy.
- 22% more patients received a mastectomy as their main operation in 2006 compared to 2001, This was also an increase in the proportion of all breast cancer surgery patients (51% vs. 58%).
- 44% of patients aged 66-74 had a mastectomy in 2006, slightly lower than the 53-56% among other age groups.
- There were twice as many women having a primary reconstruction in 2006 compared to 2001, yet only 16% of women who had a mastectomy had primary reconstruction in 2006. Patients resident in the Western Trust were least likely to receive these services (6%).
- In 2006 there were 862 patients operated on in 10 hospitals, a reduction from 20 hospitals in 1996 and 13 in 2001.
- The majority of patients were operated on within their Trust of residence in all three years, however between 2001 and 2006 there was a shift in breast cancer surgery patients out of the Northern Trust with almost one quarter of all patients resident in the Northern Trust in 2006 operated on in the Belfast Trust, with a further 9% operated on in the Western Trust and 5% operated on in private hospitals.
- There was an increase between 2001 and 2006 in the proportion of patients resident in the Southern Trust who were operated on in either the Belfast Trust, the South-Eastern Trust or in a private hospital.
- By 2001, 89% of breast surgery was performed by surgeons with high case volumes (21 or more procedures per year), an increase from the 80% in 2001 reflecting increasing specialisation in breast cancer within the region, as recommended in the Campbell Report.

- 2% of the surgery workload in 2006 was conducted by surgeons who only operated on one patient, while 2 surgeons operated on 21% of all breast cancer surgery patients (181 patients).
- The number of consultants in charge decreased by over half between 1996 and 2006 reflecting increased specialization.
- Although the total number of patients receiving hormonal therapy was similar in 2001 and 2006, the type of drug received changed considerably between the two years due to a ten fold increase in the use of Anastrozole.
- By 2006, Tamoxifen or Anastrozole was rarely given to patients who were ER negative. 96% of patients who were ER positive received Tamoxifen or Anastrozole, similar to the 97% in 2001.

Timelines

- In 2006 47% of patients were first seen at hospital within 14 days of referral. This was a considerable reduction on the 69% in 2001 and the 81% in 1996. This was accompanied by an increase in the proportion of patients waiting more than 31 days, from 6% in 2001 to 23% in 2006.
- For those aged 60 and over in 2006 50% were seen within 14 days of referral. This was also a decrease on the proportions seen within this period in 1996 and 2001.
- In 2006 younger people had longer to wait between referral and first being seen in hospital than those aged 60 and over.
- 94% of patients in 2006 were diagnosed within 14 days of first being seen at hospital. This was similar to the proportion in 2001.
- Only 1% of patients waited more than 62 days to be diagnosed in 2006.
- For those aged 60 and over 96% were diagnosed within 14 days. This was slightly higher than the 91% of those aged under 60.
- 45% of surgery patients in 2006 had their surgery within 14 days of diagnosis. There was no significant difference in this proportion for those aged under 60 and over 60 years.
- 16% of surgery patients diagnosed in 2006 waited more than 31 days. This proportion was lower for those aged 60 and over (14%) compared to those aged under 60 (19%).
- The proportion of patients receiving surgery within 14 days of diagnosis decreased from 55% to 45% between 2001 and 2006, however the proportion receiving surgery more than 62 days after diagnosis was similar in the two years.

Information and follow up care

- In 2006 almost all patients had a record of a discussion on their diagnosis and treatment plan recorded in the notes. There was a slight decrease in recording of a discussion of the treatment plan compared to 2001.
- The number of patients referred to an oncology centre increased from 87% in 2001 to 93% in 2006.
- Entry into clinical trials fell from 15% of all patients in 2001 to only 5 patients in 2006. This may reflect availability of clinical trials.
- In 2006 almost all patients (96%) were referred to GP for after care, although this was a slight reduction on 2001 levels (98%).
- The proportion of patients recorded in patient charts as having been referred to community nurses and breast care nurses decreased between 2001 and 2006.
- Total referrals to Macmillan nurses, hospices, Marie Curie nurses, palliative care specialists and psychologists remained steady in both years.
- There was a large decrease in the availability of information on support groups recorded between 2001 and 2006.
- The absolute number of patients for whom a review plan was in place in 2006 was greater than in 2001 although it represented a smaller proportion of all patients (94% vs. 90%).

- Overall, information to the GP had worsened between 2001 and 2006 especially information on diagnosis and family awareness of diagnosis, with 18% of patients in 2006 not having information on diagnosis in their GP letter.

Patient outcomes

- Survival for breast cancer patients diagnosed in 2006 was excellent and improved since 2001 and 1996, with observed survival (which includes deaths from other causes) 94.3% after one year and 90.6% after two years.
- For patients receiving surgery, 97.3% were alive one year after diagnosis while 94.5% were alive after two years.
- Observed survival for breast cancer patients was similar for those aged 16 to 49 and 50 to 65 (screening age). However after age 65 observed survival decreased with increasing age, in part due to comorbidities.
- In general survival for breast cancer patients worsened with increasing stage. In particular two-year observed survival was 31.3% for Stage IV patients compared to 82.7% for Stage III patients, 93.3% for Stage II patients and 97.3% for Stage I patients.
- Using all three years data combined observed survival for patients resident in the Belfast Trust area was significantly lower than that in the Northern, South-Eastern and Western Trusts, a result of older patients in the Belfast Trust. There was no significant difference in survival from breast cancer between residents of the other four different Health and Social Care Trusts.

Conclusions and recommendations

There are over 1,000 cases of breast cancer diagnosed among women every year with rates of the disease increasing by 1% per year.

