

# Breast Cancer Clinical Outcome Measures (BCCOM) Project

Analysis of the management of symptomatic breast cancers diagnosed in 2004

3rd Year Report December 2007



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S Nicholson  
JR Parmar  
CJ Pritchett  
EP Turton  
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#### Northern Ireland

AM Carragher  
D Gilpin  
SJ Kirk  
RAJ Spence  
WJ Stirling  
A Wilkinson

#### East Anglia & Thames

TI Abdullah  
M Allan  
T Archer  
T Bates  
JR Benson  
HA Bradpiece  
AJ Desai  
EJ Duggan  
SR Ebbs  
I Fentiman  
P Forouhi  
OJA Gilmore  
PG Gough  
G Gui  
H Hamed  
ER Inwang  
AK Johri  
GT Layer  
F MacNeill  
CJ Mortimer  
MR Pittam  
AD Purushotham  
G Querci della Rovere  
D Ravichandran  
ND Rothnie  
AR Salman  
P Sauven  
E Shah  
E Sharp

KK Thakur  
S Whitehead  
G Wishart  
A Yelland  
C Zammit

#### South West

NJ Carty  
S Cawthorn  
C Chan  
R Daoud  
PK Donnelly  
C Fowler  
M Galea  
M Graham  
JW Groome  
RG Hughes  
AM Klidjian  
PR Maddox  
FP McGinn  
MH Niayesh  
A Paterson  
D Perry  
I Ramus  
Z Rayter  
AK Sahu  
A Sammon  
Al Skene  
D Snyders  
RJ Sutton  
JM Symes  
H Umpleby  
R Watkins  
M Wise

#### North Western

R Audisio  
L Barr  
HM Bishop  
J Bonnema  
TAJ Calvey  
L Chagla  
GP Copeland  
P George  
C Harding-MacKean  
C Holcombe  
S Jmor  
DM Matheson  
IH McIntosh  
S Poonawalla  
E Redmond  
C Roshanlall  
ZA Saidan  
F Swe  
JC Tresadern  
J Winstanley

#### Trent

D Chadwick  
KL Cheung  
O Eremin  
NW Everson  
HW Holliday  
S Holt  
NH Kazzazi  
KM Kolar  
JV Psaila  
M Sibbering  
A Rashed

A Stotter  
K Valassiadou  
Y Wahedna  
R Windle

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K Abdul-Wahab  
PJ Clarke  
SP Courtney  
GH Cunnick  
MN Dehalvi  
CL Griffiths  
J Harisha  
SE Knight  
MD Rashed  
RG Souter  
RD Stewart  
HN Umeh

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RA Cochrane  
DJ Crawford  
AZ Demian  
CA Gateley  
S Goyal  
PA Holland  
S Holt  
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M Lwin  
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I Monypenny  
SG Shering  
HM Sweetland  
E Vaughan-Williams  
R Visvanathan  
RJL Williams

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J Adjogate  
PR Armitstead  
A Aukland  
R Blunt  
P Brookes  
JH Brown  
R Brown  
TE Bucknall  
A Carmichael  
AP Corder  
J Donnelly  
T Duffy  
DJ Ellis  
DW England  
JWL Fielding  
A Francis  
R Gendy  
MT Hallissey  
M Heitmann  
C Hinton  
F Hoar  
R Hurlow  
B Isgar  
A Jewkes  
B Jones  
RM Kirby  
P Matey  
R Nangalia  
SJ Parker

I Paterson  
A Przyczyna  
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S Sivapragasam  
G Sterne  
PS Stonelake  
T Usman  
L Vishwanath

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F Ashkanani  
M Barber  
D Brown  
S Chaturvedi  
U Chetty  
IR Daltrey  
JM Dixon  
JC Doughty  
P Fisher  
N Harris  
SD Heys  
AK Lannigan  
M McKirby  
RWG Murdoch  
D Murphy  
GT Neades  
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JB Rainey  
I Reid  
J Richards  
RJ Salem  
CJ Simpson  
D Smith  
AM Thompson  
W Thomson  
PV Walsh  
P Whitford  
C Wilson

### Hospitals

Aberdeen Royal Infirmary

Addenbrooke's Hospital

Airedale General Hospital

Altnagelvin Area Hospital

Antrim Area Hospital

Arrowe Park Hospital

Ashford Hospital

Ayr Hospital

Basingstoke and North Hampshire Hospital

Bassetlaw District General Hospital

Belfast City Hospital

Birmingham Heartlands Hospital

Bishop Auckland General Hospital

Borders General Hospital

Bradford Royal Infirmary

Breast Screening Centre

Bridgeway's Day Hospital Bromley

Bridlington and District Hospital

Brighton General Hospital

Bristol Royal Infirmary

Bronglais General Hospital

Broomfield Hospital

Buckland Hospital

Burnley General Hospital

Caerphilly District Miners Hospital

Caithness General Hospital

Calderdale Royal Hospital

Capio Ashtead Hospital

Capio Renacres Hall Hospital

Capio Rowley Hall Hospital

Capio West Midlands Hospital

Castle Hill Hospital

Causeway Hospital

Central Middlesex Hospital

Chapel Allerton Hospital

Charing Cross Hospital

Cheltenham General Hospital

Chesterfield Royal Hospital

Chorley & South Ribble District General Hospital

Christie Hospital

Churchill Hospital

City Hospital Birmingham

City Hospital Stoke

Classic Hospitals Lourdes

Clatterbridge Hospital

Cobham Clinic

Colchester General Hospital

Conquest Hospital

Conwy & Denbighshire NHS Trust

Cookridge Hospital

Countess of Chester Hospital

County Hospital Hereford

Craigavon Area Hospital

Cromwell Hospital

Crosshouse Hospital

Cumberland Infirmary

Daisy Hill Hospital

Darlington Memorial Hospital

Derby City General Hospital

Derbyshire Royal Infirmary

Derriford Hospital

Doncaster Royal Infirmary

Dorset County Hospital

Dr Gray's Hospital

Dumfries & Galloway Royal Infirmary

Ealing Hospital

Eastbourne District General Hospital

Elizabeth Garrett Anderson Hospital

Epsom General Hospital

Essex County Hospital

Fairfield General Hospital

|                                      |   |   |  |  |  |
|--------------------------------------|---|---|--|--|--|
| Fairwood Hospital                    | Leicester General Hospital              | Nuffield Hospital Hereford Wye Valley     | Royal Alexandra Hospital Paisley             | Spire Parkway Hospital                       | University Hospital Lewisham                                     |
| Falkirk and District Royal Infirmary | Leicester Royal Infirmary               | Nuffield Hospital Warwick                 | Royal Berkshire Hospital                     | Springfield University Hospital              | University Hospital of Coventry and Warwickshire                 |
| Frenchay Hospital                    | Lincoln County Hospital                 | Oldchurch Hospital Romford                | Royal Blackburn Hospital                     | St Anthony's Hospital                        | University Hospital of Hartlepool                                |
| Frimley Park Hospital                | Lister Hospital London                  | Ormskirk & District General Hospital      | Royal Bolton Hospital                        | St Bartholomew's Hospital London             | University Hospital of North Durham                              |
| Gartnavel General Hospital           | Lister Hospital Stevenage               | Parkside Hospital London                  | Royal Bournemouth Hospital                   | St George's Hospital London                  | University Hospital of North Staffordshire                       |
| George Eliot Hospital                | Liverpool Women's Hospital              | Perth Royal Infirmary                     | Royal Cornwall Hospital                      | St James's University Hospital               | University Hospital of North Staffordshire City General Hospital |
| Glan Clwyd Hospital                  | Llandough Hospital                      | Peterborough District Hospital            | Royal Devon and Exeter Hospital              | St John's Hospital at Howden                 | University Hospital of North Staffordshire Royal Infirmary       |
| Glasgow Royal Infirmary              | London Bridge Hospital                  | Pilgrim Hospital                          | Royal Glamorgan Hospital                     | St Luke's Hospital Bradford                  | University Hospital of North Tees                                |
| Glasgow Royal Infirmary              |   | Pinderfields General Hospital             | Royal Gwent Hospital                         | St Mary's Hospital Newport                   | University Hospital of Wales                                     |
| Glenfield Hospital                   | Luton & Dunstable Hospital              | Pontefract General Infirmary              | Royal Hallamshire Hospital                   | St Mary's Hospital Paddington                | Velindre Hospital  |
| Gloucestershire Royal Hospital       | Lydney & District Hospital              | Poole General Hospital                    | Royal Hospital Haslar                        | St Mary's Hospital Portsmouth                | Victoria Infirmary Glasgow                                       |
| Good Hope Hospital                   | Macclesfield District General Hospital  | Preston Hall Hospital                     | Royal Lancaster Infirmary                    | St Michael's Hospital                        | Walton Hospital Liverpool  |
| Great Western Hospital               | Manor Hospital Walsall                  | Prince Philip Hospital                    | Royal Liverpool University Hospital          | St Peter's Hospital Chertsey                 | Wansbeck General Hospital  |
| Guy's Hospital                       | Mayday University Hospital              | Princess Alexandra Hospital               | Royal Marsden Hospital Fulham                | St Thomas' Hospital                          | Warrington Hospital  |
| Gwynedd Hospital                     | Medway Maritime Hospital                | Princess Elizabeth Hospital               | Royal Marsden Hospital Sutton                | St.Cross Hospital Rugby                      | Warwick Hospital   |
| Hairmyres Hospital                   | Milton Keynes General Hospital          | Princess of Wales Hospital Bridgend       | Royal Preston Hospital                       | Staffordshire General Hospital               | West Cornwall Hospital   |
| Halton General Hospital              | Monklands Hospital                      | Princess Royal Hospital Haywards Heath    | Royal Shrewsbury Hospital                    | Stoke Mandeville Hospital                    | West Cumberland Hospital   |
| Harrogate District Hospital          | Montagu Hospital Mexborough             | Princess Royal Hospital Telford           | Royal South Hants Hospital                   | Sunderland Royal Hospital                    | West Suffolk Hospital  |
| Heatherwood Hospital                 | Musgrove Park Hospital                  | Princess Royal University Hospital        | Royal Surrey County Hospital                 | The Alexandra Hospital                       | West Wales General Hospital                                      |
| Hexham General Hospital              | Neath Port Talbot Hospital              | Queen Alexandra Hospital                  | Royal Sussex County Hospital                 | The Horton Hospital                          | Western General Hospital   |
| Hinchingbrooke Hospital              | New Cross Hospital                      | Queen Elizabeth Hospital Gateshead        | Royal United Hospital Bath                   | The Portland Hospital for Women and Children | Western Isles Hospital   |
| Holly House Hospital                 | Newcastle General Hospital              | Queen Elizabeth Hospital King's Lynn      | Royal Victoria Hospital Belfast              | The Princess Grace Hospital                  | Westmorland General Hospital                                     |
| Hope Hospital                        | Nightingale Macmillan Unit              | Queen Elizabeth Hospital London           | Royal Victoria Infirmary                     | The Princess Royal Hospital Hull             | Weston General Hospital  |
| Huddersfield Royal Infirmary         | Ninewells Hospital                      | Queen Elizabeth Medical Centre Birmingham | Russells Hall Hospital                       | The Royal Marsden NHS Foundation Trust       | Wexham Park Hospital   |
| Hull Royal Infirmary                 | Nobles Hospital                         | Queen Elizabeth The Queen Mother Hospital | Salisbury District Hospital                  | The Royal Oldham Hospital                    | Wharfedale General Hospital                                      |
| Ipswich Hospital                     | Norfolk and Norwich University Hospital | Queen Margaret Hospital Dunfermline       | Sandwell General Hospital                    | The Ulster Hospital                          | Whiston Hospital   |
| James Cook University Hospital       | North Devon District Hospital           | Queen Mary's Hospital Roehampton          | Scarborough General Hospital                 | Torbay Hospital                              | Whittington Hospital   |
| James Paget Hospital                 | North Middlesex University Hospital     | Queen Mary's Hospital Sidcup              | Shotley Bridge Hospital                      | UK Private/Independent Hospitals             | William Harvey Hospital  |
| Jarvis Breast Screening Centre       | North Tyneside General Hospital         | Queen's Hospital Romford                  | Singleton Hospital                           | Ulster Independent Clinic                    | Wishaw General Hospital  |
| John Radcliffe Hospital              | North West Wales NHS Trust              | Raigmore Hospital                         | Solihull Hospital                            | University College London Hospitals          | Worcestershire Royal Hospital                                    |
| Kent and Canterbury Hospital         | Norhampton General Hospital             | Rochdale Infirmary                        | South Tyneside District Hospital             | University Hospital Aintree                  | Wordsley Hospital  |
| Kent and Sussex Hospital             | Northern General Hospital               | Royal Albert Edward Infirmary             | Southampton General Hospital                 | University Hospital Birmingham Selly Oak     | Worthing Hospital  |
| Kettering General Hospital           | Northwick Park Hospital                 |   | Southeast University Hospital                | University Hospital Coventry Walsgrave site  | Wrexham Maelor Hospital  |
| Kidderminster Hospital               | Nottingham City Hospital                |   | Southmead Hospital                           |  | Wycombe Hospital   |
| King Edward VII Hospital Windsor     | Nuffield Hospital Haywards Heath        |   | Southport & Formby District General Hospital |  | Wythenshawe Hospital   |
| King's College Hospital              |   |   |  |  | Yeovil District Hospital   |
| Kingston Hospital                    |   |   |  |  | York Hospital  |
| Lagan Valley Hospital                |   |   |  |  |  |
| Lawson Memorial Hospital             |   |   |  |  |  |
| Leeds General Infirmary              |   |   |  |  |  |



Mr Ian Monypenny  
BCCOM Steering Group Chair  
Consultant Breast Surgeon,  
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**It is my great pleasure to welcome you to the second Annual Report of the BCCOM Project. The report provides information primarily on the management of breast cancers diagnosed in 2004 across the UK, but also includes an analysis of the 47,266 cases submitted during the first three years of the Project.**

Year 3 of the BCCOM Project has been a resounding success with participation from all 11 UK cancer registries. Participation by surgeons has been increasing steadily, with the majority of those who participated in Years 1 and 2 continuing to do so and new surgeons joining the Project in Year 3. This is something that the BCCOM Steering Group welcomes, and we would encourage all surgeons who are not currently part of this exciting Project to contact us to find out more about the audit and hopefully to start to participate. During Year 3 we have also noted increased participation by cancer networks, with many badging the BCCOM Project as their network audit for breast cancer. We would encourage all participants to raise this as a possibility with their local cancer networks. Additionally, we have seen more involvement in the Project by non-surgeons, particularly data managers, audit managers and in some units breast care nurses. It is encouraging that the audit is being viewed as more multi-disciplinary and, as such, that the data reflect not only the work of the individual surgeons but more the collective efforts of the multi-disciplinary team.

When working with clinical data, the requirements of data protection and confidentiality are paramount. In order to continue to safeguard these important areas, the BCCOM Project has reviewed the process for consent by participating surgeons and the issuing of data to participants for checking. Surgeons eligible to participate were sent consent forms to allow the release of their data by the relevant cancer registry. This consent will cover surgeons for the length of the Project.

Under a specifically designed service level agreement, data for all breast cancers diagnosed in 2004 were sent by 11 cancer registries (including the WMCIU) to the BCCOM team at the West Midlands Cancer Intelligence Unit (WMCIU). The team then disseminated the data to participating surgeons on behalf of nine cancer registries, while two registries sent out their own data. This allowed the team at the WMCIU to control the timeliness of the bulk of the data transfer to the participating surgeons, to agree extensions where appropriate and also to record those surgeons who received their data but did not either request their password or return their data. The Association of Breast Surgery (ABS) at the British Society of Surgical Oncology (BASO) regional symptomatic representatives were asked to encourage participation across their own region and to persuade any reticent participants. In regions where these members were actively engaged in encouraging their colleagues to participate, their efforts made a significant difference, for which the BCCOM Steering Group is very grateful.

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The BCCOM Project is solely interested in symptomatic cases and as such aims to remove screen-detected cases prior to the data being issued to surgeons. At the start of the Project not all registries were in a position to distinguish between screen-detected and symptomatic breast cancers and the number of symptomatic breast cancers in each region was inflated, by varying degrees, through the inclusion of screen-detected cases. The recent inclusion of a requirement in the new cancer registry peer review measures to have in place mechanisms for registries to obtain the details of screen-detected breast cancers from breast screening QA reference centers has greatly improved the situation, and it is hoped that this good practice will continue.

