

**Secondary.
Not second rate**

**breast
cancer
care**



**The case for change
October 2017**

Foreword

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For over a decade Breast Cancer Care has campaigned to improve care and treatment for people with incurable secondary (metastatic) breast cancer.

In 2006 we set up and coordinated the Secondary Breast Cancer Taskforce which identified gaps in treatment, care and support for people living with secondary breast cancer. Since then, we have rolled out a specialised Living with Secondary Breast Cancer service which provides the opportunity for attendees to meet up and share experiences on a monthly basis in almost 30 locations across the UK, disseminated thousands of publications, and supported people through our online Forum and Helpline.

It is through these services that people living with secondary breast cancer have told us that the care they receive is inferior or 'second rate' to the care received by people with primary breast cancer. Many feel isolated, unsupported and uncared for as a result. These feelings of neglect are often a symptom of inadequate support services, inconsistent access to specialist nursing and a lack of vital information at key points in diagnosis and treatment.

We also know that there is still no accurate, up-to-date figure on the number of people diagnosed with secondary breast cancer in the UK today. It is hardly surprising that many Hospital Trusts and Health Boards find it difficult to meet the varied and complex needs of patients when they do not know how many people are living with the disease in their local area.

These shortcomings are not acceptable, nor should they be inevitable.

Worryingly, little progress has been made since we first raised these issues in 2006. The current UK Government and the devolved governments in Scotland and Wales have reiterated their commitment to improving care for people with secondary breast cancer in their respective cancer strategies. Urgent action is now critical.

This report sets out recommendations for practical changes necessary to improve the care and support received by people with secondary breast cancer. We believe that timely diagnosis, improvements in support services and robust data collection are crucial to improving patient experience, and truly achieving world-class cancer outcomes for people living with this disease.

We thank Novartis Oncology for providing funding and support throughout this project, which we have collaborated on while maintaining editorial independence.

With thanks to Quality Health for their support with the survey design, methodology, drawing the patient sample and data analysis of the research. We also thank Apteligen who undertook the nursing research on behalf of Breast Cancer Care.

Thanks to the women living with secondary breast cancer who are pictured in our photos: Vicki, Claire and Dawn

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Introduction

For many years Breast Cancer Care has campaigned for improvements in the treatment and care of people living with and affected by breast cancer, including people living with secondary breast cancer.

However, people living with secondary breast cancer regularly tell us they feel isolated and forgotten. This, combined with inadequate evidence and intelligence on patient experience and need, led us to believe that the current care and experience of those living with secondary breast cancer is second rate.

Our recent Secondary. Not Second Rate campaign sought to confirm this by building a UK-wide picture of current need, and identify ways to improve care and support for people with secondary breast cancer.

We found that:

- many people living with secondary breast cancer experience delays in diagnosis, leading to a delay in receiving vital treatment and care

- in England, less than a third of Hospital Trusts are collecting data in full on their patients with secondary breast cancer, despite it being mandatory¹
- people living with secondary breast cancer are often not getting the care and support they need
- the current availability of specialist nursing for people with secondary breast cancer is well below the level of need. There is also a marked disparity between the level of specialist nursing support for people with primary breast cancer compared to people who have a secondary diagnosis, despite the latter often having very complex emotional and supportive care needs.

This report summaries the key findings and recommendations from the four reports published to date under the Secondary. Not Second Rate campaign. It outlines the changes in care and processes that are needed to bring the support received by people with secondary breast cancer in line with the care that is greatly valued by people being treated for primary breast cancer.



Context

Secondary breast cancer and Breast Cancer Care's services

Secondary breast cancer, also known as metastatic, advanced or stage four 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 but it can be treated. It has been estimated that around 36,000 people are living with secondary breast cancer in the UK and each year around 11,400 people die from the disease². However, there is no accurate figure for 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.

Breast Cancer Care offers comprehensive and unique support to people living with or affected by secondary breast cancer.

Living with Secondary Breast Cancer; a monthly service to help people cope with the physical, social and psychological impact of secondary breast cancer.

Residential events providing **support for younger women diagnosed with secondary breast cancer**.

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 our **Ask Our Nurses email service**, which provide information and support to those affected by secondary breast cancer from diagnosis to treatment and beyond.

These services are underpinned by our award-winning free **Secondary Breast Cancer Resource Pack** and a series of information booklets covering diagnosis and treatment of the most common secondary breast cancer sites.

In partnership with Breast Cancer Now, we deliver the **Secondary Breast Cancer Pledge** in England and Wales, a service improvement initiative which works with hospitals to deliver patient-led improvements to care and treatment for people with secondary breast cancer.

Why are we focusing on secondary breast cancer?

