Clinical Guideline

Breast cancer: diagnosis and treatment

An assessment of need

A report to the National Collaborating Centre for Cancer

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1   Introduction

The following needs assessment provides a summary of the current information available regarding the epidemiology of breast cancer regionally, nationally and internationally. Its purpose is to provide the context for the NICE guidelines on early and advanced breast cancer, presenting an overview of the size of the problem and disease burden, and assessing whether variation in epidemiology or service utilisation exists.

This full report covers both early and advanced breast cancer. Although the disease pathology is the same in both cases, the issues for the individual, the NHS and society differ markedly. For early breast cancer the main issues are the epidemiology of breast cancer and the treatment options. For those with advanced breast cancer the focus is on improving the quality of life by palliation of symptoms and managing the longer term side effects of treatment. The process of producing this document has highlighted the lack of routine data available to assess the burden of advanced breast cancer on individuals, society and the NHS.

2   Availability and use of routine data sources

2.1   Cancer Registries

Information on the incidence, mortality and survival of breast cancer for the United Kingdom is published by the Office of National Statistics[1]. It is based on data collated by 11 registries covering Northern Ireland, Scotland, Wales and 8 regional registries in England[2]. The registries are the only source of reliable population level data for the United Kingdom.

Each registry maintains systems to collect and safely store information over long time periods. Sources for this data include general hospitals, cancer centres, hospices, private hospitals, cancer screening programmes, primary care, nursing homes and death certificates. Data collected from these sources includes:

- patient details (for example name, sex, date of birth and address at time of diagnosis)
- hospital details
- diagnostic, tumour and treatment details (for example site and type of primary neoplasm, stage and grading of the tumour, and some basic treatment information)
- whether a patient is recorded as having died (for example date of death, cause and place of death, post mortem information)

Approximately two years elapses between the time an event (for example a diagnosis) takes place and the date when summary statistics for that period are published. This means that the most up to date summary information is often a couple of years old. During this time, work takes place within each registry to ensure that relevant events have been recorded reliably.

The extent of registry systems means that there is a high degree of 'completeness' in terms of capturing relevant diagnoses and deaths. However, the completeness and quality of data collected about a specific individual varies. For example, date of death is well captured and accurately recorded compared to staging information. Gaps and variations of this sort mean that national level information on overall

incidence, mortality and survival has a high degree of reliability but national information on distribution of breast cancer in specific subgroups (for example for different ethnic groups) is lacking.

Where there is a lack of comprehensive national data, there may be alternative sources available, including regional data. For example, the Breast Cancer Clinical Outcome Measures (BCCOM) project has audited a cohort of more than 16,000 individuals diagnosed in 2004, providing data on the management of symptomatic breast cancer across the UK[3]. In some instances, regional data provide the best indicator of the national position. Data on secondary breast cancers provides a good example of this.

Most registries are designed to record information about cancers apparent at the time of diagnosis of the primary neoplasm. Whereas there is some data available on the occurrence of secondary breast cancer at the time of primary diagnosis, most registries do not collect information on the occurrence and distribution of secondary breast cancer occurring *after* the primary diagnosis. A recent survey found that only one registry (West Midlands Cancer Intelligence Unit) collects information on all cases of secondary breast cancer within their area[4]. Reasons that other registries do not collect this information relate to various problems of systems, process and capacity – both within registries and amongst the institutions from which they collect data. Similar problems exist in other countries, including those contributing to the European Network of Cancer Registries, Australia, and the USA[4].

One implication of this is that population level data for describing the epidemiology of secondary breast cancer is relatively sparse. The data available tend to be framed in terms of the start and end of the illness. The argument has been made that such data are more descriptive for women with early stage breast cancer than they are for women with secondary breast cancer[5]. There is very little data available regarding secondary breast cancers, cancers which develop after the initial diagnosis of early breast cancer. This is an issue which has recently been raised by the Secondary Breast Cancer Taskforce and Breast Cancer Care[4]. This data is not collected nationally or internationally and leads to great difficulties in estimating the burden of secondary disease.

Some international data is available and is valuable for the purposes of comparison. For example, the EUROCARE project seeks to standardise cancer survival data across Europe in order to support meaningful comparisons between countries[6]. Nevertheless, it is important to keep in mind the degree to which apparent differences in survival (or other indicators) may be explained by differences in the quality of the underlying data (for example registry coverage is much lower in some countries than in the UK).

2.2 Hospital Inpatient Care

In England the Hospital Episode Statistics (HES) record information of all NHS admissions. These include all day case and inpatient admissions to NHS hospitals, including private patients and non-UK residents, plus admissions to independent providers commissioned by the NHS. The information recorded includes patient demographic information, diagnosis for each admission and date and length of admission. A similar system, Patient Episode Database Wales (PEDW), is found in Wales. These data were provided by Dr Brian Cottier at the National Cancer Services Analysis Team (NATCANSAT).

Episode data currently relates to episodes of inpatient care and not to individuals. For this reason it is possible to count the number of admissions and procedures, but not the numbers of individuals being treated, nor understand the outcomes from this treatment. As with all data the quality of the analysis is only as good as the quality of the data entry which can vary between providers. However, this data is processed and 'cleaned' nationally, removing duplicates and obvious errors, to provide the most robust data possible. Nevertheless systematic misclassification will occur but it is not possible to quantify and its effect is unknown. The purpose of including these data is to provide an estimate of the level of inpatient activity within secondary care, and so emphasise the importance of breast cancer as a resource issue.

There is work currently underway to combine the HES data with the cancer registry data. This will provide a wealth of data that may be used to assess patient pathways, including outcomes of procedures and will be an extension of previous cohort analysis performed by the West Midlands Cancer Intelligence Unit.

2.3   Hospital Outpatient Care

Outpatient data have also been collected through the hospital activity data since 2003. These data record the speciality associated with the appointment but not the diagnosis or reason for referral and so have not been examined for this assessment.

2.4   Primary Care

The majority of contacts in primary care are now recorded on electronic systems. There are several sources of this data which fall into two main groups. The first are the routinely available sources tailored to collect monitoring information for a specific purpose. An example is the monitoring of disease registers and treatment of individuals with certain health conditions through QOF (Quality and Outcomes Framework). Breast cancer is not a condition monitored through the QOF system. The second main source is a group of primary care research databases that represent a sample of practice activity but are not routinely accessible.

There are issues regarding how primary care contacts are recorded. Entries for patient contacts may be coded with the reason for attendance, underlying diagnosis or left uncoded. A survey of practice information systems in 2003 found that although 96% of paper and 94% of computerised records recorded the reason for a patient contact episode in primary care, only 48% of paper records and 34% of computerised records contained a diagnosis[7]. Furthermore systems may not detect some contacts which are related to breast cancer, for example psychological problems related to a diagnosis or treatment, unless specifically coded as breast cancer treatment.

Surveys of the population have been conducted in the past to provide information regarding the level of activity in primary care. Morbidity survey information is available from the Royal College of General Practitioners Annual Prevalence Report[8] and has been included.

2.5   Socioeconomic Status

Evidence indicates a relationship between socioeconomic status and health, including the incidence, survival and mortality from some cancers[9]. This may be due to lifestyle or environmental factors. Information regarding socioeconomic status was obtained from the literature as it is not routinely available from cancer registry data[10]. Studies have examined socioeconomic status by individual measures, place of residence or country of residence.

Place or country of residence can be summarised by two ecological methods, area of residence within the UK (health authority, census ward, enumeration district or super output area) using a deprivation measure (Carstairs[11-14], Townsend[9,13,15], IMD 2000[16]) or by Country using Gross Domestic Product (GDP) as a measure. These methods must be viewed with caution as they rely on the assumption that levels of deprivation are the same in all individuals living in a particular area[11]. This caution has been supported by a study that demonstrated a reduction in survival difference when larger geographical units were used to designate deprivation (for example electoral ward)[17]. These larger units can hide small pockets of difference in deprivation within them. Studies have also attributed socioeconomic measures, such as car ownership and housing tenure, to individuals to assess their own status[10]. Other studies have assessed socioeconomic status by level of educational attainment[18].

Status is defined by indicators which have been developed to mark material deprivation. These are socially constructed by judgements which may not be appropriate for all cultures, for example overcrowding may be a choice rather than a sign of poverty in some cultures such as South Asian[19]. There are also difficulties in assessing the socioeconomic status of women due to some classification referring to social class of the 'head of the household'[10,11] and also measuring male unemployment[11]. There is no evidence that the choice of deprivation score alters the differences found[17].

2.6   Ethnicity

Ethnicity is poorly recorded in NHS data. It is part of the dataset for cancer registries[19] but remains an optional field. NHS providers are required to collect ethnicity monitoring data for outpatients and inpatients[19], but the recording remains incomplete and the use of the 'not known' category remains high. The Quality and Outcomes Framework (QOF) has begun to encourage recording of ethnicity in primary care, but only for new registrations with a practice and the incentives to complete the recording are small. Country of birth, not ethnicity, is currently the method of recording used in UK death registrations[20]. This is not a precise method of assessing ethnicity as it does not allow for factors such as second generation immigrants, for example the South Asian population of East Africa[20], or the wide differences in populations from neighbouring countries, for example India and Bangladesh[21]. Information was obtained from the literature as no routine data are available.

Ethnicity is a social construct which is defined by individuals themselves and this adds to the uncertainty in assessing its effect on the epidemiology of breast cancer. Ethnic groups are not homogeneous, including very diverse populations, and do not account for country of residence, length of residence in the UK or lifestyle factors[22]. We may also see changes in the effect of ethnicity over time due to a potential difference in risk between first and second generation migrants to the UK[23].

The main ethnic group studied in the UK are the South Asian population and they have been identified through the use of South Asian name identifying software which ascribes South Asian ethnicity and religion according to surname. These programmes have been shown to have good positive predictive values and have been used with additional manual checking in the studies discussed[22]. The ethnic group defined as South Asian accounts for 3.9% of the current population of England and Wales[24] and is the largest minority group in the UK. The fact that the majority of women over the age of 50 years in this group were born outside the UK[19] is of particular significance when considering breast cancer.

There is a difficulty in applying ethnicity studies from other countries to the UK as definitions tend to vary. For example, in the US the South Asian population comprises Chinese, Japanese and Philipino populations whereas in the UK this definition is used for Indian, Pakistani and Bangladeshi popualtions[19]. Information from other countries may also be influenced by registration practices[22] or availability and access to healthcare.

2.7   Prescribing Data

Primary care prescribing data are collected nationally through PACT (Prescribing Analysis and Cost). Information is recorded by prescriber so it is not possible to make conclusions relating to breast cancer from the prescriptions of particular medications. The data are collected for budgetary reasons and are not allocated to individual patients or to the diagnosis or indication for prescription.

National data are not available for hospital based prescribing. However, the National Cancer Director has published an audit of the usage of cancer drugs approved by NICE[25]. The data used for the audit was taken from the IMS Health Hospital Pharmacy Audit which included hospitals covering 93% of acute beds in the UK in 2005. The audit reviewed the use of 6 drugs for cancers that included breast cancer, and trastuzamab used for breast cancer alone. This data indicates the presence of variation across the country but does not include information regarding the type of cancer, stage of disease, particularly if early or advanced breast cancer, or outcome of treatment.

2.8   Secondary Breast Cancer

There is very little data available regarding secondary breast cancers, cancers which occur after the initial diagnosis. This is an issue which has recently been raised by the Secondary Breast Cancer Taskforce and Breast Cancer Care[4]. These data are not collected nationally or internationally and this leads to great difficulties in estimating the burden of secondary disease.

Comment [AB1]: This is repeat of information in section 2.1. Better to only have it once.

2.9   Radiotherapy

Radiotherapy centres currently collect information regarding the site of treatment and the dose and number of fractions of radiotherapy delivered, but this may not include the primary site of the cancer or the indication for treatment. There has been voluntary national reporting of this data which has been collated by the National Cancer Services Analysis Team (NATCANSAT), but the completeness and quality is questionable and so not included in this report. Agreement has been reached to introduce a core data set and mandatory reporting for radiotherapy data which will enable linkage of treatment courses with the indication for treatment and separation of doses given for treatment and for palliation. However, this was not available at the time of this report.

Work has been undertaken by NATCANSAT to examine travel distances to radiotherapy centres. These data are included to highlight some of the geographical issues that impact upon patient access to treatment.

3 Epidemiology

3.1 Incidence

Breast cancer is the most commonly occurring cancer in the UK. In 2004 there were more than 44,000 new cases[26-29] (Table 1), which was almost a third of all newly diagnosed cancers. It equates to a crude incidence rate of 74.7 per 100,000 persons. However, all except 324 of these cases were found in women, amongst whom the crude incidence rate was 145.2 per 100,000. The European age-standardised rate of incidence amongst women was 120.6 per 100,000.

Amongst men the European age-standardised rate was less than 1 per 100,000. Except where specifically indicated to the contrary, the following data describe the epidemiology of breast cancer in women.

	England		Wales		Scotland		N.Ireland		UK	
Cases										
Males	272		19		31		2		324	
Females	36,939		2,362		3,917		1,117		44,335	
Persons	37,211		2,381		3,948		1,119		44,659	
Crude rate per 100,000 population										
Males	1.1		1.3		1.3		0.2		1.1	
Females	144.7		155.4		149.1		127.9		145.2	
Persons	74.3		80.6		77.9		65.4		74.7	
Age-standardised rate (European) per 100,000 population										
Males	0.9		1.0		1.1		0.2		0.9	
CI 95%	0.8	1.0	0.5	1.4	0.7	1.5	-0.1	0.6	0.8	1.0
Females	120.7		120.8		120.4		117.8		120.6	
CI 95%	119.5	121.9	115.9	125.7	116.6	124.2	110.9	124.7	119.5	121.7
Persons	63.6		64.1		64.9		62.5		63.7	
CI 95%	62.9	64.2	61.5	66.6	62.8	66.9	58.8	66.1	63.1	64.3

Table 1 Incidence and incidence rates of new cases of breast cancer in the UK, 2004[26-29]. Reproduced with permission of Cancer Research UK.

