



UNTIL THINGS CHANGE

## UNSURVIVORS

Around 11,500 people still die from breast cancer in the UK. We're demanding change so that everyone with secondary breast cancer can live well for as long as possible.

**BREAST  
CANCER  
NOW** The research  
& care charity

UNTIL WE'RE SEEN

UNTIL WE'RE HEARD

UNTIL THINGS CHANGE

# FOREWORD

## **We still lose too much and too many to breast cancer.**

We talk a lot about the progress we have made in breast cancer over recent decades - huge achievements that are to be welcomed and celebrated. But this often masks just how far we still have to go. There are an increasing number of people diagnosed with breast cancer every year in the UK and the most recent estimate suggests there are approximately 35,000 people living with a diagnosis of secondary breast cancer in the UK - when the cancer has spread to other parts of the body and is incurable. Nearly 1,000 people every single month do not survive breast cancer, almost all from secondary breast cancer.

The experiences of people with secondary breast cancer are frequently unheard, their frustrations real and painful. But their will to live, and to have the best possible support and treatment, is palpable. Living, and living well, is what people with secondary breast cancer want. Many people will live for a number of years so support and a good quality of life should be recognised as an integral part of what everyone with secondary breast cancer should expect. With progress in research and care, more people are living longer after a diagnosis of breast cancer, but the challenges of living with a diagnosis of secondary breast cancer have a considerable

effect on people's wellbeing - and this brings particular support needs. This progress in research must be matched by real change in how we assess and recognise the needs of people living with secondary breast cancer, including recognising that some people will live for many years and we must provide the support they need to live well.

That is why, at Breast Cancer Now - the UK's first comprehensive breast cancer charity - we are launching our 'Unsurvivors' campaign which highlights around 11,500 people still die from breast cancer every year in the UK and demands urgent change so that everyone can live well for as long as possible. By funding world-class research, providing caring support and information and campaigning on the issues that will make the biggest impact, we're here for anyone affected by breast cancer, the whole way through. Tackling the issues experienced by people with secondary breast cancer is an absolute priority for us and is central to our work.

Our 'Unsurvivors' campaign does not hide the incurable nature of secondary breast cancer. It challenges the very idea that everyone with experience of breast cancer can become a 'survivor'. It challenges the message that people are surviving breast cancer if they live a year, five years or even ten years after diagnosis. For people with a diagnosis of secondary breast cancer they

can never forget that their cancer is incurable. It's a hard message to hear, and we know it will be felt deeply by so many people. But it's also a rallying call for greater recognition, a call for change, a reminder that people want to live well while they can.

We are delighted that 2,102 people living with secondary breast cancer took the time to share their experiences with us - a huge honour and a huge responsibility. It reflects how the community want their voices to be heard. Based on the responses to the survey, we are calling for prompt diagnoses, for better treatments and for more specialist support, as well as for a comprehensive understanding of the number of people living right now in the UK with secondary breast cancer - something we still don't have despite a decade of calling for this and commitments from policy makers to tackle this.

Our desire and ambition for genuine change for people with secondary breast cancer is a priority that drives our new charity. But every day counts if you have secondary breast cancer. Join us now to make this change happen.



**Delyth Morgan,  
Chief Executive,  
Breast Cancer Now**

## A THANK YOU TO THE BREAST CANCER NOW SECONDARY BREAST CANCER CAMPAIGN GROUP

We established a group of 29 women with secondary breast cancer to support the development of the survey and the campaign.

This included women who have been living with secondary breast cancer for a long time and those who have been recently diagnosed; those whose first diagnosis was secondary breast cancer and those who had had primary breast cancer before; women of different ages, ethnicities and from different parts of the country. The group helped to build a picture of what is important to people with secondary breast cancer, and to test our recommendations and concept.

The group has been invaluable to the development of this campaign and we would like to thank them for their insight, advice and time. We would also like to pay tribute to two members of the group who very sadly died during the time the group was meeting. Both Rebecca and Sarah joined the group because they were passionate about helping people with secondary breast cancer. They had a strong desire to use their own experiences to improve services and support for those living with secondary breast cancer now or who might be affected in the future. We are grateful for everything they contributed.

# INTRODUCTION

The impact of secondary breast cancer is devastating. It is felt far beyond the person diagnosed; it changes the lives of parents, children, siblings, cousins, wider family and friends. Yet many people with secondary breast cancer have told us how they frequently feel alone. They feel that their experiences are little understood. And the new bonds they often make with others with a shared diagnosis are a frequent reminder of how difficult their situation is, with loss and friendship deeply intertwined.

For over a decade there have been calls for changes in key areas that would begin to improve the experiences of people with secondary breast cancer. Progress has been hampered by the lack of data on the number of people living with secondary breast cancer and their unique experiences, with change slow or not forthcoming. Those living with secondary breast cancer are desperate for their voices to be heard.

The need to focus on, and understand more about, the experiences of people with secondary breast cancer is why we undertook a comprehensive survey for this patient group.

With 2,102 people living with secondary breast cancer responding to this survey, it is the biggest ever survey for this patient group across the UK.

The results showed that many people with secondary breast cancer experience delays in diagnosis, struggle to access the support of a specialist nurse, fear they won't be able to access the treatment they need in the future, and are not given sufficient information about clinical trials.

That's why we've launched 'The Unsurvivors', a campaign that calls for urgent change for people living with incurable secondary breast cancer.

People will not survive a secondary breast cancer diagnosis. Once breast cancer has spread to another part of the body, it can no longer be cured. It cuts short the lives of thousands of people each year. People living with secondary breast cancer face fear, anxiety and uncertainty every day.

But they are here right now, living life, with the fear and the uncertainty. And they want to be seen, heard and understood. They want change.

## LIVING WITH SECONDARY BREAST CANCER

In our survey we asked people with secondary breast cancer what they wanted other people to understand about the disease.