In 2006, Breast Cancer Care set up and coordinated the Secondary Breast Cancer Taskforce. It identified gaps in the treatment, support and care of people living with secondary breast cancer³. It found that:

- the information needs of people with secondary breast cancer were not being met
- data relating to diagnosis was lacking, leading to poor understanding of the disease
- the psychosocial needs of patients were not being assessed at key points
- patients did not have prompt access to a specialist palliative care team
- people with secondary breast cancer were far less likely to have a clinical nurse specialist (CNS) than those who were diagnosed with primary breast cancer
- multi-disciplinary teams (MDTs) were not discussing patients with secondary breast cancer routinely or consistently.

Since the Taskforce was set up, commitments have been made by consecutive governments to make improvements. However our research, coupled with insight from people who use Breast Cancer Care's services, suggests that there is still much more work to do.

Current policies in the nations

England

In July 2015, the Independent Cancer Taskforce published **Achieving world-class cancer outcomes: A strategy for England 2015–2020**, which set out a strategy to deliver significant improvements to cancer care⁴. This was followed by the publication of an implementation plan in May 2016⁵.

The majority of the Cancer Strategy focuses on the prevention, treatment, support and experience of people living with and beyond primary cancers, however there are some relevant recommendations relating to those living with secondary cancers. These include the collection and publication of data on all secondary cancers, the recommendation that all cancer patients have access to a clinical nurse specialist, and the streamlining of the MDT process to allow focus on more complex cases, such as secondary breast cancer.

The National Institute for Health and Care Excellence (NICE) has two breast cancer guidelines which are applicable in England and Wales^{6,7}. However there is a lack of clear guidance on ensuring people are aware of the signs and symptoms of secondary breast cancer once they have finished treatment for primary breast cancer. Additionally NICE's suspected cancer guidance lacks advice for healthcare professionals on recognising and referring symptoms of secondary cancers⁸. These shortcomings represent a missed opportunity to ensure GPs and patients recognise the signs and symptoms of secondary breast cancer, which would enable a quicker diagnosis.

Furthermore, although it has been compulsory for data to be collected by NHS Hospital Trusts on the number of people diagnosed with secondary breast cancer in England since January 2013, in 2016 the government estimated that only a quarter of Trusts were collecting this in full and to date no data have been published⁹.

Wales

The Wales Cancer Network produced the **Cancer Delivery Plan for Wales (2016–2020)** in November 2016¹⁰. The plan recognises that 'patient experience... among metastatic patients is not as well understood as experience for other patients'. It goes on to state that services should meet the different needs of the population and outlines the need for patients with secondary cancer to be quickly identified, have data collected and have full access to services and support to meet their specialist needs through improved collection of information on the care provided, and a peer review delivered by the Wales Cancer Network.

Breast Cancer Care recognises the commitments to improving support and care services for people with secondary breast cancer in Wales. While we welcome the recent consultation on, amongst other things, the mandatory collection of data for patients with secondary cancers, there are still no up-to-date figures on the number of people living with secondary breast cancer in Wales. We urge the Welsh Government to set out plans for the delivery of these commitments.

Scotland

The Scottish Government published **Beating Cancer: Ambition and Action in 2016**¹¹ but we believe that it does not appropriately address the needs of people with secondary breast cancer.

The only relevant action in the strategy is related to data collection and prevention of secondary disease. It is worth noting that despite this action, data collection is still not mandatory though some progress has been made as the Scottish Cancer Registry, working with Breast Cancer Care, identified an estimated 4,090 patients with secondary breast cancer in 2013. We would like to see this figure updated on an annual basis.

Given the number of people living with secondary breast cancer in Scotland, the focus on survivorship for people with this disease represents a missed opportunity to improve standards of care and support for this patient group. What's more, there is currently no clinical guidance relevant to secondary cancers.



The 'Secondary. Not Second Rate' campaign

Our research shows that people with secondary breast cancer often feel forgotten. They tell us the care they receive is inferior to the care that is greatly valued by people treated for primary breast cancer.

These feelings are only exacerbated by gaps in knowledge and understanding. Breast Cancer Care's Secondary. Not Second Rate campaign

sought to rectify this by conducting in-depth research in four key areas.

1. Part one: Diagnosis
2. Part two: Data collection - 'Who's counting?'
3. Part three: Support and impact
4. Part four: Nursing care



Aims and methodology

Diagnosis, and Support and Impact reports

We used a mixture of quantitative and qualitative research techniques to gather data regarding patient experience and need before and during diagnosis, during treatment and care, and of support available and the impact of living with the disease. This included:

1. A survey, developed in partnership with people living with secondary breast cancer, which was completed by 841 respondents from England, Scotland and Wales. The respondents for this survey came from two sources:

- Firstly, the National Cancer Patient Experience Survey (CPES) 2015 in England. Unfortunately, we were unable to use patient data from the Scottish CPES (2015/16) or the then forthcoming Wales CPES (2016). Every respondent to the CPES has the option of agreeing to receive further questionnaires about their health. Women who had agreed, and were identified as having had a recurrence of primary breast cancer or who had secondary breast cancer, were contacted by post
- Secondly, we encouraged people with secondary breast cancer to take part in the survey online through our social media channels and website. This resulted in responses from across the UK

2. Stakeholder interviews. Questions were based on key themes from the findings. This enabled us to delve deeper into some of the issues and trends the quantitative evidence had highlighted.