3.1.1 Secondary breast cancer

Estimates of the number of people living with secondary breast cancer vary. The secondary breast cancer taskforce have quoted one estimate which states that between 20-70% of patients (depending on their tumour biology, initial stage of disease and subsequent therapy) will develop recurrent/metastatic disease[4]. The National Institute of Health and Clinical Excellence (NICE) guidelines on the use of trastuzumab[30] estimate that approximately 40-50% of women presenting with early or localised breast cancer will eventually develop metastatic breast cancer. However, there is concern about the age and derivation of this statistic[4].

Regional data from the West Midlands Cancer Intelligence Unit indicates that about 5% of women and men diagnosed with breast cancer between 1992 and 1994 had metastases at the time of their primary diagnosis[4]. The data also suggest that a further 35% of all those with a primary diagnosis went on to develop metastases in the 10 years following diagnosis. Currently there is little data to quantify the number of cases of secondary breast cancer developing after the 10-year time period.

3.1.2 Age

Amongst women, age-specific rates of primary diagnosis increase rapidly amongst those aged over 40 years, rising from about 1 per 100,000 in young adults to just over 400 per 100,000 in those aged over 85 years (Figure 1). The highest numbers of cases are diagnosed in the screened age groups.
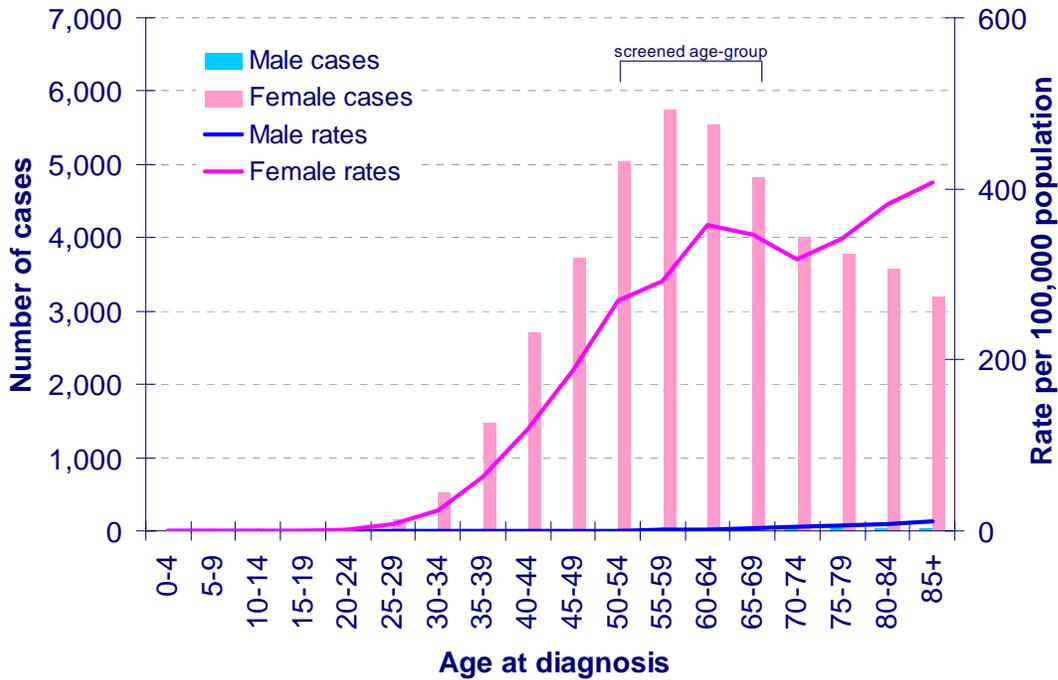
Figure 1 Age-specific incidence and incidence rates of new cases of breast cancer in the UK, 2004[26-29]. Reproduced with permission of Cancer Research UK.

3.1.3 Socioeconomic status

Studies show that women in lower socioeconomic groups are less likely to develop breast cancer[14,31,32], although one study has shown no significant difference in the incidence of breast cancer between the highest and lowest socioeconomic groups[9]. This pattern is opposite to that expected when examining the effect of socioeconomic status on other aspects of health.

3.1.4 Geography

There is a slight variation in breast cancer incidence rates between the four countries within the UK but these are not statistically significant in a single year of data after allowing for the different demographic profiles of each country (see Table 1).

Aggregating data over several years between 1991-99 reveals some statistically significant variations by region[33]: Northern and Yorkshire, Trent, West Midlands, North West and Northern Ireland had lower age-adjusted incidence rates than the average for the UK and Ireland (Figure 2). Quinn highlights flaws in the completeness of data for Northern and Yorkshire for this period which may explain some or all of the difference in this region[33].
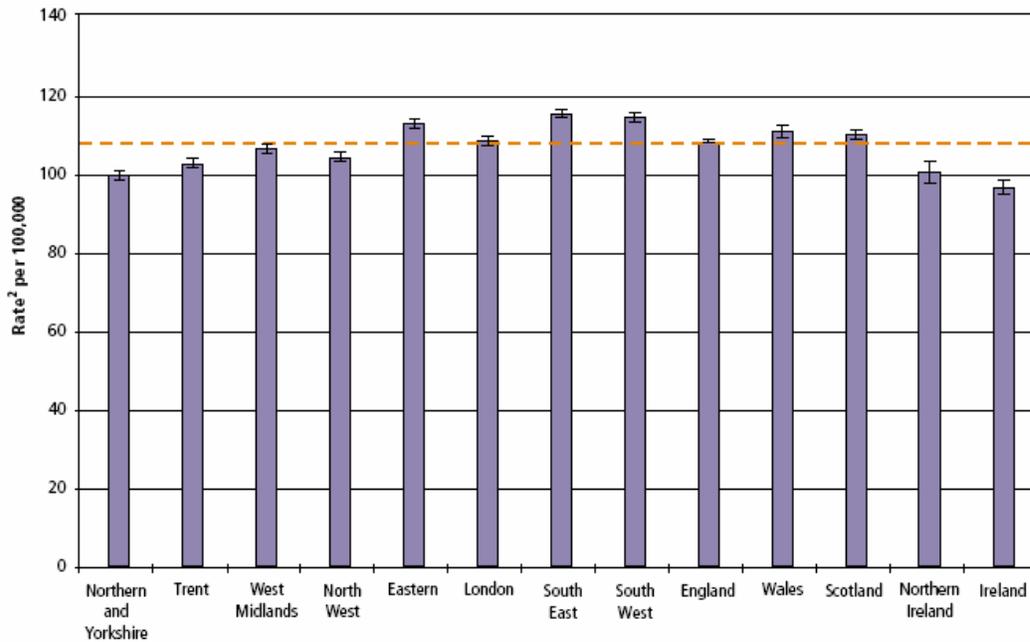
1 Northern Ireland 1993-99, Ireland 1994-99

2 Age standardised using the European standard population, with 95% confidence interval

Figure 2 Incidence rate of breast cancer by region, 1991-1999[33]

Comment [AB3]: Dotted line needs labelling

Looking beyond the UK, estimated age-adjusted incidence rates of diagnosed breast cancer in Europe varies by a factor of 2. Countries with the lowest rates comprise Eastern European and Baltic states. Those with highest rates comprise northern European countries including the UK[34] (Figure 3).
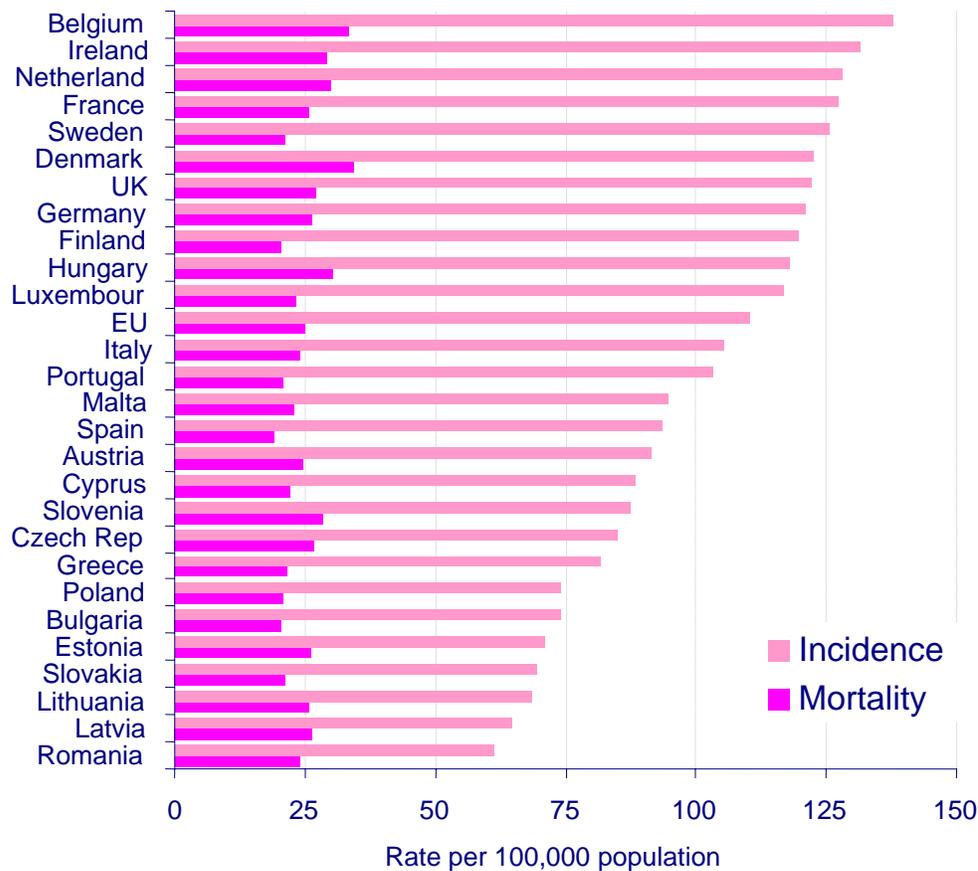
Figure 3 Age standardised rates of incidence and mortality of breast cancer in Europe, 2006[34]. Reproduced with permission of Cancer Research UK.

At a global level, the variation in incidence rates is greater still: rates in developed countries including the UK are 4-5 times higher than many countries in Africa and Asia[35].

3.1.5 Ethnicity

Studies of UK and Australian residents have shown that the incidence rate of breast cancer for immigrants lies between the rate from their country of birth and their country of residence[36-38]. For every age group, South Asian women and men have a lower incidence than the rest of the UK population[19,22,36]. One study observed that there has been an apparent increase in the incidence rate of breast cancer in the South Asian group compared to a decrease in the non-Asian population[39]. This may be related to an aging South Asian population, an increasing proportion of second generation individuals or a change in lifestyle factors.

3.1.6 Trend

Within the UK age-standardised incidence rates for England, Wales, Scotland and Northern Ireland increased by about 12% between 1993 and 2004[26-29] (Figure 4). During this time there has been no overall change in incidence amongst males.
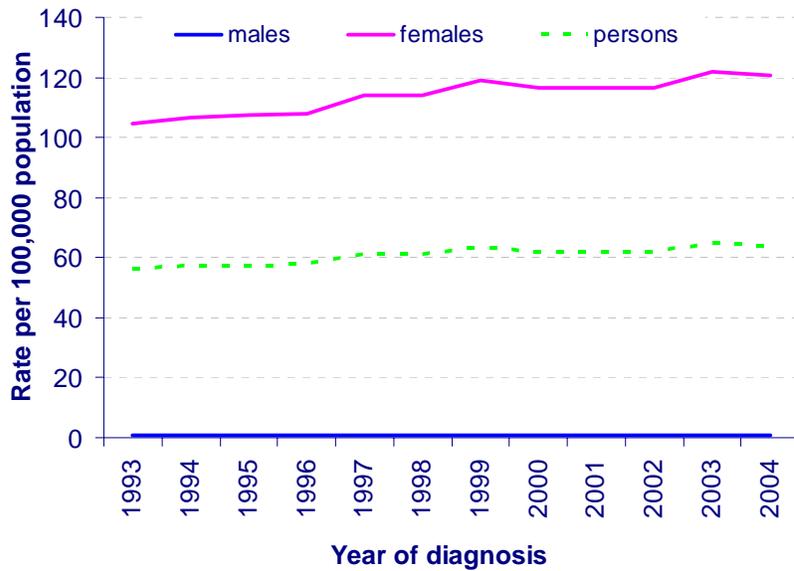
Figure 4 Age-standardised rates of incidence of breast cancer in the UK, 1993-2004[26-29]. Reproduced with permission of Cancer Research UK.

The effect of the introduction of the national screening programme was to increase the age-specific incidencen rates amongst the screened groups (Figure 5). This explains only some of the observed increase, and only towards the start of this period. The underlying increase predates national screening and is strongest in older age groups[40]. However, there is some evidence that the underlying incidence rate of breast cancer may be stabilising[41].
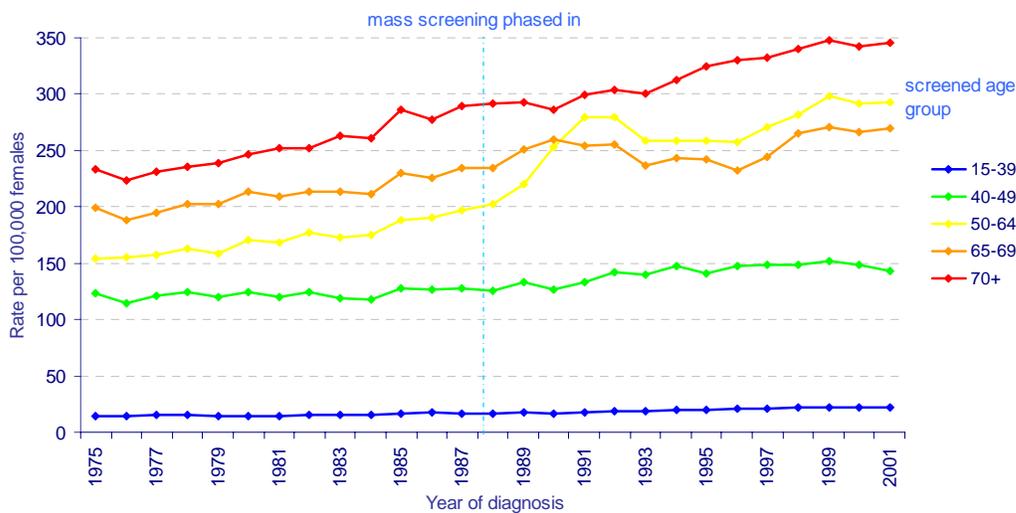
Figure 5 Trend in age-specific incidence rate of breast cancer in the UK[26-29]. Reproduced with permission of Cancer Research UK.

