

# Challenges in patient understanding of breast cancer biology and biomarkers

Results from a global survey on advanced/metastatic breast cancer

## Executive summary

# Introduction

Globally, the burden of breast cancer is increasing and with over 2.3 million new cases diagnosed in 2022 alone, it is the second most common cancer.<sup>1</sup> Around 25–40% of individuals with breast cancer will experience a diagnosis of metastatic disease (sometimes referred to as secondary or advanced breast cancer).<sup>2</sup>

Although metastatic breast cancer (mBC) is incurable, in the vast majority of cases, it is treatable.<sup>3</sup> Over recent years, our understanding of breast cancer biology has evolved, leading to new approaches to manage and treat the disease, and clinical decision-making increasingly underpinned by biomarker testing.<sup>3-4</sup> While these advances bring many benefits to patients, healthcare professionals (HCPs), and healthcare systems, they are also adding more complexity for the mBC community to navigate the expanding number of treatment options.

## BIOMARKERS EXPLAINED<sup>5</sup>

BOX

01

Biomarkers (biological markers) are a characteristic that can be measured to provide an indicator of a biological process in a person and may be used for several reasons listed below



### Risk

Indicates likelihood of developing cancer



### Diagnostic

Confirms the presence or type of cancer



### Prognostic

Estimates likelihood of disease recurrence or progression



### Predictive

Predicts efficacy from treatment



### Response

Monitors response to treatment



### Safety

Indicates potential toxicity to treatment

Advancements in the treatment landscape require improved patient understanding of breast cancer biology and biomarkers, so that they can be involved in decisions about their care and treatment. Evidence suggests that many people diagnosed with mBC are keen to work collaboratively with their healthcare teams on decision-making,<sup>6-8</sup> and patient engagement in decisions can help to ensure that they receive optimal care and may improve patient reported outcomes.<sup>9-10</sup> However, studies have shown that people with mBC are often left without adequate support or information to help them understand and navigate their diagnosis.<sup>11-14</sup> In addition, confusion around biomarker terminology resonates throughout oncology.<sup>15-16</sup>

The ABC Global Alliance partnered with AstraZeneca to deliver a global survey assessing the unmet educational needs of patients, to identify opportunities for improved information, education, and support for patients to understand their diagnosis.

This global perception study was developed using key findings from the survey alongside expert opinion from Steering Committee members.

## Patient Biomarker Survey Steering Committee

The ABC Global Alliance convened a Steering Committee of international experts in mBC care and advocacy to review findings from the global advanced/metastatic breast cancer patient biomarker survey.



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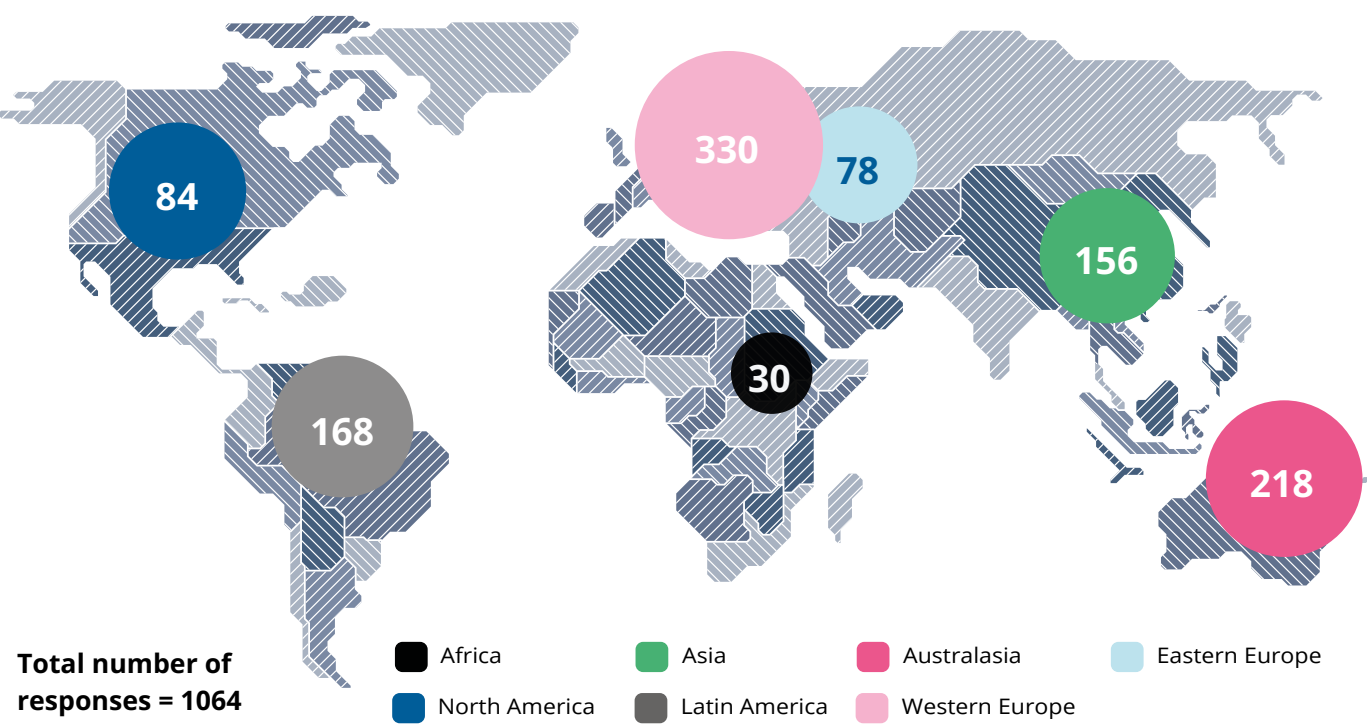
## Acknowledgements