The BCCOM Steering Group has endeavored to keep contributors to the BCCOM Project up to date on progress and emerging results. A new venture has been the publication of BCCOM newsletters, the first of which was funded by ABS at BASO. We hope that you find these of use and, if any of your colleagues wish to be on our mailing list, please do not hesitate to contact us. Additionally, we have had the pleasure of presenting BCCOM data at a number of conferences, most recently the ABS at BASO Annual Conference (May 2007) and the Nottingham International Breast Cancer Conference (September 2007). If you would like a member of the BCCOM Steering Group to provide an update at a conference you are organising, please contact us and we will facilitate this request.

In the January 2007 BCCOM newsletter we published our first attempts at devising a range of surrogate outcome measures which will provide information on the appropriateness of the management of symptomatic breast cancer across the UK. We are delighted by the positive response we have received to these measures and in particular with their adoption by some cancer networks as their *Key Performance Indicators* for breast cancer. We have devoted a chapter in this report to the analysis of the BCCOM data against these outcome measures, and we hope that you find this informative. We are eager to hear from you if you have any suggestions about additional surrogate outcome measures which we should consider.

Unfortunately, unlike many other cancer sites, breast cancer audit receives no central government funding. As such, we are indebted to the continued support for the BCCOM Project from Breakthrough Breast Cancer. Our thanks also go to all our participants who are listed at the start of this Report. The BCCOM Project depends on the dedication of a wide variety of organisations and professionals and we are very thankful for their support.

I would like to take this opportunity to remind you that data for BCCOM Year 4 (2005 cases) will be sent to participating surgeons at the start of 2008. I would ask you to ensure that your data are checked and returned to the WMCIU as quickly as possible. Finally, on behalf of the BCCOM Steering Group, I sincerely hope you enjoy this report and I look forward to working with you on further developing this important audit.

## Introduction from the President Elect of the Association of Surgery at BASO



Mr Martin Lee  
President Elect of the  
Association of Surgery  
at BASO

**Accurate monitoring of health service provision is fundamental to the development and improvement of services to patients. I am therefore delighted to see publication of the second Annual Report of the Breast Cancer Clinical Outcome Measures (BCCOM) Project.**

This retrospective UK wide audit is a valuable tool for assessing the quality of breast units and seeing if an equitable service is being delivered to patients regardless of where they live. It provides a good deal of insight into current clinical practice and highlights where breast units are not reaching standards of best practice. On a very positive note it shows areas of really good clinical practice and provides us with the opportunity to share this more widely.

Breast cancer management is constantly evolving and we have made considerable progress over the years. Virtually every woman with newly diagnosed breast cancer now has a full non-operative diagnosis, which informs the planning of appropriate care. Data from large scale audits such as BCCOM will reveal the likely success of surgical techniques for tumours with different characteristics and provide the evidence to inform these discussions.

Thankfully the days of mastectomy and axillary clearance as the main option for treating breast cancer are largely behind us, and increasingly we are able to offer conservative and reconstructive procedures in conjunction with sentinel lymph node biopsy, thus improving cosmesis and reducing the morbidity associated with staging of the axilla. The availability of these techniques along with a full range of adjuvant therapies in a multidisciplinary setting is integral to providing a modern breast service.

Eligible patients who are not treated in this manner should be audited locally to ascertain whether this is due, for example, to patient preference, or restricted access to surgical techniques and adjuvant therapies. Clinical teams should utilise the excellent data included in this report to consider their treatment policies and to discuss with their managers and commissioners how their services need to evolve to ensure consistency of high quality treatment across the UK.

Patients who do need total mastectomy should have access to reconstruction, immediate or delayed, as part of their planned treatment. The data included within this report can be utilised to predict demand for reconstruction and to quantify the capacity needed locally within services to meet this. Whilst not everyone wants to have a breast reconstruction, we need to be in a position to offer safe, suitable and timely options to those patients who wish it and for whom it is appropriate.

As we improve and extend the treatment of breast cancer, so too must we ensure that we are examining closely all aspects of care. We need to collect data at every stage of the patient journey so that we can audit new interventions and quantify their effect on disease free survival. To attain this, at least as much emphasis must be placed on the collection of high quality information on diagnosis, treatment and recurrence as is currently placed on the collection of national waiting time data; this should give us the knowledge to assess with confidence the impact of our breast services.



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# Results

**Project organisation**

**BCCOM Year 3 cohort**

**Outcome measures**

# Project organisation

**Commentators:**  
**Olive Kearins, Catherine Lagord**

Primary symptomatic breast cancers diagnosed in males and females are eligible for inclusion in the Breast Cancer Clinical Outcome Measures (BCCOM) Project. Tables and figures in this report include breast cancers submitted to three rounds of the BCCOM Project. Data from BCCOM Year 1 which was launched in December 2004, have been published previously in the 1st Year BCCOM Annual Report, March 2006. The numbers of cases submitted by surgeons in each region or Celtic country in each year of the BCCOM Project are given in Table 1.

A breast cancer dataset was designed in consultation with the ABS at BASO and the UK Association of Cancer Registries (UKACR). Data obtained from cancer registries on each breast cancer case include basic demographic details, diagnostic information, tumour characteristics and the type of surgical and adjuvant treatment.

To validate the mechanism of data collection, cancer registries send the data held to the relevant consultant surgeon. The surgeons in turn check the validity of their data by comparing them with those held on local systems, make amendments if necessary and return the data (minus the patient identifiable details) to the WMCIU. Surgeons can also submit unchecked data if they do not have the necessary support mechanisms in house to undertake this task.

From BCCOM Year 2 onwards, the initial protocol for data collection was modified to ensure compliance with Section 60 of the Health and Social Care Act 2001. It was observed that whilst only non-identifiable data were stored in the BCCOM central database, the flow of information at the beginning of the audit cycle (transfer of data from regional cancer registries to their surgeons for validation) was at an individual patient level. The updated protocol therefore requested that cancer registries obtain the written consent of all individual consultant surgeons prior to their data being released to the lead breast surgeon in each hospital.

Another modification was introduced in Year 2 whereby all consultant breast surgeons, whether members or not of the ABS at BASO, are invited to take part in the BCCOM Project. This was achieved thanks to the ABS at BASO regional symptomatic surgical representatives contacting all the lead breast surgeons in their region, asking for their support and their help in collecting their colleagues' written consent to release data.

In Year 3 the process for data transfer from the cancer registries to the relevant consultant surgeon was altered such that for all registries apart from South West, Northern Ireland and Scotland the data were distributed by the BCCOM team at the WMCIU. In addition, cancer registries provided the BCCOM team with data on all the breast cancers diagnosed in each area for that audit year (2004) so that an accurate denominator could be identified.

**Table 1: Participation in the BCCOM Project, Years 1, 2 and 3**

| Region or Celtic country | Diagnosis year |               |               |               | % Eligible cases Year 3 |
|--------------------------|----------------|---------------|---------------|---------------|-------------------------|
|                          | 2002           | 2003          | 2004          | 2002–2004     |                         |
|                          | BCCOM Year 1   | BCCOM Year 2  | BCCOM Year 3  | TOTAL         |                         |
| Eastern                  | 1,691          | 997           | 1,507         | <b>4,195</b>  | <b>65</b>               |
| North West               | 1,091          | 524           | 1,397         | <b>3,012</b>  | <b>41</b>               |
| Northern & Yorkshire     | 2,419          | 2,029         | 1,910         | <b>6,358</b>  | <b>52</b>               |
| Northern Ireland         | 640            | 367           | 432           | <b>1,439</b>  | <b>45</b>               |
| Oxford                   | 1,341          | 1,442         | 899           | <b>3,682</b>  | <b>62</b>               |
| Scotland                 | 934            | 181           | 1,836         | <b>2,951</b>  | <b>49</b>               |
| South West               | 3,253          | 1,001         | 2,234         | <b>6,488</b>  | <b>54</b>               |
| Thames                   | 1,750          | 2,709         | 1,530         | <b>5,989</b>  | <b>29</b>               |
| Trent                    | 408            | 1,588         | 1,453         | <b>3,449</b>  | <b>52</b>               |
| Wales                    | 351            | 952           | 1,201         | <b>2,504</b>  | <b>94</b>               |
| West Midlands            | 2,529          | 2,330         | 2,340         | <b>7,199</b>  | <b>77</b>               |
| <b>TOTAL</b>             | <b>16,407</b>  | <b>14,120</b> | <b>16,739</b> | <b>47,266</b> | <b>52</b>               |

## **Experience from a participating cancer registry**

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### **Mr Andy Pring, South West Cancer Intelligence Service**

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The South West Cancer Intelligence Service (SWCIS) gathers data on cancers for the South West Strategic Health Authority area, Hampshire and the Isle of Wight. This area has a population of some 6.5 million people served by 22 NHS acute hospitals. Geographically, the region is large, extending over 200 miles east to west.

In past years the collection of BCCOM data in the SWCIS region was done centrally; with data generation, despatch to consultants, phone and written reminders to prompt a response performed by staff within the registry. There were problems with this way of working and for the most recent round we made some changes. In Year 3, we made great use of Network Liaison Officers (NLOs) who are employed, in part, by the cancer registry to aid the cancer registration process. NLOs have excellent local contacts within the cancer networks and as such are in a position to identify locally derived processes to maximise data collection and accuracy.

Our approach in Year 3 was for an analyst at the cancer registry to produce the data files for participating consultant breast surgeons.

A volunteering "lead" NLO then distributed these data and local NLOs regularly prompted, reminded, "door stepped" and cajoled "their" consultants to return the data.

A local contact is a valuable asset, and the NLOs' efforts to prompt action were markedly more successful than previous year's letters and phone calls from the registry office in Bristol. This is almost certainly due to the personal touch, the local knowledge, and the fact that NLOs are part of the local NHS community, while the registry personnel are not.

This way of working has achieved a considerable improvement in response rate, and has in general been greatly appreciated by the hospital staff, both consultants and information managers. Given this success, it is unfortunate that after reductions in the cancer registry budget, several of the NLOs are no longer in post and we will be unable to run the project in this way next year.

## Project organisation

### Participation in BCCOM Year 3

In Year 3 of the BCCOM audit, all UK cancer registries supplied data on all breast cancers diagnosed in 2004 (48,983 breast cancers) to the BCCOM team in the WMCIU.

This has provided the opportunity to review accurately participation levels against the number of eligible cases and also to gain an insight into the annual breast cancer burden in the UK.

Participation by breast surgeons in the BCCOM Project is not mandatory but it is strongly encouraged by their professional body, the ABS at BASO. Previous experience with the NHS Breast Screening Programme (NHSBSP) and ABS at BASO audit of screen-detected breast cancer has demonstrated that regular audit of surgical practice drives up standards and highlights outliers whose local protocols are not in keeping with accepted best practice.

Table 2 shows that 45.3% of eligible surgeons who treated 16,739 breast cancers participated in BCCOM Year 3. Participation rates in terms of number of surgeons were particularly good in West Midlands, Oxford, Scotland and Wales, whilst the highest proportions

**Table 3: Characteristics of cases diagnosed in 2004 that were submitted to BCCOM Year 3**

| Breast cancers submitted to BCCOM Year 3 |                | No.    | %     |
|--|----------------|--------|-------|
|  | Total No.      | 16,739 | na    |
| Sex                                      | Female         | 16,611 | 99.2% |
|  | Male           | 128    | 0.8%  |
| Tumour side                              | Left side      | 8,478  | 52.0% |
|  | Right side     | 7,832  | 48.0% |
| Invasive status                          | Invasive       | 15,540 | 92.8% |
|  | Micro-invasive | 77     | 0.5%  |
|  | Non-invasive   | 979    | 5.8%  |
| Age                                      | less than 50   | 4,207  | 25.1% |
|  | 50 to 64       | 4,761  | 28.4% |
|  | 65 to 69       | 1,508  | 9.0%  |
|  | 70 or more     | 6,234  | 37.2% |

of eligible cases were submitted by West Midlands, Wales and Eastern. The good practices in these regions and countries should be emulated across the UK and the regional ABS at BASO symptomatic representatives are encouraged to review participation in their own areas and identify ways in which this could be improved.

Table 3 shows that the majority of the cases diagnosed in 2004 that were submitted to BCCOM Year 3 were invasive breast cancers (15,540) and only 979 (5.8%) non-invasive cancers were included. The proportion of non-invasive cancers is higher than

that expected from the published literature which suggests that only 3% of non-invasive breast cancers present symptomatically (ABC of breast diseases; Screening for breast cancer. R W Blamey, A R M Wilson, and J Patnick. *BMJ*. 2000 September 16; 321(7262): 689–693). This provides evidence of the contamination by screen-detected breast cancers in some regions. 16,611 female breast cancers were included in the project and 128 breast cancers arising in males. Slightly more breast cancers presented in the left breast (52% versus 48%).

**Table 2: Participation of UK surgeons in Year 3**

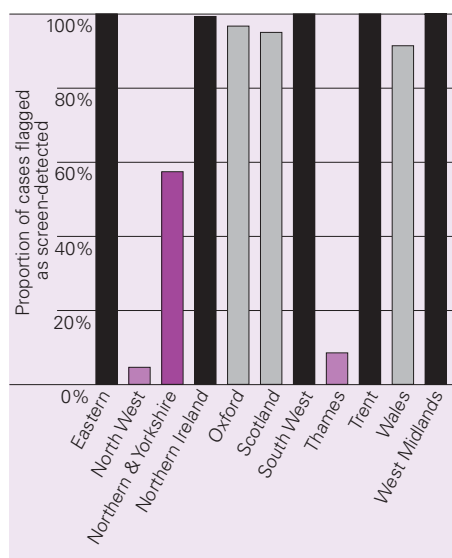
| Region or Celtic country | Eligible* surgeons |                 |                        | Eligible surgeons who submitted data |                 |                        | Take up BCCOM Year 3 |                  |
|--------------------------|--------------------|-----------------|------------------------|--------------------------------------|-----------------|------------------------|----------------------|------------------|
|                          | Number of surgeons | Number of cases | Average cases/ surgeon | Number of surgeons                   | Number of cases | Average cases/ surgeon | % eligible surgeons  | % eligible cases |
| Eastern                  | 42                 | 2,314           | 55                     | 15                                   | 1,507           | 100                    | 35.7%                | 65.1%            |
| North West               | 66                 | 3,442           | 52                     | 20                                   | 1,397           | 70                     | 30.3%                | 40.6%            |
| Northern & Yorkshire     | 55                 | 3,692           | 67                     | 25                                   | 1,910           | 76                     | 45.5%                | 51.7%            |
| Northern Ireland         | 16                 | 962             | 60                     | 6                                    | 432             | 72                     | 37.5%                | 44.9%            |
| Oxford                   | 18                 | 1,447           | 80                     | 12                                   | 899             | 75                     | 66.7%                | 62.1%            |
| Scotland                 | 46                 | 3,767           | 82                     | 30                                   | 1,836           | 61                     | 65.2%                | 48.7%            |
| South West               | 56                 | 4,121           | 74                     | 27                                   | 2,234           | 83                     | 48.2%                | 54.2%            |
| Thames                   | 77                 | 5,283           | 69                     | 18                                   | 1,530           | 85                     | 23.4%                | 29.0%            |
| Trent                    | 35                 | 2,782           | 79                     | 15                                   | 1,453           | 97                     | 42.9%                | 52.2%            |
| Wales                    | 28                 | 1,276           | 46                     | 18                                   | 1,201           | 67                     | 64.3%                | 94.1%            |
| West Midlands            | 49                 | 3,027           | 62                     | 35                                   | 2,340           | 67                     | 71.4%                | 77.3%            |
| <b>TOTAL</b>             | <b>488</b>         | <b>32,113</b>   | <b>66</b>              | <b>221</b>                           | <b>16,739</b>   | <b>76</b>              | <b>45.3%</b>         | <b>52.1%</b>     |

\*Surgeons were eligible if they treated six or more symptomatic breast cancer cases in 2004.