The following identifies some of the key themes that came from the responses, with a selection of quotes from respondents included:

### That it is frightening

*'Although we are living with secondary breast cancer, we are also only ever a quarterly scan away from potential progression of the disease which could then be terminal.'*

*'Whilst you might look great on the outside, inside you have a ticking time bomb, 24/7.'*

*'That the fear of cancer will always be there for me. That I am always scared that it has spread elsewhere.'*

*'How evil this disease is. How scary this diagnosis is.'*

*'How confused and scared I am all the time; even when I'm happy it's always there in the back of your mind.'*

*'That it is scary. I am permanently scared about my future and what my family will have to deal with without me.'*

### That it is incurable

*'That you can live with it and many people do for years. However, there is no cure and it will eventually end your life.'*

*'That it is incurable and that just because I'm walking and talking, I'm not cured.'*

*'That it is not curable. That we live under the shadow of death, yet choose to live as well as we can in the time we have left.'*

*'That it's not curable, but it does not mean you are going to die quickly. Many live years with it.'*

*'That there is no cure but if you're lucky you could survive for many years. However, it will get you eventually. Some, sadly, quicker than others.'*

*'That it's incurable and I will die of it in the not too distant future, but I cannot tell them how long I have!'*

*'I look well and people assume cancer patients look frail and ill and can't comprehend that despite oral chemotherapy and living with it for over four years that I look so well and active. Everyone assumes I'm cured which can be upsetting.'*

**Treatment is ongoing**

**'That it is a lifetime condition. Treatment is forever.'**

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**'How totally and completely it affects your life after diagnosis and how the endless doctors' appointments can begin to wear you down in no time at all.'**

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**'I am still having ongoing treatment until I die. I will always be living with cancer.'**

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**'That we are kept alive by advances in medical treatment. That those medical treatments are amazing but can have huge side effects on our health and wellbeing.'**

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**'My treatment goes on for as long as it works and this is my life now. Constant 'scanxiety', endless hospital appointments and the struggle with day-to-day living that they either don't see or understand.'**

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**'A lot of people ask when my treatment will end. It won't, until I die.'**

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**That some days are good, some days are bad**

**'That just because you may appear well you have a lot of hidden symptoms.'**

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**'That despite how well we look on the outside, there is so much we face on a daily basis. Including fatigue, pain, low mood and the greater impact on fertility and everyday life.'**

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**'Some days are good and some days are bad, people tell me I look well and expect me to do more than I am capable of.'**

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**'The emotional toll it takes on you day to day.'**

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**'That we can still live a normal active life, but there are days that throw you off that life balance.'**

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**'I look perfectly fine, but people don't always see me on a bad day, anyone that first meets me thinks there's nothing wrong with me.'**

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**That we can live with it**

**'That you can still live and work. Your life is not over.'**

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**'That, once you are told this news, you feel like your world is going to end but it doesn't - you can continue to make wonderful memories with your family/loved ones.'**

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**'It is life changing for sure but with the right help and guidance you do feel most things are possible.'**

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**'That although this diagnosis means I am life-limited, I can still live whilst I am alive!'**

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**'That you can lead a full and good life with it. Make every day count, take on something new, for example, volunteering. This for me has opened so many doors to new activities and friends. Life is good.'**

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**'People with metastatic [secondary] breast cancer are able to live with the disease for many years, leading fulfilling and active lives. Don't write us off!'**

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WE ALSO ASKED PEOPLE WHAT THREE WORDS THEY WOULD USE TO DESCRIBE THE IMPACT OF HAVING SECONDARY BREAST CANCER, THESE ARE A SELECTION OF THE RESPONSES:

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'Shell-shocked, devastated'

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'Fear, sadness, pain'

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'Devastation, fear, pain'

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'Devastating, scary, life-limiting'

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'Frightening, worrying, uncertainty'

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'Fear, loss, compromise'

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'Frightening, frightening, frightening'

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'Devastating, horrifying, desolate'

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'Devastating, life-changing, unhappy'

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'Scan, treat, repeat'

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'Disappointment, determination, positivity'

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'Catastrophic, relentless, heart-breaking'

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'Scary, despair, hope'

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'scary, painful, expensive'

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'devastated, frightened, shattered'

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'Worst, fear, realised'

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Secondary breast cancer is when breast cancer spreads to other parts of the body, such as the bones, liver, lungs or brain. It is currently incurable, but it can be treated and, for some, managed. The life expectancy varies enormously depending on the biology of the breast cancer.

Secondary breast cancer is also known as metastatic, advanced, or stage 4 cancer. All of these terms may be used by doctors, nurses, family and friends and the media, which can add confusion to people's understanding of secondary breast cancer.

There is much debate among the research, clinical and patient community about which term should be used to refer to breast cancer once it has spread to other parts of the body. Respondents to our survey told us the term they prefer to be used; the most popular answer was secondary breast cancer (40%), followed by metastatic breast cancer (27%). One fifth of respondents said that they had no preference. However, we were frequently told that none of the terms are well understood and most people have to qualify what secondary breast cancer is, often using the word 'incurable'.

UNTIL  
EVERYONE  
WITH  
SECONDARY  
BREAST  
CANCER....

Until everyone with secondary breast cancer

# RECEIVES A PROMPT DIAGNOSIS

**23%**

of respondents had to see their GP three or more times before they were diagnosed.

**ONLY 13%**

of respondents who had previously had breast cancer felt they were given enough information from healthcare professionals on the signs and symptoms of secondary breast cancer to look out for.

Early diagnosis is often talked about in the context of cancer. The significance of improving early diagnosis has been recognised for many years and it is the cornerstone of approaches to reduce the number of people dying from cancer. Yet, this ambition and drive is rarely discussed in the context of diagnosing secondary breast cancer. Addressing this is not only about a clear referral pathway for those with symptoms, it is also about informing people completing their primary treatment about the signs and symptoms of secondary breast cancer and providing healthcare professionals with the knowledge and support they need to enable a prompt diagnosis.

It is crucial that people with secondary breast cancer are diagnosed promptly so that they can begin treatment and access supportive care as quickly as possible. Timely access to treatment and care can relieve symptoms and have a dramatic impact on quality of life.

A significant finding from our survey is that people with secondary breast cancer are experiencing avoidable delays in diagnosis. **23%** of respondents had to see their GP three or more times before they were diagnosed – among respondents who had previously had breast cancer, this was **24%**. Our survey also revealed that where respondents had spoken to a healthcare professional about symptoms caused by secondary breast cancer, **41%** felt those symptoms were not taken seriously. Furthermore, **11%** of respondents who had not previously had breast cancer and **6%** of those who had had breast cancer were only diagnosed with secondary breast cancer after being seen as an emergency or in A&E.

Recognising potential cases of secondary breast cancer can be challenging for GPs. A typical GP may see very few people with secondary breast cancer, making it hard for them to gain experience in identifying potential symptoms. Secondary breast cancer can develop many years after treatment for primary breast cancer has ended, sometimes a decade or more. There are also many different symptoms of secondary breast cancer, which can vary depending on where in the body the cancer has spread to. Many of these symptoms, such as backache or nausea, are not specific to secondary breast cancer and can be caused by other health conditions.

Nonetheless, in women who have previously been treated for primary breast cancer, and therefore for whom recurrence is a possibility, non-specific but persistent symptoms must be investigated and taken seriously – for example, when a woman contacts her treatment team with concerns, during a routine follow-up appointment, or following an urgent referral by a GP who suspects secondary breast cancer. Our survey showed that among respondents who have previously had breast cancer, **20%** were initially treated for a different condition by their GP before eventually being diagnosed with secondary breast cancer.