3.1.7 Prognosis

BCCOM's audit of more than 16,000 cancers diagnosed in 2004 provides data on the distribution of breast cancers in terms of their prognosis (expressed in terms of the Nottingham Prognostic Index which is a combined score based on the grade, whether the cancer has spread to the nodes, and the size)[3]. The audit found that the majority of symptomatic cancers were invasive. Nottingham Prognostic Index (NPI) was recorded for 80% of these invasive cancers that were treated surgically. Many of the cancers for which no NPI was available were patients aged 80 or over, who were not treated surgically and so NPI could not be calculated. Where NPI was known, 51% fell into the three most favourable prognostic groups. This contrasts with 83% of screen detected tumours that fall into the same three groups.

3.2 Mortality

In 2005 there were 12,509 deaths in the UK caused by breast cancer[26-29] of which all but 92 were amongst women (Table 2). Overall these account for more than 1 in 6 of all cancer deaths in women, making it the second most frequent cause of cancer death in women (after lung cancer).

Across the UK the crude mortality rate in women is 40.5 per 100,000, and 0.3 in men. The European age-standardised mortality rates are 28.3 and 0.2 per 100,000, respectively.

	England		Wales		Scotland		N.Ireland		UK	
Deaths										
Males	78		4		7		3		92	
Females	10,297		672		1,144		304		12,417	
Persons	10,375		676		1,151		307		12,509	
Crude rate per 100,000 population										
Males	0.3		0.3		0.3		0.4		0.3	
Females	40.2		44.0		43.5		34.7		40.5	
Persons	20.6		15.6		22.7		17.9		20.8	
Age-standardised rate (European) per 100,000 population										
Males	0.3		0.2		0.2		0.3		0.2	
CI 95%	0.2	0.3	0.0	0.3	0.1	0.4	0.0	0.7	0.2	0.3
Females	28.1		28.3		30.2		27.2		28.3	
CI 95%	27.6	28.7	26.2	30.4	28.4	31.9	24.1	30.2	27.8	28.8
Persons	15.4		15.6		16.8		15.2		15.5	
CI 95%	15.1	15.7	14.4	16.8	15.9	17.8	13.5	16.9	15.2	15.8

Table 2 Breast cancer deaths and mortality rates in the UK, 2005[26-29]. Reproduced with permission of Cancer Research UK.

ioeconomic status is measured at a group level, mortality from breast
cancer follows the same socioeconomic gradient as incidence[31,42]. Women in higher
socioeconomic groups are more likely to have breast cancer recorded as their cause
of death than those in lower socioeconomic groups. Studies that have assessed
mortality by broader measures such as a country's GDP or educational levels have
had equivocal results[9]. No studies were found that assessed the risk of mortality by
socioeconomic status at an individual level.

Studies comparing mortality across European countries have found that on average
there is a 23% (95% CI 1-51%) greater risk of dying from breast cancer in the most
educated group in society compared to the least educated, although when individual
countries were studied this difference often did not reach significance[18]. These
differences appeared more significant in the 50-69 age group than in younger
women, and in those ever married compared to those never married[18]; this may be
due to the greater size of the older and ever married populations with breast cancer.

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Countries with higher GDPs also tend to have higher mortality from breast cancer than countries with lower GDPs[43].

3.2.3 Geography

An analysis of breast cancer deaths amongst women in the UK between 1991-2000 showed less than 10% variation between Northern and Yorkshire with the lowest mortality (33.4 per 100,000) and West Midlands with the highest (36.5)[33] (Figure 7). Quinn highlights flaws in the completeness of data for Northern and Yorkshire for this period which may explain some or all of this variation[33]. Similar analysis of mortality by health authority also showed little variation. The difference between these rates and those given for 2005 is due to the reduction in mortality over this time period.

1 Scotland 1991-99, Ireland 1994-2000
2 Age standardised using the European standard population, with 95% confidence interval
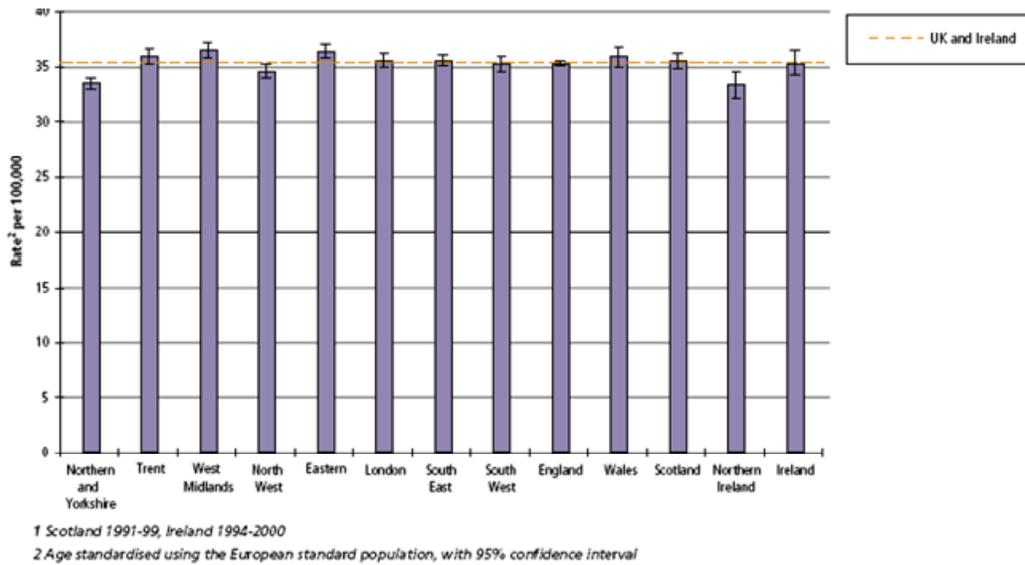
Figure 7 Mortality rate of breast cancer by region[33]

Recent projections of breast cancer mortality for 2006 by country[34] show that the UK still has a higher rate (27.3 per 100,000) compared to that of many other European counties (range 16.9 – 34.5 per 100,000).

3.2.4 Ethnicity

Studies using country of birth as a factor have found consistent results that, in UK residents, those born outside the UK have a lower mortality from breast cancer than those born within the UK[38]. This has also been found for other cancers including colon, lung, lymphoma and leukaemia[22]. When broken down there is a decreased risk of death from breast cancer for those born in Eastern Europe, Bangladesh, India, Pakistan or China; there has been an increased risk identified for those born in West Africa[20]. Studies of UK and Australian residents have shown that the mortality rate from breast cancer for immigrants lies between the rate from their country of birth and their country of residence[36-38]. In the US there is an increased risk of breast cancer death in African Americans[44] compared to the rest of the population which may be related to genetic factors, tumour factors or the ability to access screening and treatment.

3.2.5 Trend

The recent trend in age-standardised breast cancer mortality in women in the UK has been downward. Since the late 1980s, the rate has reduced by about one third[26-29]. Reductions in mortality have been greatest in women aged 40-49 (39%), with progressively smaller reductions realised in older age groups (Figure 8).

This trend towards decreased mortality has been jointly attributed to the introduction of national screening and by improvements in treatment arising from the 1984-85 overview of systemic therapy[41].
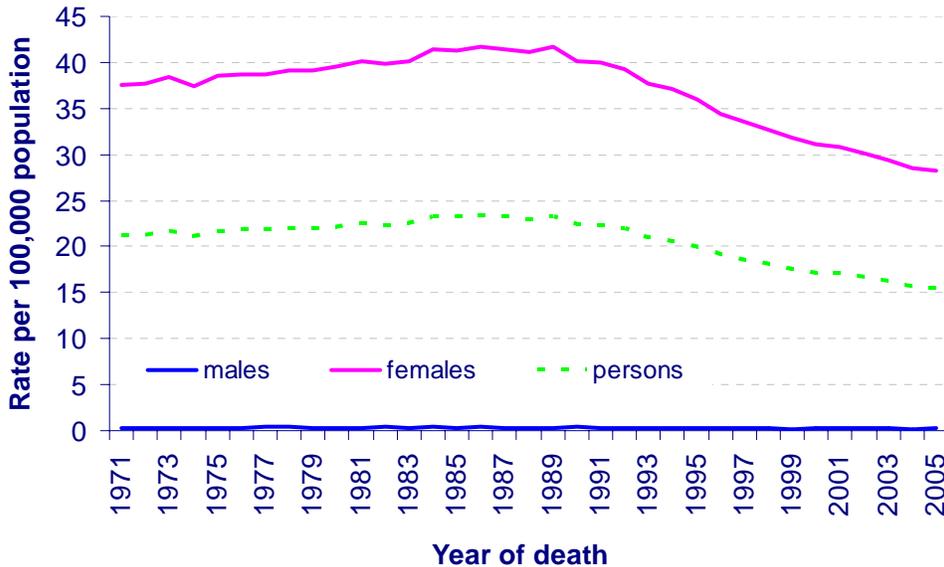
Figure 8 Age-standardised rates for breast cancer mortality in the UK, 1971-2005[26-29]. Reproduced with permission of Cancer Research UK.

3.3 Survival

Five-year relative survival for women aged 50-69 years diagnosed with breast cancer between 1996 - 1999 was over 80%[45]. Twenty-year survival (based on projections) for this group is better than 70%. Amongst younger women survival is slightly lower (Figure 9). In women aged 70 or over at diagnosis, five-year survival is 70% and twenty-year survival is projected to be about 60%.
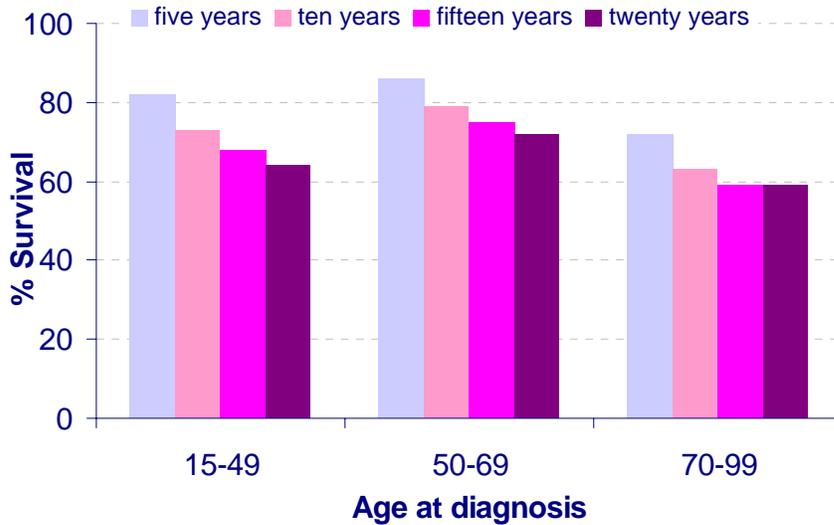
Figure 9 Breast cancer five-, ten-, fifteen- and twenty-year relative survival in England and Wales by age at diagnosis, 1996 - 1999[45]. Reproduced with permission of Cancer Research UK.

These rates of survival represent significant increases on historical rates. For example, whereas the overall five-year survival for women diagnosed in 2001-2003 was 80%, as recently as the early 1990s it was less than 70%. In the late 1970s five-year survival was less than 60% (Figure 10). This trend is attributed to the recommendations arising from the 1984-85 world overview of systemic therapy[46].
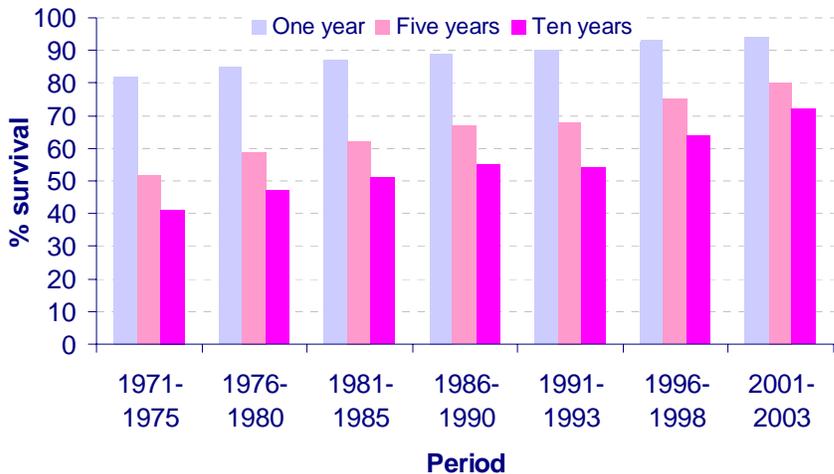
Figure 10 Age-standardised one-, five- and ten-year survival from breast cancer in England and Wales, 1973-2001

Survival also varies by staging at time of diagnosis. For women in the West Midlands diagnosed in the late 1980s, actual ten-year survival varied from almost 80% for Stage I tumours to less than 5% for Stage IV[47] (Figure 11).
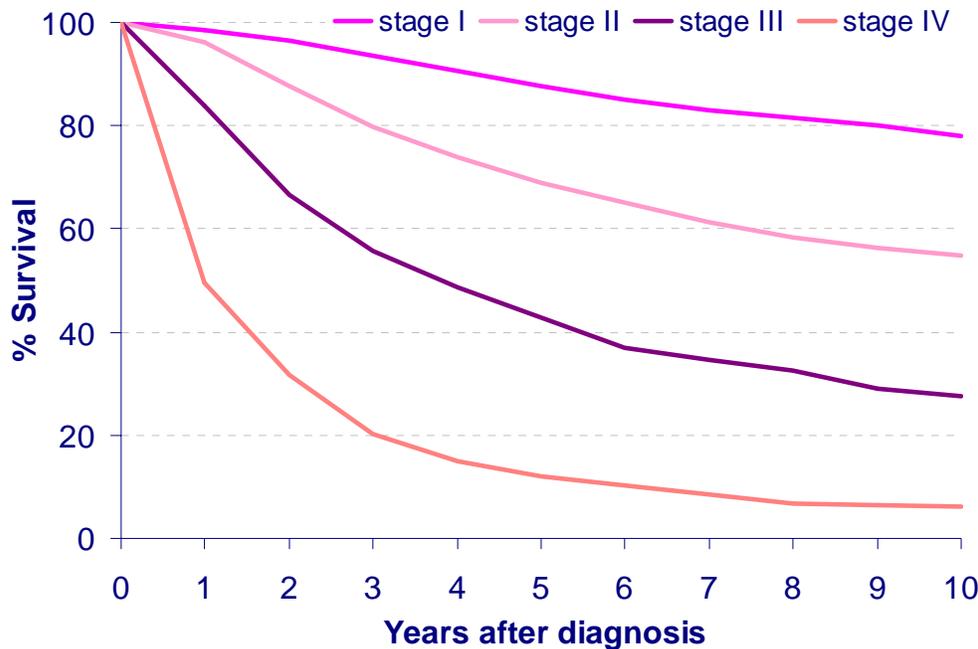
Figure 11 Ten-year relative survival for breast cancer patients diagnosed in West Midlands 1985-1989, by staging at diagnosis (as quoted by CancerStats[47]). Reproduced with permission of Cancer Research UK.