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# Research approach and responses

A multi-language online survey was distributed to people with a self-reported diagnosis of mBC, via the ABC Global Alliance member network. A total of 1064 patients across 36 countries completed the survey – to our knowledge, making it one of the most comprehensive studies to assess understanding of breast cancer biology to date.

GEOGRAPHICAL DISTRIBUTION OF PATIENTS ANSWERING THE SURVEY



## Patient recall and understanding of biomarkers

### Patient understanding of the role biomarkers play in clinical decision-making

For patients to be engaged in shared decision-making they must first understand the role that breast cancer type plays in determining care management and treatment decisions.

#### Survey results showed that:



**81%** of patients understand that breast cancer type guides **treatment decision-making**



**36%** of patients understand that breast cancer type can help to guide **discussions on prognosis**

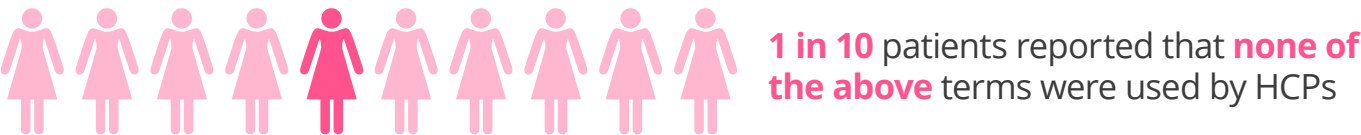
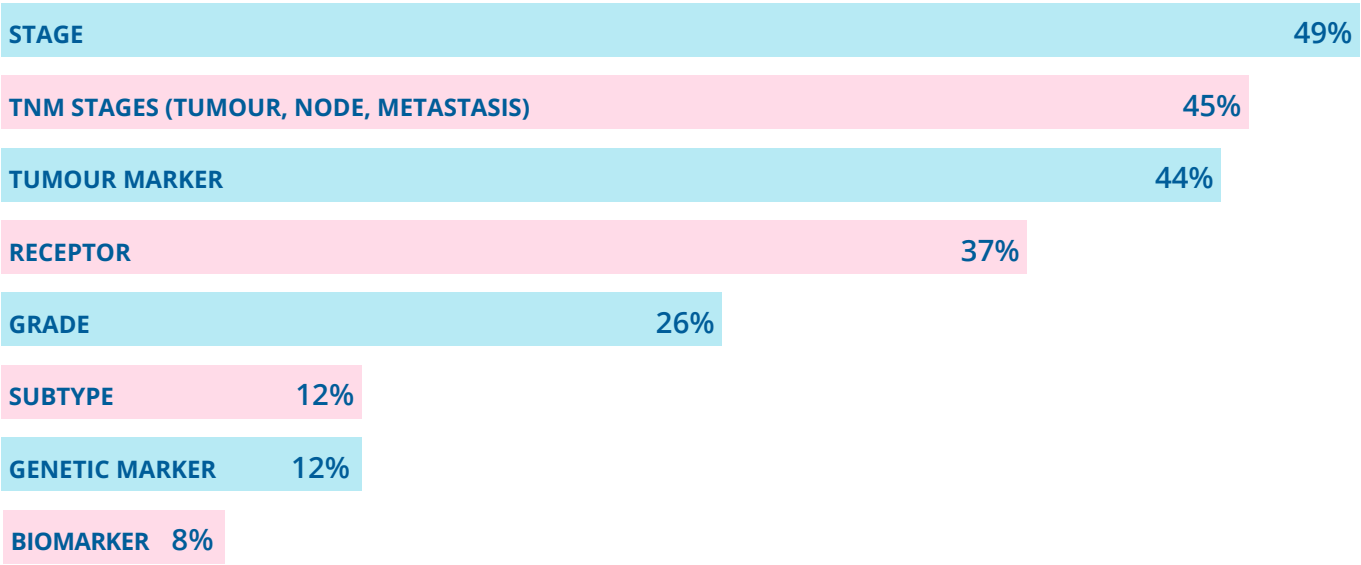
This suggests that patient understanding of the role that breast cancer type plays tends to be treatment-focused, with less knowledge surrounding its role as a prognostic marker. Steering Committee members felt this may reflect the focus of discussions with HCPs, and previous research has shown that information provided by HCPs on prognosis is often variable.<sup>6</sup> However, the focus of discussion between HCPs and patients may also be led by patients’ own preference to focus less on prognosis,<sup>12</sup> or by the availability of, and access to, testing and targeted treatments. This highlights the importance of an individualised and compassionate approach to communication based on patient preferences, the disease course, and available treatment options.

