

# Challenges in patient understanding of breast cancer biology and biomarkers

Results from a global survey on advanced/metastatic breast cancer

A summary for patients, caregivers, and advocates

# What are biomarkers and why are they important?

A diagnosis of metastatic breast cancer (mBC) can be overwhelming, and the language used to describe breast cancer biology can be complex.<sup>1,2</sup> This may make it difficult for people to understand what type of mBC they have and what it means.<sup>3</sup>

Each diagnosis of mBC is different. Biomarker testing is used to find out what type of breast cancer a person has in order to help make decisions about their care and treatment based on the specific biology of the cancer.<sup>4</sup>

## BIOMARKERS EXPLAINED<sup>4</sup>

BOX

01

Biomarkers (biological markers) are measurable signs in the body that show how a biological process is happening or changing in a person. They 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 the disease returning or worsening



### Predictive

Predicts how well the treatment will work



### Response

Monitors response to treatment



### Safety

Shows how harmful the treatment may be

Targeted treatments rely on biomarker testing to determine whether the treatment is likely to work. These types of treatments are becoming more common in mBC,<sup>5</sup> so understanding biomarkers and breast cancer type is becoming more important for patients.

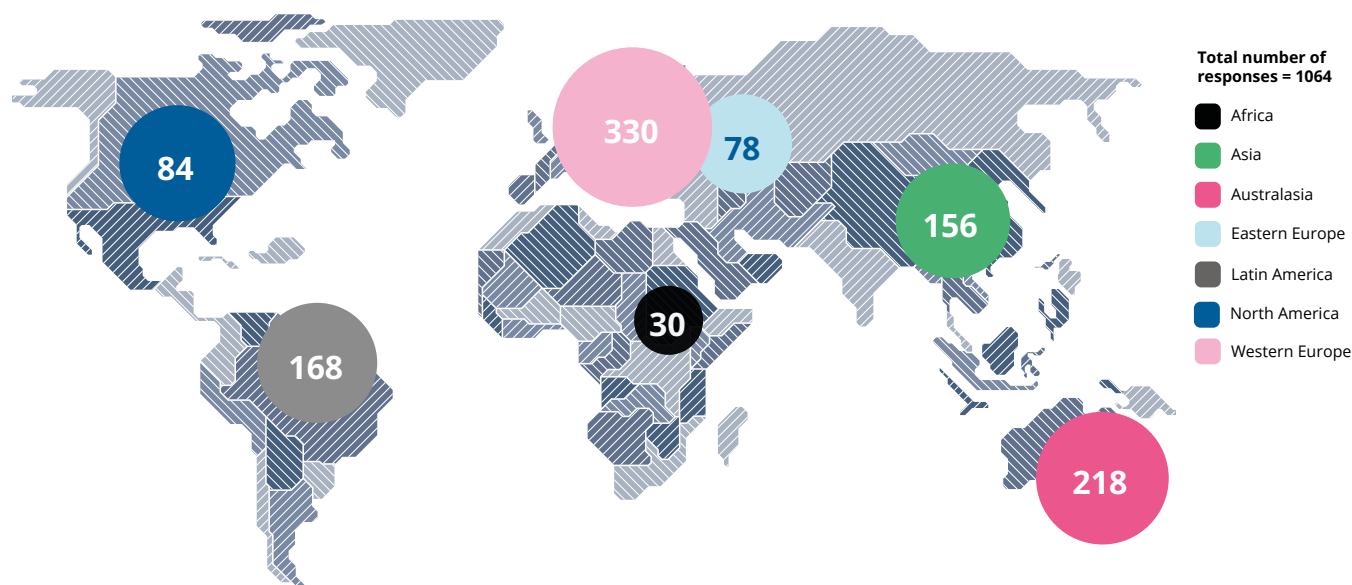
Many people with mBC want to be involved in healthcare decisions,<sup>6</sup> but often don't understand what type of breast cancer they have or what their biomarker status is.<sup>3,7</sup> Learning about breast cancer type and biomarkers can help patients to:

- Understand treatment options
- Be part of decisions about their care
- Feel more in control of the disease

## What type of study was delivered?

The ABC Global Alliance partnered with AstraZeneca to conduct a global online survey with 1064 people living with mBC in 36 countries, to better understand their educational needs and identify how to improve learning about biomarkers and participation in decisions.<sup>3</sup>

GEOGRAPHICAL DISTRIBUTION OF PATIENTS ANSWERING THE SURVEY



## What did the study find?

### Patient recall and understanding of biomarkers

It is important for people diagnosed with mBC to know about the specific type of breast cancer they have, including relevant biomarkers, and how these details impact decisions about their care and treatment.

