

UK Here & Now patient survey

Key findings

Research has shown that women with advanced breast cancer (ABC) often feel isolated from those involved in the fight against early breast cancer.¹

The UK Here & Now ABC patient survey, commissioned by Novartis Oncology, has been designed to build a richer picture of the ABC landscape. The survey explores three key themes:

PERSONAL IMPACT OF ABC

The survey examined the emotional and practical impact of living with ABC, including the wider impact on friends and family

QUALITY OF CARE

The study explored how patients feel about the current management of their disease

DIFFERENCES BETWEEN EARLY BREAST CANCER (EBC) AND ABC

This theme assessed public awareness and knowledge of EBC and ABC

The aim of this survey is to better understand the challenges experienced by the advanced breast cancer patient community at each stage of their journey, and to raise awareness of the disease to further understand the barriers to improved patient outcomes.

The **UK Here & Now survey** was edited and distributed by patient group **Breast Cancer Care** from April – May 2014.

60 patients from all over the UK took part in the survey. These respondents were recruited predominantly through Breast Cancer Care's network as well as individual healthcare professionals to **ensure all voices were heard**.

1. Results of the 2014 Realities of living with ABC survey commissioned by Novartis Oncology in the UK with 60 respondents living with advanced breast cancer distributed by Breast Cancer Care.

**THE
EMOTIONAL
IMPACT OF
ABC**

Women with ABC often feel like many areas of their lives are negatively affected by ABC.¹

- ➔ **72%** of patients feel that their emotional health has been negatively affected by ABC¹
- ➔ The vast majority of patients (78%) feel that **friends and family close to them have been negatively affected** by their diagnosis¹
- ➔ **Half of patients** (50%) stated that their relationship with their partner has suffered due to their illness¹

SUPPORT FROM FAMILY AND FRIENDS

Women with ABC would like more support from friends and family.¹

- ➔ **23%** of patients do not feel that they receive enough support from their **friends**¹
- ➔ **30%** of patients stated that they do not receive enough support from their **parents**¹

**THE CURRENT
MANAGEMENT
OF ABC**

1. SUPPORT FROM A HEALTHCARE TEAM

- ➔ An **overwhelming majority of women** (88%) felt that they received enough **support from nurses**¹
- ➔ This sentiment was also expressed about oncologists as **86%** of patients stated they were supported by their consultant¹
- ➔ **48%** of patients expressed that they would like to have **more time** to discuss their wider needs during visits with healthcare professionals who treat their ABC¹
- ➔ Just under half (48%) of patients stated that once they received their diagnosis they **weren't provided with sufficient resources** about the wider aspects of ABC such as emotional and financial support¹

2. ACCESS TO MEDICINES

Over half (51%) of patients feel that their cancer treatment options are limited.¹

- ➔ An overwhelming majority of patients (87%) feel that there needs to be **more new therapies available to treat ABC**¹
- ➔ **Over two thirds** (72%) of patients expressed that more could be done to provide greater access to new treatment for ABC patients¹

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- ➔ **43%** of patients would like to know more about new potential treatments but are unsure of who to talk to¹
- ➔ Just under half (47%) of patients are unsure (32%) or **do not feel empowered** (15%) to make their own decisions about their treatment journey¹

**DIFFERENCES
BETWEEN EBC
AND ABC**

Following an ABC diagnosis, many patients feel that the level of support from family and friends decreases compared to when they were first diagnosed with EBC.¹

CHANGING LEVELS OF SUPPORT

- ➔ **61%** of patients stated that people have treated them differently compared to when they were diagnosed with EBC¹
- ➔ **Over a quarter** (26%) of patients said that support from friends and family is not as strong now as when they were **first diagnosed with EBC**¹
- ➔ **39%** of patients stated that they do not receive enough support from other women with EBC¹
- ➔ Over **two thirds** (68%) of patients said that they receive enough support from other people with ABC¹
- ➔ **74%** of patients said that there is more information available to the public on EBC than ABC¹
- ➔ **61%** of patients feel **isolated** from the EBC community¹

MEDIA PERCEPTION OF ABC

- ➔ **94%** of patients said that there is greater coverage of EBC than ABC in the media¹
- ➔ **Three quarters** (75%) of patients stated that current reporting on ABC doesn't reflect the realities of living with ABC¹
- ➔ **42%** of patients said that if they had seen information about ABC in the media they may have **recognised their symptoms earlier**¹

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THE CALL TO ACTION

The findings from the UK Here & Now patient survey have not only furthered our understanding of the impact of advanced breast cancer on patients' lives, but have also raised a number of treatment aftercare issues that need to be addressed in order to improve the level of care and support for women living with ABC.

We share these findings with the breast cancer community in the hope that, collaboratively, we can work towards reducing the personal and emotional impact of ABC.

The findings from the survey drive an overall 'call to action' for:

- **Healthcare professionals** to understand they can do more for their patients with ABC
- **Payers, regulators and commissioners** to improve their understanding of the ABC landscape and consider their responsibilities when making decisions about access to care
- **Patient support groups** to build capabilities and feel empowered to further their support for women throughout their breast cancer journey
- **Women with ABC** to feel that they are not alone and that together they can achieve more
- **Health-aware general public** to deal with the wider emotional and psychological needs of women living with ABC

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