Breast Cancer Clinical Outcome Measures (BCCOM) Project

Analysis of the management of symptomatic breast cancers diagnosed in 2002

1st Year Report March 2006

West Midlands
Cancer Intelligence Unit

breakthrough
breast cancer

Contents

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Contributions from BCCOM Project Steering Group

Mr Ian Monypenny
BCCOM Project Steering Group Chair
Consultant Breast Surgeon, Llandough Hospital

It is my great pleasure to welcome you to the first report of the Breast Cancer Clinical Outcome Measures (BCCOM) Project which analyses the management of cases of breast cancer diagnosed in 2002. This project marks another attempt to capture and analyse symptomatic breast cancer data which are representative of current practice across the UK. In 2001/2 only 83 of UK Breast Units submitted data to the previous incarnation of a National Symptomatic Audit and this fell to 50 Breast Units in 2002/3. This meant that we had data on less than 8,000 breast cancers. An alternative approach had to be found and this led to the setting up the BCCOM Project which utilises the data already recorded on regional cancer registration databases. Already the BCCOM approach has proven very successful even though it is only in its first year. This booklet contains data on 16,407 cancers which represents a significant improvement and we hope to build on this success in future audits.

At a time when the calls on a surgeon's time are multiple and when data managers are an increasingly rare resource, I wish to thank and congratulate all of you who have contributed to this year's audit, in particular the 94 surgeons who checked or partially checked their data. A list of all surgeons whose data make up this report is included on pages 2 and 3 of this report. In addition, I wish to thank the cancer registries that were able to participate in the audit and I hope that this support will be sustained for future working together. I encourage all surgeons to work collaboratively with their cancer registries to maintain and improve this excellent resource.

The results of this audit will allow individual breast units to compare their performance within their own region and with the national average in the same way they have been able to do for the screening element of their service since 1996. Although the same numbers of performance standards do not exist for the symptomatic service, important outcome measures have been produced for some key areas including operation type, ascertainment of nodal status and access to adjuvant therapies.

Unfortunately the data included in the first BCCOM audit are not exclusively on symptomatic cases for all regions, as knowledge of which cancers were screen detected and which were symptomatic was not routinely collected by the majority of cancer registries for the period audited. During this summer the regional breast screening QA reference centres and cancer registries have been working hard to resolve this problem and I am confident that this will be less of an issue in the audit of 2003 cases.

Finally I wish to thank Breakthrough Breast Cancer whose financial support has made the BCCOM Project possible and has safeguarded the continuance of the project until 2007.

It only remains for me to say how pleased I am that the BCCOM Project is proving to be such a success and I look forward to working with you to build on this success in future audits. If you have any suggestions or comments on the audit, please do not hesitate to contact Dr Catherine Lagord, the BCCOM Project Manager, who will ensure that all such communications are circulated and discussed by the BCCOM Steering Group.

Contributions from BCCOM Project Steering Group

Dr Norman Freshney
Director of Research Management
Breakthrough Breast Cancer

Breakthrough Breast Cancer is the UK's leading charity, committed to fighting breast cancer through research and education. Breakthrough was founded in 1991 with the mission of creating a dedicated Breast Cancer Research Centre to bring scientists and clinicians together in a multi-disciplinary approach to breast cancer research. In 1999, the Breakthrough Toby Robins Breast Cancer Research Centre was opened at The Institute of Cancer Research in London and today about 100 scientists work there. In 2004 we launched the Breakthrough Generations Study, an investigation into the causes of breast cancer that will recruit and collect information from over 100,000 women in the UK.

Breakthrough's research programme is aimed at bringing scientific expertise together to develop better diagnostic and prognostic techniques, safe and targeted treatments for people with breast cancer and to find new ways of preventing the disease.

In addition to funding high quality research, Breakthrough promotes breast cancer education and awareness among the public, policy makers, health professionals and the media. We also campaign for improvements in breast cancer services and treatments. Our approach is diverse, ranging from parliamentary work, working with other cancer charities, working with health professionals and grass roots campaigning by members of the Breakthrough Campaigns and Advocacy Network (Breakthrough CAN).

In 2003, Breakthrough was pleased to agree funding for the BCCOM Project in which high quality data on breast cancer cases will be collected effectively in order to compare current practices and clinical outcome. This important study has the potential to lead to improvements in disease management and changes to clinical guidelines.

Mr Hugh Bishop
President of the Association of Breast Surgery at BASO
Consultant Breast Surgeon, Royal Bolton Hospital

Symptomatic audit in breast cancer has long been the poor relation of its screen detected cousin. A number of enthusiasts have made valiant attempts to deliver a national symptomatic breast audit. Sadly, their efforts, courageous though they were, are best summed up in the phrase, "breaking windows with guineas".

In the end, rickety financially unsupported efforts will result in unreliable data. Audit data have to be reliable if they are to be used to monitor and improve clinical practice. This costs money. The BCCOM Project is thus extremely grateful to Breakthrough Breast Cancer for providing the initial three year grant to launch this important national audit.

The concept is disarmingly simple and was devised by Gill Lawrence, who runs the BCCOM Project from the West Midlands Cancer Intelligence Unit. Essentially the BCCOM Project provides the link between the clinicians with their data and their local cancer registries which receive breast cancer data from multiple sources. All the clinician has to do is to check the quality of the data that the local cancer registries have on their patients.

The BCCOM Project has got off to a good start and so far data for 16,407 patients have been collated and analysed. Some regions have found it easier to contribute than others, but we still prefer the enthusiastic volunteer approach to compulsion. We encourage you to contribute and to allow a well conceived symptomatic breast cancer audit to flourish such that it can help us to improve the quality of service that we give to our patients.

Contributions from BCCOM Project Steering Group

Mr Chris Carrigan
National Cancer Registration Co-ordinator

There is an increased drive nationally to deliver high quality clinical audits on a UK-wide basis. This has been attempted in a variety of ways for different tumour sites, with varying levels of success in terms of outcomes and engagement with the relevant professional groups.

The significance of the BCCOM audit of symptomatic breast cancers is that it embodies a different approach to attaining this goal. The BCCOM Project aims to build on what is already collected in terms of breast cancer data and encourages clinical engagement to add additional detail and quality to the dataset. I am sure that you will agree that the results of this methodology which are summarised in this first Annual Report already endorse this innovative approach.

After only 15 months, the BCCOM Project has not only been able to capture 45% of the eligible breast cancer cases from existing data sources, but has also improved across the UK the levels of engagement between cancer registries and clinical teams. In addition, the Project has given the registries the opportunity to validate and augment their data with additional clinical details. This has all been achieved with the support of a charitable grant from Breakthrough Breast Cancer.

The bulk of the work generated by the BCCOM Project is managed locally between the cancer registries and their responsible surgeons. Once the data validation has been completed to both parties' satisfaction, the data are transferred in a non identifiable format to the West Midlands Cancer Intelligence Unit (WMCIU). The WMCIU acts as the national co-ordination centre for the BCCOM Project, ensuring that confidentiality and security best practice is followed at all times. The systems employed ensure that access to named information is limited to those individuals who already have access to these data. Also, as duplicates are removed by local cancer registries and their surgeons during the initial stages of the audit, identifiable data are not required to ensure data quality at the amalgamation and analysis stages.

The BCCOM Project has received strong support from both the United Kingdom Association of Cancer Registries and the National Cancer Registration Advisory Group and all regional cancer registries have been actively encouraged to participate. It is therefore pleasing to note that participation in the second year of the project has increased significantly, and I would like to applaud the Trent Cancer Registry in particular for having now put the systems in place to enable them and their surgeons to participate in this significant and important national audit.

Contributions from BCCOM Project Steering Group

Mr Tim Archer

CSC-IP National Clinical Lead for Breast Cancer
Consultant Breast Surgeon, Ipswich Hospital

The Cancer Services Collaborative Improvement Partnership (CSC-IP) welcomes the efforts of the BCCOM Project to improve the audit of symptomatic breast cancer in the UK and is delighted to be represented on the BCCOM Project Steering Group.

The main purpose of the CSC-IP is to improve the patient care pathway (patient journey). The widely differing standards between the audit of breast cancer in symptomatic and screened patients have long been a cause for anxiety within the CSC-IP. Accurate and audited information on the diagnosis and treatment of symptomatic breast cancer will undoubtedly lead to improvements of the outcomes of the breast cancer patient journey, as the data collected via the BCCOM Project are fed back to breast care teams as part of the audit cycle.

The CSC-IP attempts to initiate change in systems using innovative methods for service improvement. The BCCOM Project is an excellent example of the Plan Do Study Act (PDSA) cycle which can work very rapidly to enable change without recourse to unwieldy bureaucracy. As a result of the increased contact between cancer registries and breast cancer multi-disciplinary teams which is a key feature of the BCCOM Project, it is anticipated that the functioning of both groups will be enhanced, thus producing more timely, accurate information to improve breast cancer care.

Experiences from Northern Ireland

Dr Richard Middleton
Data Manager
Northern Ireland Cancer Registry

Mr Alan Wilkinson
Consultant Surgeon
Belfast City Hospital

The first year of the BCCOM Project was a learning experience for all involved in the Project. Eight local surgeons who are all also involved in the ABS at BASO audit of screen-detected breast cancer, agreed to take part in the Project. In total, information on 646 symptomatic patients was collected, which represents over half of all breast cancer patients in Northern Ireland diagnosed in 2002. The information held on these patients by the Northern Ireland Cancer Registry (NICR) was sent out to clinicians for verification.