# BCCOM Year 3 cohort

## Screening flag

In 2004, a total of 48,983 breast cancer cases were registered by cancer registries of which 9,805 (20%) were flagged as screen-detected. From the NHSBSP and ABS at BASO audit of screen-detected cancers it is known that 14,057 cases would have had a date of first offered appointment to screening in 2004,



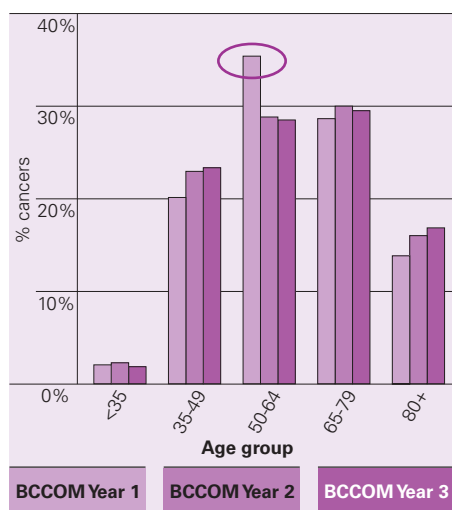
**Figure 1: Recording of screen-detected cancers by UK cancer registries in 2004**

indicating that the cancer registries have accurately assigned 70% of the screen-detected cases. Figure 1 shows the proportion of BCCOM Year 3 cases in each participating cancer registry which have a screening flag assigned. The recent inclusion of a requirement in the new cancer registry peer review measures to have in place mechanisms for registries to obtain the details of screen-detected breast cancers from breast screening QA reference centres has greatly improved the situation compared with 2003 cases, and it is hoped that in next year's audit of breast cancers diagnosed in 2005, all registries will have correctly identified all screen-detected cases.

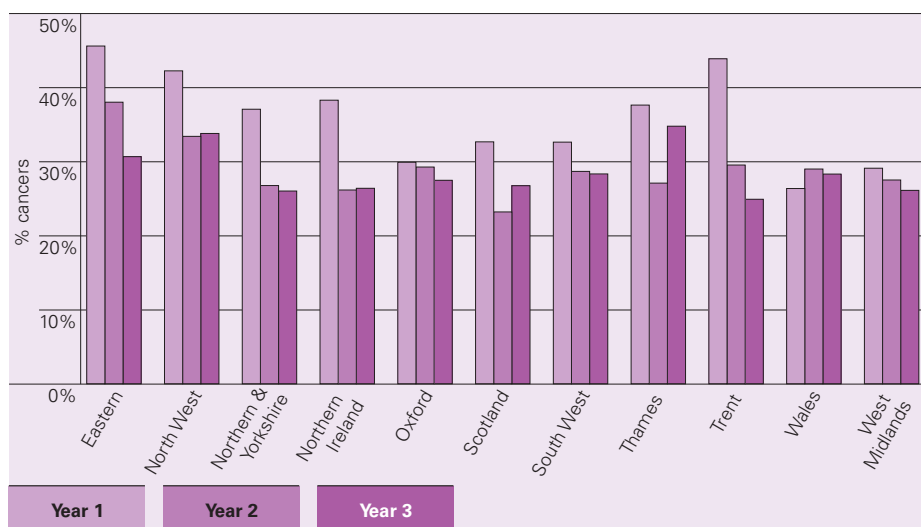
## Age distribution

In BCCOM Year 3, 25% of cases were diagnosed in patients aged less than 50, 28% in those aged 50-64, 9% in those aged 65-69 and 37% in patients aged 70 or more. Figure 2 shows that there was significant contamination by screen-detected breast cancers in the BCCOM dataset in Year 1.

Figure 3 shows for each region and Celtic country, the proportion of female breast cancers submitted to the BCCOM Project over the three year audit period that were diagnosed in the 50-64 age group and shows clearly the level of contamination by screen-detected cases in the first year of the BCCOM Project (2002 data). By Year 3, this problem appears to have been addressed by most cancer registries with the exception of North West, Eastern and Thames, where the proportion of cases in the 50-64 age group is still above 30% (see also Figure 2).



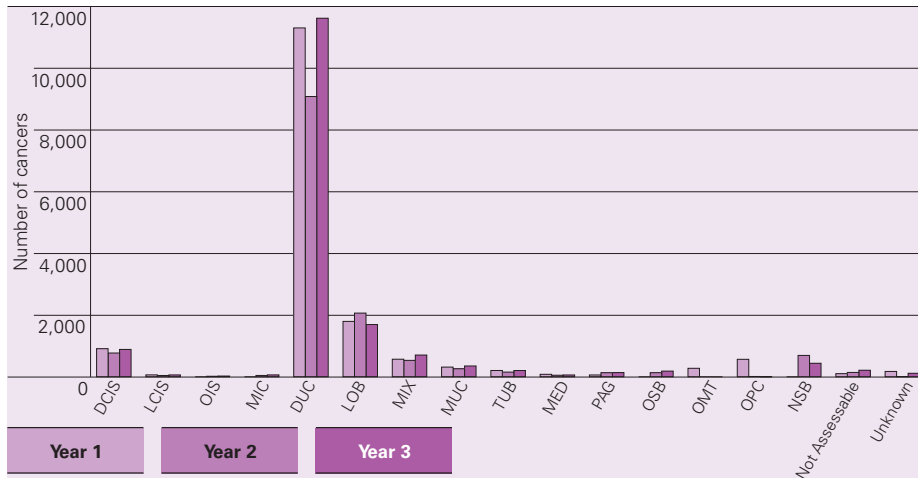
**Figure 2: Variation in the number of breast cancers with age – Comparison between three years of the BCCOM Project**



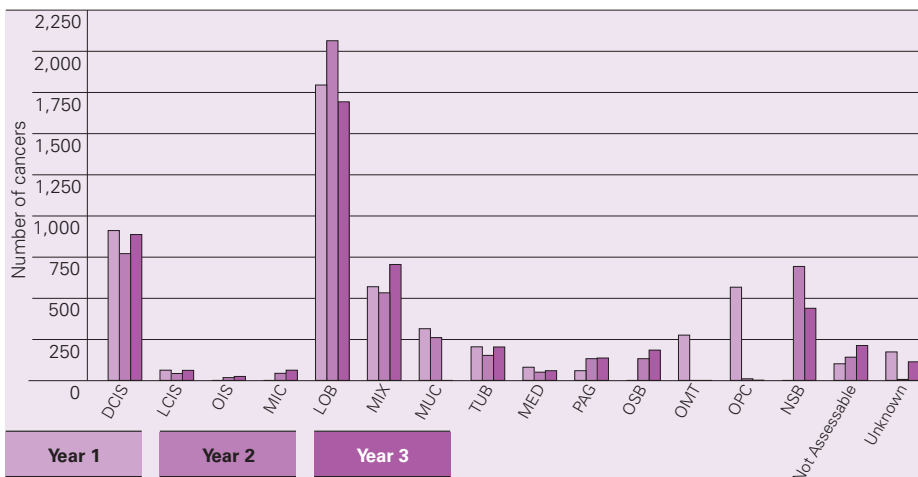
**Figure 3: Proportion of breast cancers in the 50-64 age group**

**Histological type**

Figure 4 shows the number of cancers of each histological type diagnosed over the three year audit period 2002-2004. As expected the majority of cases are invasive ductal carcinoma, with invasive lobular carcinoma being the next most common histological type. Figure 5 which excludes invasive ductal carcinomas, illustrates the excellent resource that the cancer registries provide for researchers who wish to investigate cohorts of rarer breast cancers. Cancer registries can act as a rich source of relatively large cohorts of such cases at regional or UK level for short or extended time periods.



**Figure 4: Histological tumour type**



**Figure 5: Number of breast cancers by histological type excluding ductal carcinomas**

**Lymph node status**

Of all the breast cancer cases submitted in BCCOM Year 3, 31.8% were lymph node positive, 34.3% were lymph node negative and 33.9% had unknown nodal status (Table 4). If the cases with unknown lymph node status are excluded, the node positive rate increases to 48%. For surgically treated cases, the proportion with unknown lymph node status was much lower at 14.4%, and 41.5% of these cases were lymph node positive. Part of the reason for the relatively high proportion of surgically treated cases with unknown lymph node status is that some cancer registries do not record data on lymph

node status and tumour size if the patient has received neo-adjuvant chemotherapy or radiotherapy. This is because the use of such information to determine the Nottingham Prognostic Index or pathological TNM stage at diagnosis could result in inaccurate under-staging of the cancer.

Figure 6 shows, for surgically treated invasive breast cancers, how lymph node status varies in each audit year with the age of the patient. In BCCOM Year 3 where the data are most complete, the proportion of lymph node positive cases is slightly higher in those aged less than 50 (44.5% compared to 38.9% in all other age groups). This cohort also has the lowest proportion of cases with unknown lymph node status (10.9%). It is accepted that breast cancers arising in younger patients are more aggressive. Additionally, it would be expected that these patients would be more likely to be fit for surgical intervention and as such are more likely to have an assessment of their lymph nodes. In contrast, a relatively high proportion (28%) of cancers diagnosed in patients aged 80 years and over have unknown nodal status. This suggests that surgery to the axilla is undertaken less frequently in this age group and that some older patients may have had an incomplete diagnostic work up.

**Codes for histological types**

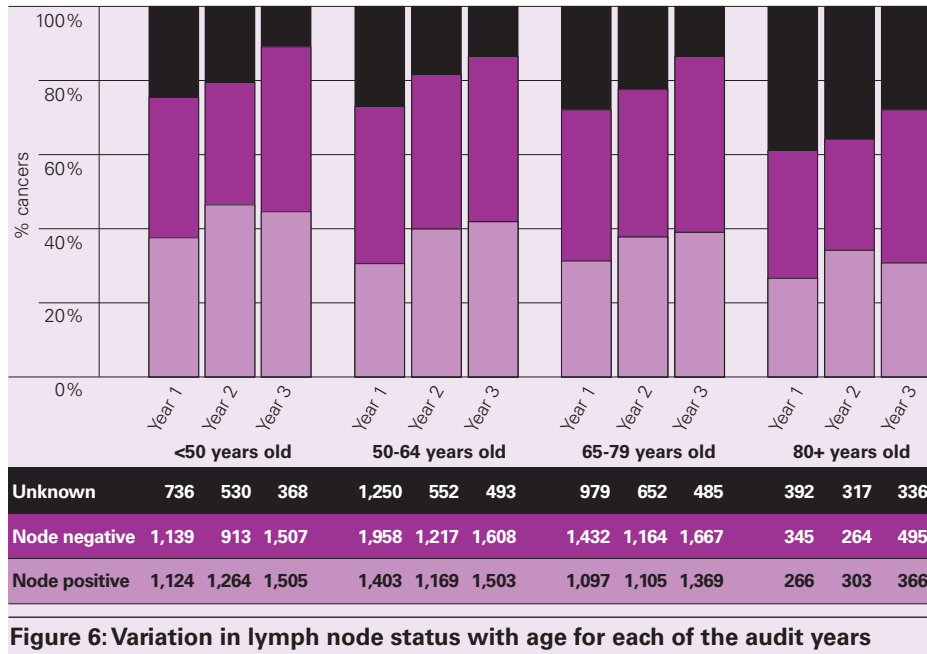
*Non-invasive*

- DCIS = Ductal carcinoma in situ
- LCIS = Lobular carcinoma in situ
- OIS = Other in situ breast cancer\*\*

*Invasive*

- MIC = Micro-invasive breast cancer\*\*
- DUC = Invasive ductal carcinoma
- LOB = Invasive lobular carcinoma
- MIX = Invasive tumour: Mixed
- MUC = Invasive mucinous/colloid carcinoma
- TUB = Invasive tubular carcinoma
- MED = Invasive medullary carcinoma
- PAG = Paget's disease of nipple
- OSB = Other specified malignant tumour of breast\*\*
- OMT = Other malignant tumour of breast\*
- OPC = Other primary carcinoma (not breast)
- NSB = Non-specific malignant tumour of breast\*\*

Codes used: \* Year 1 only \*\*from Year 2



**Figure 6: Variation in lymph node status with age for each of the audit years**

**Table 4: Characteristics of invasive breast cancers diagnosed in 2004 and submitted to BCCOM Year 3**

| Invasive breast cancers diagnosed in 2004 |                  | All invasive (15,540) |       |                  | Surgically treated only (11,725) |       |                  |
|---|------------------|-----------------------|-------|------------------|----------------------------------|-------|------------------|
|   |                  | Number of cases       | %     | % of total known | Number of cases                  | %     | % of total known |
| Nodal status                              | Positive         | 4,941                 | 31.8% | 48%              | 4,754                            | 40.5% | 47%              |
|   | Negative         | 5,332                 | 34.3% | 52%              | 5,287                            | 45.1% | 53%              |
|   | Unknown          | 5,267                 | 33.9% | na               | 1,684                            | 14.4% | na               |
| Grade                                     | I                | 1,862                 | 12.0% | 14%              | 1,501                            | 12.8% | 14%              |
|   | II               | 6,371                 | 41.0% | 48%              | 5,073                            | 43.3% | 46%              |
|   | III              | 5,152                 | 33.2% | 38%              | 4,449                            | 37.9% | 40%              |
|   | Unknown          | 2,155                 | 13.9% | na               | 702                              | 6.0%  | na               |
| Invasive size                             | <15mm            | 2,544                 | 16.4% | 22%              | 2,360                            | 20.1% | 22%              |
|   | 15-<20mm         | 2,340                 | 15.1% | 20%              | 2,220                            | 18.9% | 20%              |
|   | 20-<50mm         | 5,862                 | 37.7% | 50%              | 5,472                            | 46.7% | 50%              |
|   | 50+mm            | 968                   | 6.2%  | 8%               | 849                              | 7.2%  | 8%               |
|   | Unknown          | 3,826                 | 24.6% | na               | 824                              | 7.0%  | na               |
| NPI                                       | EPG + GPG + MPG1 | 4,896                 | 31.5% | 51%              | 4,816                            | 41.1% | 51%              |
|   | MPG2 + PPG       | 4,673                 | 30.1% | 49%              | 4,567                            | 39.0% | 49%              |
|   | Unknown          | 5,971                 | 38.4% | na               | 2,342                            | 20.0% | na               |
| Surgery                                   | Conservation     | 5,583                 | 35.9% | 41%              | 5,583                            | 47.6% | na               |
|   | Mastectomy       | 6,142                 | 39.5% | 45%              | 6,142                            | 52.4% | na               |
|   | No surgery       | 2,034                 | 13.1% | 15%              | na                               | na    | na               |
|   | Unknown          | 1,781                 | 11.5% | na               | na                               | na    | na               |

**Tumour size and grade**

In BCCOM Year 3, 31.5% of the cancers included in the cohort had an invasive cancer size less than 20mm in diameter and for 24.6% of all cases the invasive size was unknown. For surgically treated cases, the invasive size was unknown for 7.0% of cancers. In most cases, the invasive size at diagnosis will not have been recorded because the patient had neo-adjuvant treatment which may have reduced the original size at diagnosis, because of involved tumour margins or because the tumour was removed in several pieces in repeat operations.

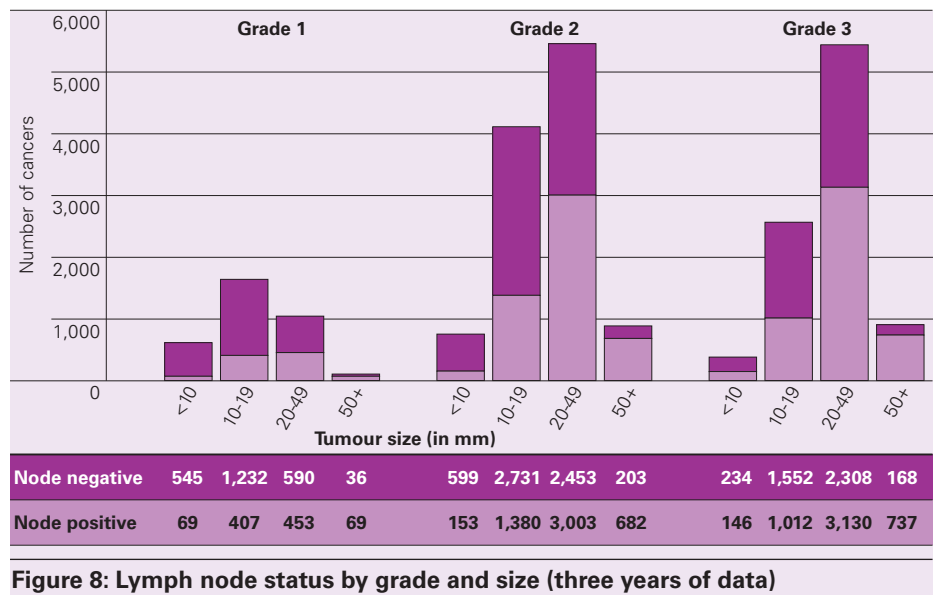
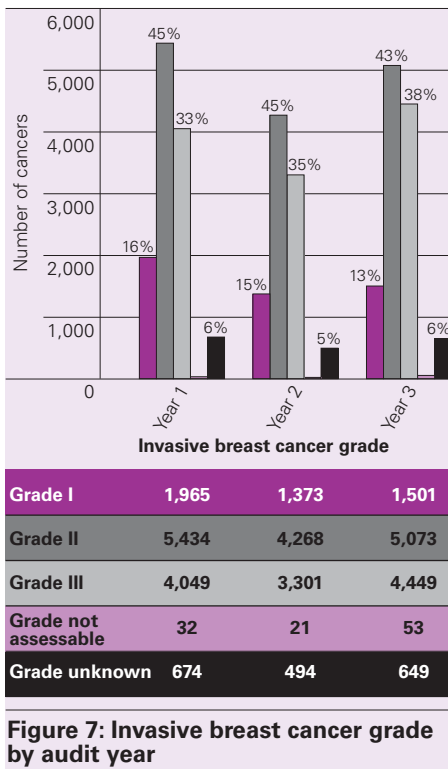
In BCCOM Year 3, only 12.0% of invasive cancers were grade I, 41.0% were grade II and 33.2% were grade III. For surgically treated cases, these proportions increased to 12.8%, 43.3% and 37.9%. Grade was

unknown for 13.9% of all cases, but this decreased to only 6.0% for surgically treated cases. Figure 7 shows the variation in tumour grade for 33,336 surgically treated invasive breast cancer cases diagnosed over the three year audit period 2002 – 2004.

