

THE THIRD ALL BREAST CANCER REPORT

Back to Basics:
Breast cancer
incidence
and
mortality

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Acknowledgements

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Foreword

In routinely published cancer incidence rates, the numerator is defined as the number of tumours registered rather than the number of patients registered with a tumour. Because the majority of people have only one cancer registration for a particular cancer site, this does not normally cause any problems.

However, if a breast cancer patient has cancers diagnosed in both breasts, each of these cancers will be included in the incidence data separately regardless of the time between diagnoses. Breast cancer patients may also have more than one morphological type of breast cancer diagnosed in the same breast on the same day or several weeks, months or years apart. Again, each of the tumours will be included separately in the incidence data.

The aim of the first section of this '*Back to Basics*' report is to examine the extent of the double counting of patients with breast cancer registrations in one year and with multiple breast cancer registrations in more than one year, and the effect that this has on routinely published breast cancer incidence rates.

As cancer survival rates improve, patients are living as cancer survivors for a long time after their diagnosis. Patients can survive for many years with multiple cancers of the same type or with more than one type of cancer. The second section of this '*Back to Basics*' report examines the different experiences of breast cancer survivors who died in 2008 who were diagnosed with breast cancer alone or who had other invasive cancers diagnosed in 1985-2008.



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Executive Summary

KEY FINDINGS

How many women each year are diagnosed with breast cancer for the first time?

CRUK and ONS cancer incidence statistics are based on the number of new tumours diagnosed each year NOT the number of people diagnosed with cancer each year with a particular type of cancer for the first time

For invasive breast cancers diagnosed in 2008, female incidence data based on the number of new tumours diagnosed are **2.5%** higher than data based on the number of women diagnosed with invasive breast cancer. For *in situ* carcinomas of the breast diagnosed in 2008, female incidence data based on the number of new tumours diagnosed are **1.1%** higher

Incidence rates in 2008 based on tumours rather than women are higher because **2.2%** of women had tumours diagnosed in both breasts in 2008, and **1.0%** of women had more than one tumour diagnosed in the same breast

In 2008, only **94.9%** of the 39,032 women diagnosed with an invasive breast cancer and **93.6%** of the 4,768 women diagnosed with an *in situ* breast carcinoma had their first breast tumour diagnosed in 2008

Female invasive breast cancer and *in situ* breast carcinoma incidence rates in 2008 are thus **4.1%** and **1.5%** higher respectively, when based on the number of tumours diagnosed rather than the number of women diagnosed with a breast tumour for the first time

What do women diagnosed with breast cancer die from?

Of the 19,758 women with invasive breast cancer and/or *in situ* breast carcinomas registered in 1985-2008 who died in 2008, **44.6%** died of breast cancer and **40.8%** died of other non-cancer causes

17.6% of women with invasive breast cancers and/or *in situ* breast carcinomas diagnosed in 1985-2008 who died in 2008 had additional cancer registrations for other invasive cancers at different anatomical sites. These women were more likely to die from their other cancer than from their breast cancer

45.6% of women with an invasive breast cancer and no other invasive cancer died of breast cancer compared with only **9.2%** of women who had an *in situ* breast carcinoma and no other invasive cancer

The median time from diagnosis to death from breast cancer was **4.0 years** for women with an invasive breast cancer, **6.4 years** for women with an *in situ* breast carcinoma and no record of invasive breast cancer

Executive Summary

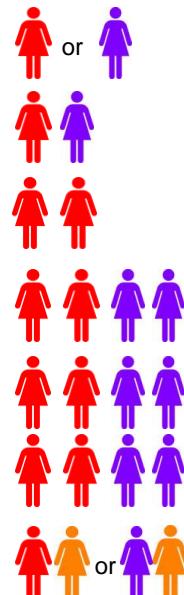
This report aims to answer two simple questions:

Each year, how many women are diagnosed with breast cancer for the first time?

What do women diagnosed with breast cancer die from?

Although the first question seems simple it is difficult to answer because of the rules that govern cancer registration in the UK.

If a woman has one invasive breast cancer (C50) or one *in situ* carcinoma (D05), she will appear once in the incidence rates for that type of breast tumour



If a woman has an invasive breast cancer (C50) and an *in situ* carcinoma (D05), she will appear in the incidence rates for both types of breast tumour

If a woman has an invasive breast cancer (C50) in both breasts, she will appear twice in the incidence rates for invasive breast cancer

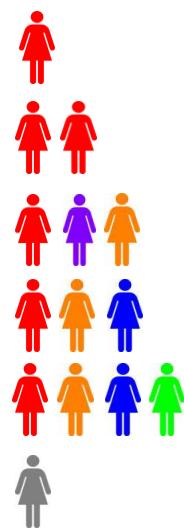
If a woman has an invasive breast cancer (C50) and an *in situ* carcinoma (D05) in both breasts, she will appear twice in the incidence rates for each type of breast tumour

If a woman has two invasive breast cancers (C50) with a different morphology and two *in situ* carcinomas (D05) with a different morphology in both breasts, she will appear four times in the incidence rates for each type of breast tumour

If a woman is diagnosed with an invasive (C50) or an *in situ* carcinoma (D05) and another invasive cancer or *in situ* carcinoma at a different anatomical site before or after their breast cancer diagnosis, she will appear in the incidence rates for both types of tumour

The answer to the second question will not be found in publications containing routine breast cancer statistics. These publications usually examine **breast cancer mortality** i.e. the number of women each year who are recorded on their death certificate as having died from breast cancer, or **breast cancer survival** i.e. the proportion of women who have survived for a given length of time after a diagnosis of breast cancer. However, because breast cancer patients have relatively good survival rates, they frequently die from causes unrelated to their breast cancer.

Women who have one invasive (C50) breast cancer can die from that breast cancer



Women who have more than one invasive (C50) breast cancer can die from any of these breast cancers

Women who have an invasive breast cancer (C50) or an *in situ* carcinoma (D05) can be diagnosed with and die from another type of invasive cancer

Women who have more than one type of invasive cancer can have other illnesses and can die from these illnesses rather than from cancer

Women who have more than one type of invasive cancer and other illnesses can die from accidental causes

The death certificate for a person who has had an invasive breast cancer (C50) may incorrectly record their death as being from breast cancer

Executive Summary

Q1 Each year, how many women are diagnosed with breast cancer for the first time?

43,433 women had an invasive C50 or *in situ* D05 breast cancer registration in 2008

- 91.7% had their only breast cancer registration in 2008
- 3.1% had multiple invasive C50 and/or *in situ* D05 breast cancer registrations in 2008
- 5.3% had previous invasive C50 and/or *in situ* D05 breast cancer registrations in 1985-2007

a) Women diagnosed with breast cancer in 2008

	C50 	D05 	D05 C50 	Total
Number of women with invasive breast cancers (C50)	38,665		367	39,032
Number of invasive breast cancers (C50)	39,637		380	40,017
Ratio C50: No. cancers: No. women				1.025
Number of women with <i>in situ</i> breast tumours (D05)		4,401	367	4,768
Number of <i>in situ</i> breast tumours (D05)		4,449	373	4,822
Ratio D05 No. tumours: No.women				1.011

The invasive breast cancer annual incidence rate in 2008 calculated on the basis of the number of invasive C50 cancers diagnosed (40,017) will be 2.5% higher than if the incidence rate was calculated on the basis of the number of women diagnosed with an invasive C50 cancer (39,032).

The *in situ* breast carcinoma annual incidence rate in 2008 calculated on the basis of the number of *in situ* D05 tumours diagnosed (4,822) will be 1.1% higher than if the incidence rate was calculated on the basis of the number of women diagnosed with an *in situ* D05 tumour (4,768).

b) Women diagnosed with their first breast cancer in 2008

	C50 	C50 	D05 C50 	D05 	Total
Women with their first invasive breast cancer in 2008 (C50)	35,749 (96.5%)	932 (2.5%)	356 (1.0%)		37,037
Women with previous breast tumours in 1985-2007		1,554 (77.9%)	36 (1.8%)	405 (20.3%)	1,995
% women with their first breast tumour in 2008					94.9%

Of the 39,032 women diagnosed with an invasive C50 cancer in 2008, 94.9% were diagnosed with their first breast tumour in 2008 and 5.1% had previous *in situ* D05 or invasive C50 breast cancer

Executive Summary

registrations in 1985-2007. Of the 2.2% of women with two invasive C50 cancers diagnosed in 2008, 75% had contralateral tumours and 25% had two ipsilateral tumours. Of the 0.8% women with one invasive C50 and one *in situ* D05 tumour diagnosed in 2008, 52% had contralateral tumours and 48% had two ipsilateral tumours.

Taking into account all invasive C50 cancers diagnosed in 1985-2008, calculating the number of women diagnosed with an invasive C50 cancer for the first time in 2008 on the basis of the number of women with an invasive C50 cancer registration in 2008 overestimates the true incidence rate by 4.1%.

	D05 	D05 	D05 C50 	C50 	Total
Women with their first <i>in situ</i> breast tumour in 2008 (D05)	4,064 (91.1%)	43 (1.0%)	356 (8.0%)		4,463
Women with previous breast tumours in 1985-2007	65 (21.3%)		3 (1.0%)	237 (77.7%)	305
% women with their first breast tumour in 2008					93.6%

Of the 4,768 women diagnosed with an *in situ* D05 tumour in 2008, 93.6% were diagnosed with their first breast tumour in 2008 and 6.4% had previous *in situ* D05 or invasive C50 breast cancer registrations in 1985-2007. Of the 0.1% of women with multiple *in situ* D05 tumours diagnosed in 2008, 46% had contralateral tumours and 56% had multiple ipsilateral tumours.

c) Other invasive cancers diagnosed in women diagnosed with breast tumours in 2008

	C50 	D05 	D05 C50 	Other invasive cancers
Number of women with invasive breast cancers alone in 2008 (C50)	38,665			1,635
Number of women with <i>in situ</i> breast tumours alone in 2008 (D05)		4,401		150
Number of women with <i>in situ</i> (D05) and invasive (C50) breast tumours in 2008			367	14

Of the 43,433 women diagnosed with an invasive C50 or *in situ* D05 tumour in 2008, 4.1% were also diagnosed with another type of invasive cancer. 20.5% of these other invasive cancers were diagnosed in 2008.

Executive Summary

Q2 What do women diagnosed with breast cancer die from?

