ABC GlobAlliance

Challenges in patient understanding of breast cancer biology and biomarkers: **Results from a global survey on advanced/metastatic breast cancer**

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AstraZeneca

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Foreword

The last 20 years have been marked by substantial scientific advancements and changes in our understanding of breast cancer biology. Tailoring care management and treatment plans to patients' individual diagnoses is now an expectation. Changes to how we manage breast cancer are translating into positive impact for patients, with many living longer with the disease, including those with a metastatic diagnosis.

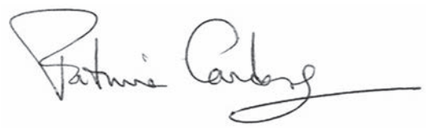
As our understanding of breast cancer biology evolves, so too does the complexity surrounding language, biomarkers, and treatment choices. These complexities raise challenges, in particular, for patients – from understanding their diagnosis to engaging in shared decision-making and feeling any sense of control over their disease. Additional factors, such as health literacy levels and increasing pressure on healthcare professionals from a time and resource perspective further exacerbate the challenge of ensuring patients understand their diagnosis.

A lack of support is a familiar feeling for those diagnosed with metastatic breast cancer (mBC) in many aspects of their daily lives and patients are often left feeling forgotten by society. A diagnosis with mBC can be difficult for patients to comprehend, let alone the increasing number of biomarker tests, treatment options, and what these mean to them in the face of an incurable disease.

The mBC community has a duty to ensure our patients are informed and equipped to participate in decisions, and advocate for the best possible care based on their preferences.

Over the past seven years, the Advanced Breast Cancer (ABC) Global Alliance has worked tirelessly to advocate for the needs of those affected by the disease and will continue to do so. However, this task cannot be undertaken alone. We continue to collaborate and engage in research across the community, such as this study, to unearth the challenges faced by patients in understanding their mBC diagnosis.

We hope that the extent of these challenges globally, as identified from a survey of over 1,000 patients, across 36 countries, will help provide patient advocacy groups, industry, healthcare professionals (HCPs), and other key stakeholders with the impetus to empower patients with improved education, support, and information so that the voices of mBC patients continue to be amplified.



Dr. Fatima Cardoso, ABC Global Alliance and Breast Unit, Champalimaud Clinical Center/ Champalimaud Foundation, Lisbon, Portugal

Rosemary Carolan, Director Global Patient Affairs, Oncology, AstraZeneca

www.abcglobalalliance.org
info@abcglobalalliance.org
@ABCGlobalAll
@ABCGlobalAll
@ABC-Global-Alliance

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Patient Biomarker Survey Steering Committee

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 biomarker survey. This study contains perspectives and insights from Steering Committee members on the survey findings and key challenges faced by patients in learning about their diagnosis, and call-to-action for the breast cancer community, along with supporting referenced literature.

Dr. Fatima Cardoso, ABC Global Alliance and Breast Unit, Champalimaud Clinical Center/ Champalimaud Foundation, Lisbon, Portugal

Runcie C.W. Chidebe, Project PINK BLUE -Health & Psychological Trust Centre, Abuja, Nigeria, Department of Sociology and Gerontology, Miami University, Ohio, USA

Prof. Lesley Fallowfield, Brighton & Sussex Medical School, University of Sussex, United Kingdom

Dr. Alexandru Eniu, Hôpital Riviera-Chablais, Vaud-Valais, Switzerland

Ranjit Kaur Pritam Singh, Breast Cancer Welfare Association Malaysia (BCWA), Petaling Jaya, Malaysia

Renate Haidinger, Brustkrebs Deutschland e.V. (German Breast Cancer Association), Munich, Germany

Eva Schumacher-Wulf, Brustkrebs Deutschland e.V. (German Breast Cancer Association), Munich, Germany

Vicki Durston, Breast Cancer Network Australia, Camberwell, Australia

Executive Summary

The number of individuals diagnosed with breast cancer is rapidly increasing and scientific developments mean many people with metastatic disease are living longer.[1-3] With targeted treatments being used more frequently, clinical decision-making has become increasingly underpinned by biomarker testing.[4] For patients to be actively engaged in decision-making and advocate for what is right for them, they require an understanding of the expanding role of biomarker testing, and its relevance to possible treatments and outcomes.

To guide improved information, education, and support for people diagnosed with mBC, this global study set out to investigate the recall and understanding of information provided with a mBC diagnosis and relevant biomarkers. The challenges outlined in this study highlight continued confusion around biomarker terminology and limitations in available information and support for patients with mBC, mirroring those from previous studies.[5-10] Opportunities for change are provided herein to empower patients with the knowledge to take an active role in their own care. While the study focused on mBC, many of the findings may be relevant across breast cancer more broadly, as well as other types of cancer, warranting collective action from the cancer community.

Effective communication is a core component of quality care

The language used to describe biomarkers is complex and used inconsistently. As a result, many patients are left feeling confused and unsatisfied with the information provided by HCPs, and do not feel confident in understanding their diagnosis. This challenge may be compounded for those who are recently diagnosed, where the initial shock of diagnosis may hinder their ability to digest information. There is a clear need to use standardised language, but also to tailor communication to individual patient needs and health literacy levels to help them understand their diagnosis and its relevance to clinical decision-making. Improved models of care delivery and support are also needed for HCPs across the multi-disciplinary team to overcome time pressures and enhance information delivery to patients throughout their experience with mBC.

This is imperative to meet increasing global expectations for shared decision-making in clinical practice and improve the overall patient experience, contributing to improved quality of care.

Patients should feel empowered not powerless

Informed patients make the best advocates for themselves, but many lack the relevant education and support needed for self-advocacy. While a plethora of information is available to patients on their diagnosis, it is often challenging to navigate and decipher which sources are most reputable, such as those provided by patient advocacy groups. Furthermore, some patients do not wish to learn more about the type of breast cancer they have or engage in shared decision-making, and sometimes this is due to a lack of education on why it is important. There is an urgent need for easily signposted, patient-focused, useful information. Additionally, empowerment campaigns and guidance on self-advocacy are crucial to educating patients on how they can be engaged and why it is important, so that they can ensure they receive the right care at the right time.

Local activation and advocacy are critical to accelerating change

Geographical barriers may hinder patients' understanding of their diagnosis. Different healthcare systems, local culture, patients' socioeconomic status, and health literacy levels can all influence the effectiveness of communication between HCPs and patients. For some patients, access to biomarker testing and associated targeted treatments remains the primary challenge. Local patient organisations are needed to facilitate research into country-specific challenges, and drive individualised education and support depending on local patient needs. In areas where access is a challenge, advocacy groups will have a critical role to play in raising awareness of the contributions those living with mBC make to society and the burden they face, to encourage investment into local policies and infrastructure. Across geographies, the collective efforts of advocacy networks will be paramount to driving macro change, by sharing insights, learnings, and best-practice initiatives to promote change across the global mBC and broader breast cancer community.

Introduction

Over 2.3 million people were diagnosed with breast cancer in 2022, making it the second most commonly diagnosed cancer worldwide.[3] This number is only set to increase, with incidence predicted to grow by over 45% by 2045.[3] Many of these patients will experience advanced or metastatic disease, which is also sometimes referred to as secondary breast cancer (for the purposes of this report the term mBC will be used). Approximately 10% of all first breast cancer diagnoses are metastatic (referred to as *de novo*), and a further ~20–30% of individuals diagnosed with breast cancer will go on to receive a metastatic diagnosis.[11] Although these statistics illustrate the significant burden of the disease, it is likely that they underestimate the true extent of mBC due to gaps in routinely collected data.[7]

Although mBC remains an incurable disease, in the vast majority of cases, it is treatable.[2] Over recent years our understanding of breast cancer biology has evolved, leading to the discovery of new breast cancer types and novel therapeutic targets.[2] This has led to significant advances in the treatment landscape for mBC, with new targeted treatments leading to optimised care and driving extended survival for many people living with the disease.[2,4] While these advances bring many benefits to patients, HCPs, and healthcare systems, they are accelerating the need for biomarker testing and, in turn, adding more complexity for the mBC community to navigate the expanding number of options.

Advancements in the treatment landscape require improved patient understanding of breast cancer biology and biomarkers, in relation to diagnosis and treatment. This is particularly important in mBC where a major goal of optimised care is maintaining quality of life, and therefore decisions require informed-input from patients.