As expected for a symptomatic cohort, overall there are fewer grade 1 cancers (14% compared with 29% for screen-detected breast cancers; ABS at BASO audit of screen-detected cancers) and, as the contamination of screening cases has been reduced over the three year audit period, the proportion of grade 1 cancers has decreased (from 16.1% to 12.8%) and the proportion of grade 3 cancers has increased (from 33.3% to 37.9%). Grade was unknown for 1,817 surgically treated invasive cancers over the three year audit period. Given the importance of grade to the

accurate monitoring and reporting of breast cancer management and outcomes, all surgically treated cases without a grade should be followed up to identify why this vital piece of information was not recorded.

Figure 8 shows for 23,892 surgically treated invasive breast cancers with known lymph node status, grade and size diagnosed over the three year audit period 2002–2004, how the number of cases with positive or negative lymph node status varies with grade and invasive tumour size. There are relatively fewer grade 1 cancers in the BCCOM cohort and the majority of these (52%) are lymph node negative with an invasive size less than 20mm. In contrast, 41% of grade 3 cancers are lymph node positive and have an invasive size greater than 20mm. There is thus a clear association between grade, lymph node status and tumour size.



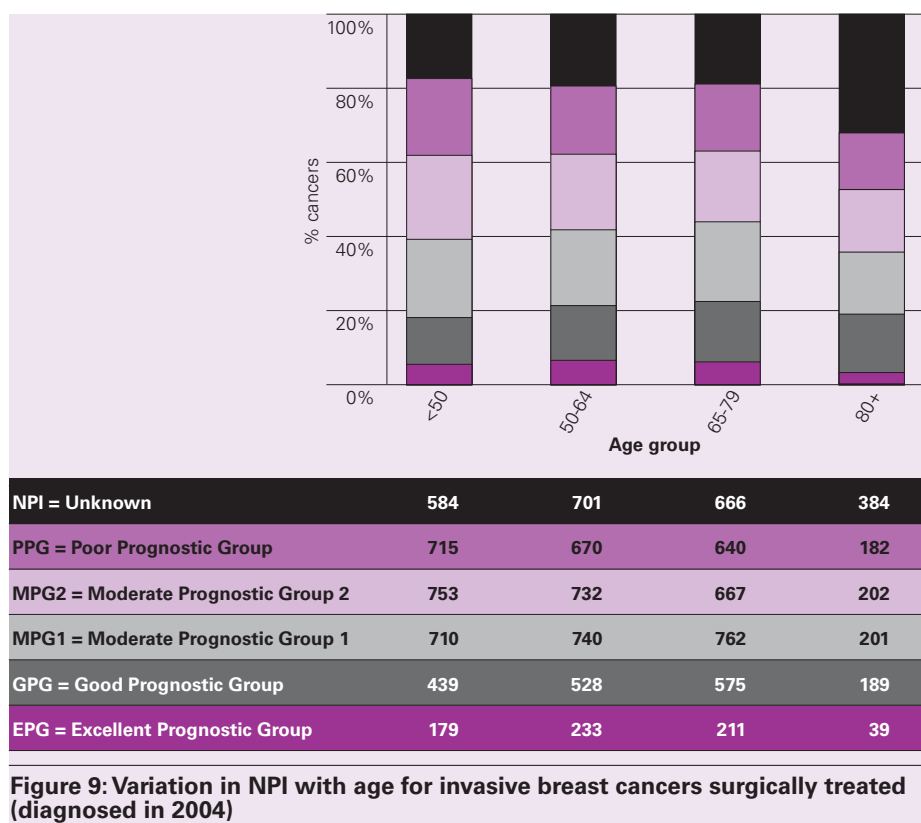


### Nottingham Prognostic Index (NPI)

Of those cases treated with surgery, 47.6% underwent a breast conserving procedure and 52.4% had a mastectomy. This is not unexpected given the relatively large size of the symptomatic breast cancers in the cohort studied. For cancers submitted in BCCOM Year 3, a Nottingham Prognostic Index (NPI) score could be calculated for the 80% of surgically treated invasive breast cancers where nodal, grade and size data were available. Of those cases with a known NPI, 51% were early breast cancers with an NPI score below 4.4 and fell into the Excellent Prognostic Group (EPG), Good Prognostic Group (GPG) or Moderate Prognostic Group 1 (MPG1) categories, while 49% were categorised in the Moderate Prognostic Group 2 (MPG2) or Poor Prognostic Group (PPG). These data are in marked contrast to those collected for screen-detected breast cancers. In the NHSBSP and ABS at BASO audit of screen-detected cases diagnosed in 2005/6, 83% of screen-detected breast cancers were early breast cancers with an NPI score below 4.4 (24% in the EPG, 36% in the GPG, 22% in the MPG1), 11% were in the MPG2 and only 6% in the PPG.

Figure 9 shows the variation in Nottingham Prognostic Index (NPI) with age for surgically treated invasive cancers diagnosed in 2004. There are few cases in the Excellent Prognostic Group (EPG) in all age groups. 41.7% of cases diagnosed in patients under 80 years have an NPI score of less than or equal to 4.4 and fall into the EPG, GPG and MPG1 categories.

Slightly fewer cases (39.8%) fall into the MPG2 and PPG categories. The NPI score was unknown for 18.6% of patients aged less than 80 and for 32.1% of patients aged over 80; Table 5 shows that this is mainly because of missing information on nodal status as discussed earlier.



**Figure 9: Variation in NPI with age for invasive breast cancers surgically treated (diagnosed in 2004)**

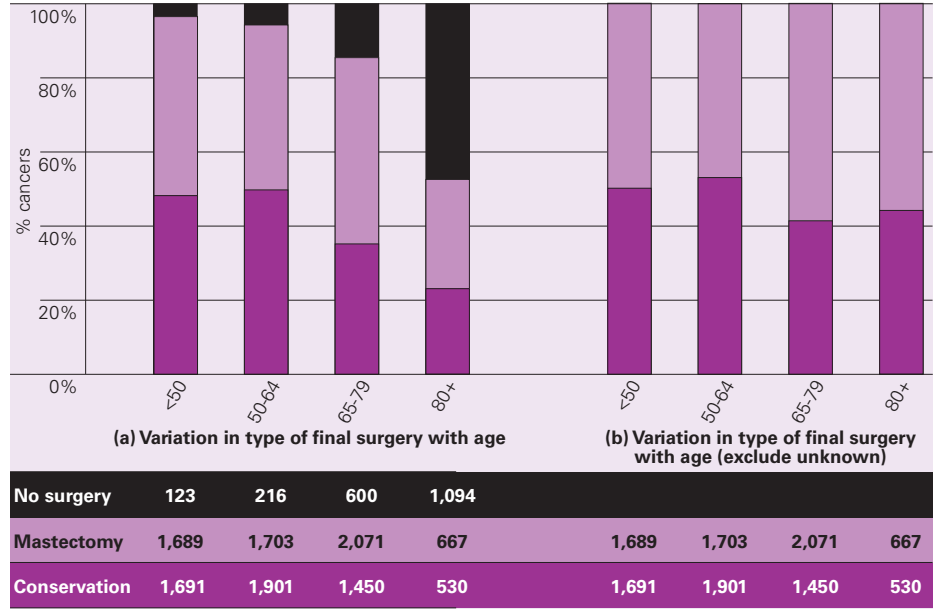
**Table 5: Variation with age of unknown nodal status and tumour grade and size for surgically treated invasive breast cancers diagnosed in 2004**

| Age group    | Total cases   | Invasive cancers surgically treated diagnosed in 2004 |           |              |           |                      |            |
|--------------|---------------|---|-----------|--------------|-----------|----------------------|------------|
|              |               | Unknown invasive grade                                |           | Unknown size |           | Unknown nodal status |            |
|              |               | No.   | %         | No.          | %         | No.                  | %          |
| <50          | 3,380         | 157   | 5%        | 271          | 8%        | 368                  | 11%        |
| 50-64        | 3,604         | 196   | 5%        | 231          | 6%        | 493                  | 14%        |
| 65-79        | 3,521         | 203   | 6%        | 203          | 6%        | 485                  | 14%        |
| 80+          | 1,197         | 93  | 8%        | 113          | 9%        | 336                  | 28%        |
| <b>TOTAL</b> | <b>11,702</b> | <b>649</b>  | <b>6%</b> | <b>818</b>   | <b>7%</b> | <b>1,682</b>         | <b>14%</b> |

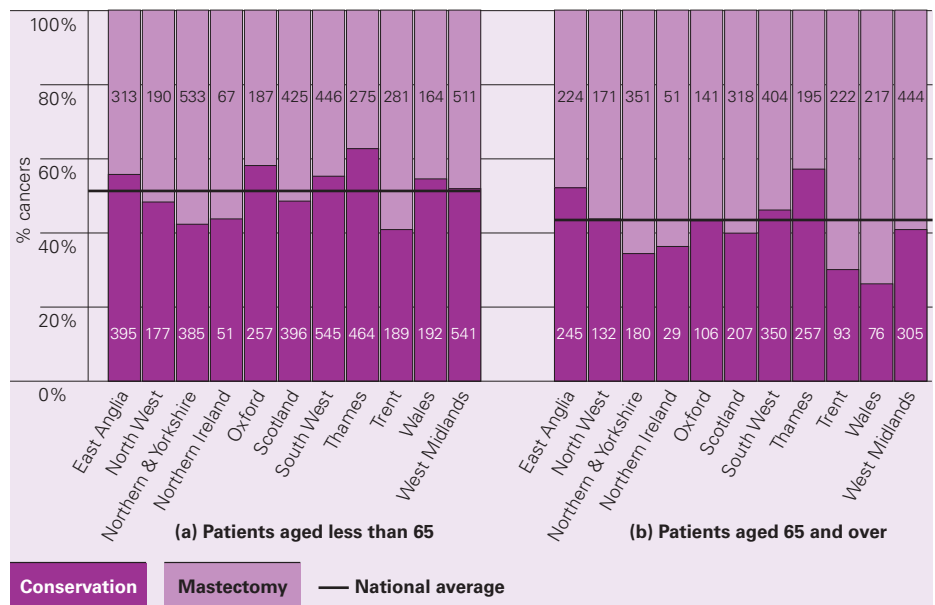
**Surgical treatment modality**

Figure 10 shows for BCCOM Year 3 cases how the type of treatment provided varies with age at diagnosis. The proportion of women not receiving surgery increases with age from only 3.5% in women aged less than 50 to 47.7% in women aged 80 or above (Figure 10a). In those women who did receive surgical treatment (Figure 10b), the proportion receiving conservation surgery decreased with age from 51.4% in women aged less than 65 to 41.9% in women aged 65 and above.

When the cases undergoing surgical treatment are broken down by region/Celtic country (Figure 11), variations in the pattern of care are suggested. For example, whether patients were aged less than 65 (11a) or 65 and over (11b), the proportion of cases receiving conservation surgery was lower than the UK average in Trent, Northern Ireland and Northern & Yorkshire; in Thames, this rate was higher than the UK average. In each region/Celtic country, the conservation surgery rate was higher in patients aged less than 65 than in patients aged 65 and over. This difference between age groups was most marked in Oxford (58% vs 43%) and Wales (54% vs 26%).



**Figure 10: Variation in surgical treatment with age for invasive cases diagnosed in 2004**



**Figure 11: Variation in type of surgery with age in each region/Celtic country (invasive breast cancers diagnosed in 2004)**

# Outcome measures

Table 6 shows the surrogate outcome measures that have been developed by the BCCOM Steering Group so that, in lieu of the inevitable delay in being able to calculate recurrence and survival rates, an insight can be gained into the appropriateness of the treatment policies used across the UK. For the purpose of this report the measures have been divided into groups that are of specific interest to different members of the multidisciplinary team and commentary is provided by the relevant members of the BCCOM Steering Group. However, as the patient is the centre of all treatment, our patient representative has provided an overview of the meaningfulness of these data from a patient perspective.

## Patient perspective

### Commentators: Norman Freshney, Breakthrough Breast Cancer and Ursula Van Mann, Patient Representative BCCOM Steering Group

In an era of patient choice and access to unlimited amounts of information on the internet, the need for accurate and representative intelligence on the management of breast cancer across the UK has never been more important. The BCCOM database provides a repository through which patients and their carers could view simple graphs and tables showing variations in treatment practice between hospital Trusts. Patients and carers could utilise this data to assure themselves of the quality of the local services available, and potentially also to inform them of where they could access certain specialised treatments such as sentinel lymph node biopsy or immediate reconstruction. Such a resource could empower patients to be active participants in their own treatment.

**Table 6: Surrogate clinical outcome measures proposed by the BCCOM Steering Group**

| Proposed surrogate clinical outcome measures  |
|---|
| 1. Number and proportion of breast cancers for which complete information is received   |
| 2. Number of symptomatic and screen-detected breast cancers treated in a hospital per annum                                     |
| 3. Number and proportion of breast cancers for which there is a non-operative diagnosis   |
| 4. Number and proportion of breast cancers given medical treatment only   |
| 5. Number and proportion of breast cancers treated surgically   |
| 6. Mastectomy rate by size of breast tumour (<15mm; ≥15mm and ≤20mm; >20mm and ≤35mm; >35mm and <50mm; ≥50mm invasive diameter) |
| 7. Number and proportion of invasive breast cancers for which nodal status is known   |
| 8. Number and proportion of histologically node negative invasive breast cancers for which more than seven nodes were harvested |
| 9. Number and proportion of invasive breast cancers treated by conservation surgery and receiving radiotherapy                  |
| 10. Number and proportion of node positive patients with invasive breast cancers, aged less than 60, receiving chemotherapy     |
| 11. Number and proportion of patients with ER positive invasive breast cancers, receiving hormone therapy                       |

The data requirements of a patient or a carer vary enormously between individuals. Some may not want any information, whereas others may feel reassured by being able to freely access data about breast cancer management within their local hospital. With this wide variation, any plans to provide patients with access to data collected through the BCCOM Project will need to be considered carefully and will require the involvement of wide representation from the multidisciplinary team. Questions that will need to be considered include:

- What data should be provided and what is the optimal format?
- What level of data should be available?
- How will patients gain access to the data; the internet or at hospital level via information leaflets?
- How will the data available encompass a disease which is as diverse as the population it affects?

A working group has been set up between the ABS at BASO, Breakthrough Breast Cancer and Breast Cancer Care to discuss these issues and seek views from stakeholders, to inform the production of a suitable data resource.

These are not insurmountable problems; the biggest challenge that has persisted to date has been gaining access to high quality information that both the multidisciplinary team and the patient can trust. This is now available thanks to the BCCOM Project.