	Breast cancer death	Other cancer death	Non-cancer causes	Total
Women with invasive breast cancer (C50) and no other invasive cancer	8,268 (51.9%)		7,018 (44.1%)	15,925
Women with invasive breast cancer (C50) and another invasive cancer	499 (15.2%)	1,700 (51.7%)	713 (21.7%)	3,290
All women with invasive breast cancer (C50)	8,767 (45.6%)	1,872 (9.7%)	7,731 (40.2%)	19,215
Women with an <i>in situ</i> breast tumour (D05) and no other invasive cancer	46 (12.8%)		292 (81.6%)	358
Women with an <i>in situ</i> breast tumour (D05) and another invasive cancer	4 (2.2%)	132 (71.4%)	31 (16.8%)	185
All women with an <i>in situ</i> breast tumour (D05)	50 (9.2%)	140 (25.8%)	323 (59.5%)	543

19,758 women with invasive **C50** and/or *in situ* **D05** breast cancer registrations in 1985-2008 died in 2008. **44.6%** of these women died of breast cancer and **40.8%** died of other non-cancer causes. **45.6%** of women with an invasive **C50** cancer and no other invasive cancer died of breast cancer compared with **9.2%** of women who had an *in situ* **D05** tumour and no other invasive cancer. **81.6%** of women with an *in situ* **D05** tumour and no other invasive cancer died of other non-cancer causes.

17.6% of women with invasive **C50** and/or *in situ* **D05** breast cancer registrations in 1985-2008 who died in 2008 had additional cancer registrations for other invasive cancers at different anatomical sites. These women were more likely to die from their other cancer than from their breast cancer. Only **15.2%** of women with an invasive **C50** cancer and another invasive cancer died from breast cancer compared with **51.9%** of women who had an invasive **C50** cancer alone. **71.4%** of women with an *in situ* **D05** tumour and an invasive cancer other than breast cancer died from the other cancer.

The median time from diagnosis to death from breast cancer was **4.0 years** for women with an invasive **C50** cancer, **6.4 years** for women with an *in situ* **D05** tumour and no record of invasive **C50** cancer and **6.3 years** for women with an *in situ* **D05** tumour followed by an invasive **C50** cancer registration

Introduction

Cancer Incidence Rates

The aim of the first section of this ‘report is to examine the extent of the double counting of patients with multiple breast cancer registrations in a single year or with breast cancer registrations in more than one year, and the effect that this has on routinely published breast cancer incidence rates.

Cancer incidence rates are calculated separately for each of the cancer site codes defined in version 10 of the International Classification of Diseases (ICD-10 codes). Cancer incidence rates are expressed as the number of cancer registrations per 100,000 population for a given ICD-10 site code. Routinely published national and international cancer incidence data^{1,2,3} normally comprise only invasive cancers (C codes in ICD10), and incidence rates for *in situ* carcinomas (which have D codes in ICD-10) are not included. For most cancer sites this does not pose a problem because the number of *in situ* carcinomas in a given population is relatively small compared to the number of invasive cancers. However, with the widespread use of imaging as a key part of the diagnostic process, the detection of *in situ* breast carcinoma (D05 in ICD-10) has increased markedly, and these tumours accounted for 10% of all breast cancer registrations in the UK in 2007⁴. In November 2012, Cancer Research UK (CRUK) published for the first time, statistics on the incidence of *in situ* breast carcinoma in the UK⁵.

In routinely published cancer incidence rates, the numerator is defined as the number of tumours registered rather than the number of patients registered with a tumour. Because the majority of people have only one cancer registration for a particular cancer site, this again does not normally cause any problems. However, a breast cancer patient will be included in the numerator of both the invasive breast cancer (C50) and *in situ* breast carcinoma (D05) incidence data if two breast tumours with different invasive status are diagnosed at different times (a three month cut off period is usually taken).

It is also possible for breast cancer patients to have cancers diagnosed in both breasts, and each of these cancers will be included in the incidence data separately, regardless of the time between diagnoses (e.g. an *in situ* breast carcinoma or an invasive breast cancer in the left breast and an invasive breast cancer in the right breast diagnosed on the same day or several weeks, months or years apart). Finally, breast cancer patients may have more than one morphological type of breast tumour diagnosed in the same breast, e.g. separate ductal and lobular invasive breast cancers. Again, both tumours will be included separately in the incidence data.

In the NHS Breast Screening Programme (NHSBSP) and Association of Breast Surgery (ABS) audit of screen-detected breast cancer⁶ and the Breast Cancer Clinical Outcome Measures (BCCOM) symptomatic breast cancer audit⁷, analyses are based on patients rather than tumours. Where a patient has had more than one invasive breast cancer registration during the audit period, the breast cancer with the worst prognosis is included. Breast cancer patients with both an invasive breast cancer and an *in situ* breast carcinoma also appear only once (as an invasive breast cancer) if the two types of tumour with different behaviour are diagnosed in the same audit period. The numbers of invasive breast cancers included in the 1st and 2nd All Breast Cancer Reports^{4,8} thus differ from the numbers of invasive breast cancers reported in CRUK and the Office for National statistics (ONS) publications covering these registration years (2006 and 2007).

Breast Cancer Survivorship

As cancer survival rates improve, patients are living as cancer survivors for many years after their initial diagnosis. Patients can survive for many years with multiple cancers or multiple types of the same cancer. The second section of this report examines the different experiences of breast cancer survivors who died in 2008 who were diagnosed with breast cancer in 1985-2008.

Methodology

Patients With Breast Cancer Diagnosed in 2008

Details of the 45,392 invasive (C50) and *in situ* breast carcinoma (D05) registrations in 2008 were obtained from the National Cancer Data Repository (NCDR), a repository of all cancers registered in England in 1985 to 2009. Extra-regional cases and cases registered solely on the basis of a death certificate (death certificate only [DCO] cases) were not included in the dataset. *In situ* breast carcinomas (D05) and all invasive cancers (C00-C97 excluding C44 non-melanoma skin cancer [nmSC]) and diagnosed in these patients in 1985-2009 were then added to the dataset. Invasive status was assigned using ICD-10 code alone. All cancers with ICD-10 C50 were considered to be invasive cancers. Micro-invasive breast cancers (247 cancers) and Paget's disease (317 cancers) with ICD-10 code C50 were included with invasive cancers. Breast cancers with laterality other than "Right" or "Left" (e.g. "U", "8", "9") were counted as unknown laterality (1,319 cancers). Nine breast cancers had laterality "B" = bilateral, which was previously a valid code. In total, 3% of breast cancers had unknown laterality.

The 1985-2009 NCDR contains a patient identifier to identify patients with more than one cancer registration, but does not contain a tumour identifier. A patient may truly have multiple primary tumours registered. However, tumours could be duplicate registrations or a recurrence could be registered as a primary tumour. An algorithm was therefore devised to determine whether two breast tumours registered in the same patient were duplicates, recurrences or multiple primary tumours, and this was used to eliminate duplicate tumours and recurrences from the dataset (Appendix 1). Patients were removed if breast cancers registered in 2008 were considered not to be true multiple primaries (135 patients). A further 155 breast cancer registrations were excluded for patients who were included.

After excluding duplicate registrations, patients with two or more breast tumours were assumed to have multiple primary cancer registrations. UK Association of Cancer Registries (UKACR) coding rules were changed in 2011 to record as a recurrence, any subsequent *in situ* breast carcinoma with the same laterality as an invasive breast cancer regardless of the morphology of the two tumours. For this report, 217 subsequent *in situ* breast carcinomas with the same laterality but a different morphology to that of the original invasive breast cancer were considered to be multiple primary tumours. For the purposes of examining invasive multiple primary tumours registered at sites other than the breast in patients with breast tumours, invasive cancers (C00-C97 excluding C44 nmSC) were grouped into broad cancer types using the ICD-10 groupings listed in Appendix 2.

Breast Cancer Patients Who Died in 2008

19,939 patients who died in 2008 who had invasive or *in situ* breast carcinoma registrations in 1985-2008 were identified in the NCDR. *In situ* breast carcinomas (D05) and all invasive cancers (C00-C97 excluding C44 nmSC) diagnosed in 1985-2008 in these patients were added to the dataset. Death certificate only cancers, extra-regional cancers and cancers diagnosed on the date of death were not included in the dataset. For simplicity, *in situ* breast carcinomas diagnosed within three months or after an invasive breast cancer were also excluded.

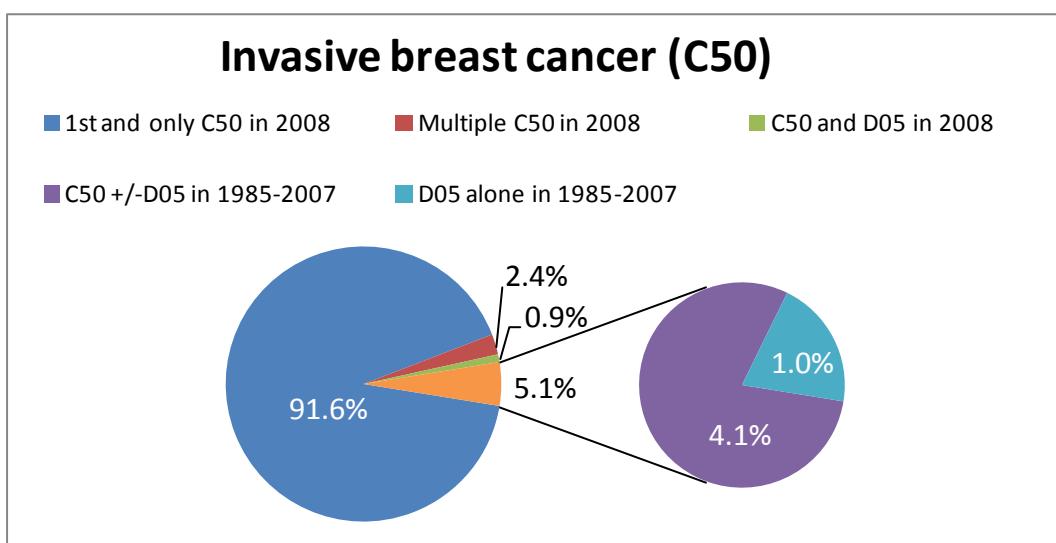
As the dataset commenced in 1985, women who died in 2008 having had their breast cancer registered before 1985 with no new primary diagnosis after 1985 could not be included in the analyses. The maximum time period from a first breast cancer registration to the date of death was thus 24 years. For the purposes of examining invasive multiple primary tumours registered at sites other than the breast in breast cancer patients who died in 2008, invasive cancers (C00-C97 excluding C44 nmSC) were grouped into broad cancer types using the ICD-10 groupings in Appendix 2. An algorithm was devised to assign cause of death (Appendix 3).