We recognise that GPs are facing unprecedented time and resource pressure. It's important that GPs are supported to develop their knowledge of secondary breast cancer and its signs and symptoms, and given all the information they need about patients' previous breast cancer diagnoses to help them recognise those symptoms. Support could include:

- Online training courses for GPs
- IT software to alert GPs to potential symptoms when there is a history of primary breast cancer
- Adding the symptoms of secondary breast cancer to treatment summaries of previous breast cancer that are shared with GPs

To complement this activity, it's important that steps are also taken to strengthen other routes to diagnosis of secondary breast cancer, in addition to via GPs.

In England, the NHS Long Term Plan committed to follow-up pathways that give people who have finished treatment for breast cancer 'rapid access to clinical support where they are worried that their cancer may have recurred'.<sup>1</sup> The Scottish Government's Cancer Strategy<sup>2</sup> has committed to implementing 'person centred follow-up protocols' and the Wales Cancer Delivery Plan<sup>3</sup> sets out that '...follow up arrangements... should be delivered in a more personalised, responsive to need and risk-stratified way'. We believe that follow-up pathways must also be a route to quickly investigate potential symptoms of secondary breast cancer.

The time taken to diagnose secondary breast cancer may be affected by the fact that many people who have had primary breast cancer are not made aware of potential symptoms to check with their GP or treatment team, or may not know who to report symptoms to. Our survey showed that just **13%** of respondents who had previously had breast cancer felt they were given enough information from healthcare professionals on the signs and symptoms of secondary breast cancer to look out for.

We believe a crucial element of follow-up support is that information on the signs and symptoms of secondary breast cancer must be given to all patients treated for primary breast cancer, at a time and in a manner that suits them. This could be written information at the end of treatment, or

through health and wellbeing events such as Breast Cancer Now's Moving Forward course, which provides information and support for people adjusting to life after treatment.

We will look at the issue of diagnosis in more detail in a future report following continued conversations with people with secondary breast cancer, GPs and the NHS.

**TO ENSURE EVERYONE WITH SECONDARY BREAST CANCER RECEIVES A PROMPT DIAGNOSIS, WE'RE CALLING ON THE NHS, IN ALL NATIONS, TO:**

-  Develop and utilise tools and resources to help GPs recognise cases of secondary breast cancer as quickly as possible
-  Provide all patients with information on the signs and symptoms of secondary breast cancer, as part of follow-up support after primary breast cancer



**'I WAS DIAGNOSED 12 YEARS ON FROM HAVING PRIMARY BREAST CANCER. NOBODY EVEN CONSIDERED IT WAS ANYTHING TO DO WITH THAT.'**

Joy



'BEING DIAGNOSED QUICKLY WOULD HAVE SAVED ME FOUR AND A HALF MONTHS OF PAIN, SUFFERING AND ANXIETY. I WAS CONSTANTLY WORRYING ABOUT WHAT WAS WRONG WITH ME'

Aliya

Until everyone with secondary breast cancer

# HAS ACCESS TO THE TREATMENTS THEY NEED

## ONE IN SIX

**respondents said they didn't feel confident they would have access to the most appropriate drug treatments in the future**

Secondary breast cancer remains incurable. This means that for people living with secondary breast cancer, treatment is a constant part of their lives. Being able to access the most effective drugs is one of the biggest priorities for people living with secondary breast cancer. And for good reason. It can mean extra months or even years of time with their loved ones and can also mean a better quality of life.

After nearly a decade of no new breast cancer drugs being approved for routine use on the NHS by NICE, recent years have seen several clinically-effective treatments for breast cancer recommended for use on the NHS by NICE and the SMC. A number of these have followed major campaigns by Breast Cancer Now to ensure that people did not miss out on life-extending drugs like Kadcyła<sup>4</sup> or Perjeta<sup>5</sup>.

We've also seen an acknowledgement by decision-makers of the need to be flexible in their approach and pharmaceutical companies of the importance of compromising on price. But even when agreements are reached and drugs become available the process can lead to delays causing unnecessary distress for patients as they wait to see whether they will be able to access a treatment.

A number of barriers still prevent new drugs reaching secondary breast cancer patients quickly. Many people with secondary breast cancer have told us they fear they won't have access to the most appropriate drug treatments in the future. More needs to be done to ensure clinically-effective breast cancer drugs are quickly made available to people with secondary breast cancer, at a price that is fair and affordable to the NHS.

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**The National Institute for Health and Care Excellence (NICE) makes decisions on which medicines will be routinely available on the NHS in England. In Wales and Northern Ireland, health bodies normally follow NICE recommendations, while the Scottish Medicines Consortium (SMC) makes independent decisions on which medicines will be available on the NHS in Scotland.**

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One of the main aims of treatment is to prolong survival by keeping the breast cancer under control and slowing its spread. Also, no one knows for certain how long a treatment will continue working for them, so having treatment options which can relieve symptoms and ensure the best quality of life for as long as possible is crucial for people with secondary breast cancer.

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**The exact treatment for people with secondary breast cancer varies from person to person. It is guided by many factors including the biology of the breast cancer, an individual's symptoms, as well as previous breast cancer treatments.**

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**'HAVING SECONDARY BREAST CANCER MEANS MY CANCER IS INCURABLE. BUT THAT DOESN'T MEAN I CAN'T LIVE WITH IT.**

**THERE CAN BE A LOT OF GOOD QUALITY LIVING THAT CAN HAPPEN - IF WE CAN ACCESS THE BEST TREATMENTS.**

**ACCESSING THE RIGHT DRUG MEANS BEING ABLE TO DO THE THINGS THAT MATTER MOST TO ME - LIKE WATCHING MY CHILDREN GO TO SCHOOL AND ALSO UNIVERSITY.'**

**Melanie**

Living with secondary breast cancer already places an enormous emotional and physical toll on people and their families. On top of this, people shouldn't have to live with the fear that they may not have access to treatments when they desperately need them. And they shouldn't have to even consider using their pensions, putting money aside or re-mortgaging their homes to help pay for treatments.

Recently, we've seen some welcome improvements in access to breast cancer drugs, with a number of treatment options being approved by NICE and the SMC. But even with these advances, we are not yet where we need to be. Worryingly, almost **one in six** respondents to our survey said they didn't feel confident they will have access to the most appropriate drug treatments in the future.

Bodies like NICE need the right methodological tools to be able to effectively appraise new and innovative medicines while manufacturers must also price their products fairly from the very start of the process.

For years, we have called on NICE to review their methodology to ensure it is fit for purpose and we are pleased they are now undertaking this review. As part of this review they must assess the reasons why pharmaceutical companies are pausing and rescheduling appraisals and take action to address this. We cannot continue to have a situation where treatments which could bring much needed benefits are left just out of reach of patients.