# Outcome measures

## Data quality

Commentator: Chris Carrigan,  
National Coordinator for Cancer  
Registration, England

### Outcome Measure 1: Number and proportion of breast cancers for which complete information is received

The usefulness of an audit is dependent on the completeness and accuracy of the data that are included. Without complete and accurate data, the intelligence derived will be flawed and possibly misleading. With this in mind, the first task undertaken by the BCCOM Steering Group is to ensure that the BCCOM data are of high quality. This can be achieved in a number of ways; firstly by surgeons reviewing the quality of the data that they have personally received from their local cancer registry as part of the BCCOM Project process and if possible adding any missing information. Surgeons who do not have the resources to check their data, are given the opportunity to submit their data unchecked on the proviso that they feel that the data are representative of their practice. Simple checks included here would be the number of patients treated and whether the treatment recorded is the typical management expected for a given tumour grade and size. In addition, the BCCOM team at the WMCIU monitors the completeness of the data available from each cancer registry and the amount of data added by individual surgeons within each region.

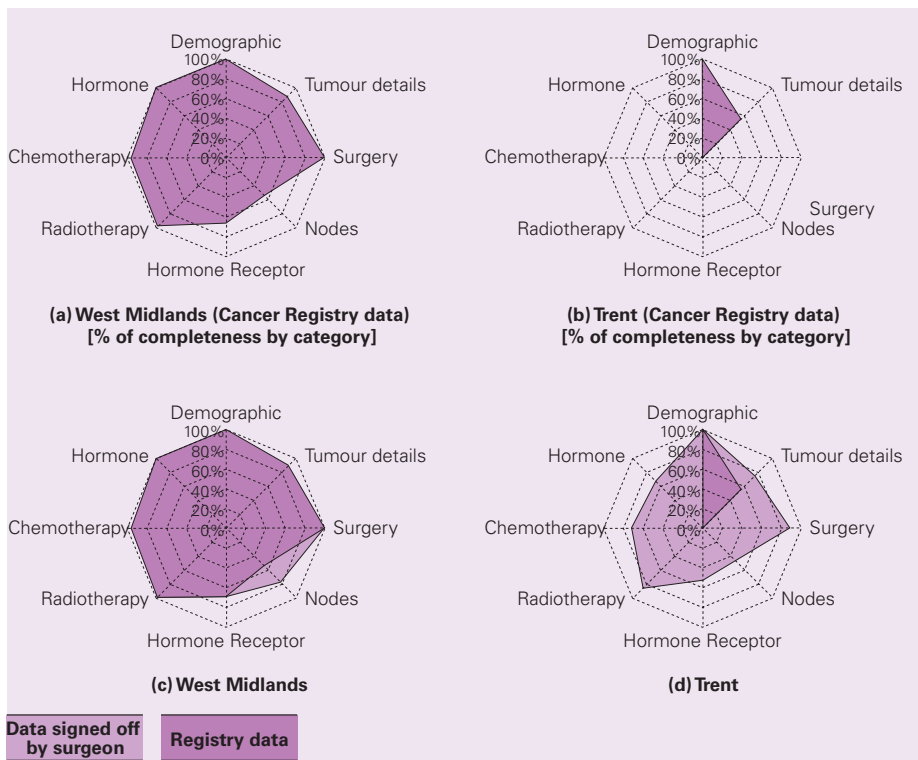


Figure 12: Radar plots showing the completeness of the data provided by two cancer registries before (a and b) and after the data have been checked and returned by participating surgeons (c and d)

Table 7: Cases received and checked

|                                     | BCCOM<br>Year 1 | BCCOM<br>Year 2 | BCCOM<br>Year 3 | Total         |
|-------------------------------------|-----------------|-----------------|-----------------|---------------|
| <b>Surgeons submitting data</b>     | <b>191</b>      | <b>206</b>      | <b>221</b>      | <b>NA</b>     |
| incl: surgeons checked              | 94              | 154             | 187             | NA            |
| or partially checked                | (49.2%)         | (74.7%)         | (84.6%)         | NA            |
| <b>Cases received from surgeons</b> | <b>16,407</b>   | <b>14,120</b>   | <b>16,739</b>   | <b>47,266</b> |
| incl: cases checked                 | 7,926           | 9,292           | 13,816          | 30,134        |
| or partially checked                | (48.3%)         | (65.8%)         | (82.5%)         | (65.9%)       |

Figures 12a and 12b demonstrate the benefits which the BCCOM process brings to overall data completeness in cancer registries where more detailed clinical data has been difficult to collect. The figures show for all cancers, the completeness of the demographic, tumour and treatment data, demonstrating how the overall data completion is improved by the BCCOM project.

The graphs are useful tools to highlight areas that need to be improved and also to congratulate registries on good practice and to facilitate a process where an insight can be gained into the practices of the more complete registries and share these with others who are having difficulties.

There are a number of means by which cancer registries can improve the quality of the data they hold. The most effective is to improve links with local hospitals to establish routine transfer of cancer data from their departments. Figures 12c and 12d indicate that additional data are available at local level which are not being transferred to and/or recorded by cancer registries. It is anticipated that participating cancer registries will review the data that are returned to them from the BCCOM Project, highlight what they did not have on their database and work with their local hospital Trusts to gain routine access to these data as quickly as possible.

Table 7 shows that the percentage of cases checked or partially checked by the treating surgeon has increased each year, with only 16% of the surgeons who participated in BCCOM Year 3 not checking their data before returning them to the WMCIU. Not only does this give a positive indication of the reliability of the data held in this year's audit, but it also demonstrates the increased commitment of surgeons to the BCCOM Project which is excellent. It is hoped that, as the BCCOM Project progresses, a stage will be reached where surgeons are only asked to review a selected number of cases which suggest practices outwith current accepted guidance e.g. invasive cancer with no nodes recorded. This will significantly reduce the burden on surgeons and data managers who participate in the audit.

At a national level, work is ongoing to enable all cancer registries to match data on their own databases to data held on national databases such as Hospital Episode Statistics (HES). From those registries which routinely compare their data with those recorded on HES, it has become apparent that access to these resources will provide useful information on operations for which the pathology reports may not be transferred to or accessed by cancer registries because no malignancy is reported. These include additional operations to remove nodes which turn out to be negative for tumour deposits and repeat operations on the breast (e.g. delayed reconstruction) which have a benign pathological outcome. Most importantly, matching cancer registration and HES data also allows the identification of surgeons and hospitals for each type of treatment where these data are not routinely collected by the cancer registry, thus increasing the number of cases that can be returned to surgeons for checking. It is anticipated that data from HES will be available for the 2006 data which will be collected as part of BCCOM Year 5.

# Outcome measures

## Surgical treatment

Commentators: Gill Lawrence, Hugh Bishop and Tim Archer

### Outcome Measure 2: Number of symptomatic and screen-detected breast cancers treated in a hospital per annum

The BCCOM Steering Group believes that all patients presenting with breast cancer should have the opportunity to be seen by a specialist breast surgeon and that their future management should be coordinated through this professional, even if surgical intervention is not appropriate. In order to assess this, cancer registry data were reviewed to ascertain the proportion of cases that did not have a surgeon assigned. Figure 13 shows that, of the 39,178 primary symptomatic breast cancer cases diagnosed in 2004, 5,749 cases (14.7%) were recorded by cancer registries without a consultant surgeon assigned.

Of the 39,178 symptomatic cases diagnosed in 2004, 16,739 (42.7%) cases were checked by the treating surgeon and entered into the BCCOM audit. A further 5,962 cases were sent to surgeons who had agreed to participate but have yet to return their data and 7,170 cases (18.3%) were attributed to surgeons who decided not to take part in the Project. 3,558 cases (9.1%) could not be included in the audit either because the treating surgeon was not contactable or because the surgeon had less than the required six cases to make them eligible for inclusion.

We are aware from feedback from some participating surgeons that not all registries have been able to assign all of their cases to the treating surgeon. There are wide differences between registries in the percentage of cases that do not have a surgeon assigned; with the registries covering the Eastern, North West and Thames regions having respectively 22.4%,

24.5% and 31.5% unassigned cases. In BCCOM Year 3, when the hospital was known but a surgeon could not be assigned, the BCCOM team piloted sending out the cases to the lead symptomatic surgeon of the hospital with a request to distribute these if possible to the treating surgeon for validation and return to the WMCIU. As cases without an assigned surgeon cannot be included in the BCCOM audit, all registries are encouraged to work with their local breast surgeons to resolve this issue, particularly as in the majority of cases the treating hospital is known.

Details of the management of the 1,219 breast cancer cases diagnosed in 2004 and treated by surgeons with a symptomatic workload of less than six cases (3.1% of the eligible cases) are given in Figure 14. 313 of these cases (25.7%) did not have surgery and for 686 (56.3%) the type of surgery was unknown. Although these cases represent a small

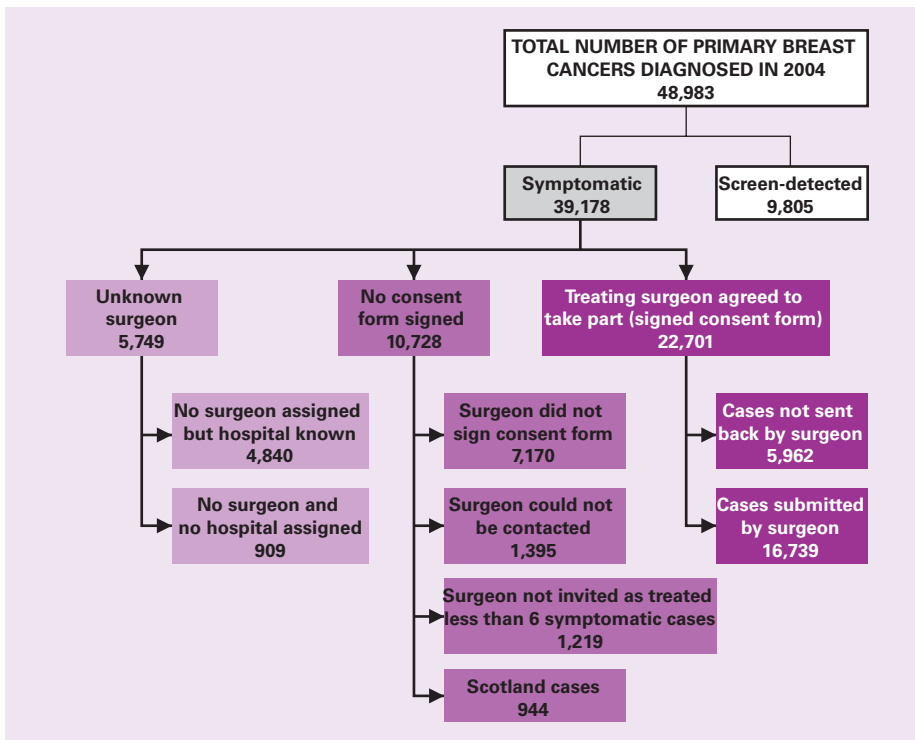


Figure 13: Primary symptomatic breast cancer cases diagnosed in 2004

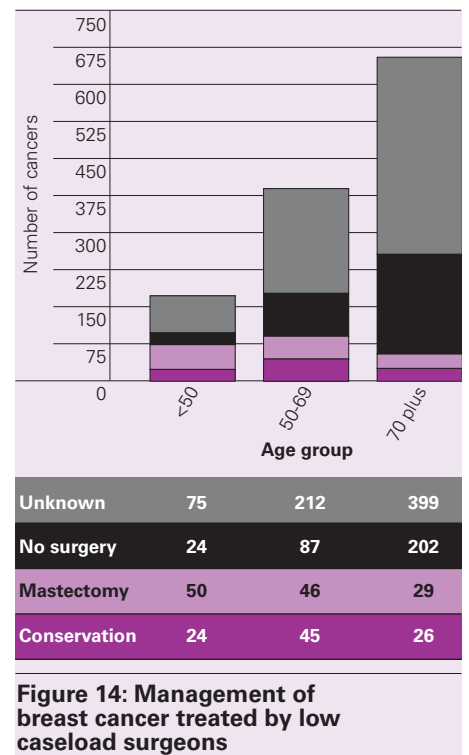
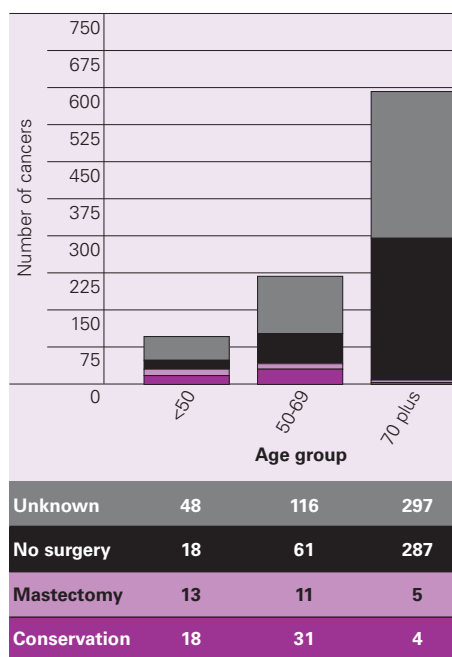


Figure 14: Management of breast cancer treated by low caseload surgeons

percentage of the 39,178 breast cancers treated in 2004, local teams and cancer networks should identify if any of the surgeons are occasional operators and not surgeons who had recently joined/left a hospital or had a large screening caseload. Site specialisation has been a cornerstone of successful breast cancer management across the UK for many years and instances of occasional operators should be quickly identified and counselled.

Of the 909 cases where neither the surgeon nor the hospital was known (Figure 15), the majority of patients had unknown (461; 50.72%) or no surgery (366; 40.26%). Of the small number who had known surgical details, 5.8% had a breast conserving procedure and 3.2% had a mastectomy.

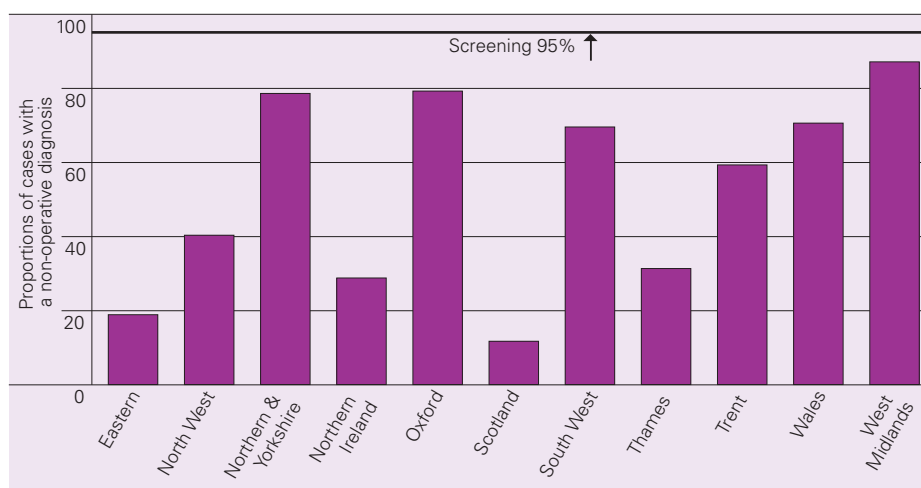


**Figure 15: Management of breast cancer for cases where the surgeon and hospital were unknown (cases diagnosed in 2004)**

### Outcome Measure 3: Number and proportion of breast cancers for which there is a non-operative diagnosis

It is accepted best practice that a diagnosis of breast cancer is made non-operatively so that the number of operations can be limited and that a decision about optimal surgical intervention can be agreed with the patient prior to their surgery. The NHSBSP and ABS at BASO audit of screen-detected breast cancer has demonstrated an improvement in achieving a non-operative diagnosis from 63% in 1996/97 to 93% in 2004/5. Accurate information on non-operative diagnosis is stored on the National Breast Screening Computer System for all women who have undergone screening. For symptomatic breast cancers, information on whether a patient has had a non-operative

diagnosis has to be derived by ascertaining whether there was a positive cytology or histology report prior to the date of the first surgery. This approach requires that cancer registries receive for each breast cancer patient a pathology report for all cytology, biopsy and excision samples, and that the dates of these reports are recorded so that the sequence of the events can be determined. Figure 16 suggests that complete information at this detailed level is only, at present, available from at most three of the cancer registries. Therefore, in order to be able to accurately monitor this important outcome measure, real improvements must be made by cancer registries in the accurate reporting, recording and extraction of the dates and nature of all cellular pathology reports.