The returns were very informative and identified key gaps in the Registry's information. In particular, because the NICR is an automated cancer registry, we do not actively search patients' notes for staging and treatment information, but rely heavily on electronic sources such as the Hospital Administration System (PAS) OPCS IV codes for information on surgery. Staging information is available only through reading of electronically received histopathology reports. This only gives us pathological stage, and it is realised that this may "understage" some patients or miss staging information completely for others.

From the clinical point of view the exercise was helpful in identifying patients in existing databases for inclusion in the Project. However, difficulties were experienced by the surgeons, in particular that there was not enough time to fully complete all the items required for the Project. There were also problems in that the cancer registry had wrongly assigned some patients to a different clinician as they usually rely on the person to whom the initial histopathology is sent. For some patients this was not necessarily the same clinician who had responsibility for the patients' overall breast cancer treatment.

In November the NICR met with the majority of the breast cancer surgeons currently operating in Northern Ireland to discuss ways to help the BCCOM Project progress. The meeting identified ways of both sides communicating better with a view to improving data quality for the Project. It is expected that more clinicians may also join in the Project. Both sides agreed that talking to one another can only benefit the whole process.

Executive Summary

Key Facts and Figures from the First Year of the BCCOM Project

Mr Tom Bates
Consultant Surgeon, William Harvey Hospital

Dr Gill Lawrence
Director, West Midlands Cancer Intelligence Unit and Regional Director of Breast Screening Quality Assurance

The following tables and figures summarise the results from Year 1 of the BCCOM Project. Data are provided for a total of 16,407 breast cancers diagnosed in 2002 in 11 of the 12 UK regions by 191 breast surgeons. Whilst the vast majority of breast cancers were diagnosed in women, 132 male breast cancers were included in the audit. Patients were aged between 22 and 102 years, with the median age being 61.4 years. 2,094 deaths (representing 12.8% of the original cohort) were recorded before 1 April 2005.

The majority of symptomatic breast cancers were diagnosed non-operatively by core biopsy with the proportion diagnosed on the basis of cytology alone rising from less than 2% in patients aged 50-64 to 12% in those aged 80 and above. Overall, 60% of invasive breast cancers had a known nodal status. The proportion of cancers with unknown nodal status rose from 32% in patients aged 50-64 to 70% in those aged 80 and above. Nodal positivity varied between 12% for small cancers (less than 10mm diameter) to 81% for large cancers (50mm diameter or more). A Nottingham Prognostic Index (NPI) score could be calculated for 55% of the invasive breast cancers. For those cases with an NPI score, 31% fell into the excellent and good prognostic groups.

The proportion of patients not receiving surgery increased from only 6% in those aged 50-64 to 41% in those aged 80 and above. Overall, 48% of the surgically treated cases received a mastectomy, but mastectomy rates varied between regions from 36% to 53% and between surgeons from 19% to 92%. Mastectomy rates were higher for large breast cancers, increasing from 30% for cancers with diameter less than 20mm to 75% for cancers with diameter greater than 50mm. The proportion of patients treated with radiotherapy and chemotherapy fell sharply with age, while the proportion treated with hormone therapy increased with age.

Comparison of Symptomatic and Screening Outcome Data in the West Midlands

The final section of this report contains a comparison of outcome data for screen-detected and symptomatic breast cancers diagnosed in the West Midlands region in 2002. Non-invasive breast cancers were less frequent in the symptomatic cohort forming only 5% of the total compared with 23% for the screen-detected cohort. Symptomatic cancers were generally larger (only 15% with diameter less than 15mm compared with 49% of screen-detected cancers) and were more likely to be node positive (43% compared with 28%). Overall, only

27% of the screen-detected breast cancers had a mastectomy compared with 40% of the symptomatic cohort, and small invasive symptomatic breast cancers were more likely to receive a mastectomy than equivalently sized screen-detected breast cancers (31% compared with 16% for cancers with diameter less than 15mm).

An NPI score could be calculated for 99% of screen-detected invasive breast cancers compared with only 72% of symptomatic invasive breast cancers. For invasive breast cancers with a known NPI score, 59% of screen-detected cancers fell into the excellent and good prognostic groups compared with only 29% of the symptomatic breast cancers. For women aged under 65, the proportion with screen-detected cancers receiving chemotherapy was much lower than in those with symptomatic cancer (20% compared with 36%). These women were also less likely to receive radiotherapy (48% compared with 63%).

Looking to the Future

The second year of the BCCOM Project is already under way and data for 2003 are being sent out by cancer registries to their local breast surgeons. Details of the steps involved in the audit and the dates by which these should be completed are provided in Appendix 2. The process will culminate in the presentation of the year 2 results at the ABS at BASO Annual Conference at the East Midlands Conference Centre in Nottingham on 14 June 2006.

In order to address issues and concerns raised during the first year of the BCCOM Project, a number of changes have been introduced. To ensure that only symptomatic breast cancers are included in the second year of the BCCOM Project, breast screening QA reference centres have sent to their local cancer registries, details of all the breast cancers detected by screening in 2003. This will mean that cancer registries should be able to exclude screen-detected breast cancers from the cohort sent out to surgeons.

In the first year of the BCCOM Project, a number of registries were either unable to prepare data for named surgeons or did so with considerable difficulty. This meant that, in some cases, a large number of breast cancers had to be excluded from the audit. Therefore, in the second year of the BCCOM Project, if the surgeon is not known but the hospital of diagnosis is recorded, breast cancer data will be sent to the lead breast surgeon in each hospital and the lead breast surgeon will liaise with his/her colleagues to validate the data. ABS at BASO regional symptomatic surgical representatives have been asked by the President of ABS at BASO to liaise with their local cancer registry to ensure that the names and contact details of all of the lead breast surgeons are known. The guidance on consent sent out to surgeons is provided in Appendix 3.

ABS at BASO regional symptomatic surgical representatives have also been asked to meet with their local cancer registry directors in order to:

- Review the process of data collection for symptomatic breast cancer in their region;
- Review the flow of data from breast units to the cancer registry in order to identify bottlenecks;
- Identify collaborative solutions to improve the completeness and accuracy of the data held at the cancer registry; and
- Plan for the future, in particular, ways to improve the engagement of local surgeons in the next BCCOM audit.

Meetings between ABS at BASO symptomatic representatives and cancer registries have now taken place in many UK regions and they have provided an excellent opportunity to start discussions on how best to resolve with local surgeons any issues regarding data completeness and accuracy raised by the BCCOM Project. The contribution from Dr Middleton and Mr Wilkinson in this Annual Report demonstrates how valuable these meetings can be.