As part of the process we also established the Secondary Breast Cancer Advisory Committee with healthcare professionals and patients from England, Scotland and Wales. This was given the task of discussing and interpreting the key themes of the research and agreeing practical solutions to some of the problems highlighted by the data.

Data collection report

It has been mandatory for Hospital Trusts in England to record the number of people diagnosed with secondary breast cancer since January 2013. However, to date no data have been published. The 'Who's counting' campaign recorded the number of Trusts which were complying with current guidance and aimed to identify the barriers preventing routine collection and publication of data on secondary breast cancer. As part of this:

- Chief Executives of acute and specialist NHS Hospital Trusts in England were contacted via members of our Campaigns Network. Non-cancer specialist Trusts and those without breast cancer services were not contacted
- where responses were not received, campaigners were invited to ask their local MP to contact the Trust on their behalf
- where responses were still not received Freedom of Information (FOI) requests were submitted
- in total 125 Hospital Trusts (93%) responded to our request for information

We did not contact Health Boards and Trusts in Scotland or Wales as data collection on the number of people diagnosed with secondary breast cancer is not currently mandatory there¹².

Nursing care report

We wanted to understand nursing provision across the UK and the value and impact of different approaches from a range of perspectives.

Qualitative and quantitative data about service delivery models and benefits of the clinical nurse specialist (CNS) role were gathered from clinical staff, patients and family members.

A survey was sent to all acute NHS Trusts and Health Boards with breast care services in England, Scotland and Wales. This explored the type of specialist nursing provision available, the number of CNSs for patients with secondary breast cancer and the perceived benefits of having a CNS. The survey was completed by 100% of Trusts and Health Boards in Scotland and Wales and 99% of Trusts in England.

In addition, in-depth interviews were carried out with staff and patients in eight different hospital sites in England, Scotland and Wales.

Findings and recommendations

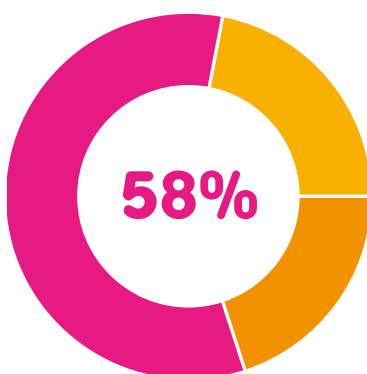
Diagnosis

Our research shows that people can experience delays in diagnosis of secondary breast cancer which can prevent timely access to vital treatment and care.

While these delays may not lead to a different clinical outcome for the patient, it is important that patients with secondary breast cancer are diagnosed quickly so that they receive the treatment and care they need to live well, for as long as possible.

We found that the signs and symptoms of secondary breast cancer were not recognised by a majority of patients¹³.

'I never thought for one minute it was cancer... I should have probably known it could come back in your bones.'



Only **22%** were aware of the possible signs and symptoms of secondary breast cancer. **20%** thought they knew, but didn't recognise the correct signs and symptoms. **58%** did not know at all.

When it came to how people were diagnosed, we found that:

- a fifth (21%) of respondents who had had a previous primary breast cancer diagnosis were initially treated for another condition by their GP, leading to a delay in diagnosis
- 8% were seen as an emergency or A&E patient
- just one in five (20%) contacted their breast care team because of their concerns. This may indicate a large number of respondents did not recognise symptoms or were unaware that they could have secondary breast cancer.

These delays are further exacerbated by evidence which suggests that people with secondary breast cancer feel their concerns are not taken seriously. Almost a third of respondents (31%) told us that they felt that healthcare professionals didn't listen to their concerns about having secondary breast cancer.

Recommendations

More needs to be done to ensure that the signs and symptoms of secondary breast cancer are recognised by healthcare professionals and people who have had primary breast cancer. Breast Cancer Care recommends that:

- All patients should be provided with information on the signs and symptoms of secondary breast cancer when finishing their hospital-based treatment for primary breast cancer. This should include a referral to a breast cancer specific health and wellbeing event, such as Breast Cancer Care's Moving Forward course, to raise awareness of these issues
- To support GPs to identify potential cases of secondary breast cancer at the earliest stage possible, common symptoms of the disease should be flagged on patients' records when there is a previous diagnosis of primary breast cancer
- NICE and the Scottish Intercollegiate Guidelines Network (SIGN) should update guidance for healthcare professionals on recognising the signs and symptoms of secondary breast cancer, and on informing patients of what to look out for following treatment for primary breast cancer.

