

**Secondary.
Not second rate.**

**breast
cancer
care**

**Secondary breast cancer
Part two: Who's counting?
September 2016**



two thirds

of Hospital Trusts in England are not collecting data in full on their secondary breast cancer patients

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Section 1: Introduction

For many years, Breast Cancer Care has pushed for significant improvements in care for those living with and affected by breast cancer, including secondary breast cancer.

We have long called for data on diagnosis and treatment of secondary breast cancer to be routinely collected by hospitals and shared publicly, so that commissioners and healthcare providers are able to identify their local patient population's needs and plan services effectively to meet them. Many of the ongoing problems in care and support can be traced back, at least in part, to the lack of available data on the disease. It is

unacceptable then that, a decade on from when Breast Cancer Care first identified this issue and started to campaign for change, no data have ever been published.

This report continues our series looking at secondary breast cancer, following our previous report on patient experience at diagnosis. It highlights the barriers that are preventing routine collection and publication of data and how these can be overcome. Future reports will include further insights into secondary breast cancer, including specialist nurse provision and the wider impact of living with the disease.



Section 2: Context

Secondary breast cancer – also known as metastatic, advanced or stage 4 breast cancer – occurs when breast cancer cells have spread from the breast to other parts of the body, such as the bones, lungs, liver or brain. Secondary breast cancer is not curable. It can be treated and median survival is estimated at around 2–3 years. However, the disease trajectory varies significantly according to site(s) of spread and response to treatment, and some people live for many years while others survive just a few months.

Breast Cancer Care offers comprehensive and unique support to those living with or affected by secondary breast cancer. In 2015, we ran monthly Living with Secondary Breast Cancer sessions in more than 20 locations across the UK to help people cope with the physical, social and psychological impact of diagnosis, treatment and living with the disease. In addition, in April 2016, 37 women aged 45 and under attended a residential event providing tailored information and support for younger women diagnosed with secondary breast cancer.

We have a website, online forum and live chats, enabling people to come together to share experiences and get support from people in similar situations. Our telephone Helpline and Ask Our Nurses email service provide information and support to those affected by secondary breast cancer from diagnosis through to end of treatment and beyond. All these services are underpinned by our free **Secondary Breast Cancer Resource Pack** and a series of information booklets covering diagnosis and treatment of the most common secondary breast cancer sites. Along with the information on our website, they are written by our own team of specialist breast care nurses, and reviewed by volunteer independent healthcare professionals and people affected by breast cancer. Our patient information is externally assessed as being up-to-date and trustworthy by the NHS England Information Standard.

In partnership with Breast Cancer Now, the breast cancer research charity, we deliver the Secondary Breast Cancer Pledge, a service improvement initiative which works with hospitals to deliver patient-led improvements to care and treatment for people with secondary breast cancer. We also support nurses who care for patients with secondary breast cancer through our Nursing Network and Secondary Breast Cancer Nursing

Forum. Through sharing best practice and clinical updates, we aim to improve the standards of care for people diagnosed and living with secondary breast cancer. All of our services are free.

The missing statistics

There is no accurate, up-to-date figure on the number of people diagnosed or living with secondary breast cancer in the UK. In January 2013, it was mandated for data on secondary breast cancer to be collected by NHS Hospital Trusts in England¹. However, to date, no such figures have been published.

In Scotland, although data collection is not mandatory, progress is being made, with the Scottish Cancer Registry identifying an estimated 4,090 patients living with secondary breast cancer in 2013². In Wales, there has been a commitment to collect data on the disease since 2012³. However, little progress has been made and there is still no single dataset available.

This lack of data across England, Scotland and Wales, coupled with poor understanding of the experiences of secondary breast cancer patients, makes it enormously difficult for commissioners and healthcare providers to plan for and implement the services that will meet the needs of those with secondary breast cancer. The lack of intelligence and understanding also means that we do not have a full picture of the long-term effectiveness of treatments for primary breast cancer; at a time when NHS budgets are increasingly under pressure, this information could help inform decisions about which treatments should be funded.

It has previously been estimated that there are around 36,000 people living with secondary breast cancer in the UK⁴ and each year around 11,600 people die from the disease⁵. However, collectively, it is not known how many people are diagnosed each year, how long they are living for, the spread of their disease, or the treatment and support they are receiving. All of this missing information means that we do not know for certain whether people living with incurable secondary breast cancer are getting the right care and support.

We do know, from the women with secondary breast cancer that we speak to regularly, that for many, their care is often inadequate. The gaps in information and intelligence add to a widely shared experience: that people with secondary breast

cancer feel forgotten or invisible; that the care they receive is inferior and not comparable to the experience and quality for those with a primary breast cancer diagnosis.

Data collection is essential in each of the nations of the UK in order to ensure that secondary breast cancer patients are getting the best possible care regardless of which country they live in. However, for this report, we have focused on England, where data collection is currently compulsory and yet, no comprehensive data have been published to date. We hope that our findings will be able to help inform the development of data collection in the other UK nations in due course.

History of data collection

Breast Cancer Care has campaigned for improved data collection since 2006, when the Secondary Breast Cancer Taskforce first highlighted the need for better data and understanding of the disease⁶. Following a successful meeting with then-Prime Minister, David Cameron, in December 2010, there was a commitment in the 2011 Cancer Strategy, Improving Outcomes: A Strategy for Cancer, to pilot collection of data on recurrence/metastasis, with an aim of undertaking full data collection from April 2012⁷. This was also intended to inform the collection of data on other secondary cancers in time.

