N. IRELAND
Cancer
Registry

Cancer Services Audit 1996 & 2001
Breast

“The doctors and nurses were very kind and attentive throughout . . . .

. . . . and kept me up to date with each step of my care.”

Queen’s University
Belfast

Cancer Services Audit 1996 & 2001
Breast

N. IRELAND
Cancer
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Cancer Services Audit 1996 & 2001
BREAST

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FOREWORD

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

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

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

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

H Campbell

Dr Henrietta Campbell
Chief Medical Officer

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The quality of data in this project is a result of the work of the present and past Registry Tumour Verification Officers especially Carmel Canning, Bernadette Anderson, Elinor Johnston, Mary McCartney, Dr Carmel Corr and Eileen Sheppard who meticulously extracted detailed information from clinical records for analysis and presentation in this report. We are grateful to Dr Karen Bailie who provided the Registry with breast cancer data for 1996. The analysis of data was largely undertaken by Heather Kinnear and Deirdre Fitzpatrick after data preparation by Pauline Monaghan. A special word of gratitude to the Medical Records staff from all the hospitals in N. Ireland who in the course of the audit for all sites pulled an estimated 10,000 charts.

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

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

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

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

Anna Gavin.

A Gavin
Director, NICR, 2005

PATIENT STORIES

"I found the lump. I went to my doctor and he referred me to the breast clinic. I was examined by a consultant and had a mammogram and an ultrasound scan followed by a needle biopsy.

I knew they were concerned. I was told that no matter what the outcome, I would need surgery. This didn't worry me but the possibility of having cancer absolutely terrified me. All I remember hearing was the word 'malignant'. After that, everything was a blur. I wanted to run away from the cancer.

I went into hospital to have a mastectomy, just over a week after my diagnosis.

A week or so later I had to return to the hospital to get my pathology results, which was probably one of the most nerve-racking times of the whole experience, not just for me, but also for the whole family. I knew I had cancer but I didn't know how serious it was or if it had spread. It was good news. Only four of my lymph nodes had been affected. However, because of the lymph node invasion I was told that I would need chemotherapy followed by a course of radiotherapy.

Like most people, I thought that anyone having chemotherapy treatment would lose their hair and be sick and tired all the time. It didn't take very long to get the chemotherapy but there was a lot of time spent beforehand waiting for blood test results. The treatment itself only took about fifteen to twenty minutes. I waited for the nausea to kick in, but it didn't. I can only thank my consultant for getting my anti-sickness drugs so right because apart from tiredness for a few days, I felt great. A couple of weeks after my first treatment my hair started to fall out. It happened very quickly; one day it was fine and the next day it was coming out like crazy. I felt very unfeminine losing my hair. That, together with having only one breast, was probably my lowest point during the illness.

I had six weeks of radiotherapy. The procedure itself took only about five minutes, but I could be up in the hospital for a couple of hours just waiting my turn. When you're a cancer patient the last thing you want is to be wasting precious time sitting in a hospital waiting room day after day.

I thought that when my treatment had finished that life would carry on as normal, however, I felt very isolated and alone. It was then that I joined the Breast Cancer Support Group at the Ulster Cancer Foundation. It was lovely to talk to women who had been through the same experience as me, and most encouraging to see the same faces each time we met. It was good to see that they were still alive and, like me, a cancer survivor."

~

"The doctors and nurses were very kind and attentive throughout my stay in hospital and kept me up to date with each step of my care."

~

"I was called for a mammogram because I was at an age where I could benefit from the National Screening Programme. After a repeat mammogram, I had a needle biopsy. Three days later I was told I had breast cancer. My treatment consisted of three stages: full mastectomy of the right breast and axillary node clearance; chemotherapy; and radiotherapy. I was very surprised by how

quickly I recovered from the mastectomy both physically and emotionally."

~

"I knew that I was going to have chemotherapy, and had personally experienced it's side effects on my aunt, who had been very sick. I thought it would have the same effect on me, but it didn't, because there have been huge developments in drug treatments since my aunt's time. I had my treatment on a Wednesday, stayed in bed on the Thursday and went back to work on the Friday or the Monday. The work kept me going."

~

"I was referred to a plastic surgeon who explained all my options and the reconstructive surgery went ahead. It was a very long operation and it took me quite some time to recover. The end result is amazing and I'm so glad I went ahead."

~

"I was totally unprepared for the way I reacted to the end of treatment. So much of my life had been taken up with hospital attendance that I became fearful of the future, and felt isolated. Fortunately I had heard about the Gerard Lynch Centre, which is situated in the grounds of Belvoir Park Hospital. The centre offers a range of therapeutic services including support, counselling and relaxation courses. I was offered a course of reflexology, which helped me to relax and to adjust from being a patient to being me."

~

"It's just over three years since my diagnosis and I feel wonderful. I try to take care of my body because I now appreciate how fragile good health can be. I eat healthily, but life's too short to deny yourself a splurge every now and then. I've returned to work but only part-time so that I can spend more time with my children. I don't know how I would manage if the cancer ever returned. It's something I try not to think about. Cancer will always be part of my life now, but I hope it will never consume my life again."

These extracts of patient stories are taken from 'Ribbons of Hope – Living Through Breast Cancer' compiled by Elvira Lowe and available from the Ulster Cancer Foundation.

INTRODUCTION

This Report is the second in a series which examines in detail the pathway of care for cancer patients in N. Ireland. Breast cancer represents a major cancer and the years 1996 and 2001 represent two points in time either side of the publication of the Campbell Report **"Cancer Services-Investing for the Future"**[1].

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

Subsequent to the publication of the Campbell Report, a Cancer Working Group in N. Ireland produced a sub-group report on Breast Cancer[2] which made 16 specific recommendations on the future of breast cancer services in N. Ireland (see below).

Standards

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 cancer nurse. The "second stage" treatment stage 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 trainee 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 have taken 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.

16. The crucial interface between primary and secondary care must be recognised and must be managed and developed appropriately.

This report also highlighted issues of particular importance including:

a. 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.

b. The need to gather information on outcomes and undertake audit on a cross N. Ireland basis was identified. The possibility of developing audit guidelines and frameworks for application across N. Ireland and establishing a multi-professional group to monitor audits should be considered.

In 1997, the NHS produced a document outlining Guidance on Commissioning Cancer Services: **"Improving Outcomes in Breast Cancer"**[3]. Key recommendations are outlined in Appendix B.

The British Association of Surgical Oncologists (BASO) in 1998 produced a report **"Guidelines for Surgeons in the Management of Symptomatic Breast Disease in the United Kingdom"**[4]. The 9 recommendations made are listed in Appendix C. We would expect that when investigating the 2001 data that the above 1997 recommendations would have been implemented.

PROJECT AIM

This Report aims to measure changes to care for patients from a baseline in 1996 and to determine whether they are in keeping with the recommendations of the Campbell Report[1].

BACKGROUND

In N. Ireland each year (1993-2001) on average, 877 women were diagnosed with cancer of the breast and 306 women died from this cancer. Cancer of the breast accounts for 21% of cancer cases and 18% of cancer deaths in women[5].

In 2001, after non-melanoma skin cancer, breast cancer was the most common cancer in females. Given the levels of disease in 2001, the risk of females getting breast cancer before the age of 65 years was 1 in 17, rising to 1 in 12 by the age of 75 years. Half of the cases were diagnosed in those under 60 years. The incidence of breast cancer peaked at 50-54 years, although rates were highest for those 75 years and older due to the smaller population in those age groups. In N. Ireland on 31st December 2001, there were 5,752 females alive who had breast cancer diagnosed between 1993 and 2001[5]. The number of cases diagnosed has risen steadily by on average 12 new cases per year (1993-2001)[5].

There were approximately 306 deaths annually from breast cancer (1993-2001). In 2001, it was the most common cancer death in females (taken over in 2002 by lung cancer). Given the levels of mortality in 2001, the risk of females dying from this cancer before the age of 75 years was 1 in 42[5]. Death rates are falling by on average 8 per year.

Survival from breast cancer is high with the most recent five-year relative survival estimate (1996–1999) for women being 82%. This was an improvement on the estimate for an earlier diagnostic period (1993–1995), where five-year relative survival was 76% ($p<0.05$). Survival from breast cancer varies significantly, depending on the stage of the disease. Females with Stage I breast cancer had a five-year relative survival of 97%, whilst Stage IV patients had a five-year relative survival of 13% (1993–2001)[5].

AETIOLOGY

The breast is made up of millions of cells that are constantly being renewed and replaced. Breast cancer develops when a single cell begins to multiply out of control. As the cancer grows, some cells may eventually break away and spread to other parts of the body. The breast has many different parts. There are around 10 to 15 sections (lobes) made up of smaller parts called lobules. These are connected to the nipple by tubes known as ducts. Breast cancer usually starts in a cell lining a duct or lobule[6].

Breast cancer, like all cancers, arises as a result of changes in genes that regulate cell growth and behaviour. Between 5-7% of breast cancer is due to inheritance of a mutated copy of either BRCA1 or BRCA2 gene. Women who inherit this mutated gene have an increased risk of breast cancer.