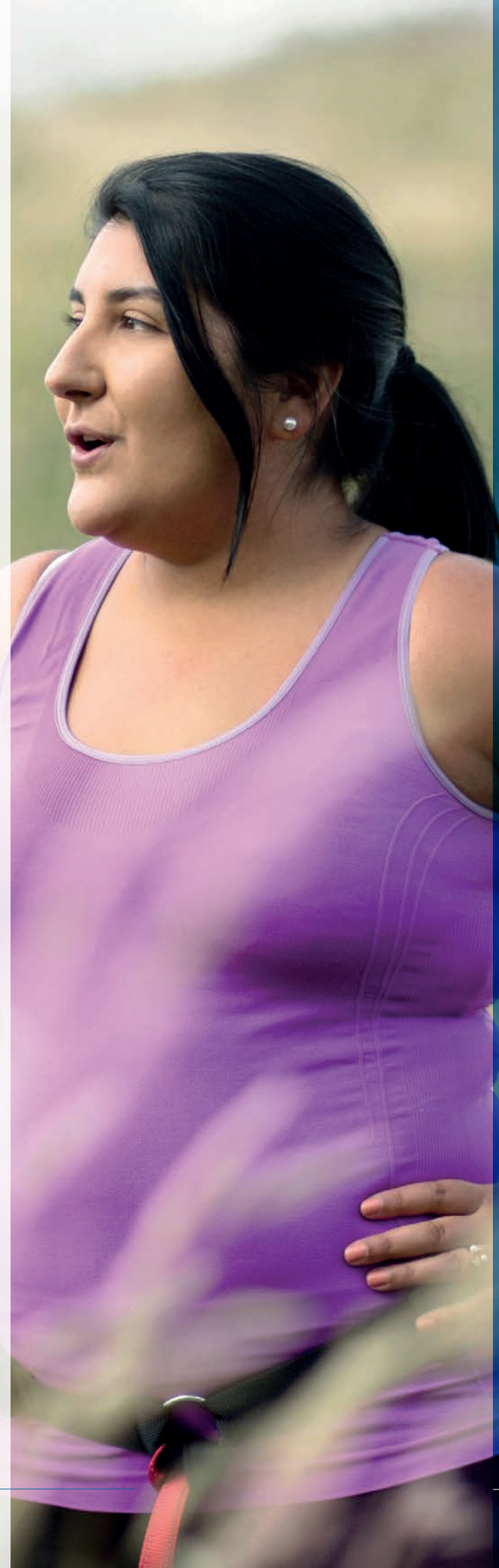
Evidence suggests that many individuals diagnosed with mBC are keen to work collaboratively with their healthcare teams.[5,12-13] Moreover, shared decision-making is associated with improved patient-reported outcomes, including reduced decisional regret and higher perceived quality of care.[14,15] Thus it is vital to promote patient involvement in shared decision-making surrounding their treatment and care management plan.

To support patients more effectively, it is essential to identify the current educational needs among those living with mBC, as well as barriers preventing them from understanding their diagnosis. The ABC Global Alliance, in partnership with AstraZeneca, launched a patient survey to assess:

- Patient understanding and knowledge of their diagnosis with mBC
- Barriers to patients receiving and understanding information about the disease they have

This perception study was developed using key findings from the survey alongside expert opinion from Steering Committee members. Steering Committee members helped to shape the recommendations provided within the study, which are intended to guide the development of improved educational tools to support people living with mBC and empower those affected to play an active role in their care.

GLOSSARY OF TERMS
ABC – ADVANCED BREAST CANCER
BRCA1/2 – **BR**EAST **CA**NCER GENE 1/2
HCP – HEALTHCARE PROFESSIONAL
HER2+ – HUMAN EPIDERMAL GROWTH FACTOR RECEPTOR-POSITIVE
HR+ – HORMONE-RECEPTOR POSITIVE
IHC – IMMUNOHISTOCHEMICAL
MBC – METASTATIC BREAST CANCER
TNM STAGES – TUMOUR, NODE, AND METASTASIS STAGES



BIOMARKERS EXPLAINED[16]

BOX 01

Biomarkers (biological markers) are a characteristic that can be measured to provide an indicator of a biological process in a person*

Risk
Indicates potential for developing cancer
e.g., inherited mutations in BRCA1/2

Diagnostic
Confirms the presence or type of cancer
e.g., MRI, CT, and PET scans, or ER†, PgR†, HER2 levels

Prognostic
Estimate likelihood of disease recurrence or progression
e.g., Ki67 levels or tumour mutations in ESR1 or PI3CKA

Predictive
Predict efficacy from treatment
e.g., ER†, PgR†, HER2, and PD-L1 levels, or mutations in PI3CKA or BRCA1/2

Response
Monitor response to treatment
e.g., Fluoroestradiol F18 levels to monitor response of ER-positive cancer

Safety
Indicate toxicity to treatment
e.g., markers for kidney function or neutrophil count

*Testing for biomarkers is recommended in disease management guidelines for mBC to inform clinical decision-making,[4] and may include several non-mutually exclusive types.[16] Testing may include genetic testing for inherited germline mutations such as BRCA1/2 or somatic mutations that occur randomly in the tumour such as ESR1 or PI3CKA, or immunohistochemical testing for HER2, PD-L1, PgR, and ER. †ER and PgR are together known as hormone receptors (HR).

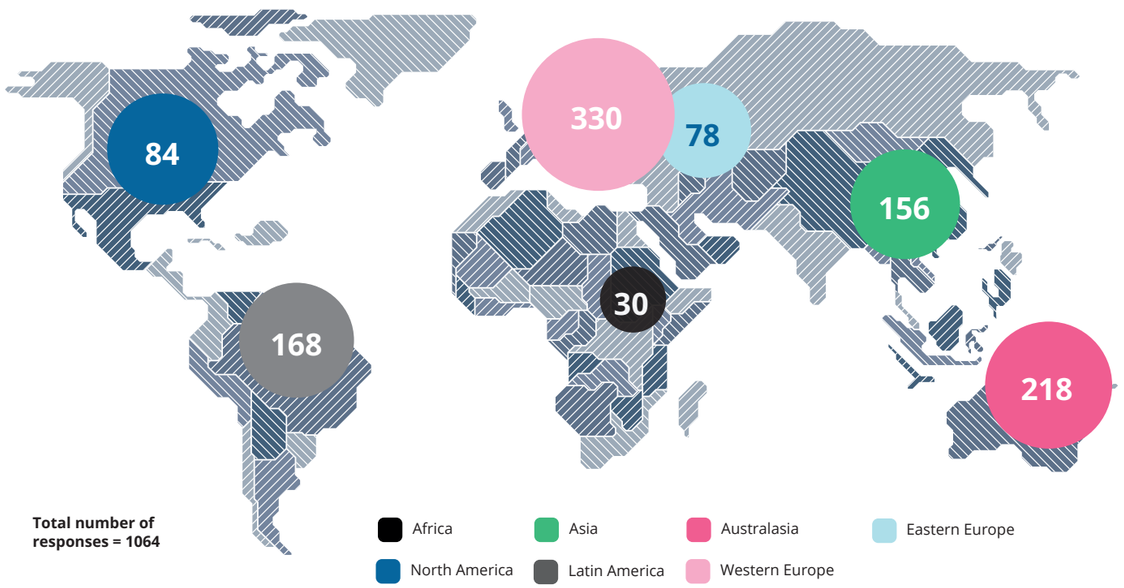
Abbreviations: BRCA – BReast CAncer gene; CT – computed tomography; ER – oestrogen receptor; HER2 – human epidermal growth factor receptor 2; HR – hormone receptor; MRI – magnetic resonance imaging; PD-L1 – programmed cell death-ligand 1; PgR – progesterone receptor; PI3KCA – Phosphatidylinositol-4,5-Bisphosphate 3-Kinase Catalytic Subunit Alpha

Research approach and responses

A survey of 15 multiple-choice questions was developed with the following objectives:

- Understand if and how HCPs explained breast cancer type, including terminology used, according to patients
- Determine how patients interpret the role of biomarkers in their disease
- Establish where patients seek information on breast cancer type and where unmet informational needs exist

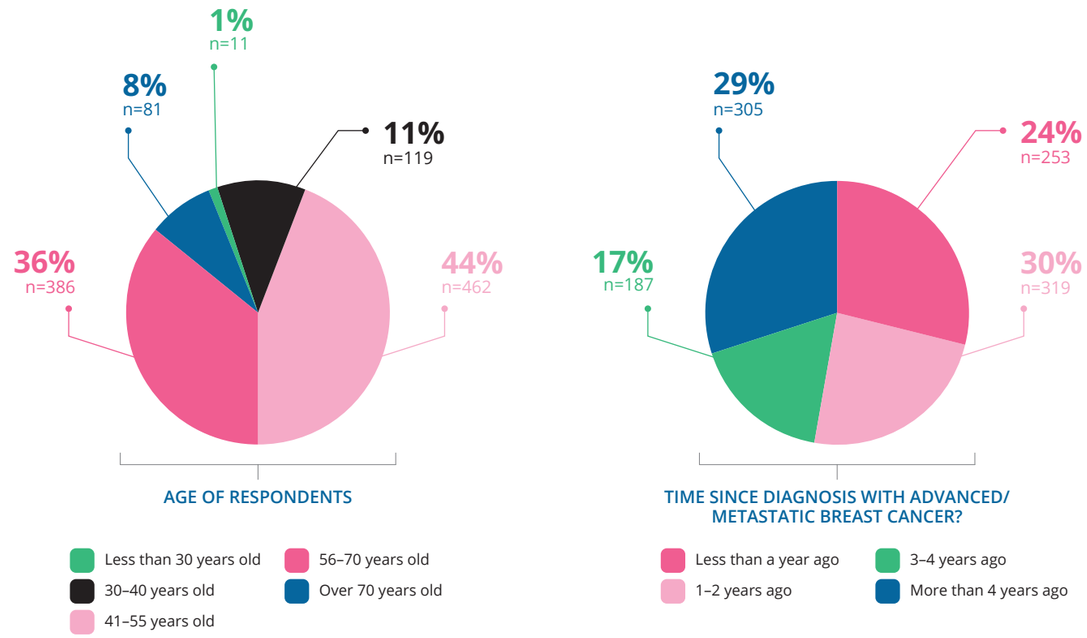
FIGURE 1: GEOGRAPHICAL DISTRIBUTION OF PATIENTS ANSWERING THE SURVEY*



*Languages for survey distribution were: Albanian, Arabic, Bosnian, Bulgarian, Brazilian Portuguese, Chinese, Simplified Chinese, Croatian, English, French, German, Greek, Italian, Latin American Spanish, Japanese, Polish, Portuguese, Romanian, and Spanish. Where a survey approved in local language was not available the English survey was used

Country	Responses	% region	Country	Responses	% region	Country	Responses	% region
Albania	22	28.2	Germany	167	50.6	Peru	27	16.1
Australia	39	17.9	Greece	10	3	Philippines	10	6.4
Austria	19	5.8	Haiti	33	19.6	Romania	13	16.7
Brazil	38	22.6	India	24	15.4	Spain	8	2.4
Bulgaria	3	3.8	Ireland	1	0.3	Sweden	74	22.4
Canada	48	57.1	Japan	10	6.4	Switzerland	6	1.8
China	63	40.4	Kenya	1	3.3	Taiwan	49	31.4
Costa Rica	13	7.7	Luxembourg	1	0.3	Uganda	1	3.3
Croatia	40	51.3	Mexico	24	14.3	UK	36	10.9
Denmark	1	0.3	Netherlands	6	1.8	USA	36	42.9
Egypt	1	3.3	New Zealand	179	82.1	Venezuela	33	19.6
France	1	0.3	Nigeria	26	86.7	Zimbabwe	1	3.3

FIGURE 2: OVERALL PATIENT CHARACTERISTICS



Based on responses to Q4: 'what is your age?' and Q7: 'when were you diagnosed with advanced/metastatic breast cancer?'
Number of respondents in left hand chart adds to less than the total number for the survey due to missing values

The survey was translated into 19 languages and distributed online across the ABC Global Alliance member network, targeting people with a self-reported diagnosis of mBC across 61 countries. Responses were provided by 1064 patients from 36 countries and varied by geography **(Figure 1)**, and to our knowledge, this is the largest and most comprehensive survey of its kind to assess patient understanding of breast cancer biomarkers to date.