The pilot project was run by the National Cancer Intelligence Network (NCIN)*, Breast Cancer Care and the Association of Breast Surgery. The subsequent report, published in March 2012,

recommended that 'all patients receiving NHS care for the management of secondary breast cancer should be reported.'⁸

Since 2013, it has been compulsory for data to be collected by NHS Trusts on people diagnosed with secondary breast cancer within their Trust, as confirmed by a letter from the Department of Health and the NCIN to Hospital Trust Chief Executives, advising that the collection of data on recurrent and/or metastatic breast cancer would be mandated from 1 January 2013¹. This should be happening within the Hospital Trust, ideally through a multi-disciplinary team (MDT) meeting and submitted to the Cancer Outcomes and Services Dataset (COSD), which includes data fields such as 'date of recurrence' and 'metastatic site'.

However, since this date no data have been published and subsequently we are no closer to better understanding the needs of this patient group or what services need to be commissioned to meet their needs. The government has continued to acknowledge the importance of better collection of data, stating:

'The Department of Health recognises that data collection on metastatic breast cancer is not as good as it should be. The Department has made it a priority for the National Cancer Intelligence Network [NCRAS] and Public Health England to rectify this. Improvements have been made, but there is still some way to go before data will be ready for publication.'⁹

However, the government has since admitted that it 'estimates about one-quarter of recurrences are currently submitted.'¹⁰ Aside from the issue of secondary breast cancers being included under the heading of 'recurrence' (see opposite), this is extremely disappointing.

We were encouraged to see that this issue was included again in the new Cancer Strategy for England, Achieving world-class cancer outcomes, published in July 2015¹¹. The strategy mentions the work undertaken on secondary breast cancer data collection to date, although it does not recognise the problems and delays that have occurred. There is a recommendation on the collection of data on all secondary cancers. Breast Cancer Care is calling for this to be implemented as a priority.

It is also positive to see that Public Health England, which is responsible for the COSD, its analysis and

publication, is continuing to review and update the COSD to improve the dataset at regular intervals. We understand that the next version of the COSD is likely to include some changes that could make it simpler and easier for Hospital Trusts to collect the data required on secondary breast cancer. However, it is disappointing to see that this process takes up to 15 months and it is likely to be April 2018 when the new version of the dataset is launched.

Recurrence versus secondary breast cancer

There is often confusion regarding what is meant by secondary breast cancer, and how this differs from a recurrence of breast cancer. Recurrence of primary breast cancer and secondary breast cancer are often grouped together under the same heading, such as they are in the COSD, despite having clear and distinct differences.

Breast Cancer Care uses the following definitions for local, regional and distant recurrence.

- Local recurrence: Breast cancer that has returned in the chest/breast area or in the skin near the original site or scar.
- Regional recurrence (also known as locally advanced breast cancer): Breast cancer that has returned and has spread to the tissues and lymph nodes (lymph glands) around the chest, neck and under the breastbone.
- Distant recurrence (also called metastatic, advanced, stage 4 or secondary breast cancer): When cancer cells from the breast have spread to other parts of the body such as the bones, lungs, liver or brain.

These distinctions are important as the needs of patients with local or regional recurrence and secondary breast cancer are quite different. For a local recurrence, the treatment may be similar to previous treatment for breast cancer, with the aim of treatment being curative. However, for secondary breast cancer, which has spread to other parts of the body and is incurable, treatment aims to control and slow down the spread of the cancer and relieve symptoms. The needs of this group of patients are very different with pain relief and symptom control, as well as emotional support, being absolutely vital for patients to live as well as possible for as long as possible with the disease.



*Now known as the National Cancer Registration and Analysis Service (NCRAS)

Section 3: Methodology

Who's counting? campaign

In March 2016, Breast Cancer Care launched the 'Who's counting?' campaign, aimed at identifying the barriers that are preventing the routine collection and publication of data on secondary breast cancer.

We invited members of our Campaigns Network to send an email to the Chief Executive of their local Hospital Trust asking whether the Trust is recording the number of people diagnosed with secondary breast cancer, and then to share the response they received with us. The request asked:

1. Is the Trust recording the number of people diagnosed with secondary (metastatic) breast cancer?
2. If so, how many people were diagnosed with the disease within the Trust in the last 12 months (or for the latest period available)? These should include:
 - (a) those who were diagnosed with secondary breast cancer at their first presentation; and
 - (b) those for whom their primary breast cancer has progressed and spread to other parts of the body. Please also include the time period this data refers to.

Letters were sent to all Hospital Trust Chief Executives before the launch of the campaign to inform Trusts of the approach we were taking, to explain the campaign aim, and to offer support or clarification if required.

After four to six weeks, campaigners who had not received a response from their Hospital Trust were offered the opportunity to ask their local MP to support them by emailing the Hospital Trust for this information on their behalf. Campaigners who had still not received a response from their Hospital Trust (either directly or via their local MP), were then asked to either send their Hospital Trust a reminder email or to submit a Freedom of Information (FOI) request to obtain the information. The campaign ran from March to July 2016. After a final reminder to ask campaigners to share any responses they had received with us, the Breast

Cancer Care Policy and Campaigns team issued FOI requests to all Hospital Trusts that were yet to respond.