Recent data shows that for women diagnosed in 2000-2001 through the national screening programme with small, early stage breast cancer in the excellent or good prognostic groups and who go on to receive treatment, five-year survival is the same as the rest of the UK female population[48]. This group equates to 61% of individuals whose cancers were detected through screening.

3.3.1 Socioeconomic status

Survival from breast cancer, for both men and women, has improved markedly in England and Wales over past decades[11]. However, inequalities exist and survival for most cancers, including breast cancer, has been found to be poorer in the lower socioeconomic groups[9,10,13,15,16,49,50]. This persists even after allowing for higher premature all cause mortality in the lower than the higher socioeconomic groups[11]. Breast cancer survival increased by 6.1% every five years from 1986-1990 to 1996-1999, an increase on the 4.4% every five years in the previous decade[11]. However, the gap in survival between the women resident in the most and least deprived census wards remained constant at 5.8%[16], a pattern mirrored in other Western European countries[51]. For many other cancers this gap in survival widened over this time period[16,31] and the gap in all cause mortality has also been widening across Western Europe between the least and most deprived groups over this time[51].

Variation in survival due to socioeconomic status may be due to the length of time individuals wait before seeking help, the timeliness of their referrals, biological differences (morphology, size, and spread) in the tumour at the time of diagnosis, the

treatment given and compliance with that treatment[11], changes in childbearing practices[51] and their pre-existing morbidity[11].

There is no evidence to support the theory that women from higher socioeconomic groups present earlier to services[14], or that their referral to hospital is more timely[52]. Nor is there evidence that differences are due to losses in registration. Modelling has shown that 30% of survivors in the least affluent group would need to be lost to registration to affect the differences observed in all cancers[16].

Women from lower socioeconomic backgrounds, at any age, were more likely to be diagnosed with more advanced disease[15], although differences were more pronounced in the 65-99 age group[53]. However, differences in survival have been found to persist even after adjusting for the stage of disease at diagnosis in two English registry areas[11,53] with survival being poorer at every stage of the disease[14].

Women in the more deprived groups appear to have greater contact with their GP following treatment and more hospital admissions for problems unrelated to cancer[52]. Poorer survival in the most deprived group may be due to higher levels of co-morbidity[52]. Obesity is a factor linked to both breast cancer and to deprivation and may influence survival[14].

There is an interaction between socioeconomic status and ethnicity. South Asian women with breast cancer tend to be younger and live in more deprived areas than non-South Asian women in England and Wales[19,23,36,39]. This may reflect the age and socioeconomic distribution of South Asian women the UK[23,39]. Despite this their survival has been found to be better than others in the UK with similar levels of deprivation[19]. It is possible that this may be influenced by an overestimation of deprivation due to the inclusion of an overcrowding measure in the deprivation scores. For every age group South Asian women and men have a better survival than the rest of the UK population even when allowing for the stage of disease at the time of diagnosis[19,22,36]. Some regional studies have not found a difference in recurrence free or overall survival[23,39].

3.3.2 Geography

In an international comparison of women diagnosed between 1990-1994, five-year survival rates for England, Wales and Scotland were significantly lower than the European average (Figure 12). More advanced stage of disease at diagnosis is argued to be a key explanation for the lower survival rates found in Western Europe, including England, Scotland and Wales amongst people diagnosed in the early 1990s[54].
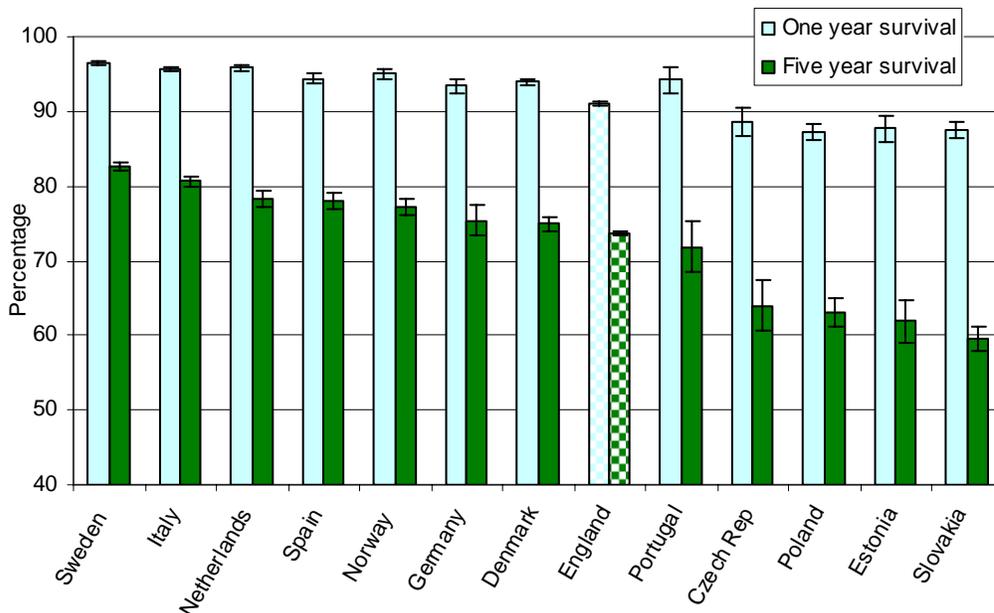
Figure 12 Breast cancer one- and five-year survival by country, 1991-1994[55]

> **Comment [AB4]:** Do we need to mark the European average on this graph?

3.3.3 Other factors affecting survival

Variation in tumour biology can affect survival from breast cancer. This is not universally well recorded by cancer registries, but information is available for symptomatic breast cancers from the Breast Cancer Clinic Outcomes Audit of patients diagnosed in 2004[3]. The audit included around 16,000 symptomatic breast cancers diagnosed by almost 200 breast surgeons. The majority (over 15,500) of all the cancers were invasive and of these 12% were Grade 1, 41% Grade 2 and 33% Grade 3. The nodal status was known for 66% of the invasive cancers, rising to 86% of those treated surgically. This varied by age with 14% of those surgically treated in the 50-64 age group having unknown lymph node status, rising to 28% in those over 80 years. The chance of nodes being positive increased with size and grade of tumour; 11% of small Grade 1 tumours had positive nodes compared with 81% for large Grade 3 tumours.

Women from higher socioeconomic groups are more likely to attend for breast screening[14] and women with tumours detected by screening have a better prognosis than those with symptomatic tumours[14]. Detection by screening may lead to earlier treatment and so improve survival. A study from one centre in England found that women with screen detected tumours were more likely to be from affluent areas and least likely to be from less affluent areas when compared to women with symptomatic tumours[12]. Women from the South Asian population are less likely than the non-South Asian population to have screen detected tumours[23]. Those from deprived areas are also more likely to have lymphatic spread at the time of diagnosis, but this difference can be accounted for by the lower percentage of screen detected tumours in this group[14]. No other differences in tumour factors have been found. This does mean, however, that women from the lowest deprivation groups are more likely to have a diagnosis with a poorer prognosis than affluent women[14].

No differences have been found in tumour site, spread, morphology or grade when the tumours of South Asian women are compared to those of the non-South Asian population[19,23,39]. However this is difficult to assess as tumour characteristics are not

fully recorded in cancer registry data[23]. South Asian women have been found to have larger tumours than other groups, but studies disagree as to whether they have a greater delay in presenting to their General Practitioner[36,39]. High phytoestrogen intake in Asian populations has been suggested as protective against breast cancer but there is a lack of consensus in the literature[56,57].

In London, between 1994 and 2004, black women were significantly younger at diagnosis than white women (median of 46 years vs. 67 years) but with no difference in socioeconomic status or the stage of tumour at presentation[58]. Black women had more aggressive tumour types (grade 3 tumours, positive nodes, negative receptor status and basal like subtype histology). Those with small tumours were also twice as likely to die as white women with similar tumours, findings that are consistent with previous studies of African Americans[59].

3.4 Prevalence

Based on numbers of women diagnosed up to the end of 1992, and historical survival patterns it has been estimated that in 2003 there were approximately 172,000 women in the UK who have a history of breast cancer. This number is likely to be an underestimate in view of the increases in incidence and survival experienced in the UK since the early 1990s. The proportion of these living with secondary breast cancer is not known[60].

4 Treatment

The information available on breast cancer treatment in the UK is more open to interpretation than the preceding epidemiological data. It falls broadly into three types; data recorded to monitor activity, specially collected audit data and published research. The activity data is particularly useful to provide an estimate of the impact of breast cancer on healthcare services and can provide some indication of variation across the country. Activity data cannot currently allow us to assess the number of individuals receiving treatment or reveal patient's journey's through the healthcare system. This may be possible in the future when it is linked to the robust registry data. This will allow the relation of the date of diagnosis, and the registry diagnosis itself, to admissions and procedure data. There is currently no way of examining treatment by stage of disease and the indication for treatment is not recorded, so we cannot say which interventions are intended as treatments and which as palliation.

4.1 Hospital Activity

The HES (Hospital Episode Statistics) for England are recorded by hospitals at the time of a patient's episode of care. These episodes of care include day cases but do not include outpatient episodes so we do not know the level of activity in that setting. A similar system, PEDW (Patient Episode Database Wales), is used in Wales and analysis of this data is also included. These data were obtained with thanks from Dr Brian Cottier at NATCANSAT.

4.1.1 HES data

Activity over time - England

Figure 13 illustrates the number and type of procedures carried out in episodes of care coded with the first diagnosis 'breast neoplasm'. 'Other excision' refers to procedures such as wide local excision or quadrantectomy of the breast. The numbers of 'other excision' are approximately double that of 'mastectomy' and both procedures are increasing over time. The numbers of 'biopsy' procedures appear to be falling, but this may reflect a change in practice with a move to performing such procedures in the outpatient clinic. It is possible that there may be some misclassification occurring, for example wide local excision being coded as inpatient biopsy.
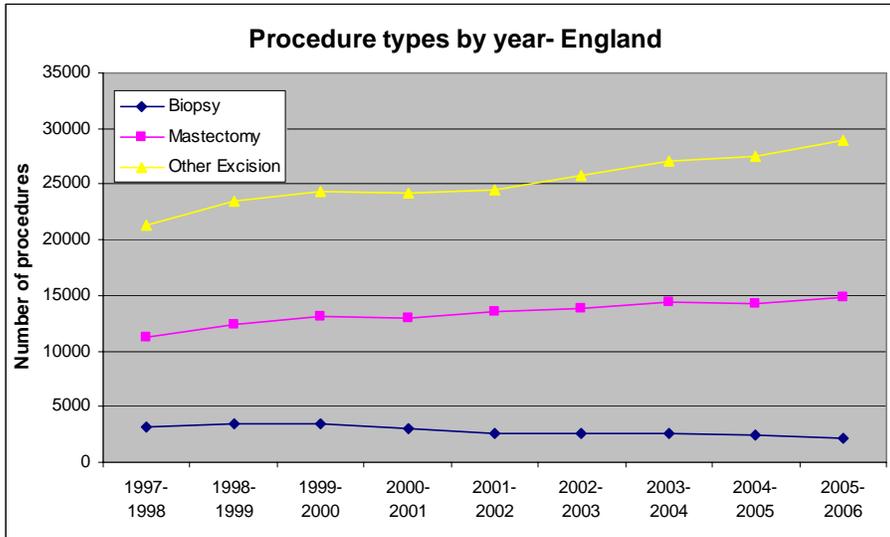
Figure 13 Number of procedures by type in England, 1997-2006. Data source: NATCANSAT.

> **Comment [AB5]:** Need to delete title on picture as covered by figure legend

Table 3 shows the diagnosis of individuals coded as 'breast neoplasm' over time. The numbers of episodes associated with a malignant or in-situ diagnosis have been increasing, whereas those related to benign disease have remained relatively static. However, when the percentages of procedures are examined there is little change year by year.