Key Results for the United Kingdom

1. Participation

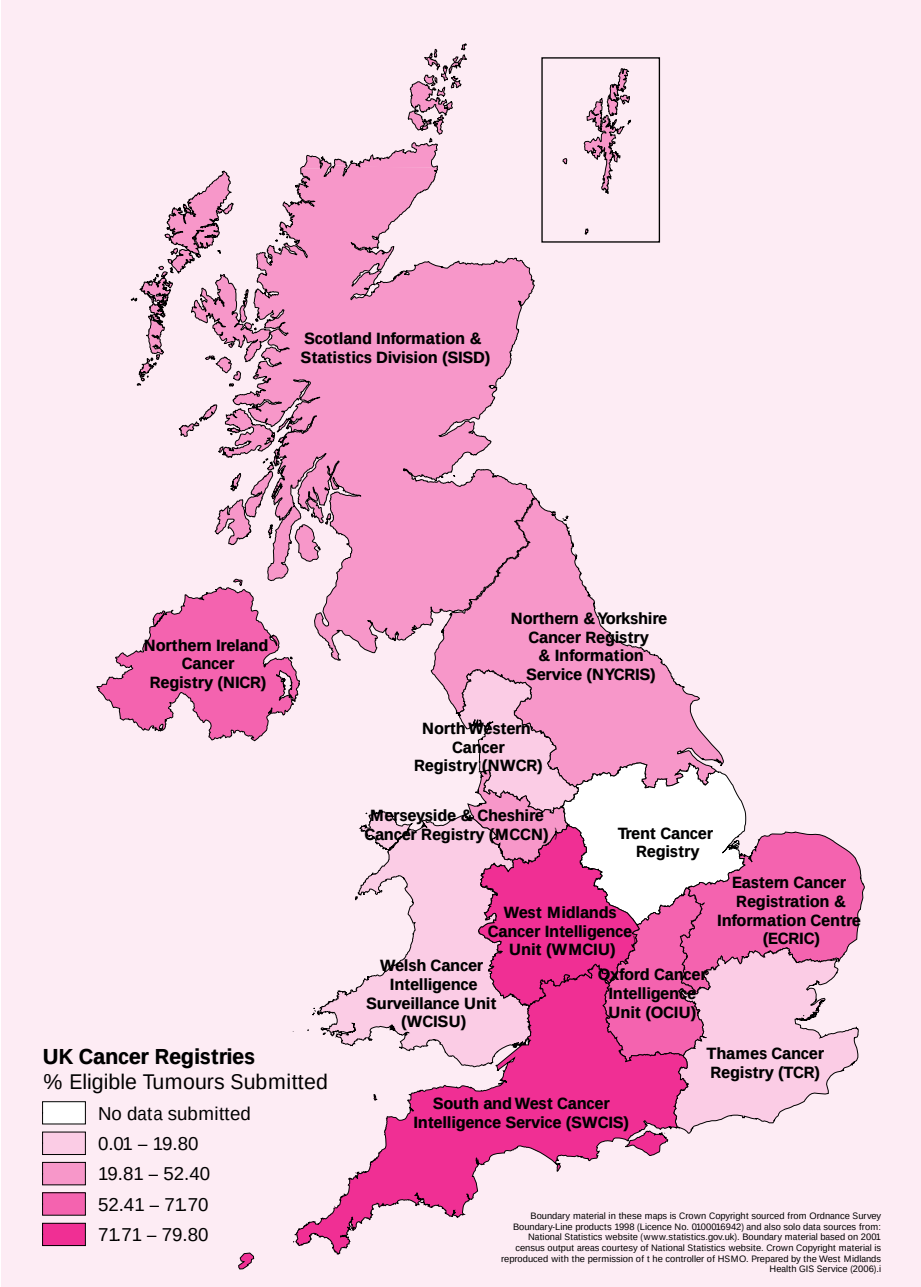


Figure 1: Participation of UK cancer registries

Primary symptomatic breast cancers diagnosed in 2002 were eligible for inclusion in Year 1 of the Breast Cancer Clinical Outcome Measures (BCCOM) Project. The data obtained from cancer registries for each case included basic demographic details, diagnostic information, tumour characteristics and the type of surgical and adjuvant treatment. Data were received from 11 cancer registries incorporating 191 consultant surgeons who contributed a total of 16,407 cases [Figure 1, Table 1]. The Trent Cancer Registry was not able to take part in the first year of the BCCOM Project, but has agreed to participate in Year 2. The data items collected in Year 1 of the BCCOM Project are summarised in Appendix 1.

Only symptomatic primary breast cancers were eligible for inclusion. However, at the time of this audit, not all cancer registries had established a link with their local breast screening quality assurance reference centre allowing them to flag on their database the breast cancers detected as part of the NHS Breast Screening Programme.

On the other hand, some breast cancers fulfilling BCCOM inclusion criteria were not submitted. In most cases, this occurred when a surgeon could not be assigned to the cancer.

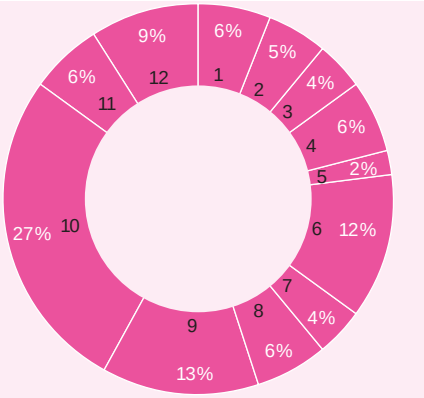


Fig 2a: Surgeons invited (ABS at BASO)

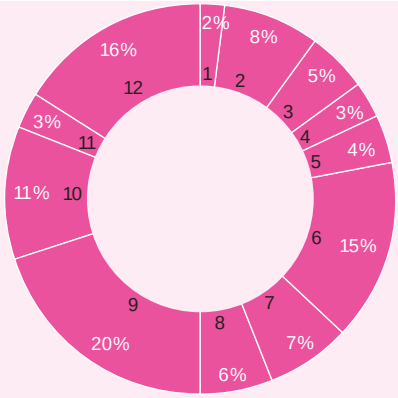


Fig 2b: Surgeons taking part

1 Trent	7 Oxford CIU
2 East Anglia	8 Scotland
3 MCCN	9 SWCIS
4 North Western	10 Thames
5 Northern Ireland	11 Wales
6 NYCRIS	12 WMCIU

Figure 2: Participation of UK surgeons (%)

This occurred when the cancers were registered at the cancer registry on the basis of only a death certificate, when the cancers had no known surgeon, or where the surgeon had retired or left the region. Other reasons for non-submission included surgeons with a caseload of less than six cases and surgeons declining the invitation to take part in the BCCOM Project.

To validate the mechanism of data collection, cancer registries sent to consultant surgeons the data held on patients under their care. The surgeons in turn checked the validity of their data by comparing them with those held on local systems, made amendments if necessary and returned the data (minus the patient identifiable details) to the West Midlands Cancer Intelligence Unit (WMCIU). Surgeons could also submit unchecked data if they did not have the necessary support mechanisms in house to undertake this task. Initially, only consultant surgeons who were members of the Association of Breast Surgery at the British Association at Surgical Oncology (ABS at BASO) were invited to take part. However, consultant surgeons who were not members of the ABS at BASO were also welcome to participate if they so wished.

49% of surgeons checked or partly checked their data [Table 1]. Details of nearly half the breast cancers (48.3%) included were checked or partly checked by the treating surgeon. The category "partly checked" includes surgeons checking between 10% and 50% of their cases, or surgeons not checking specific data items for all of the breast cancers in their caseload.

The BCCOM Project Steering Group is aware that some breast units found the checking of data difficult. The collaboration between cancer registries and their local surgeons stimulated by the BCCOM Project should, however, result in new ways to improve the data collection process and ultimately in further improvements of the data quality in subsequent rounds. It is therefore anticipated that the "checking" stage will eventually become unnecessary.

The contribution of each UK region to the BCCOM Project, in terms of number of participant surgeons, is illustrated in Figure 2. For example, whilst 13% of UK eligible consultant surgeons practised in the South West (SWCIS) [Figure 2-a], participant surgeons from this region represented 20% of the surgeons submitting data to BCCOM [Figure 2-b]. Note that although the Trent Cancer Registry did not take part in the BCCOM Project, surgeons in one breast unit in this region did submit their data directly to the BCCOM Project.

Table 1: Cases received from surgeons – Cohort characteristics

	Primary symptomatic breast cancers diagnosed in 2002					
	Invasive	Non-inv	Micro-inv	Unknown	Total	No. surgeons
All eligible UK cases	*	*	*		**35,859**	386
Cases received from surgeons	15,214	1,037	78	78	**16,407**	191
Cases checked/partly checked	7,366	431	54	75	**7,926**	94
Male breast cancer	122	7	1	2	**132**	77
Sex and/or age unknown	184	5	0	7	**196**	6
Woman less than 50	3,334	223	17	7	**3,581**	187
Woman 50-64 years old	5,107	552	43	11	**5,713**	189
Woman 65 years or older	6,467	250	17	51	**6,785**	188

Key Results for the United Kingdom

2. Characteristics of BCCOM Year 1 Cohort

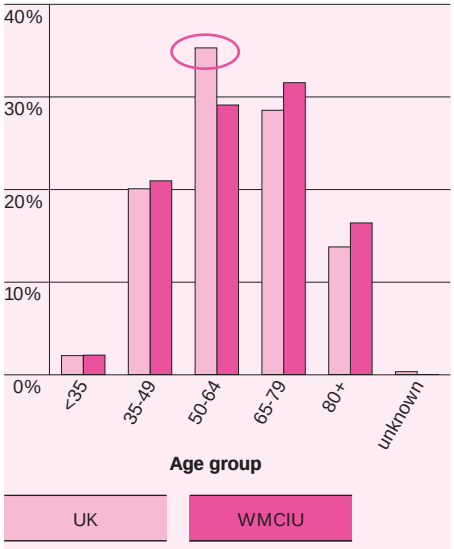


Figure 3: Variation in the number of breast cancers with age (comparison between UK and WMCIU data)

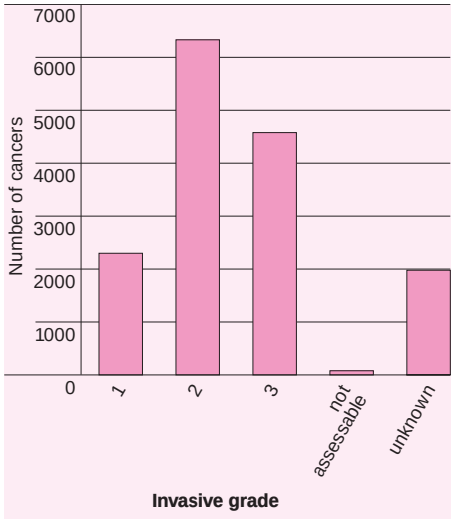


Figure 4: Invasive breast cancer grade (number of cancers)

2.1 Gender and laterality

Whilst the vast majority of the breast cancers included in the BCCOM Project were diagnosed in women [Table 1], 132 male breast cancers were included. 8,230 breast cancers (50.2%) were diagnosed in the left breast, 7.629 (46.5%) were right side, 129 (0.8%) bilateral and for 419 (2.5%) the laterality was unknown.

2.2 Age

Patients included were aged between 22 and 102 years (average 62.3 years; median 61.4 years). 77% of the patients were aged 50 years or older [Figure 3]. In the UK as a whole, the number of breast cancers diagnosed was highest (5,787; 35%) in the age group 50-64. However, as discussed earlier, a significant number of screen-detected breast cancers were included in the BCCOM cohort. Because in 2002 most screen-detected breast cancers were detected in women aged 50-64, it is very likely that a proportion of cancers in the 50-64 years age group were in fact screen-detected [see circle in Figure 3]. This is further illustrated when the age distribution is compared between the UK as a whole (35% of cases diagnosed in the 50-64 year old age group, decreasing to 28.5% in those aged 65-79) and the West Midlands, where no screen-detected cases were included amongst the BCCOM cohort (28.5% of cases diagnosed in the 50-64 year old age group and 31.5% in those aged 65-79).