RISK FACTORS[6]

- The strongest risk factor for breast cancer is age. The older a woman, the greater her chances of getting the disease.
- The more children a woman has, the lower her risk of breast cancer. Being younger when having children also decreases risk.
- The longer a woman breastfeeds her children, the lower her risk of breast cancer.
- Starting periods at a younger age or having a late menopause increases the risk.
- Taking the contraceptive pill may cause a small increase in risk, but risk returns to normal after stopping it.
- The risk of breast cancer is likely to increase the longer a woman takes hormone replacement therapy (HRT).
- Being overweight after the menopause slightly increases a woman's risk of breast cancer, as body fat affects hormone levels.
- Research suggests that regularly drinking large amounts of alcohol slightly increases risk.
- Risk is greater if a close relative had breast cancer before the age of 50, or if two close relatives of any age have been affected.
- If a woman has had benign (non-cancerous) breast lumps in the past then she may have a slightly increased risk of breast cancer.

METHODS

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 N. Ireland Cancer Registry. Data was then entered into an electronic proforma, which had been developed with the guidance of relevant clinicians; copy available at www.qub.ac.uk/nicr

EXCLUSIONS

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

RESULTS

Study patients

Patients	Numer of Patients	
	1996	2001
Total patients	910	1047
Exclusion - Death Certificate Only	5	1
Exclusion - In situ	70	104
Exclusion - lack of information	71	61
Total exclusions	146	166
Total reported on	764 (100%)	881 (100%)
Average age at diagnosis (years)	60	60
Median age at diagnosis (years)	60	59

- Data were available on 910 women in 1996 and 1047 in 2001. After exclusions, 764 remained in 1996 and 881 in 2001.
- The increased number of patients by 2001 reflects a rise in the number of breast cancers due to several factors including an ageing population and enhanced early diagnosis due to the screening programme. This rise has been documented for N. Ireland at an average of 12 cases per year (1993-2001)[5].

Socio-economic status of breast cancer patients

Deprivation Quintile	Number of Patients (%)	
	1996 *(n=764)*	2001 *(n=881)*
Quintile 1 (most affluent)	160 (21%)	154 (18%)
Quintile 2	137 (18%)	153 (17%)
Quintile 3	138 (18%)	155 (18%)
Quintile 4	148 (19%)	187 (21%)
Quintile 5 (least affluent)	181 (24%)	232 (26%)

- If a disease is not related to deprivation in the general population, it is expected that 20% of all cases of disease would fall in each quintile. Our data showed that there was no difference in the levels of breast cancer with deprivation in these populations ($\chi^2 = 4.523$, $p>0.05$). This probably reflects the relatively small numbers as, in previous N. Ireland Cancer Registry reports, a higher level of disease among affluent groups has been shown when data were combined from several years[5].

Source of referral to specialist care

Source	**Number of Patients (%)**	
	1996 *(n=764)*	**2001 *(n=881)***
GP (General Practitioner)	**541 (71%)**	**594 (68%)**
Breast Screening Unit (BSU)	**106 (14%)**	**180 (21%)**
Action Cancer	**15 (2%)**	**26 (3%)**
Other*	**51 (6%)**	**60 (6%)**
Not recorded	**51 (7%)**	**21 (2%)**

**** These included referrals from Consultants, Family Planning Clinics and Well Woman Clinics.***
Also included are patients who self referred, private patients and patients who were being regularly reviewed.

- Over two thirds of all breast cancer cases in both years came from GP referrals.
- Referrals from the Breast Screening Unit increased so that by 2001, a fifth of cases were from that source. Data from the Breast Screening Unit for all years between 1996 and 2001 indicate a consistent trend in increasing referrals from this source (not shown).

Family history of breast cancer (any relative)

Family History	**Number of Patients (%)**	
	1996 *(n=764)*	**2001 *(n=881)***
Yes	**195 (26%)**	**247 (28%)**
No/not recorded	**569 (74%)**	**634 (72%)**

Family history of breast cancer (first degree relative)

Family History	**Number of Patients (%)**	
	1996 *(n=764)*	**2001 *(n=881)***
Yes	**124 (16%)**	**129 (15%)**
No/not recorded	**640 (84%)**	**752 (85%)**

Family history of other cancer

Family History	**Number of Patients (%)**	
	1996 *(n=764)*	**2001 *(n=881)***
Yes	**82 (11%)**	**195 (22%)**
No/not recorded	**682 (89%)**	**686 (78%)**

- A quarter of women with breast cancer had a positive family history with about 15% having a first degree relative with a history of breast cancer.
- Recording of family history of any cancer in the family improved by 2001.

Co-morbidities (NOTE: each patient may present with more than one co-morbidity)

Co-morbidities	Number of Patients (%)	
	1996 (n=764)	2001 (n=881)
Hypertension	164 (21%)	226 (26%)
History of breast disease (benign)	128 (17%)	174 (20%)
Arthritis	100 (13%)	153 (17%)
COPD*	58 (8%)	86 (10%)
Ischaemic heart disease	114 (15%)	86 (10%)
Cerebrovascular disease	25 (3%)	46 (5%)
Diabetes	40 (5%)	45 (5%)
Oesteoporosis	10 (1%)	33 (4%)
Psychiatric disorder	25 (3%)	20 (2%)
Dementia	12 (2%)	19 (2%)
Alzheimers	1 (<1%)	5 (<1%)
History of breast cancer	3 (<1%)	4 (<1%)
Parkinsons disease	6 (<1%)	4 (<1%)
Other malignancy	32 (4%)	40 (5%)
No co-morbidities	273 (36%)	296 (34%)

**** Chronic Obstructive Pulmonary Disease***

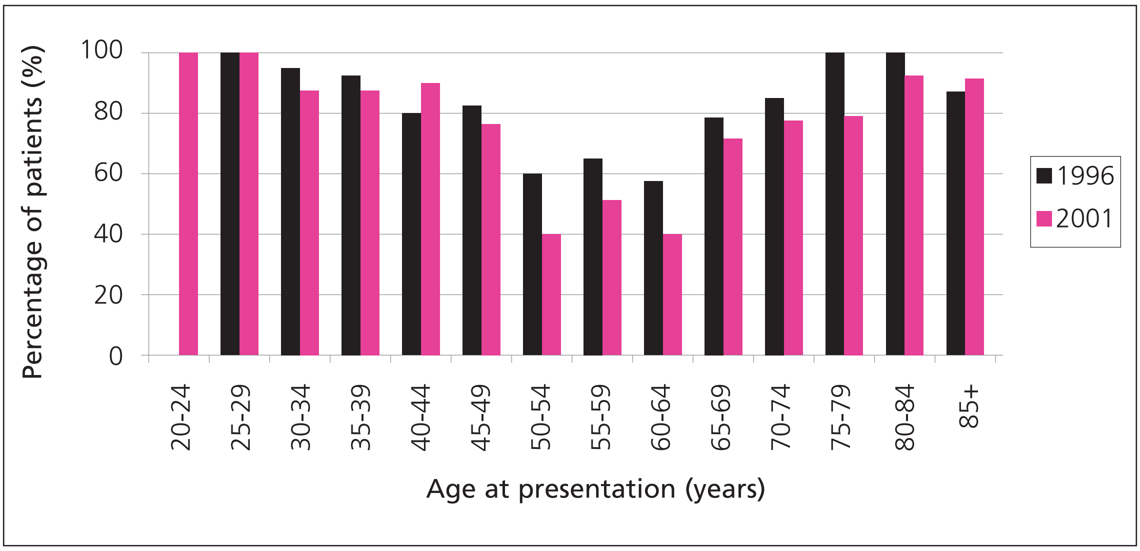
- There was little difference in the incidence of co-morbidities for patients in either year of study.
- About a fifth of patients had a history of benign breast disease.
- In both years less than 1% of patients had a previous personal history of breast cancer.
- About 5% of patients in each year had a history of other malignancy.

Symptoms at presentation (NOTE: patients may present with more than one symptom)

Symptom	Number of Patients (%)	
	1996 *(n=764)*	2001 *(n=881)*
Breast/axillary lump	600 (79%)	576 (65%)
Breast pain	120 (16%)	163 (19%)
Nipple discharge/abnormality	100 (13%)	123 (14%)
Abscess	12 (2%)	20 (2%)
Deformity	46 (6%)	69 (8%)
Skin changes	125 (16%)	164 (19%)
Weight loss	31 (4%)	38 (4%)
Asymptomatic	92 (12%)	193 (22%)

- The most common presenting symptom was a breast/axillary lump. The number of women presenting with this fell between 1996 and 2001. This most likely reflects the increasing proportion of screen detected tumours.
- 4% of patients presented with weight loss in each year.
- 21% of asymptomatic patients in 1996 and 85% in 2001 were referred by the Breast Screening Unit (not shown).

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



- Among women aged 50-65 years, 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 cancer screening programme before a lump is palpable. This was more marked in 2001 than 1996.