Most patients answering the survey were between 41–70 years old (80%) and were diagnosed with mBC three or more years ago (46%; **Figure 2)**. Around a quarter of patients (24%) were diagnosed with mBC less than a year ago.

Analyses were conducted in subgroups classified by geography, disease history, attitudes towards seeking information, and level of patient interaction with healthcare teams, to explore key trends.

The use of a self-administered online survey may have introduced biases in the sample population based on several factors:

- Educational status influencing patients' ability to answer the survey in the provided language
- Socioeconomic status influencing patients' ability to access the internet
- Online literacy levels influencing patients' ability to complete an online survey

To mitigate some of these challenges, physicians in Venezuela completed the survey with patients and recorded the answers offline, which may also bias the demographics of respondents relative to other countries.

Variations in survey responses may depend on the strength and reach of country-level ABC Global Alliance member network organisations responsible for distributing the survey to patients. Some regions are heavily weighted by responses from certain countries which may impact the results described (e.g., responses in Africa are almost exclusively from Nigeria). For countries where local language translation was not available, the survey was provided in English **(Figure 1)**. Language was reported by ABC Global Alliance members to be a barrier to completion for some patients in Bangladesh, Haiti, India, the Netherlands, South Korea, and Sweden. Survey responses may also be limited by the translatability of the survey into certain languages.

Patient recall and understanding of biomarkers

KEY FINDINGS

- 81% of patients understand that breast cancer biology plays a role in treatment decision-making
- However, wide variation exists in patient recall of terminology used to discuss breast cancer
- Recognition of specific biomarker terminology used to describe breast cancer type at first diagnosis is low
- Beyond recall of specific terminology, 33% of patients are not confident they know what type of breast cancer they have or understand what it means

81% of patients understand that breast cancer biology plays a role in treatment decision-making

The underlying biology of a tumour determines its potential response to targeted treatments and how quickly it is likely to grow or spread.[2,11] Defining breast cancer type, therefore, plays a critical role in determining the care management and treatment plan for people diagnosed with mBC.[4] For patients to be engaged in shared decision-making they must first understand the role breast cancer type plays in these decisions.

Survey results demonstrated that patients often understand the role breast cancer type can play in clinical decision-making, with very few patients reporting that they did not know its relevance. While most patients understood that defining breast cancer type helps with treatment decision-making (81% of patients selected 'choose treatment type' and 'understand how the cancer might control treatment' as roles breast cancer type can play), only a third of patients reported that it can help them to discuss prognosis (36%; **Figure 3A**).

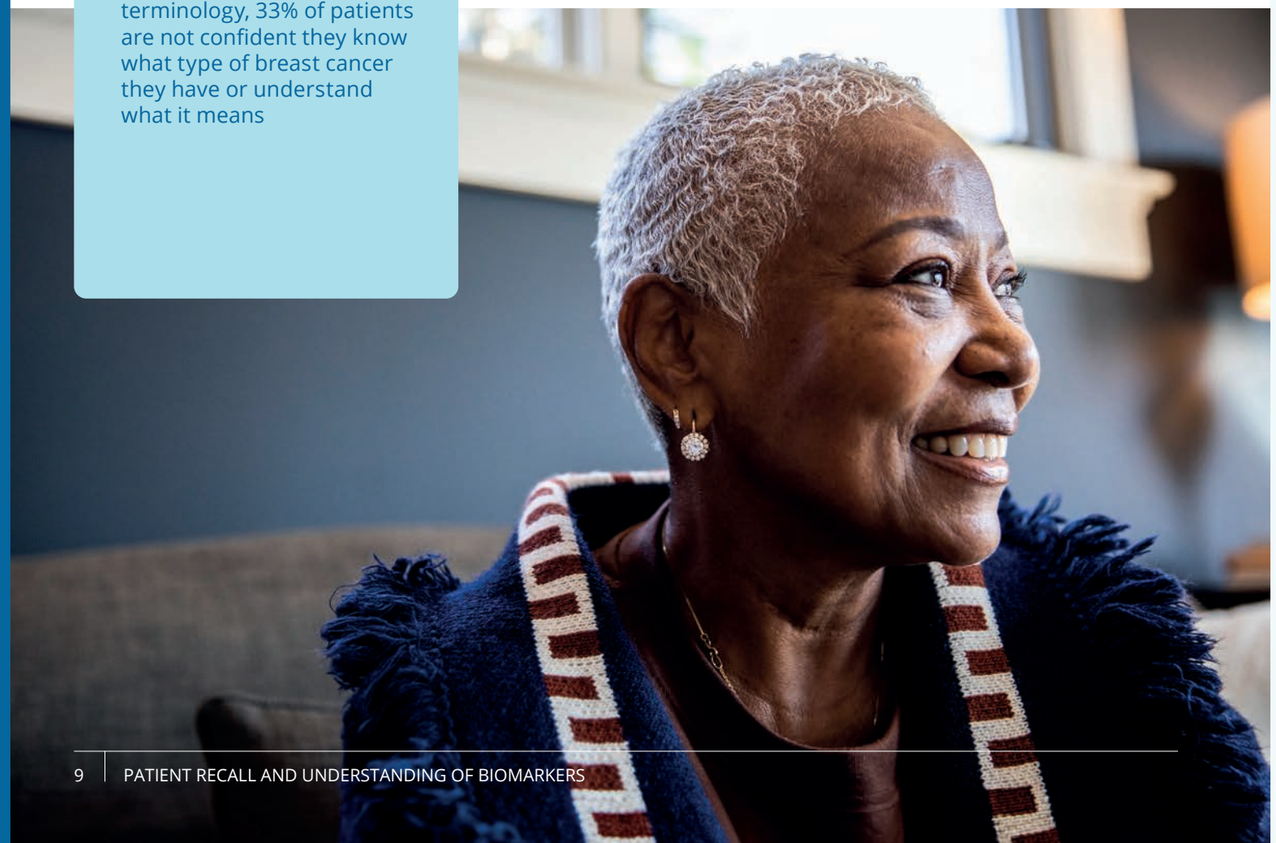
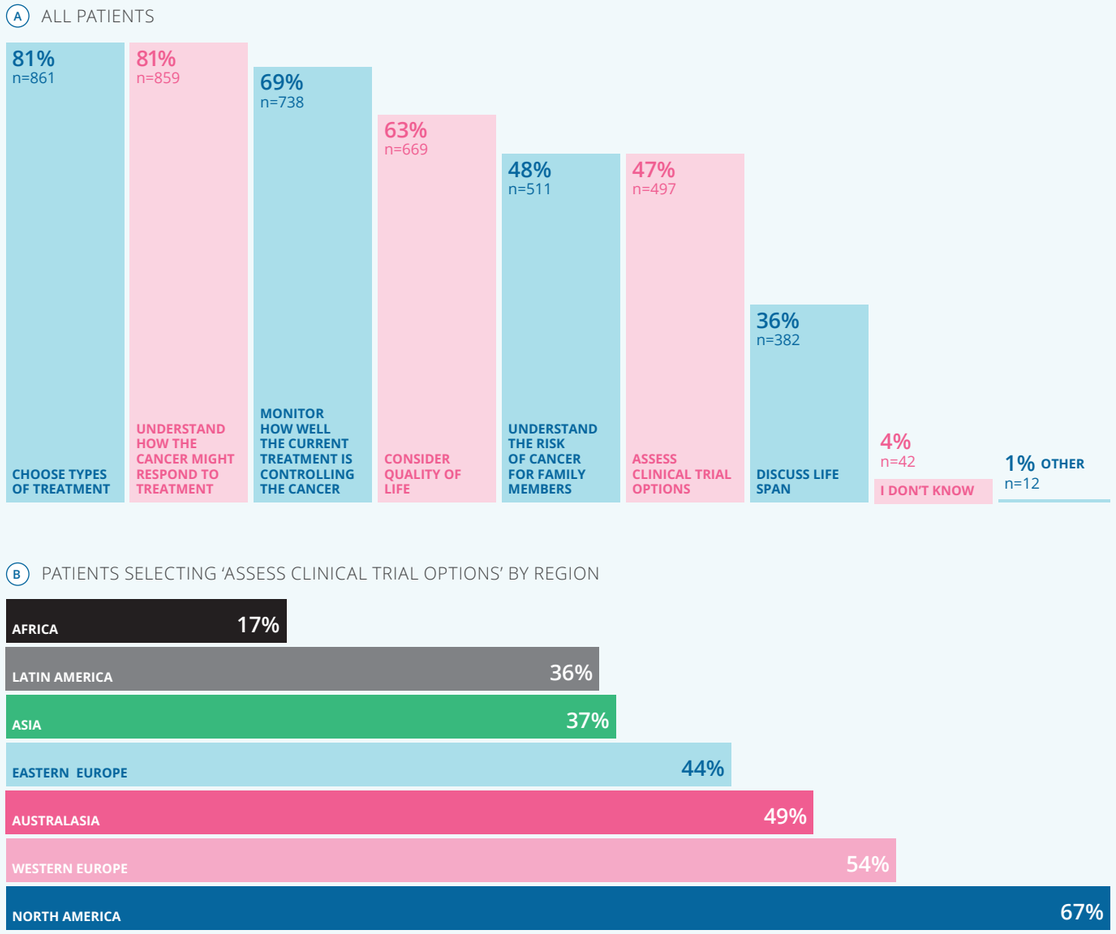


