

## Pan-European Here & Now patient and carer survey Key findings

The Pan European Here & Now patient and carer survey, commissioned by Novartis Oncology, has uncovered **new and in-depth insights** into the **real life impact of advanced breast cancer (ABC)**, which have not previously been explored on this scale.

To build a **richer picture** of the ABC landscape, the survey explored two key themes:

### THE GREY ECONOMY

The survey examined the socio-economic contributions of women living with ABC, ie performing work that is not recognised or traditionally valued by national / EU government statistics – also referred to as the ‘grey economy’. This includes the loss of ‘useful work’ that patients’ feel they have experienced or are experiencing as a result of their illness, and the subsequent impact on society.

### THE PERSONAL IMPACT OF ABC

This theme looked at the emotional and practical impact of women living with ABC, including the wider impact on family and friends.

The survey involved nine countries:

**France • Italy • Spain • Netherlands • Greece • Austria • Poland • Denmark • Sweden**

**158 patients + 146 carers** took part in the survey, a total of **304 respondents**.

### THE PERSONAL IMPACT OF ABC

Patient feelings focus on worry, living in the moment (the Here & Now) depression and fear for the future. Whilst women with ABC seemingly try to retain some level of positivity, negative feelings are at the forefront of their minds:

- ➔ Following a diagnosis of ABC, **over half** of patients surveyed are worried and **41%** claim to be depressed<sup>1</sup>
- ➔ **Less than a third** of patients feel ‘strong’, are ‘looking forward’ or feel they are ‘surviving’ since their ABC diagnosis<sup>1</sup>

In addition to the emotional impact of ABC, **50%** of patients experience pain and discomfort that affects their daily life.<sup>1</sup>

THE SOCIO-ECONOMIC IMPACT OF ABC

## PERCEPTIONS

**Over half** (51%) of ABC patients surveyed **believe they are perceived negatively by society**.<sup>1</sup> This underlines the need and urgency to improve the level of support for women living with ABC so that they feel included and valued by society.

## TRADITIONAL WORK AND CONTRIBUTIONS

- ➔ **40%** of women in Europe with ABC who were surveyed are working and of those, a quarter work full-time<sup>1</sup>
- ➔ Following an ABC diagnosis, **half of patients** had to make some change to their employment status, with the most common changes to employment being related to a reduced working life (56%)<sup>1</sup>
- ➔ **56%** of patients have experienced a decline in their household income as a result of ABC, with the majority claiming their income has fallen by **30%** or more<sup>1</sup>
- ➔ At the same time, an overwhelming majority, **87%**, said their expenditure had to increase to cover treatment (52%) and further medication (5%). As a direct result of this, **39%** have experienced psychological or physical problems

## SOCIETAL CONTRIBUTIONS (THE GREY ECONOMY)

Following an ABC diagnosis, patients' ability to fulfil an active role in their **home life** falls significantly:

- ➔ **Before** an ABC diagnosis, **74%** of women surveyed were responsible for the housework, **25%** responsible for childcare and **17%** looked after their grandchildren<sup>1</sup>
- ➔ **However**, following an ABC diagnosis, only **35%** are able to conduct housework, **11%** are responsible for childcare and just **9%** are able to look after their grandchildren<sup>1</sup>

Following an ABC diagnosis, patients' ability to fulfil an active role **in the wider community** falls significantly – there is a **29%** decrease in patients' ability to undertake activities outside the home:<sup>1</sup>

- ➔ **Before** an ABC diagnosis, **almost a third** (32%) of patients provided emotional support to friends/neighbours and **21%** carried out voluntary/charity work<sup>1</sup>
- ➔ **However**, following an ABC diagnosis, this drops to **25%** and **11%** respectively as a direct result of their illness<sup>1</sup>

**SUPPORT  
NEEDS OF  
ABC  
PATIENTS**

Only **36%** of women living with ABC have received support from patient groups following an ABC diagnosis and only **37%** have received support from fellow breast cancer patients (ABC and EBC).<sup>1</sup>

- ➔ Only **20%** of patients use patient support groups as a source of information about ABC<sup>1</sup>
- ➔ Patients receive the most support from their family (**88%**), healthcare providers (85%) and friends (59%)<sup>1</sup>
- ➔ In relation to services offered to ABC patients, **79%** of patients surveyed feel it is necessary to improve personal well-being/quality of life and access to treatment (72%), while **68%** also think it is important to improve access to and interactions with healthcare professionals<sup>1</sup>

**ADDRESSING THE CHALLENGES IN ABC**

The findings from the Pan-European Here & Now patient and carer survey have not only furthered our understanding of the true impact of advanced breast cancer on patients' lives, they raise a number of socio-economic issues to address 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 socio-economic 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 feel proud of this generation of women, recognising their value in society