You spoke.
We listened.

THE BIG BREAST CANCER SURVEY REPORT

BREAST CANCER NOW
The research & support charity

INSIDE THIS REPORT

FOREWORD

While there's been huge progress in diagnosing and treating breast cancer over the last few decades, it's still one of the UK's biggest health challenges. More people are being diagnosed than ever before, too many lives are being lost to the disease and having breast cancer can be a life-changing experience for people, during and beyond their diagnosis and treatment.

Unless we act now, the number of people diagnosed will continue to rise, thousands will continue to lose their lives to this devastating disease and many more will have to live with the long-term effects of it.

We have a bold vision – that by 2050, everyone diagnosed with breast cancer by breast cancer will live, and be supported to live well. But to make that a reality, we need to keep learning, adapting and changing.

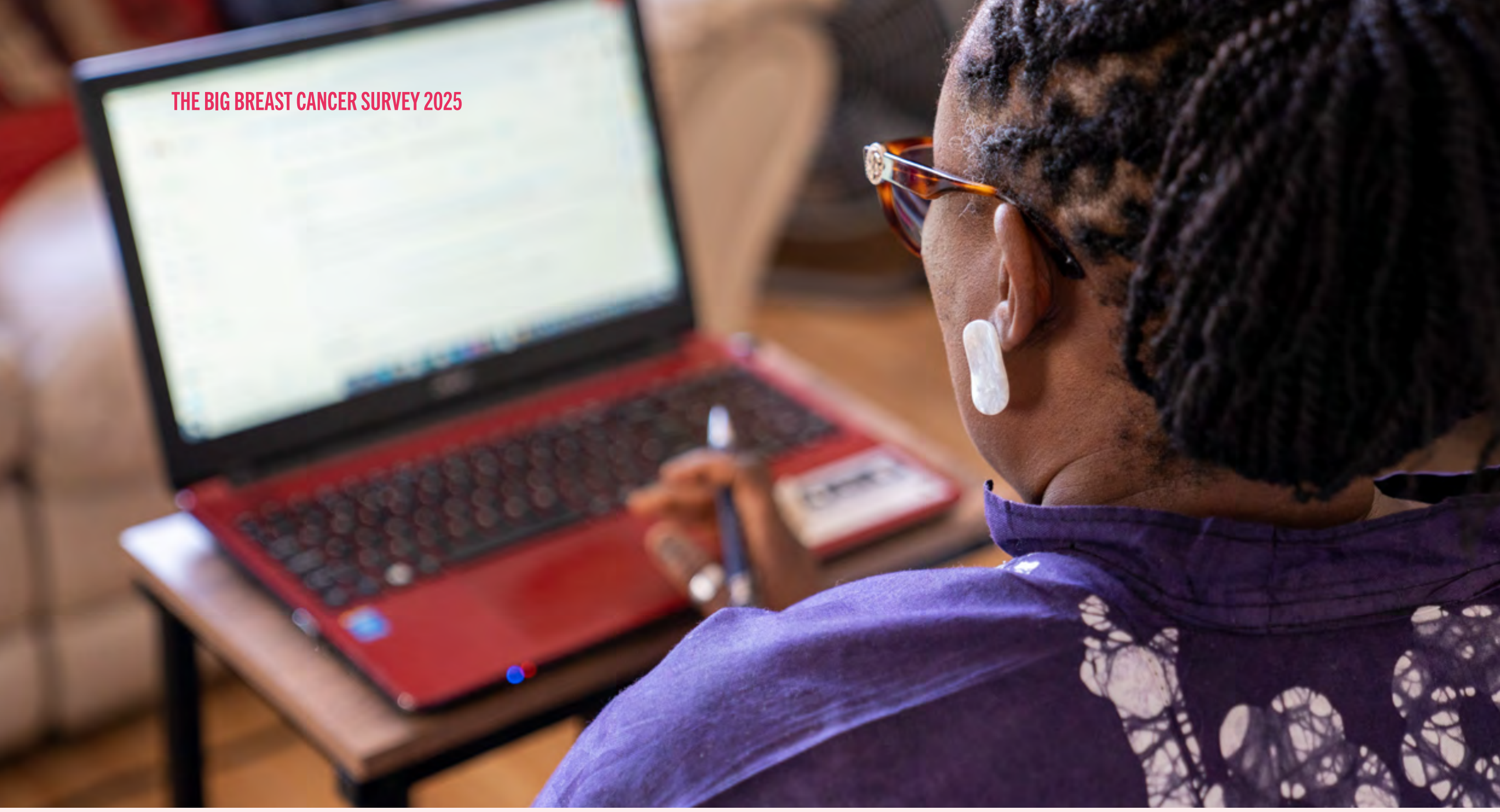
As we look to develop our new strategy, we needed to ask ourselves what the biggest challenges in breast cancer are, and how we can go about tackling them. And to do that, we needed to hear from as many people affected by the disease as possible. Being able to hear the honest voices of people affected by breast cancer is vital. And the more people we hear from, the more we know, and the more we can do to make sure everyone affected by breast cancer lives and is supported to live well.