Results – Incidence

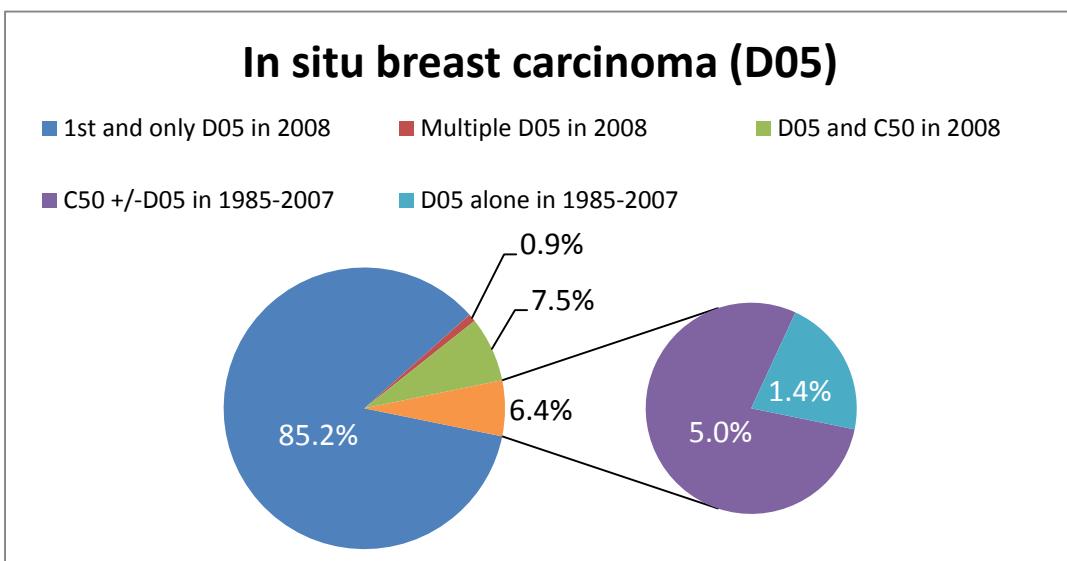
Incidence: Breast Cancers Diagnosed in 2008

Summary

Of the 39,032 women with an invasive C50 cancer registration in 2008, 91.6% (35,749) were diagnosed with their first and only invasive C50 breast tumour in 2008. 932 women (2.4%) had multiple invasive C50 tumours diagnosed in 2008, and another 356 (0.9%) had invasive C50 and *in situ* D05 tumours diagnosed in 2008. A further 5.1% of the women also had previous invasive C50 or invasive C50 and *in situ* D05 registrations (1,590: [4.1%]) or previous *in situ* D05 registrations alone (405: [1.0%]) in 1985-2007.



Of the 4,768 women with an *in situ* D05 cancer registration in 2008, 85.2% (4,064) were diagnosed with their first and only *in situ* D05 breast tumour in 2008. 43 women (0.9%) had multiple *in situ* D05 tumours diagnosed in 2008 and another 356 (7.5%) had invasive C50 and *in situ* D05 tumours diagnosed in 2008. A further 6.4% of women also had previous invasive C50 or invasive C50 and *in situ* D05 registrations (240 [5.0%]) or *in situ* D05 registrations alone (65: [1.4%]) in 1985-2007.



Results – Incidence

Invasive and *in Situ* Breast Cancers Diagnosed in 2008

43,721 patients with breast cancer registrations in 2008 were included in the analyses. Of these, 43,433 were female and 288 male. The 288 males were registered with 293 breast cancers of which 280 were invasive (C50) and 13 were *in situ* (D05). Breast tumours diagnosed in males are not considered further in this report.

Of the 43,433 women who had breast cancer registrations in 2008, 39,032 (89.9%) had an invasive C50 cancer. Of these, 1,324 (3.4%) had multiple breast tumours in 2008 (Table 1). 957 (2.5%) had more than one invasive C50 cancer and 367 (0.9%) had at least one *in situ* D05 tumour as well as their invasive C50 cancer (Figure 1). Of the 367 women with invasive C50 and *in situ* D05 tumours in 2008, 11 had previous breast tumours recorded in 1985-2007 (7 had one invasive C50, 4 had one or more *in situ* D05 [5 D05 tumours]). Of the 4,401 women with *in situ* D05 tumours alone in 2008, 46 (1.0%) had more than one breast cancer registration in 2008 (Table 1).

Figure 1: Women with breast cancer registrations in 2008

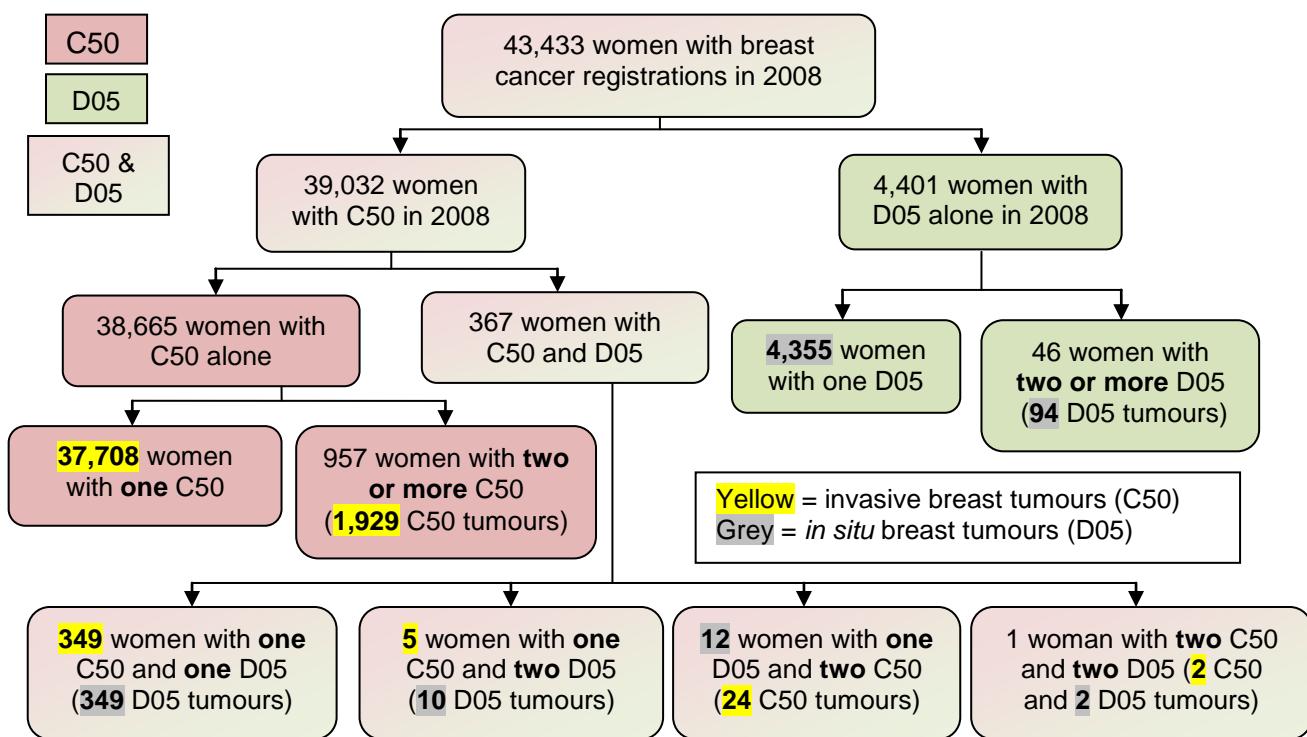


Table 1: Women with one or more breast cancer registrations in 2008

	Women with invasive C50		Women with <i>in situ</i> D05 alone		Women with invasive C50 and/or <i>in situ</i> D05	
	No.	%	No.	%	No.	%
Women with one breast cancer registration in 2008	37,708	96.6%	4,355	99.0%	42,063	96.8%
Women with multiple breast cancer registrations in 2008 (single or mixed invasive status)	1,324	3.4%	46	1.0%	1,370	3.2%
Total	39,032	100%	4,401	100%	43,433	100%

Results – Incidence

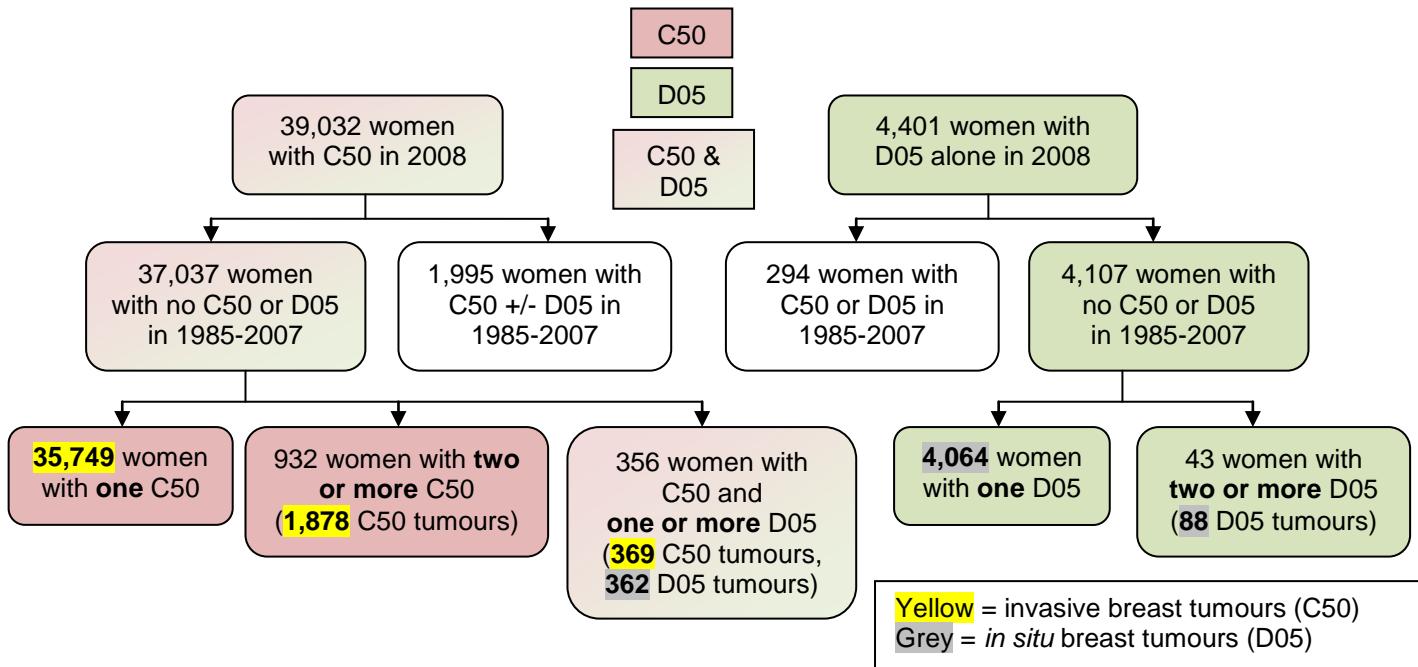
In 2008, of the 43,433 women had breast cancer registrations, 39,032 had invasive C50 registrations and 4,401 had *in situ* D05 registrations. The 43,433 women were registered with 44,839 breast cancers of which 40,017 were invasive (C50: yellow in Figure 1) and 4,822 were *in situ* (D05: grey in Figure 1).