Symptoms and duration

Symptom		1month or less	2-5 months	6-11 months	12 or more months	Not recorded	Total Patients
Breast/axillary lump	**1996**	**266 (44%)**	**87 (15%)**	**25 (4%)**	**55 (9%)**	**166 (28%)**	**600**
	2001	**342 (59%)**	**80 (14%)**	**29 (5%)**	**31 (5%)**	**94 (16%)**	**576**
Breast pain	**1996**	**41 (34%)**	**23 (19%)**	**7 (6%)**	**13 (11%)**	**36 (30%)**	**120**
	2001	**59 (36%)**	**16 (10%)**	**3 (2%)**	**6 (4%)**	**79 (48%)**	**163**
Nipple discharge/abnormality	**1996**	**17 (17%)**	**11 (11%)**	**9 (9%)**	**7 (7%)**	**56 (56%)**	**100**
	2001	**35 (28%)**	**13 (11%)**	**3 (2%)**	**10 (8%)**	**62 (50%)**	**123**
Weight loss	**1996**	**6 (19%)**	**7 (23%)**	**1 (3%)**	**2 (6%)**	**15 (48%)**	**31**
	2001	**5 (13%)**	**4 (11%)**	**7 (18%)**	**6 (16%)**	**16 (42%)**	**38**

- Two fifths of patients in 1996 and three fifths in 2001 who presented with a breast/axillary lump reported its presence for less than one month suggesting a trend of earlier symptom reporting.
- The proportion of patients with breast/axillary lumps for over 12 months decreased between 1996 and 2001 but this did not reach significance (p>0.05).
- Around one in twelve patients had symptoms for over one year.

Hospital of presentation

Hospital	Number of Patients (%)	
	1996 *(n=764)*	2001 *(n=881)*
Belfast City (BCH)*	58 (8%)	251 (28%)
Ulster (UH)**	100 (13%)	157 (18%)
Altnagelvin (AH)**	66 (9%)	88 (10%)
Craigavon Area (CAH)**	78 (10%)	136 (15%)
Antrim (ANT)**	30 (4%)	160 (18%)
Royal Victoria (RVH)	170 (22%)	1 (<1%)
Mater (MIH)	12 (2%)	6 (<1%)
Coleraine (COL)	37 (5%)	2 (<1%)
Mid Ulster (MUH)	4 (<1%)	2 (<1%)
Tyrone County (TCH)	15 (2%)	13 (1%)
Whiteabbey (WHA)	5 (<1%)	0
Daisy Hill (DHH)	35 (5%)	2 (<1%)
Erne (ERN)	15 (2%)	17 (2%)
Downe (DH)	11 (1%)	3 (<1%)
Lagan Valley (LVH)	21 (3%)	5 (<1%)
Ulster Independent Clinic (UIC)****	8 (1%)	24 (3%)
South Tyrone (STH)	5 (<1%)	0
Armagh Community (ACH)***	1 (<1%)	1 (<1%)
Ards (AR)***	1 (<1%)	0
Banbridge (BBH)***	0	1 (<1%)
Moyle (MLE)ºº	1 (<1%)	0
Musgrave Park (MPH)	0	1 (<1%)
Braid Valley (BVH)***	0	1 (<1%)
Massereene (MAS)	68 (9%)	0
Bangor Community (BGR)***	3 (<1%)	0
Not Recorded	20 (3%)	10 (1%)

** Cancer Centre*

*** Cancer Unit*

**** Changed to community health facility with no inpatient facilities by 2001*

***** The Ulster Independent Clinic is a private hospital.*

ººFacility still had 2 palliative beds in 2001.

- 764 patients presented to 22 hospitals in 1996 and 881 patients presented to 19 hospitals in 2001 (19 and 14 if single presentations are excluded).
- In 2001, 90% of patients presented to a Cancer Unit/Cancer Centre.
- There was a major shift in hospital of presentation from the Royal Victoria Hospital to the Belfast City Hospital in keeping with the recommendations of the Northern Ireland subgroup report on Breast Cancer[2].

Patients presenting within their own Board

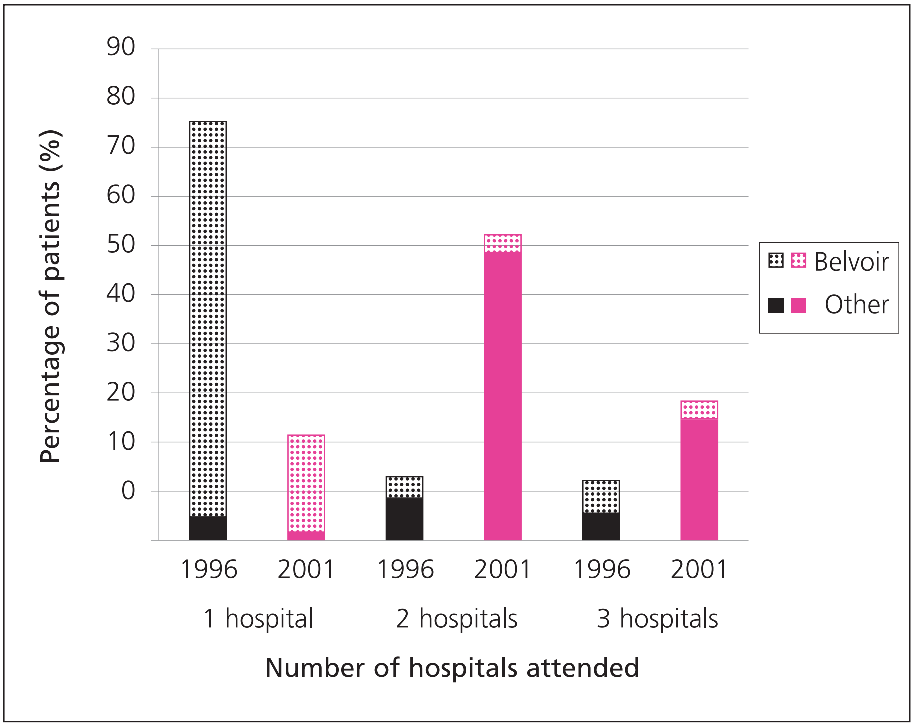
Board of Residence	Number of Patients (% presenting within own Board)	
	1996	2001
NHSSB	**144 (74%)**	**162 (77%)**
EHSSB	**317 (95%)**	**380 (99%)**
SHSSB	**117 (85%)**	**131 (80%)**
WHSSB	**94 (96%)**	**114 (97%)**

- By 2001, the majority of patients were presenting to a hospital within their own Board of residence. Those who did not, mostly presented to a hospital within the Eastern Board.

HOSPITALS ATTENDED

- In 1996, 585 patients attended one hospital, 93 patients attended two hospitals and 86 attended three hospitals. In 2001, 166 patients attended one hospital, 491 attended two hospitals and 224 attended three hospitals.
- By 2001, patients were more likely to attend two or three hospitals for their treatment compared with 1996. The changes are due to increased numbers of patients attending Belvoir Park Hospital (N.Ireland Radiotherapy Centre) (135 in 1996 and 661 in 2001) and reflect increased referral for adjuvant radiotherapy and chemotherapy.

Percentage of patients attending one, two or three hospitals



Investigations (NOTE: Patients may have received more than one type of investigation)

Investigation	Number of Patients (%)			
	All Patients		Surgery Patients	
	1996 *(n=764)*	2001 *(n=881)*	1996 *(n=677)*	2001 *(n=805)*
Mammogram	655 (86%)	823 (93%)	610 (90%)	779 (97%)
Fine Needle Aspiration (FNA)	653 (85%)	748 (85%)	584 (86%)	694 (86%)
Core biopsy	54 (7%)	370 (42%)	51 (8%)	351 (44%)
Excision biopsy (diagnostic)	79 (10%)	12 (1%)	79 (12%)	12 (1%)
Ultrasound breast	207 (27%)	627 (71%)	199 (29%)	593 (74%)
Chest X-ray	375 (49%)	520 (59%)	321 (47%)	489 (61%)
Ultrasound abdomen	212 (28%)	425 (48%)	188 (28%)	398 (49%)
CT scan	18 (2%)	45 (5%)	15 (2%)	32 (4%)
Brain scan	19 (2%)	15 (2%)	12 (2%)	9 (1%)
Bone scan	165 (21%)	356 (40%)	146 (22%)	331 (41%)

- Between 1996 and 2001 there was increased use of mammography, breast ultrasound and core biopsy with an associated shift away from excision biopsy for all patients including surgery patients. This is in keeping with current BASO guidelines[4] which recommended a triple assessment process (clinical examination, imaging, and cytology).
- Between 1996 and 2001 the use of other imaging techniques to detect metastatic disease increased, most notably for isotope bone scanning and ultrasound of abdomen with smaller increases in chest X-ray and CT scanning.
- A similar level of investigation was observed for surgery patients and all patients.

HISTOPATHOLOGY

Histopathological type

Type	Number of Patients (%)	
	1996 *(n=764)*	2001 *(n=881)*
Adenocarcinoma	34 (4%)	0
Carcinoma	109 (14%)	81 (9%)
Infiltrating ductal	465 (61%)	663 (75%)
Infiltrating lobular	90 (12%)	97 (11%)
Malignancy, NOS*	57 (7%)	15 (2%)
Paget's disease of breast	5 (1%)	23 (3%)
Other	4 (1%)	2 (<1%)

**** NOS = Not Otherwise Specified***

- All cases of breast cancer had a histological/cytological diagnosis in both years.
- As expected the majority of breast cancers in both years were infiltrating ductal carcinomas.

STAGING

- Over three quarters of all surgery patients had a stage recorded in the notes by 2001 (not shown).

When stage was not recorded and there was sufficient information available in the clinical notes, Registry TVO's were able to assign a stage group (Registry-assigned stage). The UICC TNM staging classification was applied[7].