What is it like to live with the disease? What kind of support would make the biggest difference to your life? What does it mean to live well with and beyond breast cancer? This is what we asked. And what people told us paints an honest, unvarnished picture of the realities of breast cancer right now.

This picture will help us shape the future of our charity. And it will serve as a reminder to everyone who has a role to play that there is much more to be done to shift the dial on breast cancer.

I want to say a huge thank you to everyone who took part in the survey and shared their experiences with us. Your involvement will have an incredibly powerful effect on our future direction. And I want to thank all of our partners who helped us by sharing the survey with their audiences and networks, helping us to reach more people and get a fuller picture of the problem.

Claire Rowney
Chief executive



INTRODUCTION

In 2024, we started the process of developing our next strategy – the plan we'll use to guide our work over the coming years. And we want the experiences of people affected by breast cancer to be at the heart of it.

Our strategy will set out how we'll work to improve the picture for everyone affected by breast cancer. But to do this, we need to know what the biggest challenges in breast cancer are, and how we can have the biggest impact. And to do that, we needed to hear from as many people affected by breast cancer as possible.

That's why we carried out the Big Breast Cancer Survey, in partnership with Kaleidoscope Health & Care and Ipsos. We wanted to understand the needs and challenges that people affected by breast cancer face, as well as what it means to them to 'live well'.

Through interviews and surveys, we heard from nearly 3,000 people from England, Wales, Scotland and Northern Ireland. This includes people with primary and secondary breast cancer, people who are at – or worried they are at – increased risk because of their family history, and family and friends of people with the disease.

We learned about the distinct challenges each group faces, their support needs – and where they aren't being met – and the kind of change they want to see. In this document, we've summarised the key findings of this work. We've included our methodology and much of the survey data in the appendices, for you to refer to if you're interested.

We'll use what we've learnt – along with input from researchers, healthcare professionals, decision makers and people with lived experience – to set out what we'll do to make lasting change. And we'll be publishing this in our strategy later in 2025.

OUR FINDINGS – AT A GLANCE

When we asked people about their experiences of breast cancer, we found that the biggest overarching gap in support for people was around their mental health and wellbeing.

This came through from people at different walks of life and at different stages of their breast cancer experience.

When we broke it down into the different groups we spoke to, the following came through strongly:

- **People living with secondary breast cancer** experience serious gaps in support throughout their experience due to the nature of their diagnosis
- **People with primary breast cancer** experience a particular gap in support after they've finished their hospital treatment
- **People who are at, or worried they are at, increased risk of breast cancer** due to their family history experience gaps in support in understanding and coming to terms with the knowledge they've been given
- **Family and close friends of people with breast cancer** experience gaps in support throughout their experience, in particular around how to support their loved one

And when we asked people what they wanted to see change, 6 things came back strongly:

- ▶ **More funding for research into the causes, treatments and prevention of breast cancer**
- ▶ **Shorter waiting times for diagnosis and treatment**
- ▶ **Better availability of treatments**
- ▶ **Better access to mental health support**
- ▶ **Better support for quality of life during treatment**
- ▶ **More support to manage the long-term effects of treatment**

> "KEEPING MY PERSONALITY; STAYING ME. I DON'T WANT CANCER TO STEAL ME."
>
> - Secondary breast cancer interviewee

THE TRUE IMPACT OF BREAST CANCER

PEOPLE WITH PRIMARY BREAST CANCER

Around 55,000 women and 400 men in the UK are diagnosed with breast cancer each year. And a further 7,000 people are diagnosed with DCIS (an early form of breast cancer) each year.

What challenges do they face?

Diagnosis

People with primary breast cancer told us the main challenges at diagnosis are concerns about the impact on their family and friends (68%), followed by the impact on their own mental health and wellbeing (58%) and managing their day-to-day life (34%).

For people who had challenges with their mental health and wellbeing, the biggest challenges are worries about whether their treatment would work, followed by the potential side effects in the immediate and long term.

People are often given incomplete or inconsistent information from healthcare professionals at diagnosis. And many feel unprepared for what lies ahead, creating more anxiety during an already stressful time.

> "I was the last appointment on Good Friday and there was no support available after the appointment. I didn't even know what kind of breast cancer I had. The diagnosis was too much, at a time with zero support available."
> - **Primary breast cancer interviewee**

For support to live the life they want to live now, people look to friends and family (53%) and breast cancer charities (39%) as the main sources.

Clear written information, such as health information booklets, is also useful. As is reliable online information.

For all of these support services, finding them early helps people navigate this challenging period more effectively.

Treatment

People's main challenge during treatment is managing their physical symptoms and side effects (48%). But worries about the impact of breast cancer on their family and friends continue to weigh heavily, ranking as the second biggest difficulty (42%). This is followed by not knowing what to expect from their treatment (41%) and worries about the future (41%).