FIGURE 3: UNDERSTANDING THE ROLE OF BREAST CANCER TYPE



Total number of respondents per region are: Africa, n=30; Latin America, n=168; Asia, n=156; Eastern Europe, n=78; Australasia, n=218; Western Europe, n=330; North America, n=84

Based on responses to Q13: 'Select all statements that you think are correct from the list below. Understanding the type of breast cancer that you have can help you and your healthcare team to:'

Clinical decision-making may also include the option to participate in clinical trials giving patients early access to novel treatments if they are eligible. Although around half of all patients (47%) indicated that breast cancer type plays a role in assessing clinical trial options, this varied considerably by region (**Figure 3B**). Selection was lower for Africa (17%), Latin America (36%) and Asia (37%), and higher for patients from North America (67%) and Western Europe (54%), which may reflect regional disparities in access to clinical trials.[17]

Overall results indicate that patients' understanding of the role of breast cancer type tends to be treatment-focused, with less knowledge surrounding its role as a prognostic marker. Steering Committee members felt that this may mirror the focus of discussions led by HCPs with patients during consultations. Additional research has demonstrated that discussions on prognosis between HCPs and patients are often inconsistent;[5] however, this could also be influenced by whether patients desire to have these conversations, with some preferring less information on prognosis.[7] In addition, the level of discussion between HCPs and patients on breast cancer types and biomarkers may be impacted by the availability of, and access to, testing and targeted treatments.

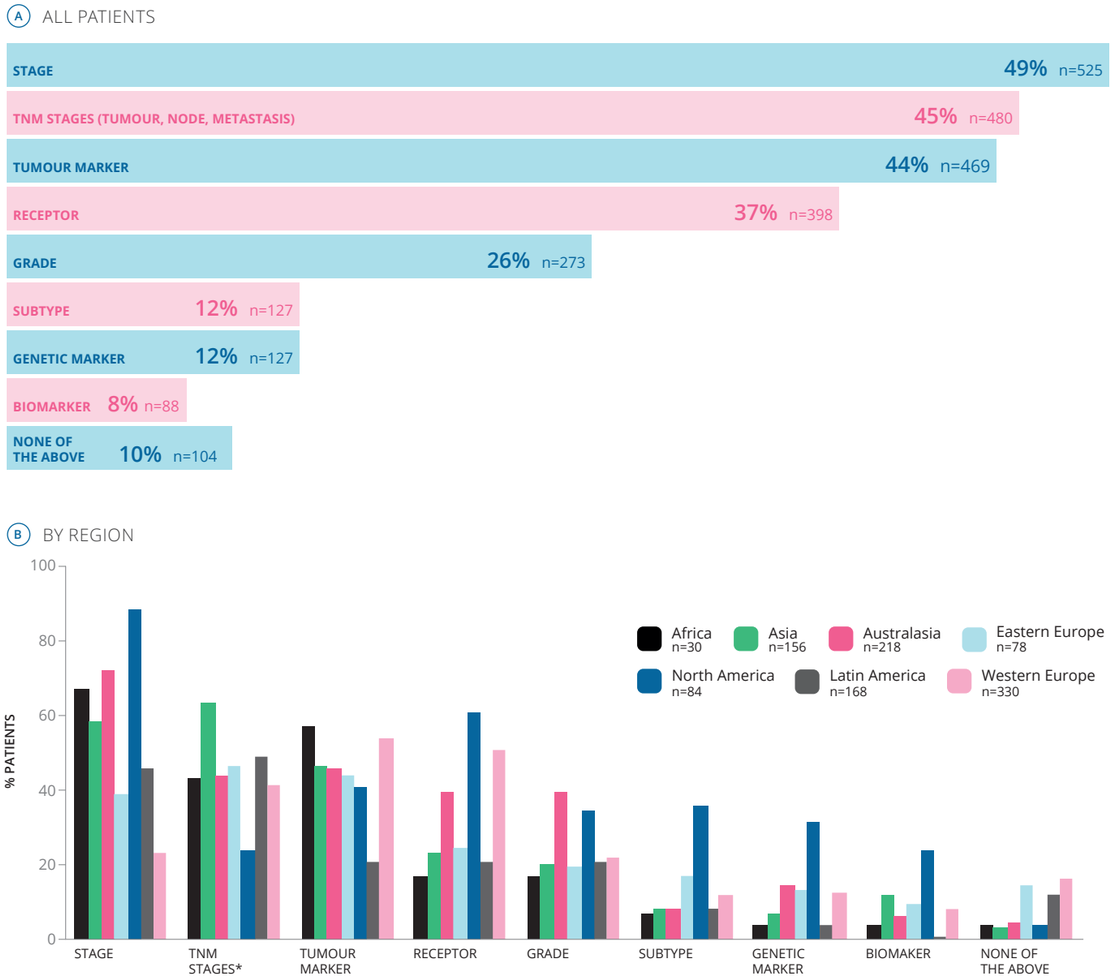
Wide variation exists in patient recall of terminology used to discuss breast cancer

While patients demonstrated an understanding of the role breast cancer type plays, survey results suggested that many patients may lack an understanding of the specifics of their disease. 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.[8]

This may make it difficult for some patients to understand the type of breast cancer they have and engage in shared decision-making, and therefore it is imperative that communication is clear and patient-focused.

There was wide variation in the recall of terminology HCPs had used to talk about their diagnosis (**Figure 4A**), with the most frequently used terms reported as 'stage' (49%), 'TNM stages' (45%), and 'tumour marker' (44%).

FIGURE 4: TERMINOLOGY USED TO DESCRIBE BREAST CANCER



Based on responses to Q9: 'Which of the following terms has your healthcare team used when talking about breast cancer with you?'; *answer in full provided in the survey was 'TNM stages (Tumour, Node, Metastasis)'

Nevertheless, these were recalled by less than half of all patients and other terms were reportedly used infrequently, such as 'subtype' (12%), 'biomarker' (8%), and 'genetic marker' (12%). This may indicate an overall preference for using certain words or phrases. For example, Steering Committee members felt that the word biomarker is not often used with patients, despite its use more broadly in the field.

There were also significant differences between regions and regional preferences in the selection of some terms over others (**Figure 4B**). 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% patients from Asia reported that this term had been used compared with 24% from North America. Patients from Western Europe were most likely to select that none of the terms had been used by their healthcare team (17%). By contrast, most of the words or phrases were selected more frequently by North American patients compared with those from other regions. Geographical differences in the selection of specific terms indicates a lack of consistency between regions in the terminology used to discuss breast cancer.

"I had to figure out on my own that your three top terms, biomarker, molecular and genomic, were all the same thing because the doctors just say stuff"[9] – Lung Cancer Patient

Recognition of specific biomarker terminology used to describe breast cancer type at first diagnosis is low

When patients were asked more specifically about biomarker terminology that was used when they were first diagnosed with mBC, recall levels were much lower than for more general terminology.

11% of all patients reported that they did not know which terms were used by healthcare teams to describe their diagnosis (**Figure 5**). In addition, less than half of all patients (44%) reported that the term hormone receptor-positive (HR+) was used, which is considerably lower than the average prevalence of HR+ mBC* (~78%)[18] This suggests that some patients diagnosed with this tumour type may not be selecting the term, because either they have not been told or they do not understand the terminology. Notably, selection of HER2-positive (HER2+) was higher than the average prevalence of this marker* (~14%)[18] which could suggest confusion between options. When separated by region, 73% of patients from North America reported the term HR+ was used, while for other regions recall of this term was much lower (14-56%).

In addition, other biomarkers which may be tested for (BRCA1/2, PDL1, PIK3CA) were also selected infrequently, which may reflect the availability of biomarker-specific testing and targeted treatment options, compared with more commonly used breast cancer classification.