In order to avoid this bias in the next round of the BCCOM Project, improved mechanisms for data exchange between breast screening quality assurance reference centres (recording all UK screen-detected breast cancers) and cancer registries have been implemented.

2,094 deaths were recorded in the BCCOM cohort (closure date: 1 April 2005) representing 12.8% of the patients. The link now established for the BCCOM cohort with cancer registries, will allow a regular update of the mortality data for these cases at local and national level.

2.3 Invasive status and grade

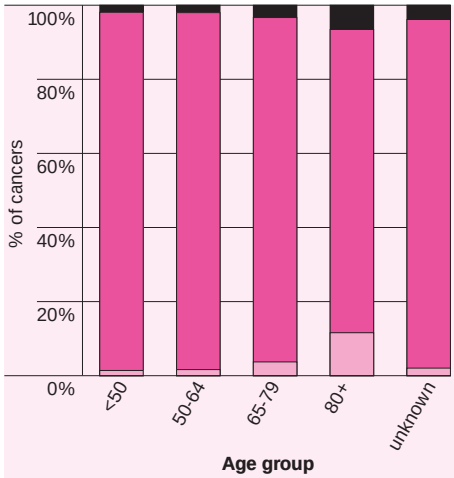
99.5% of the breast cancers had a known invasive status [Table 1]; 93.2% were invasive, 6.3% non-invasive and 0.5% micro-invasive. 15% of the invasive breast cancers were Grade 1, 42% were Grade 2, 30% were Grade 3 and for 13% the grade was unknown [Figure 4].

2.4 Method of diagnosis and histological type

The vast majority of breast cancers (97%) were first diagnosed by core biopsy and/or cytology [Figure 5]. The proportion of cases diagnosed on the basis of cytology alone increased with age, rising from 1.6% in patients aged 50-64 to 11.6% in patients aged 80 and above. When patients had bilateral breast cancers or multiple primaries, participants were asked to select and include in the BCCOM Project the cancer with the worst prognostic features. Most invasive breast cancers displayed a ductal cellular morphology [Figure 6].

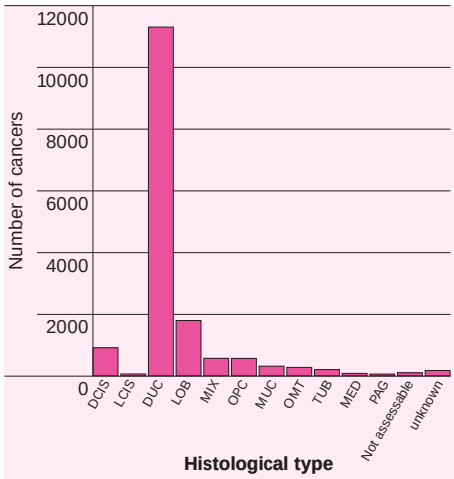
2.5 Nodal status

60% of invasive breast cancers had a known nodal status [Figure 7]. The proportion of cancers with unknown nodal status varied with age, rising from 32% in patients aged 50-64 to 70% in patients aged 80 and over. Nodal positivity varied between 12% for small (less than 10mm diameter), Grade 1 cancers [Figure 8-a] and 81% for large (50mm diameter or more), Grade 3 cancers [Figure 8-c].



	Age group				
	<50	50-64	65-79	80+	unknown
Other	75	112	151	148	2
Histology of primary	3503	5584	4356	1850	48
Cytology	48	91	175	263	1

Figure 5: Variation in method of diagnosis with age (% of cancers)



Codes for histological types

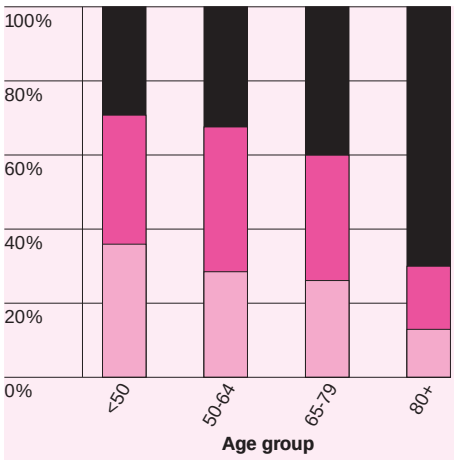
Non-invasive

DCIS = Ductal carcinoma in situ
LCIS = Lobular carcinoma in situ

Invasive

DUC = Invasive ductal carcinoma
LOB = Invasive lobular carcinoma
MIX = Invasive tumour: mixed
OPC = Other primary carcinoma (not breast)
MUC = Invasive mucinous/colloid carcinoma
OMT = Other malignant tumour of breast
TUB = Invasive tubular carcinoma
MED = Invasive medullary carcinoma
PAG = Paget's disease of nipple

Figure 6: Histological tumour type (number of cancers)



	Age group			
	<50	50-64	65-79	80+
Unknown	984	1678	1777	1525
Node negative	1179	2022	1505	370
Node positive	1210	1478	1156	282

Figure 7: Variation in nodal status with age (invasive breast cancers only)

Key Results for the United Kingdom

2. Characteristics of BCCOM Year 1 Cohort continued

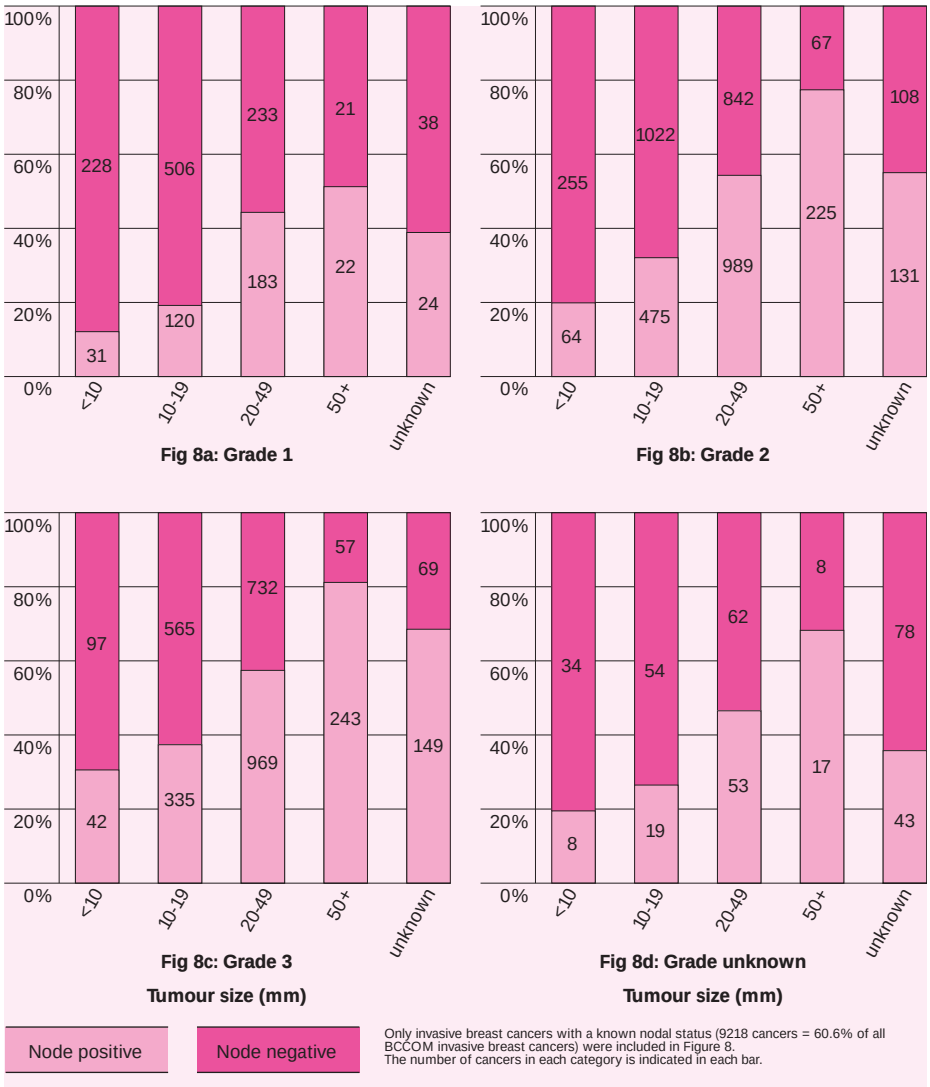


Figure 8: Nodal status of invasive breast cancers: variation with grade and size

2.6 Nottingham Prognostic Index

The Nottingham Prognostic Index (NPI) is a combined score based on the size, grade and nodal status of invasive breast cancers. Across the UK, the NPI was recorded (or could be calculated) for 55% of the invasive breast cancers [Figure 9-a]. This varied between regions from 21% to 83%. In the UK as a whole, the proportion of invasive breast cancers with unknown NPI increased with age, rising from 37% in patients aged 50-64 to 74% in patients aged 80 and over. For a large proportion of the patients aged 80 or over [41.4%, see Figure 10], invasive breast cancers were not surgically treated, therefore no NPI could be calculated. When taking into account only patients receiving surgery, the proportion of cases with unknown NPI in the older group decreased to almost the same level as that seen in the other age groups [Figure 9-b]. The higher proportion of older patients with unknown NPI is also partly explained by the relatively high proportion of these cases with unknown nodal status [see Figure 7].

Where NPI was known, 31% of invasive breast cancers fell into the two best prognostic groups (EPG and GPG).