Despite the heavier workload that these trends involve, the quality of investigation and treatment has improved as evidenced by:

- Reductions in mortality rates and continued improvements in observed survival.
- Centralization of breast cancer services in each Trust area with 86% of patients operated on within a cancer centre/unit and 89% operated on by surgeons with high case volumes.
- Increased use of investigative techniques including FNA, ultrasounds and CT scans to detect metastatic disease.
- Increases in the use of Multidisciplinary Team Meetings (MDTs).

There is however room for improvement as indicated by:

- Diagnosis of patients at a later stage and/or poorer NPI compared to 2001.
- Low participation in clinical trials (0.5%).
- Increased waiting times compared to 2001.
- Variation in discussion of patients at MDTs by Health Trust, only reaching a high level in the Western Trust with patients treated in private hospitals, and Belfast and Northern Trusts having the lowest levels.
- Variation in breast reconstruction following mastectomy by Health Trust, with patients in the Western Trust area least likely to have this procedure.
- Less information recorded in the letter to GP than in previous years.
- 22 surgeons providing the main surgery on less than 5 breast cancer patients.
- Sentinel node biopsy occurring only for patients treated in Altnagelvin and Ulster hospitals.

Recommendations

- There are geographic inequalities with regard to the use of sentinel node biopsies and breast reconstruction following mastectomy that need to be addressed.
- Further improvements in the recording of TNM stage would prove beneficial with regard to international comparisons and for monitoring purposes.
- Recruitment to clinical trials was poor and deserves further consideration.
- All patients should be discussed at an MDT.
- Service providers should further reduce the number of low volume operators.

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APPENDIX A – Summary of recommendations for the treatment and care of breast cancer patients

1996: Cancer Services – Investing for the future¹

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 N. Ireland Cancer Registry should be adequately resourced.

1996: Cancer Services – Investing for the future – Cancer working group sub-group reports²

1. There should be one Breast Unit in each of the Northern, Southern and Western Board areas and two Units within the Eastern Board area (one Unit which should form part of the Cancer Centre) in order that populations of approximately 250,000 – 300,000 can be served. This population size would be expected to produce 150+ patients with breast cancer per year.
2. The Breast Unit at each of the five locations should be staffed by multidisciplinary teams, specialising in the treatment of breast disease. The “first stage” diagnostic team should include surgeons, radiologists, radiographers, a pathologist and a breast care nurse. The “second stage” treatment team should include the following additional members – oncologist, reconstructive/plastic surgeon and a psychologist.
3. The Breast Unit should provide a “one stop shop” at the initial diagnostic assessment clinic. Diagnosis should normally be based on triple assessment, which is clinical opinion followed by imaging and cytology or needle histology as required. Psychological/counselling support should also be available to the patient at the initial assessment clinic, with the breast care nurse playing a key role.
4. An initial treatment plan for the patient with breast cancer should be developed and explained to the patient at the initial assessment clinic. The treatment plan should be devised on the basis of multidisciplinary case discussion. The best method of achieving this should be for local unit determination.
5. Purchasers (General Practitioners and Boards) should ensure contracting arrangements determine that patients with suspected breast disease are only referred to the breast specialist at the Breast Unit. Purchasing patterns should reflect this practice.
6. Breast screening and symptomatic services should be integrated and common standards should apply across both where relevant.
7. Patients attending a Breast Unit for diagnostic purposes should be seen by a senior doctor with a specialist interest in breast disease, i.e. a breast specialist surgeon (consultant surgeon or associate specialist with special training in breast disease) or level 3 trainees in breast disease. Higher surgical trainees should only give unsupervised opinions in breast diagnostic clinics when judged competent to do so by the supervising consultant. They should also have been working on the Breast Unit for at least two months.
8. In the case of operative treatments, all patients’ operations should either be undertaken by, or supervised by, a specialist breast care consultant surgeon. The consultant’s supervisory role permits the training needs of future specialists to be met and, simultaneously, ensures the delivery of a high quality of care.
9. Each specialist Breast Unit should be in a position to offer reconstructive breast surgery, preferably undertaken by a surgeon with an interest in this aspect of breast disease. If such an arrangement is not possible then patients should be referred to another unit where such expertise is available.
10. Surgeons training in breast disease should get some exposure to the various reconstructive techniques.
11. Radiologists working in the Breast Unit should be consultant radiologists with appropriate training and experience as defined by the Royal College of Radiologists Breast Sub-Group.
12. Pathologists reporting breast specimens should follow the guidelines issued in “Pathology Reporting in Breast Cancer Screening”, published by the National Co-ordinating Group for Breast Screening, Pathology. In addition, when reporting cytology, pathologists should follow the guidelines “Cytology Procedures and Reporting in Breast Cancer Screening”, published by the same group. Pathologists should also be encouraged to participate in the National Breast Screening EQA Programme.
13. A further multi-disciplinary case team discussion should take place after surgery has been performed on new patients and histology results have been received, in order to determine the detailed treatment plan. This plan should be shared with the patient and the GP in an appropriate format.

14. Guidelines for the management of patients with breast disease should be disseminated to all General Practitioners.
15. Surgeons with an interest in breast cancer and who wish to maintain that interest should work within Breast Unit arrangements.

This report also highlighted issues of particular importance including:

1. The importance of good communication with patients (and their relatives and friends) and the need to share relevant information (written or otherwise) throughout all stages of a patient's care. It recognised a need to develop different types of information for patients, relatives and General Practitioners.
2. The need to gather information on outcomes and undertake audit on a cross Northern Ireland basis was identified. The possibility of developing audit guidelines and frameworks for application across Northern Ireland and establishing a multi-professional group to monitor audits should be considered.
3. The crucial interface between primary and secondary care must be recognised and must be managed and developed appropriately.
4. Screening and diagnostic services should be integrated to capitalize on the expertise developed within screening services as a result of multiprofessional and team based approach to service provision.