Conclusion 1: Annual incidence rates calculated on the basis of the number of breast cancer registrations rather than the number of women diagnosed with a breast tumour are **2.5%** higher for invasive (**C50**) cancers (40,017/39,032) and **1.1%** higher for *in situ* (**D05**) breast tumours (4,822/4,768).

Women Diagnosed With Breast Cancer in 2008 With No Breast Cancers Diagnosed in Previous Years (1985-2007)

41,144 women who had a breast cancer registration in 2008 had no previous cancers registrations in 1985-2007. Of these, 1,331 (2.6%) had more than one breast cancer registration in 2008. Of the 39,032 women who had invasive C50 registrations in 2008, 37,037 (94.9%) did not have a previous breast cancer registration in 1985-2007. A further 4,401 women had only *in situ* (D05) registrations in 2008. Of these, 4,107 (93.3%) did not have a previous breast cancer registration in 1985-2007 (Figure 2).

Figure 2: Women with breast cancer registrations in 2008 with no previous breast cancer registrations in 1985-2007



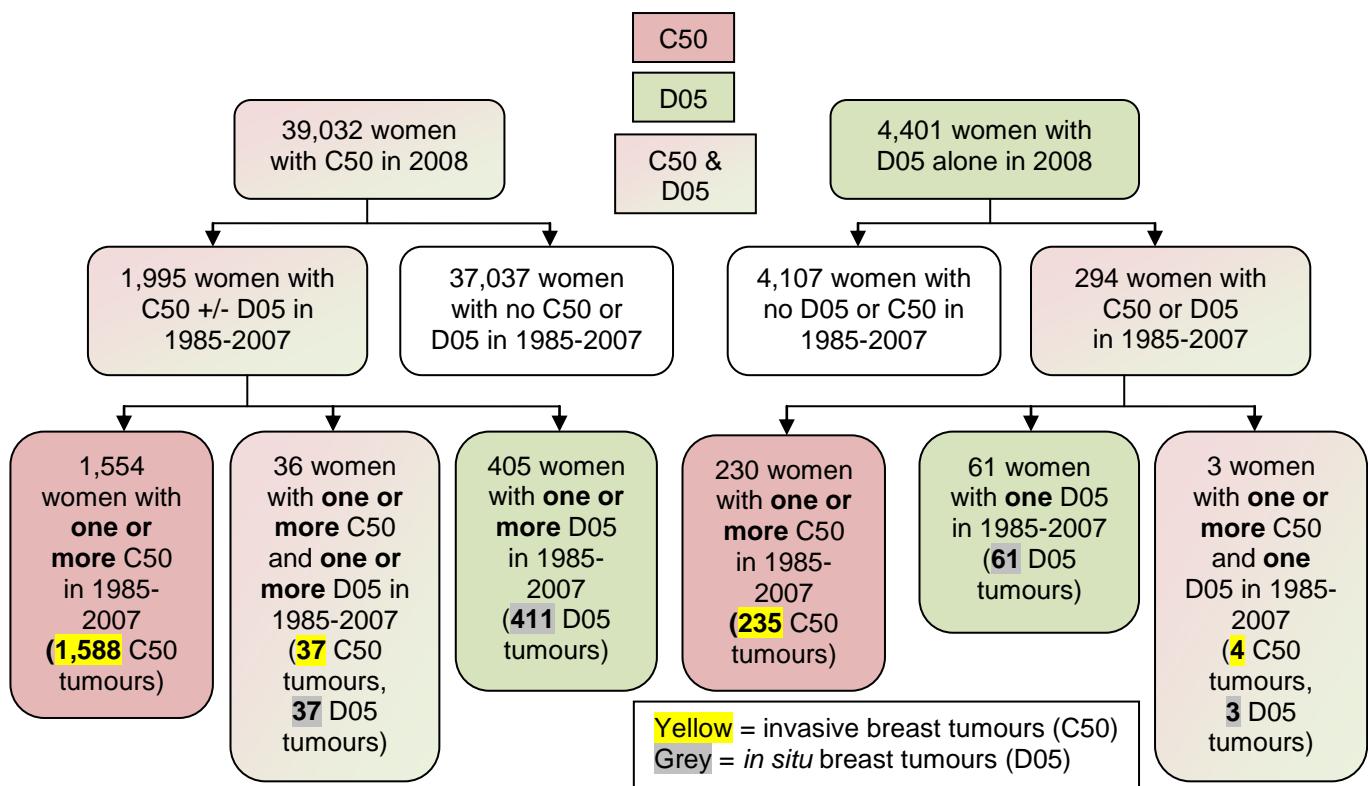
Of the 37,037 women with invasive C50 registrations in 2008 with no previous cancer registrations in 1985-2007, 1,288 (3.5%) had more than one invasive C50 and/or *in situ* D05 tumour. These women had 2,247 invasive C50 and 362 *in situ* D05 tumours in total. Of the 4,107 women with *in situ* D05 registrations in 2008 with no previous cancers registrations in 1985-2007, 43 (1.0%) had more than one *in situ* D05 registration in 2008 (4,152 *in situ* D05 tumours in total).

Results – Incidence

Women Diagnosed With Breast Cancer in 2008 With Breast Cancers Diagnosed in Previous Years (1985-2007)

Of the 43,433 women with breast cancer registrations in 2008, 2,289 (5.3%) had previous breast cancer registrations in 1985-2007. 1,995 (5.1%) of the women with invasive C50 registrations had a previous breast cancer registration, and 294 (6.7%) of the women with *in situ* D05 registrations alone had a previous breast cancer registration. Of the 2,376 breast cancer registrations in 1985-2007 which occurred in women with breast cancer registrations in 2008, 1,864 were invasive C50 tumours (yellow in Figure 3) and 512 were *in situ* D05 tumours (grey in Figure 3).

Figure 3: Women with breast cancer registrations in 2008: previous breast cancer registrations in 1985-2007



The 1,995 women with invasive C50 registrations in 2008 had 1,625 previous invasive C50 and 448 previous *in situ* D05 registrations. As 1,590 of these women had previous invasive C50 tumours in 1985-2007, the number of women diagnosed for the first time in 2008 with an invasive C50 tumour is 37,442 (39,032-1,590). This is 4.1% lower than the number of women with invasive C50 registrations in 2008. The 441 women with invasive C50 tumours in 2008 who had 448 previous *in situ* D05 tumours in 1985-2007 presumably had invasive C50 recurrences in 2008 of their previous *in situ* D05 tumours.

The 4,401 women with *in situ* D05 registrations in 2008 had 239 previous invasive C50 and 64 previous *in situ* D05 registrations. The number of women diagnosed for the first time in 2008 with an *in situ* D05 tumour is 4,337 (4,401-64). This is 1.5% lower than the number of women with *in situ* D05 registrations in 2008. Also of interest are the 233 women who had 239 previous invasive C50 tumours in 1985-2007.

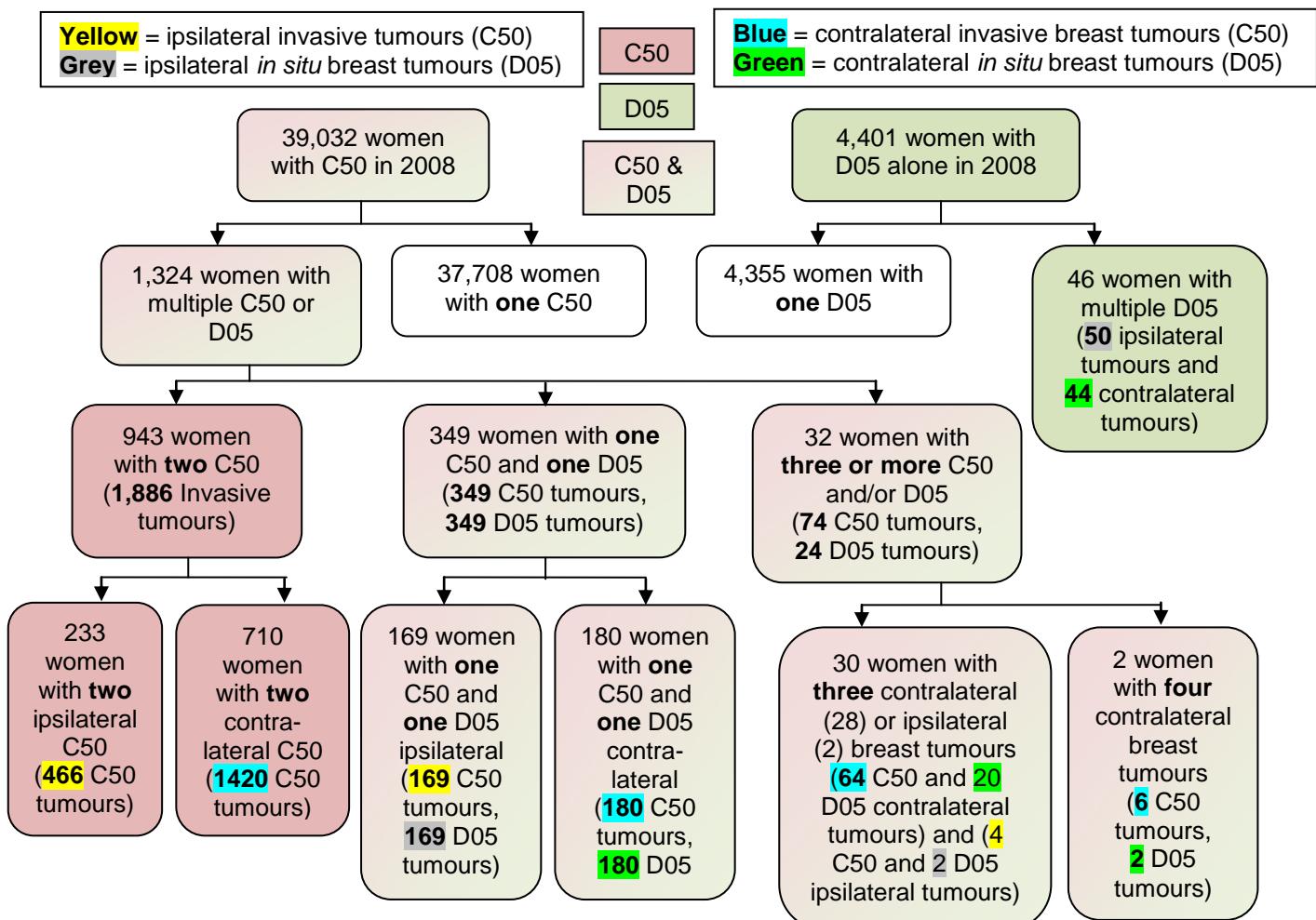
Results – Incidence

Conclusion 2: Taking into account all invasive C50 tumours diagnosed in 1985-2008, calculating the number of women diagnosed with an invasive C50 tumour for the first time in 2008 on the basis of the number of women with an invasive C50 registration in 2008 will overestimate the true incidence rate by **4.1%**.