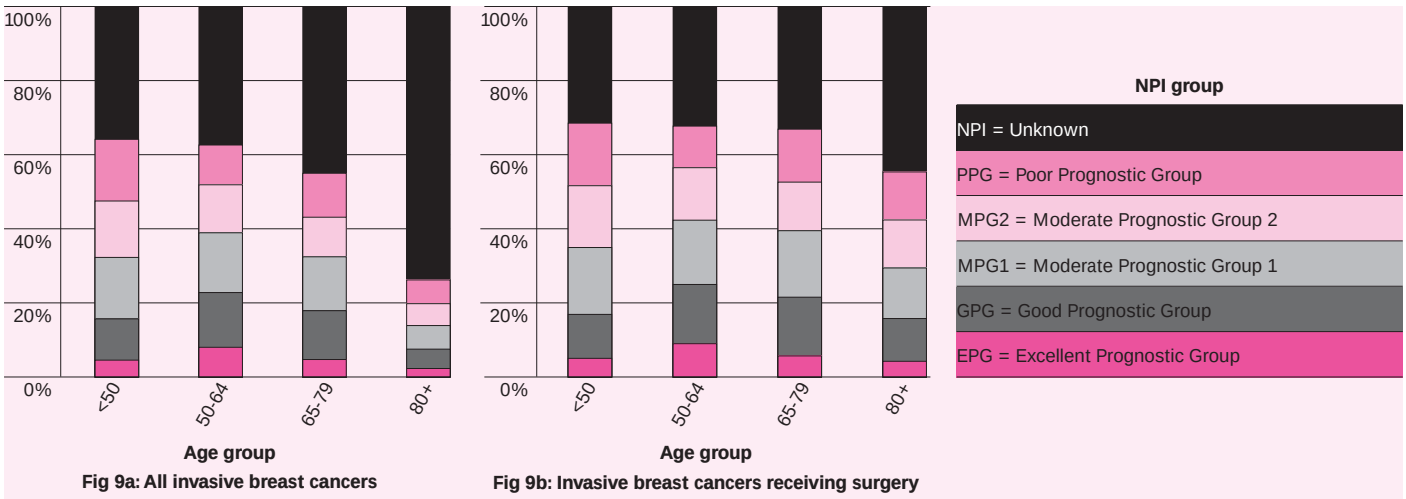


Fig 9a: All invasive breast cancers

Fig 9b: Invasive breast cancers receiving surgery

Figure 9: Variation in Nottingham Prognostic Index (NPI) with age group

Key Results for the United Kingdom

3. Surgical and Adjuvant Treatment

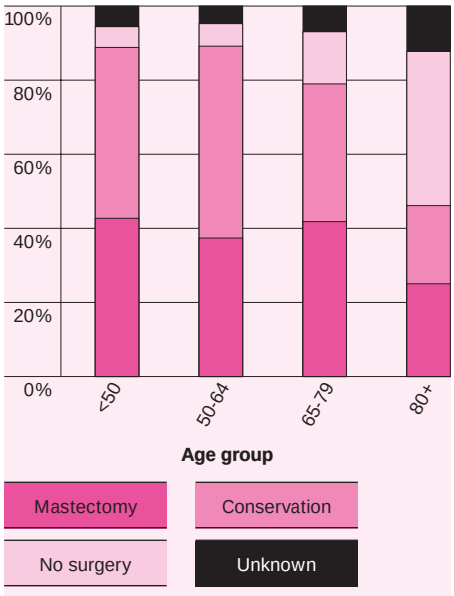


Figure 10: Variation in type of final surgery with age (invasive breast cancers)

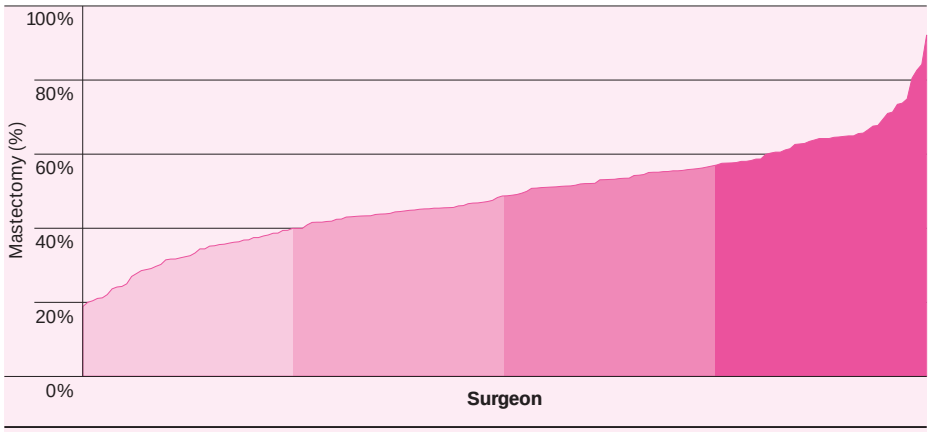


Figure 11: Variation in mastectomy rates between surgeons (%)

Surgeons treating less than 14 cases and cases not known to have received surgery (i.e. "No surgery" or "unknown surgery") were excluded.

3.1 Type of surgery to the breast

For each breast cancer, only details of the last surgical therapeutic intervention (excluding axillary procedures) were collected. Operations were then classified as either conservation surgery or mastectomy. The proportion of cases not receiving surgery increased with age from 5.9% in patients aged 50-64 to 41.4% in patients aged 80 and over. In the UK as a whole, the mastectomy rate for all invasive breast cancers was 38.5%. When considering only the invasive breast cancers treated surgically, 48.2% received a mastectomy [Figure 10].

Mastectomy rates varied between regions from 36.4% to 53.2%, and between surgeons from 19% (for a surgeon with 74 cancers included in BCCOM, 69 of which had surgery) to 92% (for a surgeon with 40 cancers included in BCCOM, 13 of which had surgery) [Figure 11].

The proportion of patients receiving a mastectomy varied slightly with age, from 38% in patients aged 50-64 to 42% in patients aged 65-79 and 25% in patients aged 80 and over. Mastectomy rates were higher for large breast cancers [Figure 12], increasing from 30% for cancers with diameter less than 20mm to 75% for cancers with diameter greater than 50mm.

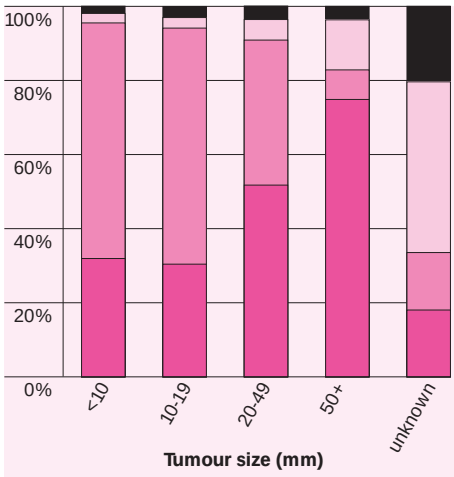
40 breast cancers were assigned to surgeons treating less than 10 symptomatic breast cancers in 2002. The other cancers were assigned to surgeons treating between 14 and 200 symptomatic primary breast cancers (average 89, standard deviation 41; median 85) [Figure 13]. There was no obvious relationship between surgical caseload and the proportion of cases receiving a mastectomy.

3.2 Adjuvant treatment

Complete radiotherapy, chemotherapy and hormonal therapy data were available for 8,219 cases (50%). Amongst the cases with information available concerning all three types of treatment, 1,889 breast cancers (23%) had surgery, hormonal therapy and radiotherapy (no chemotherapy) and 1,887 breast cancers (23%) had hormonal therapy with or without surgery.

The proportion of breast cancers treated by hormonal therapy varied slightly with age, increasing from 43% in patients aged 50-59 (41% in patients aged 50-64) to 49% in patients aged 70 and over [Figure 14]. The proportion of breast cancers treated by radiotherapy varied markedly with age, decreasing from 53% in patients aged 50-59.

(50% in patients aged 50-64) to 16% in patients aged 80 and over. Similarly, there was a sharp decrease with age in the proportion of patients treated with chemotherapy: from 39% in patients aged 50-59 (32% in patients aged 50-64) to 1% in patients aged 80 and over. The proportion of node positive patients receiving chemotherapy also varied with age, decreasing from 64% in patients aged 50-64 to 24% in patients aged 65-79 (not shown). The proportion of patients receiving radiotherapy after conservation surgery was 66% in patients aged 50-64, 64% in patients aged 65-79 and decreased to 37% in patients aged 80 and over.