2002: NHS Guidance on Cancer Services - Improving Outcomes in Breast Cancer³

1. Multidisciplinary team working: All patients with breast cancer should be managed by multidisciplinary teams and all multidisciplinary teams should be actively involved in network-wide audit of processes and outcomes. Multidisciplinary teams should consider how they might improve the effectiveness of the way they work. Some units should consider working together to increase the number of patients managed by the team.
2. Minimising delay: No patient should have to wait more than four weeks for any form of treatment or supportive intervention.
3. Follow-up: The primary aims of clinical follow-up should be to identify and treat local recurrence and adverse effects of therapy, not to detect metastatic disease in asymptomatic women. Long-term routine hospital-based follow-up should cease, except in the context of clinical trials.
4. Review of services for screened and symptomatic patients: Each cancer network should review its arrangements for breast screening, with the goal of bringing services for screened and symptomatic patients into closer alignment. Networks should aim to achieve consistency in clinical policies, organisation and care, irrespective of the patient's point of entry into the system.

Recommendations in specific topic areas:

1. Patient-centred care

- 1.1. There should be minimal delay between referral from GP and an out-patient appointment, and between the first consultation and communication of diagnosis to the patient.
- 1.2. There should be pre-booking systems for appointments.
- 1.3. Whilst administrative delay and delays before treatment should be minimised, patients need adequate time to consider and discuss treatment options.
- 1.4. At every stage, patients should be offered clear, objective, full and prompt information in both verbal and written form.
- 1.5. Patients should also be informed about sources of social and practical help, such as local support groups and disability and benefits helplines, both verbally and in written form. Information should be provided in appropriate languages for patients from ethnic minorities.
- 1.6. Providers must be sensitive to potential problems with communication. Members of the breast care team should have special training in communication and counselling skills.
- 1.7. Senior members of the breast care multidisciplinary team should have formal training in communication skills.
- 1.8. Patients should be given adequate time to reflect before being expected to make any decisions about treatment.
- 1.9. There should be agreed procedures and protocols for breaking bad news at key transition points in the disease.
- 1.10. There should be a named breast care nurse with whom each patient can communicate at any time.
- 1.11. There should be a system for dealing with complaints by patients. Complaints should be taken seriously and answered promptly.
- 1.12. Psychosocial support should be available at every stage to help patients and their families cope with the effects of the disease. Health care personnel should have training to improve their ability to recognise the psychological needs of patients and to deal with them appropriately.
- 1.13. Social support should be available and there should be close liaison with local social services.
- 1.14. The breast care nurse should liaise with community occupational therapy services, which can play an important role in providing equipment, adaptations to patients' homes, and practical advice on activities of daily living.

2. Rapid and accurate diagnosis

- 2.1. The same standard of care should be provided for all patients with suspected breast cancer, whether they are identified by screening or referred with symptoms.
- 2.2. The combination of clinical examination, mammography/ultrasound and image-guided core biopsy or fine needle aspiration (FNA) - known together as triple assessment - should be available for women with suspected breast cancer at a single visit. Both mammography and ultrasound imaging should be available. Centres which predominantly use core biopsy should also maintain expertise in FNA cytology so that this method can be used when appropriate.
- 2.3. All facilities and staff needed to carry out these three types of test should be in close proximity, and diagnostic services must be able to provide rapid and accurate information on imaging results and tissue samples. A breast care nurse should be available for support and counselling.
- 2.4. The results of tests should be given to the patient within five working days and within three days if possible.
- 2.5. The accuracy of triple assessment depends on the quality of each constituent test. There is wide variation in the adequacy of cytology samples taken by fine needle aspiration. Pathologists and cytologists should record the adequacy of samples; if they fall below the necessary standard for accurate diagnosis, surgeons and pathologists may require additional training in the technique and interpretation of samples, respectively.
- 2.6. Surgical biopsy is appropriate when triple assessment does not give a definitive result.
- 2.7. After surgery, the pathologist should give detailed reports on excised cancers which include information on tumour type, pathological size, histological grade, vascular invasion, extent of ductal carcinoma in situ, tumour margins, and lymph node status when appropriate. This information should also be given to the cancer registry.
- 2.8. Pathologists who provide reports on breast cancer resection specimens should participate in the National Breast Pathology External Quality Assurance Scheme.
- 2.9. Assays to measure hormone receptor status should be carried out on all excised tumour samples. Oestrogen receptor status should be assessed first; if the tumour is oestrogen-receptor negative or poor, progesterone receptor status should be measured. Tissue blocks from individual patients should be retained for possible future use.
- 2.10. All laboratories which carry out hormone receptor status assays or other tests intended to predict response to therapy should participate in the national quality assessment scheme.

3. Surgery

- 3.1. Sufficient tissue should be removed to ensure that no tumour is found at the surgical margins, since positive or narrow (<2mm) margins are associated with high rates of local recurrence. The minimum pathology dataset should include information on the distance of the closest margin to the edge of the tumour.
- 3.2. The pathologist should confirm that the margins of excised tissue are free of tumour cells. Patients who are found to have positive margins should be offered re-excision or mastectomy.
- 3.3. Axillary lymph node status is the single most powerful prognostic indicator for breast cancer. The possible adverse effects and anticipated benefits of axillary sampling or clearance should be discussed with patients.
- 3.4. Teams in centres which routinely carry out axillary clearance should consider training in less invasive forms of surgery. When axillary sampling is used, at least four nodes should be removed.
- 3.5. Sentinel node biopsy is an alternative to axillary sampling or clearance which provides information on the probable tumour status of other axillary lymph nodes; when sentinel node histology is negative, further treatment to the axilla may not be necessary. Teams which use sentinel node biopsy should have adequate training, should audit their results, and should be able to demonstrate false negative rates below 10%.

