

**Secondary.
Not second rate.**

**breast
cancer
care**

**Secondary breast cancer
Part one: diagnosis
July 2016**



ONLY 8%

expected it to be
secondary breast cancer

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

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Section 1: Introduction

For many years, Breast Cancer Care has led the way in driving up improvements and care for those living with and affected by breast cancer, including secondary breast cancer.

Because of a dearth of evidence on patient experience and need, and as part of our ongoing focus on secondary breast cancer, we set about revisiting the landscape for those living with the disease across England, Scotland and Wales. We wanted new and up-to-date insight and intelligence to help identify ways to improve the often inadequate care and support people with secondary breast cancer receive. Not only is this information invaluable for Breast Cancer

Care's ongoing campaigning and influencing in this area, but we hope that breast care teams, commissioners and providers will use the data we have gathered to plan for, and respond to, the needs of the patients they care for and treat.

This report marks the first in a series looking at what it's like to live with secondary breast cancer in England, Scotland and Wales today. Our first report focuses on diagnosis and the support and information people need. Future reports will be published in the coming months examining secondary breast cancer patients' experiences of treatment and care, data on the numbers of people diagnosed with the disease, and the wider impact of living with secondary breast cancer.



Section 2: Context

What is secondary breast cancer and why are we focusing on it?

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. It can be treated and median survival is 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. There are an estimated 36,000 people living with secondary breast cancer in the UK and each year around 11,600 people die from the disease.

Breast Cancer Care offers comprehensive and unique support to people 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, 35 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 our Ask Our Nurses email service provide information and support to those affected by secondary breast cancer with the opportunity to get support and information, from diagnosis through to treatment. 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, 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.

Making the case for change in secondary breast cancer

In 2006, Breast Cancer Care set up and coordinated the Secondary Breast Cancer Taskforce. A two-year initiative, the Taskforce was established in recognition that people with secondary breast cancer were not receiving the best possible standard of care. A national coalition of healthcare professionals, charities, policy makers and people with secondary breast cancer, the Taskforce identified gaps in the treatment, support and care of people living with secondary breast cancer, through a series of meetings, a survey, other research and expert consensus.

The Taskforce identified the following gaps in meeting the needs of secondary breast cancer patients.

- People with secondary breast cancer were far less likely to have a clinical nurse specialist, who can help co-ordinate care and provide emotional support, as part of their care and treatment, in direct contrast to the experience of many primary breast cancer patients.
- Multi-disciplinary teams (MDTs) were not discussing secondary breast cancer patients routinely or consistently.
- The information needs of secondary breast cancer patients were not being met.
- The psychosocial needs of patients were not being assessed at diagnosis of secondary breast cancer or at key points thereafter.
- A lack of prompt and timely access to a specialist palliative care team.

However, since the Taskforce findings were published over eight years ago¹, and despite commitments made by governments to improve this situation, little has changed and problems with inadequate care and treatment still persist.

Information garnered from those who use Breast Cancer Care's services highlights that there are still significant gaps: access to a clinical nurse specialist is variable; and people are unaware of the range of services a palliative care team offers, often associating palliative care only with the end of life and not with the management of pain and other symptoms. Information is often not provided at key times: at diagnosis; as treatment changes; or as the disease progresses. Much of this means that patients are not getting the support to live with the pain and side effects of their diagnosis and treatment, nor are they, or their loved ones, getting the emotional support they need.

The National Cancer Patient Experience Surveys (CPES) across England, Scotland and Wales, as a measurement tool, are helping to drive improvements in cancer care². While these surveys are effective in gaining a national understanding of patient experience and need on a wide range of different cancers, to date they have not allowed us to draw conclusions about the specific needs and experiences of secondary breast cancer patients³. The wording on 'type of diagnosis' precludes easy identification of these patients. Consequently, making national improvements in secondary breast cancer care, as a result of this limited intelligence, is difficult and non-specific.

Furthermore, we still don't have accurate, up-to-date figures on the number of people diagnosed or living with secondary breast cancer today. In January 2013 it became mandatory for data to be collected by NHS hospital trusts in England on the number of people diagnosed with secondary breast cancer. 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 with secondary breast cancer in 2013. In Wales, there is a commitment to collect data but little progress has been made and there is still no national 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 to plan for and implement services that really meet the needs of those with secondary breast cancer. Without this intelligence and understanding we do not have a full picture of the effectiveness of treatments for primary breast cancer; at a time when NHS budgets are increasingly under

pressure, this information would help inform decisions about which treatments should be funded.

These 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 to the care that is greatly valued by people treated for primary breast cancer.

Reviewing the picture today

It is therefore timely and important that Breast Cancer Care has reviewed the picture of secondary breast cancer across England, Scotland and Wales as it is today. Our survey of patient experience and need is one of the largest of its kind focussed on this group.

The key aims for our survey on patient experience and need were:

- to ascertain what the current experiences and needs of people living with secondary breast cancer are in accessing care and treatment from statutory and non-statutory providers
- to see what/how much had changed since the Taskforce findings in 2008
- to identify gaps in care, treatment, support and information
- to explore ways Breast Cancer Care may increase access to its services for people with secondary breast cancer, using the new information and evidence the survey generates.

The results are startling. From awareness of the possible signs and symptoms of secondary breast cancer, to diagnosis and the impact of secondary breast cancer on patients' families and everyday lives, it's clear little has changed and there is still much to be done.



Section 3: Methodology

Questionnaire design and development

The questionnaire was designed and developed towards the end of 2015 and in early 2016. This involved a detailed process of drafting, reviewing, testing and revising the questions. Breast Cancer Care worked closely with Quality Health on designing and agreeing the final questions set.