Conclusion 3: Taking into account all *in situ* D05 tumours diagnosed in 1985-2008, calculating the number of women diagnosed with an *in situ* D05 tumour for the first time in 2008 on the basis of the number of women with an *in situ* D05 registration in 2008 will overestimate the true incidence rate by at least **1.5%**

Ipsilateral and Contralateral Multiple Primary Breast Cancers Diagnosed in 2008

Figure 4: Laterality of multiple breast cancer registrations in 2008 and their invasive status



Multiple primary breast tumours can be either in the same breast (ipsilateral) or in different breasts (contralateral). Of the 43,433 women with breast cancer registrations in 2008, 429 (1.0%) had two or more ipsilateral breast cancers in 2008 (Figure 4). Of these, 404 had ipsilateral invasive C50 tumours and 25 had ipsilateral *in situ* D05 tumours (Table 2). 941 women (2.2%) had two or more contralateral breast cancer registrations in 2008. Of these, 920 had contralateral invasive C50 tumours and 21 had contralateral *in situ* D05 tumours.

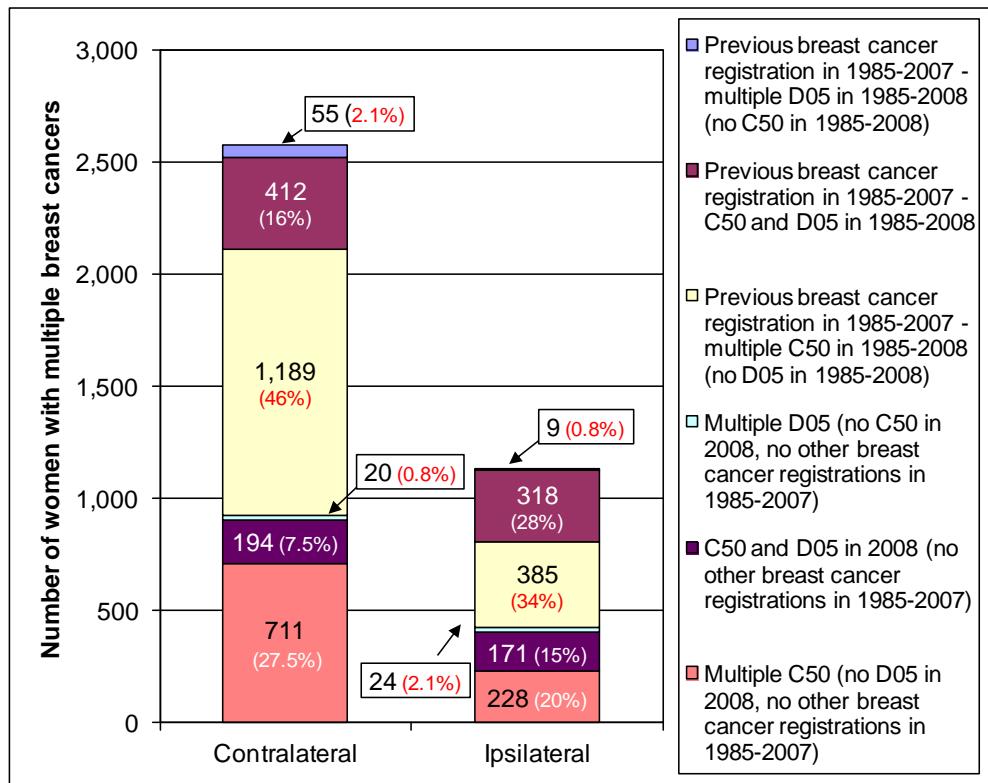
Results – Incidence

Table 2: Women with ipsilateral or contralateral breast cancer registrations in 2008

	Women with invasive C50		Women with <i>in situ</i> D05 alone		Women with invasive C50 and/or <i>in situ</i> D05	
	No.	%	No.	%	No.	%
Women with one breast cancer registration in 2008	37,708	96.6%	4,355	99.0%	42,063	96.8%
Women with multiple ipsilateral breast cancer registrations in 2008	404	1.0%	25	0.6%	429	1.0%
Women with multiple contralateral breast cancer registrations in 2008	920	2.4%	21	0.5%	941	2.2%
Total	39,032	100%	4,401	100%	43,433	100%

Figure 5 shows the number of women with invasive C50 and/or *in situ* D05 cancer registrations in 2008 who had contralateral or ipsilateral multiple primary invasive C50 and/or *in situ* D05 tumours either in 2008 or in the previous 23 years.

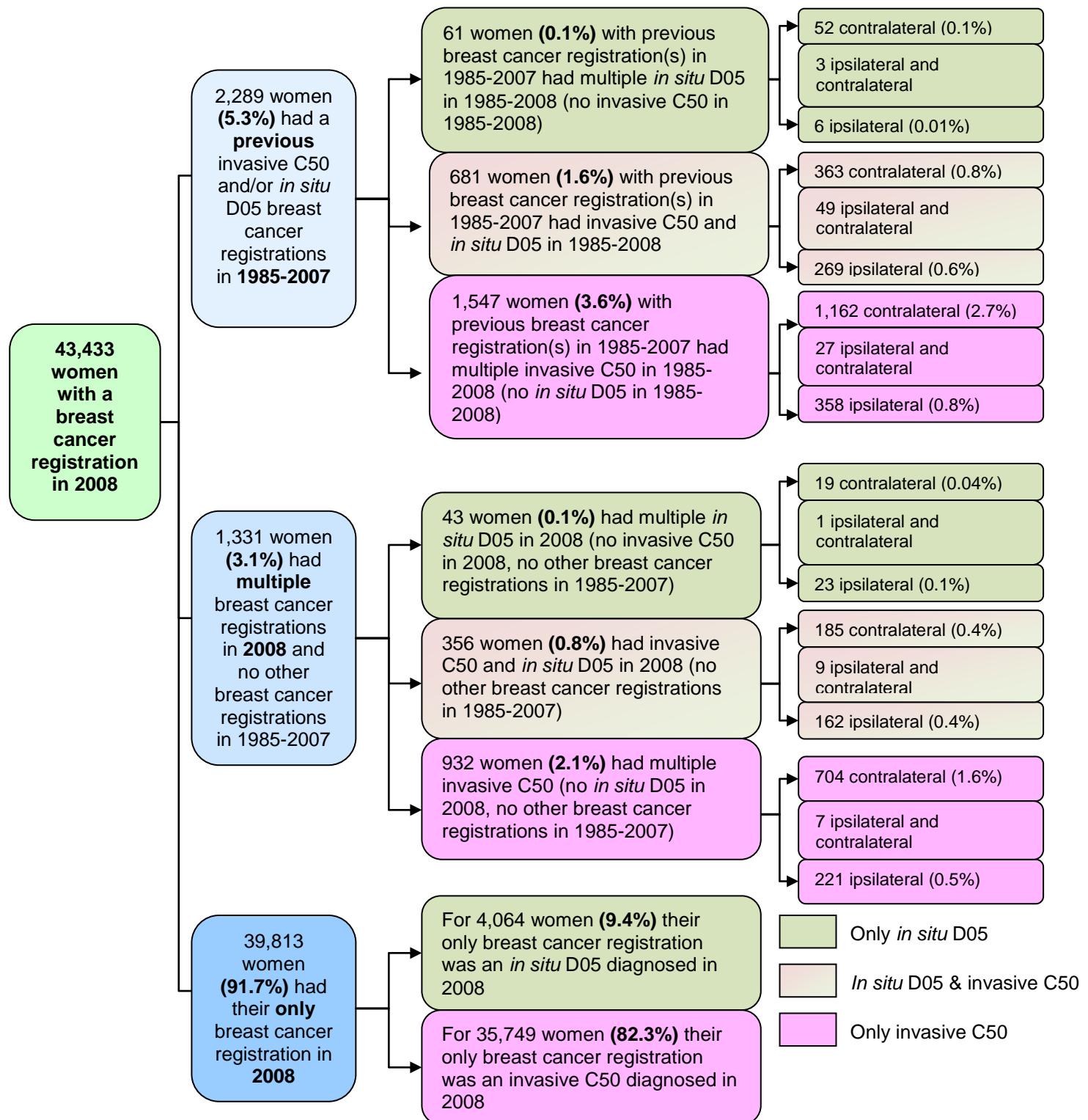
Figure 5: Contralateral and ipsilateral breast cancer registrations in 1985-2007 and 2008 in women with breast cancer registrations in 2008



Of the 43,433 women with breast cancer registrations in 2008, 2,581 (5.9%) had contralateral breast cancer. 36% of these contralateral tumours were diagnosed in 2008. 1,135 (2.6%) of the 43,433 women with breast cancer registrations in 2008 had multiple ipsilateral cancer registrations. 37% of these multiple ipsilateral tumours were diagnosed in 2008.

Results – Incidence

The following summary diagram shows for the 43,433 women with invasive and/or non-invasive breast cancer registrations in 2008, the number and proportion with multiple ipsilateral and/or contralateral breast cancer registrations either in 2008 or in the previous 23 years.



Results – Incidence

Other Invasive Cancers in Women Diagnosed With Breast Cancer in 2008

Of the 43,433 women with invasive C50 and/or *in situ* D05 cancer registrations in 1985-2008, 4.1% had an invasive cancer in a different anatomical site diagnosed either before or in the same 3-month period as their first breast cancer registration in 2008 (Table 3). Over the 24-year period studied, 1.2% of women had a gynaecological cancer diagnosed before or within the same 3-month period as their breast cancer and 0.9% had a bowel cancer diagnosed. This finding is consistent with the increased risk of gynaecological cancers known to be associated with BRCA1 and BRCA2 mutations in breast cancer patients⁹.