	1997-1998	1998-1999	1999-2000	2000-2001	2001-2002	2002-2003	2003-2004	(Percentages subject to rounding) Total
Malignant	123,010 (89%)	133,864 (89%)	158,379 (89%)	164,512 (89%)	150,618 (88%)	155,866 (88%)	167,249 (89%)	1,053,498 (89%)
Benign	7,547 (5%)	7,760 (5%)	8,040 (5%)	7,572 (4%)	7,679 (4%)	7,839 (4%)	7,882 (4%)	54,319 (5%)
In Situ	3,390 (2%)	3,791 (3%)	4,205 (2%)	4,319 (2%)	4,743 (3%)	4,946 (3%)	5,300 (3%)	30,694 (3%)
Other[*]	4,581 (3%)	4,924 (3%)	6,865 (4%)	8,297 (4%)	7,887 (5%)	7,505 (4%)	7,746 (4%)	47,805 (4%)
Total	138,528	150,339	177,489	184,700	170,927	176,156	188,177	1,186,316

* 'Other' includes multiple and unknown diagnoses.

Table 3 Diagnosis over time 1997-2004.

The types of admission over time are examined in Table 4. Other admission relates to maternity and hospital attendance other than day case, inpatient stay or outpatient visit (which is not included in the HES data). Day case admission remains the most frequent type of admission throughout the period. There appears to have been a rise in the 'other admission' group which may be related to a change in clinical or in coding practice.

	1997-1998	1998-1999	1999-2000	2000-2001	2001-2002	2002-2003	2003-2004	Total
								(Percentages subject to rounding)
Day case admission	74,037 (53%)	86,525 (58%)	99,940 (56%)	91,597 (50%)	82,481 (48%)	77,360 (44%)	84,397 (45%)	596,337 (50%)
Ordinary admission	64,491 (47%)	63,814 (42%)	66,532 (37%)	65,717 (36%)	66,463 (39%)	70,499 (40%)	74,501 (40%)	472,017 (40%)
Other admission	0	0	11,017 (6%)	27,386 (15%)	21,983 (13%)	28,297 (16%)	29,279 (16%)	117,962 (10%)
Total	138,528	150,339	177,489	184,700	170,927	176,156	188,177	1,186,316

Table 4 Type of admission over time 1997-2004.

Figures 14 and 15 illustrate the numbers of 'other excision' and 'total cxcision' by age group for two time periods, the financial years 1998-2001 and 2001-2004. The scale of the y axis on the 'other excision' graph is double that on the 'total excision' graph due to the difference in the numbers of these procedures performed. The figures demonstrate a general increase in the numbers of procedures performed over the two time periods, particularly in the 55 to 85 year age range. The greatest numbers of procedures fall within the 50 to 65 year age range, the breast screening programme age range at that time.
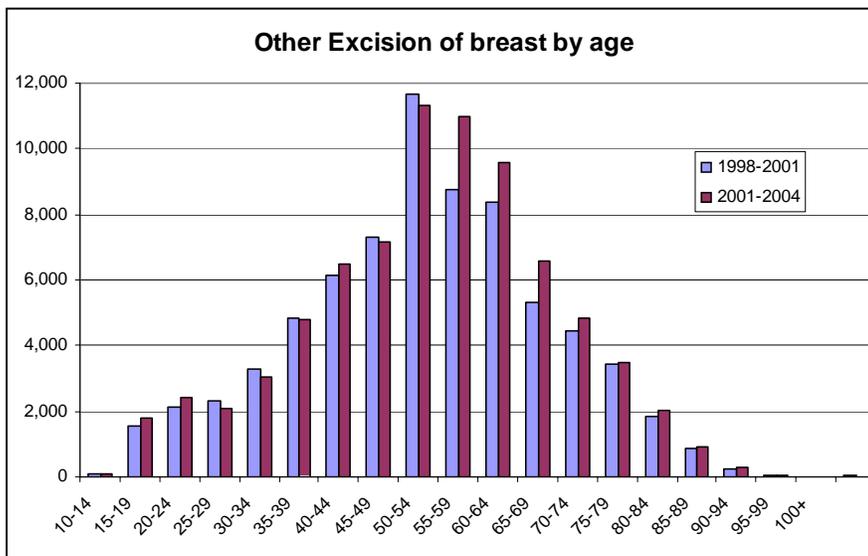
Figure 14 Number of 'other excisions' performed by age in England, 1998-2001 and 2001-2004. Data source: NATCANSAT.

Comment [AB6]: Remove title on graph. Units on axes?

In Figure 14 there appears to be a small peak in the 15 to 30 age range which may be related to procedures performed for benign breast disorders. In Figure 15 there is a secondary peak in the 65 to 79 year age group which may be related to increased presentation of symptomatic breast cancer.

Total Excision of breast by age
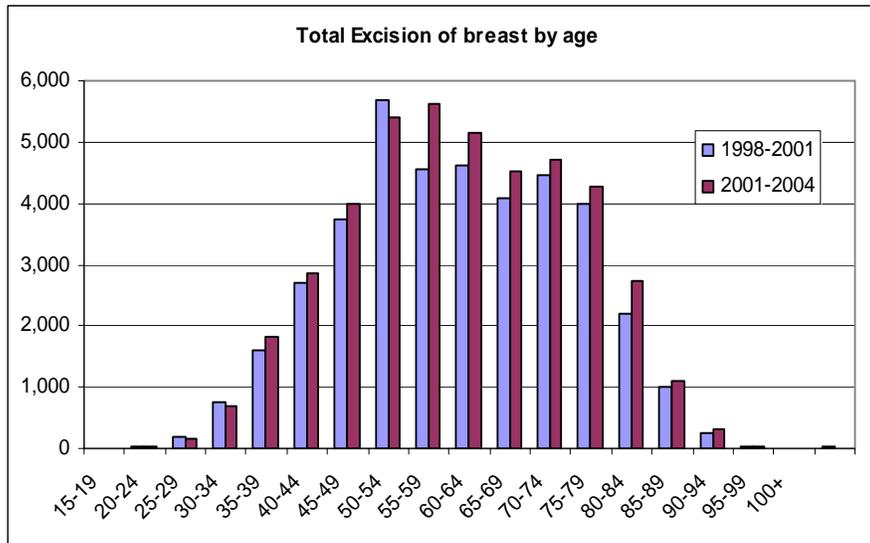
Figure 15 Number of 'total excisions' performed by age in England, 1998-2001 and 2001-2004. Data source: NATCANSAT.

Comment [AB7]: Delete title and label axes

These data also indicate that there may be some inequity in surgical treatments for breast cancer. We know that in the 5 year age bands over 75 years the numbers of breast cancer cases are around half those in the 5 year age bands in the screened age group (see Figure 1). The HES data show that the number of procedures performed in the older age bands is much lower than half those in the screened age bands. The BCCOM audit[3] has shown that from 2002 to 2004 those in the older age group were least likely to receive surgical treatment; 4.3% of those aged less than 35 years did not receive surgery compared to 37.1% of those over 80 years. These percentages varied across the country. The differences in the type of surgery performed have not been found to be related to socioeconomic status[61].

Ethnicity is not available from the HES data. We know from the literature that South Asian women have a higher mastectomy rate than other groups, but this can be accounted for by the larger size of their tumours at presentation[39]. There is no other evidence that ethnicity affects the timeliness of treatment or the types of treatment received[39,58].

4.1.2 PEDW data

The PEDW data was available for the financial years 1997-1998 to 2004-2005 and was analysed for breast tumour related episodes to produce a comparison with the English HES data. It is produced for the same purpose and has the same data quality issues as the HES data. The population of Wales is around 3 million people which compares to approximately 49 million people in England[62].

The PEDW data relates to episodes occurring within a Welsh hospital, or to individuals living in Wales who receive treatment in England. 95.8% of episodes for Welsh residents occurred in Welsh hospitals. During the same time period 99.8% of episodes in Welsh hospitals were for Welsh residents. This demonstrates that the majority of activity within the PEDW data is related to Welsh residents and hospitals. Residents of Wales appear to be more likely to have breast cancer treatment in England than English residents are to be treated in Wales.

Activity over time - Wales

Figure 16 illustrates the procedure types performed over time in Wales, and can be compared to the English data in Figure 13. In Wales the most frequent procedure is 'other excision', but the data does not otherwise follow the English trends. 'mastectomy' comprises a larger proportion of the procedures than in England and there is no increasing trend in the total numbers of procedures performed. 'Biopsy' also appears to comprise a greater proportion of procedures than in England.
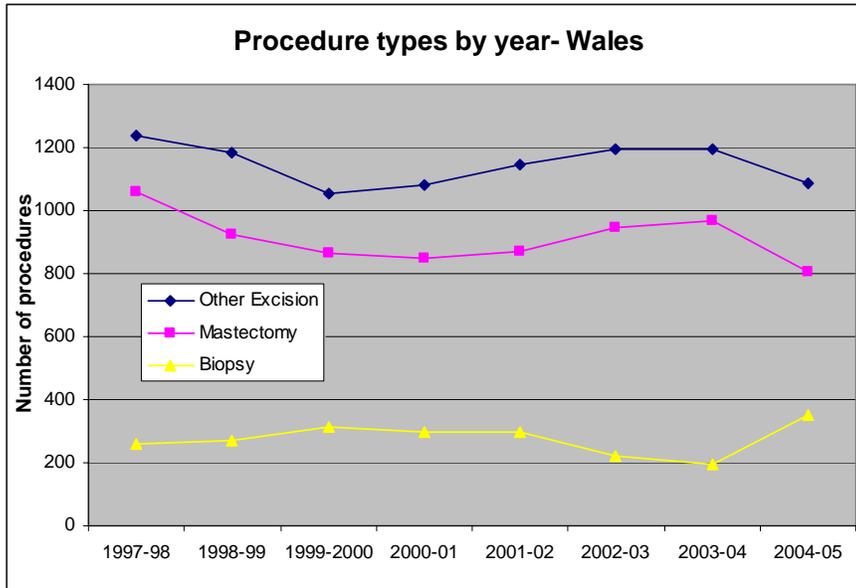
Figure 16 Number of procedures by type in Wales, 1997-2005. Data source: NATCANSAT.

Comment [AB8]: Delete figure title

This finding may be related to differences in clinical or coding practices between Wales and England. The data suggests that a higher proportion of mastectomy procedures are performed in Wales than in England. It is possible that 'biopsy' procedures are misclassified, or are more likely to be carried out in hospital rather than in outpatients.

Diagnoses over time are summarised in Table 5. These data are consistent with that of the English data. There is an increase in episodes related to malignant diagnoses with a decrease in episodes related to benign diagnoses.

	1997-1998	1998-1999	1999-2000	2000-2001	2001-2002	2002-2003	2003-2004	2004-2005	Total
Malignant	8,399 (91%)	8,985 (92%)	9,775 (93%)	9,924 (93%)	9,247 (92%)	19,625 (94%)	14,281 (94%)	14,610 (96%)	94,846 (93%)
Benign	444 (5%)	395 (4%)	319 (3%)	355 (3%)	330 (3%)	385 (2%)	326 (2%)	287 (2%)	2,841 (3%)
In Situ	226 (2%)	220 (2%)	210 (2%)	233 (2%)	272 (3%)	538 (3%)	357 (2%)	217 (1%)	2,273 (2%)
Other	157 (2%)	133 (1%)	154 (1%)	189 (2%)	233 (2%)	291 (1%)	216 (1%)	184 (1%)	1,557 (2%)
Total	9,226	9,733	10,458	10,701	10,082	20,839	15,180	15,298	101,517

Table 5 Diagnosis over time 1997-2005.

The type of admission data for Wales reveals that the most common method of admission is 'other'. The proportion in this category and the difference from the English data suggests that there are significant differences in coding practices and so the type of admission data has not been included.

Figures 17 and 18 illustrate the numbers of 'other excision' and 'total excision' in Wales by age group for two time periods, the financial years 1998-2001 and 2001-2004. These charts can be compared with the English data in figures 14 and 15. There has been an increase in both 'other excision' and 'total excision' over the two time periods. This is more marked for the 'other excision' group which mirrors the pattern in England with an increase in the breast screening age group. Figure 17 also demonstrates a small peak in the under 25s which is probably related to benign breast disease.
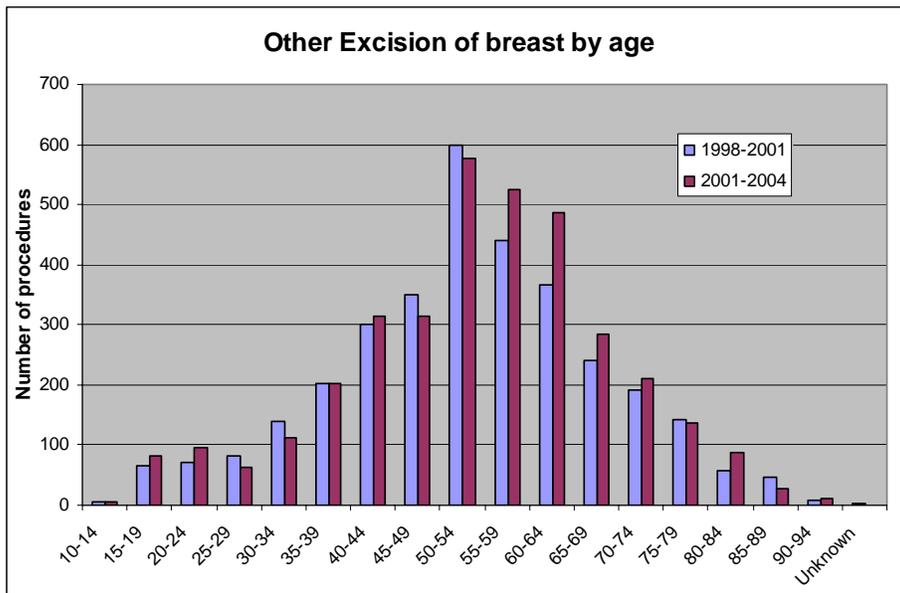
Figure 17 Number of 'other excisions' performed by age in Wales, 1998-2001 and 2001-2004. Data source: NATCANSAT.