As part of the process, cognitive testing was carried out with volunteers who have secondary breast cancer. The volunteers completed the draft questionnaire and were then invited to share their answers to the questions, to comment on the wording, the response options, any omissions, and any comments on the layout and length of the survey. In total, 14 people were interviewed and we are immensely grateful for their time and input.

Identifying the sample

The respondents for this survey came from two sources.

Firstly, data that had been gathered as part of the National Cancer Patient Experience Survey (CPES) 2015 in England was used. Unfortunately, we were unable to use patient data from the Scottish CPES (2015/16) or the forthcoming Wales CPES (2016).

Every respondent to CPES has the option of agreeing to receive further questionnaires about their health. It is only these people who we approached with our survey.

On other occasions when follow-on surveys have been sent to CPES respondents, a unique identifier (ICD10 code) is used to identify the cohort of patients required. However, people with secondary breast cancer are not easily identified using this code. Therefore, we first extracted a sample which included all women with breast cancer (primary and secondary), and then applied rules to that data⁴ depending on how the women had answered specific questions in the survey. This way, we were able to identify women who either had a recurrence of their primary breast cancer or who had secondary breast cancer.

The total sample size was 1,000. It was expected that around half of those in the sample would not be eligible to complete the survey due to them having had a recurrence, not a diagnosis of

secondary breast cancer. There is more about this in the section 'Limitations of research'.

Secondly, Breast Cancer Care invited people with secondary breast cancer to take part in the survey online using a range of social media and other networks, including Facebook and Twitter, targeted email communications to people using our secondary breast cancer services and our campaigns community. This was particularly useful for inviting those from Scotland and Wales to take part.

Timescales and fieldwork

The fieldwork was undertaken between 7 March and 31 May 2016.

Online, we ran two bursts of activity: one to launch the survey and another, through Facebook location targeting, to further promote the survey in geographical areas with low engagement.

Additionally (and to date), six qualitative interviews were undertaken by telephone. We identified these participants from people who indicated they would be happy to take part in further research after completing the survey. The questions for the interviews were based on emerging key themes from the findings, enabling us to delve deeper into some of the issues and trends the quantitative evidence had highlighted. Some information gathered from the interviews is included here in the form of quotes; these are anonymised.

Response rate

A total of 430 people with secondary breast cancer responded to the postal survey, representing a 45% response rate⁵. In addition to this, 411 people completed the online survey, via Breast Cancer Care's online channels. A total of 841 responses were received.

Limitations of research

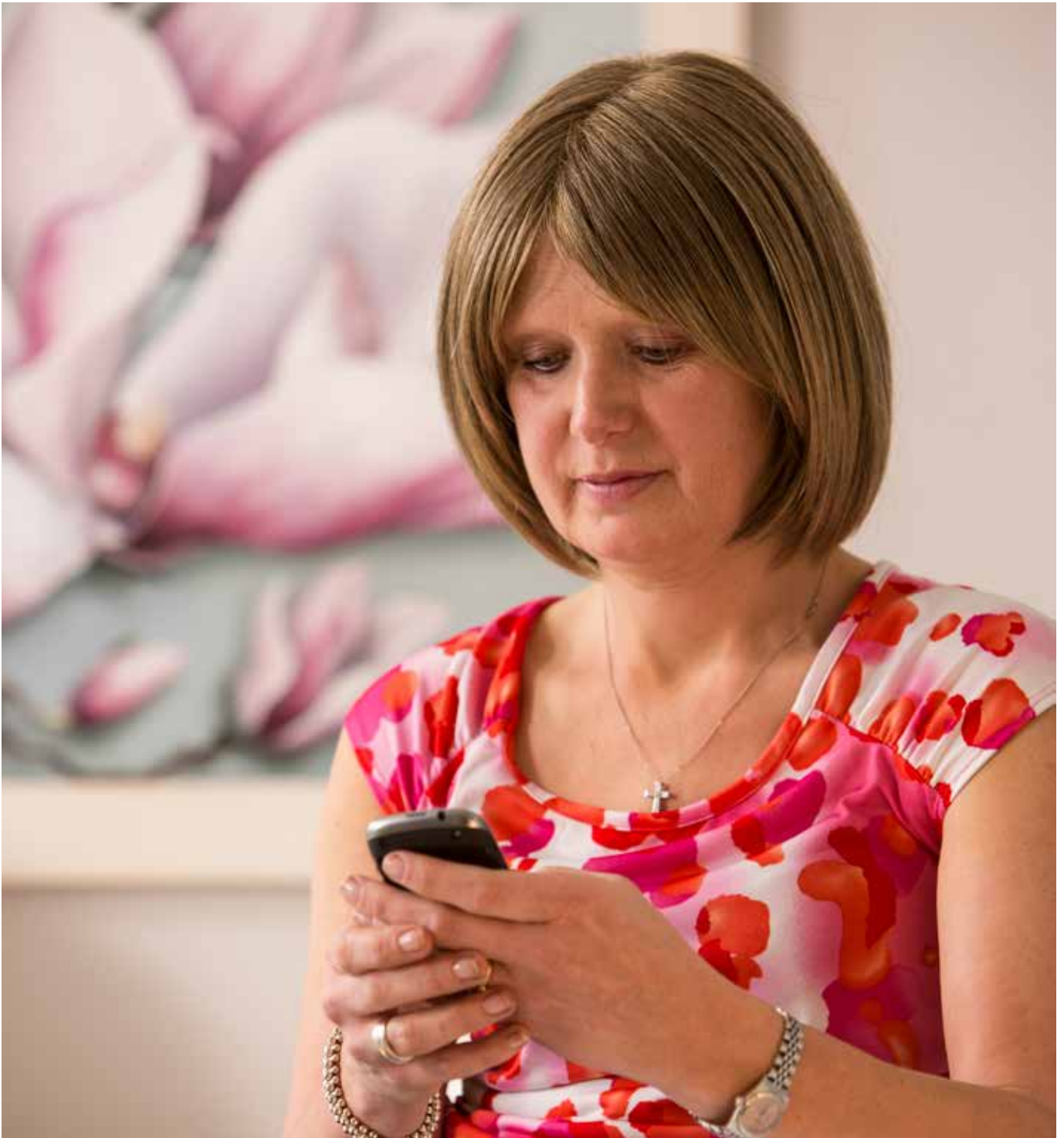
It's possible that those with particularly negative or positive experiences may have been more motivated to take part, in order to share their experiences.