Excluded Trusts

The Who's counting? campaign applied to 134 NHS Trusts out of the 149 acute and specialist Trusts across England. Some non-cancer specialist Trusts (such as Moorfields Eye Hospital NHS Foundation Trust and Great Ormond Street Hospital for Children NHS Foundation Trust) and those that informed us that they do not have breast cancer services were excluded from the campaign.

Response rate

125 Hospital Trusts (93%) responded to our request for information, enabling us to capture a comprehensive picture of data collection across England.

There may be instances where Trusts have responded to the original request from a campaigner and this response has not been returned to the Breast Cancer Care Policy and Campaigns team. However, we did attempt to mitigate this with clear instructions sent via email, several reminder emails to campaigners throughout the campaign, as well as issuing final FOI requests to Trusts we had not received a response from.

Criteria used

When responses were received, each response was evaluated and categorised using the following criteria:

Yes:

- The Trust is recording data and can provide the number of people diagnosed overall, as well as being able to differentiate between those diagnosed at first presentation and those diagnosed following treatment for primary breast cancer

No:

- The Trust responded to say no, they are not collecting this data, OR
- The Trust records all breast cancers, but is unable to distinguish between primary, recurrent and metastatic breast cancer, OR
- The Trust confirmed that information is only recorded in paper form and would require analysis of individual patients records, rather than being collated and regularly used by the Trust

Partial:

- The Trust is unable to provide figures for the last 12 months, but has established a new process or set up a new project and is working on full data collection, OR
- The Trust can provide overall figures, but is unable to distinguish between first presentation of breast cancer and those diagnosed following previous treatment for primary breast cancer, OR
- The Trust records either first presentation of secondary breast cancer, or spread of primary breast cancer, but not both, OR
- The Trust is collecting data internally but is not reporting these to the COSD, OR
- The Trust produced figures but explained that they are not robust or complete

Case studies

Further to the requests for information, we also contacted a number of Trusts to build in-depth case studies to understand more about best practice and barriers to implementing routine data collection for secondary breast cancer. In total, five case studies were identified, two of which were from Trusts categorised as 'Yes', two categorised as 'Partial', and one categorised as 'No'. We are extremely grateful to those Trusts who gave their time to support this research.

Roundtable meeting

Finally, in September 2016, Breast Cancer Care invited Public Health England, healthcare professionals and people living with secondary breast cancer to discuss the current issues with data collection and what solutions may be available. We are grateful to those who attended the roundtable. Our recommendations, in particular, were influenced by the discussions at the meeting.



Section 4: Findings

How many Hospitals Trusts are collecting data on secondary breast cancer?

We were disappointed, but not surprised, to discover that not every Hospital Trust in England is collecting data on secondary breast cancer, despite it having been compulsory for them to do so since 2013.

In fact, from the responses we received, we found that only a third (33.6%) of Trusts are meeting this requirement in full, i.e. they have systems and processes in place to collect data and are then submitting this to the COSD. Furthermore, we have found that some Trusts that are collecting data are also using this information internally to help understand their local patient populations and improve services.

Unfortunately, nearly one in five Hospital Trusts (19.2%) are not collecting any data on their secondary breast cancer patients. This means that those Trusts have no real idea how many people are being diagnosed each year, how many people are living with the disease in their local area, and therefore, are unable to identify whether or not they are appropriately supporting these patients. This includes having adequate specialist nursing provision, access to palliative care, and information and support for patients that meets their needs. Given that it has been over three and a half years since Trusts have been required to collect this data, it is extremely disappointing that patients diagnosed and treated at a fifth of England's Hospital Trusts continue to not be counted.

The remaining Trusts (47.2%) are collecting some data but do not appear to be meeting their requirement in full. In some cases, new processes have been set up and we were pleased to see that our Who's counting? campaign acted as a catalyst to this for some Trusts, including in some cases, the establishment of a new MDT for secondary breast cancer patients or a dedicated slot at an existing MDT meeting. In other situations, Trusts were collecting some data but it was clear that these were incomplete. For example, a large group of Trusts were able to identify those patients who were diagnosed with secondary breast cancer at their first presentation ('de novo') or patients who

had primary breast cancer which later spread to other parts of their body and metastasised, but not for both groups of patients.

It is encouraging that these Trusts are making progress in either setting up or improving their processes for collecting data on secondary breast cancer. We hope this will mean that, soon, it will be possible to more accurately identify the number of people diagnosed with secondary breast cancer in England each year.

However, it cannot be ignored that two thirds of Hospital Trusts are not collecting full data on their secondary breast cancer patients as they are mandated to do. Were this to be the case for other cancer statistics, such as the Cancer Waiting Times Monitoring Dataset, there would undoubtedly, and rightly, be outrage and a clear plan for improvement would be prioritised and implemented. The same is required for those living with incurable breast cancer so that we can identify the improvements in care and support that these patients urgently require.