Data collection: 'Who's counting?'

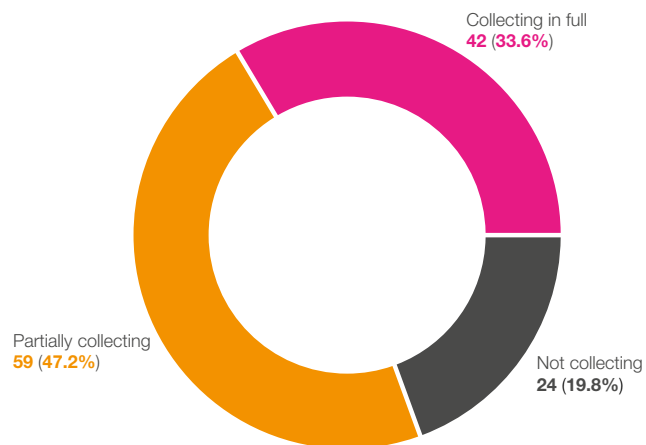
Our research shows that less than a third of Hospital Trusts in England are collecting data in full on their patients with secondary breast cancer¹⁴.

This is despite the fact that it has been compulsory for NHS Trusts in England to record the number of people diagnosed with secondary breast cancer since January 2013.

This collection should take place within the Hospital Trust, ideally through a MDT meeting, and be submitted to the Cancer Outcomes and Services Dataset (COSD). However, no data on this have been published to date.

Of the 134 Hospital Trusts contacted as part of the 'Who's counting?' campaign, 125 (93%) responded. This allowed us to capture a comprehensive picture of data collection across England.

We found that:



Only a **third of Trusts** were collecting data in full, and submitting it to the COSD. Just under half (**47.2%**) of Trusts were partially collecting data. Almost **20%** were not collecting data at all.

We were disappointed, but not surprised, to discover that not every Hospital Trust in England is collecting data on secondary breast cancer.

Without data on diagnosis and treatment of secondary breast cancer, Trusts have no real idea how many people are being diagnosed each year or how many people are living with the disease in their local area. They are therefore unable 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 this lack of data on the disease.

We identified a number of reasons why full compliance has not been achieved in so many Hospital Trusts. These included:

- **a lack of awareness that data have to be collected:** despite the fact it has been mandated for over four years, some Trusts are unaware of the data that they need to collect or how this data should be collected
- **a lack of available resources to support collection:** limited resources mean attempts to set up and maintain processes for routine data collection can be side-lined, especially where nurses are expected to collect data on top of their agreed role
- **confusion over the definition of secondary breast cancer:** some debate exists among clinicians over the definition of metastatic breast cancer, particularly in relation to a breast cancer recurrence. This is exacerbated by

confusing definitions within the COSD whereby recurrences and secondary breast cancer fall under the same heading¹⁵

- **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 apparent where Trusts did not have either a dedicated CNS for secondary breast cancer or an MDT meeting for patients with secondary breast cancer.

Recurrence versus secondary breast cancer

Our research suggests there is often confusion surrounding the difference between secondary breast cancer and recurrence of breast cancer.

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:** 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.

In contrast, Hospital Trusts that were collecting data in full appeared to have:

- **infrastructure in place to collect data:** this includes anything from an administrative support team to a cancer management team responsible for collecting data
- **a dedicated secondary breast cancer MDT:** a meeting where patients with secondary breast cancer are discussed represents one of the most obvious opportunities for data on these patients to be collected and collated
- **buy-in and involvement from relevant staff:** this should include consultants, cancer managers, and MDT coordinators.

Example of best practice: Maidstone and Tunbridge Wells NHS Trust

Data on people diagnosed with breast cancer at the Trust is collected on two databases. One is coordinated by the secondary breast cancer oncology team, using an in-house system, which collects key information including date and how they present with the diagnosis, for example in crisis through A&E or through GP follow up, site(s) of disease at presentation, treatments, pathology of disease and referrals as well as discussion of outcomes at Metastatic MDT meetings.

The system 'InfoFlex' is also used to feed into the Trust's submissions to the COSD, led by the MDT coordinator. There is a dedicated weekly Metastatic Breast MDT meeting. This supports peer discussion and review for those patients' undergoing radiological assessment as well as complex case review. The data have been used to highlight that patients treated within the Trust are living longer with their secondary breast cancer diagnosis, and that questions around resources within primary and secondary services will need to be addressed to meet the demands on patient care as a result.

Furthermore, the information was pivotal to secure external funding for a new Cancer Support Worker post to free up more clinical time of the Nurse Clinician currently in post at the Trust, by predominantly removing the administrative work burden.