Tumour size (mm)	<10	10-19	20-49	50+	unknown
Unknown	22	129	195	35	666
No surgery	30	129	309	126	1419
Conservation	731	2795	2199	75	489
Mastectomy	367	1334	2899	704	561

Figure 12: Type of final surgery and size of cancers (invasive cancers only)

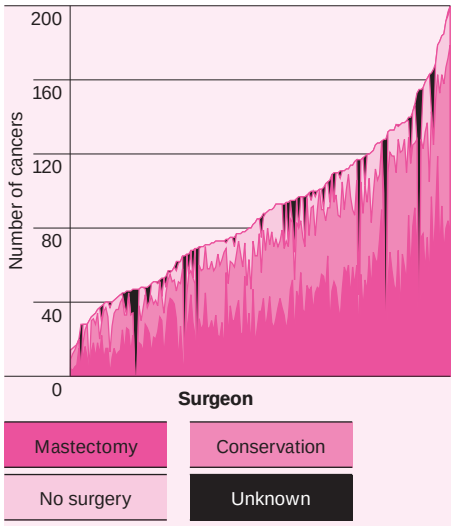


Figure 13: Variation in the number of primary symptomatic breast cancers diagnosed in 2002 by each surgeon and the type of final therapeutic surgical treatment (number of cancers)

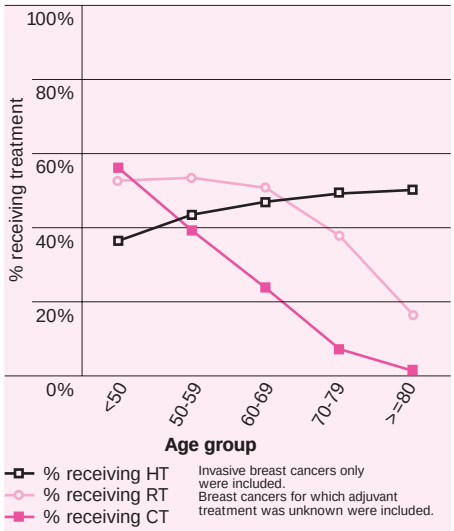


Figure 14: Adjuvant therapy (% receiving treatment)

Comparison of Symptomatic and Screening Outcome Data for the West Midlands

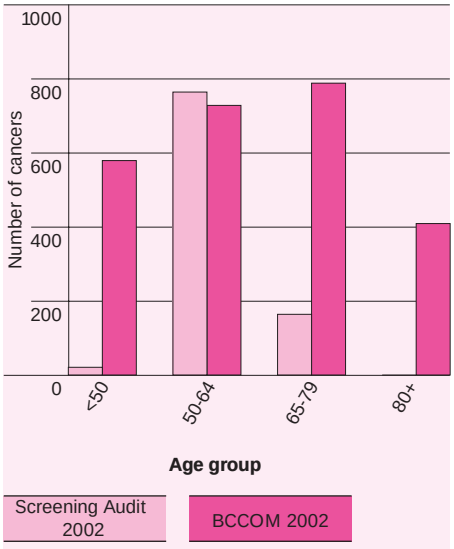


Figure 15: Variation with age and method of detection in the number of female breast cancers diagnosed in the West Midlands in 2002 (number of cancers)

In 2002, three out of nine of the breast units in the West Midlands had begun to implement the extension of the NHS Breast Screening Programme to women aged up to 70 years old. In the remaining units, routine screening was offered to women aged 50-64 years. 4,203 primary breast cancers were registered on the West Midlands cancer registration database in 2002, of which 25 were diagnosed in men. 949 cases (22.6%) were included in the audit of screen-detected breast cancers, 2,529 (60.2%) were included in the BCCOM audit and 725 (17.2%) were not included in either audit. This section compares data from the female symptomatic breast cancers included in the BCCOM cohort, with data from the screening cohort.

In the BCCOM cohort, women were aged between 23 and 101 years old (average 63.5 years; median 63.9 years). Women included in the screening audit were aged between 46 and 78 years old (average 58.8 years; median 58 years). 80.5% of the women included in the screening audit were aged between 50 and 64, 17.3% were in the age group 65-79 and only 2.2% were aged less than 50 years [Figure 15]. As expected, the age distribution for BCCOM patients was markedly different with 29.1% aged between 50 and 64, 31.5% in the age group 65-79, 16.3% aged 80 years or more and 23.1% aged less than 50 years.

Table 2:

Audit name	BCCOM			Screening Audit		
West Midlands Data	No. cancers		%	No. cancers		%
Non-invasive	116		**4.63** (116/2504)	206		**21.71** (206/949)
Micro-invasive	12		**0.48** (12/2504)	10		**1.05** (10/949)
Mastectomy when invasive size <15mm	103	(i)	**30.75** (103/335)	56	(i)	**15.64** (56/358)
Mastectomy when whole size <15mm	75	(ii)	**27.99** (75/268)	33	(ii)	**12.13** (33/272)
Mastectomy when non-invasive	51	(iii)	**43.96** (51/116)	67	(iii)	**32.52** (67/206)
Conservation when whole size >50mm	19	(iv)	**11.45** (19/166)	7	(iv)	**17.95** (7/39)

Notes:
(i) % of invasive small (invasive size <15mm) breast cancers receiving mastectomy.
(ii) % of invasive small (whole size <15mm) breast cancers receiving mastectomy.
(iii) % of non-invasive breast cancers receiving mastectomy.
(iv) % of large breast cancers (whole size >50mm) receiving conservation surgery.

Non-invasive or micro-invasive breast cancers were less frequent in the BCCOM cohort (5.1%) than in the screening cohort (22.8%) [Table 2]. Screen-detected invasive breast cancers were of lower grade than the breast cancers included in BCCOM. 34% of screening cases were Grade 1, compared with 13.5% of the symptomatic invasive breast cancers, and 17% were Grade 3 compared with 34% in the BCCOM cohort.

The number of breast cancers with an invasive size less than 15mm was much lower in the BCCOM cohort (335 breast cancers, 14.9% of all symptomatic invasive breast cancers) than in the screening cohort (358 cancers, 49% of all screen-detected invasive breast cancers) [Table 2, (i)]. The proportion of cases having a mastectomy as their final surgical treatment was 30.75% in the BCCOM cohort compared to 15.64% in the screening cohort [Table 2, (i)]. Thus, small invasive symptomatic breast cancers were less common, but more likely to be treated by mastectomy than screen-detected breast cancers. When taking into account the whole size of small invasive cancers (i.e. invasive size + size of non-invasive component when relevant), a similar trend was observed (27.99% of symptomatic cases had mastectomy but only 12.13% of the screen-detected cases) [Table 2, (ii)].

Non-invasive symptomatic breast cancers of all sizes were more likely to receive mastectomy than screen-detected breast cancers [Table 2, (iii)]. In both cohorts, few breast cancers larger than 50mm received conservation surgery (11.45% of symptomatic cases and 17.95% of screen-detected cases) [Table 2, (iv)].

A Nottingham Prognostic Index (NPI) score could be calculated for 98.5% of the screen-detected invasive breast cancers and for 71.5% of the BCCOM cohort [Figure 16]. Where NPI was known, the proportion of breast cancers falling into the two best prognostic groups (EPG and GPG) was much higher in the screening (59.1%) than in the symptomatic (28.6%) cohort.

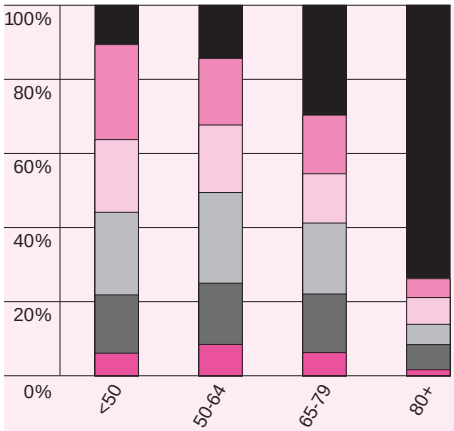


Fig 16a: BCCOM Project

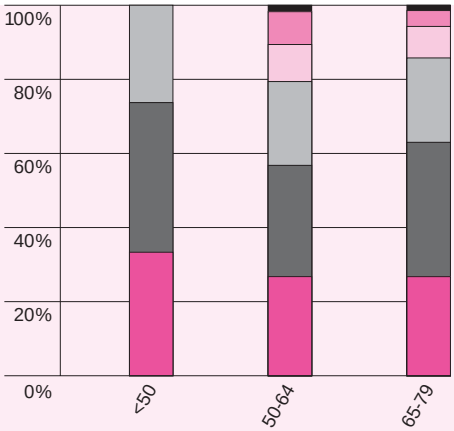


Fig 16b: Screening audit

Fig 16a: BCCOM Project	Age group <50	50-64	65-79	80+
EPG	33	55	47	6
GPG	87	113	119	27
MPG1	122	163	144	24
MPG2	108	123	100	27
PPG	140	120	120	22
Unknown	59	99	222	296

Fig 16b: Screening audit	<50	50-64	65-79
EPG	5	154	35
GPG	6	178	48
MPG1	4	132	30
MPG2	0	59	11
PPG	0	53	6
Unknown	0	9	2

Code
EPG = Excellent Prognostic Group, GPG = Good Prognostic Group, MPG1 = Moderate Prognostic Group 1, MPG2 = Moderate Prognostic Group 2, PPG = Poor Prognostic Group.