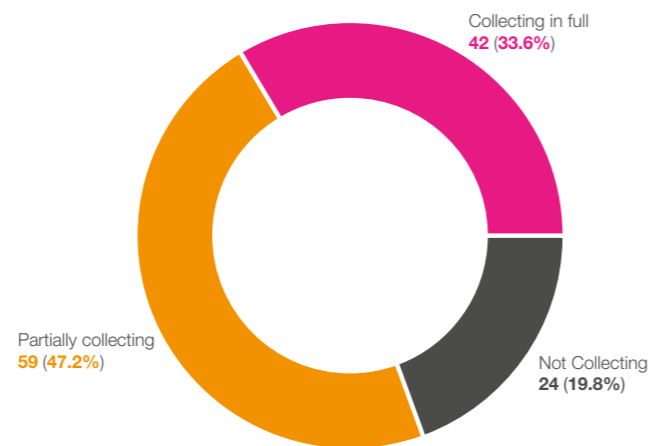


Figure 1: How many Hospital Trusts are collecting data?

Regional variations

Much like the national picture, no single region is doing particularly well in addressing the issue of data collection on secondary breast cancer. As Table 1 shows, the North West has the highest percentage of Trusts collecting data in full. However, this still represents less than half of Hospital Trusts in the region. The South West and Yorkshire and Humber regions have similar proportions of Trusts collecting data in full. The South West also has, along with the East of England region, the lowest percentage of Trusts not collecting any data.

Table 1

Table of regions by percentage

Region	Collecting	Partially	Not collecting
East Midlands	37.5	37.5	25.0
East of England	37.5	50.0	12.5
London	25.0	62.5	12.5
North East	12.5	50.0	37.5
North West	45.0	40.0	15.0
South East	31.6	47.4	21.1
South West	43.8	43.8	12.5
West Midlands	16.7	50.0	33.3
Yorkshire and Humber	40.0	40.0	20.0

Table 2

Table of Strategic Clinical Networks (SCNs) by percentage

Region	Collecting	Partially	Not collecting
Cheshire and Mersey	20.0	60.0	20.0
East Midlands	25.0	25.0	50.0
East of England	31.3	50.0	18.8
Greater Manchester, Lancashire and South Cumbria	50.0	35.7	14.3
London	29.4	58.8	11.8
North East, North Cumbria and North Yorkshire	22.2	44.4	33.3
South East Coast	50.0	40.0	10.0
South West	30.8	53.8	15.4
Thames Valley	25.0	50.0	25.0
Wessex	42.9	42.9	14.3
West Midlands	18.2	54.5	27.3
Yorkshire and Humber	45.5	45.5	9.1

Similar patterns can be seen across Strategic Clinical Networks (SCNs) as shown as Table 2. Both Greater Manchester, Lancashire and South Cumbria SCN and South East Coast SCN have half of the Hospital Trusts in their area collecting data in full. The Yorkshire and Humber SCN has over 90% of its Trusts at least partially collecting data.

There are three specialist cancer centres in England: The Christie NHS Foundation Trust, The Clatterbridge Cancer Centre NHS Foundation Trust and The Royal Marsden NHS Foundation Trust. It would be expected that, as world-leading centres for cancer care, these three Trusts would be collecting data on their secondary breast cancer patients. It was therefore surprising to see that only one of these cancer centres is collecting these data in full. The other two were unable to break down their figures by de novo diagnoses and spread of the disease, calling into question the completeness and robustness of their data. This may be at least partly explained by the more complex nature of tertiary centres, such as the specialist cancer centres, treating patients that may have initially been diagnosed in a separate Hospital Trust.

Reasons for less than full compliance

Each of the Hospital Trusts that responded and demonstrated that they were either not collecting data or only partially collecting data on secondary breast cancer were then categorised depending on any reasons given.

Among those Trusts that are not collecting any data, the majority gave no further reason for this. However, 21% (five Trusts) explained that they were collecting data on all breast cancer patients but that they were unable to break this down further into primary, recurrent or metastatic (secondary) breast cancer. This means that they are likely to be fulfilling other cancer data requirements, for example their submissions to the Cancer Waiting Times Monitoring Dataset. However, by being unable to identify secondary breast cancer patients, the Trust is not meeting its requirement on submitting data to the COSD as it should be.

A further 17% of Trusts (four) explained that the data was available but only by sifting through individual patient records. We rejected this premise as it highlighted that these Trusts do not have any processes in place for the routine collection of data on secondary breast cancer, nor are the data likely to be regularly used in any meaningful way to assess and improve local services.

Case study 1: A Trust in Yorkshire and Humber

There is a desire to collect data at the Trust but it is difficult for this to happen. Two reasons are given: the lack of a dedicated MDT for secondary breast cancer and the lack of administrative support. Patients may be discussed at one of the two existing MDT meetings but it is accepted that not every secondary breast cancer patient will be discussed. Furthermore, without administrative support, there is no capacity for nurses or others to collect data. Two new posts, both part-time, have been secured using the little data that is available. However, it has taken some time for these to be agreed.