For those who found managing their physical health a big challenge, the main concern is managing side effects, followed by managing pain or discomfort, and dealing with changes to their body and self-esteem.

21% of people told us that they needed information, support or advice with mental health challenges at this stage of their journey but didn't get it. And an extra 43% only partly got what they needed.

People also face challenges with poor communication and coordination between medical teams. Many say they feel unheard or disempowered in treatment decisions, and struggle to advocate for themselves at a time when they feel particularly vulnerable.

> "Information does not flow between [medical teams] particularly well. That is quite stressful when you are having to run around and sort things out."
> - **Primary breast cancer interviewee**

People told us that the most valuable support during their treatment came from having a consistent care team. This often includes named care providers who offer continuity of care, such as a nurse who regularly checks on them and who they could call with any questions.

Mental health support from charities and counselling services is also crucial, as is ongoing peer support. And clear information about side effects and how to manage them helps people feel more prepared and in control of their situation.

After treatment

Many people face significant challenges after their treatment ends. This is often when people start to process what they've just been through, emotionally and mentally. This is also the point at which there are the biggest gaps in support, with 21% of people saying they needed information, support or advice but didn't get it, and a further 45% only partly getting what they needed.

This gap in support once treatment ends is a big challenge for patients. The people we spoke to told us that they struggle to process the whole experience, at a time when everyone else around them seems to have moved on. This often manifests as pressure from themselves and others to return to ‘normal’.

> “People tell you ‘you’ve got to be positive’. I felt I was a disappointment to people because I wasn’t positive all the time. Sometimes I was just down. I was struggling; I wasn’t positive all the time.”
> **- Primary breast cancer interviewee**

This is exacerbated by the fact that many people say they feel suddenly dropped by their care team, without clarity on what happens next. They also say they’re unsure about how long the physical recovery process takes and what it will be like.

> “When I finished chemo the first time, I felt there was a bit lacking in terms of what to look out for. If you read literature, you’ll scare yourself silly.”
> **- Primary breast cancer interviewee**

Some of the biggest concerns people have after treatment are the impact on their mental health (60%), as well as managing physical symptoms (54%) and day-to-day life (19%).

In terms of mental health challenges, the biggest is worries about the cancer coming back or spreading. 90% of people who have mental health challenges say they have a fear of recurrence or metastasis following their treatment.

> “That it will come back. Every time you have an ache or a pain you think ‘oh God, not again. Where will it attack me this time’.”
> **- Primary breast cancer interviewee**

And alongside this, many people say they’re confused about how to identify and report any concerns or symptoms. And the impact of possible long-term side effects and issues around body image and self-confidence, particularly for people who have breast reconstruction surgery, are significant.

In terms of the physical health challenges, the biggest concern is managing side effects, followed by managing pain. This mirrors the biggest physical concerns for people going through treatment, suggesting these difficulties persist throughout and beyond treatment.

When it comes to physical concerns, positively, people said they generally got what they needed during and after treatment in terms of information, advice and support. The kind of support that people need at this time focuses on clear information about follow-up care, as well as more information about the signs and symptoms of the breast cancer coming back or spreading.

People also need continued access to mental health support, as well as peer support from others with similar experiences.

> “Navigating all of the niggly side effects afterward. No one really asks, ‘so what’s ongoing for you?’. They save your life and that’s it. No one asks, ‘how is your quality of life, are you struggling with anything at home, are you feeling fatigued?’”
> **- Primary breast cancer interviewee**

What does living well mean to them?

For people with primary breast cancer, ‘living well’ mainly means getting back to a life as close as possible to the one they had before their diagnosis. This includes being physically healthy and not in pain as the most important aspect (51%). Being able to do the things they enjoy is also important (21%).

Some people also say that maintaining their relationships (with partners, 42%, and children, 31%) while coming to terms with their body image concerns and other changes to their sense of self are really important.

> “Living well to me means not thinking about [cancer] all the time - having a life without a shadow constantly behind you.”
> **– Primary breast cancer interviewee**

PEOPLE WITH SECONDARY BREAST CANCER

Secondary breast cancer, also known as metastatic breast cancer, occurs when breast cancer cells spread from the breast to other parts of the body. While it can be treated, it currently cannot be cured. We don't know exactly how many people are living with secondary breast cancer in the UK, but it is estimated that there are around 61,000.

What challenges do they face?

Diagnosis

A secondary breast cancer diagnosis is especially difficult for people, as the disease is currently incurable.

People living with secondary breast cancer consistently report significant unmet needs.

The biggest difficulty they face is concern about the impact on their family and friends (58%). This is followed by impact on their own mental health and wellbeing (51%) and managing day-to-day life (33%).

The period before people get their diagnosis is when they feel least supported. 43% of people said they needed information, support or advice with the physical symptoms of secondary breast cancer, but that they didn't get what they needed, and a further 27% only partly got what they needed. And 29% told us they needed information, support or advice with mental health challenges, but they didn't get it, and 25% only partly got what they needed.