Survey results showed that generally patients were aware that breast cancer type helps to determine treatment decisions but were less aware of its role in guiding discussions on how likely the cancer is to worsen or spread (also known as prognosis).<sup>3</sup>

#### Survey results showed that:



**81%** of patients know that breast cancer type helps to guide **treatment decisions**

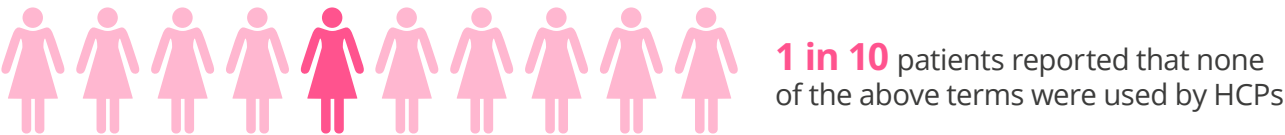
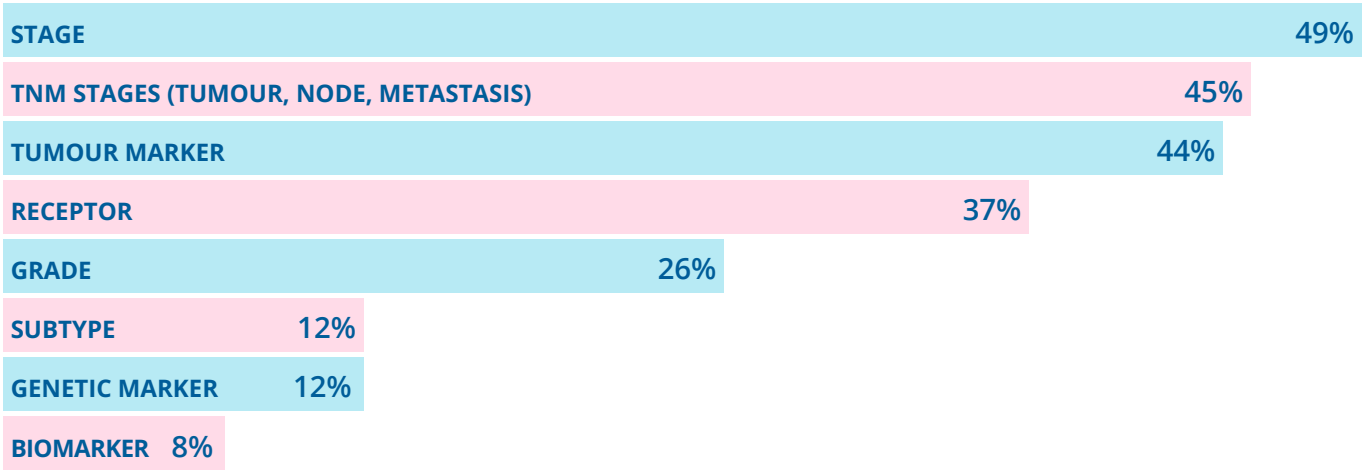


**36%** of patients know that breast cancer type helps to guide **discussions on prognosis**

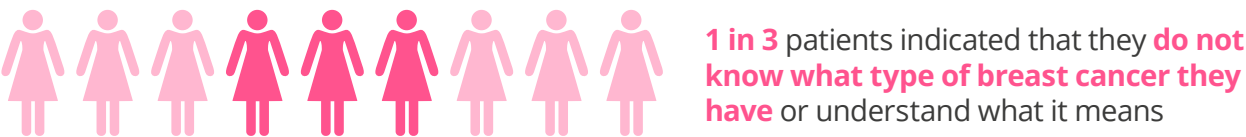
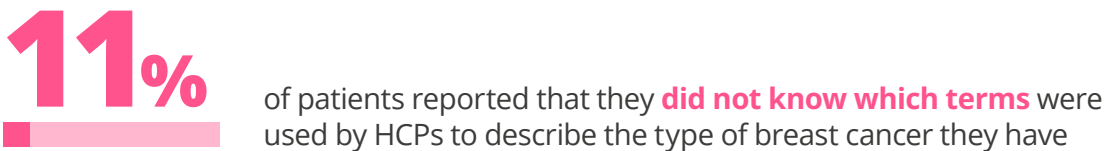
This suggests that discussions with healthcare professionals (HCPs) may focus more often on treatment, rather than on prognosis. In some cases, patients may prefer less information on prognosis, while others may wish they had more so that they feel prepared and can make decisions based on the full picture of the disease.<sup>1</sup>

Understanding the specifics about an mBC diagnosis can also be difficult for patients, with complicated language or scientific jargon often used.<sup>2</sup> Patients reported large differences in the terms used by their HCPs to describe a diagnosis.<sup>3</sup>

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



Furthermore, patients had low recall of the specific biomarkers that might be used to determine breast cancer type (e.g., hormone receptor-positive) and there were widespread gaps in patient understanding.<sup>3</sup>



This suggests that patients are not receiving clear information about the details of their diagnosis to help them participate in decisions about their care and treatment.