Comment [AB9]: Delete title

Figure 18 demonstrates smaller increases and less difference between the breast screening age group and the second smaller peak in the 70s in 'total excisions' than in England.
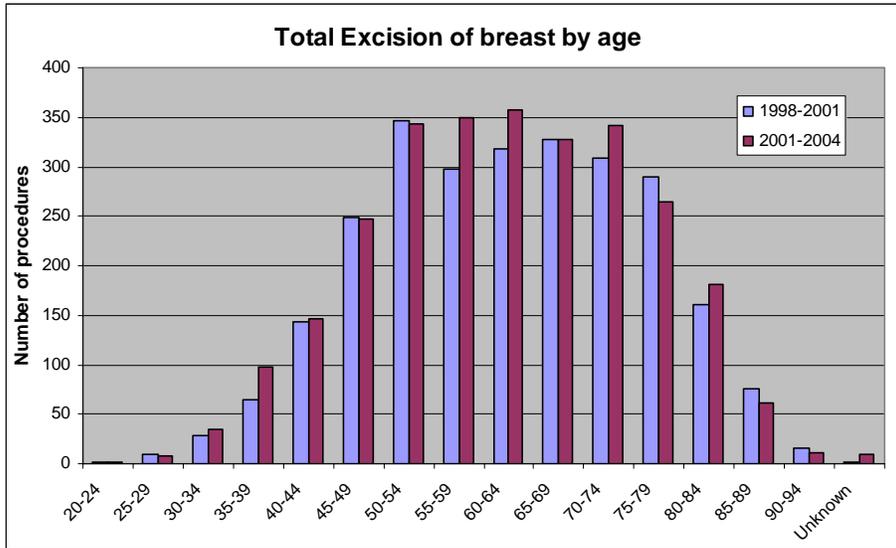
Figure 18 Number of 'total excisions' performed by age in Wales, 1998-2001 and 2001-2004. Data source: NATCANSAT.

4.1.3 English data – 2005-2006

Further analysis of the English HES data was performed to examine differences by region and of length of stay. A single year was chosen to ensure stability when comparing areas such as Networks or SHAs. Procedures undertaken under general surgery are included for the length of stay analysis to eliminate differences found with the small number of procedures conducted under plastic surgeons. Patients that died or were transferred between hospitals were excluded from the analysis.

Type of admission

All episodes of care involving any breast neoplasm were examined by classification of admission according to whether the procedure was undertaken as a day case or during an inpatient stay. There were 45,912 episodes with valid classification of admission and these are summarised in Table 6. The 'other' group shown in the table includes those with multiple codes plus those with unknown type of disease.

	Day case	Inpatient	Total
Benign	4,897 (62.0%)	1,813 (4.8%)	6,710 (14.6%)
In Situ	601 (7.6%)	3,854 (10.1%)	4,455 (9.7%)
Malignant	2,100 (26.6%)	29,666 (78.0%)	31,766 (69.2%)
Other	296 (3.8%)	2,685 (7.1%)	2,981 (6.5%)
Total	7,894 (100%)	38,018 (100%)	45,912 (100%)

Table 6 Type of admission by type of disease 2005-2006

From Table 6 it can be seen that in 2005-2006 62% of day case breast procedures were for benign disease and 78% of inpatient breast procedures were for malignant disease. It should be noted that just over a quarter of day case procedures were undertaken for malignant disease, 6.6% of all of the treatments for malignant disease.

The difference in type of admission by procedure performed is shown in Table 7. The majority of day case procedures are related to 'other excision', for example wide local

excision, with only very small numbers of 'total excision' as would be expected. However, the majority of all procedures, except biopsy, are performed as an inpatient procedure. The most frequent inpatient procedure is 'other excision' at almost 60%, followed by 'total excision' at almost 40%.

	Day case	Inpatient	Total
Biopsy of Breast	1,215 (15.4%)	1,010 (2.7%)	2,225 (4.8%)
Other Excision of Breast	6,661 (84.4%)	22,256 (58.5%)	28,917 (63.0%)
Total Excision of Breast	18 (0.2%)	14,752 (38.8%)	14,770 (32.2%)
Total	7,894 (100%)	38,018 (100%)	45,912 (100%)

Table 7 Type of admission by procedure 2006-2007

Male and Female patients

Approximately 0.1% of malignant tumours occur in male patients[26-29]. Figure 19 illustrates the types of procedures performed by sex for 'all breast tumour' types, including other benign breast disease. In 2006-2007 there were 53,491 breast procedures that fell in the categories wide local excision, mastectomy or mastectomy with reconstruction. Three episodes did not have a gender assigned in the data and so the 53,488 episodes were summarised. Male patients accounted for 3.2% of episodes when all tumours were considered, proportionately higher than would be expected.
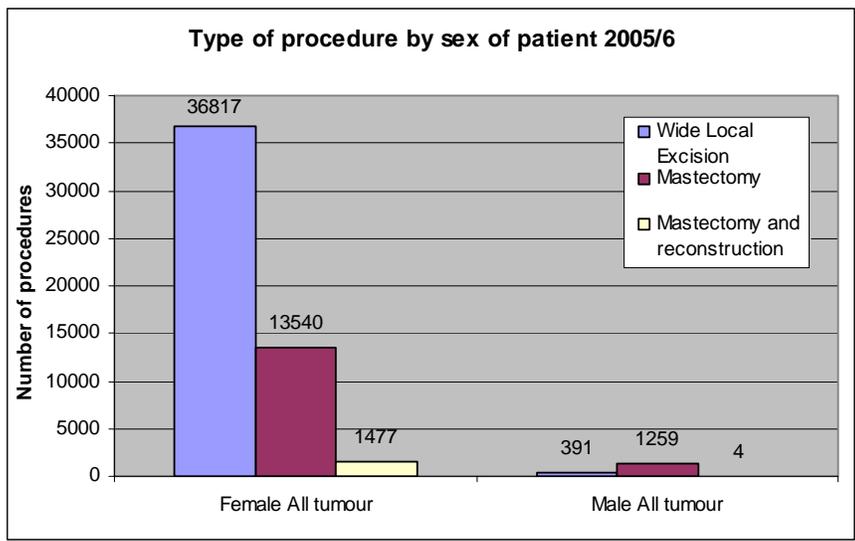
Figure 19 Number of procedures by type performed for males and females, 2005-2006. Data source: NATCANSAT.

Comment [AB11]: Delete title on figure

Figure 20 illustrates the numbers of procedures performed on male patients that were associated with a distinct breast tumour (benign or malignant) or no distinct tumour (other benign breast disease) diagnosis code. Male patients accounted for 0.5% of episodes linked to a distinct tumour diagnosis, the majority of procedures were performed for other breast disease (for example fibroadenosis, tumour from another site or missing code).

Breast Procedures for male patients 2005/6
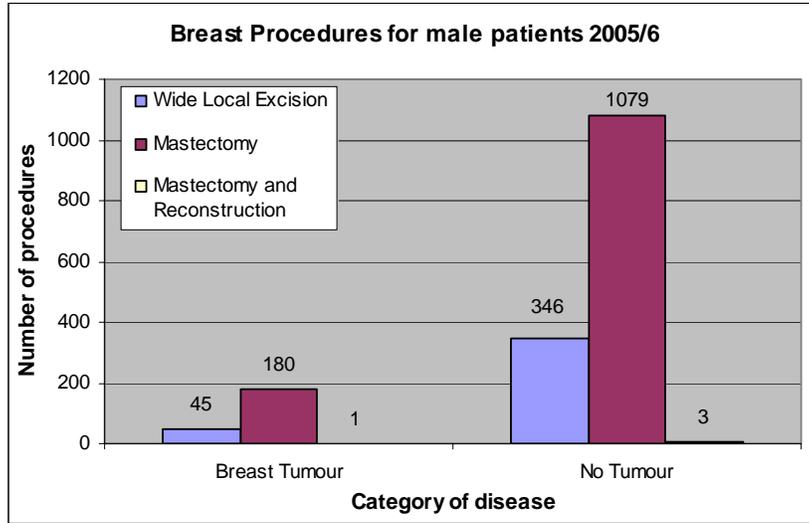
Figure 20 Number of breast procedures in males by pathology, 2005-2006. Data source: NATCANSAT.

Comment [AB12]: Delete title from figure

Figure 21 illustrates the same data for female patients. The pattern contrasts with that for male patients. 96.8% of all these procedures were performed on women and of those 80.1% were for malignant disease. The type of procedure is also contrasting. The majority of male patients underwent mastectomy whereas the majority of female patients underwent wide local excision.

Comment [AB13]: This figure only relates to data on women so isn't this statement a bit odd?

Breast Procedures for female patients 2005/6
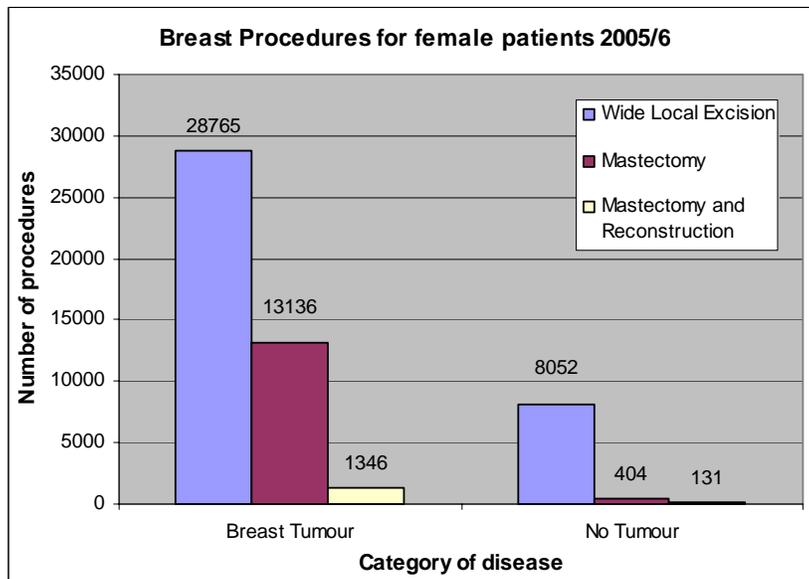
Figure 21 Number of breast procedures in females by pathology, 2005-2006. Data source: NATCANSAT.

Comment [AB14]: Delete title from figure

4.1.4 Variation in procedures by Strategic Health Authority (SHA)

Figure 22 examines the type of procedures performed by where a patient lives (SHA of residence). These are shown as rates to allow comparison between SHAs with different population sizes. Across England there is clear variation in the type of procedures performed and also whether reconstruction is performed at the same time as mastectomy.
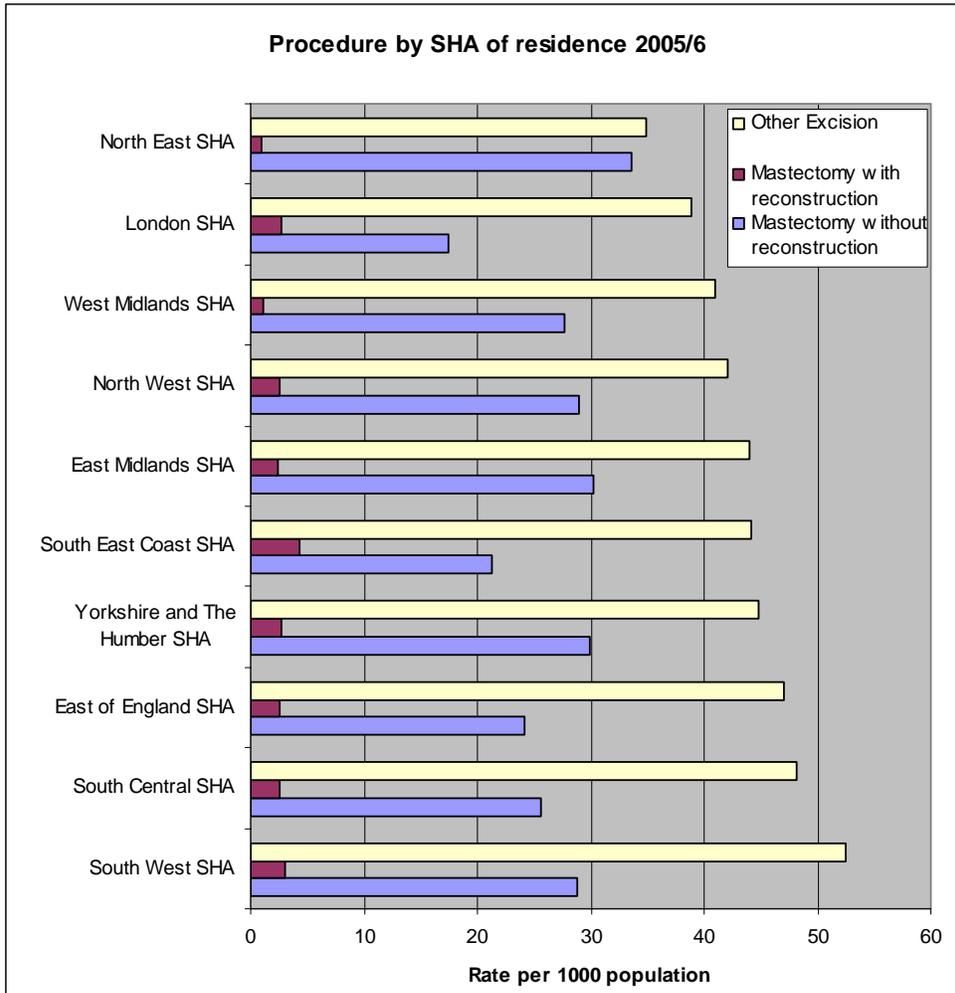
Figure 22 Rate of the three main procedure types by SHA of residence of the patient, 2005-2006. Data source: NATCANSAT.

> **Comment [AB15]:** Delete title from figure

Variation occurs across England. There are similar rates of 'other excision' and 'mastectomy without reconstruction' in the North East, whereas in London and South Central the rates of 'other excision' are around twice that of 'mastectomy without reconstruction'. The data also shows that South East Coast has double the rate of 'mastectomy with reconstruction' compared with the North East and the West Midlands. This difference may be related to how episodes are coded or to actual differences in clinical practice. The 1st report of BCCOM confirmed that mastectomy rates for symptomatic breast cancer varied by region (36.4% to 53.2%) and also by surgeon (19% to 92%)[63].