However, the main limitation of our research was in the sampling of the data. As explained, drawing the sample from data taken from CPES in England made it difficult to target respondents in Scotland and Wales. To resolve this, we also replicated the survey online so that those with a diagnosis of

secondary breast cancer who had not received a copy of the postal survey and/or who lived in Scotland or Wales could participate.

As stated above, using the data gathered from CPES in England also made it difficult to separate those who had a diagnosis of recurrence from those with secondary breast cancer. Some people with a recurrence of breast cancer may have received the survey. As a caveat against this, an explanation of secondary breast cancer (and recurrence) was fully explained in the covering

letter that accompanied the postal questionnaire and another shorter explanation was also given on the front page of the questionnaire itself. Anyone who had not had a confirmed diagnosis of secondary breast cancer was asked to disregard the questionnaire. We also provided information on Breast Cancer Care's and Quality Health's telephone helplines for patients to call in case of any concern or if they were unsure whether they were eligible for the survey.



Section 4: Findings and recommendations

The survey was broken down into key sections relating to the pathway that many follow – this being:

- before diagnosis of secondary breast cancer and finding out what was wrong
- treatment and care
- support for people with secondary breast cancer
- the impact of living with the disease.

This report focuses on the first two sections of the survey: ‘before diagnosis’ and ‘finding out what was wrong’, also including questions on information and support provided at diagnosis.

Demographics

There was one male respondent to the survey, with all others (840) identifying themselves as female.

14% of respondents were aged between 25 and 44; 56% of respondents were aged between 45 and 64; 30% were aged over 65⁶. There were no respondents under the age of 25.

95% of respondents identified themselves as being white British; 2% white other, 1% as black/black British and 1% Asian.

72% of respondents had had a previous diagnosis of primary breast cancer; for 28% their diagnosis of secondary breast cancer was their first diagnosis (meaning that the breast cancer had already spread at the point of diagnosis).

Just under half (44%) had started treatment for secondary breast cancer between one and three years ago. 28% had started treatment within the last year, 16% between three and five years ago, and 12% had started treatment more than five years ago.

Before diagnosis

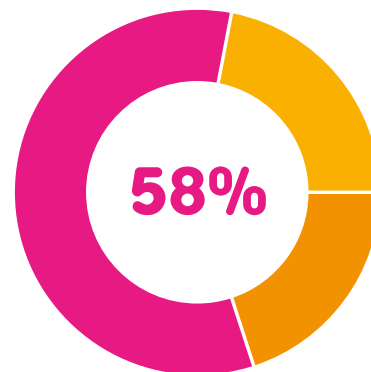
The questions in this section looked at respondents’ experience before their diagnosis, including whether they had previously received a diagnosis of primary breast cancer; whether they knew what the signs and symptoms of secondary breast cancer were; and whether they knew how to get back into hospital care.

Awareness of the possible signs and symptoms of secondary breast cancer

We understand the ongoing fear many women have of their breast cancer returning or spreading so we asked a number of questions about how aware people are of the possible signs and symptoms of secondary disease.

It’s difficult to list all the symptoms of secondary breast cancer and in addition many symptoms may be the same as those of other conditions. For example, aches and pains in the bones may be due to ageing or arthritis. Some symptoms, such as tiredness and loss of appetite, can also be normal side effects that many people experience as a consequence of cancer treatment. However, any symptoms that are new and persistent and have no obvious cause should be reported to the specialist team or GP. Examples include:

- pain in bones (especially proximal bones such as the back, hips or ribs) that doesn’t improve with pain relief, persists for more than one to two weeks and is often worse at night
- unexplained weight loss and a loss of appetite
- a constant feeling of nausea
- discomfort or swelling under the ribs or across the upper abdomen
- feeling constantly tired
- a dry cough or a feeling of breathlessness
- severe or ongoing headaches
- altered vision or speech.

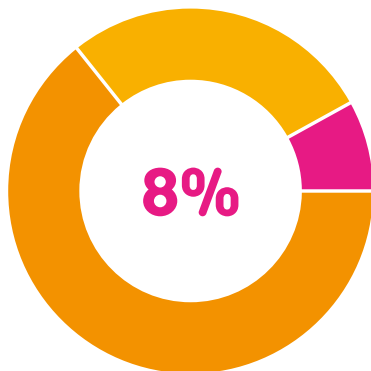


Only **22%** were aware of the possible signs and symptoms of secondary breast cancer. **20%** thought they knew, but didn’t recognise the correct signs and symptoms. **58%** did not know at all.

Knowledge of the signs and symptoms of secondary breast cancer is low, with less than a quarter of respondents (22%) knowing what to look for. When broken down by age, those in the older age bands (65+) were less likely to know the signs and symptoms than those aged 25–44 and 45–64.

'I never thought for one minute it was cancer. I just don't know why... I think because it seemed to be the bones area and obviously I should have probably known it could come back in your bones.'