People's immediate concerns in the period leading up to diagnosis often centre on the impact on family members. This is especially true for people who have children, with it being the top ranked issue for people reporting challenges with their mental wellbeing. This is followed by worries about whether they have breast cancer and feeling isolated.

Many people experience delays with, and poor communication of, their diagnosis, adding stress to an already challenging situation. And they often experience overwhelming anxiety about the future, which can be debilitating without proper support.

The support people receive improves slightly after diagnosis, although there are still gaps. Again, a significant minority said they needed information, support or advice on mental health and wellbeing (26%) and physical impacts (16%) at this time, but that they didn't get it. And the needs were only partly met for a further 33% for mental health and wellbeing and 48% for physical impacts.

At this stage, people really value clear information delivered in accessible formats, alongside early access to mental health counselling and family support services. Having access to specialist nurses to provide consistent support and information also proves particularly valuable.

> "When you're diagnosed with secondary no one gives you any information. When you get a primary diagnosis, you get loads of information."
> **- Secondary breast cancer interviewee**

Better coordinated care between their former primary breast cancer team and their new secondary team (where participants had received a diagnosis of primary breast cancer prior to their diagnosis of secondary breast cancer) is also considered really important.

> "As soon as I was diagnosed with secondary I was passed over to a different unit for secondary cancer. [I] no longer had that named nurse and really good relationships. I don't have a named nurse anymore, just a helpline."
> **- Secondary breast cancer interviewee**

Living with secondary breast cancer

Treatment for secondary breast cancer brings many challenges, the top ranked being concerns about the impact on people's family and loved ones (56%) – the same as for at diagnosis. This is followed by living with the uncertainties of treatment (55%) and managing physical symptoms (47%).

People face uncertain and changing treatment plans while trying to manage physical symptoms, frequently complicated by poor coordination between healthcare providers. For people who struggle with managing their physical health, the biggest challenges are managing side effects, managing pain and needing help with day-to-day activities. And many often worry whether their treatment will work.

When it comes to physical health, positively, more people at least partly got the information, support and advice they needed. But there is still room for improvement.

People experience difficulties accessing medications, and speak of inequities in the availability of medicines between the nations. This adds another layer of stress to what is already a challenging experience, with many people dealing with ongoing anxiety and depression, alongside a loss of independence. It can be difficult to navigate their daily lives with fatigue and other symptoms, all while managing uncertainty about the future. Work and financial pressures add extra strain.

The support that people find most valuable during this time includes having named nurses for consistent contact, and a sense that someone is advocating on their behalf, when this is available to them. People also value care that is responsive and kind, particularly when it comes to pain management, alongside practical help managing side effects.

Peer support networks – where people can talk to others who understand what it's like to live with secondary breast cancer – also provide crucial emotional support.

Support that people want but often can't find includes accessible information on how to manage and prepare for the side effects of treatment, including information on cold caps.

"A big overarching [concern] is how long will this treatment last? You become very aware of the treatment options you have left or lack thereof. It's difficult and scary to change treatment plans."
- Secondary breast cancer interviewee

For people who were diagnosed with secondary breast cancer after a primary diagnosis, there were many aspects of information, support and advice people would have liked but didn't get. This included signs and symptoms of secondary breast cancer (64%), lifestyle changes to reduce risk (62%), managing long-term side effects (55%), support for family and friends (52%) and local support available (50%).

As secondary breast cancer progresses, support for family members becomes increasingly important. Parents are particularly concerned about how to talk about it with their children and prepare them for the future.

"I worry about the impact on my kids and mummy being a lot more tired than normal, and the impact on them when I'm not here."
- Secondary breast cancer interviewee

What does living well mean to them?

People with secondary breast cancer told us that 'living well' means maintaining their sense of self and independence while managing ongoing treatment.

They face the challenge of balancing work and life demands with treatment schedules and side effects. Staying connected to support networks, access to information and enjoying normal daily activities are crucial for emotional wellbeing.

"Keeping my personality; staying me. I don't want cancer to steal me."
- Secondary breast cancer interviewee

PEOPLE AT, OR WORRIED THEY'RE AT, INCREASED RISK OF BREAST CANCER

We don't know exactly how many people are at an increased risk of breast cancer due to their family history. But we know that genetics plays a part. 5-10% of women with breast cancer are thought to have an inherited altered gene that increases their risk. And there is likely a greater proportion of cases where inherited genes play a part in increasing risk, as part of a wider combination of factors. We also know that even where people don't have an increased risk, it can feel worrying when a close family member is diagnosed.

What challenges do they face?

The biggest challenge people at high risk, or who are worried about being at increased risk, face is the impact on their family and friends (39% for people undergoing a family history risk assessment and 42% for people undergoing a genetic test). This is followed by the impact on their mental wellbeing (35% for both groups) and managing day-to-day life (19% and 13%).

The biggest concern people have about their family is about the possible implications for them. This is followed by concerns about the emotional effect on family and children.

For people having family history assessments who are struggling with their mental wellbeing, the biggest challenge is worries about the impact on their life, about being at higher risk of breast cancer and about what the results mean for their future health.