## Barriers to patient understanding of biomarkers

### HCP COMMUNICATION

HCPs around the world are dealing with growing demands on their time and resources making it harder for them to communicate effectively with patients.<sup>8</sup>


Survey results suggested that even if HCPs explain why breast cancer type is important to decisions about which treatment to use, they might not always go into the detail about the specifics of diagnosis.<sup>3</sup> In some cases, HCPs might find it difficult to explain information about the specifics of diagnosis to patients,<sup>12</sup> or might not explain in a way that patients understand.

**66%**



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

**44%**



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

### INFORMATION SOURCES

Although HCPs remain an important information source, patients often rely on the internet for healthcare information because it lets them find answers in their own time when questions come up and may help to fill gaps in their knowledge.<sup>13</sup>

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



**70%** used the **internet**



**64%** asked their **doctors**



**45%** asked **other patients**



**39%** turned **to patient advocacy or support groups**

The internet was the most commonly reported source of information. However, this comes with risks because unreliable sites can spread misinformation. The amount of information available online can also be overwhelming, and it is often hard to find clear and useful information specifically about mBC.<sup>13,14</sup>

Responses also showed that many people with mBC look to others who have had similar experiences with the disease to learn more. Although some individuals do turn to patient advocacy or support groups for information, results suggest more could be done to help patients find the reliable and patient friendly resources that these groups offer.

## INDIVIDUAL FACTORS

A person's ability to understand their diagnosis can also vary depending on their individual circumstances, their preferences, or the different stages of the disease.



**In early stages, initial shock or denial can limit patient recall and understanding of information**, and their ability to engage with their doctor.<sup>3,9</sup> Patients diagnosed less than a year ago were ~10% less likely to understand their diagnosis, or ask their doctor for more information compared with patients diagnosed more than a year ago.



**Patients may also have differing abilities to understand and use medical information or concepts**, in part due to their education background.<sup>7</sup>



**Some patients may have low motivation to learn about their diagnosis**, with 7% saying they do not want to learn more. This may be because they believe it is too difficult, or that it is not necessary, instead relying on HCPs to make decisions.<sup>9,11</sup> Others may believe that nothing can be done, due to the lack of cure or if there are not treatments available to them.



**A lack of access to testing and treatments** may mean that, for some patients, breast cancer type is not assessed or discussed.<sup>3</sup>



In some countries, **information resources may be less accessible** due to most being in English or countries may lack patient advocacy groups that can support education about biomarkers.<sup>8</sup>



**Between populations or geographies, local culture may influence beliefs and behaviour towards the patient-doctor relationship.**<sup>10</sup>

This may impact how reliant patients are on doctors to make decisions, and how much they feel the need to understand and learn about their diagnosis so that they can be involved.<sup>10-11</sup>

# What can be done to improve education about biomarkers for people with mBC?<sup>3</sup>

1

## Improve communication between patients and HCPs



- Expand best practices that improve communication between patients and HCPs, like patient navigation services, specialised nurses, and shared decision-making resources
- Update and adapt patient education resources to include information about biomarkers and breast cancer type, and share widely with patient and medical organisations
- Establish joint educational platforms for patients and HCPs, either online or in person, to enable better two-way communication
- Publicise best practice materials and resources among the medical community to raise awareness of the need for improved communication around biomarkers

2

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



- Encourage patients with lived experiences to share their stories to prompt other patients to take an active role in learning about their diagnosis
- Expand peer support systems by:
  - Facilitating access to peer support groups for those with mBC to share information and resources
  - Implementing peer-navigation programs that equip patients with the right information and resources at the right time
- Develop self-advocacy guidance, including online or face-to-face sessions for self-advocacy training, empowering patients with methods on how to manage their diagnosis and what to ask HCPs throughout their experience