**Figure 16: Variation in non-operative diagnosis rates across the regions/Celtic countries**

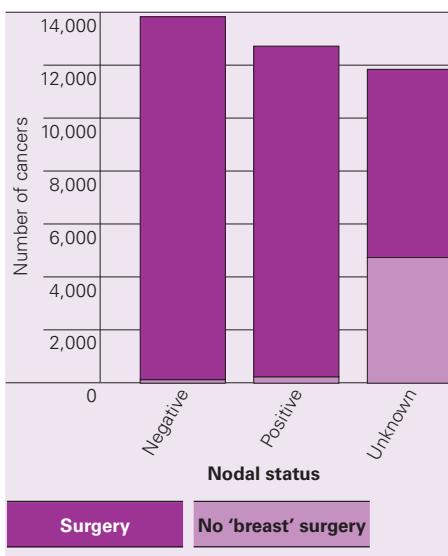
# Outcome measures

## Outcome Measure 7: Number and proportion of invasive breast cancers for which nodal status is known

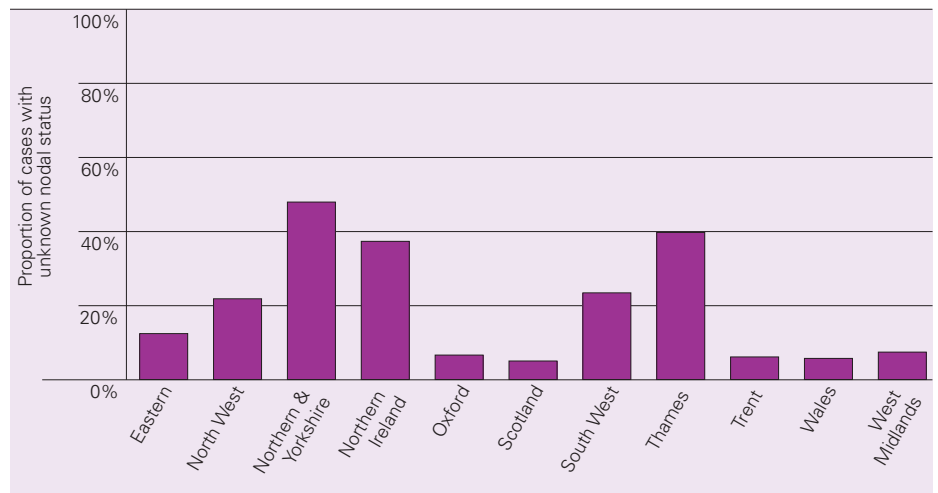
Figure 17 shows that over the three year audit period 2002-2004, nodal status was unknown for 11,862 invasive breast cancers. For the 7,113 of these cancers that were treated with surgery, a known nodal status would be expected. This equates to 21% of the total number of cancers receiving surgery. Figure 18 shows how the proportion of surgically treated cancers without a known nodal status varies between regions and Celtic countries and indicates that there are particular issues to be addressed in Northern & Yorkshire, Thames, Northern Ireland, North West and South West where more than 20% of the surgically treated cases have unknown nodal status.

The severity of this issue from a clinical point of view is difficult to quantify, as it could arise either because the cases did not undergo a nodal procedure or because of data collection problems. The majority of the data supplied to cancer registries are obtained through the abstraction of the pathology reports which are automatically identified if the outcome is confirmed as cancer. As most cases have the breast and axillary specimen reported on the same pathology report, it is unlikely that 21% of cases were simply those that were not accessed by or sent to the registries because the pathology details were benign. It is, however, possible that a significant proportion of these cases had repeat operations involving only nodes where no tumour deposits were found (e.g. where a non-invasive non-operative diagnosis proves to be invasive in an operation where no nodes were removed).

Reports for these operations are not always identified to be sent to or accessed by registries as the histology code is not malignant. Such operations can, however, often be identified when cancer registration data are matched to HES data and the additional pathology reports can then be requested. Nodal status data are required in the same way as accurate and complete data on whole tumour size and grade to calculate case-mix adjusted survival rates, as this factor also strongly influences the outcome of the disease. Surgeons are therefore again encouraged to work with registries to ensure that the recording of nodal status data is as complete as possible.



**Figure 17: Nodal status of all the breast cancers diagnosed in 2002-2004**



**Figure 18: Variation with region and Celtic country in the proportion of surgically treated invasive cancers for which nodal status is unknown (breast cancers diagnosed in 2002-2004)**

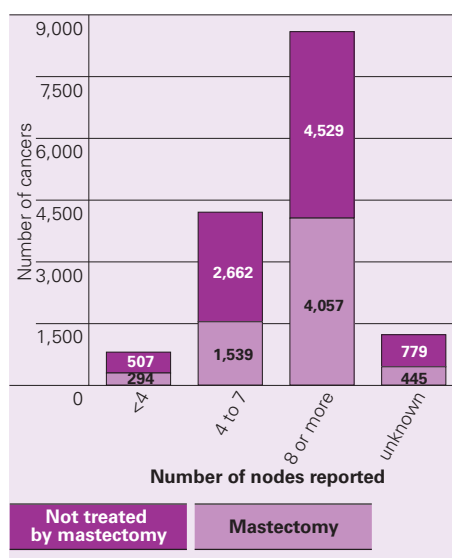


**Outcome Measure 8:  
Number and proportion of  
histologically node negative invasive  
breast cancers for which more than  
seven nodes were harvested**

Figure 19 shows that during the three year audit period 2002-2004, 8,586 cases had more than seven nodes reported for a cancer that was lymph node negative. Of these, 4,529 (53%) had their nodal operations undertaken in conjunction with a breast conserving procedure and, whilst 33% of these cases were grade 3, only 20% had an invasive size of greater than or equal to 25mm. The majority of these cancers were therefore of a relatively small size and breast units should carefully consider the benefits of removing such large numbers of nodes against the increased risk of the development of lymphoedema. Hopefully, with the introduction of sentinel lymph node biopsy, the number of cancers with large numbers of negative nodes reported will decrease rapidly.

Previously, guidelines have indicated that invasive cancers should have a minimum of four nodes removed to allow the full staging of the disease. However, with the advent of sentinel lymph node biopsy, suitable cases are only having the sentinel lymph node(s) removed in the first instance. Of the 801 cases in BCCOM Year 3 with fewer than four nodes removed, 17.5% had undergone a sentinel lymph node dissection procedure. This may, however, be an underestimate as, for 60.9% of cases, it was not known if a sentinel lymph node biopsy was performed. There is a higher rate of lymph node positivity in symptomatic breast cancers than in screen-detected breast cancers (when nodal status was obtained, 48% of the invasive cases included in BCCOM Year 3 were found to be node positive compared to 23% of the cases included in the NHSBSP/ABS at BASO audit of cancers screen-detected in 2005/6).

It is therefore anticipated that the use of sentinel lymph biopsy procedures will be more limited within the symptomatic field. However, surgeons are urged to contact their local cancer registry to ensure that they are informed when sentinel lymph node procedures have been undertaken and to ensure that they are able to accurately record these data.



**Figure 19: Variation with operation type in the number of nodes reported for cases with a negative nodal status**

## Outcome measures

### Outcome Measure 6: Mastectomy rate by size of breast tumour (invasive diameter): less than 15mm, 15-20mm, 21-35mm, 36-49mm, 50+ mm

The size of a breast cancer has been demonstrated to be the main factor affecting the decision to perform breast conserving surgery or a mastectomy. It is anticipated that smaller tumours can generally be treated safely with a breast conserving procedure, whereas large tumours would generally require a mastectomy. However, patient choice has a major impact on the type of therapeutic operation chosen and consequently one can see cases where a mastectomy has been undertaken for a small tumour or a conservative procedure for a large cancer.

In Figure 20 data are presented for invasive tumour size, as whole tumour size, a measure which includes any non-invasive component, is not recorded currently by all cancer registries. Figure 20 shows a clear increase in mastectomy rate with increasing invasive tumour size for the 43,661 invasive cases diagnosed in the three year audit period 2002–2004. However, the 31% mastectomy rate for breast cancers with invasive tumour size <15mm is of concern compared with the 19% mastectomy rate seen for screen-detected cancers of the same size range (NHSBSP and ABS at BASO audit, May 2007), and it is unlikely that this high value can solely be explained by patient choice.

It is accepted that other factors such as the presence of co-morbidities that have not been measured in this audit may have influenced decisions on operation type. Mastectomy might also be necessary for small invasive cancers when there is presence of a large non-invasive component. However, multi-disciplinary teams are encouraged to compare their own rates against these national data and to assess their own performance.

The invasive size of the tumour was unknown for 1,276 cases (7.7%) undergoing a breast conserving procedure and for 1,630 cases (9.7%) having a mastectomy. Figure 21 shows the variation in operation type between regions/Celtic countries for tumours with an invasive size <15mm. At 42% Trent appears to

have the highest mastectomy rate for this group and Northern Ireland and North West the lowest (19% and 23% respectively). However, as the proportion of cases with unknown operation type is very high in Northern Ireland and in the North West region; the pattern of care demonstrated for these areas may be inaccurate. The recording of operation type is essential, not only for the accurate auditing of breast cancer treatment, but also for monitoring survival variation in the future. Surgeons in these areas are therefore strongly encouraged to ascertain why the operation type is so poorly recorded by their local cancer registry and to work with them to ensure that this data item is recorded more completely in future.

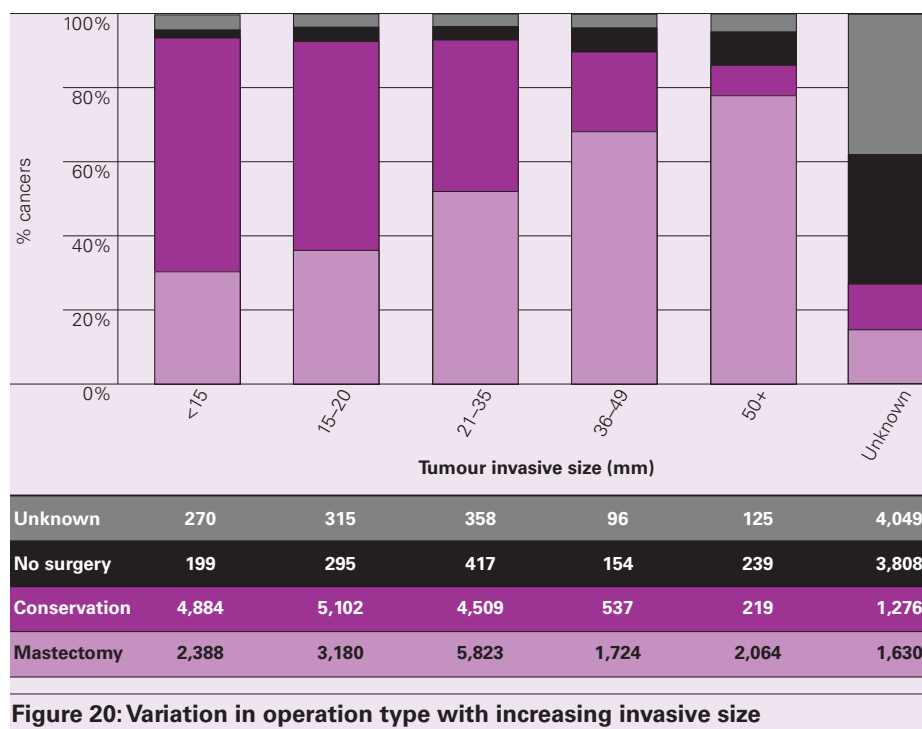


Figure 20: Variation in operation type with increasing invasive size

**Outcome Measure 4:  
Number and proportion of  
breast cancers given medical  
treatment only**

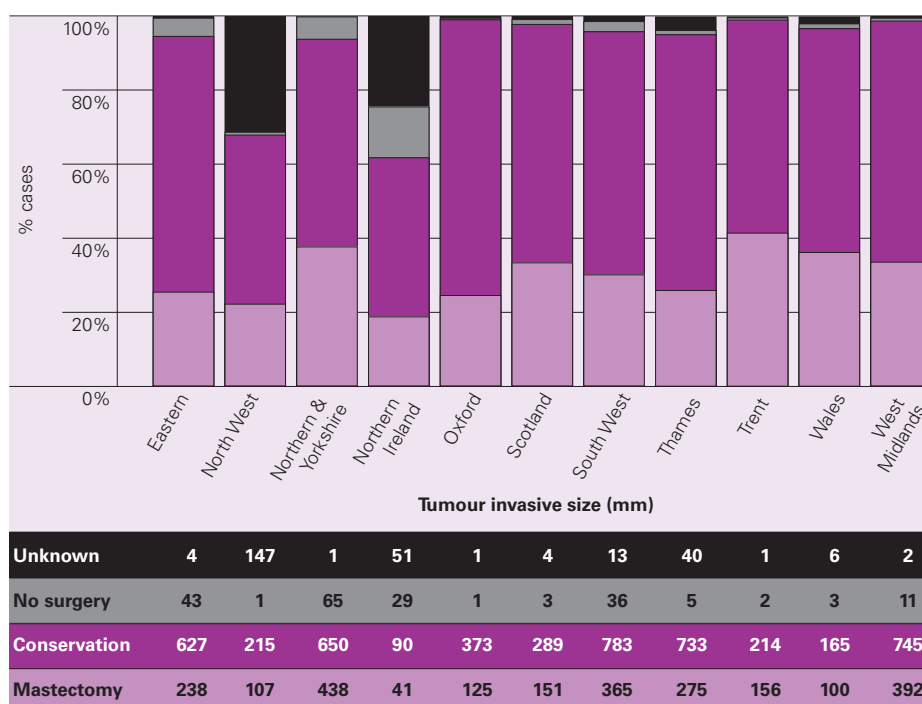
It is difficult to ascertain accurately the number of patients who are solely treated non-surgically following a diagnosis of breast cancer. From the BCCOM data, only the number of patients who did not undergo surgery can be identified and, until data collection of adjuvant treatment improves, this will be used as a proxy for this outcome measure.

Of the 43,661 patients diagnosed with invasive breast cancer in the three year audit period 2002–2004, 5,112 (11.7%) did not undergo any form of surgical treatment. Figure 22 shows that, as expected, the number of patients who did not receive surgery rises with increasing age, with only 39 (4.3%) of the 903

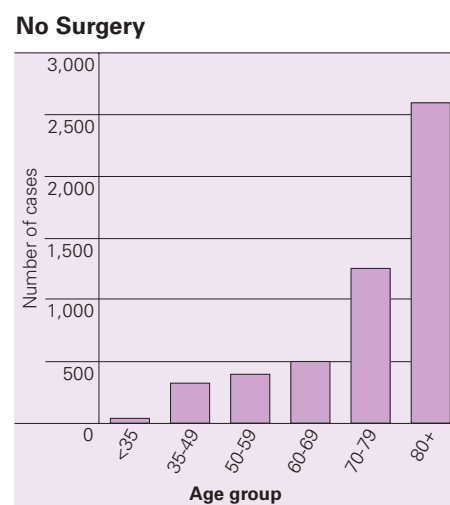
patients aged less than 35 not having surgery compared with 2,594 (37.1%) of the 7,002 patients aged over 80. It would be anticipated that the majority of the latter cases would have had strong contraindications against the use of surgery and as such would have been treated with hormonal therapy. Of the 5,112 invasive breast cancers cases that did not have surgery, 3,106 (61%) were recorded as having received hormone therapy but only 2,176 (43%) had known ER status. ER status is almost always available on pathology reports but is not always recorded by cancer registries.

Given the importance of receptor status in determining whether hormone therapy is provided, those cancer registries which do not record ER status presently should strive to do so in future.

When the cases not undergoing surgical treatment are broken down by region/Celtic country (Figure 23), big variations in the pattern of care are suggested, with the proportion of non-surgically treated cases being relatively high in Northern Ireland in cases aged under 50 (25% compared with 4% in the UK as a whole) and in cases aged 50-69 (18% compared with 6% in the UK as a whole). In Trent, Northern & Yorkshire and West Midlands more than 36% of cases aged 70 and over were recorded as not having surgical treatment. It is possible that these variations reflect true differences in clinical practice, and they could also be due in part to differences in population structure. A more likely explanation is, however, that other cancer registries are not receiving details of all the cases that are not surgically treated.