For people having a genetic test who are struggling with their mental wellbeing, the biggest challenge in relation to this is worries about what the results mean for their future health, whether they have inherited an altered gene and the impact on their life.

There can often be challenges around how a person's risk is communicated to people who haven't had a diagnosis of breast cancer, but who have an increased risk of developing the disease. Many people receive poor or unclear communication about their risk levels and what this means for their future.

> "No one explains what lifetime risk means. You just hear 85%, but it isn't explained properly, and you just go away with this giant number, and you don't know what it means."
> **- Increased risk interviewee**

30% of people who had a family history risk assessment and 33% who had a genetic test said they were not offered information, support or advice on lifestyle changes they could make to reduce their risk of breast cancer, but they would have appreciated this. But most people who did receive this information said it met their needs.

Counselling support for people close to them is also an area people at high risk would have liked information, support or advice on but weren't offered it. 30% of people who had a family history risk assessment and 36% of people who had a genetic test told us this.

People are frequently frustrated about being dismissed or denied testing, despite meeting eligibility criteria. Many people face lengthy delays in accessing stratified or additional screening services. And the physical experience of screening itself often involves significant pain and anxiety, which adds ongoing stress to the process.

People at increased risk often experience constant worry about developing cancer. This is made more difficult by worrying about what their genetic risk could mean for their children and other family members. The impact on and implications for their family is consistently ranked as one of the biggest challenges this group face.

"I know if my children do test positive, I will feel guilt. Or maybe it's not guilt, it's sadness for your child. My daughter, when she was 4, did say 'Mummy, will I have to chop off my boobs when I'm older like you?' And I said, 'I don't know.'"
- Increased risk interviewee

People also often have to balance staying vigilant about their health with trying to maintain a normal life.

"It takes over your life. You become hyper vigilant about everything and it can be very overwhelming. It's the only thing you can think about and you struggle with that a lot because you haven't really got anything wrong with you. You've just got this overwhelming feeling of vulnerability and fear."
- Increased risk interviewee

The support that people value most focuses on clear, consistent information from healthcare providers about risk management and stratified screening options. Mental health support and counselling are also important for managing their anxiety about potential future diagnoses.

Many people want guidance for discussing their risk status with family members, particularly children, highlighting the need for specialised resources in having difficult conversations. Peer support networks are valuable spaces for sharing experiences and coping strategies with others in similar situations.

"At the hospital I did get counselling and that was helpful because it did discuss the options and which route I wanted to go down. Not to say that I won't change, but I found that helpful to talk about my feelings and any anxieties once I'd got the results."
- Increased risk interviewee

What does living well mean to them?

For people worried about their increased risk, 'living well' means maintaining control over the things they can influence, such as lifestyle choices and attending their screening appointments.

Managing screening-related anxiety while keeping a positive outlook is also difficult but essential. And many people highlight the importance of getting the right support while not letting their risk status dominate their lives.

"Being at increased risk has caused me a lot of distress and taken over my life at points. But now, I feel that I am in control and have removed everything that can be removed, I feel as in control as I can be."
- Increased risk Interviewee

FAMILY AND FRIENDS OF PEOPLE WITH BREAST CANCER

What challenges do they face?

Family members and close friends of people with breast cancer face their own set of challenges while supporting their loved ones.

One of the main difficulties is not knowing the most effective way to support their loved one (38%), followed by the impact on their family and friends (28%, including partners and children) and providing emotional support (27%).

"We are all worried about our loved one. Most importantly, I'm worried about whether my aunt could make a comeback. She is so drained emotionally. I think it's draining her mental health."
- Family and friends interviewee

The biggest challenge in not knowing how best to support their family or friend was knowing when to offer support and when to leave them alone. This was followed by knowing what to say, and knowing when to take action about their medical care (for example, taking them to A&E or chasing for test results).

Nearly a quarter (24%) of people said they needed support with mental health challenges but didn't get it.

"My brother gave up his flat and his job to become mum's carer [...] the only support offered to my brother was sleeping tablets, no support for him as her carer or because of his bereavement. No counselling or help. With hindsight, we felt a bit let down after she had passed"
- Family and friends interviewee"

Family members tell us that communication with medical teams is often challenging. There is frustration about long wait times, poor information sharing and unexplained changes in appointments or treatment plans.

And people with a family history of breast cancer have additional worries about their own genetic risk, creating another layer of anxiety to manage.

Financial pressures are another source of concern. People often have to reduce their work hours or leave work altogether so they can support their loved one. Another common challenge is balancing caring for their loved one with other life responsibilities, which creates stress in their daily lives.

"The impact on your own health and wellbeing was not at any point asked of me as a family member. No one asks you, 'what support can we give to you?' You're going through this experience as well. I wanted some support offered at some stage and the opportunity to access that."
- Family and friends interviewee

It's often a struggle to balance caring responsibilities with other life demands, all while trying to maintain quality time with their loved one facing breast cancer.