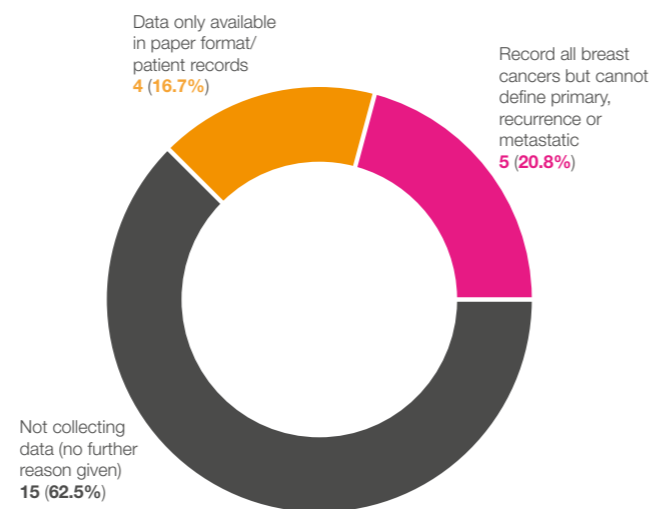


Figure 2: Reasons for not collecting data

For the Hospital Trusts categorised as partially collecting data on secondary breast cancer, there was one common reason why many are not collecting data in full. 61% of these Trusts (36) provided an overall figure for the number of secondary breast cancer patients diagnosed in the previous 12 months. However, they were unable to break this down into de novo diagnoses and those diagnoses following the progression and spread of a known primary breast cancer.

This distinction is important for a number of reasons. Firstly, a Trust providing both figures gives more confidence that their data are complete, particularly as it is arguably easier for a Trust to collect de novo diagnoses rather than instances of progression and spread. This is especially so when considering that some patients may have a significant disease-free period between their primary and secondary breast cancer diagnoses.

More importantly, these two figures offer different stories for a Trust's patients. Every de novo diagnosis of secondary breast cancer must be considered as a late diagnosis of breast cancer. With so much effort and attention given to the importance of early detection and diagnosis of cancer, every de novo diagnosis of secondary breast cancer has to be seen within the context of needing to further improve early diagnosis rates. These data, therefore, should be used by Hospital Trusts and commissioners to identify where improvements to early detection are needed, as well as highlight where public health services should target their efforts.

It is also important for a Hospital Trust to know the number of patients who are diagnosed with secondary breast cancer following a diagnosis and treatment of primary breast cancer. For these patients, it is vital that there is easy access back into the pathway, particularly for those who have had a long period of time since their primary breast cancer treatment. As our recent report on secondary breast cancer patient experience at diagnosis demonstrated, there are improvements that can, and should, be made at this point too¹².

Further reasons for less than full compliance with regard to data collection include that the Trust in question records only de novo diagnoses and spread of the disease but not both (8.5%/five Trusts), the Trust admitting that their data are not complete or robust (8.5%/five trusts), or that the data are being collected internally but not being submitted to the COSD as they should be (5.1%/three Trusts). The remaining Trusts (16.9%/10 Trusts) were unable to provide any statistics on diagnosis rates following our request but did explain that they have recently, in some cases as a result of our campaign, set up new processes to be able to do this in the future. We hope that they make good progress on this. Likewise, for the other Hospital Trusts only partially collecting data, some small changes could make a big difference in increasing the quality and completeness of the data on secondary breast cancer needed to lead to improvements in patient care.

Case study 2: A Trust in the South East

At one Hospital Trust, one specialist nurse took responsibility for collecting data after becoming aware of the requirement for the Trust to do so, as well as recognising that this information would be useful to help better understand patients and the support available to them. The nurse set up a spreadsheet and time was taken to input the information from patient notes. However, this has now ceased as it was so time consuming and there is confusion about exactly what information is required. The spreadsheet does not link up to the national datasets but has been used to inform annual reports. It is hoped that the spreadsheet will provide evidence that can be used for a business case for an additional post. Unfortunately, the nurse is moving to a new role outside the Trust and, as a result, it is unclear whether or how this work will continue.

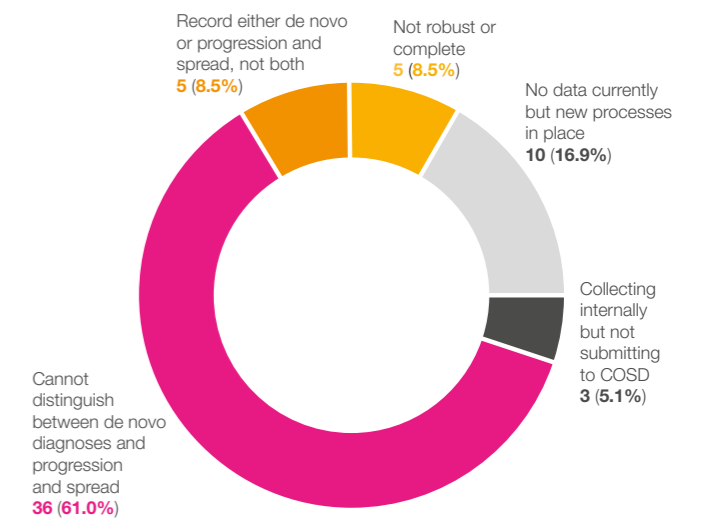


Figure 3: Reasons for 'partial' collection of data

From the responses we received and the in-depth case studies we sought, we were able to identify a number of reasons why full compliance has not been achieved in so many Hospital Trusts.

- Lack of available resources to collect data** – patient care is, and always should be, prioritised above all else. However, this can mean that attempts to set up and maintain processes for routine data collection can be sidelined, particularly by those Trusts without appropriate administrative support and where nurses are expected to collect data on top of their usual caseload.