- 3.6. Patients who do not appear to have tumour in the lymph nodes should be informed about alternative methods of axillary management, the risks believed to be associated with each and the uncertainty about which is best, and their views should be respected.
- 3.7. Surgeons should discuss breast reconstruction with all patients. Reconstruction should be available at the initial surgical operation.
- 3.8. A range of primary operations should be available. If the cancer is not too large or diffuse, surgical options include mastectomy (removal of the whole breast) or breast conserving surgery (wide local excision or lumpectomy). In such cases, the choice should be made jointly by the surgeon and the patient, who should be fully informed of all the options and their potential risks, benefits and implications for further treatment. Surgeons should have the technical skills to support a full range of choices. Suitable patients should be offered breast conserving surgery.
- 3.9. Breast surgery, the management of excised specimens, and treatment decisions based on pathology and other prognostic information should follow locally written protocols based on BASO guidelines. Surgical treatment should not be offered or withheld on grounds of age alone.
- 3.10. After surgery, women should be given information on wound care, advice on exercise, and information on dealing with the after-effects of surgery. Support and counselling should be available and women should be given opportunities to talk over their feelings and fears with an experienced breast care nurse.

4. Radiotherapy

- 4.1. Breast cancer site-specific groups should produce network-wide guidelines on the appropriate use of radiotherapy for patients with invasive or in-situ disease. Radiotherapy should be regarded as standard therapy for all women who have undergone breast conserving surgery, and should also be discussed with women who have had mastectomy. An additional boost dose of radiation to the tumour bed should be considered for younger women, particularly those below the age of 40. Radiotherapy may be given as adjuvant or neo-adjuvant treatment, or it may be used as the sole local treatment modality when surgery is inappropriate.
- 4.2. Patients should be given clear information about both anticipated benefits and potential hazards of radiotherapy. In situations where there is uncertainty about the balance of risk and benefit.
- 4.3. Radiotherapy centres should have sufficient staff and capacity to guarantee access to radiotherapy within four weeks of identification of need.
- 4.4. Imaging that shows the heart and major blood vessels should be used in planning radiotherapy so that the cardiovascular system can be adequately protected during treatment.
- 4.5. A high quality radiotherapy service should be available for all patients. When one radiotherapy centre serves several cancer units, clinical oncologists should work between sites to assess and advise patients in one location and treat them in another.
- 4.6. The option of radiotherapy should be discussed with suitable patients before primary surgery, particularly those who are to have breast conserving surgery. Radiotherapy to the axillary area should not normally be given after surgical clearance of the axilla. Patients should be given clear information on the anticipated benefits and potential risks before decisions are made about treatment.
- 4.7. There should be adequate facilities such as hospital and hotel beds, and access to radiology and pathology services. An experienced oncology nurse should be available for all patients who require help, information or support.

5. Systemic therapy for early breast cancer

- 5.1. Combination chemotherapy and hormone therapy, normally using the same drugs as would be given in an adjuvant setting, may be considered to downstage tumours before surgery.
- 5.2. Women at intermediate or high risk of recurrence, who have not had neo-adjuvant chemotherapy, should normally be offered four to eight cycles of multiple-agent chemotherapy which includes anthracyclines.
- 5.3. All women with hormone receptor-positive tumours should be offered hormone treatment for five years after primary therapy.
- 5.4. Oncology wards should be available for patients who may not have adequate home support to cope with the adverse effects of chemotherapy. Systems are also required to provide support for patients in the community who may have problems associated with chemotherapy.
- 5.5. Chemotherapy should only be prescribed by specialist non-surgical oncologists working with chemotherapy nurse specialists, expert pharmacy and laboratory support. It should be administered in designated day-care facilities or on an oncology ward.
- 5.6. Patients should be encouraged to participate in well-designed clinical trials whenever possible. Patients asked to participate in clinical trials should receive a full explanation of the trial, together with written information about what taking part would involve.
- 5.7. Almost all patients with invasive breast cancer should be offered adjuvant systemic therapy (hormone therapy and/or chemotherapy). Systemic therapy should not be offered or withheld on grounds of age alone.
- 5.8. The choice of systemic therapy for individual women should be guided by guidelines based on up-to-date research knowledge and agreed by the breast care team. Risks and benefits of different options should be discussed with patients, who should have continuing access to a specialist nurse for support, practical advice and information.
- 5.9. Chemotherapy should only be given in units or centres where close supervision by oncologists and chemotherapy nurse specialists is available, plus expert pharmacy and 24 hour laboratory support.
- 5.10. Patients receiving chemotherapy and their GPs should have access to emergency care, information and advice from oncology trained staff on a 24 hour basis. They should be given written information on appropriate action for dealing with side effects of chemotherapy. There should be written guidelines on the management of complications and toxicities.