In addition, most respondents did not think that they had secondary breast cancer before they were diagnosed. 64% said that they did not suspect it was secondary breast cancer, while only 8% said they fully expected their diagnosis. This may be expected for those respondents who had never had a previous diagnosis of breast cancer. However, even amongst those that had a previous diagnosis of primary breast cancer, over half (56%) did not think they had secondary breast cancer, indicating awareness of the disease is low.



Only **8%** expected it to be secondary breast cancer, **28%** suspected it might be secondary breast cancer while **64%** did not think it would be secondary breast cancer at all.

'...had no idea that my breast cancer could return as a secondary. I don't think this was ever explained to me.'

Finally, of those who had had a previous primary breast cancer diagnosis, only 40% were told how to get back into hospital care if they had any signs and symptoms of secondary breast cancer. 60% were not informed. The youngest age bands (25–44) reported being told how to get back into hospital care more often than their older counterparts.

Recommendations

It's clear from the findings that women need information when finishing their hospital-based treatment for primary breast cancer. More needs to be done to ensure that people are aware of the possible signs and symptoms of secondary breast cancer and how to get back into hospital care if they have a symptom or concern. While a prompt diagnosis may not lead to a different clinical outcome for the patient, it's important that people with secondary breast cancer are diagnosed quickly for a number of reasons including: commencing treatment with a view to lengthening periods of progression free survival; improving the patient's quality of life (including their emotional wellbeing); and reducing the chances of serious complications from the cancer such as spinal cord compression (when a spinal bone collapses putting pressure on the spinal cord).

Breast Cancer Care provides a number of free services which help to improve people's awareness of the signs and symptoms of secondary breast cancer.

A session on breast and body awareness after treatment, which includes the signs and symptoms of secondary breast cancer, forms a key component of our Moving Forward courses. Our **Moving Forward resource pack** and our publication **After breast cancer treatment: what now?** also include considerable information on both recurrence and secondary breast cancer. The lack of knowledge of the signs and symptoms of secondary breast cancer highlights a need for Moving Forward courses to be commissioned as part of the breast cancer pathway so that more people are better informed about the possible signs and symptoms of secondary disease.

For a significant number of respondents, their diagnosis of secondary breast cancer was their first breast cancer diagnosis. For 25–44 year olds, this figure was 39% compared with 22% of 65–84 year olds. Given the focus in recent years

on breast health awareness and early diagnosis to ensure good clinical outcomes, and bearing in mind that younger people especially will not be invited to participate in the national screening programmes, further investigation is needed into why people are still being diagnosed at such a late stage, and what steps might be taken to reduce this. Alongside this, Breast Cancer Care will continue to support the breast cancer prevention and awareness agenda, including national campaigns such as Be Clear on Cancer.

The National Institute for Health and Care Excellence (NICE) is currently in the process of updating their clinical guideline, Early and Locally Advanced Breast Cancer: Diagnosis and Treatment^{7, 8}. This guideline provides recommendations about the treatment and care of people diagnosed with primary and locally advanced breast cancer across England and Wales. Currently, the guideline states that patients treated for breast cancer should have an agreed, written care plan. This should include 'signs and symptoms to look for and seek advice on'. Breast Cancer Care is calling for the updated guideline to include clearer guidance on the importance of informing patients of possible signs and symptoms of a recurrence, and specifically, of secondary breast cancer.

In Scotland, the current Scottish Intercollegiate Guidelines Network (SIGN) clinical guideline, Treatment of Primary Breast Cancer⁹, recommends it may be helpful to 'Mention and discuss the possibility of recurrence and advise patients to report on specific symptoms.' Breast Cancer Care recommends that, similarly to NICE guidance, the SIGN guidance be updated to include clearer guidance on the specific signs and symptoms of secondary breast cancer.

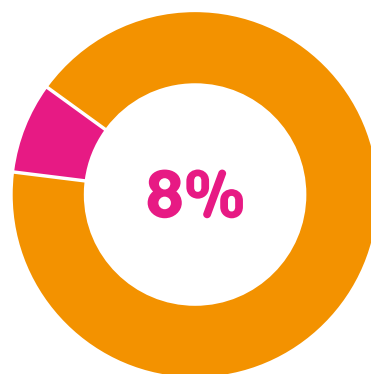
In England, alongside the update of the NICE guideline, the Cancer Strategy¹⁰ recommends (recommendation no.65) that NHS England should work to improve services for those living with and beyond cancer, including provision of information for those finishing treatment on: 'Potential markers of recurrence/secondary cancers and information on what to do in these circumstances' and a 'Key contact point for rapid re-entry if recurrence markers are experienced or if serious side effects become apparent'. Given our findings, this recommendation should be implemented as a matter of priority.

Routes to diagnosis

When it came to how people were diagnosed with secondary breast cancer, 21% of respondents who had had a previous primary breast cancer diagnosis were initially treated for another condition by their GP, thereby leading to a delay in their eventual diagnosis.

'I took [the letter] to my GP, who refused to do an MRI, because he said it wouldn't show anything anyway. He said everybody gets back ache, you're at the age where it's really common, you really just need to get on with it. So I went away, and it wasn't until it was almost 18 months after I'd first had back pain where I got to the stage that I could barely walk. And I was only 38, so you know, not of any age. You know, I wasn't in my 80s, which you might expect.'

While such a delay may not lead to a different clinical outcome for the patient, it's important that secondary breast cancer patients are diagnosed quickly so that they receive the treatment and care they need to live well, as soon as possible, for as long as possible. Furthermore, 8% were seen as an emergency/at A&E, suggesting that the signs and symptoms of secondary breast cancer were not recognised or reported promptly. Just one in five (20%) contacted their breast care team because of their concerns; it is unclear why this is so low but it could be due to the fact that many respondents were unaware that they could have secondary breast cancer.