Recommendations

It is imperative that robust data on secondary breast cancer is collected and reported. Breast Cancer Care recommends:

- Public Health England should publish the secondary breast cancer data submitted to the Cancer Outcomes and Services Dataset (COSD) so it is available for commissioners, healthcare providers, charities, patients and others. Public Health England should also provide clearer guidance on what level of data is required by Hospital Trusts in England to help improve data collection
- NHS England should urgently address how it will implement recommendations in the Cancer Strategy for England on the collection of data on secondary cancers
- As part of the Welsh Government's review on the data collection of metastatic patients, data should be specifically coded for metastatic patients and must not be 'grouped' with recurrence. This should be implemented through the introduction of the single cancer dataset
- The Scottish Cancer Registry updates the estimated number of patients with secondary breast cancer on an annual basis.

Support and impact

Our research shows that although people living with secondary breast cancer are greatly affected by the disease, they are often not getting the care and support they need to live well. Our research points to a number of shortcomings.

Firstly, the information needs of patients are not being met. The data suggests that the longer a person lives with secondary breast cancer, the less support they receive. When asked when they were given information, respondents to our survey told us that:

- 55% were given information about secondary breast cancer at diagnosis
- 41% during their treatment
- 16% as their cancer changed
- 20% as their treatment changed
- 16% were not given information at any point during their treatment.

Secondly, patients are not being consistently signposted or referred to available services. This means they are not benefiting from often free services that could improve their quality of life. We found that:

- less than a third were made aware of palliative care services
- only 36% were made aware of counselling or psychotherapy
- less than half were made aware of local support groups or opportunities to speak to other people with secondary breast cancer.

Of respondents who had accessed services we found that only 6% of people had accessed pain management clinics. This is despite the fact that 90% of people with secondary breast cancer have reported that they experience physical pain¹⁶. Furthermore, only 25% had used counselling or psychiatric services, despite the obvious emotional strain of living with an incurable life-limiting disease.

A diagnosis of secondary breast cancer is life changing. To gain a better insight into the broad impact of secondary breast cancer we asked respondents about side effects, finance, employment, and relationships with friends and family. The data shows people affected by secondary breast cancer are having particular difficulty accessing financial support and support for carers.

Nearly three quarters of respondents said that secondary breast cancer had a financial impact on them.

‘We lost quite a lot of money through me not working, and the extra costs involved. In transporting me, feeding me, clothing me, keeping the heating on because it was over winter.’

72% of respondents indicated that their friend or family member had not been offered support.

‘I don’t think a lot is told about how it affects people’s personal relationships. Cancer can break or make a marriage and this issue never gets discussed.’

Finally, our research shows that care can feel disjointed because of the large number of healthcare professionals involved in the support and treatment of patients.

Almost a fifth (19%) did not feel that all the healthcare professionals they came into contact with had a good understanding of them and their condition.

Less than a third (31%) said that all the different people caring for them always worked well together to give them the best possible treatment.

‘Sometimes I feel as if I’m falling through the medical cracks as no one seems to be prepared to just take responsibility for coordinating appointments.’

As treatments improve, people with secondary breast cancer will live longer. It is vital that patients are given the right information, are provided with adequate support and signposted to available services. This is both for the benefit of the patient and to prevent later, more costly interventions which would place further strain on the NHS.



Recommendations

A lack of support in dealing with the wide-ranging impact of secondary breast cancer has a deep impact on the lived experience of people with the disease, on people's trust in the healthcare system and their healthcare professionals, and on their emotional health and wellbeing. Breast Cancer Care recommends:

- Dedicated MDTs, or specific sections of existing MDTs, should routinely discuss patients with secondary breast cancer to help improve the care and support received by these patients
- The Recovery Package¹⁷ should be adapted to meet the unique needs of patients with secondary breast cancer and should include:
 - Referral to specific secondary breast cancer support services such as Breast Cancer Care's Living with Secondary Breast Cancer service
 - A bespoke Holistic Needs Assessment (HNA) at the point of diagnosis and as treatment changes, and care planning for secondary breast cancer that considers palliative care needs
 - A Treatment Summary and Cancer Care Review which meets the specific needs of patients with secondary breast cancer and improves communication between secondary, primary, and palliative care, as well as patients.

Nursing care

Our research shows that the current availability of specialist nursing to support people with secondary breast cancer is well below the level of need.

There is also a marked disparity between the level of specialist nursing support for people with primary breast cancer compared to people who have a secondary diagnosis despite the latter often having very complex emotional and supportive care needs.

While the role of CNS doesn't have a clear, unified UK-wide definition¹⁸, the benefits of the specialist nurse are well documented.

The National Cancer Patient Experience Survey in England shows that patients who have been allocated a CNS are more positive about their

experience of care and the CNS is viewed as playing a valuable role in decision making and as a trusted source of information¹⁹. Likewise the Welsh Cancer Patient Experience Survey 2016 reported that patients with a named CNS 'gave more positive answers than those patients who did not have one.'²⁰ This is also reflected in the Scottish Cancer Patient Experience Survey 2015²¹.