4.1.5 Length of stay

The type of procedure performed has consequences for the individuals and for the health service. Figure 23 illustrates that for those admitted for 'other excision' in 2005-2006 the median length of stay was 2 days, compared to the median length of stay of 5 days for mastectomy.
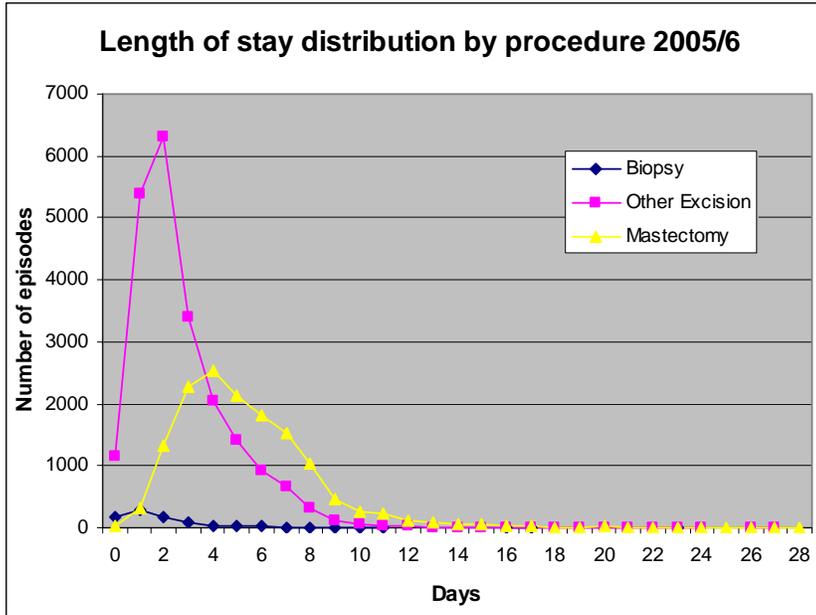
Figure 23 Length of stay for three main procedures, 2005-2006. Data source: NATCANSAT.

> **Comment [AB16]:** Delete title from figure

Figure 24 illustrates that the difference in length of stay between mastectomy and other excision has been relatively constant over the past nine years and that there has been a downward trend in both over that time.
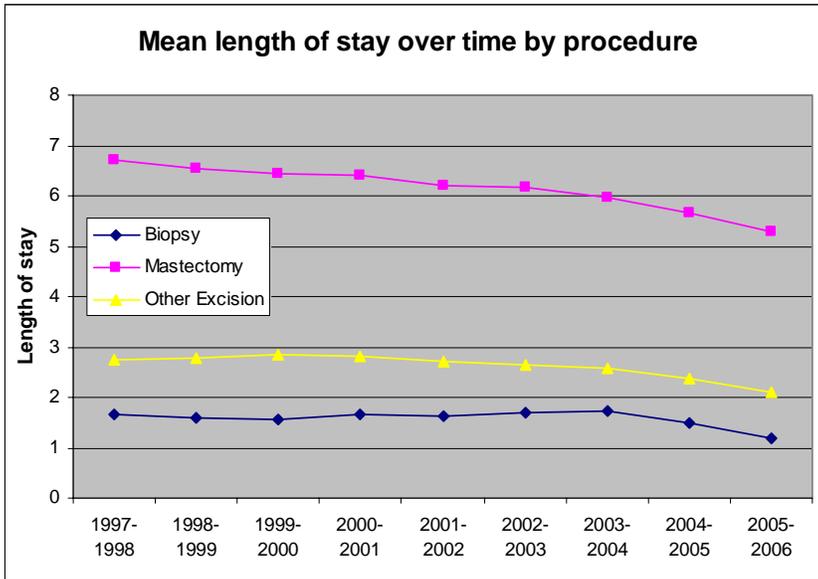
Figure 24 Mean length of stay for three main procedures, 1997-2006. Data source: NATCANSAT.

Length of stay for mastectomy is related to whether reconstruction is performed during the same inpatient episode. Over the past nine years 8.2% of the mastectomy episodes included reconstruction, for 2005-2006 alone this percentage was 9.8%. Figure 25 illustrates the range of length of stay for mastectomies with or without reconstruction over the period 1997-2006. Two y axes are used due to the comparatively small number of simultaneous reconstruction procedures. The median length of stay for mastectomy without reconstruction was 5 days, and with reconstruction was 7 days.
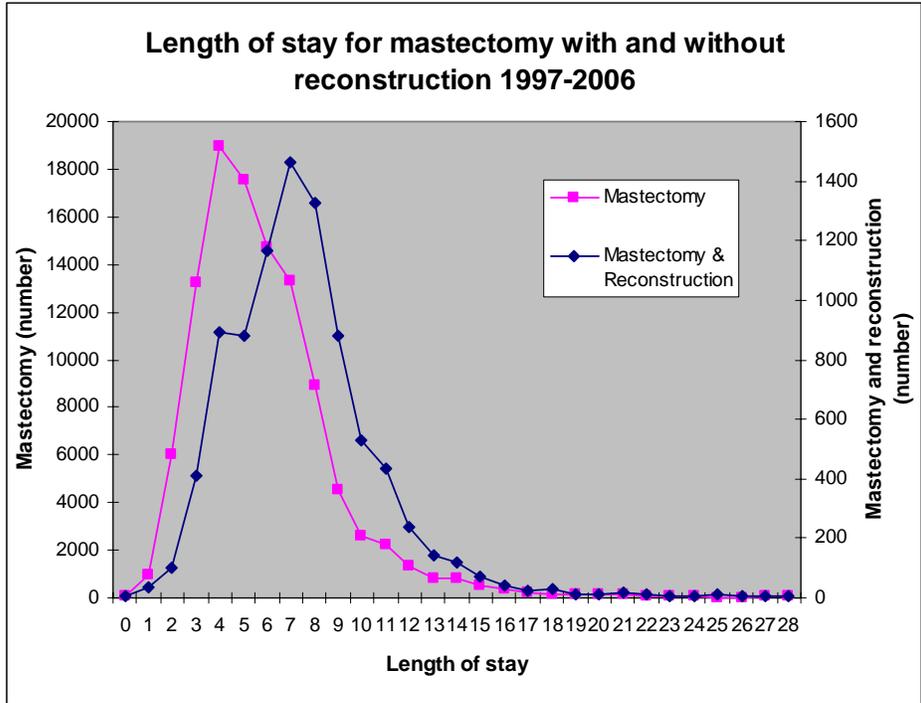
Figure 25 Length of stay for mastectomy with and without reconstruction, 1997-2006. Data source: NATCANSA.)

Comment [AB17]: Delete title from figure

The data for 2005-2006 are summarised in Table 8. The mean length of stay for mastectomy with reconstruction is 1.72 days longer than for mastectomy alone.

Type of procedure	Number of Procedures	Mean length of stay(days)	Bed Days
Mastectomy	13,096	5.21	68,260
Mastectomy & Reconstruction	1,283	6.93	8,891
Total	14,379	5.37	77,151

Table 8 Length of stay for mastectomy with and without reconstruction 2005-2006

Length of stay is also related to the hospital providing care. The mean length of stay for 'other excision', 'mastectomy' and 'mastectomy and reconstruction' are summarised by Cancer Network in the Figure 26. Cancer Network was chosen as the practices of providers within a network are more likely to be similar than other providers in the same geographical area. There is a clear difference in the average time a patient remains in hospital for these procedures depending upon which hospital is providing their care. The reason behind this variation is not known. When the number of procedures performed in the network are plotted against the length of stay for that procedure no relationship is found.
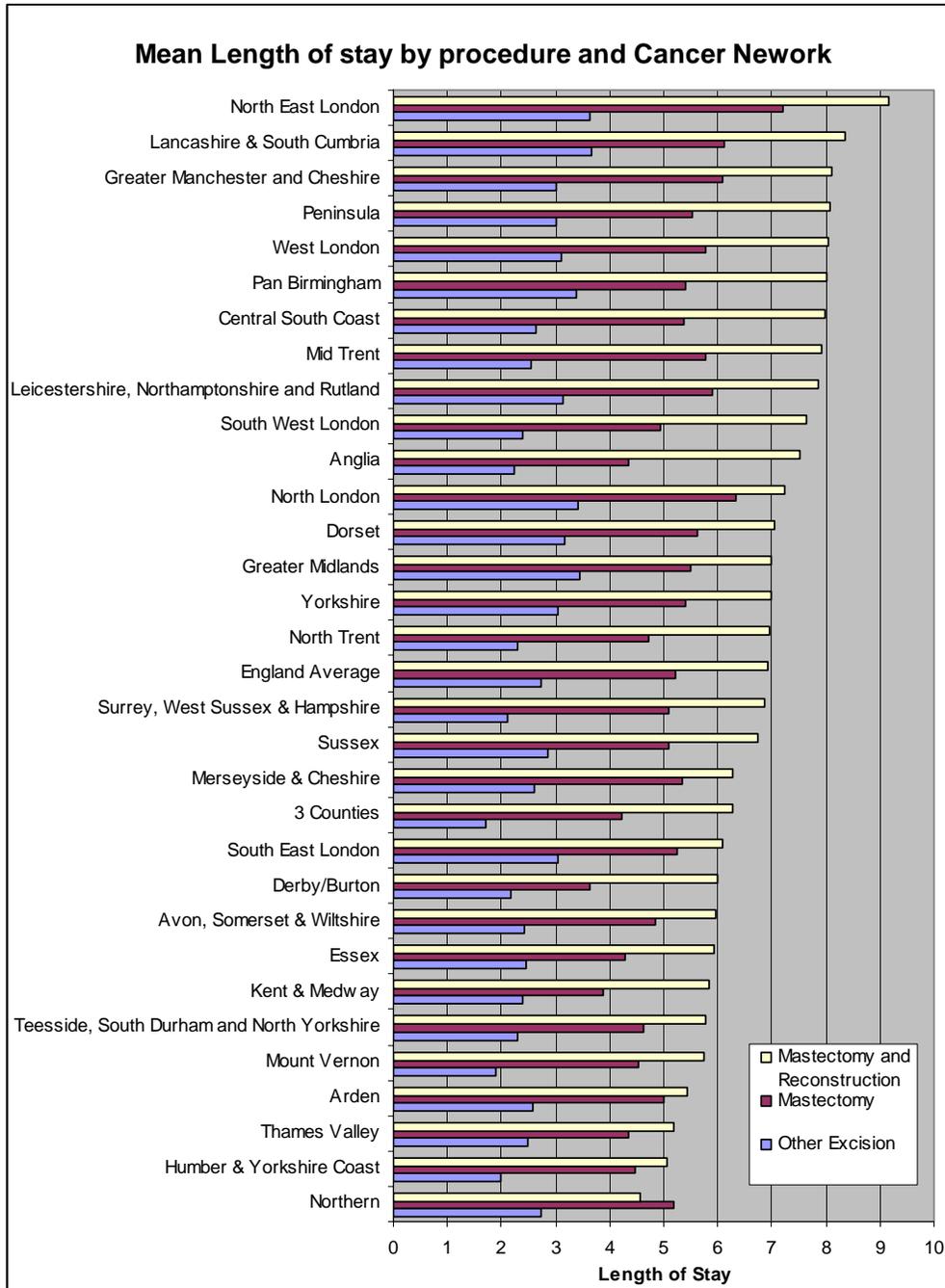
Figure 26 Mean length of stay for three main procedures by Cancer Network of provider, 2005-2006. Data source: NATCANSAT.

Comment [AB18]: Delete title from figure

All networks have a longer average length of stay for mastectomy with reconstruction than without, except Northern. This difference may be related to coding errors or to patient selection. 'Other excision' consistently has around half the length of stay of 'mastectomy' which has implications for the patient and the NHS.

4.1.6 Variation in numbers of procedures performed by consultant

In 2005-2006 there were 427 surgical consultants recorded as performing mastectomies in the HES data. The Association of Breast Surgery advises that only specialist teams should manage breast cancers, and that each surgeon should see between 30 and 150 new patients per year[64]. We know from the data that approximately one third of breast surgical procedures are mastectomies. From this we can infer that consultants treating 30 new patients per year should be performing around 10 mastectomies per year, the other 20 patients receiving other excisions or biopsies. In 2005-2006 the 427 surgeons performed between 1 to 120 mastectomies each. The distribution of the number performed by consultant is illustrated in Figure 27. 57 of the 427 consultants (13.3%) performed fewer than 10 mastectomies in that year. The first BCCOM audit found that 40 patients, out of 16,407 with symptomatic breast cancer, were treated by surgeons treating fewer than 10 symptomatic cancers in the year[63].
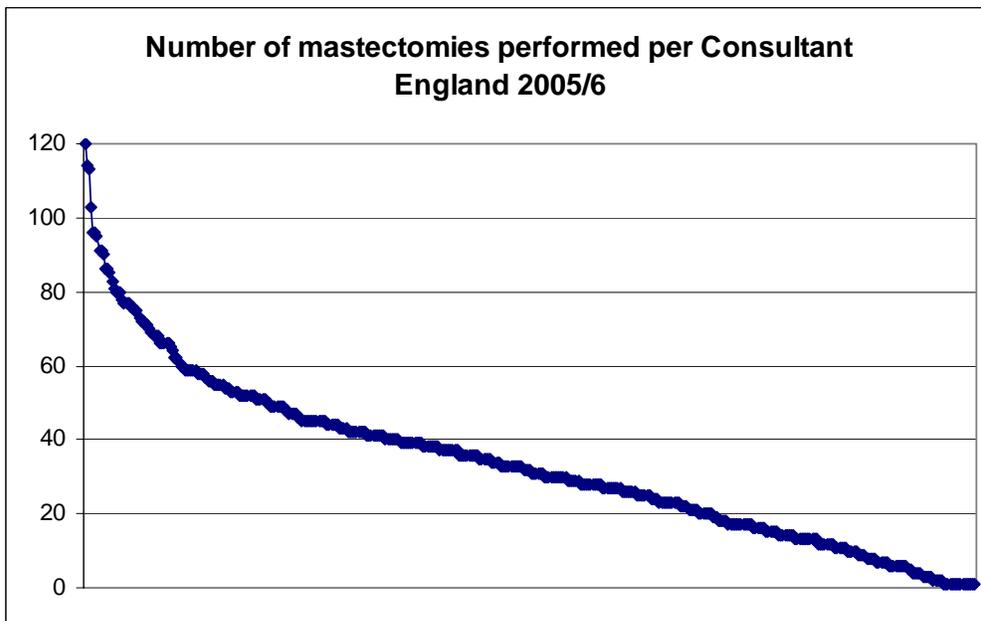
Figure 27 The number of mastectomies performed by individual consultants in a single financial year, 2005-2006. Data source: NATCANSAT.