## Patient recall of terminology used to discuss breast cancer diagnosis

The terminology used to describe different types of breast cancer and the underlying biology can be complex due to the focus on scientific jargon and the use of multiple terms with similar meanings,<sup>16</sup> making it difficult for patients to follow. Although patients may know that breast cancer type guides treatment decisions, survey results suggested that many patients may not know the specifics of their diagnosis.

Patients reported wide variation in the terminology used by HCPs to discuss breast cancer diagnosis.

PATIENT REPORTED TERMS USED BY THEIR HEALTHCARE TEAM TO DISCUSS BREAST CANCER



This may indicate an overall preference for using certain words or phrases, and some words used commonly in the field (such as biomarker) may not often be used with patients.

## Patient recall of specific terminology used to describe breast cancer type

When patients were asked more specifically about biomarker terminology (for example, hormone receptor-positive (HR+) or HER2+) that was used when they were first diagnosed with mBC, recall levels were low.

11%

of patients reported that they **did not know which specific biomarker terms** were used by HCPs to describe breast cancer type

44%

of patients reported that the term **HR+** was used, which is considerably lower than the average prevalence of HR+ mBC\* (~78%)<sup>17</sup>

In addition, selection of HER2+ was much higher than the average prevalence for this marker\* (29% compared with ~14%)<sup>17</sup>, which may suggest confusion between options, such as HER2+ and HR+, or lack of knowledge from patients about what type of breast cancer they have. Notably, selection of HR+ was much higher for patients from North America (73%) compared with the average for all patients.

### Low levels of recall of biomarker terminology could be for a variety of reasons, including:

- Steering Committee members felt the provided terminology **may not be commonly used or explained to patients**, due to the use of alternative, more patient-friendly language. Alternatively, limited implementation of testing,<sup>18</sup> or low HCP confidence in discussing the information,<sup>19</sup> may mean terms are not discussed
- **Patients may not understand the terminology** that is used,<sup>15-16,20</sup> affecting their level of recall
- **Patients may not recall what was discussed** due to the shock or denial associated with mBC diagnosis,<sup>21</sup> or as discussed by Steering Committee members, fear of the implications of information (e.g., BRCA1/2)

\*Statistics cited for the US (2015-2019) and may vary by geography and race

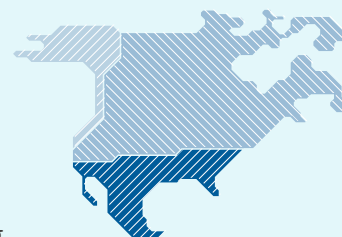
## REGIONAL DIFFERENCES

**There were significant differences between regions in the selection of some terms over others.**

For example, while 'stage' was reportedly used with 88% of patients from North America, only 23% of patients from Western Europe selected this term, and conversely for 'TNM stages' 63% of patients from Asia reported that this term had been used compared with 24% from North America.

**Overall recall of both specific and more general terminology was lower among patients from low-and-middle-income regions (e.g., Africa and Latin America).**

Steering Committee members agreed this may reflect limited access to testing and targeted treatments impacting how much patients are able to learn about their diagnosis.