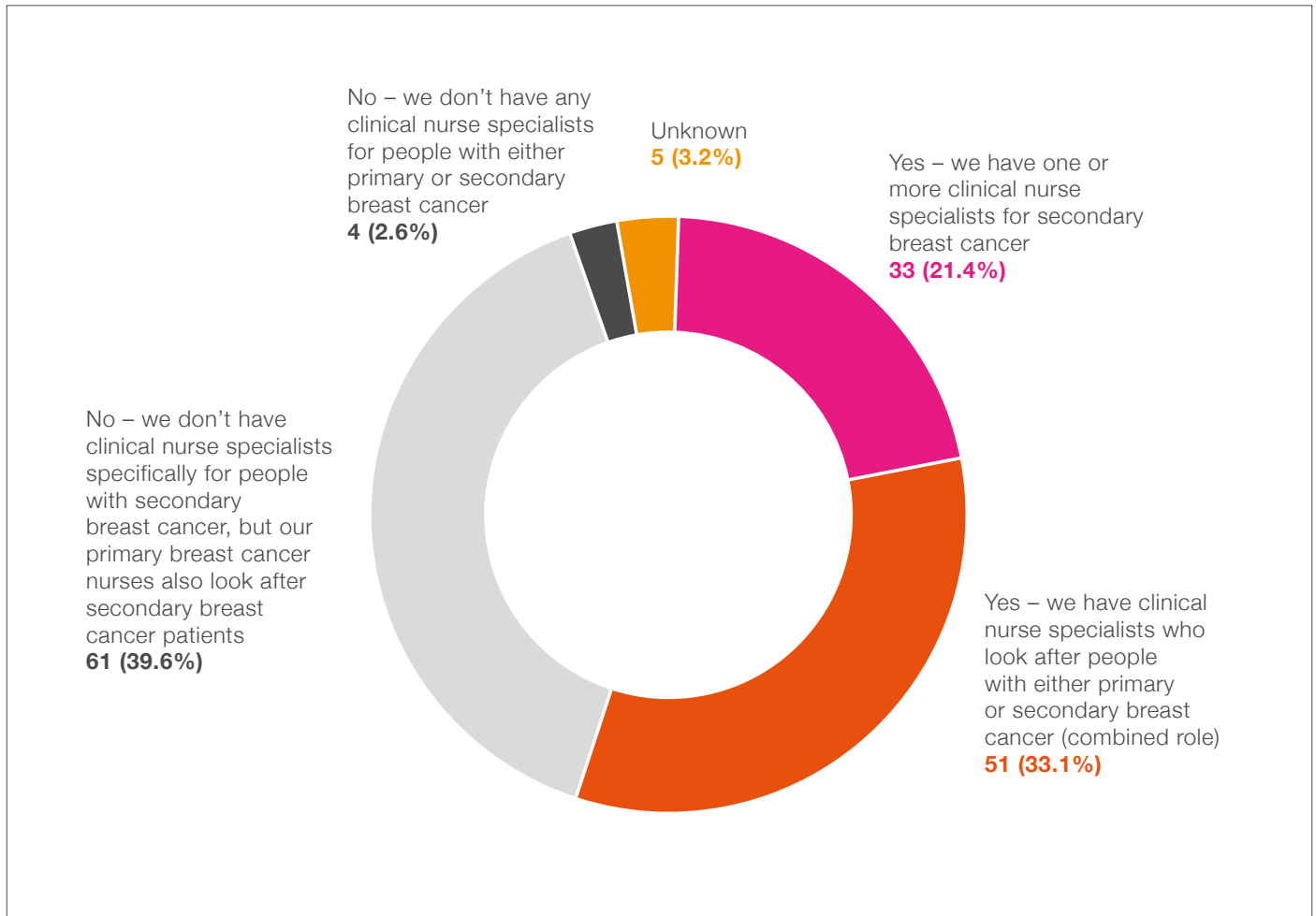
Our research supports these findings and provides additional insight into the value of having a CNS for patients with secondary breast cancer. Around two-thirds of staff who responded to our survey identified the main benefits of the role as:

- supporting patients to make decisions relating to their treatment and care (66%)
- giving patients the information they need to distinguish potential disease progression and side effects of treatment (63%)
- supporting patients to access symptom control to maximise quality of life (62%).

Interviews with staff also highlighted the vital role the CNS plays in the wider multi-disciplinary team, supporting other healthcare professionals and acting as a key source of advice, information and support for patients. Staff we spoke to felt that the CNS was often best placed to carry out a truly holistic needs assessment with people who have very complex medical and non-medical needs.

The CNS therefore represents an essential central component to drive up standards, be this related to the collection of data through MDTs or the provision of essential and complex support.