6. Follow-up after treatment for early breast cancer

- 6.1. All patients who have undergone treatment for breast cancer should have continuing access for an indefinite period to a breast care nurse.
- 6.2. Patients should be encouraged to contact the breast care nurse if they have any problems that could be linked with their cancer or treatment.
- 6.3. Routine long-term follow-up has not been shown to be effective and should cease.
- 6.4. Networks should agree evidence-based policy on the frequency of mammography for women who have been treated for breast cancer.
- 6.5. GPs should take responsibility for looking after women on long-term treatment with Tamoxifen or other hormone-modifying drugs, and for stopping such treatment after five years.
- 6.6. At the end of primary treatment, the patient and specialist should agree a written care plan. Intensive follow-up of women who have been treated for primary breast cancer should not be offered by the breast unit as a matter of routine.
- 6.7. Locally agreed measures should be developed to support the woman's transition from treatment by the unit.
- 6.8. General practitioners should be involved in shaping local arrangements for followup whenever routine breast unit follow-up is to be discontinued or reduced in scale.

7. Management of advanced, recurrent and metastatic disease

- 7.1. Every patient with advanced, recurrent or metastatic disease should be treated by a breast cancer multidisciplinary team (MDT) which includes a specialist oncologist. The team should have close links with a pain specialist and orthopaedic services.
- 7.2. Patients with locally advanced (T4) tumours are likely to have metastatic disease, so pre-treatment staging should include a bone scan, liver function tests and a chest x-ray as well as clinical evaluation. Local treatment should follow systemic therapy with chemotherapy, hormone treatment, or, in most cases, both.
- 7.3. Patients who respond well to systemic therapy should be offered surgery and radiotherapy to control local disease. Those with a poor response should normally be treated with radiotherapy.
- 7.4. The management of each patient with local recurrence should be discussed by the breast cancer MDT. Any combination of the major therapeutic modalities – surgery, radiotherapy and systemic treatment may be appropriate, the optimum treatment depending on various factors including previous treatment, the patient's general fitness, the site and extent of the recurrence, and tumour characteristics.

8. Palliative care

- 8.1. A palliative approach, involving both symptom control and attention to the psychological, social and spiritual well-being of the patient and her family/carers, should be provided throughout the course of the illness.
- 8.2. Women with breast cancer should have access to a range of services based in hospitals, hospices and in the community to ensure the delivery of effective palliative treatments and care.
- 8.3. Palliative care should be integrated between services provided by the breast care unit, the primary health care team, and specialist palliative care services, including the voluntary sector.
- 8.4. Palliative and supportive care networks have been established alongside cancer networks to co-ordinate care. These networks should be responsible for developing palliative care strategy and service delivery plans and for ensuring that services are fully integrated and coordinated within the network.
- 8.5. Multidisciplinary specialist palliative care teams should be available to provide optimal relief of pain and other symptoms and psychological, social and spiritual support for patients and their relatives and carers. The palliative care team should include a consultant in palliative medicine, nurses trained in palliative care, a social worker or other person trained in counselling patients who are dying and/or in pain.
- 8.6. The team should have ready access to the following services: physiotherapy, occupational therapy, counselling for both patients and relatives/carers.
- 8.7. All members of the palliative care team should participate in regular meetings to discuss patient care.
- 8.8. A specialist pain relief team should be available, as should access to spiritual support for women of different religions and those with no religious faith.
- 8.9. Women and their GPs should have access to the palliative care team on a 24-hour basis, and should have continuity of contact with a named member of the team. Appointment of a key worker to co-ordinate the care provided by different teams for each patient should be considered.
- 8.10. Patients should be helped to remain in the place they prefer, whether this is their home, a care home or hospice, and should choose where they wish to die.

9. The breast care team

- 9.1. The breast care team should be made up of individuals who have experience with breast cancer patients, substantial fixed time commitment to breast cancer patients, and where appropriate, specialist qualifications in breast cancer work.
- 9.2. The core breast team should include the designated breast surgeon(s), breast care nurse(s), a pathologist, a radiologist, an oncologist a coordinator and a team secretary.
- 9.3. The team as a whole should be responsible for planning care in a seamless way so that each patient receives prompt and appropriate care throughout the process of diagnosis and treatment, up to and including the period when palliation may be needed. The team must maintain close contact with all other professionals who are actively involved in supporting the patient or carrying out the treatment strategy decided by the core team. This includes the following: GPs/primary care teams, palliative care specialist/team, a breast radiographer, a psychiatrist/clinical psychologist, a social worker, a plastic surgeon, a clinical geneticist/genetics counsellor, a physiotherapist/lymphoedema specialist, a nominated orthopaedic surgeon with expertise in management of bone metastases, neurosurgeon, and an occupational therapist.
- 9.4. Teams based in cancer units must have close liaison with the associated cancer centre.
- 9.5. At any one time, a named member of the team should be the principal clinician to whom the patient relates. Patients should be given information about the members of the team involved in their management.
- 9.6. All new patients should be discussed, as well as any other patients whose cases are thought to require discussion as their condition or treatment progresses. Audit, clinical trials, and other issues should also be discussed at these meetings. There should be an operational policy meeting at least once a year at which the breast care team discusses and reviews its policies.
- 9.7. The core team should work closely together and meet on a regular basis (normally weekly) to discuss each patient with confirmed breast cancer both after initial diagnosis and after surgery to plan and monitor treatment. Decisions about future treatment should be discussed at these meetings.
- 9.8. The team must have adequate support to ensure that all decisions are recorded and communicated to patients and all those outside the core team.
- 9.9. The team should allocate adequate time to audit the activities and outcomes of the unit.
- 9.10. All breast referrals should be to specialist breast teams working in units which deal with at least 100 new cases of breast cancer per year.