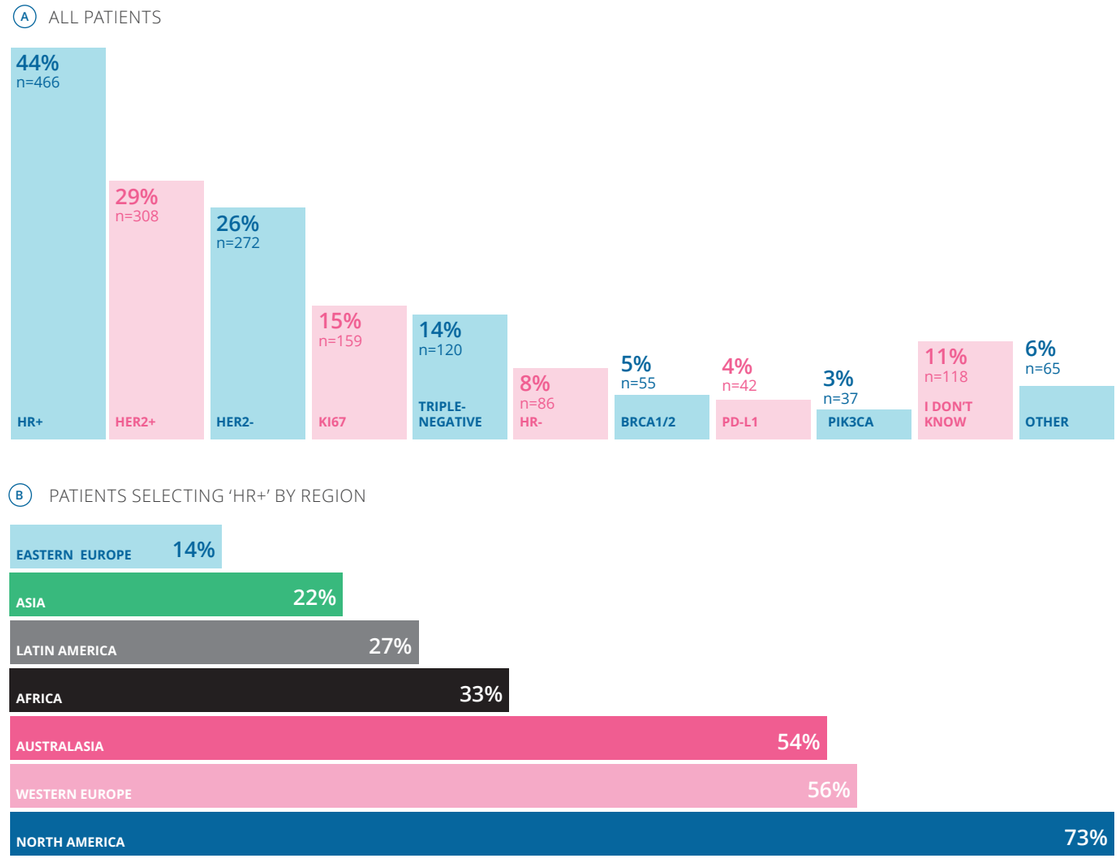
Overall, low levels of recall of the terminology used to discuss breast cancer type could be due to several reasons:

- **The provided terminology may not be commonly used or explained to patients, due to the use of alternative language, lack of relevance, or limited HCP confidence discussing genetic information:**
  - HCPs may not be using terminology due to concerns about overwhelming patients with information, and in some instances, Steering Committee members suggested that they may choose to use alternative language or descriptions to convey the same meaning
  - For certain biomarkers, it was also felt that limited implementation of biomarker testing, or the availability of subsequent targeted therapies (for example due to limited access),[19] may also mean terms are not discussed
  - In the case of genetic testing for BRCA1/2, in the absence of trained genetic counsellors, some nurses or physicians may find it challenging to discuss the potential implications of genetic germline testing on the family and future generations and thus actively avoid discussions[20]
- **Patients may not understand the terminology that is used, affecting their level of recall.** The language surrounding precision medicine is not patient-friendly, making it difficult for patients to understand what is being discussed.[8,9] This may lead to patients being unable to recognise biomarker testing terms, even if tests were part of their disease management pathway or language was used with them[9,21]
- **Patients may not recall what was discussed due to the shock or denial associated with mBC diagnosis, or fear of the implications of information.** Following diagnosis the initial shock may limit the ability of patients to retain information,[22] or, for other patients, denial may be used as a coping strategy preventing them from remembering information.[7] This may be particularly challenging for those diagnosed with mBC, given the incurability of the disease. In the case of testing for BRCA1/2, Steering Committee members added that a fear of the implications of familial breast cancer risk for insurance coverage and societal stigma may also lead to patients avoiding the information and limit their recall

Selection of both specific and more general biomarker terminology was lower among patients from regions made up predominantly by low-and-middle-income countries, namely Africa, Asia, and Latin America, compared with higher-income regions. Steering Committee members agreed that this may reflect limited access to biomarker testing and associated targeted treatments in low-and-middle income countries, meaning that they are not discussed by HCPs as they are not deemed relevant.

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

FIGURE 5: BIOMARKER TERMINOLOGY USED TO DEFINE BREAST CANCER TYPE



Total number of respondents per regions are: Africa, n=30; Latin America, n=168; Asia, n=156; Eastern Europe, n=78; Australasia, n=218; Western Europe, n=330; North America, n=84

Based on responses to Q11: 'At the time of diagnosis of advanced/metastatic breast cancer, which of the following terms were used by your healthcare team to describe the type of breast cancer that you have?'. Patients were provided with complete explanations for biomarker terms, for example for HR+ the full answer provided was: 'Hormone receptor-positive (HR+), this may have also been called oestrogen or progesterone positivity, or hormone receptor sensitivity or hormone-dependent cancer'. Patients from Australasia are missing from the answer 'Triple-negative'

Abbreviations: BRCA – BReast CAncer gene; HER2 – human epidermal growth factor receptor 2; HR – hormone receptor; PD-L1 – programmed cell death-ligand 1; PI3KCA - Phosphatidylinositol-4,5-Bisphosphate 3-Kinase Catalytic Subunit Alpha

It was shared that access is often limited in the public health setting and therefore is restricted to those who can afford to pay privately. For example, in Africa many pathology centres lack the facilities to conduct immunohistochemistry biomarker testing (e.g., testing for HR- or HER2- positivity) with some frequently outsourcing testing, leading to high costs for patients.[23]

It was also felt that higher income regions, particularly North America, had better access to resources in terms of healthcare system and patient advocacy groups, and were therefore better equipped for supporting patients with information and education, when compared with lower income countries.

The higher recall of terminology by North American respondents may indicate that discussions with HCPs differ for patients in this region, or that the patients surveyed are more informed, with increased understanding compared with patients in other regions. Potential explanations include the presence of local efforts focused on improving the clarity of communication with patients on their diagnosis. For example, the Precision Medicine Plain Language Lexicon (Box 2) was developed to enable clarity and consistency of language used between healthcare stakeholders to improve patient understanding.[8,24] English-speaking patients in North America may also have better access to available information resources to help them understand their diagnosis and thus recall terminology better, compared with patients in non-English speaking countries.[25] Additionally, policies have been introduced mandating direct access to diagnostic reports through patient portals, which require accompanying discussions with HCPs.[26] Although direct access to test results can pose a risk to patients if they are not explained properly, the levels of recall of specific diagnostic terminology in North America may suggest that in many cases test results are being accompanied by explanations from HCPs.

BEST PRACTICE EXAMPLE

BOX 02

Precision Medicine Plain Language Lexicon

A series of patient-friendly plain language terms and definitions to explain precision medicine biomarker testing and genetic testing was developed by the Cancer Support Community (CSC), a US-based charitable organisation.[24] The Lexicon was developed using input from healthcare providers, patients, and caregivers to provide clarity and consistency around the language to use to help promote mutual understanding of precision medicine concepts among multiple stakeholder groups. Although the Lexicon is available to the oncology community, collaboration with global organisations to help share the materials and translate them into multiple languages will help to improve the reach to patients outside of the US.

Beyond specific terminology, 33% of patients do not feel confident they know what type of breast cancer they have or understand what it means

As described earlier, patient recall of the terminology used to describe breast cancer type can be influenced by several factors and may leave some patients without an adequate understanding of their diagnosis. 67% of patients indicated they had been able to learn about and understood the type of breast cancer they have, with a remaining third of patients not selecting this option.* This may represent those patients that lack a clear understanding of their diagnosis and its implications, aligning with previous research highlighting that many patients' do not know about or understand the biomarker tests that they have had.[9,21] Thus, results from this study, and others, suggest many patients may not understand the full picture of their disease 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.

*Based on responses to Q15: 'Which of the following statements relate to learning about the type of breast cancer that you have?', those selecting answer 'I have been able to learn about my type of breast cancer and I understand what it means'. Patients' responses from China and Taiwan are missing from this question

CALL-TO-ACTION AREAS OF FOCUS

- Standardise patient-focused terminology used to describe mBC biology and biomarkers to improve the clarity and consistency of information
- Promote and translate best-practice initiatives between geographies that empower patients with information and support using existing advocacy networks (e.g., patient-friendly communication of diagnostic information, patient training and programmes, diversity and inclusion in clinical trials, lobbying access to targeted treatments)
- 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

To see more details on our call-to-action see page 27 of this document

Barriers to patient understanding of biomarkers

KEY FINDINGS

- While HCPs may help patients recognise the role of breast cancer type, information is insufficient to meet patients' needs and may prevent them understanding their diagnosis
- Patients often seek alternative sources of information to supplement their understanding, with many turning to the internet
- Patients demonstrate differing trends in understanding of their diagnosis and information-seeking behaviour by geography or varying disease experience

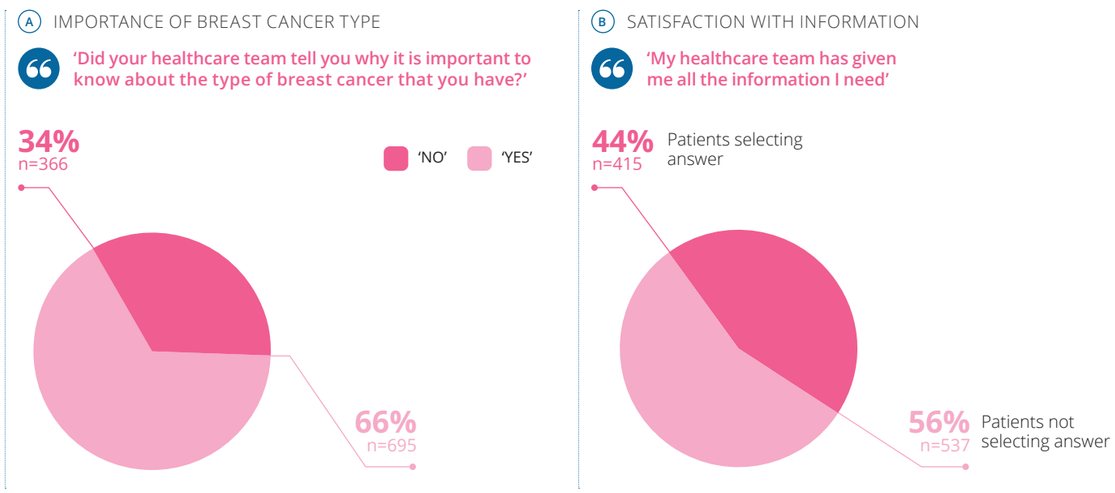
While HCPs may help patients recognise the role of breast cancer type, information is insufficient to meet patients' needs and may prevent them understanding their diagnosis

Earlier results demonstrated that patients generally understood the role that breast cancer type plays in clinical decision-making, which is an important step towards encouraging patients to take an active role in care.[27] Results suggest that HCPs are an important factor in this process, with two-thirds of patients (66%) reporting that their healthcare team had told them why it is important to know about the type of breast cancer they have **(Figure 6A)**.