Despite the benefits, the support of a CNS is not available for everybody. Our research on the coverage of specialist nursing provision for secondary breast cancer in England, Scotland and Wales shows that 42% of Hospital Trusts and Health Boards do not provide dedicated, specialist nursing care for people with secondary breast cancer. What is more, three-quarters (76%) of NHS Trusts and Health Boards across the UK said themselves that there is not enough specialist nursing care for people with incurable secondary breast cancer²².



These findings are in stark contrast to the level of specialist nursing provision for people with primary breast cancer. According to the National Cancer Patient Experience Survey in England 2015, 95% of patients with primary breast cancer were given the name of a CNS who would support them through their treatment. Data on non-primary and patients with secondary breast cancer is not currently available from existing patient experience analyses for Scotland or Wales.

Recommendations

It is clear from our findings that the current provision of specialist nursing for people with secondary breast cancer in England, Scotland and Wales is not enough, and that there is a great disparity between this provision and the care provided to people with primary breast cancer. Breast Cancer Care recommends that:

- All patients diagnosed with secondary breast cancer should have access to, and support from, a designated Clinical Nurse Specialist (CNS) with appropriate skills, knowledge and experience of secondary breast cancer, and specific time and resource to support these patients²³.

Conclusion

Our research paints a worrying picture. People living with secondary breast cancer across the UK are greatly affected by the disease, but they are often not getting the care and support they need to live as well as possible for as long as possible.

Poor experiences, which have a profound impact on a patient's quality of life, are apparent from diagnosis, through treatment and at the end of life. They are fuelled by a lack of support, through inadequate provision of high-quality information at the right time, limited access to the wide range of appropriate support services and variable access to specialist nursing care.

These failings are only exacerbated by a lack of data relating to the number of people living with secondary breast cancer. To ensure that the right services and healthcare staff are in place, the collection and publication of data on the number of people diagnosed with secondary breast cancer is critical.

If we are to improve the lives of people living with secondary breast cancer and achieve world-class cancer outcomes, it is imperative that rapid improvements are made in the areas we have highlighted. We have outlined a series of practical recommendations which, with the support of NHS bodies, governments and policy-makers, would help to improve the care and support for patients living with incurable secondary breast cancer.



Summary of recommendations

Breast Cancer Care wants all patients with secondary breast cancer to receive the best possible care and support. For this to happen, the English, Scottish and Welsh Governments must urgently implement the secondary cancer specific recommendations in their respective cancer strategies.

Diagnosis

There is more work needed to ensure that the signs and symptoms of secondary breast cancer are recognised by healthcare professionals and people who have had primary breast cancer. Recognising the signs and symptoms of secondary breast cancer can lead to an earlier diagnosis, with a view to lengthening periods of progression-free survival and improving quality of life. A fifth of people who had a previous primary breast cancer diagnosis were incorrectly treated for another condition by their GP before their secondary breast cancer was diagnosed. Breast Cancer Care recommends:

- All patients should be provided with information on the signs and symptoms of secondary breast cancer when finishing their hospital-based treatment for primary breast cancer. This should include a referral to a breast cancer specific health and wellbeing event, such as Breast Cancer Care's Moving Forward course, to raise awareness of these issues
- To support GPs to identify potential cases of secondary breast cancer at the earliest stage possible, common symptoms of the disease should be flagged on patients' records when there is a previous diagnosis of primary breast cancer
- NICE and SIGN should update guidance for healthcare professionals on recognising the signs and symptoms of secondary breast cancer, and on informing patients of what to look out for following treatment for primary breast cancer ²⁴.

Data collection

Despite secondary breast cancer data collection being mandated in England in 2013, no such figures have been published on the number of people diagnosed with the disease each year. This lack of data makes it difficult for services to be planned to meet the needs of those living with the disease. The secondary cancer specific

recommendations in the Cancer Strategy for England will help improve care for people living with secondary breast cancer, but progress on implementing these has been slow. Action is also needed in Scotland and Wales. Breast Cancer Care recommends:

- Public Health England should publish the secondary breast cancer data submitted to the Cancer Outcomes and Services Dataset (COSD) so it is available for commissioners, healthcare providers, charities, patients and others. Public Health England should also provide clearer guidance on what level of data is required by Hospital Trusts in England to help improve data collection
- NHS England should urgently address how it will implement recommendations in the Cancer Strategy for England on the collection of data on secondary cancers
- As part of the Welsh Government's review on the data collection of metastatic patients, data should be specifically coded for metastatic patients and must not be 'grouped' with recurrence. This should be implemented through the introduction of the single cancer dataset
- The Scottish Cancer Registry updates the estimated number of patients with secondary breast cancer on an annual basis.