## DRUGS AREN'T REACHING PEOPLE WITH SECONDARY BREAST CANCER QUICKLY ENOUGH

Even when there are new and innovative secondary breast cancer drugs, far too often there are delays in them being assessed for use, becoming available on the NHS and reaching the people that urgently need them.

Two innovative drugs, olaparib (Lynparza) and talazoparib (Talzenna), have both received their license by the European Medicines Agency.

These are known as PARP inhibitors and are a targeted treatment option for patients with secondary breast cancer who have inherited BRCA mutations.<sup>6</sup>

NICE aims to make a decision on the use of a drug on the NHS as close as possible to the drug having received its marketing authorisation. Despite this, the timelines for the NICE assessments of both drugs

have been significantly revised following requests from the companies in order to wait for additional data. It is believed that these drugs may currently struggle to get approval through the current NICE appraisal system. The drugs also haven't yet been submitted for assessment with the SMC.

These treatments were approved by the US Food and Drug Administration (FDA) for certain patients with secondary breast cancer in 2018.

But due to current delays, it is likely that it will be over a year from when these drugs received their marketing authorisations to a decision being made about their use on the NHS. This isn't good enough. For people living with secondary breast cancer, every day counts.

Sometimes patients can access treatments before they are approved for use on the NHS via compassionate access schemes, run by pharmaceutical companies. These schemes have enabled people to access drugs which haven't yet been approved and for which there are often limited alternative treatment options. However, there is currently a lack of clarity and transparency about the use of compassionate access schemes, while the use of the schemes can vary across hospitals.

An issue that has been raised by some women with secondary breast cancer is that the secondary breast cancer drugs which have recently been made available on the NHS have generally been in the first and second line setting. This can be incredibly agonising for those who have already progressed beyond these treatment options.

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**First line setting means the first treatment given for breast cancer. Second line setting means a treatment that is given after the initial treatment**

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The Accelerated Access Collaborative (AAC) brings together the NHS, pharmaceutical industry, government and patient groups providing a route to highlight areas of unmet need so innovators know which problems they need to solve.<sup>7</sup> We will work with people affected by secondary breast cancer, clinicians and researchers to input into the new and expanded AAC. We want to work with others to highlight the areas of unmet need in the treatment of secondary breast cancer.

A future report will look at the issue of access to treatments in more detail.

**TO ENSURE THAT EVERYONE WITH SECONDARY BREAST CANCER HAS ACCESS TO THE TREATMENTS THEY NEED, WE'RE CALLING ON UK GOVERNMENTS, THE NHS, PHARMACEUTICAL INDUSTRY, NICE AND THE SMC TO COMMIT TO WORKING TOGETHER, ALONGSIDE BREAST CANCER NOW, TO ENSURE SECONDARY BREAST CANCER DRUGS CAN REACH PATIENTS QUICKLY, AT A PRICE THE NHS CAN AFFORD.**

This must include:

-  Urgently tackling the reasons why pharmaceutical companies are pausing drug appraisals
-  Developing a more consistent use of compassionate access schemes for secondary breast cancer patients

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## RADIOTHERAPY AND SURGERY

**While drugs are a fundamental part of treatment for people with secondary breast cancer, radiotherapy and surgery can also be used in certain circumstances.**

**Radiotherapy may be used to control breast cancer or relieve symptoms if the cancer has spread to the bones or brain. 48% of respondents told us they had received radiotherapy for their secondary breast cancer**

**Surgery may also be considered in some circumstances and there is a recognition that more research is needed in this area. 28% of respondents said they had received surgery as part of their secondary breast cancer treatment.**

**We will explore access to radiotherapy and surgery for secondary breast cancer patients in a future report.**

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'WHEN YOU HAVE SECONDARY BREAST CANCER, IT'S SO DIFFICULT TO PLAN ANYTHING TOO LONG TERM AS YOU HAVE NO IDEA WHEN YOUR CANCER MAY PROGRESS. SO YOU TEND TO FOCUS INSTEAD ON LIVING YOUR LIFE AS WELL AS YOU CAN IN THE MOMENT.

BUT THE PRECARIOUS AND UNCERTAIN SITUATION WITH ACCESS TO NEW DRUGS HAS MEANT THAT MY HUSBAND AND I DECIDED WE NEEDED TO SAVE A POT OF MONEY. THIS MEANS WE COULD IMMEDIATELY SPEND IT ON DRUGS IF THE DRUG I NEED IN THE FUTURE IS NOT FUNDED QUICKLY ENOUGH BY THE NHS.

THE GREAT PARADOX AND PROBLEM WITH THIS SAVING FOR "WHEN THE TIME COMES FUND" IS THAT I'M NOT ACTUALLY ABLE TO SPEND MONEY ON THE THINGS THAT I WANT TO DO NOW AND MAKE THE MOST OF THE LIFE THAT I HAVE NOW WITH MY FAMILY.

I RECENTLY FOUND OUT MY PARENTS HAVE ALSO BEEN GOING WITHOUT AND NOT DOING THINGS THEY WOULD OTHERWISE BE DOING IN RETIREMENT BECAUSE THEY HAVE A SECRET POT OF MONEY FOR ACCESSING DRUGS IN CASE THE HEALTHCARE SYSTEM LETS ME DOWN.'

Claire



Until everyone with secondary breast cancer

# HAS INFORMATION ABOUT CLINICAL TRIALS

**23%**

of respondents had discussed taking part in a specific clinical trial with a healthcare professional

**53%**

of respondents said they had not been given enough information about clinical trials by healthcare professionals

Clinical trials help to determine the safety and effectiveness of potential new treatments, and existing treatments being used in different ways. They inform decisions about whether treatments should be licensed for use and made available on the NHS. Trials also provide an important route for people with secondary breast cancer to potentially access new treatments. For those with secondary breast cancer, who have few treatment options, clinical trials can offer hope for the future. In the Long Term Plan, NHS England committed to increasing the number of people registering to take part in health research to one million by 2023/24.<sup>1</sup>

**23%** of respondents had discussed taking part in a specific clinical trial with a healthcare professional. Just over half (**53%**) of respondents said they had not been given enough information about clinical trials by healthcare professionals.

Research suggests that there are a number of reasons why clinicians may not have conversations with patients about clinical trials. These include that they are not involved in clinical trials themselves, or aware of appropriate trials, the lack of time to find out about relevant trials and discuss this with patients, and patients not asking about them.<sup>8</sup> There may also be no recruiting trials that their patients are eligible for.



Flora

**'BEING ON CLINICAL TRIALS HAS GIVEN ME OPPORTUNITIES TO POTENTIALLY ACCESS TREATMENTS THAT I WOULDN'T OTHERWISE HAVE HAD.'**

Connie

Although there are several databases that provide information about trials in the UK, patients often tell us that they can be difficult and time consuming to use.