Even though many HCPs may be offering clear explanations on why it is important to define breast cancer type, less than half of all (44%) patients in the survey reported their healthcare team had given them all the information they need in relation to the type of breast cancer they have **(Figure 6B)**. Taken together with earlier results demonstrating inconsistencies in the recall of biomarker terminology, this suggests that more in-depth explanations or provision of information may be lacking.

As such, there is a critical need for standardisation of the lexicon describing biomarkers, while tailoring communication with patients according to their individual needs and preferences.

FIGURE 6: INFORMATION RECEIVED FROM HEALTHCARE TEAMS



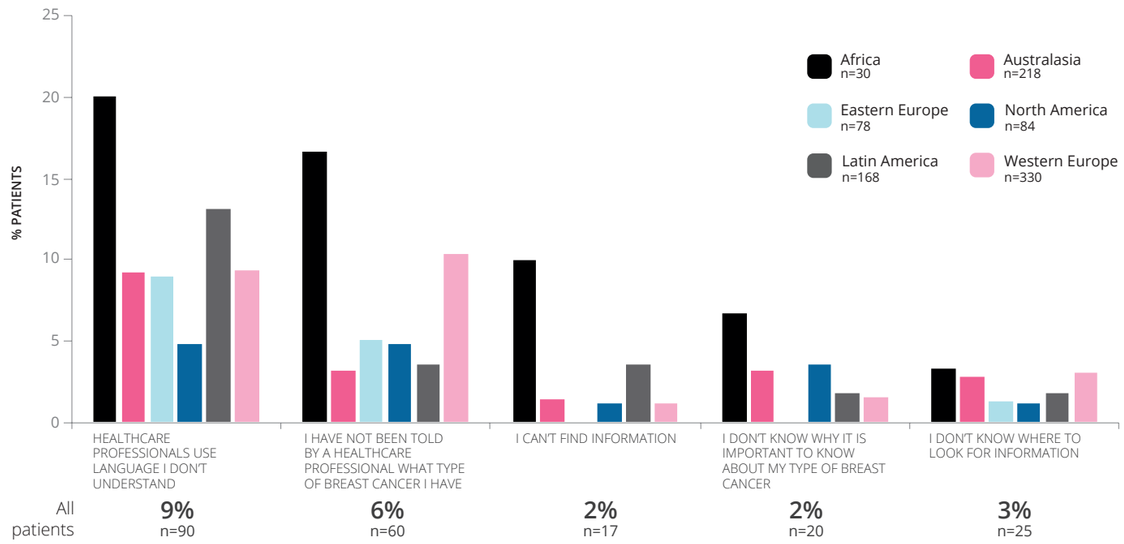
B) Based on response to Q15: 'Which of the following statements would you select related to learning about the type of breast cancer that you have?'. Patients' responses from China and Taiwan are missing from this question. Number of respondents adds to less than the total number for the survey due to missing values

Despite many patients globally being unsatisfied with the information received from HCPs, specific challenges faced by patients in learning about breast cancer were highly varied by region **(Figure 7)**.

Patients from Africa most frequently reported challenges, with 20% of patients reporting that HCPs use language they don't understand and 17% not being told the type of breast cancer they have. Steering Committee members felt that identified challenges could reflect low implementation of biomarker testing used to define breast cancer type and low levels of health literacy impacting how this information is received.[21] Lower resource levels and cultural factors in the region may also impact how HCPs communicate with patients. In Nigeria, where most patients representing Africa in the survey reside, a high patient to oncologist ratio burdens oncologists with a heavy workload, which may impact their ability to communicate effectively.[28] Additionally, inherent gender biases and traditional power dynamics may influence how male HCPs communicate with women diagnosed with mBC, limiting the amount of information that is shared.[29] These gender biases may be even worse for women from lower socioeconomic backgrounds or rural communities compounding pre-existing challenges associated with low health literacy.[29] Where such social norms exist, women may not be aware of alternatives to paternalistic models of care, or question their role in shared decision-making, perpetuating the problem.

10% of patients from Western Europe also highlighted they had not been told by HCPs 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 **(Figure 7)**. Overall, the low number of patients reporting specific challenges, along with the regional variation observed, may indicate that the survey did not capture all the complex barriers faced by patients.

FIGURE 7: REGIONAL BARRIERS TO LEARNING ABOUT BREAST CANCER TYPE



Based on responses to Q15: 'Which of the following statements would you select related to learning about the type of breast cancer that you have?'. Patients' responses from Asia are missing from this question

Previous studies have demonstrated that the delivery of information from HCPs is insufficient to meet patients' needs.[5-7,25] Both within and beyond breast cancer, reported barriers to effective communication by HCPs 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.[21,25,30] HCPs themselves may also lack confidence in implementing biomarker testing, understanding results, or describing information on the tests to patients.[20,31] Particularly in more rural settings, a lack of education and support for physicians in implementing biomarker testing and explaining information, when compared with well-funded academic centres, may compound these barriers.[21,31]

Persisting negative beliefs towards mBC patients may also impede how HCPs communicate with patients. Steering Committee members felt that fatalistic attitudes towards mBC (believing that it is too late to treat and nothing can be done) can lead to the dismissal of patients and inadequate treatment. Even where HCPs take a pragmatic but optimistic approach to treatment, it was felt they may instead focus on addressing the disease rather than the person, ignoring emotional aspects, in turn leading to ineffective communication.

Patients often seek alternative sources of information to supplement their understanding, with many turning to the internet

Despite results suggesting some patients may not understand their diagnosis and what it means, relatively few reported difficulties finding information about the type of breast cancer they have (all patients, 2%; **Figure 7**).

Patients sought information about their diagnosis from a variety of sources, and perhaps unsurprisingly, patients most frequently reported using the internet (70%; **Figure 8A)**. This was closely followed by their doctors (64%) and other patients diagnosed with breast cancer (45%), which may indicate that many patients wish to receive information from those they feel have shared experiences.

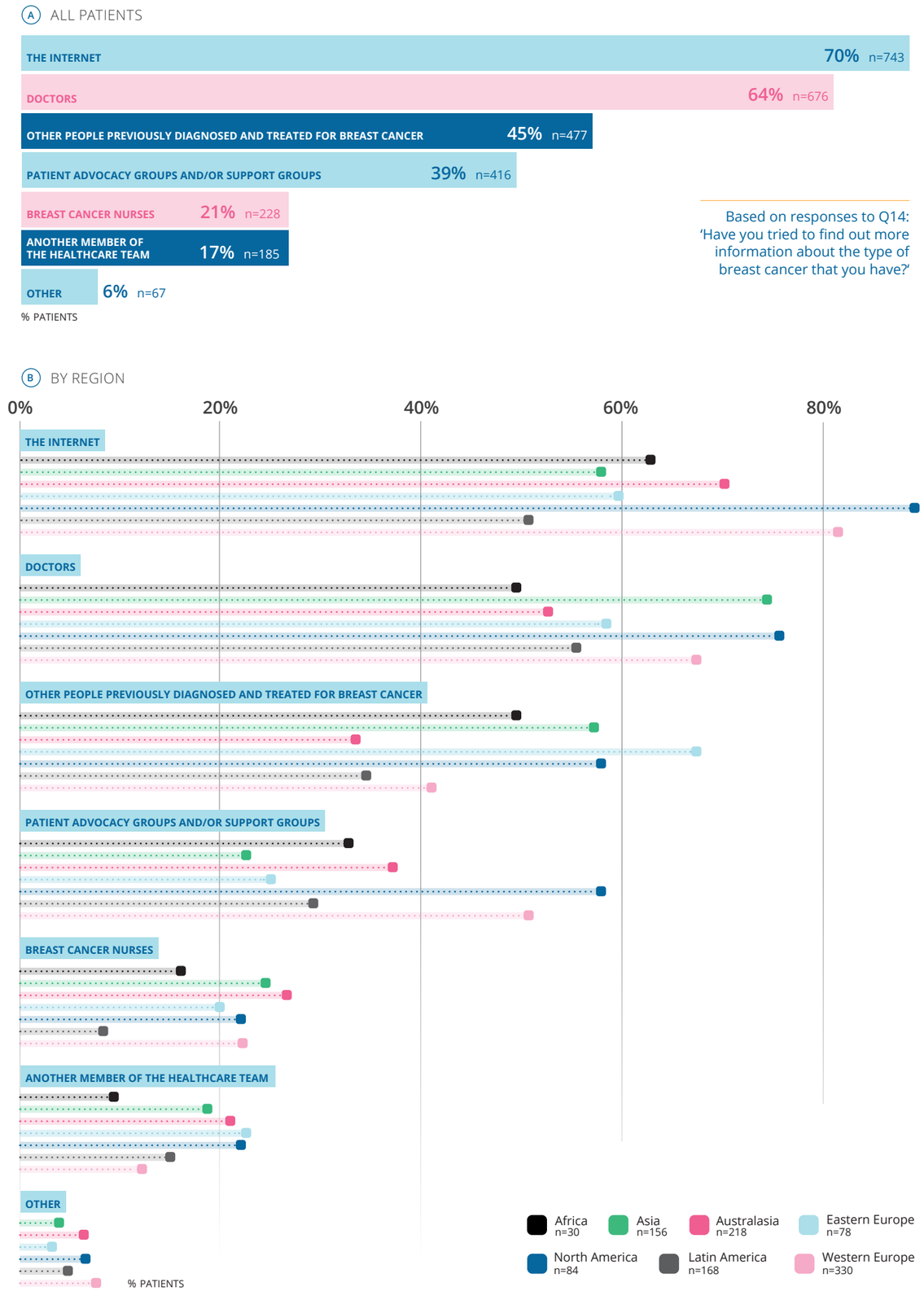
Notably, there was some variation by region, with patients from Asia being more likely to seek information from their doctor (75%) than the internet (58%), which may reflect local cultural norms leading patients to rely more heavily on medical professionals **(Figure 8B)**. Steering Committee members added that depending on local cultural norms some patients may seek information from others who are not medically qualified, nor have received a diagnosis with breast cancer, which may include religious leaders or alternative healers, for example in Asia.