2. **Lack of awareness of the need to collect data and/or how to collect data** – some Trusts are still unaware of the data that they need to collect, even though it has been mandated for over three years. Furthermore, some do not know what data are required or how it should be collected. One reason frequently given is that available software for cancer databases, such as Somerset Cancer Register and InfoFlex, does not allow for the collection of data on secondary breast cancer, despite this not being the case.
3. **Confusion over the definition of secondary breast cancer** – we know there is some debate among clinicians as to the exact definition of metastatic breast cancer, particularly in relation to a breast cancer recurrence. This has led to some confusion, particularly around how such patients can and should be recorded. Some Hospital Trusts explained that they were not collecting data on secondary breast cancer as there was no ICD-10 code. These codes are used for all cancers and include one for breast cancer. While there is no specific code for secondary breast cancer, this does not preclude patients with the disease being recorded as part of the Trust's submissions to the COSD. Furthermore, the lack of consensus around the definition of secondary breast cancer has led to various different terms being frequently used in different settings, including 'secondary', 'metastatic', 'recurrent', 'progression', and 'transformation', increasing the chance of duplication and error.
4. **Lack of buy-in and leadership** – in some cases, it is clear that no one within the Trust has taken responsibility for data collection. This was particularly the case where Trusts did not have either a dedicated clinical nurse specialist (CNS) for secondary breast cancer or an MDT meeting for secondary breast cancer patients, a situation that we know, unfortunately, to be the norm in many Trusts.

Tackling these issues is not simple and there is unlikely to be a single solution that will solve every problem. However, those Hospital Trusts that are not collecting data in full can look to those that are fully compliant for best practice to help improve their own processes.

Case study 3: A Trust in the South East

The Trust does collect some data but it is incomplete and not robust. There is no dedicated secondary breast care nurse or MDT, meaning that data are not routinely collected and many secondary breast cancer patients are not known about. The clinical nurse specialists collect some data on an ad hoc basis when patients are referred to them. The oncologists at the Trust have begun to use InfoFlex to collect their own data. However, pressures on their time mean that this is not complete. The Trust feels confident that they can say how many de novo diagnoses have occurred in the past two years but the total number of patients being cared for is unknown.

Best practice in data collection

Conversely, there are a number of themes that come out of those Hospital Trusts collecting data in full. Unsurprisingly, they were linked to the same barriers that Trusts not collecting data in full were experiencing.

1. **Infrastructure** – Trusts doing well appeared to have some infrastructure behind their collection, analysis and use of data. This includes anything from a dedicated administrative support position to a full cancer management team with responsibility for data collection.
2. **A dedicated secondary breast cancer MDT** – a meeting where every secondary breast cancer patient is discussed represents one of the most obvious opportunities for data on that patient to be collected and collated. Even if the patient is being cared for by an oncologist and does not require surgery, there are other clear benefits to ensuring that patients are receiving the right support and care.
3. **Buy-in and involvement of all relevant staff** – Trusts that are collecting data often have a culture that data collection is the responsibility of more than just one person. For it to work well, it requires nurses, consultants, cancer managers, and MDT coordinators to work together.

It is recognised that for some Trusts, implementing some of these ways of working may be seen as too difficult or not feasible within current budgets. However, given the importance of data and how it could transform patient care if it was available, it should be the ambition of every Hospital Trust to implement the changes needed to enable the routine and robust collection of data.

Case study 4: Maidstone and Tunbridge Wells NHS Trust

Data at the Trust is collected for two databases. One is coordinated by the secondary breast cancer nurse using an in-house system, which collects key information including date of diagnosis, site(s) of disease, treatments, referrals and discussion outcomes at MDT meetings. InfoFlex is also used to feed into the Trust's submissions to the COSD, led by the MDT coordinator. There is a dedicated MDT meeting for secondary breast cancer where all patients are discussed. The data have been used to highlight that patients at the Trust are living longer after their secondary breast cancer diagnosis and that questions around sustainability of services will need to be addressed. Furthermore, the information was used to secure external funding for a new administrative post to free up time of the nurse in future.

Case study 5: Frimley Health NHS Foundation Trust

The Trust has a cancer administrative team with dedicated posts for the collection and analysis of cancer information. De novo diagnoses are captured via histology and radiology reports, while those who previously had primary breast cancer are recorded after presenting to a clinical nurse specialist (CNS) or A&E. The Trust points to the importance of communication between clinical and administrative staff in their ability to collect data robustly. One example of this is the CNS and MDT coordinator sitting next to each other in the office to facilitate good communication and use the respective expertise of each role. The Cancer Team have recognised the need to train clinical staff on the importance of their involvement in data collection and are planning further activity to achieve this.

Data completeness

When contacted as part of our Who's counting? campaign, Hospital Trusts were asked to provide statistics on the number of people diagnosed with secondary breast cancer in the previous 12 months, or whatever recent timeframe was available. This was to demonstrate that the Trust is collecting data. It was not intended to provide an accurate figure of the number of people diagnosed with secondary breast cancer in England, as it is difficult to account for any overlapping or double

counting between Trusts. However, despite this, the figures we received were illuminating as they identified that the data from many Trusts may not be robust or complete.

We were most surprised by the range of responses when Trusts were asked how many people were diagnosed with secondary breast cancer in the previous 12 months. These ranged from 3 to 446. One Trust confirmed that they were collecting data but that no patients had been diagnosed. Over half of the Trusts claimed less than 40 diagnoses of secondary breast cancer, while the average was 54.