Figure 16: Variation in Nottingham Prognostic Index (NPI) with age group – West Midlands data

Comparison of Symptomatic and Screening Outcome Data for the West Midlands continued

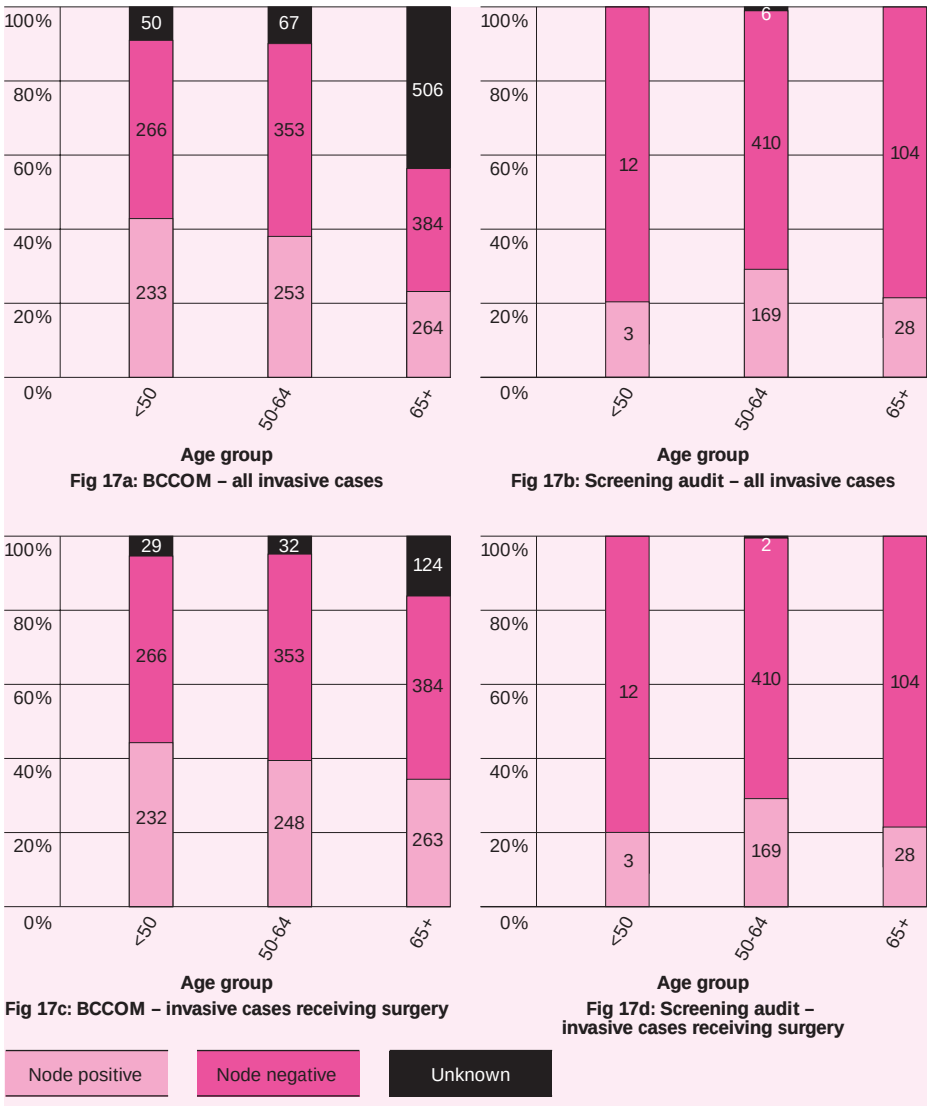


Figure 17: Variation in nodal status with age group – West Midlands data

The nodal status of most invasive screen-detected breast cancers was known (0.8% unknown). The same was not true for symptomatic invasive breast cancers, for which the proportion of cancers with unknown nodal status increased from 9.6% in women aged less than 65 years to 78.1% in women aged 65 or more [Figure 17-a&b]. This was mainly due to the smaller proportion of older symptomatic patients receiving surgical treatment [Figure 17-c]. However, even in those patients aged 65 or more receiving surgery, 16% had no nodal status recorded. In women aged less than 65 years, when nodal status was known, 44% of the symptomatic invasive breast cancers were positive compared with 29% of the screen detected breast cancers.

In the screening cohort as a whole, the mastectomy rate for all invasive breast cancers was 27.0% compared with 40.5% in BCCOM cohort. When considering only the invasive breast cancers treated surgically, 49.8% of the symptomatic breast cancers [Figure 18-a] and 27.2% of the screen-detected breast cancers [Figure 18-b] received a mastectomy. The average age of women receiving a mastectomy for an invasive breast cancer was 63.7 years in the BCCOM cohort and 58.9 years in the screening cohort.

Table 3: West Midlands Data

Adjuvant Treatment Received	Women aged 50-64 years		Women all ages	
	BCCOM %	Screening Audit %	BCCOM %	Screening Audit %
Hormone therapy	**49.9** (336/673)	**56.6** (331/585)	**51.2** (1230/2376)	**59.3** (434/732)
Chemotherapy	**35.5** (239/673)	**20.3** (119/585)	**27.4** (651/2376)	**18.2** (133/732
Radiotherapy	**63** (424/673)	**48.4** (283/585)	**51.4** (1222/2376)	**44.5** (326/732)

*Number of tumours indicated in brackets.

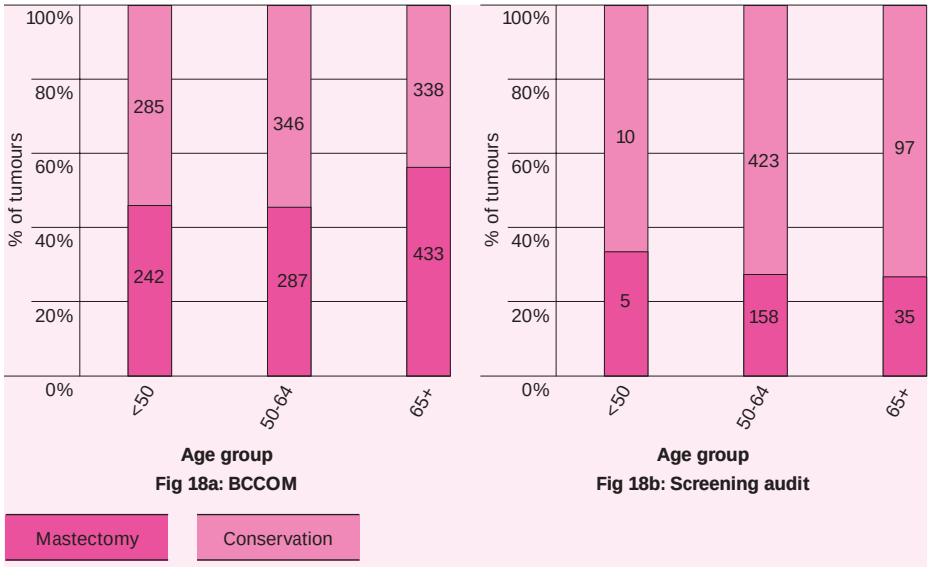


Figure 18: Variation in type of surgery with age group – West Midlands Data (% of tumours)

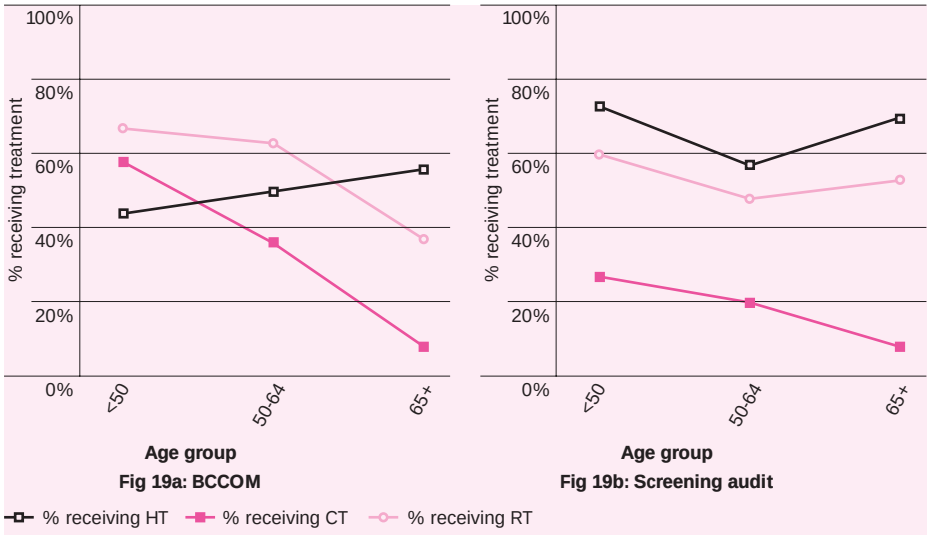


Figure 19: Variation in adjuvant therapy with age group – West Midlands data (% receiving treatment). Adjuvant therapy received by female invasive breast cancers, in each age group.

As described in [Table 3] and [Figure 19], there were variations between the BCCOM and screening cohorts in the adjuvant treatment received for invasive breast cancer. Women aged 50-64 years with symptomatic breast cancer were more likely to have received chemotherapy and radiotherapy [Figure 19-a] than women with screen-detected invasive breast cancer [Figure 19-b]. Conversely, more screening than symptomatic patients received adjuvant hormone therapy. The same trends, although attenuated, were seen when all age groups were pooled [Table 3].