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.[5,32-33] The internet has transformed the way in which patients can access healthcare information, allowing them to learn about their diagnosis in their own time and provide them with additional detail if they want to know more.[33]

Social media adds to the allure of online channels for information, providing accessible bitesize snippets. However, the heavy reliance on information from online sources and non-medically trained individuals has potential to expose patients to misinformation. Additionally, some patients may find the quantity of available online information overwhelming and difficult to navigate to useful sources.[10,33]

Even if information is available, it may not be patient-friendly or meet their needs.[7,10,25] Most information is aimed at those with an early breast cancer diagnosis, rather than for the needs of those diagnosed with metastatic disease,[7] and information is also usually provided by high-income English-speaking countries,[25] which may lack local nuance. A recent survey in the UK found that mBC patients commonly did not find internet searches helpful, and recommended patients should instead rely on trusted sources signposted by HCPs,[5] suggesting that challenges in navigating to useful information are universal. So, while patients may be able to find information, this may not necessarily be useful to them in understanding their diagnosis.

FIGURE 8: SOURCES OF INFORMATION



"There are issues navigating the huge amount of opposing information available on breast cancer treatment"* – mBC Patient

"I wanted to know a lot more about my particular type of cancer ...but had to resort to looking up scientific articles in medical journals for the most up-to-date information"* – mBC Patient

Less than half of all patients turned to patient advocacy and support groups for more information on their diagnosis (39%; **Figure 8A**). Even in regions where such groups are prominent, less than 60% of patients reported using them for information. Patient advocacy and support groups were consulted by 58% of patients in North America, 51% in Western Europe, and 38% in Australasia. These findings contrast a recent study based in the UK, reporting that 66% of patients used support groups for information, and this disparity may reflect differences in the sampled populations.[5]

Results from this survey may indicate underutilisation of these groups as a source of information in many countries and may also suggest that HCPs are not signposting patients to existing information available on these platforms, with previous research highlighting that patients are often unaware of who their local advocacy groups are.[25]

Steering Committee members noted that some HCPs may lack trust in available support groups and therefore may not refer patients to them, or that information on these platform remains insufficient to meet many patients' needs.

Overall, relatively few patients reported that they had sought information from breast cancer nurses and other healthcare team members, besides their doctors. Steering Committee members shared how in many countries oncology or dedicated breast cancer nurses are lacking, despite their widely appreciated role in complementing physicians to support patients.[34] It was highlighted that in low-and-middle-income countries breast cancer nurses could play a particularly beneficial role in improving patient care and outcomes given the low physician to patient ratio.

Nurses play an integral role in multidisciplinary care.[25,34] In many healthcare systems multi-disciplinary cancer care is commonplace, playing a critical role in ensuring high-quality care is delivered consistently and with continuity, including the provision of appropriate information and support.[34,35] Patient navigators (who may be specialised nurses or other individuals) can have an important function in ensuring effective integration of multidisciplinary cancer care, helping to provide a point of continuity and coordinate different aspects of care throughout the patient pathway.[36] However, evidence for patient navigation programmes is lacking in many of the countries surveyed,[36] the role of multidisciplinary team cancer care varies by geography, and even in countries where multidisciplinary team cancer care exists, functioning is often inconsistent between centres.[34]

While this survey was not powered to determine country-level findings and the role of multi-disciplinary care in the delivery of diagnostic information, it is possible that it may contribute to the variation in patients' understanding of their diagnosis and the ability to recall information shared with them. Indeed, most evidence for patient navigation programmes appears to be US and Canada-based correlating with the higher levels of recall of biomarker terminology outlined in previous sections.[36]

*quote provided by Steering Committee

Spotlight: differing trends in patient understanding of their diagnosis and information-seeking behaviour

Patients' informational needs and decision-making preferences vary throughout their experience with mBC.[10,13] Factors such as gender, race, socioeconomic status, and educational attainment also influence patients' experience with HCPs, information seeking behaviour, and subsequent understanding of their diagnosis.[7,21,29,37] Although the survey did not investigate all of these characteristics, findings revealed several factors associated with patients' understanding of their diagnosis and desire to find out more information, which may indicate the need for specific activities targeting certain groups of patients.

Type of mBC diagnosis

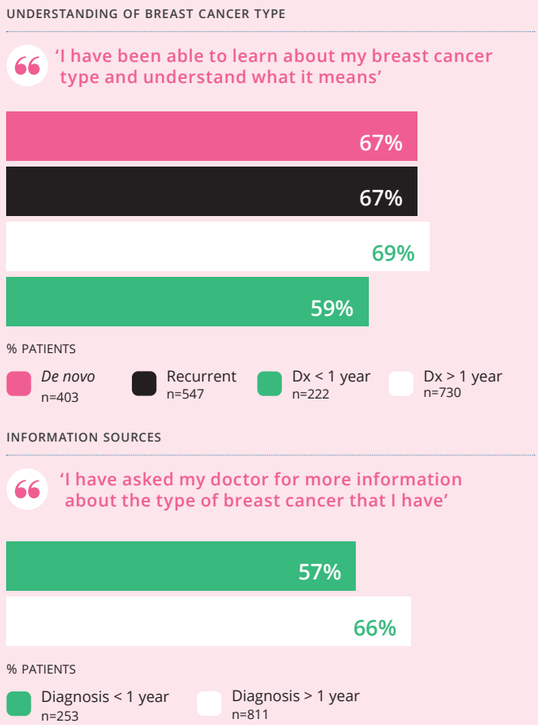
People diagnosed with recurrent mBC have historical experience with breast cancer diagnosis compared with those diagnosed *de novo* with metastatic disease. While the way diagnosis occurs does not substantially change prognosis, patients who are told they have mBC at first diagnosis may experience great difficulty in coming to terms with and understanding the disease.[5] However, analysis of survey findings demonstrated very similar responses between these two patient groups **(Figure 9)**.

Steering Committee members suggested that patients may not correctly identify the type of breast cancer they have been diagnosed with based on the answers provided. Alternatively, patients may not understand or know the way in which they were diagnosed with mBC. Supporting this notion, ABC Global Alliance affiliates from Zimbabwe reported a barrier to survey completion was that for many patients the stage of breast cancer is not specified. Research has also highlighted that many patients are not aware of the possibility of being diagnosed with mBC following early breast cancer, or even what having mBC means.[5,25] Thus, a key limitation with this data is that they represent patients' self-reported diagnosis with *de novo* or recurrent mBC, which may be inaccurate.

Time living with mBC

Following a cancer diagnosis, many patients enter a state of shock and may have difficulty retaining information.[22] Diagnosis with mBC may be particularly difficult for patients to initially understand and come to terms with due to the lack of an available cure.[7]

FIGURE 9: IMPACT OF DIFFERING DISEASE EXPERIENCE



Based on responses to Q15: 'Which of the following statements would you select related to learning about the type of breast cancer that you have?'. Patients' responses from China and Taiwan are missing from this question. Number of respondents does not add to the total number for the survey due to missing values

As patients spend longer living with the disease they may experience multiple rounds of treatments and thus have accompanying discussions, which may promote understanding and prompt further research or questions. 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 (**Figure 9**). Patients receiving a diagnosis within the past year (at time of survey completion) were less likely to report that they had learnt about and understood the type of breast cancer they have, which may indicate that experience with the disease shapes understanding.

Similarly, research in both early and mBC has demonstrated that informational and support needs are higher in those who have been diagnosed most recently.[7,10] In addition, patients diagnosed less than a year ago were also significantly less likely to ask their doctor for more information. This may suggest that some patients diagnosed recently may have a lower motivation to ask their physician questions, or as Steering Committee members noted, may simply not know what to ask.

Motivation to seek information

Attitudes towards the HCP–patient relationship have evolved from more paternalistic models of care to an increasing focus on activities empowering patients with the tools to participate in shared decision-making. Although literature suggests that most patients wish to participate in shared decision-making, some may wish to have less responsibility.[12,38]

7% of all patients answering the survey reported that they did not want to learn or find out more information about the type of breast cancer that they have and these patients were less likely to seek information from a variety of sources **(Figure 10A)**. In line with low motivation to seek information, these patients also less frequently understood the type of breast cancer they have and what it means **(Figure 10B)**.