TNM Stage (recorded in notes or Registry-assigned)

Stage	Number of Patients (%)			
	All Patients		Surgery Patients	
	1996 *(n=764)*	2001 *(n=881)*	1996 *(n=677)*	2001 *(n=805)*
I	251 (33%)	308 (35%)	245 (36%)	308 (38%)
IIA	199 (26%)	216 (25%)	193 (29%)	215 (27%)
IIB	129 (17%)	157 (18%)	127 (19%)	156 (19%)
IIIA	44 (6%)	29 (3%)	43 (6%)	29 (4%)
IIIB	16 (2%)	31 (4%)	12 (2%)	22 (3%)
IIIC	1 (<1%)	0	1 (<1%)	0
IV	59 (8%)	38 (4%)	27 (4%)	16 (2%)
Staging Not Possible*	65 (9%)	102 (12%)	29 (4%)	59 (7%)

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

- It was possible to determine stage in approximately 90% of cases in both years but with slightly fewer patients staged in 2001.
- The majority of patients for whom staging was not possible were over 70 years at the time of diagnosis

Patients with insufficient data for TNM Staging

Area of Residence	Number of Patients (%)	
	1996	2001
NHSSB	18 (9%)	11 (5%)
EHSSB	35 (11%)	59 (16%)
SHSSB	5 (4%)	18 (11%)
WHSSB	7 (7%)	14 (12%)
N.Ireland	65 (9%)	102 (12%)

- The percentage of patients for whom it was not possible to determine a stage decreased in the Northern Board between the two years with all other Boards showing an increase in the percentage of patients in whom stage could not be determined.

Nottingham Prognostic Index (NPI)

The NPI is a clinically relevant prognostic index which is used to stratify breast cancer patients for adjuvant therapy[8]. 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 been validated both by single centres and internationally since then. It is a simple calculation based on tumour size, histological grade and number of lymph nodes positive.

NPI = 0.2 x Tumour size (cm) + tumour grade + nodal stage

[nodal stage] = 1 (if node negative), 2 (if 1-3 nodes positive), 3 (if 4 or more positive)

eg Tumour size = 2.0cm, grade 3, number involved nodes = 5

= 0.2 x 2.0 + 3 + 3

= 6.4 ie Poor prognosis

It stratifies patients into one of 3 prognostic groups with different chances of surviving breast cancer:

Good (<3.4), **Moderate** (3.4-5.4), **Poor** (>5.4)

Nottingham Prognostic Index (NPI) (recorded in notes or Registry-assigned)

(NOTE: It is only appropriate to calculate the NPI score for patients with operable breast cancer)

NPI Score	Number of Patients (%)	
	1996 *(n=677)*	2001 *(n=805)*
less than 3.4	215 (32%)	273 (34%)
3.4 – 5.4	249 (36%)	311 (38%)
5.4 or greater	86 (13%)	159 (20%)
Not Possible*	127 (19%)	62 (8%)

**** Allocation of a NPI score was not possible due to a lack of information recorded in the notes***

- By 2001, it was possible to assign an NPI score for 92% of patients who had breast surgery, compared with 81% in 1996.
- There were 61 patients in 1996 (8%) and 82 patients in 2001 (9%) who were not allocated either a TNM stage or a NPI score. The majority of these patients were over 70 years at the time of diagnosis (not shown).

Patients with insufficient data for an NPI score

Area of Residence	Number of Patients (%)	
	1996	2001
NHSSB	52 (41%)	32 (51%)
EHSSB	21 (17%)	13 (20%)
SHSSB	28 (22%)	12 (19%)
WHSSB	26 (20%)	6 (10%)
N.Ireland	127	62

Nodal Involvement

The British Association of Surgical Oncology Guidelines (BASO)[9] specifies that 4 axillary nodes should be sampled in breast cancer patients. The American Joint Committee on Cancer (AJCC)[10] – Cancer Staging Manual specifies that 6 axillary nodes should be sampled.

- By 2001, the percentage of patients having four or more nodes examined increased to 96% as did the proportion having six or more examined (95%). By 2001, one fifth of patients had 21 or more nodes examined.
- Examination of 4 or more nodes occurred in both years in all patients treated at the Cancer Centre and Cancer Units. In 2001, Coleraine, Daisy Hill, Erne, Lagan Valley, Mater, Tyrone County and Ulster hospitals and the Ulster Independent Clinic also examined 4 or more nodes in patients in keeping with the BASO guidelines[9].

Number of lymph nodes examined, surgery patients only

Nodes	Number of Patients (%)	
	1996 *(n=677)*	2001 *(n=805)*
None	63 (9%)	11 (1%)
1 - 3	37 (5%)	2 (<1%)
4 - 5	59 (9%)	8 (1%)
6 – 11	309 (46%)	180 (22%)
12 – 20	180 (27%)	427 (53%)
21 or more	26 (4%)	158 (20%)
Not recorded	3 (<1%)	19 (2%)

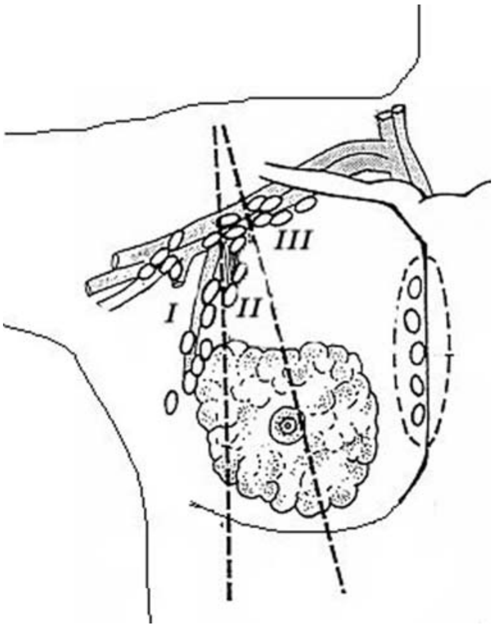
- By 2001, lymphadenectomy practice had improved with 73% of surgery patients having 12 or more nodes examined, more than twice that of 1996 (30%).
- Almost two thirds (65%) of surgery patients whose level of lymph node excision was not recorded were over 70 years at the time of diagnosis.

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 armpit), internal mammary (located along each side of breast bone) and supraclavicular (located above 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.

Level	Number of Patients (%)	
	1996 *(n=677)*	2001 *(n=805)*
I	135 (20%)	43 (5%)
II	311 (46%)	163 (20%)
III	108 (16%)	490 (61%)
Not recorded	123 (18%)	109 (14%)

- By 2001, 61% of patients had more extensive axillary surgery to level III nodes.



Multidisciplinary Team Meetings

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

Multidisciplinary team meetings recorded in the notes

MDM	Number of Patients (%)	
	1996 *(n=764)*	2001 *(n=881)*
Yes	30 (4%)	230 (26%)
No	734 (96%)	651 (74%)

- Recording in the clinical notes that discussion at a MDM had taken place improved from 4% in 1996 to 26% in 2001.

- In 1996, a record of MDMs having taken place was found in the clinical notes from 8 hospitals (Altnagelvin, Antrim, Belfast City, Craigavon, Coleraine, Downe, Royal Victoria and Ulster) and by 2001 this had improved with the notes from 5 additional hospitals (Armagh Community, Daisy Hill, Erne, Lagan Valley and Ulster Independent Clinic) containing evidence of MDMs taking place.

Surgical Procedures

Surgery includes mastectomy and the following breast conserving procedures; excision biopsy, partial mastectomy, quadrantectomy, segmental mastectomy, wide local excision, lumpectomy and other procedures not specified. These procedures may each also include axillary node clearance or sampling.

Number of operations by hospital

Board	Hospital	Number of operations	
		1996 *(n=677)*	2001 *(n=805)*
NHSSB	Antrim	81	107
	Coleraine	36	47
	Mid Ulster	8	0
	Whiteabbey	4	0
EHSSB	Royal Victoria	167	0
	Belfast City	46	193
	Ulster	82	148
	Lagan Valley	19	47
	Ulster Independent Clinic	11	26
	Ards	4	0
	Downe	9	0
	Mater	8	1
SHSSB	Craigavon	72	112
	Daisy Hill	34	11
	South Tyrone	2	0
WHSSB	Altnagelvin	65	85
	Erne	15	17
	Tyrone County	13	11
	North West Clinic	1	0

- In 1996, 677 surgical procedures were carried out in 19 hospitals, while in 2001, 805 procedures were performed in 12 hospitals.
- In the Northern Board, surgery was performed mainly in Antrim and Coleraine hospitals.
- For patients residing in the Eastern Board, fewer main hospitals performed surgery in 2001. Lagan Valley, the Ulster Hospital and the Ulster Independent Clinic each saw an increase in surgery, while by 2001 the breast cancer service had been transferred from the Royal Victoria Hospital to the Belfast City Hospital.
- Within the Southern Board there was a major shift from Daisy Hill Hospital to Craigavon Hospital.
- In the Western Board most operations took place in Altnagelvin Hospital in 1996 and 2001.

Centre Workload

- The major shift in service was from the Royal Victoria Hospital to the Belfast City Hospital. Also there were increases in workload in the Cancer Units.
- Workload increased in the following non-Cancer Units – Coleraine, Lagan Valley and Erne hospitals and the Ulster Independent Clinic.
- Only Antrim, Belfast City, Ulster and Craigavon hospitals undertook over 100 operations in 2001.