When it came to the route of diagnosis for secondary breast cancer, 21% who had had a previous primary breast cancer diagnosis were treated for another condition by their GP. 8% were seen as an emergency/A&E patient. Just one in five (20%) contacted their breast care team because of their concerns.

'I think when someone has a history of primary breast cancer; you know that should be the first thing. But [the GP] assured me that the tests that he had done were conclusive, and we didn't need to do any more.'

For those respondents who had not had a previous diagnosis of primary breast cancer, a majority were referred by their GP; some were picked up at screening but 9% were treated by their GP for another condition and 9% were seen as an emergency/at A&E.

A key focus of governments and health bodies across England, Scotland and Wales is on the importance of early detection in order to improve survival rates. However, any patient diagnosed with secondary breast cancer as their first diagnosis, particularly those with an emergency presentation, is a sign of failure in efforts towards early diagnosis.

We asked respondents how long it was between them first thinking something might be wrong and first seeing a hospital doctor. 40% of respondents said this was within two weeks. However, for 20% of respondents this was more than eight weeks.

Having concerns taken seriously

Breast Cancer Care hears regularly from people with secondary breast cancer about how they feel that their concerns are not always taken seriously.

Our findings back up this anecdotal evidence; almost a third of respondents (31%) felt that healthcare professionals didn't listen to their concerns about having secondary breast cancer. 69% felt that healthcare professionals did listen to their concerns about having secondary breast cancer with the oldest age group being the most positive.

'I was made to feel like I was making a fuss.'

This mirrors CPES (2015) in England and is a general trend in other national survey programmes, where older patients tend to be more positive.

Recommendations

We recognise that GPs are under enormous time and resource pressure, and over the course of a year are unlikely to see many patients who have suspected secondary breast cancer. Symptoms, such as nausea and back pain, are vague and can be attributable to a number of causes not related to breast cancer. These factors can make it very difficult to correctly identify potential secondary breast cancer. However, it's vital that concerns about a possible sign or symptom are adequately investigated to either rule out or diagnose secondary breast cancer. GPs need to be supported to identify possible cases of secondary breast cancer, so they can feel confident in referring people on as appropriate.

Further work is needed to understand what would be most useful in providing this support. For those who have a previous primary diagnosis, potential solutions could include:

- a flagging system on patient records which reminds the GP to consider a person's previous breast cancer diagnosis
- use of a treatment summary which includes the opportunity for the specialist team to communicate symptoms that require referral back to them
- a guide to 'red flag' symptoms, such as back pain, to consider in conjunction with the flagging system (referenced above)
- resources for GPs provided by Breast Cancer Care
- direct entry back into the hospital/breast care team, without the need for a referral by a GP¹¹.

There is currently no national guidance for primary care professionals on recognition and referral of potential secondary breast cancer.

NICE's guideline, Suspected Cancer: Recognition and Referral (NG12), makes recommendations in this area, and is followed in England and Wales¹². The guideline was updated in 2015. However, it does not include guidance on recognising and referring potential secondary cancers. Breast Cancer Care believes that this was a missed opportunity, considering our findings. The Scottish Referral Guidelines for Suspected Cancers also do not include reference to recognising and referring potential secondary cancers.

Breast Cancer Care recommends that these guidelines are reviewed and updated, and information about recognising suspected secondary cancers is included¹³.

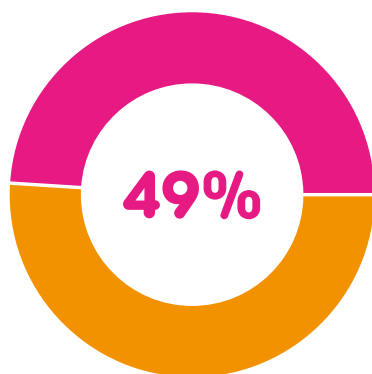
Further investigation is needed to determine the reasons behind delays in people being seen by a hospital doctor. The delay in being seen could occur at a number of points in the system, such as if a patient postpones talking to their GP or specialist team about their symptoms or the healthcare professional delays in referring on for tests. There may also be delays due to waiting times. Identifying where the delay occurs along this pathway would enable clearer next steps to be identified. In partnership with others, Breast Cancer Care will raise awareness of and explore the reasons behind these delays.

Finding out what was wrong

This section of the survey asked respondents what happened to them during the course of their diagnosis. For example, it asked questions on information they were given; signposting to and support from other services, including palliative care and pain management; whether they were told they could bring someone with them and how they were told.

Having support at diagnosis of secondary breast cancer

We asked whether respondents were advised to bring someone with them when they were diagnosed with secondary breast cancer. We know that the diagnosis process is varied for people with secondary breast cancer. Patients can be diagnosed in a number of different ways and settings, depending on the route of presentation, the site of spread, investigations and the speed of results. However, it's concerning that so many people are missing out on a crucial opportunity to have support at such a key stage. Almost half of respondents (49%) were not advised to bring someone with them, although older people were more likely to have been advised to do this than women aged 25–44.



Almost half (49%) were not advised that they could bring someone with them when they were diagnosed.

When compared to the overall score for all cancers covered in the National Cancer Patient Experience Surveys, it's clear that secondary breast cancer patients have a far worse experience of this. Across all cancers, almost 80% of people in England, 72% in Scotland and 70% in Wales are told they could bring someone with them, compared to just 51% for secondary breast cancer. Our findings are also in direct contrast to the experience of breast cancer patients overall (all stages). The 2015 CPES in England found that 83% of breast cancer patients were told they could bring someone with them when they were diagnosed. In Scotland's version of the survey, 75% of breast cancer patients (all stages) were told they could bring someone with them^{14 15}.