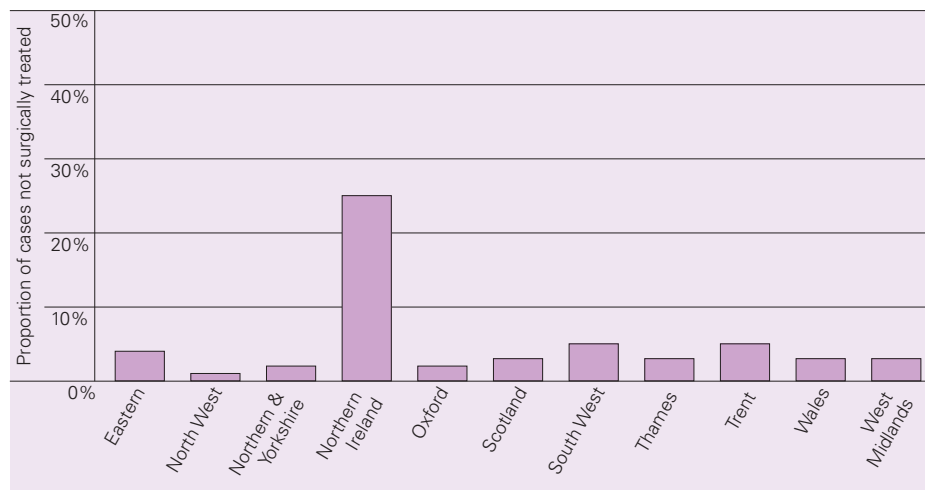
**Figure 21: Regional/Celtic country variation in operation type for tumours with an invasive size of less than 15mm**



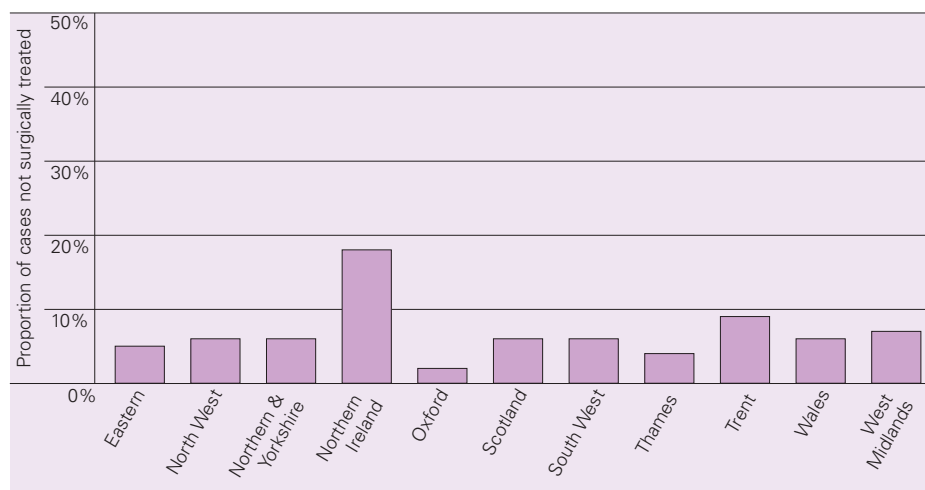
**Figure 22: Variation with age at diagnosis in the number of cases not undergoing surgical treatment**

## Outcome measures

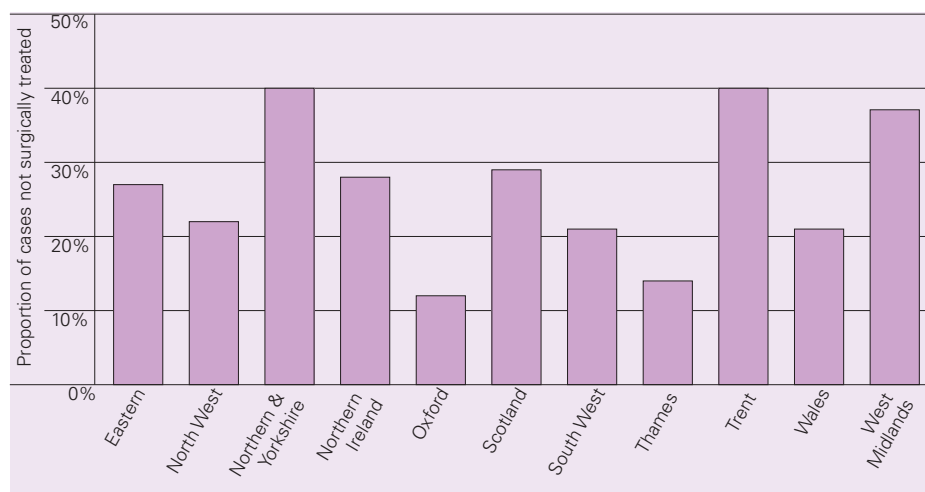
### Cases in age group "less than 50", not surgically treated (whole UK: 4%)



### Cases in age group "50-70", not surgically treated (whole UK: 6%)



### Cases in age group "70 or more", not surgically treated (whole UK: 28%)



**Figure 23: Variation with region and Celtic country in the proportion of invasive cases not receiving surgery (excluding cases with "unknown surgical treatment")**

All cancer registries are therefore encouraged to work with their local breast multidisciplinary teams to ensure that they are receiving details of all the non-surgically treated cancers diagnosed within their catchment area and particularly those in elderly patients. Similarly, Northern & Yorkshire and the West Midlands should investigate their cases without surgical treatment to ensure that they are not missing treatment data. The Trent cancer registry does not record surgical information, but participating surgeons checked 58% of the cases included in the age group "70 or more." For these checked cases, the figure of 40% of older patients not receiving surgery is therefore likely to be a true reflection of surgical practice.

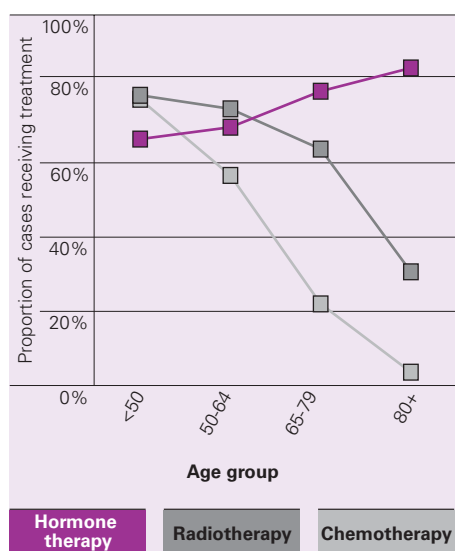
## Adjuvant therapy

Commentator: Adrian Harnett

The adjuvant treatment data collected by the BCCOM Project can be used to examine whether or not patients were treated with radiotherapy, chemotherapy and/or hormone therapy. Figure 24 combines data for the three year audit period 2002–2004 to examine how the proportions of patients recorded as having radiotherapy, chemotherapy and hormone therapy vary with age.

The recorded use of hormone therapy increases with age, with 85.6% of patients aged 80 and over receiving hormone therapy compared with 66.4% of patients aged less than 50. This older age group is less likely to receive surgical intervention and as such hormone therapy may be the only form of active treatment provided. In contrast, the recorded use of radiotherapy decreases with increasing age. 78.3% of the patients aged less than 50 received radiotherapy compared with 30.6% of patients aged over 80. The effect of age on recorded treatment modality is most marked for chemotherapy, where 77.2% of patients aged less than 50 received chemotherapy but only 21.9% of patients aged 65–79 and 16% of patients aged 65 and over.

Whilst these variations in treatment pattern with age are essentially those that one might expect to see, it is possible that the proportion of patients in each age band receiving each type of adjuvant therapy is underestimated because of incomplete data recording. Table 8 shows the improvement in adjuvant treatment data completeness in the three years since the start of the BCCOM Project. It is anticipated that adjuvant therapy data completeness will continue to improve as cancer registry databases are matched to Radiotherapy Dataset (RTDS) data and e-prescribing databases and with the continued support of the consultant surgeons across the UK in checking the data submitted to the Project.



**Figure 24: Variation in adjuvant treatment with age group for all cases submitted to BCCOM in 2002–2004 with known treatment**

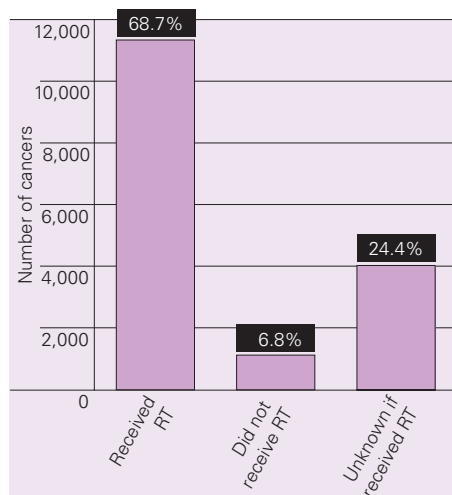
**Table 8: Percentage of cancers with unknown adjuvant treatment**

| % invasive cancers for which adjuvant treatment is unknown |              |              |                 |
|--|--------------|--------------|-----------------|
| Year of audit  | Radiotherapy | Chemotherapy | Hormone therapy |
| BCCOM Year 1   | 37%          | 36%          | 39%             |
| BCCOM Year 2   | 42%          | 46%          | 48%             |
| BCCOM Year 3   | 33%          | 32%          | 30%             |

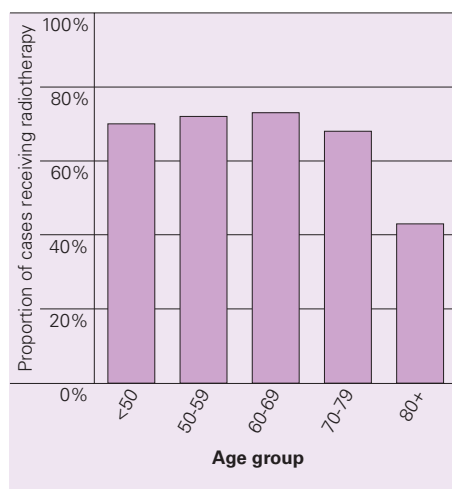
## Outcome measures

### Outcome Measure 9: Number and proportion of invasive breast cancers treated by conservation surgery and receiving radiotherapy

Data from clinical trials indicate that patients with invasive breast cancers treated with breast conserving surgery should be considered for adjuvant radiotherapy. 16,487 patients diagnosed with invasive breast cancer



**Figure 25: Administration of radiotherapy after conservation surgery**



**Figure 26: Variation in the administration of radiotherapy after conservation surgery with increasing age**

in the three year audit period 2002-2004 were treated with conservation surgery. Figure 25 shows that radiotherapy was recorded as having been received by 68.7% of these patients. 1,126 cases (6.8%) were recorded as not having received radiotherapy. For a further 4,029 case (24.4%), it was not known whether or not radiotherapy was provided.

Figure 26 shows, for the 11,332 cases treated with conservation surgery that were recorded as having received radiotherapy, that the administration of radiotherapy appears to be dependent, to a degree, on the age of the patient. Thus, only 43% of patients aged 80 and above received radiotherapy following their breast conserving surgery compared with 73% of patients in the 60-69 age group and 71% of those aged under 60.

At 69%, the proportion of patients treated with conservation surgery who received radiotherapy is somewhat lower than one might have expected, had multidisciplinary teams been basing their practice on the evidence from clinical trials. It is certainly possible that a significant proportion of the cases with unknown radiotherapy treatment did in fact receive radiotherapy. However, 1,126

cases were recorded as not receiving radiotherapy. Possible reasons for not prescribing radiotherapy are patient and tumour characteristics, the availability of radiotherapy resources and the distance that patients have to travel.

Table 9 shows the tumour characteristics of the 1,126 cases recorded as not receiving radiotherapy. 36% were node negative and 20% were grade 1 tumours. Only 95 were grade 3, node positive cancers.

It is interesting to also consider the use of radiotherapy following mastectomy. Figure 27 shows that 58.8% (6,584 cases) of patients received radiotherapy following a mastectomy. When these data are broken down by age, similar but less marked differences are apparent to those seen for patients having conservation surgery. Once again, radiotherapy rates decrease with increasing age, with only 23% of patients aged 80 or over (412 patients) receiving radiotherapy compared with 48% of patients aged under 50. Of the patients treated with a mastectomy who received radiotherapy, 68% had positive nodes.

**Table 9: Characteristics of the cases treated by conservation surgery without radiotherapy**

| Invasive grade | Node negative | Node positive | Unknown nodal status | TOTAL        |             |
|----------------|---------------|---------------|----------------------|--------------|-------------|
| 1              | 98            | 15            | 116                  | 229          | 20%         |
| 2              | 165           | 88            | 159                  | 412          | 37%         |
| 3              | 112           | 95            | 100                  | 307          | 27%         |
| Unknown        | 30            | 19            | 129                  | 178          | 16%         |
| <b>TOTAL</b>   | <b>405</b>    | <b>217</b>    | <b>504</b>           | <b>1,126</b> | <b>100%</b> |
|                | <b>36%</b>    | <b>19%</b>    | <b>45%</b>           | <b>100%</b>  |             |

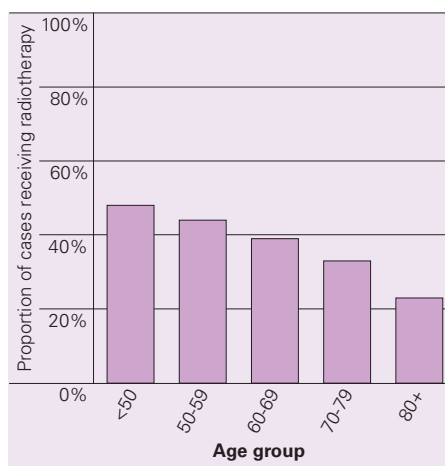
**Outcome Measure 10:  
Number and proportion of node positive patients with invasive breast cancers, aged less than 60, receiving chemotherapy**

The use of chemotherapy is indicated for invasive cancers with positive axillary nodal status.

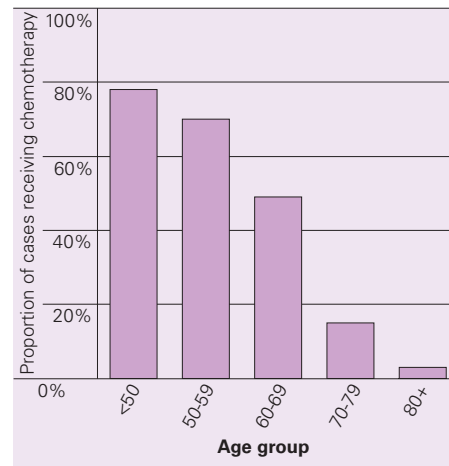
13,100 (30%) patients diagnosed with invasive breast cancer in the three year audit period 2002-2004 were node positive. Chemotherapy was recorded as having been received by 53% of these patients. 2,630 cases (20.1%) were recorded as not having received chemotherapy. For a further 3,524 case (26.9%), it was not known whether or not chemotherapy was provided.

Figure 28 shows how the proportion of node positive cancers recorded as receiving chemotherapy in the three year audit period 2002-2004 varies with age. There is a significant variation with age, with only 49% of node positive patients aged 60-69 receiving chemotherapy and less than 12% of patients aged 70 or over receiving chemotherapy.

This is in marked contrast to the 75% of patients aged less than 60 receiving chemotherapy. This difference may be a true reflection of decisions taken by oncologists on the basis of using tools such as Adjuvant-on-line to calculate the benefit from chemotherapy which indicate that the benefit of chemotherapy may be very small (less than 5%) even with 1-3 positive nodes. The balance of risks and benefits for the use of chemotherapy in the elderly may thus be different to that in younger patients. Hopefully, further information on this will be provided by the ACTION trial of chemotherapy in the elderly which is just opening. In the meantime, analysis of survival rates for elderly patients in the BCCOM cohort who were given chemotherapy, could give an indication of the efficacy of such treatment in the general population.



**Figure 27: Variation in the administration of radiotherapy after mastectomy with increasing age**



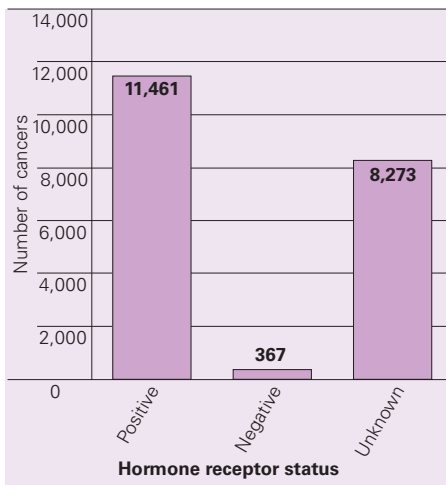
**Figure 28: Variation in chemotherapy rates with increasing age in node positive patients**

## Outcome measures

### Outcome Measure 11: Number and proportion of patients with ER positive invasive breast cancers, receiving hormone therapy

The role of hormone therapy in the treatment of female breast cancers is well documented. As such one would expect that all women with an ER or PR positive breast cancer would be prescribed hormone therapy. In the UK, ER status was known for 19,062 (43.6%) invasive cancers and PR status for 7,089 (16.2%) cancers. The BCCOM data in Figure 29 combine cases that are ER and/or PR positive and class these as hormone receptor positive.