Where patients had their surgery

Board of Residence	Board of Operation					
	Year	NHSSB	EHSSB	SHSSB	WHSSB	Total patients
NHSSB	1996	128 (74%)	43 (25%)	1 (<1%)	0	172
	2001	149 (76%)	44 (22%)	2 (1%)	1 (<1%)	196
EHSSB	1996	2 (<1%)	280 (99%)	0	0	282
	2001	0	341 (99%)	1 (<1%)	0	342
SHSSB	1996	0	20 (16%)	107 (84%)	1 (<1%)	128
	2001	2 (1%)	26 (17%)	120 (79%)	4 (3%)	152
WHSSB	1996	0	2 (2%)	0	93 (98%)	95
	2001	3 (3%)	3 (3%)	1 (1%)	108 (93%)	115

- The majority of patients were operated on within their Health Board of residence in both years.

Surgery for breast cancer

Surgery	Number of Patients (%)	
	1996 *(n=677)*	2001 *(n=805)*
Mastectomy	301 (44%)	349 (43%)
Local excision	119 (18%)	68 (8%)
Partial mastectomy	33 (5%)	95 (12%)
Quadrantectomy	8 (1%)	42 (5%)
Wide local excision	195 (29%)	216 (27%)
Lumpectomy	17 (3%)	10 (1%)
Other	4 (<1%)	25 (3%)

- Between 1996 and 2001 there has been a 19% absolute increase in the number of patients undergoing breast surgery. Mastectomy rates have remained steady at about 40% of patients while breast conserving surgery has increased.
- About 10% of patients in each year (87 in 1996, 76 in 2001) did not have surgery.

- There was no significant variation in the proportion of mastectomies, wide local excisions and other procedures performed in each hospital (p>0.05) or in each of the four Board areas by 2001 (p>0.05).

Primary reconstruction (mastectomy and partial mastectomy patients)

Reconstruction	Number of Patients (%)	
	1996 *(n=334)*	2001 *(n=444)*
Yes	10 (3%)	41 (9%)
No	324 (97%)	403 (91%)

- There was a three fold increase in the number of women having a primary reconstruction between 1996 and 2001, yet only 9% of women had primary reconstruction by 2001.
- By 2001, primary reconstructions were performed in the Cancer Centre as well as Altnagelvin, Antrim, Ulster, Coleraine and Lagan Valley hospitals. Other women may have subsequently had a primary reconstruction but was not recorded in the notes at the time of data collection.

Treatment for breast cancer patients

Treatment	Number of Patients (%)	
	1996 *(n=764)*	2001 *(n=881)*
Surgery alone	10 (1%)	27 (3%)
Chemotherapy alone	0	1 (<1%)
Radiotherapy alone	0	1 (<1%)
Hormone therapy alone	45 (6%)	49 (6%)
Combination chemo & radio	1 (<1%)	3 (<1%)
Combination chemo & surgery	4 (<1%)	5 (<1%)
Combination radio & surgery	7 (1%)	28 (3%)
Combination hormone therapy and surgery	166 (22%)	114 (13%)
Combination hormone therapy and chemo	3 (<1%)	1 (<1%)
Combination hormone therapy and radio	8 (1%)	3 (<1%)
Combination chemo, radio & surgery	22 (3%)	93 (11%)
Combination surgery, hormone therapy & chemo	35 (5%)	39 (4%)
Combination surgery, hormone therapy & radio	273 (36%)	300 (34%)
Combination hormone therapy, chemo & radio	3 (<1%)	5 (<1%)
Combination surgery, hormone therapy, chemo & radio	184 (24%)	205 (23%)
None of the above treatments	2 (<1%)	6 (<1%)
Not recorded	1 (<1%)	1 (<1%)

chemo - chemotherapy, radio – radiotherapy

- Overall use of chemotherapy increased from 33% to 39%. This trend was also seen for radiotherapy (65% to 72% by 2001).
- By 2001, there was a small increase in the number of patients having combined modality therapy (eg. surgery and chemotherapy).
- Less than 1% of patients in both years did not have surgery, chemotherapy, radiotherapy or hormonal therapy, suggesting that the vast majority of patients underwent some form of curative or palliative treatment.
- Of those patients who did not receive any treatment regime, 100% in 1996 presented with stage IV disease and were over 80 years at the time of diagnosis. A third of patients in 2001 also presented with stage IV disease, a further two were over 80 years at diagnosis and the remainder declined treatment (not shown).

Oestrogen Receptor Status (ER Status)

Oestrogen Receptor Status is a good predictive factor for response to hormonal therapy such as Tamoxifen which improves disease and overall survival especially in postmenopausal women[11]. A pathology 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 can be used to block the receptor on the tumour cell and prevent the growth of the cancer. Tamoxifen is a standard adjuvant therapy for early stage breast cancer and is first line therapy for metastatic breast cancer.

ER status for patients tested

ER Status	Number of Patients (%)	
	1996 *(n=169)*	2001 *(n=795)*
Positive	43 (25%)	596 (75%)
Negative	126 (75%)	199 (25%)

- There was a marked increase in the number of patients who, by 2001, had an ER status recorded (90%).
- 75% of patients with ER status recorded were oestrogen receptor positive in 2001.

Tamoxifen prescription and ER status of patients

Year	Tamoxifen prescribed			
	ER Status	Yes	No	Total
1996	Positive	37 (86%)	6 (14%)	43
	Negative	114 (90%)	12 (10%)	126
	Not known	507 (85%)	88 (15%)	595
2001	Positive	558 (94%)	38 (6%)	596
	Negative	19 (10%)	180 (90%)	199
	Not known	34 (40%)	52 (60%)	86

See shaded boxes above for the most appropriate treatments

- There was an increase in ER positive patients who received Tamoxifen so that by 2001, 94% received this type of hormonal therapy.
- By 2001, the prescription of Tamoxifen was more targeted to ER positive patients who could benefit (see shaded boxes above).

Patients receiving hormonal therapy

Hormone drugs	Number of Patients (%)	
	1996 *(n=718)*	2001 *(n=716)*
Tamoxifen	695 (97%)	673 (94%)
Arimidex	3 (<1%)	25 (3%)
Trial drugs	17 (2%)	13 (2%)
Zoladex	2 (<1%)	0
Other	1 (<1%)	5 (<1%)

- Although the total number of patients receiving hormonal therapy was similar in both years, the percentage pf patients receiving it decreased from 94% in 1996 to 89% in 2001.

Frequency of breast cancer operations carried out by surgeon

Procedures	Number of Surgeons (% of procedures)	
	1996	2001
41 or more procedures	7 (61%)	9 (65%)
21 - 40 procedures	2 (10%)	5 (16%)
11 - 20 procedures	5 (10%)	6 (12%)
6 - 10 procedures	7 (8%)	3 (3%)
2 - 5 procedures	20 (9%)	7 (2%)
1 procedure	17 (2%)	14 (2%)
Total surgeons*	58	44
Consultant surgeons in charge	40	19
Total procedures	677	805

includes surgeons in training

- The number of surgeons in charge decreased by over half between 1996 and 2001 (40 to 19) reflecting increased specialisation.
- There was a reduction by a quarter in the number of surgeons, including surgeons in training, operating between 1996 and 2001 to 44.
- By 2001, 81% of breast surgery was performed by surgeons with high case volumes (21 or more procedures per year) reflecting increasing specialisation in breast cancer within the region, as recommended in the Campbell Report[1].
- About 2% of the surgery workload in each year was conducted by surgeons who only operated on one patient. Single operators performed operations which included excision biopsy and mastectomy.
- The largest number of operations performed by a single surgeon was 83 in 1996 and 82 in 2001.

Timelines/Waiting times

Timelines were examined for the following categories: all patients and for all patients aged under 60 years at the time of diagnosis.

Summary timeline for all patients

Time	Referral - First Seen at Hospital		First Seen - Diagnosis		Diagnosis - Surgery	
	1996 *(n=764)*	2001 *(n=881)*	1996 *(n=764)*	2001 *(n=881)*	1996 *(n=677)*	2001 *(n=805)*
Same day	98 (13%)	48 (5%)	395 (52%)	560 (64%)	149 (22%)	60 (7%)
1 – 14 days	404 (53%)	563 (64%)	215 (28%)	109 (12%)	332 (49%)	455 (57%)
15 – 42 days	74 (10%)	187 (21%)	74 (10%)	33 (4%)	144 (21%)	251 (31%)
43 – 84 days	11 (1%)	21 (2%)	30 (4%)	8 (<1%)	5 (1%)	6 (1%)
More than 84 days	8 (1%)	3 (<1%)	13 (2%)	10 (1%)	21 (3%)	17 (2%)
Minus values*	4 (<1%)	0	26 (3%)**	141 (16%)**	5 (1%)	15 (2%)
Not recorded	165 (22%)	59 (7%)	11 (1%)	20 (2%)	21 (3%)	1 (<1%)

Patient was either first seen at hospital before referral, diagnosed before first seen at hospital or had surgery prior to diagnosis. **The majority of these patients were referred from the Breast Screening Unit (BSU).