'I just went on my own. I don't think I was asked initially. When I was diagnosed with primary, yes I was advised to bring somebody with me. With the secondary, the initial secondary no, but subsequently I've always had somebody with me when it's been scan results.'

Understanding the diagnosis

59% of respondents were aware that secondary breast cancer was a life-limiting disease when they were told about their diagnosis. 21% thought it might be but weren't sure, while one in five didn't know that secondary breast cancer was life limiting. Younger women (aged 25–44) were more likely to be aware that it was a life-limiting disease than women aged 45–64 and 65+.

When asked if they understood the explanation they were given of what secondary breast cancer is, half of respondents (51%) said they completely understood the explanation. 7% did not understand the explanation, with the remaining respondents understanding some of the explanation given. Slightly at odds with the statement above, our findings showed that those in the older age group were slightly more likely to understand the explanation that was given about secondary breast cancer.

ONE IN FIVE

didn't know that secondary breast cancer was life limiting

The 2015 CPES in England found almost 78% of respondents with breast cancer completely understood the explanation of what was wrong with them¹⁶.

'I don't think they used the term secondary breast cancer. He just said you have tumours in your spine. And I said that means it's terminal doesn't it? And he said to me 'there's certainly nothing I can give you that will cure you', which you know, is a slightly different way of looking at it. So I did understand the implications of that, but not particularly because of anything they said at that particular point in time. I just had known from my primary and googling the various things that, you know, if it went elsewhere that it wasn't good.'

Recommendations

Breast Cancer Care wants every person affected by breast cancer to get the best treatment, information and support wherever they live. Understanding the diagnosis and other information at this initial stage plays a key part in this.

At diagnosis, healthcare professionals should check that the patient has understood the key information given to them, whether they have any additional questions, as well as who to contact with any queries after the appointment.

Breast Cancer Care's Secondary Breast Cancer Taskforce Report¹⁷ includes an information checklist, which was produced in collaboration with people living with secondary breast cancer. The checklist includes:

- diagnosis – where the cancer is
- possible effects of cancer in that part of the body/site
- treatment options
- prognosis – if the individual wants to know.

This checklist is still relevant, and should be used as a template for discussions between healthcare professionals and their patients.

Healthcare professionals can also signpost patients to Breast Cancer Care's information and support services. Our **Secondary Breast Cancer resource pack** includes information on what

secondary breast cancer is, treatment options and a glossary of frequently used terms. Our Helpline and Ask Our Nurses email service are available to provide additional support and information.

Having someone with them at the diagnosis appointment can help people to 'share the load' in remembering important details explained at the appointment, such as treatment options, as well as providing additional and vital emotional support. This is hugely important as we see from our findings that many respondents are not expecting a diagnosis of secondary breast cancer. As much as possible healthcare professionals should ensure that people are informed that they have the option of bringing someone with them to their appointment. This could be either in the appointment letter or during a prior discussion with the patient, if these opportunities arise.

Provision of information at diagnosis

The Secondary Breast Cancer Taskforce reported that patients were not given enough information at key points during their cancer journey¹⁸. This situation has not changed. Users of online forums and attendees at our face-to-face services regularly report this important gap in support and findings from our survey on patient experience and need also highlight this as a key issue.

We asked respondents what written information they were given when they were told they had secondary breast cancer. A range of information was given including information from the hospital where the patient was being treated and national charities such as Breast Cancer Care. However, almost a third of respondents (30%) said they were not given any additional information.

ALMOST A THIRD
said they were not given
any additional information

Nearly two-thirds of respondents (62%) said that they were given written information that they could completely understand, however, 38% were not able to understand either some or most of it. Those in the older age group (65+) were less likely to answer positively to this question. This contradicts slightly the findings that highlighted

this age group were more likely to understand the explanation given to them about their diagnosis. It is unclear as to why this is but it could be because older people can be less willing to criticise their doctors.

When compared to the overall score from CPES (2015) in England, secondary breast cancer patients report a worse experience; by comparison, 76% of all breast cancer patients reported being given written information that they could completely understand. Our findings are slightly more comparable in Scotland and Wales, where 61% of respondents with breast cancer in Scotland and 69% of respondents with breast cancer in Wales reported receiving information that was easy to understand¹⁹.

Respondents were asked if they were told about additional sources of information. There was a range of responses; being given the details of a clinical nurse specialist/breast care nurse/key worker was by far the most common response (59%). However, one in five (22%) were not told how to find additional information, suggesting that they were lacking information following their diagnosis of secondary breast cancer.

'Feels like I've been more proactively seeking information and support rather than it being freely offered.'

In addition to information, we also asked respondents what healthcare professionals they talked to when they were diagnosed, other than their oncologist; two-thirds (66%) said that they spoke to a clinical nurse specialist. However, almost one-quarter (23%) didn't speak to anyone other than their oncologist.

70% of respondents used online information to find further information about their diagnosis. Yet, only 20% of respondents reported being told to only look at trusted websites for online information.

'It really struck me how different it is being a secondary patient - with the primary diagnosis there was so much info and help on offer from both the hospital, charities and friends and family it was like a pink tsunami of support and the key message was "you can kick cancer's butt and we're rooting for you!"...With the secondary diagnosis it's been all hushed, sympathetic voices. I have felt very alone.'