**By contrast, recall was much higher for North American patients than other regions.**

Possible reasons include:

- Policies which mandate direct access to diagnostic information<sup>22</sup>
- Better access to available resources in their native language<sup>11</sup>
- Localised educational efforts promoting better understanding in the region of precision medicine concepts<sup>23</sup>

## Patient understanding of breast cancer type

Beyond the recall of specific terms, survey results indicated that patients do not feel confident about their diagnosis.



**1 in 3 patients** indicated that they do not know what type of breast cancer they have or understand what it means

Findings align with previous research highlighting that many patients do not know about or understand the biomarker tests that they have had.<sup>15,20</sup> This suggests that many patients may not understand the full picture of their diagnosis, and the implications for treatment options and the disease course, limiting their ability to advocate for themselves and be part of shared decision-making discussions.



# Barriers to patient understanding of biomarkers

## HCP COMMUNICATION

HCPs play an important role in helping patients understand how their breast cancer type relates to clinical decision-making. However, survey results indicate that in-depth explanations or the provision of information on the specifics of a patient's diagnosis may be lacking.

**66%**

of patients reported that their HCPs **had told them why it is important** to know about the type of breast cancer they have

**44%**

of patients reported that their HCPs had **given them all the information** they need about the type of breast cancer they have

This suggests that information is often insufficient to meet patients' needs, and may prevent them from understanding and taking part effectively in decisions. It also corroborates multiple other studies highlighting gaps in the information provided by HCPs.<sup>6,11-13</sup>

Both within and beyond breast cancer, reported barriers to effective HCP communication with patients include pressures on consultation times, which can limit physicians' capacity to explain information, and a lack of tailoring of information to the health literacy level of the average patient.<sup>11,20,24</sup> HCPs themselves may also lack confidence in implementing biomarker testing, understanding results, or describing information on the tests to patients.<sup>19,25</sup> These issues may be more pronounced for HCPs in lower resource and more rural healthcare settings, along with difficulties accessing tests and treatments in the first place.<sup>20,25</sup>

**10%**

of patients from **Western Europe** reported that **HCPs had not told them what type of breast cancer they have**, suggesting that challenges in the delivery of information by HCPs may exist for some patients in regions with better access to testing, support, and informational resources



## INFORMATION SOURCES

Patients reported seeking information from a variety of sources to learn more about the type of breast cancer they have:



**70%** cited using the **internet**



**64%** reported asking their **doctors**



**45%** asked **other people diagnosed with breast cancer**, which may indicate that many patients wish to receive information from those they feel have shared experiences

Patient preference for the internet as an information source in this survey aligns with the heavy reliance on online healthcare information demonstrated in other studies.<sup>6,26-27</sup> Although online information carries many benefits, allowing patients to seek information in their own time and provide extra detail, it also has potential for spreading misinformation.<sup>27</sup> Moreover, navigating to useful information specific to mBC can be difficult and the quantity of information can be overwhelming.<sup>14,27</sup>



**39%** of patients turned to **patient advocacy and support groups** for more information on their diagnosis

Despite these groups forming an important method of peer-to-peer information dissemination, other studies have shown that patients are often unaware of who their local advocacy groups are.<sup>11</sup> Taken together with survey results, this suggests patient-centred organisations may be an underutilised source of information and that HCPs may not be signposting patients to them.<sup>11</sup>

## Trends in patient understanding of their diagnosis and information-seeking behaviour




### TIME LIVING WITH MBC

A diagnosis with mBC can be difficult to come to terms with, and individuals may experience a state of shock and denial impacting their ability to retain information.<sup>12,21</sup> Over time, patients may learn more about the disease as they have additional rounds of treatment, prompting further discussions, questions, or research. Therefore, patients' understanding and motivation to seek information on the type of breast cancer they have may evolve during the disease course.

Supporting this notion, survey results showed that patients' understanding, and informational needs differed depending on time living with mBC.


Diagnosis **less**  
**than a year ago**

**59%**



Understanding  
breast cancer type


**57%**




Asking doctors  
for more information

Diagnosis **more**  
**than a year ago**

**69%**



**66%**



Patients receiving a diagnosis within the past year (at time of survey completion) were less likely to report that they had understood the type of breast cancer they have (compared with those diagnosed more than a year ago), which may indicate that experience with the disease shapes understanding.