"[I want] More time to see my mum but it's difficult because I've got two young children and work as well. I'd like to give her a bit more of my time, especially now, not knowing how long she has left. A bit more quality time with her."
- Family and friends interviewee

People said they could do with more information to guide them through the experience. 28% reported needing information to help them with navigating the health system but not getting what they needed, and 20% said the same about providing support with their family member or friend's physical needs (20%).

> "I would have liked much more support on a range of different things. How to support my mother with her breast cancer, what to do and what not to do would have been useful. Unless you've been in that position it's hard to get things right."
> **- Family and friends interviewee**

Clear communication channels with medical teams is essential to be able to properly care for someone, as is access to financial advice and support. Bereavement support is also a crucial need, but that it isn't always available.

Many people find peer support networks specifically for family members and carers valuable, allowing them to share their experiences with others who understand their situation.

What does living well mean to them?

For family and friends, 'living well' means being able to support their loved ones while maintaining their own emotional wellbeing. People want to know that their loved ones are properly cared for and are also living well, but they face challenges in properly caring for them, both emotionally and financially.

DIFFERENCES BY DEMOGRAPHIC GROUPS

When it comes to the challenges, needs, gaps, and what 'living well' means for people with breast cancer, there are differences among groups based on demographics and what stage of their cancer experience they're in.

- **By age:** When it comes to living the life they want, people aged 51 to 80 with breast cancer say that their physical health is more important, but for people aged 45 and under, mental health is more important. In particular, younger women highlight the need for personalised support.
- **By social grade:** Finances are more important to people in social grades C2DE (lower socio-economic groups, commonly defined as working class) for living the life they want than those in social grades ABC1 (higher socio-economic groups, commonly defined as middle class).
- **Parents or carers of under 18s:** These people's relationships with their children is the single most important area to them in living well.
- **Before and after treatment:** For people who have not yet completed their hospital treatment, hope for the future and a sense of control over their lives are more important. For people who have completed their treatment, physical health is more important. And mental health is more of a concern for people diagnosed in the last 5 years than people diagnosed longer ago.
- **By region:** Improving access to drugs and addressing regional inequalities in availability of treatment is very important to people.

WHAT CHANGES DO PEOPLE AFFECTED *BY BREAST CANCER WANT TO SEE?*

We asked people affected by breast cancer what change they want to see that would make the biggest difference to them. The things that came back most strongly were:

- More funding for research into the causes, treatments and prevention of breast cancer
- Shorter waiting times for diagnosis and treatment
- Better availability of treatments
- Better access to mental health support
- Better support for quality of life during treatment
- More support to manage the long-term effects of treatment

All groups said they want to see more research, but beyond that their priorities differed:

For people with primary breast cancer, the most important improvements are waiting times for treatment and diagnosis and mental health support.

The people we spoke to told us about the importance of support with breast reconstruction, and age-appropriate support. This is particularly a priority for younger women, as well as more research into the fertility implications of breast cancer.

> “I would love more data on fertility and how the medicine impacts it so that I can make an informed decision… It’s kind of assumed that anyone who has breast cancer wouldn’t have more kids. I’ve heard, ‘Surely you’re not having kids.’ But I’m a 32-year-old woman, why would you assume that?”
> **– Primary breast cancer interviewee**

For people with secondary breast cancer, the most important improvements are the availability of treatments, better quality of life during treatments and support with mental health and wellbeing.

The people we spoke to told us that they want to see improvements in access to drugs, addressing regional inequalities in treatment and better coordination and continuity of care, particularly during the transition from primary to secondary breast cancer care.

> “Access to drugs… There’s a severity cap so people can only access drugs when their condition is considered severe enough which isn’t fair.”
> **– Secondary breast cancer interviewee**

For people at, or worried they’re at, increased risk, the most important improvements are support with mental health and the availability of treatments for breast cancer.

The people we spoke to told us that they also prioritise prevention research and early detection initiatives, as well as better support in discussing genetic risk with family members, particularly children, and improved access to genetic testing and mental health counselling services.

> “There’s also no information about how to talk to children about what’s happening and how not to scare them. I remember trying to talk to my children about why I was going to the hospital and why I looked very different than I did before.”
> **– Increased risk interviewee**

For family members and friends, the most important improvements are shorter waiting times for treatment and diagnosis, and better availability of treatments.