Table 3: Other invasive cancers diagnosed before or within the same 3-month period as the first breast cancer registration in 2008

Anatomical sites of other invasive cancers diagnosed in women with breast cancer	Other invasive cancers diagnosed in 1985-2008		Other cancers diagnosed in 2008 and overall % diagnosed in 2008	
	No.	%	No.	%
Gynaecological	530	1.2%	59	11.1%
Bowel	408	0.9%	82	20.1%
Haematological	212	0.5%	54	25.5%
Skin - malignant melanoma	200	0.5%	20	10.0%
Urological	137	0.3%	25	18.2%
Lung	119	0.3%	71	59.7%
Head & Neck	88	0.2%	12	13.6%
Upper Gastro-intestinal	54	0.1%	25	46.3%
Hepatobiliary & Pancreas	28	0.1%	17	60.7%
Brain & Central Nervous System	26	0.1%	5	19.2%
Other	61	0.1%	21	34.4%
Women with other invasive cancers (excluding nmsc)	1,799	4.1%	369	20.5%
Women with breast cancer in 2008	43,433	100%		

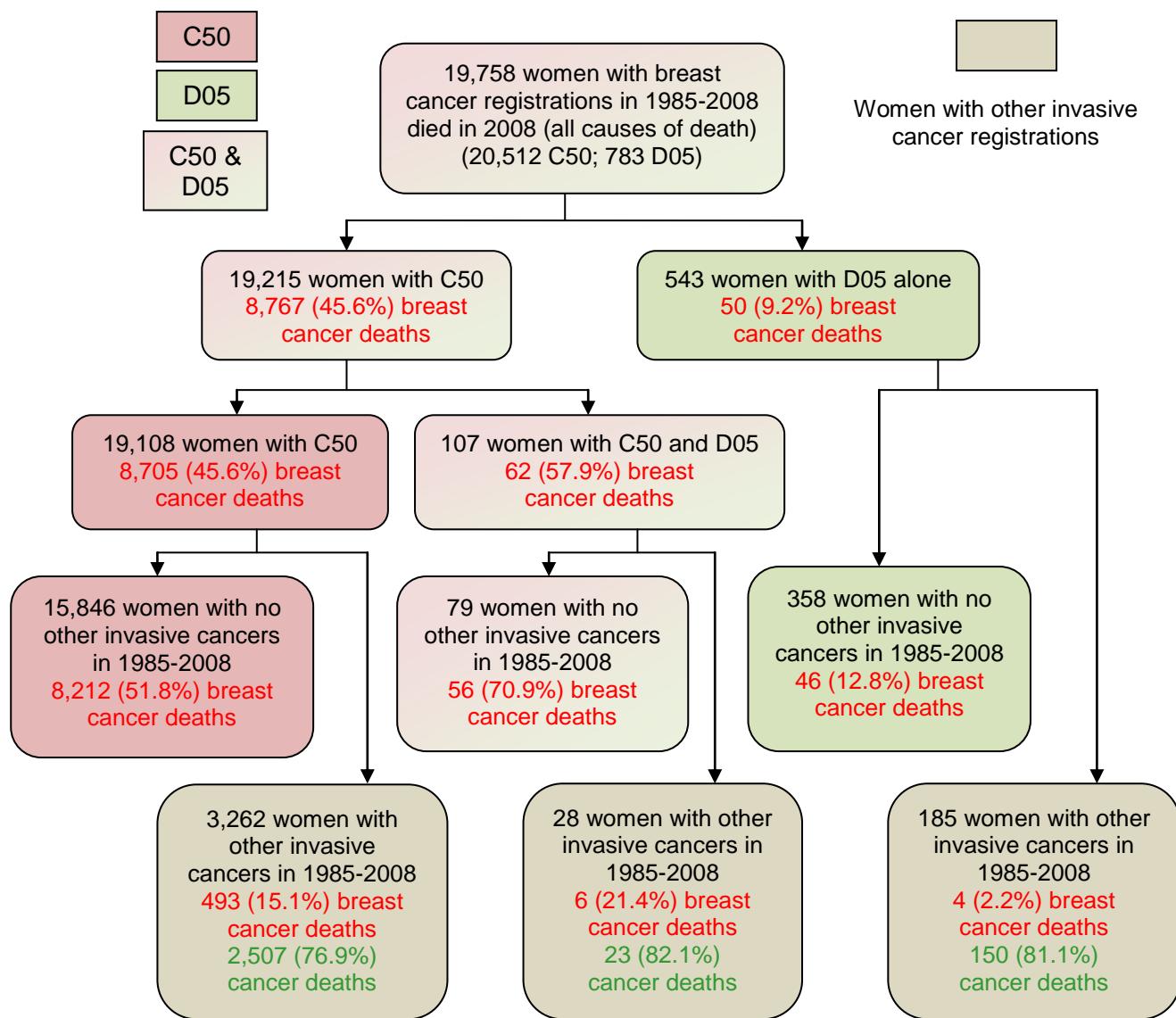
Overall, 20.5% of the other invasive cancers diagnosed in women with invasive C50 and/or *in situ* D05 registrations in 2008 were diagnosed 2008. High proportions of the invasive hepatobiliary and pancreatic (60.7%), lung (59.7%) and upper GI tract (46.3%) cancers occurring in women with breast cancer registrations in 2008 were diagnosed in 2008 (Table 3). This reflects the relatively poor prognosis of these cancers in that fewer women diagnosed with these cancers live long enough to be diagnosed with a subsequent breast cancer.

Results – Survivorship

Survivorship: Breast Cancer Patients Who Died in 2008

19,939 patients (19,758 women, 181 men) died in 2008 who had invasive C50 or *in situ* D05 cancer registrations in 1985-2008. Of the 181 men, 176 had invasive C50 tumours and 11 had *in situ* D05 tumours, and 50 (27.6%) died from breast cancer. Excluding breast cancers mentioned only on the death certificate or diagnosed on the day of death, 20,688 invasive breast cancers (20,512 in women, 176 in men) and 794 *in situ* breast tumours (783 in women, 11 in men) were diagnosed in 1985-2008 in the 19,939 breast cancer patients who died in 2008. Deaths in male breast cancer patients are not considered further in this report.

Figure 6 : Women with breast cancer patients who died in 2008



Cause of Death

Overall, of the 19,758 women who died in 2008 who had invasive C50 or *in situ* D05 cancer registrations in 1985-2008, 44.6% died of breast cancer. Cause of death varied with the invasive

Results – Survivorship

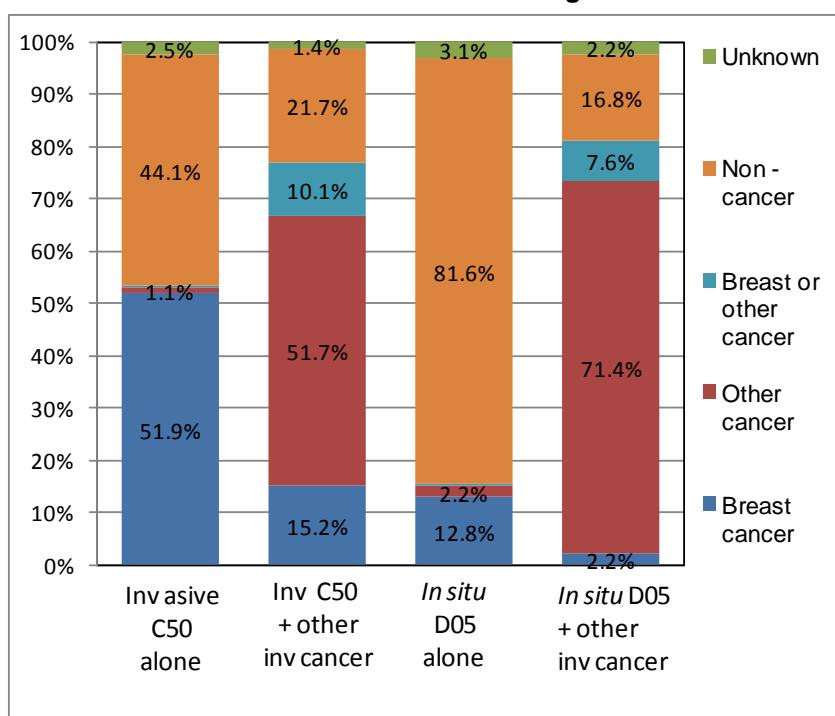
status of the breast tumour (Figure 6). Thus, 45.6% of all women with C50 invasive tumours and 9.2% of all women with *in situ* D05 tumours died of breast cancer (Table 4), and 40.2% of all women with invasive C50 tumours and 59.5% of women with *in situ* D05 tumours died of other non-cancer causes.

3,475 women (17.6%) with breast cancer registrations in 1985-2008 who died in 2008 also had additional registrations for invasive cancers at other anatomical sites in the same time period (Table 4 and Figure 6). These women were more likely to die of cancer than women who only had breast cancer registrations (77.1% compared to 57.5%). They were also more likely to die from their other invasive cancer than from their breast cancer (14.5% died of breast cancer, 52.7% died from the other invasive cancer and a further 9.9% died of cancer, but it could not be determined whether this was breast cancer or the other invasive cancer).

Table 4 : Causes of death for women who died in 2008 who had breast cancer and other invasive cancer registrations in 1985-2008

	Death cause											Total deaths	
	Cancer						Total cancer deaths	Other causes					
	Breast cancer		Other cancer		Breast or other cancer			Non-cancer		Unknown			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	No.	
All women with breast cancer	8,817	44.6%	2,012	10.2%	416	2.1%	11,245	56.9%	8,054	40.8%	459	2.3%	19,758
All women with invasive C50	8,767	45.6%	1,872	9.7%	401	2.1%	11,040	57.5%	7,731	40.2%	444	2.3%	19,215
All women with <i>in situ</i> D05 and no invasive C50	50	9.2%	140	25.8%	15	2.8%	205	37.8%	323	59.5%	15	2.8%	543
All women with breast cancer and other invasive cancers	503	14.5%	1,832	52.7%	345	9.9%	2,680	77.1%	744	21.4%	51	1.5%	3,475

Figure 7: Causes of death for women who died in 2008 who had invasive C50 or *in situ* D05 and other invasive cancer registrations in 1985-2008



Results – Survivorship

Figure 7 shows the causes of death for women who died in 2008 who had invasive C50 or *in situ* D05 cancer registrations in 1985-2008 and who did or did not have other invasive cancer registrations. Of the 3,290 women with invasive C50 registrations who also had other invasive cancers, only 15.2% died of breast cancer compared with 51.9% of women who did not have other invasive cancers, and 51.7% died from their other invasive cancer. This effect was even more marked for women with *in situ* D05 registrations. Thus, of the 185 women with *in situ* D05 registrations who also had other invasive cancers, 81.6% died from their other invasive cancer(s) and only 2.2% died from breast cancer.

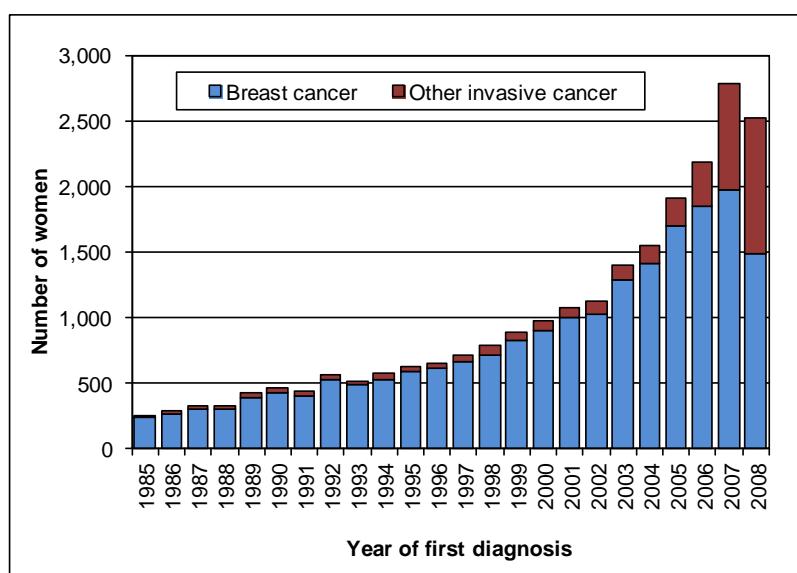
A small, interesting subgroup of the 19,215 women who died in 2008 having had invasive C50 registrations in 1985-2008, are the 107 women (0.6%) who had an *in situ* D05 registration in a previous episode (i.e. more than three months before the invasive C50 registration). For 62 of these women (57.9%), the initial *in situ* D05 tumour progressed to an invasive C50 resulting in death from breast cancer.