Making information about clinical trials - and the risks and benefits of participating in them - quickly and easily accessible to both clinicians and patients will be crucial to ensuring patients feel better informed and increasing participation in health research.

*Be Part of Research* from the National Institute for Health Research (NIHR)<sup>9</sup> is a new site that replaces a previous database and NIHR is seeking feedback to help improve it. Cancer Research UK is reviewing how it can make its *Find a Trial* database easier to use and help people find trials that are relevant to them.<sup>10</sup>

In some parts of the UK, the NHS either has, or is developing, a way of people registering their interest in taking part in research and viewing opportunities to participate - for example the NHS App in England<sup>11</sup> and SHARE in Scotland.<sup>12</sup>

We will work with Cancer Research UK to facilitate feedback on the *Find a Trial* database from secondary breast cancer patients. We will work with both patients and healthcare professionals to review our information on clinical trials and ensure that resources are available to support conversations about them. We will also work with healthcare professionals to understand how they can be better enabled to have these conversations with patients.

The NHS Constitution in England already pledges to inform patients of research studies in which they may be eligible to participate.<sup>13</sup> To help ensure that its target to increase participation in research is met, NHS England has recently committed to introducing a right of referral to research.<sup>14</sup>

**'I THINK WHETHER YOU RECEIVE INFORMATION ABOUT CLINICAL TRIALS DEPENDS ON YOUR ONCOLOGIST.'**

**Lindsey**

**TO ENSURE EVERYONE WITH SECONDARY BREAST CANCER HAS INFORMATION ABOUT CLINICAL TRIALS, WE'RE CALLING FOR:**

- NHS England to provide more detailed information on the right of referral to research, with a clear plan for introducing it, underpinned by appropriate support for patients, clinicians and local systems
- Similar commitments to be implemented by the NHS in Scotland, Wales and Northern Ireland

Until everyone with secondary breast cancer

# IS SUPPORTED BY A CLINICAL NURSE SPECIALIST (CNS)

**ONLY 73%**

of respondents were given the name of a CNS at diagnosis

**ONLY 30%**

of respondents said they see a CNS regularly, and those who said they do have one received much better support

**ONLY 65%**

of respondents said that their CNS has enough time to spend with them

Clinical nurse specialists play a crucial role in coordinating care and providing the information and support people need to manage their diagnosis and treatment. Their value has long been recognised and it is clear from Cancer Patient Experience Surveys (CPES) across the UK that the support of a CNS is the single most important contributing factor to people's positive experience of care.<sup>15</sup> Access to a CNS is particularly important for people with secondary breast cancer who will be on lifelong treatment and often have very complex emotional and supportive care needs. Yet thousands of people with secondary breast cancer are likely to be missing out on this vital support and have been left to navigate their treatment without a CNS.<sup>16</sup>

Breast Cancer Now has campaigned over a number of years for everyone with secondary breast cancer to have access

to a CNS. In 2006, its legacy organisation Breast Cancer Care set up and coordinated the Secondary Breast Cancer Taskforce, a two-year initiative which brought together healthcare professionals, charities, policymakers and people with secondary breast cancer. The Taskforce identified that people with secondary breast cancer were far less likely to have a CNS than people with primary breast cancer. Despite our campaigning and commitments made by governments over the years to improve this situation, little progress has been made. UK Governments must act now to ensure that everyone with secondary breast cancer has access to a CNS.

**'ONE DAY I SAT WITH MY CNS AND WE WENT THROUGH EVERYTHING THAT HAD HAPPENED SINCE MY DIAGNOSIS.**

**SHE REALISED THAT I DIDN'T HAVE A GREAT QUALITY OF LIFE AND REFERRED ME TO A MARIE CURIE HOSPICE WHERE I DID A RELAXATION COURSE AND OTHER COMPLEMENTARY THERAPIES. IT WAS MY LIFELINE AND BROUGHT ME BACK TO LIVING.'**

**Jen**

## Access to a CNS

National Cancer Patient Experience Surveys are used to measure patient experience and need, and to gain a national understanding of access to a CNS across a wide range of cancers. The most recent National CPES findings for each of the English, Welsh and Northern Irish surveys showed that **93%** of breast cancer patients (both those with primary breast cancer and secondary breast cancer) were given the name of a CNS at diagnosis who would support them through their treatment.<sup>17</sup> In Scotland, **95%** of breast cancer patients were given the name of a CNS at diagnosis.<sup>18</sup> However, we are currently unable to draw conclusions about the specific needs and experiences of people with secondary breast cancer because, with the exception of the survey in Wales, there is currently no way of identifying these patients in the surveys.

Our survey reveals a very different picture, with only **73%** of respondents given the name of a CNS at diagnosis. With an estimated **35,000** people living with secondary breast cancer in the UK, this could mean that thousands do not have access to a CNS and the crucial support they provide.<sup>15</sup>

### The importance of a CNS

Our survey also asked respondents whether they had seen a CNS since their diagnosis. **25%** of respondents said they had not seen a CNS since diagnosis and less than a third (**30%**) said they had seen a CNS regularly.<sup>19</sup> This is worrying, given the significant differences in the support received by those who had seen a CNS regularly and those who had not seen a CNS since diagnosis.

Those who have not seen a CNS since diagnosis were **three times as likely** to feel they were not given enough emotional and psychological support from healthcare professionals during their treatment and care as those who saw their CNS regularly.<sup>20</sup>

We also found that those who saw their CNS regularly were **nearly three times more likely** to have had the opportunity to discuss their wider concerns and needs, known as a Holistic Needs Assessment (HNA), compared to those that had not seen a CNS since diagnosis.<sup>21</sup>

In fact, for all but one type of support included in our survey<sup>22</sup>, people who saw their CNS regularly were **at least twice as likely** to be referred or signposted and receive the support they needed, when compared to those who had not seen a CNS since diagnosis. For some types of support, such as support with childcare or care for other family members, and support with body image, sex and intimacy, those who saw their CNS regularly were **more**

**than five times as likely** to be referred or signposted and receive the help they need.<sup>23</sup>

Despite the clear benefits of regular contact with a CNS, of those that had seen a CNS since diagnosis, only **65%** said that their CNS had enough time to spend with them.<sup>24</sup> Many respondents expressed concern that their nursing team were 'understaffed', and said that their CNS seemed 'too busy', 'overworked' and 'stretched too thin' with a 'high workload.' Many also commented about the impact of this and said their nurse did not have enough time to support them and the many other patients under their care.