- Between 1996 and 2001 the percentage of patients seen within 2 weeks of referral increased slightly from 66% to 69% indicating an improvement.
- In 2001, two thirds of women had their diagnosis made on the day of their initial assessment, in compliance with the subgroup recommendations[2].
- The percentage of patients having surgery on the same day as diagnosis decreased from 22% in 1996 to 7% in 2001 indicating more pre surgery diagnosis.
- In 1996, 6% of patients had their diagnosis confirmed more than 6 weeks from presentation to hospital compared with 2% in 2001.

Summary timeline for all patients under 60 years

Time	Referral - First Seen at Hospital		First Seen - Diagnosis		Diagnosis - Surgery	
	1996 *(n=382)*	2001 *(n=451)*	1996 *(n=382)*	2001 *(n=451)*	1996 *(n=371)*	2001 *(n=444)*
Same day	43 (11%)	27 (6%)	186 (48%)	279 (62%)	82 (22%)	32 (7%)
1 – 14 days	202 (53%)	274 (61%)	108 (28%)	52 (12%)	189 (51%)	247 (56%)
15 – 42 days	40 (11%)	106 (24%)	36 (9%)	19 (4%)	83 (22%)	143 (32%)
43 – 84 days	5 (1%)	10 (2%)	21 (6%)	4 (<1%)	2 (<1%)	1 (<1%)
More than 84 days	4 (1%)	1 (<1%)	10 (3%)	4 (<1%)	7 (2%)	12 (3%)
Minus values*	0	0	14 (4%)	82 (18%)	2 (<1%)	8 (2%)
Not recorded	88 (23%)	33 (7%)	7 (2%)	11 (3%)	6 (2%)	1 (<1%)

**** Patient was either first seen at hospital before referral, diagnosed before first seen at hospital or had surgery prior to diagnosis***

Patients Under 60 Years

- About two thirds of patients under 60 years in both 1996 and 2001 were seen within two weeks of referral.
- About three quarters of patients in both years had their diagnosis confirmed within two weeks of presentation.
- Almost three quarters of patients in 1996 and almost two thirds in 2001 had surgery within two weeks of diagnosis.
- These results do not differ significantly from those for all patients.

Follow-Up Care Details This relates to information recorded in the discharge letter from hospital to GP.

After Care (Note: patients may have had more than one referral).

Aftercare	Number of Patients (%)	
	1996 *(n=764)*	2001 *(n=881)*
GP	239 (31%)	861 (98%)
Community nurse	169 (22%)	382 (43%)
Macmillan nurse	27 (4%)	25 (3%)
Hospice	28 (4%)	19 (2%)
Marie Curie nurse	10 (1%)	4 (<1%)
Palliative care specialist	14 (2%)	25 (3%)
Psychologist referral	12 (2%)	20 (2%)
Info on support groups/education supplied	68 (9%)	130 (15%)
Breast care nurse	75 (10%)	227 (26%)
Review plan	572 (75%)	826 (94%)
No onward referral recorded	22 (3%)	1 (<1%)

- By 2001, the provision of information on support groups had increased.
- Total referrals to Macmillan nurses, Hospices, Marie Curie nurses, Palliative care specialists and psychologists remained steady in both years.
- There was an increase in the number of patients for whom a review plan was in place, by 2001, 94% of patients had a review plan recorded in their notes.
- There was a three fold increase in referrals to breast care nurses reflecting increased availability of this service, yet only a quarter of patients had such a referral recorded by 2001.

Information recorded in notes

Information	Number of Patients (%)	
	1996 *(n=764)*	2001 *(n=881)*
Diagnosis discussed with patient	156 (20%)	842 (96%)
Treatment plan discussed with patient	159 (21%)	841 (95%)
Written information given	22 (3%)	324 (37%)
Consultation taped	0	2 (<1%)
Referred to oncology centre	534 (70%)	768 (87%)
Entered for clinical trial	29 (4%)	133 (15%)
Patients unaware of diagnosis	29 (4%)	17 (2%)

- By 2001, almost all patients had information on discussion of diagnosis and treatment plan recorded in the notes.
- The number of patients referred to an oncology centre increased from 70% to 87%.
- The provision of written information increased so that by 2001, over one third of patients were provided with information.
- Entry into clinical trials quadrupled so that 15% were enrolled by 2001.

Information in GP letter

Information	Number of Patients (%)	
	1996 *(n=764)*	2001 *(n=881)*
Diagnosis	696 (91%)	865 (98%)
Patient aware of diagnosis	405 (53%)	808 (92%)
Family aware of diagnosis	199 (26%)	403 (46%)
Diagnosis discussed with patient	529 (69%)	821 (93%)
Diagnosis discussed with family	232 (30%)	401 (46%)
Proposed systemic treatment including toxicity	78 (10%)	366 (42%)
Prognostic information	186 (24%)	352 (40%)

- Overall, information to the GP has greatly improved from 1996 to 2001 especially patient and family awareness of diagnosis.

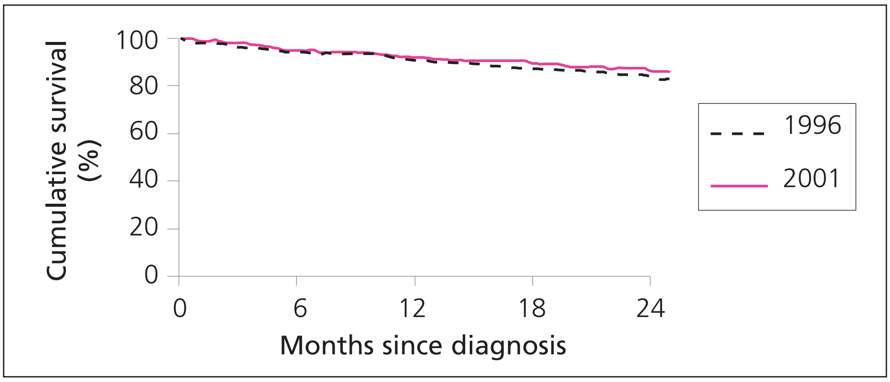
PATIENT OUTCOMES

Survival analysis was performed on patients diagnosed in 1996 and 2001 with subgroup analysis for surgery patients and for stage at diagnosis.

Percentage of patients alive at various times after diagnosis

Time	Surgery only patients		Non-surgery patients		All patients	
	1996	2001	1996	2001	1996	2001
30 days	99%	100%	87%	90%	98%	99%
60 days	99%	99%	81%	83%	97%	98%
6 months	97%	98%	69%	65%	94%	95%
1 year	95%	97%	62%	42%	91%	92%
2 years	90%	93%	44%	30%	85%	87%
Total patients	677	805	87	76	764	881

Breast cancer observed survival by year (all patients)

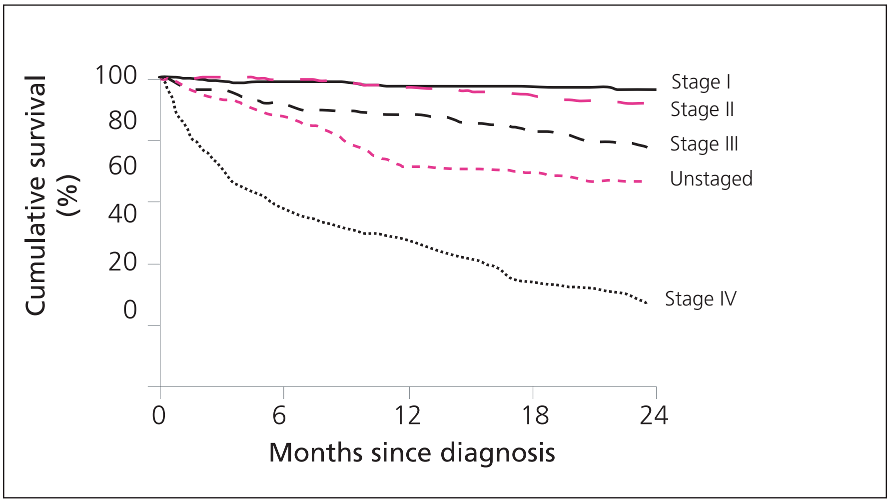


- Survival from breast cancer is good with observed two year survival at 87% for 2001 patients with no significant difference in the overall survival of patients in 1996 and 2001 ($p>0.05$). This is not unexpected as longer follow-up for a larger number of patients would be required to show survival differences.

Percentage of patients alive at various times after diagnosis by Stage of disease

Time	Stage I	Stage II	Stage III	Stage IV	Unstaged
30 days	100%	100%	97%	85%	97%
60 days	99%	100%	97%	75%	94%
6 months	99%	99%	92%	58%	88%
1 year	99%	97%	88%	44%	74%
2 years	97%	92%	77%	25%	65%
Total patients	559	701	121	97	167

Breast cancer observed survival for all patients by stage



- There was a very highly significant difference in the overall survival of patients by stage of disease (p<0.001), with 97% of Stage I patients alive at two years and as expected, stage IV disease patients having the poorest observed survival (25% at 2 years).
- There was no significant difference in observed survival for patients who presented with infiltrating ductal and infiltrating lobular carcinomas (p>0.05) (not shown).

"It's just over three years since my diagnosis . . .

. . . and I feel wonderful".