Such significant variations are possible. Larger hospitals and cancer centres would be expected to have higher numbers of diagnoses compared to smaller hospitals. Yet, with the best estimate of the number of people living with the disease at 36,000 across the UK, some of the figures at the lower end of the range appear particularly low.

Given the vast breadth in the numbers, it calls into question how accurately secondary breast cancer diagnoses are being recorded, even amongst those Trusts who have processes in place. One Trust initially provided a figure of 1,194 diagnoses. However, when we queried this with the Trust, it was withdrawn, as it was found to be inaccurate.

This is further supported when looking at those Trusts that were able to provide both de novo diagnoses and patient numbers where a primary breast cancer has spread. In these cases, 28% (11 Trusts) reported having a higher number of de novo diagnoses. While possible, this is unexpected. Numbers for progression and spread would normally be higher for two reasons; firstly, efforts to improve early diagnosis should, over time, reduce the number of de novo secondary breast cancer diagnoses, and secondly, with the number of people living longer following a diagnosis of breast cancer, the number of people who later develop secondary breast cancer should increase.

All of this calls into question just how robustly Hospital Trusts are collecting data on secondary breast cancer where they claim to be. It is clear that all Hospital Trusts should check how complete their data are in order to ensure their data are accurate and reliable.

Section 5: Recommendations

It must now be considered a high priority that the issue of data collection for secondary breast cancer is finally dealt with. A decade on from when Breast Cancer Care's Secondary Breast Cancer Taskforce called for data collection on the disease, and over three and a half years since it was mandated for Hospital Trusts in England to do so, it is imperative that data is routinely and robustly collected, analysed and published. Only then will the information and intelligence be available to identify how to improve the care and support for people living with this incurable disease. Once robust processes are established for secondary breast cancer data collection, similar processes could be set up for other metastatic cancers.

- **Recommendation 1:** By 2020, when the current Cancer Strategy is due to end, there must be a formal process for the publication and analysis of diagnosis data on secondary breast cancer, which is widely available for commissioners, healthcare providers, researchers, charities and others.
- **Recommendation 2:** Following the regular publication of diagnosis data, there must be an action plan to build on and expand the existing dataset so that data on prevalence, duration living with the disease, treatments and any other useful data are also routinely collected, analysed and published.

In order to meaningfully tackle the barriers that have long prevented the consistent and routine collection of data on secondary breast cancer in England, it is essential for everyone to take a role, from the government down to staff in individual Hospital Trusts.

Government

The government first committed to data collection for secondary breast cancer in 2010. Six years on and its commitment has still not been achieved. It is necessary for the Department of Health to show leadership, to drive this agenda forward, and identify opportunities to support and encourage Hospital Trusts to collect data.

- **Recommendation 3:** The government should initiate and publish a national audit of secondary breast cancer. This would provide the vital information that commissioners and healthcare

providers need to effectively plan their services. It would also highlight those areas that are not currently complying with data collection requirements and set out an action plan to rectify these.

- **Recommendation 4:** The government should reduce the bureaucracy surrounding changes and updates to the COSD and other cancer datasets so that the time required is shorter than the current 15 months. This would allow the COSD to be more agile and ensure it works at all times for clinicians and administrative staff inputting their data.

NHS England

As the lead organisation for the implementation and delivery of the Cancer Strategy, Achieving world-class cancer outcomes, NHS England has the opportunity to make data collection on secondary breast cancer a priority. It must recognise that until full and robust data collection is achieved, it is difficult to see how other key recommendations, such as ensuring that every cancer patient has access to a CNS, can be delivered.

Furthermore, NHS England should consider appropriate ways to incentivise data collection or penalise those Trusts not collecting data. A tariff-based incentive could encourage senior buy-in across Hospital Trusts to provide the necessary local leadership. Another approach could be to report breaches in data compliance in quarterly reports, highlighting those Hospital Trusts that need to improve their processes for data collection.

- **Recommendation 5:** NHS England should urgently address how it is going to implement recommendations from the Cancer Strategy that are key to secondary breast cancer patients, including the recommendation to mandate the collection of data on all secondary cancers (Cancer Strategy recommendation 90), and for secondary breast cancer patients to be more routinely discussed at MDT meetings (Cancer Strategy recommendations 38 and 46).
- **Recommendation 6:** NHS England should consider appropriate incentives and/or penalties to encourage and support compliance of the mandate for Hospital Trusts to collect data on secondary breast cancer.
- **Recommendation 7:** NHS England should identify other opportunities to learn and share best practice on data collection for secondary

breast cancer, such as using the Cancer Vanguard sites.

Public Health England

As the organisation with responsibility for the collection and analysis of cancer data, Public Health England must look at how it can inform and support Hospital Trusts to collect the data that are required of them. Alongside this, Public Health England must continue to review and update the COSD to make it work for Trusts collecting data.