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### Breast Cancer Now's specialist support services for people living with secondary breast cancer

We've been running Living with Secondary Breast Cancer monthly meet ups since 2011. Currently held in 38 locations across the UK, these meet ups provide tailored information and support but most importantly, offer people the chance to meet and talk openly with others with the same diagnosis. We also offer Younger Women with Secondaries Together, an annual two-day event for women aged up to 45 who can feel particularly isolated given their unique concerns and needs.

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**'I FEEL AS THOUGH I'VE MISSED OUT NOT HAVING A CNS FOR ALMOST 12 YEARS. WHEN YOU ARE DIAGNOSED WITH SECONDARY BREAST CANCER, YOU FALL INTO THIS BIG GAP OF EMPTINESS AT THE TIME YOU MOST NEED SUPPORT.'**

**YOUR WHOLE WORLD FALLS APART AND YOU THINK "WHAT NOW?" HAVING ACCESS TO A CNS WOULD MAKE ME FEEL THAT I AM VALUED AND I MATTER.'**

**Laura**



**'[My CNS] is nice enough but is always far too busy and I feel put off from approaching her because of this. I certainly don't have any kind of relationship with her or feel that I can ask her anything unless it is really vital. Forget any emotional support!'**

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**'My CNS is overstretched and it must be impossible for her to deliver the service and care she would like to.'**

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**'I get the impression she is too busy because of the number of patients she has to help. I have to ask for help, I am not offered it.'**

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**'She is excellent, however, she is extremely overloaded and the caseload is undoable. I suspect that the excellent support we receive is due to her working over and above her hours.'**

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**'Overworked, stressed, doesn't know who I am.'**

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**'Spread too thin, not available. No one to help at worst time of your life.'**

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### **Current policy across the nations**

Various commitments have been made by UK Governments to improve access to a CNS but it is clear from our survey findings that urgent action is now required to ensure that everyone living with secondary breast cancer has access to a CNS and receives the best care possible.

While cancer strategies in Scotland<sup>2</sup> and Wales<sup>3</sup> do not specifically address the support needs of patients with secondary cancers, the Scottish Government has committed to producing recommendations to improve secondary breast cancer services and the Welsh Government has now established a Task and Finish group to assess the need for secondary breast cancer nurses. We welcome this focus but concrete outcomes are now needed.

A cancer strategy is currently being developed for Northern Ireland and this must include a commitment that everyone with secondary cancers should have access to a CNS.

The importance of having a CNS was acknowledged in NHS England's Long Term Plan published earlier this year. The Long Term Plan includes a commitment that by 2021, all patients, including those with secondary cancers, will have access to a CNS or other support worker<sup>1</sup>. The UK Government must act now if it is to deliver on this promise.

Cancer Alliances in England are currently developing five-year strategic plans which assess population needs and propose the practical actions needed to deliver the commitments set out in the Long Term Plan. These plans are being developed based on limited intelligence; it is crucial that Cancer Alliances know how many people with secondary breast cancer are under their care if these plans are to be effective and it is also vitally important that National Cancer Patient Experience Surveys are updated to allow identification of patients with secondary cancers. Without this information, it will be impossible to effectively measure progress against the commitment that all patients with secondary cancers will have access to a CNS or other support worker by 2021.

## Until everyone with secondary breast cancer **IS ACKNOWLEDGED**

### **TO ENSURE THAT EVERYONE WITH SECONDARY BREAST CANCER IS SUPPORTED BY A CNS, WE'RE CALLING ON ALL UK GOVERNMENTS TO:**

- Review and publish a breakdown of the current number of FTE CNSs supporting people with secondary breast cancer and how much time they dedicate to doing this
- Take urgent action to address the shortfall of CNSs, including providing the investment needed to recruit and train enough CNSs to support people with secondary breast cancer now and in the future

### **Nobody knows how many people are currently living with secondary breast cancer in the UK.**

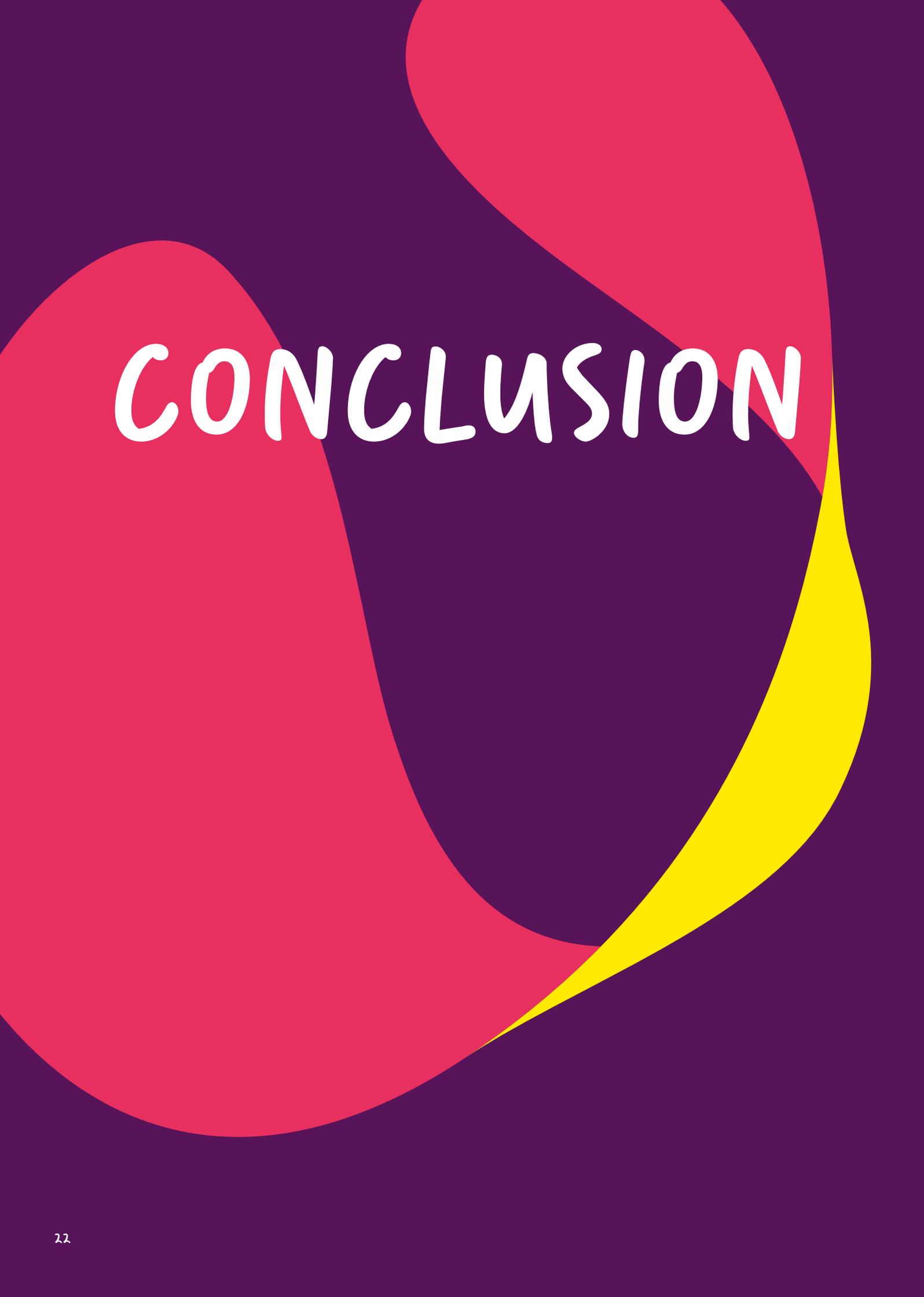
It is estimated to be around 35,000 people, but we still don't have an accurate, up-to-date figure. Although in England it has been mandatory for Hospital Trusts to collect data on new diagnoses of metastatic breast cancer since 2013, this has not routinely happened in practice. In addition, our Freedom of Information request sent in 2018 found that 40% of trusts and health boards were unable to say how many patients with secondary breast cancer were in their care.<sup>25</sup>