Conclusion 4: **44.6%** of women diagnosed with breast cancer who died in 2008 died of breast cancer and **43.1%** died of other non-cancer causes. **45.6%** of women with an invasive C50 cancer died of breast cancer compared with **9.2%** of women who had only an *in situ* D05 tumour. **81.6%** of women with an *in situ* D05 tumour alone died of other non-cancer causes.

Time From Diagnosis to Death

Figure 8 shows for the 19,758 women who died in 2008 who had breast cancer registrations in 1985-2008, the years of first diagnosis of their breast cancers and of their other invasive cancers.

Figure 8 : Year of first diagnosis for women who died in 2008 who had breast cancer and other invasive cancer registrations in 1985-2008



The time from diagnosis to death was shorter for women with breast cancer registrations who also had other invasive cancer registrations. Thus, while 51.3% of women had their first breast cancer diagnosis in 2002 or earlier, only 23.7% of the 3,475 women who also had other invasive cancer registrations had their first other invasive cancer diagnosis in 2002 or earlier.

Results – Survivorship

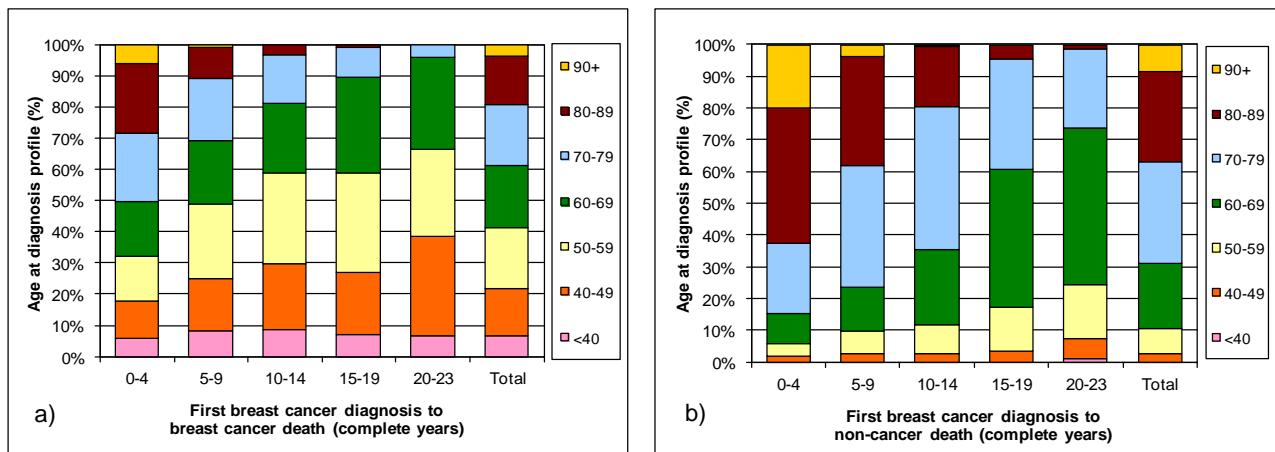
The median time from invasive cancer diagnosis to death from breast cancer for the 19,215 women who died in 2008 and who had invasive C50 registrations in 1985-2008 was 4.0 years. For the subset of these women who were initially diagnosed with *in situ* D05 tumours, the median time from the initial *in situ* D05 diagnosis to the invasive cancer diagnosis was 6.3 years, and the median time from the invasive cancer diagnosis to death from breast cancer was 2.5 years. 50 of the 543 women who died in 2008 who had *in situ* D05 tumours diagnosed in 1985-2008 with no invasive C50 tumours recorded, died of breast cancer i.e. invasive breast cancer was mentioned on the death certificate. The median time from the diagnosis of the *in situ* D05 tumour to death from breast cancer for these women was 6.4 years.

Age at Diagnosis and Death

Overall, 57.7% of women with invasive C50 and/or *in situ* D05 registrations who died of breast cancer in 2008 died within 5 years of their initial diagnosis compared to only 37.3% of the women who died of non-cancer causes. 74.6% of women aged 70 years and over at diagnosis who died of breast cancer died within 5 years of their initial diagnosis compared to only 46.8% of women aged less than 70 years. Only 18.4% of women aged less than 70 years at diagnosis who died of non-cancer causes died within 5 years of their initial diagnosis compared to 45.9% of women aged 70 years and over.

Similar proportions of women who died of breast cancer within 5 years of their initial breast cancer diagnosis were aged 70 years and over (50.5%) or less than 70 years (49.5%) (Figure 9a). In contrast, 84.6% of women who died of non-cancer causes within 5 years of their initial diagnosis were aged 70 years and over and only 15.4% were aged less than 70 years (Figure 9b).

Figure 9 : Variation with age at diagnosis in the time from first breast cancer diagnosis to death a) from breast cancer or b) death from non-cancer causes for women who died in 2008 who had breast cancer registrations in 1985-2008



Other Cancers Diagnosed in Women With Breast Cancer Who Died in 2008

17.6% of women with breast cancer registrations (invasive C50 and *in situ* D05) in 1985-2008 who died in 2008 also had additional invasive cancers diagnosed at other anatomical sites (Table 5). Gynaecological (4.1%), bowel (3.4%) and lung (3.3%) cancers were the most common other cancers diagnosed. The relatively high proportion of multiple primary gynaecological cancers is consistent with the known association between BRCA1 and BRCA2 breast cancer mutations and increased risk of some gynaecological cancers⁹.

Results – Survivorship

Table 5 : Other invasive cancers diagnosed since 1985 in women with breast cancer registrations in 1985-2008 who died in 2008

Other invasive cancer grouping	No.	%	Cause of death					
			Breast cancer		This other cancer		All cancer deaths	
			No.	%	No.	%	No.	%
Gynaecological	732	3.7%	125	17.1%	337	46.0%	569	77.7%
Lung	604	3.1%	65	10.8%	418	69.2%	545	90.2%
Bowel	593	3.0%	76	12.8%	249	42.0%	388	65.4%
Haematological	304	1.5%	59	19.4%	120	39.5%	192	63.2%
Upper gastro-intestinal	214	1.1%	20	9.3%	149	69.6%	193	90.2%
Hepatobiliary & pancreas	206	1.0%	8	3.9%	158	76.7%	191	92.7%
Urological	181	0.9%	24	13.3%	76	42.0%	116	64.1%
Skin - malignant melanoma	112	0.6%	38	33.9%	22	19.6%	66	58.9%
Head & neck	99	0.5%	16	16.2%	35	35.4%	61	61.6%
Brain & central nervous system	53	0.3%	6	11.3%	34	64.2%	45	84.9%
All other invasive malignancies	191	1.0%	52	27.2%	-	-	162	84.8%
2+ other invasive cancers	186	0.9%	14	7.5%	-	-	152	81.7%
Women with breast cancer and another invasive cancer	3,475	17.6%	503	14.5%	1,598	46.0%	2,680	77.1%
Women with breast cancer	19,758	100.0%	8,817	44.6%	3,196	16.2%	11,245	56.9%
Gynaecological (+/- other invasive cancers)	815	4.1%	133	16.3%	349	42.8%	638	78.3%
Bowel (+/- other invasive cancers)	665	3.4%	81	12.2%	270	40.6%	444	66.8%
Lung (+/- other invasive cancers)	650	3.3%	67	10.3%	443	68.2%	587	90.3%

Overall, women with breast cancer who also had other invasive cancers were more likely to die from the other invasive cancer than from their breast cancer (46.0% compared with 14.5%; Table 5). Women with invasive hepatobiliary (76.7%), upper gastro-intestinal (69.6%) and lung (69.2%) cancers were most likely to die of their other cancer rather than their breast cancer. The relatively small proportion of women with melanoma skin cancer (0.6%) were more likely to die from breast cancer than their other invasive cancer.

Figures 10, 11 and 12 show for women with breast cancer who were also diagnosed with invasive gynaecological, bowel or lung cancers and no other invasive cancers, the proportion surviving in each year after the diagnosis of their breast or other invasive cancer before they died from either cancer or any cause. Women diagnosed with other invasive cancers had a shorter time from the diagnosis of their other invasive cancer to death than from the diagnosis of their breast cancer. Thus, of the 732 women with breast and invasive gynaecological cancers, 71.2% were breast cancer patients for at least 5 years, but only 31.1% had at least 5 complete years as a gynaecological cancer patient. Similarly, of the 593 women with breast and invasive bowel cancers, 64.4% were breast cancer patients for at least 5 years, but only 33.9% had at least 5 complete years as a bowel cancer patient. Survival times of women with breast cancer patients after the diagnosis of a multiple primary lung cancer were even shorter. Of the 604 women with breast and invasive lung cancers, 67.5% were breast cancer patients for at least 5 years, but only 6.1% had at least 5 complete years as a lung cancer patient.