Of the cases with known hormone treatment and that were receptor positive, 11% (1,241 cases) did not receive any form of hormone treatment. For 16% (2,418 cases) of the receptor positive invasive cancers, the treatment details were unknown.

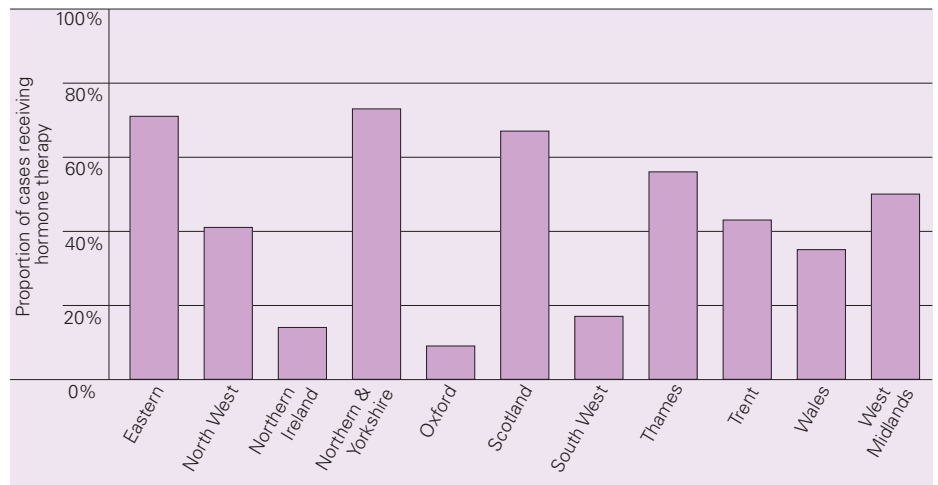


**Figure 29: Receptor status of invasive cases receiving hormone therapy**

Only 3,961 cases were receptor negative and of these, 9% (367 cases) were prescribed hormone therapy even though there is little evidence of any benefit apart from a small reduction in the occurrence of contra-lateral breast cancer to counteract the risk of such patients developing a uterine cancer or thromboembolism.

For a large number of cases it was not known whether or not hormone therapy was prescribed. Figure 30 shows that during the three year audit period 2002–2004, only three of the 11 registries (Eastern, Northern & Yorkshire and Scotland) appear to have reliably and completely recorded whether or not hormone therapy was provided. Recent changes indicate that data quality will improve in this area to support future years of the BCCOM Project. However, the level of detail being recorded for hormone therapy needs to be carefully examined.

Currently, the majority of cancer registries simply record that the patient received hormone therapy and not whether it is Tamoxifen or an Aromatase Inhibitor. Similarly, details of patients who have switched regimes due to side effects or as part of planned treatment protocols are not collected. As this information will be considered the minimum requirement in the monitoring of equal access to cancer treatment in the future, processes need to be implemented now to ensure that this level of detail can be routinely collected and recorded. The introduction of the e-prescribing initiative in acute Trusts and the roll out of electronic patient records systems in general practice should mean that these important data are more widely available in future.



**Figure 30: Variation in the number of invasive cases receiving hormone therapy by region/Celtic country**



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# Non-invasive breast cancer

# Non-invasive breast cancer

### **Non-invasive breast cancers are rarely diagnosed in symptomatic patients due to the infrequent occurrence of non-mammographic signs and symptoms.**

During the first three years of the BCCOM Project, a total of 2,842 (6%) non-invasive breast cancers were submitted to the audit. 19 of these cancers were diagnosed in males. Table 10 shows the number of non-invasive breast cancers submitted by each cancer registry in each year of the BCCOM audit. The data indicate that there may be some contamination with screen-detected non-invasive breast cancers, particularly in those registries where non-invasive breast cancers constitute more than 7% of the total. This is reinforced by the data in Figure 31 which show that the highest numbers of non-invasive breast cancers were found in the screening age group 50-64.

The majority (67.6%) of the non-invasive cases had an unknown size. This is a frequent issue with non-invasive cancers as the tumour size can be larger than the standard blocks utilised in pathology departments.

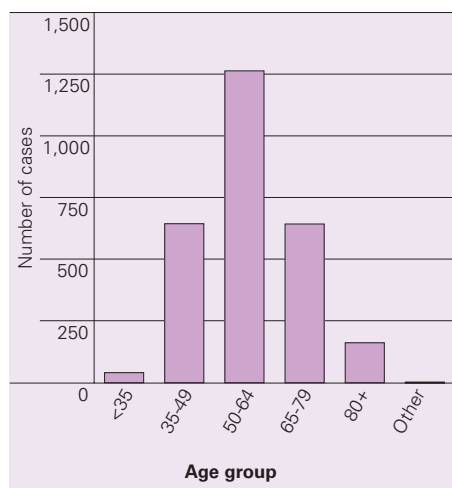
Figure 32 shows that the majority of non-invasive breast cancers (44.8%) were treated with breast conserving surgery. Figure 33 shows the variation in the number of non-invasive cancers treated by 302 individual surgeons during the three year audit period 2002-2004. The mean number of cases treated by an individual surgeon is 9 and the range 1 to 40.

In the future, it is hoped that more accurate recording by cancer registries of the method of detection should allow detailed comparison of symptomatic non-invasive cases included in BCCOM with the screen-detected non-invasive cases included in the Sloane Project (The Sloane Project Annual Report, May 2007, [www.sloaneproject.co.uk](http://www.sloaneproject.co.uk)).

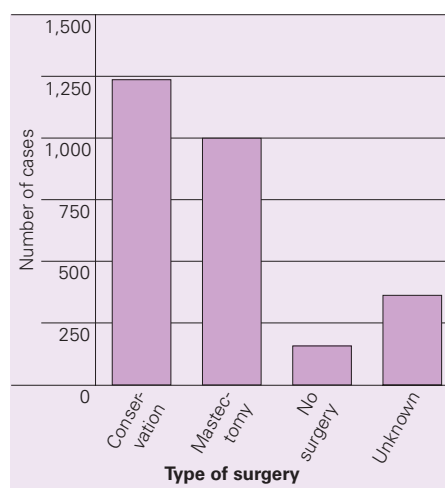
**Table 10 – Distribution by region/Celtic country of the non-invasive breast cancers included in BCCOM cohort**

| Region or Celtic country | Year of Diagnosis |              |                |               |              |                |               |              |                |
|--------------------------|-------------------|--------------|----------------|---------------|--------------|----------------|---------------|--------------|----------------|
|                          | 2002              |              |                | 2003          |              |                | 2004          |              |                |
|                          | All cases         | Non-invasive | % non-invasive | All cases     | Non-invasive | % non-invasive | All cases     | Non-invasive | % non-invasive |
| Eastern                  | 1,691             | 167          | 9.9%           | 997           | 93           | 9.3%           | 1,507         | 98           | 6.5%           |
| North West               | 1,091             | 47           | 4.3%           | 524           | 32           | 6.1%           | 1,397         | 109          | 7.8%           |
| Northern & Yorkshire     | 2,419             | 187          | 7.7%           | 2,029         | 107          | 5.3%           | 1,910         | 114          | 6.0%           |
| Northern Ireland         | 640               | 58           | 9.1%           | 367           | 20           | 5.4%           | 432           | 27           | 6.3%           |
| Oxford                   | 1,341             | 69           | 5.1%           | 1,442         | 76           | 5.3%           | 899           | 52           | 5.8%           |
| Scotland                 | 934               | 40           | 4.3%           | 181           | 6            | 3.3%           | 1,836         | 76           | 4.1%           |
| South West               | 3,253             | 278          | 8.5%           | 1,001         | 56           | 5.6%           | 2,234         | 121          | 5.4%           |
| Thames                   | 1,750             | 25           | 1.4%           | 2,709         | 225          | 8.3%           | 1,530         | 114          | 7.5%           |
| Trent                    | 408               | 39           | 9.6%           | 1,588         | 83           | 5.2%           | 1,453         | 73           | 5.0%           |
| Wales                    | 351               | 8            | 2.3%           | 952           | 24           | 2.5%           | 1,201         | 99           | 8.2%           |
| West Midlands            | 2,529             | 119          | 4.7%           | 2,330         | 104          | 4.5%           | 2,340         | 96           | 4.1%           |
| <b>TOTAL</b>             | <b>16,407</b>     | <b>1,037</b> | <b>6.3%</b>    | <b>14,120</b> | <b>826</b>   | <b>5.8%</b>    | <b>16,739</b> | <b>979</b>   | <b>5.8%</b>    |

Highlighted in purple, regions where more than 7% of all cases were non-invasive.

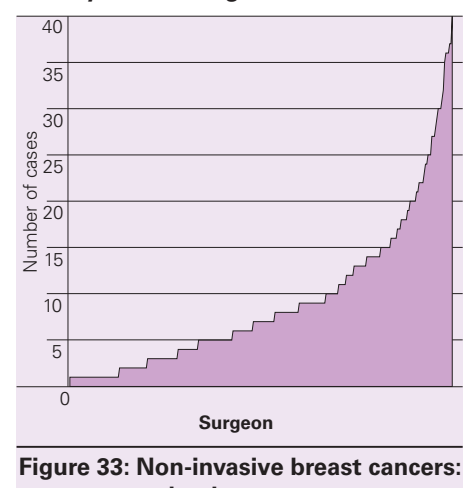


**Figure 31: Non-invasive breast cancers: age distribution**



**Figure 32: Non-invasive breast cancers: surgical treatment**

**Cases treated by 302 surgeons over three years (Average = 9)**



**Figure 33: Non-invasive breast cancers: surgeon caseload**

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# Male breast cancers

# Male breast cancers

## 384 male breast cancers were included in the BCCOM Project.

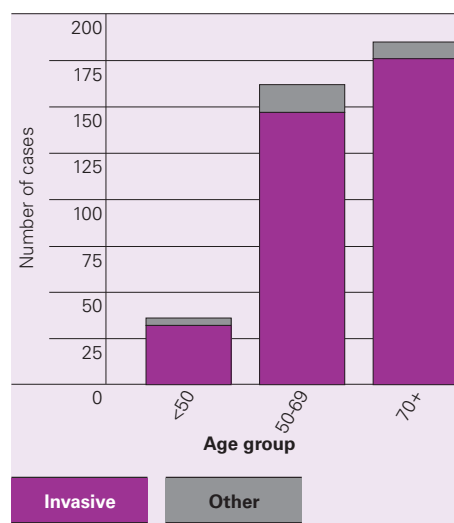
The age distribution of the cases is shown in Figure 34. 48% (185 cases) were in the 70+ age group and 9% were aged under 50. 68% of the invasive cases (243 cases) were treated with mastectomy (Figure 35) and only 8% by conservation surgery. Owing to the small number of male breast cancers, it is unsurprising that the number of cases treated by the 180 surgeons is very low with a mean of 2 (range 1 to 8).

The Nottingham Prognostic Index (NPI) score could be calculated for 199 (56%) invasive cases. Absence of nodal status was the main reason why NPI could not be calculated: 85% of the cases for which NPI could not be calculated had an unknown nodal status. Figure 36 shows that the NPI scores were spread relatively evenly through the Good (GPG), Moderate (MPG1, MPG2) and Poor (PPG) prognostic groups, with only a few cases included in the Excellent Prognostic Index Group (EPG).

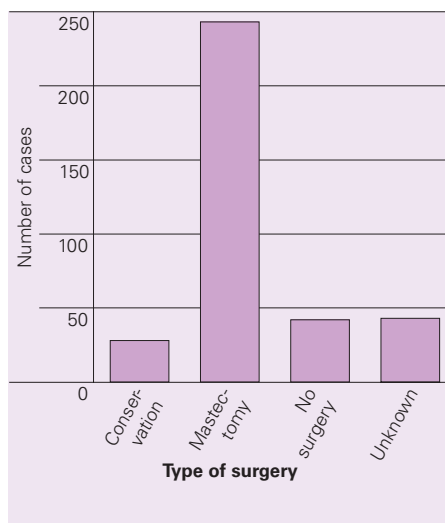
This is likely to be due to patients not noticing or ignoring symptoms for a length of time either due to embarrassment or lack of knowledge that breast cancer can affect males. Most cases with a known NPI had a mastectomy. Cases with an unknown NPI score were treated primarily with mastectomy but 14 underwent breast conserving surgery.

Of the 42 invasive male breast cancer patients who were not treated surgically, 27 were recorded as having had at least one form of adjuvant therapy. Of the 356 invasive male breast cancers diagnosed in 2002–2004, 146 (41%) had a positive hormone receptor status recorded. Of these, 76% were prescribed hormone therapy. This is very similar to the situation found for invasive female breast cancers, with 35% (14,972/43,302) recorded as having a positive receptor status and 76% of those receiving hormone therapy.

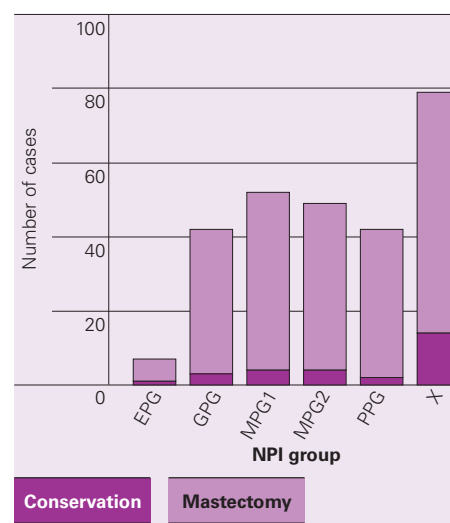
Detailed information about male breast cancer is currently being collected as part of the Male Breast Cancer Study which is being carried out by Professor Anthony Swerdlow at the Institute of Cancer Research and Professor Alan Ashworth, Director of the Breakthrough Breast Cancer Research Centre. The Male Breast Cancer Study is a five year study recruiting 1,000 men who have breast cancer in England and Wales and 1,000 men of a similar age and background who have not had breast cancer. Participants will be asked to complete a questionnaire (this will be done by face-to-face interview with a nurse) and provide a blood sample. The study will provide information on the genetic, environmental and behavioural causes of male breast cancer and may also provide novel insights into the causes of breast cancer in women.



**Figure 34: Male breast cancers: age distribution**



**Figure 35: Male breast cancers: surgical treatment**



**Figure 36: Variation in the treatment of male breast cancers with NPI**

## Abbreviations

|                    |   |
|--------------------|---|
| <b>ABS at BASO</b> | Association of Breast Surgery at the British Association at Surgical Oncology |
| <b>BC</b>          | Breast Cancer   |
| <b>BCCOM</b>       | Breast Cancer Clinical Outcome Measures                                       |
| <b>CT</b>          | Adjuvant chemotherapy   |
| <b>EPG</b>         | Excellent Prognostic Group (NPI group)  |
| <b>ER</b>          | Oestrogen receptor  |
| <b>GPG</b>         | Good Prognostic Group (NPI group)   |
| <b>HER2</b>        | Human epidermal growth factor receptor 2                                      |
| <b>HT</b>          | Adjuvant hormone therapy  |
| <b>MPG1</b>        | Moderate Prognostic Group 1 (NPI group)                                       |
| <b>MPG2</b>        | Moderate Prognostic Group 2 (NPI group)                                       |
| <b>PPG</b>         | Poor Prognostic Group (NPI group)   |
| <b>NHSBSP</b>      | NHS Breast Screening Programme  |
| <b>NPI</b>         | Nottingham Prognostic Index   |
| <b>PgR</b>         | Progesterone receptor   |
| <b>QARC</b>        | Quality Assurance Reference Centre  |
| <b>RT</b>          | Adjuvant radiotherapy   |
| <b>UK</b>          | United Kingdom  |
| <b>UKACR</b>       | The United Kingdom Association of Cancer Registries                           |
| <b>WMCIU</b>       | West Midlands Cancer Intelligence Unit  |