Support and impact

While NICE's Quality Standards on Breast Cancer states that MDTs play a vital role in improving the health outcomes of those with secondary breast cancer, we know that patients with secondary breast cancer are often not discussed at MDTs. The Recovery Package, which is currently being rolled out in England and Wales, has also been shown to greatly improve the outcomes of care for primary cancer patients. Breast Cancer Care recommends:

- Dedicated MDTs, or specific sections of existing MDTs, should routinely discuss patients with secondary breast cancer to help improve the care and support received by these patients
- The Recovery Package should be adapted to meet the unique needs of patients with secondary breast cancer and should include:
 - Referral to specific secondary breast cancer support services such as Breast Cancer Care's Living with Secondary Breast Cancer service
 - A bespoke Holistic Needs Assessment (HNA) at the point of diagnosis and as treatment changes and care planning for secondary breast cancer that considers palliative care needs

- A Treatment Summary and Cancer Care Review which meets the specific needs of patients with secondary breast cancer and improves communication between secondary, primary, and palliative care, as well as patients.
- All patients diagnosed with secondary breast cancer should have access to, and support from, a designated CNS with appropriate skills, knowledge and experience of secondary breast cancer, and specific time and resource to support these patients.

Nursing care

The English, Scottish and Welsh Cancer Patient Experience Surveys show that the support of a CNS is key to a person having a positive experience of care. However, three quarters of NHS Trusts and Health Boards told us they do not have enough specialist nursing care for people with secondary breast cancer. Breast Cancer Care recommends:



References and notes

- 1 Data collection is not currently mandatory in Scotland or Wales
- 2 Cancer Research UK, numbers from 2014, only invasive breast cancer (doesn't include DCIS) <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer/incidence-invasive#heading-Zero>
- 3 Breast Cancer Care, Secondary breast cancer taskforce, improving the care of people with metastatic breast cancer, 2008
- 4 Independent Cancer Taskforce, Achieving World Class Outcomes: A Cancer Strategy for England 2015-2020, 2015
- 5 NHS England, Achieving World Class Outcomes, Taking the Cancer Strategy Forward, May 2016
- 6 NICE, CG81: Advanced Breast Cancer: Diagnosis and Treatment, July 2014
- 7 NICE, CG80: Early and Locally Advanced Breast Cancer, March 2017
- 8 NICE, NG12: Suspected Cancer: recognition and referral, June 2015
- 9 Department of Health, Breast Cancer: Written question – 32369, April 2016
- 10 Wales Cancer Network, Cancer Delivery Plan for Wales 2016-2020, November 2016
- 11 The Scottish Government, Beating Cancer: Ambition and Action, March 2016
- 12 In 2015 Breast Cancer Care Scotland worked with the Scottish Cancer Registry to obtain the approximate number of people living with secondary breast cancer in Scotland, which was estimated at 4,090 people in 2013
- 13 The symptoms of secondary breast cancer can be vague. However, new and persistent symptoms with no obvious cause should be reported to the GP or specialist team. Symptoms include; persistent pain in bones which doesn't improve with pain relief, unexplained weight and appetite loss; nausea; swelling or discomfort under the ribs; feeling constantly tired; a dry cough; ongoing headaches and altered vision or speech
- 14 Health Boards and Trusts in Scotland or Wales weren't contacted as data collection on the number of people diagnosed with secondary breast cancer is not mandatory there
- 15 An updated version of the COSD (v.8) will be introduced in April 2018. It will include a new 'Non-primary pathway' to differentiate between primary cancer and other stages of cancer and the ability to record the recurrence or metastatic type and metastatic site or sites
- 16 Breast Cancer Care, Share your Experiences Survey. Survey was completed by 204 patients with secondary breast cancer from 19/08/2014 to 22/09/201411

- 17 The Recovery Package is a series of key interventions which, when delivered together, can greatly improve outcomes for people living with and beyond cancer. It relates specifically to England and Wales. In Scotland the Transforming Care After Treatment (TCAT) programme, a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities, is supporting a redesign of care following active treatment of cancer
- 18 Breast Cancer Care uses the following definition: “Clinical nurse specialist is a nurse working in either the hospital or community setting with the job title Clinical Nurse Specialist, and who holds specialist expertise in either primary or secondary breast cancer. This role is usually graded a band 7. It is important to recognise that there remains variation in how job titles are used in practice
- 19 Quality Health, National Cancer Patient Experience Survey, 2015
- 20 Welsh Government, Wales Cancer Patient Experience Survey National Report, 2017
- 21 NHS Scotland, Scottish Cancer Patient Experience Survey 2015/16, 2016
- 22 In Scotland and Wales, the picture is more positive, with 33% and 60% of Health Boards respectively reporting that there is not enough specialist nursing care for people with incurable secondary breast cancer
- 23 Whilst there are commitments to ensuring access to CNSs across the UK, urgent action is needed to turn this into a reality
- 24 Current guidance includes:
 - SIGN, Scottish Referral Guidelines for Suspected Cancer, 2015
 - NICE, NG12: Suspected Cancer Guideline recognition and referral, 2017



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.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **[breastcancercare.org.uk](https://www.breastcancercare.org.uk)**

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