BREAST CANCER SUMMARY

PRESENTATION

- Patients presented to 22 hospitals in 1996 and 19 hospitals in 2001 (19 and 14 if single presentations are excluded).
- In 2001, 90% of patients presented to a Cancer Unit/Cancer Centre.
- Over two thirds of breast cancer cases in both years came from GP referrals.
- Referrals from the Breast Screening Unit increased so that by 2001, a fifth of cases were from that source.
- The majority of patients presented to hospitals within their own Health Board of residence.
- By 2001, patients were more likely to attend two or three hospitals for their treatment compared with 1996. The changes are due to increased numbers of patients attending Belvoir Park Hospital (N. Ireland Radiotherapy Centre) (135 in 1996 and 661 in 2001) and reflect increased referral for adjuvant radiotherapy and chemotherapy.
- While a quarter of patients had a positive family history of breast cancer, about 15% had a first degree relative with a history of breast cancer, a fifth had a personal history of benign breast disease and less than 1% had a personal history of breast cancer.
- There was evidence of earlier presentation of disease.
- The most common presenting symptom was a breast/axillary lump. The number of women presenting with this fell between 1996 and 2001. This was most marked among women eligible for screening and most likely reflects the increasing proportion of screen detected tumours.

INVESTIGATIONS AND STAGING

- Between 1996 and 2001 there was increased use of mammography, breast ultrasound and core biopsy with an associated shift away from excision biopsy. This is in keeping with current BASO guidelines[4] which recommended a triple assessment process (clinical examination, imaging and cytology).
- Between 1996 and 2001, the use of other imaging techniques to detect metastatic disease increased, most notably for isotope bone scanning and ultrasound of abdomen with smaller increases in chest X-ray and CT scanning.
- In both years, those over 80 years were significantly less likely to receive various investigations.
- A similar level of investigation was observed for surgery patients and all patients.
- It was possible to determine stage in approximately 90% of cases in both years but with slightly fewer patients staged in 2001.
- The percentage of patients for whom it was not possible to determine a stage decreased in the Northern Board between the two years with all other Boards showing an increase in the percentage of patients unstaged.
- Over three quarters of all surgery patients had a stage recorded in the notes by 2001.
- 8% of surgery patients in 1996 and 9% in 2001 were not allocated TNM or NPI score.
- By 2001, lymphadenectomy practice had improved with 73% of surgery patients having 12 or more nodes examined, more than twice that of 1996 (30%).
- By 2001, 61% of patients had more extensive axillary surgery to level III nodes.

HISTOLOGY

- All cases of breast cancer had a histological/cytological diagnosis in both years.
- As expected the majority of breast cancers in both years were infiltrating ductal carcinomas.

RECORDING OF MULTIDISCIPLINARY TEAM MEETINGS

- Recording in the clinical notes that discussion at a MDM had taken place improved from 4% in 1996 to 26% in 2001.

SURGERY AND ONCOLOGY

- In 1996, 677 surgical procedures were carried out in 19 hospitals, while in 2001, 805 operations were performed in 12 hospitals.
- The number of surgeons in charge decreased by over half between 1996 and 2001 (40 to 19) reflecting increased specialisation.
- There was a reduction by a quarter in the number of surgeons, including surgeons in training, operating between 1996 and 2001 to 44.
- In the Northern Board, surgery was performed mainly in Antrim and Coleraine hospitals.
- For patients residing in the Eastern Board, fewer main hospitals performed surgery in 2001. Lagan Valley, the Ulster Hospital and the Ulster Independent Clinic all saw an increase in surgery, while by 2001 breast cancer services had been transferred from the Royal Victoria Hospital to the Belfast City Hospital.
- Within the Southern Board there was a major shift in services from Daisy Hill Hospital to Craigavon Hospital.
- In the Western Board most operations took place in Altnagelvin Hospital in 1996 and 2001.
- By 2001, 81% of breast surgery was performed by surgeons with high case volumes (21 or more procedures per year) reflecting increasing specilisation in breast cancer within the region, as recommended in the Campbell Report[1].
- The largest number of operations performed by a single surgeon was 83 in 1996 and 82 in 2001.
- About 2% of the surgery workload in each year was conducted by surgeons who only operated on one patient.
- Only Antrim, Belfast City, Ulster and Craigavon hospitals undertook over 100 operations in 2001.
- Between 1996 and 2001 there has been a 19% absolute increase in the number of patients undergoing breast surgery. Mastectomy rates have remained steady at about 40% of patients while breast conserving surgery has increased.
- About 10% of patients in each year (87 in 1996, 76 in 2001) did not have surgery.
- By 2001, there was a small increase in the number of patients having combined modality therapy (eg. surgery and chemotherapy).
- Less than 1% of patients in both years did not have surgery, chemotherapy, radiotherapy or hormonal therapy suggesting that the vast majority of patients underwent some form of curative or palliative treatment.
- Overall use of chemotherapy increased from 33% to 39%. This trend was also seen for radiotherapy (65% to 72% by 2001).
- There was a three fold increase in the number of women having a primary reconstruction between 1996 and 2001, yet only 9% of women had primary reconstruction by 2001.

- Although the total number of patients receiving hormonal therapy was similar in both years, the percentage of patients receiving it decreased from 94% in 1996 to 81% in 2001.
- By 2001, the prescription of Tamoxifen was more targeted to ER positive patients who could benefit.

TIMELINES/WAITING TIMES

- Between 1996 and 2001 the percentage of patients seen within two weeks of referral increased slightly from 66% to 69% indicating an improvement.
- In 2001, two thirds of women had their diagnosis made on the same day of their initial assessment, in compliance with the subgroup recommendations[2].
- The percentage of patients having surgery on the same day as diagnosis decreased from 22% in 1996 to 7% in 2001 indicating more pre surgery diagnosis.
- In 1996, 6% of patients had their diagnosis confirmed more than 6 weeks from presentation to hospital compared with 2% in 2001.

ONWARD REFERRAL

- By 2001, the provision of information on support groups had increased.
- Total referrals to Macmillan nurses, Hospices, Marie Curie nurses, Palliative care specialists and psychologists remained steady in both years.
- There was an increase in the number of patients for whom a review plan was in place, by 2001, 94% of patients had a review plan recorded in their notes.
- There was a three fold increase in referrals to breast care nurses reflecting increased availability of this service, yet only a quarter of patients had such a referral recorded by 2001.

COMMUNICATION

- By 2001, almost all patients had discussion of diagnosis and treatment plan recorded in the notes.
- The number of patients referred to an oncology centre increased from 70% to 87%.
- The provision of written information increased so that by 2001, over one third of patients were provided with information.
- Entry into clinical trials quadrupled so that 15% were enrolled by 2001.
- Overall, information to the GP had greatly improved from 1996 to 2001 especially patient and family awareness of diagnosis.

OUTCOMES

- Survival from breast cancer is good with observed two year survival at 87% for 2001 patients with no significant difference in the overall survival of patients in 1996 and 2001 ($p>0.05$). This is not unexpected as longer follow-up for a larger number of patients would be required to show survival differences.
- There was a very highly significant difference in the overall survival of patients by stage of disease ($p<0.001$), with 97% of Stage I patients alive at two years and as expected, stage IV disease patients having the poorest observation survival (25% at 2 years).

CONCLUSION AND KEY ISSUES

By 2001, the following improvements were apparent:

- The process of specialisation of breast cancer surgery had progressed well.
- Waiting times were reduced.
- Recording of MDM discussion had improved but further improvement is necessary in this area.
- Staging practices had improved.
- Better use of diagnostic tools, e.g. ER status has resulted in better targeting of treatment.
- Improved communications with patients and primary care was evident.
- Clinical trials recruitment had improved.

Key Issues

- There was evidence of earlier disease presentation yet about one in twelve of patients had symptoms for over one year. This points to the need to continue to raise awareness of symptoms among the population.
- There is a need to improve recording of stage related information.
- The recording of multidisciplinary team meetings needs to be improved. This will need additional resources.
- Although much change has happened, the process of centralisation of breast cancer services, by 2001, was not fully complete. Further work needs to be done on this.

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GLOSSARY

Aetiology -

The study of the causes or origins of disease.

Observed survival -

The probability that a group of patients with a given disease will be alive at specified time-point after diagnosis, irrespective of the cause of death.

Relative survival -

Observed survival is always likely to be lower in older patients because they are at greater risk of dying from other causes. Relative survival attempts to overcome this by calculating survival as the ratio of the observed survival divided by the survival that the patients would have experienced if they had the same probability of dying as the general population of the same age and sex.

APPENDIX A

Campbell Report[1]: Recommendations regarding Cancer Services in N. Ireland, 1996

1. The management of patients with cancer should be undertaken by appropriately trained, organ and disease specific medical specialists.
2. All patients with cancer should be managed by multidisciplinary, multiprofessional specialist cancer teams.
3. A Cancer Forum should be established involving all key interests in the delivery of cancer services.
4. Cancer Units should, in conjunction with local GPs and other providers, develop an effective communication strategy.
5. N. 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.