Recommendations

A key recommendation from the Secondary Breast Cancer Taskforce Report in 2008²⁰ was that, at the point of diagnosis, every patient must be made aware of, or referred to, local and national support services specifically for secondary breast cancer. This recommendation is still relevant and necessary today. In addition to this, we would expect Breast Cancer Care's Helpline and website details to be shared with patients; an overwhelming majority of respondents (75%) said that our website was the most helpful when diagnosed. We also want Cancer Alliances being formed in England, The Wales Cancer Network and the regional cancer networks in Scotland to include service information for people with secondary breast cancer.

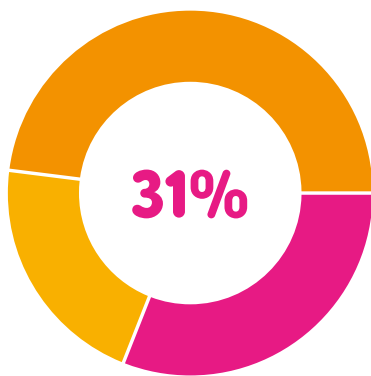
Breast Cancer Care is planning to increase the coverage of breast cancer information points in hospitals across England, Scotland and Wales. As we look to roll these out, we will also review the information available and, alongside our Helpline and services information, will include key Breast Cancer Care resources relevant to those with secondary disease, where appropriate. These could include our publications that explain follow up after treatment for primary breast cancer and the possibility (as well as the signs and symptoms) of recurrence and spread.

Breast Cancer Care's **Secondary Breast Cancer resource pack** is a highly valued and well used resource for people diagnosed and living with the disease. It includes information on what secondary breast cancer is, as well as living with secondary breast cancer, and where to go for further support. With our Nursing Network, and our Secondary Breast Cancer Nurses Forum, we will continue to encourage that, as people are diagnosed, they are provided with a copy of the resource pack, supporting them from diagnosis and beyond.

Awareness of, and support, with pain management and palliative care at diagnosis

When undertaking the survey, we asked questions about whether pain management and palliative care were discussed at diagnosis, knowing from those who use our services that prompt access to palliative care, including pain management, can be a significant issue.

Specifically, we asked respondents whether a healthcare professional discussed how to manage symptoms and pain when they were diagnosed. Just under half (48%) felt equipped to manage pain symptoms and pain; 21% did discuss symptom and pain management but felt they needed more information and support, while 31% said that they didn't discuss with any healthcare professional at diagnosis how to manage their symptoms or pain. Older people (aged 65+) were more likely to have answered this positively.



Less than half (48%) felt equipped to manage their symptoms and pain. 21% felt they needed more information, and 31% didn't discuss with any healthcare professional how to manage their symptoms and pain.

In addition, only one-third (33%) of respondents to our survey said that they were given information about palliative care services at diagnosis.

Recommendations

Palliative care offers much more than just pain management. Services play a crucial role in offering emotional and psychological support, as well as support for family members and carers, areas that patients feel are often neglected. The World Health Organisation defines palliative care as: 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.' Amongst other things

palliative care: 'provides relief from pain and other distressing symptoms; enhance[s] quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.'²¹

Breast Cancer Care's standards of care on secondary breast cancer²² highlight how: 'At the point of diagnosis, [people should] be made aware of the benefits of local palliative and supportive care services and the support they can offer.' It complements national strategies²³ on palliative care which, amongst other things, emphasise the importance of considering a palliative care approach from the point of diagnosis onwards. The NICE guideline for Advanced Breast Cancer²⁴ currently states, in line with policy initiatives across Scotland and Wales, that there should be an assessment of a patient's needs at diagnosis, during and after treatment, at relapse and when death is approaching. This assessment should cover physical as well as psychosocial and spiritual needs.

In line with our standards, NICE guidance and other national strategies, it is evident that people living with secondary breast cancer need prompt and timely access to expertise in palliative care. Patients must be referred as early as possible to a palliative care team, preferably at the point of diagnosis and, crucially, before some of the most debilitating symptoms take hold.

We know that there are barriers to prompt and timely access. Many palliative care services do not have sufficient resources to meet the needs of all who could benefit from their care, input or intervention. This means that they may need to prioritise care delivery to those with uncontrolled symptoms or in need of end of life care, making it difficult for specialist teams to refer some patients.

'I'm not at that stage. That's not something we even need to think about yet.'

Additionally, a lack of understanding, by both professionals, people with a terminal illness and families, of what palliative care seeks to achieve and its potential positive impact on quality of life, acts as an additional barrier, along with under-developed links between condition specialists and palliative care specialists in some areas²⁵.

Breast Cancer Care therefore still has a large role to play, in conjunction with palliative care specialists, to raise awareness about the range of services a palliative care team offers at the same time as breaking down the misunderstanding and stigma behind the term. If people with a secondary breast cancer diagnosis know about palliative care and what it offers, they are more likely to access the services they need, when they need them.

Our survey backs up findings which highlighted how people are not routinely being referred to palliative care services²⁶. Some of this might be

about a lack of awareness among healthcare professionals, but we also know that conversations about pain management and palliative care can be difficult to have when there is a misunderstanding of the term. As a result of this, training must be provided to oncologists, GPs and nurses so that they can have positive conversations with patients about palliative care, and the range of services that are offered.



Section 5: Conclusion

The findings on how, when, and where people are diagnosed with secondary breast cancer are concerning and it is clear that much more needs to be done.

Overall, they paint a worrying picture: people are unsure about the possible signs and symptoms of secondary breast cancer; many (including those with a previous diagnosis of primary breast cancer) are unsuspecting of the diagnosis that awaits them and are unaccompanied when their diagnosis is delivered. Some are unclear that secondary breast cancer is a life-limiting disease and are given little additional information or the option to speak to someone following their diagnosis.

Poor experiences prior to, and at, diagnosis can have a profound effect on people's trust in the healthcare system, their GPs, or their breast care team, as well as on their emotional health and wellbeing.