These patients were also less likely to ask their doctor for more information compared with those diagnosed more than a year ago, which may suggest they have lower motivation to ask questions, or as Steering Committee members noted, may simply not know what to ask. Taken together, these findings align with previous research demonstrating that the informational and support needs are higher for people who have been diagnosed with breast cancer most recently.<sup>12,14</sup>



## MOTIVATION TO SEEK INFORMATION

Attitudes towards the HCP–patient relationship have evolved from more paternalistic models of care to an increasing focus on shared decision-making, with many patients indicating that they would like to be involved.<sup>6,8</sup> However, some patients may wish to have less responsibility.<sup>7,28</sup>

7%

of patients reported that they **did not want to learn** more about the type of breast cancer that they have

These patients were less likely to:

- Seek information from a variety of sources
- Understand what type of breast cancer they have
- Be told by HCPs why it is important to know what type of breast cancer they have

For some patients, they may not know why it is important for them to know about their breast cancer type and be engaged in decision-making. Steering Committee members noted that a lack of explanation from HCPs may contribute to patients’ low motivation to seek information, setting the course for their level of interest. Alternatively, some patients may not want to know about their diagnosis and thus are unlikely to be willing to engage in or recall discussions with their healthcare team.

### Steering Committee members also discussed a variety of reasons for why patients may not want to find out more about their diagnosis, including:



**Health literacy levels:** patients’ health literacy levels may influence not only their ability to understand information, but also their desire to find out more information.<sup>30</sup> Some patients may find seemingly complex terms or concepts too overwhelming and avoid the burden of too much information and rely on doctors to ‘know best’<sup>24,28</sup>



**Access to testing and treatments:** socioeconomic or geographical barriers to accessing biomarker testing and treatments may limit patients’ ability to learn about their diagnosis and impact their motivation. It may also leave HCPs with an ethical dilemma of whether to discuss information regarding diagnostic or therapeutic approaches that patients will not have access to



**Language barriers:** available resources are mainly available in English making it difficult for non-English speaking patients to learn about their diagnosis outside of consultations,<sup>30</sup> particularly given the use of the internet as a key information source



**Cultural norms or preferences:** cultural or religious factors may influence patient willingness to understand the type of breast cancer they have and be involved in shared decision-making. Paternalistic models of care may be more common in certain geographies where patients rely on healthcare professionals to make decisions and therefore believe there is no need to learn about their diagnosis.<sup>29</sup> Reliance on faith can also play a large role in some communities<sup>2,7</sup>

## REGIONAL DIFFERENCES

The **proportion of patients from Latin America** (17%) was much higher in the **‘low motivation’ subgroup** compared with other regions (0-10%).

Steering Committee members noted this may in part reflect the above factors, with disparities in access to testing and treatments, cultural norms relying more heavily on faith and HCPs for their fate, lower health literacy levels, and limited access to local language educational resources.

This survey was not powered to understand the barriers in many lower socioeconomic countries, and additional research, in lower resource settings (both within and outside of Latin America) will be important to explore these factors further and provide tailored support.



# What can be done to improve education about biomarkers for people with mBC?

1

## Elevate the effectiveness of communication between HCPs and patients



- Standardise and promote the use of patient-focused terminology to describe mBC biology and biomarkers to improve the clarity and consistency of information
- Leverage and expand existing care models and practices to facilitate effective two-way communication and information delivery across the patient pathway, such as patient navigation services, flexible and remote consultations, specialised nurses, and shared decision-making tools

2

## Empower patients with information and guidance for self-advocacy



- Activate the mBC patient community to self-advocate for better knowledge and engagement in decisions through improved support, guidance, and empowerment campaigns
- Improve the accessibility of patient advocacy and support groups and their available resources to accelerate education and patient empowerment
- Accelerate and expand access to peer-to-peer support groups by developing frameworks to improve information sharing practices and better serve patient understanding

3

## Activate local patient advocacy groups to drive change and advocacy



- Promote and translate best-practice initiatives between geographies that empower patients with information and support using existing advocacy networks to strengthen collaboration
- Activate and support local patient advocacy groups to conduct targeted research into specific challenges and create tailored solutions to drive equity in access to information about diagnosis

**Findings highlight widespread educational needs for people living mBC to help them understand their diagnosis. We encourage the breast cancer community to collaborate across geographies, disciplines, and disease areas to empower patients with the knowledge about their biomarker status, to engage more effectively in shared decision-making and advocate for the best possible care for themselves.**



**Additional documents summarising findings from the survey are available at:**  
<https://www.abcgloballiance.org/resources#biomarker-survey>

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