10. Interprofessional communication

- 10.1. The breast care team must develop and implement systems that ensure rapid and effective communication between all healthcare professionals involved in each patient's management. There should be adequate means for communicating information on referral, diagnosis and treatment, follow-up and supportive/palliative care. District nurses and practice nurses in primary care must be linked into the communication network and be aware of referral criteria and routes to the breast care team for women who have been treated for breast cancer.
- 10.2. There should be sufficient administrative support, and the unit should be equipped with up-to-date facilities to aid communication. The need for confidentiality should be recognised in all communication.
- 10.3. There should be an agreed system for referral to the specialist breast team if the assessment centre is not part of the breast cancer unit.

11. Clinical guidelines, up-to-date practice and continuing professional development

- 11.1. Breast care units should adhere to explicit protocols in the management of breast cancer patients, so that patients are treated according to pre-defined evidence-based courses of action.
- 11.2. The entry of patients into appropriate clinical trials in which management is governed by protocols can be a valuable means of improving standards of care, as well as contributing to knowledge.
- 11.3. As evidence defining the effectiveness of interventions for breast cancer accumulates, it should be reflected in changing practice.
- 11.4. Members of the breast care team should continue their education in order that proven advances in treatment may be adopted. Team members should also be trained in non-clinical aspects of their work, particularly counselling and communication. Training for GPs particularly in cancer detection and follow-up after surgery is necessary to ensure that they can adequately fulfill their role in these areas.

12. Environment and facilities

- 12.1. Breast cancer treatment should be offered in a pleasant and appropriate physical environment. There should be private areas where patients and staff can discuss the diagnosis and treatment, where patients can be counselled without being overheard, and sufficient space for each woman to be accompanied by a friend or relative.
- 12.2. Attention should be paid to matters such as privacy in changing facilities, arrangements for the fitting of prostheses, availability of refreshments, and proximity and privacy of toilets.
- 12.3. Single-sex wards or bays should be available.
- 12.4. All units ideally should be equipped to offer dedicated diagnosis and treatment of all stages of breast cancer (other than radiotherapy facilities, which will be based in cancer centres).
- 12.5. Providers should also ensure that adequate transport facilities are available for patients. These should recognise and meet the needs of sick and vulnerable patients who may have to travel long distances for repeated episodes of treatment which may make them feel very unwell (radiotherapy and chemotherapy), and may compromise their employment and reduce compliance. Car or minicab services should be arranged for such patients.

1995: British Association of Surgical Oncologists (BASO) Guidelines for Surgeons in the Management of Symptomatic Breast Disease in the United Kingdom⁴

1. The unit should be seeing at least 50 new breast cancer cases per year.
2. A formal multidisciplinary meeting attended by members of the breast care team involved in primary treatments should be held weekly.
3. All patients diagnosed with breast cancer should have access to a breast care nurse, preferably preoperatively.
4. Women should be referred to a trained surgeon who works within a multidisciplinary breast clinic.
5. 80% of urgent referrals (as deemed by the surgeon) are to be seen within 5 working days of receipt of the referral.
6. 70% of all other new referrals are to be seen within 15 working days. (This has been superseded by the Government two week waiting time for all patients suspected of having cancer).
7. Over 90% of Fine Needle Aspirations from lesions which subsequently prove to be a cancer should be adequate as deemed by the breast pathologist.
8. 90% of palpable breast cancers should be diagnosed pre-operatively. Less than 10% of primary operable breast cancers should receive a frozen section.
9. Over 90% of patients proven to have breast cancer or an abnormality requiring an operation should be told within 5 working days of the date of the investigation.
10. Diagnosis should be based on triple assessment (Examination, Ultrasound/Mammography, Cytology).
11. 90% of patients should be admitted for an operation within 10 working days of the surgical decision to operate for diagnostic purposes. 90% of patients for therapeutic operations for cancer should be admitted within 15 working days of informing the patient of the need for surgical treatment. This should be carried out by trained breast surgeons, trainees with sufficient training in breast disease or trainees under direct supervision at operation.
12. Units should provide data on the number of patients treated, and by what methods.
13. Histological node status should be obtained on all invasive tumours either by sampling or clearance. It is recommended that "a sample" should contain at least 4 lymph nodes.
14. The Benign:Malignant operation ratio should be no more than 1:1 (This is for diagnostic operations only, excluding women who wish the lump to be removed even though it is benign and operations for nipple discharge and abscess).
15. Less than 10% of patients undergoing treatment for primary operable breast cancer should develop local recurrence at 5 and 10 years.
16. Reports of imaging examination should include details of site, size (in mm) and nature of any abnormality with an opinion as to the most likely diagnosis and make appropriate recommendations for further intervention where appropriate.
17. Mammographic localisation biopsy specimens must be X-rayed to ensure removal of the abnormality.
18. Adjuvant radiotherapy should start within 4 weeks of surgery.
19. GPs should receive communication giving diagnosis, care plan, and toxicity profile of any proposed systemic treatment from the first post-operative review and at the change of any treatment. BASO suggest annual mammography of the treated breast.
20. Survival and loco-regional recurrences at 5 and 10 years should be monitored.
21. Centres offering breast cancer treatment should ensure that there are adequate terminal care facilities to support the primary care team.

2005: NICE Referral guidelines for suspected cancer⁶

General recommendations

1. A patient who presents with symptoms suggestive of breast cancer should be referred to a team specialising in the management of breast cancer.
2. In most cases, the definitive diagnosis will not be known at the time of referral, and many patients who are referred will be found not to have cancer. However, primary healthcare professionals should convey optimism about the effectiveness of treatment and survival because a patient being referred with a breast lump will be naturally concerned.
3. People of all ages who suspect they have breast cancer may have particular information and support needs. The primary healthcare professional should discuss these needs with the patient and respond sensitively to them.
4. Primary healthcare professionals should encourage all patients, including women over 50 years old, to be breast aware in order to minimise delay in the presentation of symptoms.