Figures 10, 11 and 12 show that 51% of women with breast cancer who also had invasive gynaecological, bowel or lung cancers survived for 8 years after their breast cancer diagnosis. However, only half the women with breast and invasive gynaecological or bowel cancers survived for more than 2 years after the diagnosis of their gynaecological or bowel cancer (Figures 10, 11) and only 32.8% of women with breast and invasive lung cancers survived for 1 year after the diagnosis of their lung cancer (Figure 12)

Results – Survivorship

Figure 10 : Women with breast and invasive gynaecological cancer registrations in 1985-2008: Years from diagnosis of breast or gynaecological cancer to death from all causes or death from cancer

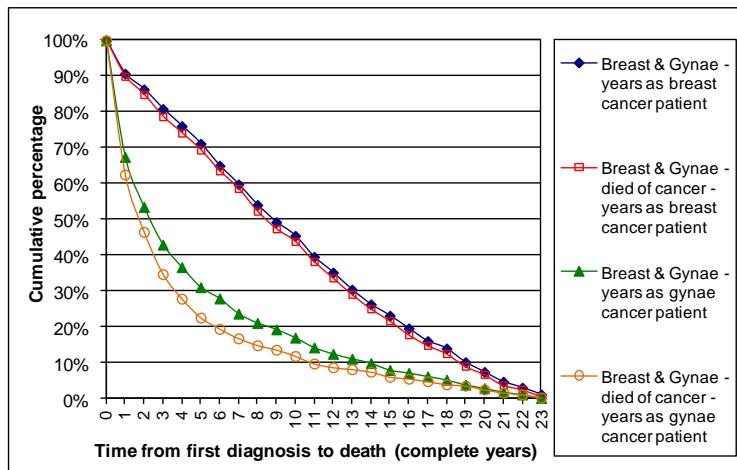


Figure 11 : Women with breast and invasive bowel cancer registrations in 1985-2008: Years from diagnosis of breast or bowel cancer to death from all causes or death from cancer

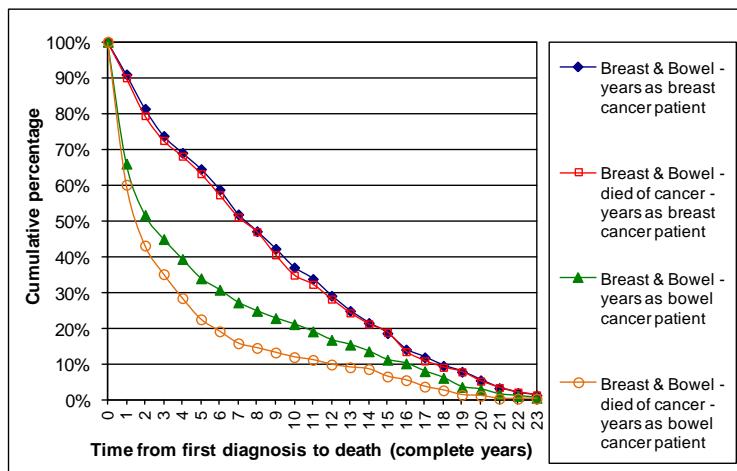
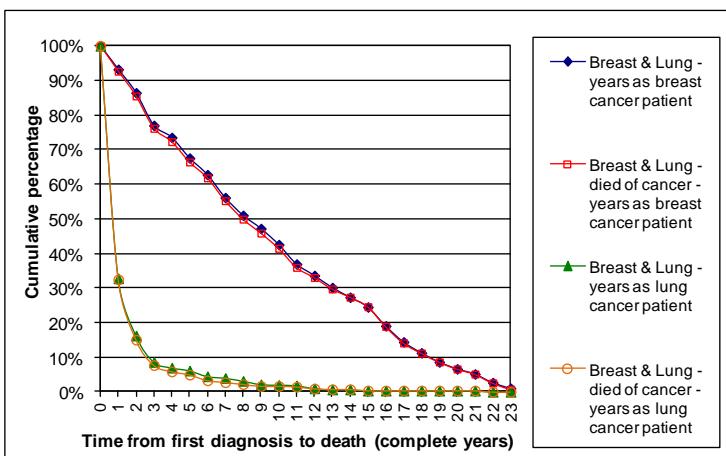


Figure 12 : Women with breast and invasive lung cancer registrations in 1985-2008: Years from diagnosis of breast or lung cancer to death from all causes or death from cancer



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Abbreviations

Abbreviation	Full Text
ABCR	All Breast Cancer Report
ABS	Association of Breast Surgery
BCCOM	Breast Cancer Clinical Outcome Measures
BRAC1 And BRAC2	Human genes that produce tumour suppressor proteins which repair DNA. Specific inherited mutations in these genes increase the risk of female breast and ovarian cancer
CRUK	Cancer Research UK
DCIS	Ductal Carcinoma <i>In Situ</i>
ICD-10	International Statistical Classification of Diseases and Related Health Problems 10th Revision
ICD-O-2	International Classification of Diseases for Oncology, 2nd Edition
ICD-O-3	International Classification of Diseases for Oncology, 3rd Edition
NCDR	National Cancer Data Repository
NCIN	National Cancer Intelligence Network
NHSBSP	National Health Service Breast Screening Programme
nmsc	Non-melanoma skin cancer
ONS	Office for National Statistics
UKACR	United Kingdom Association of Cancer Reistries

Appendix 1 Duplicates and Recurrences

For each patient with invasive breast cancer, the earliest invasive breast cancer registered in 2008 was flagged as the index invasive cancer. Patients with *in situ* breast carcinoma in 2008 were assigned an index *in situ* breast carcinoma in the same manner. Each tumour in the dataset was compared to the morphology and laterality (ipsilateral, contralateral) of the index cancer(s) for the patient. When comparing *in situ* breast carcinomas and invasive cancers, the first four digits of the ICD-O-2 or ICD-O-3 morphology code were used.

If laterality was unknown and the patient had more than one tumour, three rules were used to assume laterality. The first two rules were based on the protocol used historically by the West Midlands Cancer Intelligence Unit (WMCIU) for recording subsequent cancers with unknown side. The third rule was introduced to assume laterality for the 15 patients with “Right”, “Left” and “Unknown” laterality breast cancers.

- Laterality Rule 1: When comparing to the index, assume unknown laterality equals known laterality.
- Laterality Rule 2: When comparing with cancer with the same morphology, assume the unknown laterality has the same laterality as the earliest tumour with known laterality with the same 4 digit morphology.
- Laterality Rule 3: When the index tumour has unknown laterality and Rules 1 and 2 assume both a “Right” and a “Left” tumour to be the same laterality as the index cancer, instead assume that the “Right” and “Left” tumours were one ipsilateral and one contralateral cancer to the index cancer.

The following three rules were then used to determine if a breast tumour was a possible duplicate or recurrence of another breast tumour included in the dataset. Breast tumours were compared to the index tumour and all other breast tumours registered for the patient.

- Exclusion Rule 1: Assume two breast tumours with the same ICD-10 code in the same patient with the same morphology and laterality are duplicates or recurrences and exclude the later one.
- Exclusion Rule 2: Assume an *in situ* breast carcinoma (D05) diagnosed after or within 3 months of an invasive breast cancer (C50) in the same patient with the same morphology and laterality is a duplicate or recurrence and exclude the *in situ* breast carcinoma.
- Exclusion Rule 3: If the index tumour is excluded, choose a new index tumour if possible or exclude the patient.

Note: The algorithm cannot eliminate all duplicates. For example two cancer registries could register the same breast cancer from two different sources, with general or specific breast cancer morphology codes.

Appendix 2 Cancer Site Groupings

Cancer site grouping	ICD-10	Cancer site
Head & Neck	C00	Lip
	C01	Base of tongue
	C02-C14	Oral cavity and pharynx
	C30	Nasal cavity and middle ear
	C31	Accessory sinuses
	C32	Larynx
	C73	Thyroid gland
Upper Gastro-intestinal (Upper GI)	C15	Oesophagus
	C16	Stomach
Bowel	C17	Small intestine
	C18	Colon
	C19	Rectosigmoid junction
	C20	Rectum
	C21	Anus and anal canal
	C26	Other and ill-defined digestive organs
Hepatobiliary & Pancreas (HPB)	C22	Liver and intrahepatic bile ducts
	C23	Gallbladder
	C24	Other and unspecified parts of biliary tract
	C25	Pancreas
Lung	C33	Trachea
	C34	Bronchus and lung
	C39	Other and ill-defined sites in the respiratory system and intrathoracic organs
Melanoma skin	C43	Malignant melanoma of skin
Breast - invasive	C50	Breast
Gynaecological	C51	Vulva
	C52	Vagina
	C53	Cervix uteri
	C54	Corpus uteri
	C55	Uterus, part unspecified
	C56	Ovary
	C57	Other and unspecified female genital organs
	C58	Placenta
Male genitalia	C60	Penis
	C62	Testis
	C63	Other and unspecified male genital organs
Prostate	C61	Prostate
Urological	C64	Kidney
	C65	Renal pelvis
	C66	Ureter
	C67	Bladder
	C68	Other and unspecified urinary organs
Brain & Central Nervous System (CNS)	C47	Peripheral nerves and autonomic nervous system
	C69	Eye and adnexa
	C70	Meninges
	C71	Brain
	C72	Spinal cord, cranial nerves and other parts of central nervous system
Haematological	C81-C85	Lymphoma
	C88	Immunoproliferative disease
	C90-C95	Myeloma & leukaemia
	C96	Other and unspecified lymphoid and haematopoietic tissues
Other	C37	Thymus
	C38	Heart, mediastinum and pleura
	C40	Bone and articular cartilage of limbs
	C41	Bone and articular cartilage of other and unspecified sites
	C45	Mesothelioma
	C46	Kaposi's sarcoma
	C48	Retroperitoneum and peritoneum
	C49	Other connective and soft tissue
	C74-C75	Adrenal and other endocrine glands
	C76-C80	Ill-defined, secondary and unspecified sites
	C97	Independent (primary) multiple sites

Appendix 3 Death Cause

Assigning Death Cause

The death certificate is divided into two sections

Part 1: cause of death

Part 2: contributing to the death but not related to the cause of death

Death cause was assigned using ICD-10 invasive cancer codes (see Appendix 2) or free text in the death certificate fields cod_1a, cod_1b, cod_1c or cod_2 of the NCDR.

Death cause	Description
Breast cancer	Invasive breast cancer in Part 1 of the death certificate with no other site-specific invasive cancer in Part 1 Or Invasive cancer of no specific site in Part 1 and no other site-specific invasive cancer diagnosed from 1985 onwards or listed in Part 2 of the death certificate (see Note)
Other cancer	One or more site-specific invasive cancers other than invasive breast cancer in Part 1 of the death certificate. Breast cancer not mentioned in Part 1.
Cancer (unknown between breast and other)	Invasive breast cancer and invasive cancer(s) other than invasive breast cancer in Part 1 of the death certificate Or Invasive cancer of no specific site in Part 1 and invasive cancer other than invasive breast cancer diagnosed from 1985 onwards or listed in Part 2 of the death certificate
Non cancer	No invasive cancer in Part 1 of the death certificate
Unknown	Part 1 of the death certificate not recorded

Note: If there is invasive cancer of no specific site in Part 1 (e.g. "carcinomatosis" is a consequence of invasive cancer but no specific site is mentioned), cancer registration staff determine whether a new primary should be registered from the death certificate based on the complete cancer record for the patient held on the cancer registry database.

This report only includes cancers diagnosed from 1985 onwards. For this report it is assumed that invasive cancer of no specific site in Part 1 of the death certificate refers to a cancer diagnosed from 1985 onwards. 225 (1.1%) of the 19,939 women who died in 2008 with breast cancer diagnosed in 1985-2008 had invasive cancer of no specific site in Part 1 of the death certificate and no other site-specific invasive cancer diagnosed in 1985-2008 or listed in Part 2 of the death certificate. It is assumed that even if there were other cancers diagnosed before 1985, the breast cancer diagnosed in 1985-2008 was the cancer that caused the death.