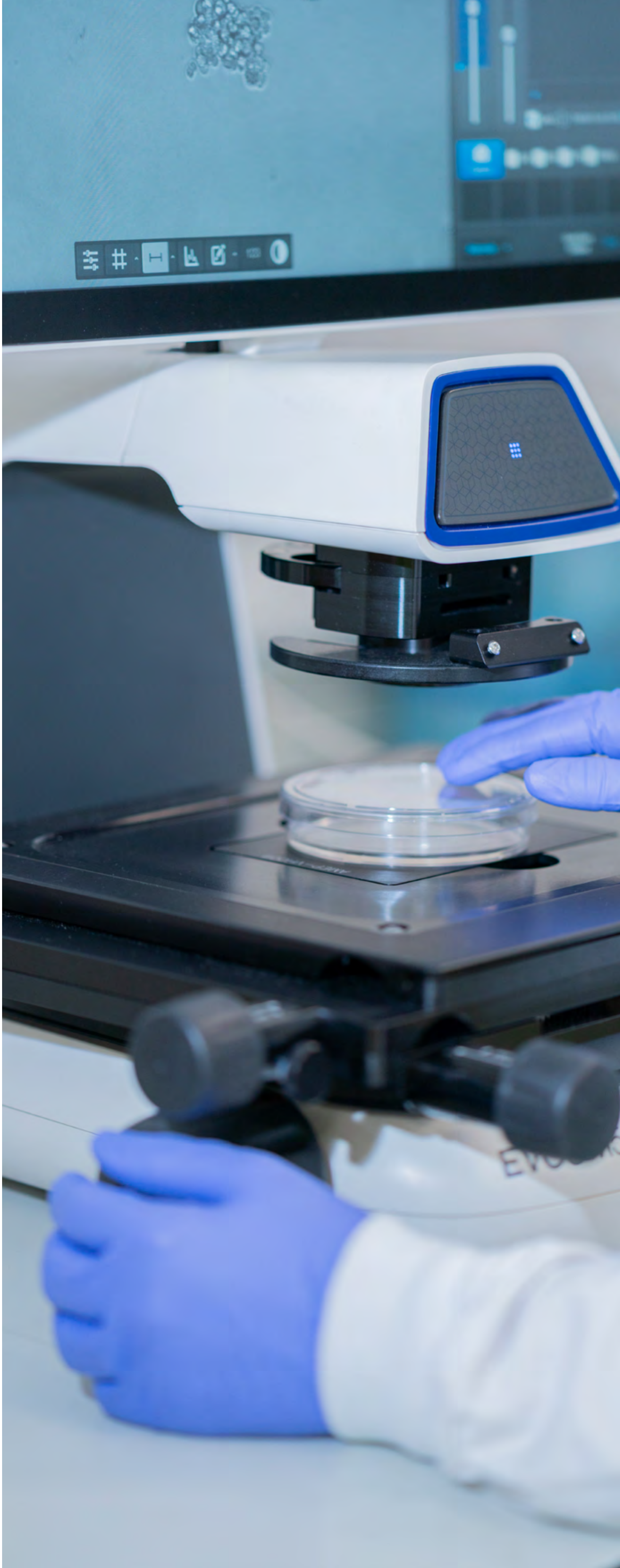
The people we spoke to told us that they also prioritise dedicated support services for carers and loved ones. This includes bereavement support, and practical guidance on providing care and support managing the emotional demands of caring for someone with breast cancer.

They also want to see better communication channels with healthcare teams.

> "First priority I would say is make sure that the patient gets everything they need, help and emotional support. I think that should be the biggest priority."
> **– Family and friends interviewee**

THE IMPORTANCE OF PERSONALISED SUPPORT

All groups talked about the importance of support that is personalised and tailored to them and their specific circumstances. But this was particularly true for younger women with breast cancer, as well as people at increased risk.



CONCLUSION

This research lays bare the experience and needs of people affected by breast cancer across the UK. Some common themes come through strongly, such as the need for support with mental health, better coordination of care and the importance of people getting the right information to help them understand and manage their situation.

And it shows us where, and how, the gaps in support are felt most deeply. For people living with secondary breast cancer, who have to live with the uncertainty of what the future holds – for them and their loved ones. For people discharged from hospital-based treatment for primary breast cancer, who can easily find themselves adrift and unsure how to move forward. For people worried about their personal risk of developing breast cancer, who often don’t get the information and support to help them cope with this new reality. And for family members and friends, who can struggle to know how to care for someone with breast cancer while also looking after themselves.

And by telling us what changes they want to see – for themselves and for future generations – their voices can shape how we direct our time, money and efforts. Its clear people want to see more funding for research, shorter waiting times, better availability of treatments and more support for mental health and wellbeing.

We look forward to announcing our next 5-year strategy in autumn 2025, shaped by and directly addressing what people have told us about the realities of living with, and being affected by, breast cancer. And we’ll work tirelessly to drive the change that people affected by breast cancer need to see.

But this piece of work serves as a critical reminder of the responsibility that we all – not only ourselves and the healthcare sector, but society broadly – have to shift the dial on breast cancer. We have a leading role to play in this, and we’ll work tirelessly to drive change. But we’re also calling on everyone else to play their part. Because only by working together can we reach our vision that by 2050, everyone diagnosed with breast cancer will live, and be supported to live well.

APPENDICES

Methodology

This study used a mixed-methods research design with a quantitative survey to reach a large sample, followed by focus groups and interviews to explore the findings on a more nuanced level.

To ground the data collection and analysis in lived experience and ensure alignment with key stakeholder groups, an advisory panel was recruited, made up of people with lived experience from the four target populations.