Specific recommendations

1. A woman's first suspicion that she may have breast cancer is often when she finds a lump in her breast. The primary healthcare professional should examine the lump with the patient's consent. The features of a lump that should make the primary healthcare professional strongly suspect cancer are a discrete, hard lump with fixation, with or without skin tethering. In patients presenting in this way an urgent referral should be made, irrespective of age.
2. In a woman aged 30 years and older with a discrete lump that persists after her next period, or presents after menopause, an urgent referral should be made.
3. Breast cancer in women aged younger than 30 years is rare, but does occur. Benign lumps (for example, fibroadenoma) are common, however, and a policy of referring these women urgently would not be appropriate; instead, non-urgent referral should be considered. However, in women aged younger than 30 years: with a lump that enlarges, or with a lump that has other features associated with cancer (fixed and hard), or in whom there are other reasons for concern such as family history an urgent referral should be made.
4. The patient's history should always be taken into account. For example, it may be appropriate, in discussion with a specialist, to agree referral within a few days in patients reporting a lump or other symptom that has been present for several months.
5. In a patient who has previously had histologically confirmed breast cancer, who presents with a further lump or suspicious symptoms, an urgent referral should be made, irrespective of age.
6. In patients presenting with unilateral eczematous skin or nipple change that does not respond to topical treatment, or with nipple distortion of recent onset, an urgent referral should be made.
7. In patients presenting with spontaneous unilateral bloody nipple discharge, an urgent referral should be made.
8. Breast cancer in men is rare and is particularly rare in men under 50 years of age. However, in a man aged 50 years and older with a unilateral, firm subareolar mass with or without nipple distortion or associated skin changes, an urgent referral should be made.

Investigations

1. In patients presenting with symptoms and/or signs suggestive of breast cancer, investigation prior to referral is not recommended.
2. In patients presenting solely with breast pain, with no palpable abnormality, there is no evidence to support the use of mammography as a discriminatory investigation for breast cancer. Therefore, its use in this group of patients is not recommended. Non-urgent referral may be considered in the event of failure of initial treatment and/or unexplained persistent symptoms.

APPENDIX B – Staging of breast 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). It is best achieved by a combination of techniques including physical examination, with careful inspection of the skin, palpation of the breast and regional lymph node areas (axillary, supraclavicular, internal mammary nodes), mammography and/or ultrasound and biopsy. Adjuncts to staging such as CT scanning and isotope bone scanning should be performed when clinically indicated. Pathological staging adds significant information to this process. It involves histological examination of the surgically resected specimen including evaluation of the total number of regional nodes removed and the number containing metastatic tumour. The TNM classification of breast carcinoma (6th Edition)¹⁹ is shown in Table 1.

Determining the tumour size (T)

The majority of breast tumours are staged pathologically. This is more precise as it is a measurement of the size of the invasive tumour. In a minority of cases clinical staging only is possible. In this case, as the estimation of tumour size by physical examination and mammography frequently give different results, accuracy can be improved using the formula:

Tumour size (T) = 0.5 x physical examination size + 0.5 x mammographic size.

Careful clinical examination of the skin to look for oedema, ulceration & satellite skin lesions is essential in all cases as these findings will upstage the T factor and may be unapparent at the time of pathological examination. The surgeon should therefore inform the pathologist of such clinical findings to prevent pathological understaging. In cases of multiple tumours within one breast the size of the largest tumour should be used to determine the T factor.

Determining the nodes (N)

As the majority of breast tumours are pathologically staged, information on the number of axillary nodes examined and the number involved by tumour will be available. The N factor is designated by the number of involved axillary nodes with 3 main categories N1-N3. Within each category subdivisions exist to allow for inclusion of internal mammary nodes detected by sentinel node biopsy or that are clinically apparent.

Determining metastases (M)

A proportion of patients will have metastatic disease detected by clinical examination, imaging and/or laboratory investigations at presentation, which will be designated M1. A negative clinical history and examination are sufficient to designate M0.

Stage group

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

Example:

- 1.5cm invasive breast tumour. T = T1c
- 8 axillary nodes have histologically verified metastases. N=N2a
- clinically/radiologically there is no evidence of distant metastases. M=M0

The TNM profile of this example is T1 cN2a M0 and is thus assigned to stage group IIIA as it is known that the survival prospect associated with this profile is similar to the other TNM profiles within stage IIIA (ie. T2 N2 M0, T3 N1 M0 and T3 N2 M0).

Table 1: TNM classification of breast cancer

Tumour size		
T0	T0	No evidence of primary tumour
T1	T1mic	tumour size <0.1cm (microinvasive)
	T1a	tumour size >0.1 <0.5cm
	T1b	tumour size >0.5 <1.0cm
	T1c	tumour size >1.0 <2.0cm
T2	T2	tumour size >2.0 <5.0cm
T3	T3	tumour size >5.0cm
T4	T4a	tumour of any size with extension to chest wall
	T4b	tumour of any size with oedema, ulceration or satellite skin lesions
	T4c	both T4a and T4b
	T4d	Inflammatory carcinoma

Nodes		
N0	N0	no regional nodes involved
N1	N1a	metastases in 1-3 axillary nodes
	N1b	metastases in clinically inapparent internal mammary nodes
	N1c	metastases in 1-3 axillary nodes + N1b
N2	N2a	metastases in 4-9 axillary nodes
	N2b	clinically apparent metastases in internal mammary nodes without axillary node metastases
N3	N3a	metastases in >10 axillary nodes or metastases in infraclavicular nodes
	N3b	clinically apparent metastases in internal mammary nodes with >1 axillary node metastases or clinically inapparent metastases in internal mammary nodes with >3 axillary node metastases.
	N3c	metastases in supraclavicular nodes