Comment [AB19]: Delete title from figure

4.2 Primary Care Activity

Primary care provides a great deal of healthcare to individuals with a current diagnosis or past history of breast cancer. This will include contacts for physical problems associated with the cancer and its treatment, plus social and psychological support. Primary care data is not recorded or compiled in a way that allows analysis of the workload within primary care, but survey estimates are available. The RCGP Annual Prevalence Report[8] reveals that an average practice of 10,000 patients will have around 23 registered patients who consult their GP regarding their breast cancer each year.

4.3 Adjuvant Treatment

There is limited data available on the use of adjuvant therapy in breast cancer. The audit of the use of NICE approved cancer drugs by the National Cancer Director

included the use of trastuzamab[25]. This data is assumed to apply mainly to use in advanced breast cancer as the review was prior to its use in early breast cancer. Although there was a nearly three-fold difference in the level of its use by acute trusts across England in 2005, this had reduced from an over four fold variation in 2003. A similar pattern was seen for the other cancer drugs reviewed.

4.4 Other Variations in Treatment

The BCCOM audit data[3] covers approximately 46,000 cases of symptomatic breast cancer diagnosed from 2002 to 2004.This has shown variation in treatment modalities by age. 66.4% of all patients aged less than 50 years of age were treated with hormonal therapy increasing to 85.6% in those over 80 years. Radiotherapy treatment decreased with age, being used in 78.3% of those aged less than 50 years of age and 30.6% of those over 80 years. A decrease was also seen in those receiving radiotherapy after conservation surgery. This pattern was also seen in chemotherapy treatment which was used in 77.2% of those aged less than 50 years but only 16% of those over 80 years. This pattern was seen even in node positive patients.

Researchers have examined how variation in treatment occurs across the country by different groups as this may explain variations in outcome. Variations in breast cancer survival are greatest in the first six months after treatment[11]. Contradictory results have been found when examining treatments received by socioeconomic groups. One study found no difference in surgical, chemotherapeutic and hormonal treatments between affluent and deprived groups[52]. Others have found that those living in less affluent areas were less likely to have surgery, receive radiotherapy or have breast conserving surgery[15] and may be less likely to receive day case treatment[65].

4.5 Radiotherapy

4.5.1 Distance from radiotherapy centres

Distance from radiotherapy centres is a significant factor in the equity of provision of radiotherapy services. The impact in early breast cancer is considerable as patients are often required to travel daily for treatment. Palliative radiotherapy is usually delivered as a single dose but may require several visits to the centre. The map, provided by NATCANSAT, illustrates the hospitals that provide local radiotherapy services and their catchment areas. The shaded areas show those census wards that are over 50 kilometres by road from the radiotherapy centre at their local provider.

The map is generally as would be expected and reveals that in rural areas, for example around the Wash, West Wales, the rural north of England and the rural South West, patients are likely to be furthest by road from the centres. There are however some anomalies for example the northerly tip of the Oxford Radcliff hospital catchment area and the westerly tip of the Addenbrooks catchment area are closest to Northampton General Hospital rather than their local provider.

Pure distance is one method of assessing access but does not capture all the variables which affect equity. This may also be affected by the availability of public transport in the area and the time taken to travel on these roads. Time to travel is affected by distance and speed limits, but also congestion which is a variable associated with time of day and also time of year for example school holidays. Travel times are difficult to calculate as the time effect of congestion in different areas is variable and so distances need to be viewed with consideration of these other variables.

There are large areas on the map that are over 50km by road from the radiotherapy centre of that catchment area. These are rural areas with low levels of population. When the population is included in the assessment we can see that only 7% of the population of England and Wales live more than 50km from their radiotherapy centre (Figure 28).
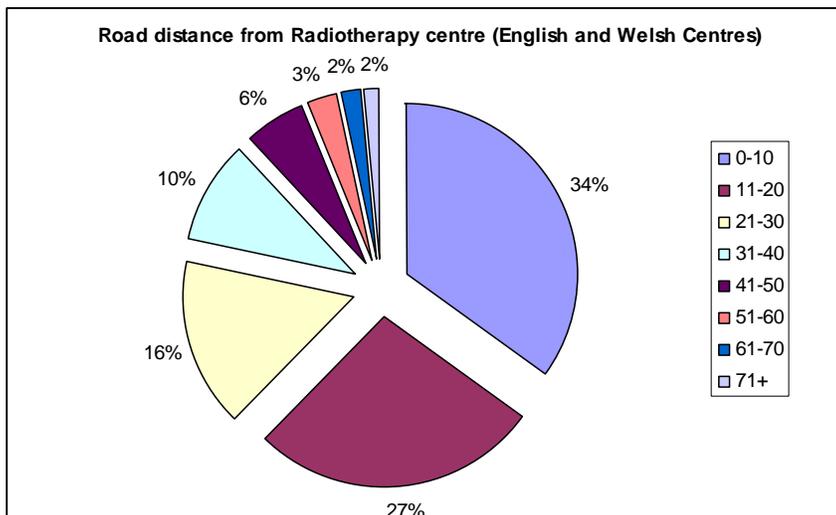
Figure 28 Distance by road of the population of England and Wales from their local radiotherapy centre. Data source: NATCANSAT.

Comment [AB20]: Delete title from figure. Need units

Distance is a more significant factor in Wales and the three Welsh centres are considered in Figure 29. The analysis relates to the population within the catchment areas of the three Welsh centres, and not to the resident population of Wales. This is particularly pertinent for the residents of central Powys who tend to use Gloucester hospital. 15% of the catchment population of the three Welsh centres live more than 50km away.
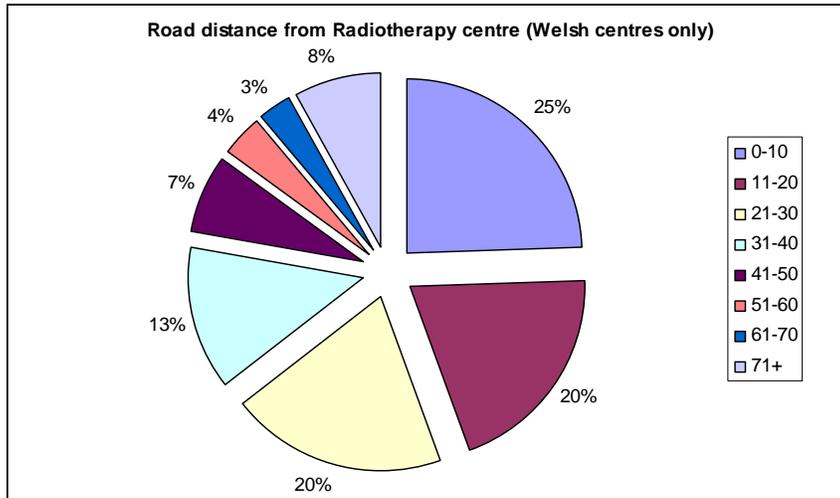
Figure 29 Distance by road of the population of Wales from their local radiotherapy centre. Data source: NATCANSA.)

> **Comment [AB21]:** Delete title from figure. Need units

The difference in the two countries can be clearly seen when cumulative percentages of population are examined by distance, as shown in Table 9.

Distance from centre (km)	English and Welsh centres	Welsh centres only
<10	34%	25%
<20	61%	45%
<30	77%	65%
<40	87%	78%
<50	93%	85%
<60	96%	89%
<70	98%	92%
70+	100%	100%

Table 9 Cumulative percentage of population living within x distance by road from radiotherapy centre.

It can be seen that there is significant inequity in physical access to radiotherapy centres in England and Wales, more marked in the rural areas of the countries, particularly Wales.

4.5.2 Variation in treatment

Data has been collected by NATCANSAT from radiotherapy centres for diagnosis, dose delivered and the number of fractions in each course. Returns have been on a voluntary basis and the returns made are variable in quality and completeness. A review of the current data does not reveal any apparent variation between centres for breast cancer treatment but the quality of the data is not sufficient for any further analysis.

Agreement has been reached to introduce a core data set and mandatory reporting for radiotherapy data. This will allow analysis of treatment regimes plus the indication for treatment, the area treated and importantly enables separation of doses given for treatment and for palliation. This will enable data to be analysed in the future but was not available for this report.

5   Summary

Breast cancer is the most commonly occurring cancer in women accounting for 48,000 new cases in 2004. In 2003 there were an estimated 172,000 women living in the UK with a history of breast cancer. The rates have been steadily increasing over the past 10-15 years but they may now be stabilising. Only a small number of cases, less than 0.1% of the total, occur in men. The numbers of cases of breast cancer are highest in the screened age group, 50 to 69 years, but the rates are highest in those aged over 85 years. It is estimated that 5% of women have metastases at diagnosis and a further 35% will develop them over the following 10 years. There is little geographical variation in the incidence rates across the country but we know that rates are highest in those in higher socioeconomic groups. The incidence in the UK is higher than other countries, in particular those in Eastern Europe and the risk of developing breast cancer appears to increase in those who move from a lower incidence country to the UK.

Breast cancer accounts for 1 in 6 female cancer deaths. It is the most common cancer in women but they are more likely to die from lung cancer. Mortality from breast cancer increases with age and is highest in those over 85 years of age. Mortality is also highest in those from higher socioeconomic groups. Despite the increasing incidence of breast cancer, mortality has been on a downward trend since 1990 due to improved survival. There is little variation in mortality across the UK, but it is higher than many other European countries.

Women aged 50 to 69 years who were diagnosed with breast cancer between 2001 and 2003 had an over 80% chance of surviving 5 years, and are predicted a 70% chance of surviving 20 years. Survival has improved in all socioeconomic groups in society but remains poorer in those in the lowest groups, despite their lower risk of developing breast cancer. The reason for this is uncertain but may be related to screening uptake or higher levels of co-morbidity. Survival rates are better than average in women of South Asian ethnic origin despite some evidence that they tend to present with larger tumours. Survival rates in the UK remain lower than the rest of Western Europe.

The secondary care workload associated with breast cancer has been increasing over time. This increase is particularly associated with malignant disease and those in the screened age group. It is not possible to assess the change in workload in primary care due to a lack of national data.

Variation in treatment occurs across the country. The types and rates of procedures performed vary by geography and by clinician. The length of time patients are in hospital for these procedures also varies. Around 13% of consultants undertaking mastectomies were performing 10 or fewer procedures in 2005-2006.

Inequality in treatment also exists. Those in the older age groups are less likely to receive surgical treatment than younger women. Although the numbers of men with breast cancer are small, they are more likely to receive mastectomies than more conservative surgery. Audit and research has shown that treatments vary according to the patient's age and socioeconomic status, although the reasons for this are not known. Physical access to services is also inequitable with 7% of the population of England and Wales living over 50 km from their local radiotherapy centre.

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7 Glossary

Age specific mortality rate
The number of deaths from breast cancer per 100,000 persons per year in a specific age group. Five year age groups are commonly used.

Benign
Something that does not metastasise and treatment or removal is curative.

Carstairs index
A geographical measure to assess socioeconomic deprivation based upon male unemployment rates, the proportion of households in social classes 4 and 5, car ownership and overcrowding (more than 1 person per room in private households).

Co-morbidity
The effect of all other diseases an individual patient might have other than the primary disease of interest.

Crude incidence rate
The number of new cases of breast cancer over the total population without considering age or other factors, usually expressed as a rate per 100,000 persons per year.

Crude mortality rate
The number of deaths from breast cancer over the total population without considering age or other factors, usually expressed as a rate per 100,000 persons per year.

European age standardised rate
The rate that would have been found if the population had the same age-composition (proportion of total population in each five year age class) as a hypothetical European population, usually expressed per 100,000 persons per year.

HES
English Hospital Episode Statistics data which relates to episodes of patient care whilst in hospital.

IMD 2000
A geographical measure of socioeconomic deprivation based upon income, employment, health deprivation and disability, education, skills and training, housing and geographical access to services.

Incidence
The number of new cases occurring in a period of time in a defined population.

In-situ
A tumour is in-situ if it is confined to its tissue of origin and has not spread into neighbouring or distant tissues.

Malignant
Cancerous. Malignant tumours can invade and destroy nearby tissue and spread to other parts of the body.

Mortality
The number of deaths attributed to breast cancer in a specified period of time in a defined population.

Neoplasm
Any new and abnormal growth, specifically when uncontrolled and progressive. Neoplasms may be benign or malignant.

PEDW
Patient Episode Database Wales data which relates to episodes of patient care whilst in hospital in Wales, or for Welsh patients in England.

Prevalence
The number of cases of a disease existing in a population at a specific point in time

Prognosis
A prediction of the probable course and outcome of a disease.

Relative survival
The survival rate adjusted for deaths caused by other diseases.

Statistically Significant
A difference is said to be statistically significant if it is unlikely to have occurred by chance.

Survival
Refers to a number of different ways of describing the length of time that people live after diagnosis, for example the survival rate is the proportion of those who survive the disease for a given period per person diagnosed with the disease

Townsend Index
A geographical measure to assess socioeconomic deprivation based upon unemployment as a percentage of those aged 16 and over whom are economically active, non-car ownership as a percentage of all households, non-home ownership as a percentage of all households, household overcrowding.