- **Recommendation 8:** Public Health England should coordinate a working group of key clinicians to agree clear definitions that identify secondary breast cancer diagnoses and separate these from other recurrences, which can then be used in the next version of the COSD.
- **Recommendation 9:** Public Health England should use the opportunity of updating the COSD to simplify and rationalise the data requested from Trusts for the dataset. This should include reducing the opportunity for error or duplication, and setting rules to ensure that key data fields, for example 'metastatic site', are mandatory.
- **Recommendation 10:** Public Health England should analyse and publish whatever data are available on diagnosis of secondary breast cancer, even if this is currently incomplete, as well as non-conformers, so that it is possible to start building a picture of secondary breast cancer.
- **Recommendation 11:** Public Health England should look at how it can best support Hospital Trusts to collect robust data in order to improve compliance. This should include simple guidance on how to complete the COSD with a clear checklist for which data Trusts must collect for secondary breast cancer. Public Health England should ensure that any such guidance is widely available and well known.
- **Recommendation 12:** Working with Health Education England, Public Health England should look at training for breast care teams (through e-learning or otherwise) to ensure that they are aware of the importance of data collection, understand that this is not just a bureaucratic exercise, and know how data should be collected.

Strategic Clinical Networks/Cancer Alliances

One of the priorities of both Strategic Clinical Networks, and Cancer Alliances when they are established, must be to see how rates of data collection can be improved within their region. This is especially important for some of the worst performing areas.

- **Recommendation 13:** Strategic Clinical Networks and the new Cancer Alliances should develop local action plans to support their Hospital Trusts to routinely collect data on secondary breast cancer, where this is not already happening. This could include opportunities to share learning, work shadowing and peer mentoring.

Software providers

We understand that the organisations that provide Hospital Trusts with database systems for their cancer data regularly update their systems to align with the requirements of the COSD and other cancer datasets. However, there is a further opportunity for software providers to support increased compliance with data collection requirements in relation to secondary breast cancer.

- **Recommendation 14:** Software providers should ensure that all new clients are aware of their requirements to collect data on secondary breast cancer. Furthermore, these providers should also ensure ongoing support, guidance and training is available to Hospital Trusts to correctly collect data.

Hospital Trusts

Individual Hospital Trusts in England must look to their own processes for secondary breast cancer data collection and ensure that these are adequate. We have identified some of the key components of effective and robust data collection and encourage Trusts to use this best practice in their own settings.

- **Recommendation 15:** Hospital Trusts should consider appointing a project manager or lead person for secondary breast cancer. This is not someone who is expected to input all of the data themselves but should have the role of coordinating the right healthcare professionals and administrative staff to ensure that the Trust is compliant.
- **Recommendation 16:** Senior management within Hospital Trusts must buy into the need for data collection and support staff within the Trust to achieve this. A culture should be adopted so that data collection is the responsibility of everyone working within cancer services and beyond.
- **Recommendation 17:** Hospital Trusts should ensure that they have a good database system and IT infrastructure to enable the routine collection of data and not rely on spreadsheets maintained by individual staff.
- **Recommendation 18:** Hospital Trusts should ensure that the appropriate administrative support is available for data collection. This will free up nurses and consultants to focus on patient care.
- **Recommendation 19:** Hospital Trusts should establish, where not already set up, a dedicated MDT for secondary breast cancer patients, or at the very least, a specific section in an existing MDT meeting for secondary breast cancer patients to be routinely discussed. This will provide a prime opportunity to record key data.

Breast Cancer Care

We recognise that Breast Cancer Care, as the only UK-wide organisation providing specialist information and support for people affected by breast cancer, still has a role to play in securing the routine and robust collection of data on secondary breast cancer. We will monitor progress in this area and will continue to speak out if, and when, necessary. We will also work with Hospital Trusts to share best practice, including disseminating our findings. Finally, we will continue to link people living with secondary breast cancer with this issue, giving them a voice on something that they feel extremely passionate about.

If these recommendations are implemented in full, we would expect to see near universal collection of data on secondary breast cancer diagnoses. Once basic data, such as diagnosis rates, are established, the dataset should be expanded to include additional information including progression and spread of the disease, treatments, duration since diagnosis, etc. This would allow for much better understanding of the disease and the care that patients require and deserve. It would lead to improvements in patient care and support. Furthermore, once in place, best practice can be used to inform similar processes to be established for other metastatic cancers.

This report has focused solely on secondary breast cancer in England, where data collection is mandated. However, it is disappointing that work in this area has not progressed in the other UK nations as a fundamental basis to understand and meet the needs of those living with secondary breast cancer. The devolved governments and administrations should look to either improve or initiate data collection within their own health systems. Priorities within each government aside, it is likely that, given smaller populations, data collection could be simpler in the long term to achieve.

Section 6: Conclusion

Our Who's counting? campaign and this subsequent report have highlighted that our understanding of the number of people living with secondary breast cancer and the support they are receiving is woefully inadequate. It is disappointing that more than three and a half years after it was mandated for Hospital Trusts in England to collect data on the disease, we are still no closer to having a robust and definitive figure for the number of people diagnosed each year. This is a failing that must be urgently addressed.

The problems have been known for some time and this report highlights some of the key solutions that can address these. Now is the time for everyone – from government through to healthcare professionals – to accept that progress must finally be achieved on this important issue. Leadership is needed, both at national and local level, to drive this agenda forward so that real progress is made. Until then, secondary breast cancer patients are unlikely to get the support they need to live with this incurable disease as well as possible for as long as possible. Fundamentally, achieving this will see England and the UK take a giant leap forward towards the ultimate ambition of world-class cancer outcomes.

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When you have breast cancer, everything changes. At Breast Cancer Care, we understand the emotions, challenges and decisions you face every day, and we know that everyone's experience is different.

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