With the evidence we have uncovered, Breast Cancer Care will continue to work in partnership with governments and the NHS to address and improve the situation. If we want to support people to live well with cancer, including those with secondary breast cancer, then it is imperative that improvements are made rapidly, not only for those diagnosed, but also for those yet to be diagnosed.



References and notes

1. Breast Cancer Care (2008), Secondary Breast Cancer Taskforce: Improving the care of people with metastatic breast cancer.
2. The Cancer Patient Experience Surveys commenced in England in 2010, in Scotland, 2015/16; and in Wales in 2013.
3. The 2016 Cancer Patient Experience Surveys for Wales has included a specific question which indicates that splitting out those with a diagnosis of recurrence from those with secondary disease may be possible (Q.77: When your cancer came back did it: Come back only in the same place as before; Spread to somewhere else in the body?).
4. The rules involved identifying those women who ticked 'yes' to the following question: 'Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?'. If they ticked 'no' to that question, but 'yes' to the following option in the next question: 'My cancer was taken out/treated without any sign of further problem, but has since come back/spread to other parts of my body', they were also included in the sample.
5. While a 45% response rate is still significant, it is lower than the 65.7% response rate for the 2015 Cancer Patient Experience Survey in England from where the data was drawn. This can be attributed to the fact that not all of those drawn from the sample were expected to have secondary breast cancer; the others were expected to have had a breast cancer recurrence and therefore were ineligible to participate.
6. For the purposes of this report, and to ensure that numbers were sufficient to draw meaningful conclusions, age bands were merged as follows: (25-34 and 35-44; 45-54 and 55-64; 65 and above).
7. The current version of the guidance applies to both England and Wales. At the time of writing the updated guidance will only cover England – but Wales may decide to adopt it too.
8. National Institute for Health and Care Excellence (NICE) (2015), Early and Locally Advanced Breast Cancer: Diagnosis and Treatment (CG80).
9. Scottish Intercollegiate Guidelines Network (SIGN) (2013), SIGN clinical guideline 134: Treatment of Primary Breast Cancer.
10. The Independent Cancer Taskforce (2015), Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020.
11. Open access back to the breast clinic is offered by some units (patients can contact their team, report symptoms and be seen where necessary without further referral). Other units discharge patients, meaning all non-planned consultations require a GP referral.
12. National Institute for Health and Care Excellence (NICE) (2015), Suspected Cancer: Recognition and Referral (NG12).
13. We look forward to the findings of the current pilots in Wales focusing on the single pathway approach from the point of suspected cancer and hope that they consider our findings in relation to secondary breast cancer.
14. NHS England/Quality Health, 2015, (England) National Cancer Patient Experience Survey, <http://www.ncpes.co.uk/index.php/reports/national-reports/2489-cpes-2015-national-report-pdf/file>; Scottish Government/Macmillan Cancer Support, 2015/16 Scottish Cancer Patient Experience Survey, <http://www.gov.scot/Resource/0050/00501127.pdf>; Welsh Government/Macmillan Cancer Support/Quality Health, 2013 Wales Cancer Patient Experience Survey, <https://www.quality-health.co.uk/resources/surveys/welsh-cancer-experience-survey/2013-welsh-cancer-perience-survey/wales-cancer-patient-experience-reports-english-language-versions>.
15. This data is not available from CPES in Wales (2013).
16. NHS England/Quality Health (2015), (England) National Cancer Patient Experience Survey; Scottish Government/Macmillan Cancer Support (2015/16), Scottish Cancer Patient Experience Survey; Welsh Government/Macmillan Cancer Support/Quality Health (2013), Wales Cancer Patient Experience Survey.

17. Breast Cancer Care (2008), Secondary Breast Cancer Taskforce: Improving the care of people with metastatic breast cancer.
18. *ibid* ref 1.
19. NHS England/Quality Health (2015), (England) National Cancer Patient Experience Survey; Scottish Government/ Macmillan Cancer Support (2015/16), Scottish Cancer Patient Experience Survey; Welsh Government/Macmillan Cancer Support/Quality Health (2013), Wales Cancer Patient Experience Survey.
20. Breast Cancer Care (2008), Secondary Breast Cancer Taskforce: Improving the care of people with metastatic breast cancer.
21. World Health Organisation (WHO) (2016), WHO Definition of Palliative Care, available at: <http://www.who.int/cancer/palliative/definition/en/> [accessed 13 July 2016].
22. Standards of care for secondary breast cancer, Breast Cancer Care, due to be published late 2016.
23. Department of Health/NHS (2008), The End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life; NHS Wales, Welsh Government and Macmillan Cancer Support (2013), Together for Health, Delivering end of life care. A Delivery Plan up to 2016 for NHS Wales and its partners; Scottish Government (2015), Strategic Framework for Action on Palliative and End of Life Care 2016-2021.
24. National Institute for Health and Care Excellence (NICE) (2009; updated 2014), Advanced breast cancer: diagnosis and treatment (CG81).
25. In 2014 a Breast Cancer Care survey on palliative care showed an overwhelming majority of respondents (70%) initially associated the term 'palliative care' with the end of life. Breast Cancer Care (2014), 'Share your Experiences' survey with 204 secondary breast cancer patients between 19/08/2014 to 22/09/2014.
26. Findings from a Breast Cancer Care survey showed that 2 out of 5 respondents had never been offered a referral to a palliative care team. Breast Cancer Care (2014), 'Share your Experiences' survey with 204 secondary breast cancer patients between 19/08/2014 to 22/09/2014.

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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.

For breast cancer care, support and information, call us free on **0808 800 6000** or visit **breastcancercare.org.uk**

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