Three co-design workshops were conducted with this advisory panel. The first focused on testing the research framework and key research questions. The second workshop focused on the qualitative research plan, testing guides for the interviews and focus groups. In the third workshop, the findings were tested and validated to identify if anything was missing or needed additional context or nuance.

Survey

The survey questionnaire was designed by Ipsos and Kaleidoscope in consultation with Breast Cancer Now and the advisory panel to address the key research questions and capture the experiences of the four priority populations. The questionnaire was administered in two ways:

1. Through Ipsos' online access panels, in order to reach those who may not already be connected with Breast Cancer Now, and;
2. Through an open link that was shared through a wide network of Breast Cancer Now partners and Kaleidoscope partners.

The survey was open between 20 September and 16 October 2024 and a total of 2,921 people took part. For the survey through Ipsos' online panels a nationally representative sample of the UK general public was invited to take part, with only people affected by breast cancer progressing to the full survey.

Survey data was reviewed following fieldwork close to check for any differences in profile between the two samples.

Differences noted included:

- More people with a breast cancer diagnosis took part in the open link survey, and those that did so were more often diagnosed within the last five years.
- Family and friends of those affected by breast cancer diagnosis were more likely to take part through the online access panel survey.
- People at increased risk of a breast cancer diagnosis in the future were more likely to take part through the open link survey.
- More broadly, the sample for both surveys overrepresented people from socio-economic group ABC1 and white ethnic groups.

It was decided not to correct for any differences in profile between the two samples due to a lack of consistent profiling information for the four priority populations. Survey data presented is therefore unweighted and combines data from both the online access panel and open link.

Audience	Number of completed surveys
People with a primary breast cancer diagnosis	1,404
People with a secondary breast cancer diagnosis	257
Family/friends of people affected by breast cancer (defined as those with at least one family member or friend with a diagnosis of breast cancer)	1,240
People at increased risk of a breast cancer diagnosis in the future	537

Demographic profile of survey sample	Proportion of completed surveys
Gender	
Female	87%
Male	12%
Age	
18-24	2%
25-34	7%
35-44	13%
45-50	10%
51-60	27%
61-70	26%
71-80	13%
81+	1%
Region	
England (NET)	
Northwest	11%
Northeast	4%
Yorkshire and Humberside	10%
West Midlands	9%
East Midlands	8%
East of England	9%
Greater London	9%
Southeast	15%
Southwest	9%
Wales	5%
Scotland	9%
Northern Ireland	3%
Socio-economic group	
ABC1 (higher socio-economic groups, middle class)	81%
C2DE (lower socio-economic groups, working class)	19%
Ethnicity	
White, including white minorities	93%
Ethnic minorities	6%

Where relevant, differences between sub-groups have been included. Where differences have not been included it is either because there are no significant differences by subgroups, or the size of subgroups is too small for robust analysis (less than 100).

Interviews and focus groups

Twenty semi-structured interviews and four focus groups were conducted (one with each of the target populations) following the quantitative data collection. Interview and focus group participants were recruited through the survey; people were randomly selected (across all four target populations) who provided their contact information and agreed to be contacted to provide further information when they completed the survey.

Guides for the interviews and focus groups were developed with Breast Cancer Now and tested with the advisory panel. Interviews and focus groups were transcribed and coded and the coding was tested for interrater reliability. Thematic analysis of the interviews and focus groups was conducted based on the key research questions in the research framework.

The findings were synthesised from the quantitative and qualitative research and the emergent key findings tested with Breast Cancer Now and the lived experience advisory panel.

References

“Around 55,000 women and 400 men are diagnosed with breast cancer each year.”

Cancer registration statistics, England: 2021 (2023). NHS Digital. Average figures for 2019-21. Cancer Incidence in Scotland (2023). Public Health Scotland. Average figures for 2019-21. Breast cancer incidence (2023). Welsh Cancer Intelligence and Surveillance Unit. Average figures for 2018-20. Northern Ireland Cancer Registry (2023). Average figures for 2019-21.

“A further 7,000 people are diagnosed with DCIS (an early form of breast cancer) each year.”

Based on in situ breast carcinoma incidence statistics, 2016-18 average. Cancer Research UK.

“We don’t know exactly how many people are living with secondary breast cancer in the UK, but it is estimated that there are around 61,000.”

Based on findings from Palmieri, C., Owide, J., & Fryer, K. (2022). Estimated Prevalence of Metastatic Breast Cancer in England, 2016-2021. JAMA Network Open, 5(12), e2248069 doi.org/10.1001/jamanetworkopen.2022.48069. This paper estimates 57,215 people living with secondary breast cancer in England in 2020/21. Combined with requested data from Public Health Scotland (2022) estimating 3,945 people living with secondary breast cancer at the end of 2020.

“5-10% of women with breast cancer are thought to have an inherited altered gene that increases their risk.”

A beginner’s guide to BRCA1 and BRCA2. The Royal Marsden. NHS Foundation Trust

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