Metastases		
M0	M0	No distant metastases
M1	M1	distant metastases

Stage	T	N	M
I	T1	N0	M0
IIA	T0	N1	M0
	T1	N1	M0
	T2	N0	M0
IIB	T2	N1	M0
	T3	N0	M0
IIIA	T0	N2	M0
	T1	N2	M0
	T2	N2	M0
	T3	N1	M0
	T3	N2	M0
IIIB	T4	N0	M0
	T4	N1	M0
	T4	N2	M0
IIIC	Any T	N3	M0
IV	Any T	Any N	M1

Histological grade

Although histological grade (Nottingham Combined Histological Grade) is a significant prognostic factor it has not yet been incorporated into the TNM classification, largely due to concerns about its reproducibility. It is likely that this will change in the next edition of the TNM.

Nottingham Prognostic Index (NPI)²⁰

The NPI is a clinically relevant prognostic index which is used to stratify breast cancer patients for adjuvant therapy. It was derived in 1982 from a retrospective multivariate study of patients with primary operable breast cancer who underwent simple mastectomy and triple node biopsy at the Nottingham City Hospital and has since been validated both by single centers and internationally.

It is a simple calculation based on tumour size, histological grade and number of positive lymph nodes.

$$\begin{aligned}
 \text{NPI} &= 0.2 \times \text{Tumour size (cm)} + \text{tumour grade} + \text{nodal stage} \\
 \text{[nodal stage]} &= 1 \text{ (if node negative), } 2 \text{ (if 1-3 nodes positive), } 3 \text{ (if 4 or more positive)} \\
 \text{eg Tumour size} &= 2.0\text{cm, grade 3, number involved nodes} = 5 \\
 &= 0.2 \times 2.0 + 3 + 3 \\
 &= 6.4 \text{ ie Poor prognosis}
 \end{aligned}$$

It stratifies patients into one of 3 prognostic groups with different chances of surviving breast cancer: Good (<3.4), Moderate (3.4-5.4) and Poor (>5.4).

APPENDIX C – Incidence and mortality of breast cancer: 1993-2007

Incidence

Year	Number of cases	Percentage of all cancers	Crude rate	EASIR (95% CI)	Odds, 1 in:
1993	770	18.0%	92.0	93.0 (86.2, 99.9)	13.8
1994	831	20.0%	98.7	100.6 (93.5, 107.7)	13.2
1995	879	20.9%	104.0	104.2 (97.0, 111.3)	12.3
1996	849	19.2%	99.7	99.7 (92.8, 106.7)	13.0
1997	856	19.7%	100.0	99.4 (92.5, 106.3)	13.1
1998	910	20.8%	105.9	104.6 (97.5, 111.6)	12.3
1999	940	21.4%	109.2	105.0 (98.0, 112.0)	12.5
2000	948	21.4%	109.9	106.0 (99.1, 113.0)	12.2
2001	927	21.5%	107.2	103.9 (97.0, 110.8)	12.3
2002	952	20.8%	109.7	102.6 (95.8, 109.3)	12.6
2003	1,035	22.0%	119.0	112.3 (105.2, 119.3)	11.4
2004	1,140	24.2%	130.5	119.5 (112.3, 126.7)	10.9
2005	1,088	22.9%	123.6	111.3 (104.4, 118.1)	11.8
2006	984	19.9%	110.8	99.5 (93.1, 106.0)	12.8
2007	1,147	22.5%	127.8	115.5 (108.6, 122.4)	11.1
93-07	14,256	21.1%	110.0	105.4 (103.6, 107.2)	12.3
03-07	5,394	22.3%	122.3	111.6 (108.5, 114.7)	11.6

EASIR: European age-standardised incidence rate per 100,000 persons (95% confidence interval)

Mortality

Year	Number of deaths	Percentage of all cancer deaths	Crude rate	EASMR (95% CI)	Odds, 1 in:
1993	329	18.9%	39.3	38.0 (33.7, 42.3)	33.7
1994	338	19.2%	40.2	37.1 (32.9, 41.3)	36.1
1995	327	19.8%	38.7	35.5 (31.5, 39.6)	36.3
1996	305	18.1%	35.8	31.8 (28.0, 35.5)	39.7
1997	259	14.8%	30.3	26.9 (23.4, 30.3)	49.4
1998	299	17.2%	34.8	31.3 (27.6, 35.0)	41.1
1999	290	16.6%	33.7	29.8 (26.2, 33.4)	43.3
2000	286	16.0%	33.2	29.3 (25.7, 32.8)	43.1
2001	315	18.0%	36.4	31.0 (27.4, 34.5)	42.0
2002	278	15.8%	32.0	26.4 (23.2, 29.7)	50.8
2003	282	15.3%	32.4	26.3 (23.1, 29.6)	52.0
2004	324	17.8%	37.1	30.7 (27.2, 34.2)	41.4
2005	301	16.5%	34.2	26.6 (23.4, 29.8)	54.7
2006	300	16.3%	33.8	27.2 (24.0, 30.5)	48.4
2007	305	17.2%	34.0	26.3 (23.1, 29.4)	52.3
93-07	4,538	17.1%	35.0	30.1 (29.2, 31.0)	43.7
03-07	1,512	16.6%	34.3	27.4 (25.9, 28.8)	49.3

EASMR: European age-standardised mortality rate per 100,000 persons (95% confidence interval)

CDS N112832

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ISBN 9780853899655