The NHS also do not have a clear picture of the experiences of those living with secondary breast cancer. The National Cancer Patient Experience Surveys (CPES) across the UK capture the experiences of thousands of breast cancer patients. However, we are unable to draw conclusions about the specific needs and experiences of people with secondary breast cancer, because there is currently no way of distinguishing their survey results from those of patients with primary breast cancer for three of the four national surveys. As our survey has revealed there is significant variation in access to a CNS when compared to the findings of all National CPESs, it is vital that data on people with secondary breast cancer is made available to drive improvements in their diagnosis, treatment and support.

### **TO ENSURE THAT EVERYONE LIVING WITH SECONDARY BREAST CANCER IS ACKNOWLEDGED AND WE UNDERSTAND MORE ABOUT THEIR EXPERIENCES, WE'RE CALLING ON:**

- All UK Governments to commit to undertake national secondary breast cancer audits covering diagnosis, treatment and access to support
- Public Health England to publish whatever data are available on diagnosis of secondary breast cancer, even if this is currently incomplete, so that it is possible to start building a picture of secondary breast cancer

These are vital to ensuring that commissioners and healthcare providers have the information they need to effectively plan their services.

The background is a solid purple color. Overlaid on this are several large, overlapping, organic shapes. A large red shape covers the left and top-right areas. A yellow shape is located in the bottom-right corner, overlapping the red shape. The word "CONCLUSION" is written in white, uppercase, rounded letters across the center of the red shape.

# CONCLUSION

People living with incurable secondary breast cancer have told us of the fear and uncertainty they face, not knowing how long it is until their treatment stops working and whether they will be able to access the treatment they need, when they need it. We also know that, for people with secondary breast cancer, it's not only important that they live for as long as possible but that they receive the support they need to live well, doing the things they love with the people closest to them. However, it is clear from our survey that there is still so much more to be done to ensure that everyone living with secondary breast cancer has access to the treatment and care they need.

#### Our survey found that:

- People with secondary breast cancer are experiencing avoidable delays in diagnosis. **23%** of respondents had to see their GP three or more times before they were diagnosed and only **13%** of respondents who had previously had breast cancer felt they were given enough information from healthcare professionals on the signs and symptoms of secondary breast cancer to look out for
- More needs to be done to ensure all secondary breast cancer patients have timely access to the treatments they need, with **one in six** respondents lacking confidence that they will have access to the most appropriate treatments in the future.
- **23%** of respondents had discussed taking part in a specific clinical trial with a healthcare professional and **53%** of respondents said they had not been given enough information about clinical trials by healthcare professionals
- Only **73%** of respondents to our survey in England were given the name of a clinical nurse specialist at diagnosis – at least **20%** fewer than the figure for all people with breast cancer estimated by National Cancer Patient Experience Surveys. Urgent action is needed to ensure that everyone with secondary breast cancer has access to a clinical nurse specialist.

In addition to the above, nobody knows how many people are living with secondary breast cancer in the UK, making planning for services extremely difficult.

This report has provided an introduction to the key issues arising from our survey and identified a range of actions that UK Governments must take in order to address these. We will continue to work in partnership with UK governments and the NHS to address these issues and to improve the lives of people with secondary breast cancer. We will publish a series of in-depth reports over the next year that explore the individual issues in greater detail.

#### We won't stop until:

- we know how many people have secondary breast cancer
- everyone with secondary breast cancer receives a prompt diagnosis
- everyone with secondary breast cancer has access to the treatments they need
- everyone with secondary breast cancer is supported by a clinical nurse specialist.

# APPENDIX AND METHODOLOGY

## Survey design and development

Breast Cancer Now worked closely with the Secondary Breast Cancer Campaign Group, made up of 29 women with secondary breast cancer, to support the development of the survey. The Group met face-to-face and communicated by email in between meetings.

We produced a draft survey focussing on issues that the Group felt were most important to people with secondary breast cancer. The Group then completed the draft survey and were asked to comment on the wording, the response options, any omissions, and any comments on the layout and length of the survey.

We are incredibly grateful for their insight and advice. We also sought advice from healthcare professionals and clinicians, and worked closely with Quality Health in finalising the questions set.

## Identifying the sample

The respondents for the survey came from two sources. Firstly, we invited patients who had completed the National Cancer Patient Experience Survey for England in 2017 and 2018, and who had agreed to receive further questionnaires about their health, to take part in our survey. Unfortunately, we were unable to use patient data from the National Cancer Patient Experience Surveys in Scotland, Northern Ireland and Wales. We applied rules to a sample of people with breast cancer to help identify those who most likely had secondary breast cancer. The total sample size was **4,145**.

Secondly, Breast Cancer Now 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, and paid advertisement. We sent targeted email communications to people using our secondary breast cancer services and our campaigns community, and shared the survey with our Nursing Network and other healthcare professionals, to encourage them to share the survey with their patients. This was particularly useful for inviting those from Scotland, Wales and Northern Ireland to take part.

## Timescales and fieldwork

The fieldwork was undertaken between 21 June and 12 August 2019. Additionally, we held three focus groups in Scotland, Wales and Northern Ireland between July and August 2019. We identified the participants by advertising the focus groups on social media and to our secondary breast cancer service users. The focus groups allowed us to gain deeper insight into some of the issues highlighted by the Secondary Breast Cancer Campaign Group and in particular, how these issues were affecting people with secondary breast cancer in different parts of the UK.