General and Cancer Registries

ABS at BASO Association of Breast Surgery at the British Association at Surgical Oncology

BCCOM Breast Cancer Clinical Outcome Measures

CT Adjuvant chemotherapy

EPG Excellent Prognostic Group (NPI group)

ER Oestrogen receptor

GPG Good Prognostic Group (NPI group)

HER2 Human epidermal growth factor receptor 2

HT Adjuvant hormone therapy

MPG1 Moderate Prognostic Group 1 (NPI group)

MPG2 Moderate Prognostic Group 2 (NPI group)

PPG Poor Prognostic Group (NPI group)

NPI Nottingham Prognostic Index

PgR Progesterone receptor

QARC Quality Assurance Reference Centre

RT Adjuvant radiotherapy

UK United Kingdom

UKACR The United Kingdom Association of Cancer Registries

vNPI Van Nuys Prognostic Index

HISTOLOGICAL CODES

DCIS Ductal carcinoma in situ

DUC Invasive ductal carcinoma

LCIS Lobular carcinoma in situ

LOB Invasive lobular carcinoma

MED Invasive medullary carcinoma

MIX Invasive tumour: Mixed

MUC Invasive mucinous/colloid carcinoma

OMT Other malignant tumour of breast

OPC Other primary carcinoma (not breast)

PAG Paget's disease of nipple

TUB Invasive tubular carcinoma

CANCER REGISTRIES

ECRIC Eastern Cancer Registration and Information Centre

MCCN Merseyside and Cheshire Cancer Registry

NICR Northern Ireland Cancer Registry

NWCR North Western Cancer Registry

NYCRIS Northern & Yorkshire Cancer Registry and Information Service

OCIU Oxford Cancer Intelligence Unit

SISD Scotland Information and Statistics Division

SWCIS South and West Cancer Intelligence Service

TCR Thames Cancer Registry

Trent Cancer Registry

WCISU Welsh Cancer Intelligence and Surveillance Unit

WMCIU West Midlands Cancer Intelligence Unit

Appendix 1

BCCOM Project Year 1 Dataset

Data item	Description of data item
Cancer Registry	Name of cancer registry
Patient Number	Patient's number at cancer registry
Tumour Number	Registration number of the primary breast cancer
Assigned Hospital	Hospital
Managing Surgeon Name	Managing consultant surgeon's name
Managing Surgeon Code	Managing consultant surgeon's GMC code
Sex	The patient's gender
Date of Birth	The patient's date of birth
Laterality	The laterality of the primary tumour
Diagnosis Date	This field records the date of diagnosis of the tumour. It is required with the date of birth to derive the age at diagnosis
Basis of Diagnosis	This field records the eligibility of the tumour for registration based on the best source of information known to the Trust and allows derivation of the degree of certainty of diagnosis. It is therefore an indicator of data quality, with microscopic histological verification being viewed as the 'gold standard' diagnosis
Pre-operative Diagnosis	Whether the presence of cancer was confirmed histologically or cytologically BEFORE surgery took place. If cancer registry has a pathological report on record for this tumour AND if the date of this report is before the date of first surgery, then pre-operative diagnosis = Yes
Invasive Status	Tumour behaviour
Histological Tumour Type	The cell type of the tumour
Grade of Differentiation Invasive Tumour	Qualitative assessment of the differentiation of the tumour expressed as the extent to which an invasive tumour resembles the normal tissue at that site
Grade of Differentiation Non-Invasive Tumour	Qualitative assessment of the differentiation of the tumour expressed as the extent to which a non-invasive tumour resembles the normal tissue at that site
Invasive Size	The size (maximum diameter) of the invasive component of the tumour
Whole Tumour size	The size of the invasive tumour and any surrounding in situ disease
Vascular or Lymphatic Invasion	The presence of unequivocal tumour in vascular and/or lymphatic spaces
Excision Margins	Whether all the excision margins were clear of tumour after the final operation to the breast
Local/Regional Nodes Examined	The total number of local/regional nodes examined. If several axillary procedures were performed, add the nodes obtained and enter this sum
Local/Regional Nodes Positive	The number of local/regional nodes reported as being positive for the presence of tumour metastases. If several axillary procedures were performed, add the positive nodes obtained and enter this sum
ER Status	Measure of estrogen receptor expression
PgR Status	Measure of progesterone receptor expression
ErbB-2/ HER-2 Status	Measure of ErbB-2 (HER2) expression

Appendix 1 continued

BCCOM Project Year 1 Dataset continued

Data item	Description of data item
Radiotherapy	Whether the patient received radiotherapy as treatment for her/his breast cancer. Exclude treatment for recurrence
Chemotherapy	Whether the patient received chemotherapy as treatment for her/his breast cancer. Exclude treatment for recurrence
Hormone Therapy	Whether the patient received hormone therapy as treatment for her/his breast cancer. Exclude treatment for recurrence
Type of Final Therapeutic Surgery to the Breast	Exclude axillery surgery, reconstruction, treatment to recurrence
Any Sentinel Node Procedure?	This field will be more easily completed by managing surgeons
Death Date	The date the patient died. Leave blank if the patient is still alive
NPI	Nottingham Prognostic Index score (Invasive cancer) **NPI = 0.2 x Invasive Size (cm) + Grade + Nodes** where Grade is the tumour grade (Bloom & Richardson): 1, 2 or 3 where Nodes equals 1 (0 positive nodes) or Nodes equals 2 (1, 2 or 3 positive nodes) or Nodes equals 3 (≥4
vNPI	Van Nuys Prognostic Index (Non Invasive cancer) **VNPI = Size score + Margin score + Pathological classification score** where size score is: 1 (≤15mm); 2 (16 to 40mm); 3 (≥40) where margin score is: 1 (width ≥10mm); 2 (width 1 to 9mm); 3 (width <1mm) where path classification score is: 1 (non-high grade without necrosis); 2 (non-high grade with necrosis); 3 (high grade with/without necrosis)
pT Category	The extent of the primary tumour after excision or biopsy of the primary cancer. This can be derived from Local Invasion – Tumour Extent and Structure(s) Invaded data items in the RC Path pathology dataset
pN Category	The histological evidence of the absence or presence and extent of regional lymph node metastases. This can be derived from Local/Regional nodes positive. Other Nodes positive and Marker lymph node 1 positive data items in the RC Path pathology dataset
pM Category	The histological evidence of the absence or presence of distant metastases. This can be derived from the Distant Metastases data item in the RC Path pathology dataset
Overall Pathological TNM Stage Grouping	The combination of pT with pN and pM into stage groupings that are more or less homogeneous in respect of survival and for which the survival rates are distinctive
Patient's Hospital Number	The patient's hospital number at surgery (or at diagnosis if no surgery was performed). If a patient had several surgical operations, give the hospital number for last surgery
Date of Last Surgery to the Breast	Exclude axillery surgery, reconstruction, treatment to recurrence
Hospital of Chemotherapy	The hospital at which chemotherapy took place
Date of Chemotherapy	The date the chemotherapy treatment started
Hospital of Radiotherapy	The hospital at which radiotherapy took place
Date of Radiotherapy	The date the radiotherapy treatment started
Date of Hormone Therapy	The date the hormone treatment started

Appendix 2

BCCOM Project Year 2 Audit Flow Chart

Person responsible	Action		Deadline
Local cancer registry	Identify primary breast cancer diagnosed in 2003		**16 January 2006**
	Exclude screen-detected breast cancers (details of these cancers are available via local breast screening QA reference centres)		
	Where possible assign a consultant breast surgeon: • If surgery, surgeon who performed the first surgery • If no surgery, surgeon at diagnosis		
	Surgeon can be assigned	Surgeon cannot be assigned	
	Check surgeon has signed the consent form to release data (if consent has not been given by an ABS at BASO surgeon, inform regional ABS at BASO surgical representative and ABS at BASO offices)	Assign a treating hospital: • If surgery, hospital of first surgery • If no surgery, hospital of diagnosis Check consent form has been received from lead surgeon of treating hospital (if consent has not been given by an ABS at BASO surgeon, inform regional ABS at BASO surgical representative and ABS at BASO office)	
	Send "surgeon level" data to lead surgeon of treating hospital	Send "hospital level" data to lead surgeon of treating hospital	
Lead surgeon	Allocate cases to relevant consultant surgeon Request consultant surgeons to check/amend and sign-off the data Send signed-off data to local cancer registry		**14 April 2006**
Local cancer registry	Send data checked by surgeons to WMCIU		**15 May 2006**
WMCIU/BCCOM Steering Group	Collect and analyse results at Present main results at ABS at BASO annual meeting		**14 June 2006**

Appendix 3

Guidance on Consent for BCCOM Project Year 2

Background

- Patients may be under the care of more than one clinician during the course of their treatment (e.g. breast surgeon, oncologist and plastic surgeon) and not all cancer registries collect the name of the treating clinicians, therefore data cannot always be provided for individual breast surgeons. In order to maximise the number of cases included in BCCOM, it is proposed that the cancer registries provide data on all breast cancers diagnosed in the year in question in each NHS Trust to the lead breast surgeon who will then work collaboratively with his/her colleagues to allocate the cases to the responsible surgeon.
- As the information is at an individual patient level, the cancer registries need the written consent of the consultant surgeons operating in each NHS Trust during the time period examined for their data to be sent to the lead breast surgeon. This will be achieved through the lead surgeon asking all his/her colleagues in the hospital to sign off a consent form.

Protocol

- Each consultant breast surgeon signs a "consent form" stating that he/she is happy for individual patient level data for cases under his/her care to be sent to his/her lead breast surgeon.
- Cancer registry sends data to lead breast surgeon.
- Lead breast surgeon allocates cases to the responsible consultant surgeon for checking. Cases assigned to a surgeon who has not signed the consent form are NOT included in BCCOM.
- Each consultant breast surgeon checks his/her data, signs them off ("surgical confirmation form") and sends them back to local cancer registry.

Case assigned to a retired surgeon/ not practising: lead surgeon to inform the local cancer registry which consultant surgeon has taken over patients from retired surgeon. Cancer registry can then send cases to lead surgeon if successor has signed the consent form.

Case assigned to a surgeon who has signed the consent to release data but whose patient has been assigned to a private hospital: send data to NHS lead surgeon.

Case assigned to a registrar: all cases should be checked/ signed off by a consultant surgeon.