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

APPENDIX B

NHS Improving Outcomes in Breast Cancer[3]: Key Recommendations

- Patients with breast cancer should be managed by multi-disciplinary specialist breast care teams. These are likely to be most effective and cost-effective when dealing with a throughput of at least 100 new breast cancer patients per annum. They should work within written guidelines promoting the use of treatments such as adjuvant therapies, the effectiveness of which have been demonstrated by research.
- The breast care team should develop and implement a policy to ensure that good verbal and written information is given to patients. This policy should be backed up by protocols which will ensure that suitable information is provided. Key personnel should have training in communication skills.
- The diagnosis of primary disease should normally be carried out using "triple assessment" for each new patient at a single visit. This will increase the accuracy and reduce the cost of diagnosis, and decrease anxiety resulting from delay.
- In view of the lack of evidence of benefit from routine follow-up (other than mammography), purchasers and providers should critically review arrangements in order to reduce the intensity and frequency of routine follow-up after primary treatment of breast cancer and benign breast disease. Before present arrangements are changed, however, a locally agreed pattern must be established which ensures that patients are prepared for transition from treatment by the unit and that they have speedy access to advice if required. This will release resources without compromising outcomes, and specialists will be able to concentrate on those who are more likely to benefit from their attention.
- Purchasers should monitor long-term outcomes. This requires both routine audit and the basic infrastructure for collection of data concerning patients, their disease, treatment and outcomes, and systematic reporting and recording of pathology data. This basic infrastructure already exists in the form of cancer registries across the UK, but specific data collection and analysis may need further development. This information should be sufficiently detailed to allow cancer to be staged at an individual level and for case-mix to be recorded at a population level by cancer registries.

Recommendations in specific topic areas:

1 PATIENT-CENTRED CARE

- There should be minimal delay between the referral from the GP and an outpatient appointment, and between the first consultation and communication of the diagnosis to the patient.
- At every stage, patients should be offered clear, objective, full and prompt information in both verbal and written form. They should be offered well-produced information leaflets which are both accurate and comprehensible, and guidance from a member of the breast care team when required.
- 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.
- Providers must be sensitive to potential problems with communication. Members of the breast care team – particularly those providing direct clinical care should have special training in communication and counselling skills.
- Psychosocial support should be available at every stage to help patients and their families cope with the effects of the disease. Social support should be available and there should be close liaison with local social services.

2 RAPID AND ACCURATE DIAGNOSTIC SERVICES

- Diagnostic services must be able to provide rapid and accurate information on imaging results and tissue samples.
- Triple assessment should be available for women with suspected breast cancer at a single visit. The results of tests should be given to patients within five working days.
- A breast care nurse should be available for support and counselling.
- Surgery biopsy is appropriate when triple assessment does not give a definitive result.
- After surgery, the pathologist should give detailed reports on excised cancers which include information on tumour type, pathological site, histological grade, oestrogen receptor status, 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.
- Following primary treatment, regular mammography should be available.
- Radiography facilities and imaging should be subject to the same quality assurance criteria as the NHS Breast Screening Programme.

3 SURGERY

- A range of primary operations should be available. If the cancer is not too large or diffuse, surgical options include mastectomy and breast conserving surgery. 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. Breast reconstruction should be discussed with patients who are to undergo mastectomy.
- Surgical treatment should not be offered or withheld on the grounds of age alone.
- 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.
- The axilla should normally be staged by sampling at least four nodes or by clearance. The possible adverse effects and anticipated benefits of axillary sampling or clearance should be discussed with patients.
- 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; women should be given the opportunity to talk over their feelings and fears with an experienced breast care nurse.

4 RADIOTHERAPY

- A high quality radiotherapy service should be available for all patients.
- 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.
- 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.
- The radiotherapy service should conform with guidelines in Quality Assurance in Radiotherapy.

5 SYSTEMIC THERAPY

- 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.
- The choice of systemic therapy for individual women should be guided by protocols 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.
- 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. Chemotherapy should be given in a designated day case area.
- 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 protocols on the management of complications and toxicities.
- Immunotherapy should not be offered to breast cancer patients except possibly in the context of a well-conducted clinical trial.

6 PATIENT FOLLOW-UP

- 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 now be offered by the breast unit as a matter of routine.
- Regular mammography is important to detect local recurrence or a second primary in the other breast.
- Locally agreed measures should be developed to support the woman's transition from treatment by the unit. Each woman should have a contact number for her breast care nurse and should be aware of other ways of accessing the specialist breast care team.
- GPs should be involved in shaping local arrangements for follow-up whenever routine breast unit follow-up is to be discontinued or reduced in scale.

7 PALLIATIVE CARE

- Although palliative care is particularly important in the later stages of illness, 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.
- All patients and health care professionals should have access to specialists in palliative care.
- 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. 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.
- 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/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. The team should have ready access to – Physiotherapy, Occupational therapy and Counselling for both patients and relatives/carers.

- All members of the palliative care team should participate in regular meetings to discuss patient care.
- 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.
- Patients should be helped to remain in the place they prefer, whether this is their home, a nursing home or hospice, and should choose where they wish to die.

8 THE BREAST CARE TEAM

- 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.
- The core breast team should include designated breast surgeons, breast care nurses, a pathologist, a radiologist and an oncologist.
- 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 (GPs, palliative care specialist, breast radiographer, social worker, plastic surgeon, clinical geneticist and physiotherapist).
- The core team should work closely together and meet on a regular basis 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.
- The team must have adequate support to ensure that all decisions are recorded and communicated to patients and all those outside the core team.
- The team should allocate time to audit the activities and outcomes of the unit.

9 INTERPROFESSIONAL COMMUNICATION

- 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. 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.
- There should be sufficient administrative support, and the Unit should be equipped with up-to-date facilities to aid communication.
- 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.

10 CLINICAL GUIDELINES, UP-TO-DATE PRACTICE AND CONTINUING PROFESSIONAL DEVELOPMENT

- 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.
- 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.
- Providers should be alert to new information and should use it to update protocols and guidelines. They should have access to databases of high quality systemic reviews.

- 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 fulfil their role in these areas.

11 ENVIRONMENT AND FACILITIES

- 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. 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, which are important to patients.
- Hospitals may wish to set up breast care clinics and wards in such a way that early breast cancer patients are separated from women with advanced disease, in order to be sensitive to the feelings of the two groups of patients.
- Single-sex wards or bays should be available.
- 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.

There is more information on anticipated benefits, evidence, measurement and resource implications for each of the above sections which are available on the web at
www.nice.org.uk/pdf/Breast_Cancer_researchevidence.pdf

APPENDIX C

Recommendations from the British Association of Surgical Oncologists (BASO) Guidelines for Surgeons in the Management of Symptomatic Breast Disease in the United Kingdom[4].

1 BREAST CARE TEAM

- The unit should be seeing at least 50 new breast cancer cases per year.
- A formal multidisciplinary meeting attended by members of the breast care team involved in primary treatments should be held weekly.

2 COMMUNICATION

- All patients diagnosed with breast cancer should have access to a breast care nurse, preferably pre-operatively.

3 REFERRAL

- Women should be referred to a trained surgeon who works within a multidisciplinary breast clinic.
- 80% of urgent referrals (as deemed by the surgeon) are to be seen within 5 working days of receipt of the referral.
- 70% of all other new referrals 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).

4 DIAGNOSIS

- Over 90% of Fine Needle Aspirations from lesions which subsequently prove to be a cancer should be adequate as deemed by the breast pathologist.
- 90% of palpable breast cancers should be diagnosed pre-operatively. Less than 10% of primary operable breast cancers should receive a frozen section.
- 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.
- Diagnosis should be based on triple assessment (Examination, Ultrasound/Mammography, Cytology).
- 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.

5 SURGERY

- This should be carried out by trained breast surgeons, trainees with sufficient training in breast disease or trainees under direct supervision at operation.
- Units should provide data on the number of patients treated, and by what methods.
- 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.

- 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).
- Less than 10% of patients undergoing treatment for primary operable breast cancer should develop local recurrence at 5 and 10 years.

6 RADIOLOGY

- 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.
- Mammographic localisation biopsy specimens must be X-rayed to ensure removal of the abnormality.

7 RADIOTHERAPY

- Adjuvant radiotherapy should start within 4 weeks of surgery.

8 PATIENT FOLLOW-UP

- GP 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.
- Survival and loco-regional recurrences at 5 and 10 years should be monitored.

9 PALLIATIVE CARE

- Centres offering breast cancer treatment should ensure that there are adequate terminal care facilities to support the primary care team.

A full list of the guidelines can be found in the European Journal of Surgical Oncology 1998; 24(6): 464-76.

APPENDIX D

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)[7] is shown in Table 1.

DETERMINING THE TUMOUR SIZE (T) FACTOR

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[12].

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 inapparent 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 tumour within one breast the size of the largest tumour should be used to determine the T factor.

DETERMINING THE (N) FACTOR

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 clinically apparent.

DETERMINING THE (M) FACTOR

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.

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.

Table 1 TNM classification of breast cancer[7]

		Tumour
T0	T0	No evidence of primary tumour
T1	T1mic	tumour size ≤0.1cm (microinvasive)
	T1a	tumour size >0.1cm ≤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 innapparent 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

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:

- 2cm invasive breast tumour, therefore T = T1c
- 8 axillary nodes have histologically verified metastases and is therefore N2a
- clinically/radiologically there is no evidence of distant metastases and is therefore M0

TNM profile is pT1c pN2a M0 (p = determined pathologically, c = clinically determined)

This TNM profile is 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. (T2N2M0, T3N1M0 & T3N2M0).

Table 2 Stage Group Breast Cancer

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

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