## Responses

A total of 962 people with secondary breast cancer responded to the postal survey. In addition to this, 1,140 people with secondary breast cancer in the UK completed the online survey, via our online channels. A total of 2,102 eligible responses were received.

Some respondents chose not to answer certain questions, so for that reason the base varies between questions. We have made it clear in the report where only a subset of respondents were directed to a particular question.

- 89% of respondents lived in England, 6% lived in Scotland, 3% in Wales and 1% in Northern Ireland
- We asked respondents when they were diagnosed with secondary breast cancer. The responses were:
  - 9% were diagnosed in the last 6 months,
  - 9% 6-12 months ago
  - 27% 1-2 years ago,
  - 37% 2-5 years ago,
  - 14% 5-10 years ago, and
  - 4% more than 10 years ago

- 71% of respondents had had a previous diagnosis of primary breast cancer or DCIS. 29% said that their first diagnosis was of secondary breast cancer
- The survey asked what year respondents were born. 1% were aged 16-24 years, 3% were aged 25-34, 12% were aged 35-44, 28% were aged 45-54, 32% were aged 55-64, 19% were 65-74 years old, and 5% were aged 75-84. We had no respondents that were aged 85 and above

- The majority of respondents were female (98%), and 2% were male
- 93% of respondents were White English/Welsh/Scottish/Northern Irish/British. 2% were White Irish and another 2% were from any other white background. Only 1% were Indian and another 1% preferred not to say. For the remaining ethnic groups, the number of respondents were too low to be statistically significant.



Judy

# ENDNOTES

- 1 NHS England (2019), NHS Long Term Plan Available at: <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>
- 2 Scottish Government (2016), Beating Cancer: Ambition and Action. Available at: <https://www.gov.scot/publications/ beating-cancer-ambition-action/>
- 3 Wales Cancer Network (2016), Cancer Delivery Plan for Wales 2016-2020. Available at: <http://www.walescanet.wales.nhs.uk/sitesplus/documents/1113/Cancer%20Delivery%20Plan%202016-2020.pdf>
- 4 Kadcyla is also known as trastuzumab emtansine.
- 5 Perjeta is also known as pertuzumab.
- 6 PARP inhibitors were first shown to target weaknesses in cancers which have faults in BRCA genes by researchers at the Breast Cancer Now Tony Robins Research Centre at The Institute of Cancer Research, London and colleagues elsewhere. Having funded some of the research that showed how these drugs work, Breast Cancer Now receives a proportion of the royalties generated from the associated intellectual property.
- 7 More information on the recent changes to the Accelerated Access Collaborative is available at: <https://www.gov.uk/government/news/nhs-patients-to-get-faster-access-to-pioneering-treatments>
- 8 University Hospital of Southampton NHS Foundation Trust (2015), Engaging for increased research participation, Public and healthcare professionals' perceptions. Available at: <https://www.uhs.nhs.uk/Media/Southampton-Clinical-Research/Marketresearch/Engaging-for-increased-research-participation-full-report-v2.pdf>
- 9 More information on Be Part of Research is available at: <https://bepartofresearch.nihr.ac.uk/>
- 10 The Find a Trial database is available at: <https://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial>
- 11 More information on the NHS App is available at: <https://www.nhs.uk/apps-library/nhs-app/>
- 12 More information on SHARE is available at: <https://www.registerforshare.org/>
- 13 Department of Health and Social Care (2015), The NHS Constitution for England Available at: <https://www.gov.uk/government/publications/the-nhs-constitution-for-england>
- 14 NHS Long Term Plan Implementation Framework: system support offer, NHS England, June 2019. Available at: <https://www.longtermplan.nhs.uk/publication/implementation-framework-support-offer/>
- 15 Achieving world-class cancer outcomes: A strategy for England 2015-2020. Available at: [www.england.nhs.uk/wp-content/uploads/2016/10/cancer-one-year-on.pdf](http://www.england.nhs.uk/wp-content/uploads/2016/10/cancer-one-year-on.pdf)
- 16 23% of respondents said that they were not given the name of a CNS at diagnosis. With an estimated 35,000 people living with secondary breast cancer, this could mean that over 8000 people were not given the name of a CNS at diagnosis.
- 17 National Cancer Patient Experience Survey 2018: National Results. Available at: <https://www.ncpes.co.uk/reports/2018-reports/national-reports-2018>  
  
Welsh Cancer Patient Experience Survey 2016: National Report. Available at: <https://gov.wales/sites/default/files/publications/2019-01/wales-cancer-patient-experience-survey-2016.pdf>  
  
Northern Ireland Cancer Patient Experience Survey 2018: All Trusts Report. Available at: <https://www.quality-health.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey-2018/northern-ireland-cancer-patient-experience-survey-reports-2018/709-northern-ireland-cancer-patient-experience-survey-2018-all-trusts-report/file>
- 18 Scottish Cancer Patient Experience Survey 2018: National Report. Available at: <https://www.gov.scot/publications/scottish-cancer-patient-experience-survey-2018-national-report/pages/9/>
- 19 All respondents were asked if they had seen a CNS since their diagnosis of secondary breast cancer. The findings in this section are based on a combination of those who answered 'I have not seen a CNS since diagnosis' and 'I have never seen a CNS'; compared to those who answered 'yes, I see them regularly'.
- 20 53% of those who had not seen a CNS since diagnosis said that they did not receive enough emotional or psychological support from healthcare professionals during their treatment and care, compared to just 16% of those who saw a CNS regularly.
- 21 46% of those who saw a CNS regularly said that they had a Holistic Needs Assessment in the weeks following their diagnosis, compared to 16% of those who had not seen a CNS since diagnosis.
- 22 This excludes complementary therapies e.g massage or art therapy.
- 23 Support with childcare or care for other family members: 35% of those who see a CNS regularly were referred or signposted and received the support they needed, compared to 6% of those who had not seen a CNS since diagnosis.  
  
Support with body image, sex and intimacy: 35% of those who see a CNS regularly were referred or signposted and received the support they needed, compared to 6% of those who had not seen a CNS since diagnosis.
- 24 Based on those who strongly agreed or agreed that their CNS has enough time to spend with them. 19% of respondents neither agreed nor disagreed.
- 25 Breast Cancer Care (2018), Secondary support package: Evidence report. Available at: [https://breastcancernow.org/sites/default/files/secondary\\_support\\_package\\_evidence\\_reportjan2019.pdf](https://breastcancernow.org/sites/default/files/secondary_support_package_evidence_reportjan2019.pdf)



Miranda

**WE'RE HERE IF YOU  
EVER NEED TO TALK**

Our breast care nurses and highly trained staff on our **free Helpline** are here for you, whatever you're going through.

We're ready to listen on **0808 800 6000** or you can find information and support online at **[breastcancernow.org](https://www.breastcancernow.org)**

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