3

## Work with local patient advocacy groups to drive change and advocacy



- Strengthen patient organisation networks focused on mBC, breast cancer, and cancer generally, and support them to develop and work towards common goals
- Promote best-practice initiatives and insights among patient organisations globally, focused on both mBC and cancer generally
- Activate local patient advocacy groups to conduct further research into local barriers, and help them develop solutions that address local needs (e.g., culture, education levels, access to testing), improving equal access to information



**This document is a summary of a whitepaper available at:**

<https://www.abcgloballiance.org/global-abc-mbc-patient-biomarker-survey-white-paper>

A SUMMARY FOR PATIENTS, CAREGIVERS, AND ADVOCATES

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## References

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1. mBC Decade report. Global status of Advanced/ Metastatic Breast Cancer. Available from: [https://breastcancernow.org/sites/default/files/global\\_status\\_of\\_metastatic\\_breast\\_cancer\\_2005\\_to\\_2015\\_decade\\_report\\_full\\_report.pdf](https://breastcancernow.org/sites/default/files/global_status_of_metastatic_breast_cancer_2005_to_2015_decade_report_full_report.pdf). Accessed October 2024.
2. Cancer Support Community. Patient Preferences and Understanding of a Precision Medicine Lexicon—Towards the Development of Patient- Friendly, Consistent Terminology. Available from: [https://www.cancersupportcommunity.org/sites/default/files/file/2021-11/AONN\\_2021\\_Poster\\_Precision\\_Medicine.pdf](https://www.cancersupportcommunity.org/sites/default/files/file/2021-11/AONN_2021_Poster_Precision_Medicine.pdf). Accessed October 2024.
3. Challenges in patient understanding of breast cancer biology and biomarkers: Results from a global survey on advanced/metastatic breast cancer. Available from: <https://www.abcgloballiance.org/global-abc-mbc-patient-biomarker-survey-white-paper>. Accessed October 2024.
4. FDA-NIH Biomarker Working Group. BEST (Biomarkers, EndpointS, and other Tools) Resource. Silver Spring (MD): Food and Drug Administration (US); 2016-. Co-published by National Institutes of Health (US), Bethesda (MD).
5. Miglietta F, Bottosso M, Griguolo G, Dieci MV, Guarneri V. Major advancements in metastatic breast cancer treatment: when expanding options means prolonging survival. *ESMO Open*. 2022;7(2):100409.
6. Fallowfield L, Starkings R, Palmieri C, Tait A, Stephen L, May S, et al. Living with metastatic breast cancer (LIMBER): experiences, quality of life, gaps in information, care and support of patients in the UK. *Support Care Cancer*. 2023;31(8):149.
7. Fortune EE, Zaleta AK, Saxton MC. Biomarker testing communication, familiarity, and informational needs among people living with breast, colorectal, and lung cancer. *Patient Educ Couns*. 2023;112:107720.
8. Fallowfield L, Boyle FM, Travado L, Kiely BE, Jewell P, Aubel D, et al. Gaps in Care and Support for Patients With Advanced Breast Cancer: A Report From the Advanced Breast Cancer Global Alliance. *JCO Glob Oncol*. 2021;7:976-984.
9. Cancer Research UK. How cancer can make you feel. Shock and Denial. Available from: <https://www.cancerresearchuk.org/about-cancer/coping/mental-health-cancer/how-cancer-make-you-feel/shock-denial>. Accessed October 2024.
10. Ginsburg O, Vanderpuye V, Beddoe AM, Bhoo- Pathy N, Bray F, Caduff C, et al. Women, power, and cancer: a Lancet Commission. *Lancet*. 2023;402(10417):2113–66.
11. Rocque GB, Rasool A, Williams BR, Wallace AS, Niranjani SJ, Halilova KI, et al. What Is Important When Making Treatment Decisions in Metastatic Breast Cancer? A Qualitative Analysis of Decision- Making in Patients and Oncologists. *Oncologist*. 2019;24(10):1313-1321.
12. White S, Jacobs C, Phillips J. Mainstreaming genetics and genomics: a systematic review of the barriers and facilitators for nurses and physicians in secondary and tertiary care. *Genet Med*. 2020;22(7):1149-1155.
13. Holmes MM. Why People Living With and Beyond Cancer Use the Internet. *Integr Cancer Ther*. 2019;18:153473541982983.
14. Breast Cancer Network Australia. BCNA Member Survey Report 2017. Available from: [https://bcna-dxp.azureedge.net/media/alci/mm2/bcna\\_member-survey-report\\_2017.pdf](https://bcna-dxp.azureedge.net/media/alci/mm2/bcna_member-survey-report_2017.pdf). Accessed October 2024.