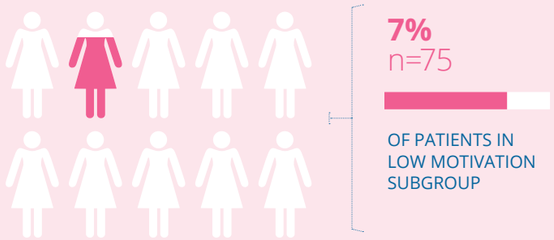
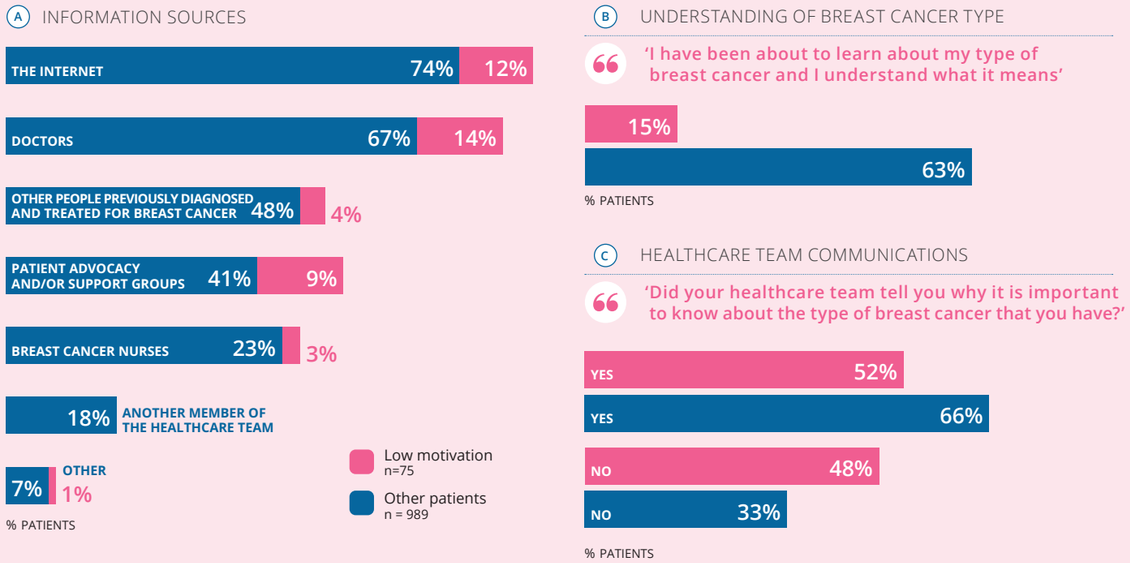


FIGURE 10: MOTIVATION TO SEEK INFORMATION



The low motivation subgroup was defined based on patients answering to Q14: 'Have you tried to find out more information about the type of breast cancer that you have?' with 'No, I don't want to find out more information', and to Q15: 'Which of the following statements would you select related to learning about the type of breast cancer that you have?' with 'I don't want to learn more'. Other patients are those not in the low motivation subgroup. A) based on responses to Q14 and B) based on responses to Q15, as indicated above. Patients' responses from China and Taiwan are missing from Q15

Patients with low motivation to seek information were also less likely to have been told by their healthcare team why it is important to know about the type of breast cancer they have **(Figure 10C)**. One potential explanation is that some patients don't 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 suggested that avoidance of information by some patients may in turn inhibit HCPs from communicating effectively with them, leading to further breakdown in communication between HCPs and patients during subsequent consultations.

People diagnosed with mBC may struggle to accept that they are living with an incurable disease, and face significant impact on their emotional wellbeing.[5,7] Methods used to cope with the emotional burden such as denial may in turn limit patients' willingness to seek more information about their diagnosis.[7,22] For some patients, particularly those diagnosed with certain types of mBC, the limited availability of treatments that can extend their survival may prevent them from wanting to learn more about the type of breast cancer they have. However, patients' understanding of their diagnosis may also help to improve acceptance and reduce the associated psychological burden.[7]

Alternatively, a lack of explanation from HCPs may contribute to patients' low motivation to seek information, setting the course for their level of interest. Steering Committee members noted that HCP misconceptions about mBC can influence levels of patient engagement, with some HCPs taking a fatalistic approach to the disease and therefore have lower levels of motivation to enable patient understanding. Some patients report unhelpful interactions, such as HCPs focusing too much on end-of-life decisions or lacking empathy.[5,25] HCPs may also carry preconceptions about patients' willingness to engage in shared decision-making, assuming that most patients rely on their physician to take this responsibility because they do not want the burden.[12,27] HCP biases may be particularly problematic when consulting patients with lower education levels, who HCPs may assume would be confused by the options and less capable of making treatment

> **"The reality is that the majority of the patients have a huge amount of trust in the doctor"[12]** – Oncologist

decisions.[27] In turn this may influence how much information is shared with patients and HCPs may not provide them with adequate context to decide how much they wish to be involved.

In some cases, patients may entrust physicians with the responsibility to make decisions on their behalf.[12-13] Steering Committee members noted that the willingness of patients to entrust HCPs with decisions in their best interest may require continuity of care from healthcare teams for patients to build a rapport with them. However, several studies have shown that, while the majority of patients express a desire for shared decision-making, there is incongruence with how frequently this takes place in practice.[12-13]

Steering Committee members discussed how socioeconomic or geographical barriers to accessing biomarker testing and targeted treatments may also limit patients' motivation to find out about their diagnosis. For example, particularly in low-and-middle-income countries, limitations in healthcare coverage and affordability of both tests and treatments may leave patients to adopt a fatalistic attitude. Access issues can often leave HCPs with an ethical dilemma of whether to discuss information regarding diagnostic or therapeutic approaches that patients will not have access to.

It was also reported that patients in more rural areas may have to travel long distances to get to a breast cancer centre and are thus less likely to receive testing and be engaged in discussions with physicians where they learn about their diagnosis. This may be exacerbated in lower resource settings with fewer specialist centres. For example, in Nigeria only 15.5% of patients have access to a comprehensive cancer centre within one hour of travel.[39]

"They say things like 'it's in the hands of god' or 'Allah will determine my outcome, I don't need information'"* – Psycho-oncology Expert

Steering Committee members also shared how, for many patients, cultural, or religious factors may influence their willingness to understand the type of breast cancer they have and be involved in shared decision-making. For instance, some patients may have a strong reliance on the authority of HCPs, while others may place their faith in God determining the outcomes of the disease course.[12]

It was suggested that reliance by patients on others to determine their fate was associated with patients' education levels. Research has shown that the health literacy level of patients not only influences their ability to understand information, but also correlates with their desire to find out more information.[37] Steering Committee members agreed that those with low health literacy levels may find seemingly complex terms or concepts overwhelming and consequently avoid the burden of too much information or may simply be unaware of the need to understand or learn more about their diagnosis.

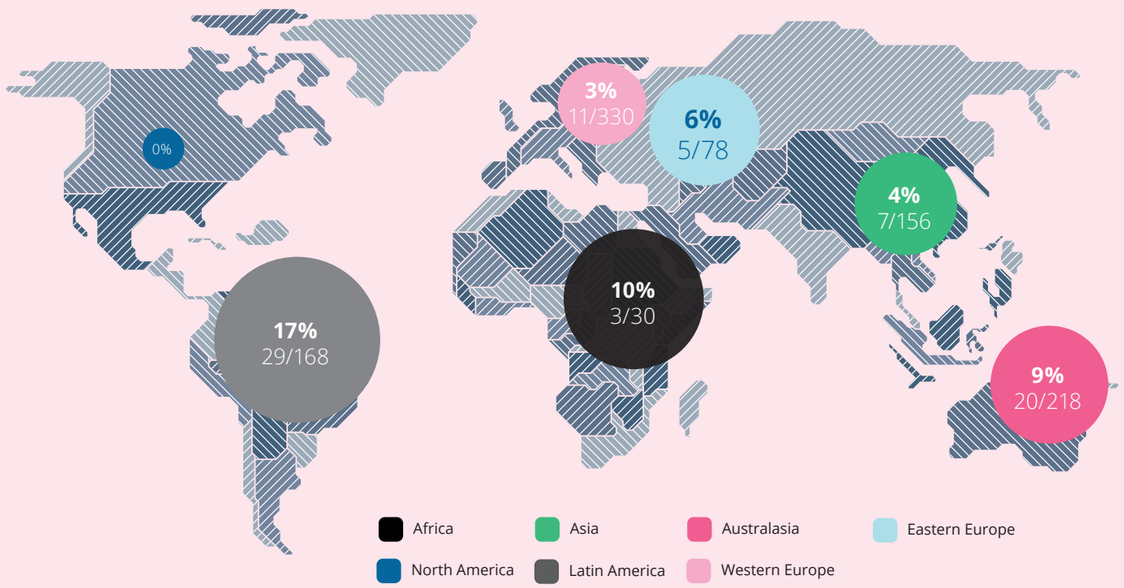
Thus, some patients may have low motivation to learn about the type of breast cancer they have and engage with HCPs in shared decision-making, which may be based on variety of socioeconomic or cultural factors, or even based upon negative interactions with HCPs themselves. These patients are likely to require different interventions to improve their understanding by focusing on their motivation to learn more about the disease and highlighting why they should be engaged.

Regional representation of low motivation patients

Regional variation in the socioeconomic and cultural factors discussed above may lead to geographical differences in patients' motivation to seek information, with patients from Latin America overrepresented in the low motivation subgroup **(Figure 11)**. Notably, a large proportion of Latin American respondents were from lower-income countries such as Haiti and Venezuela, with patients from some key countries missing (e.g., Argentina). Thus, findings may not be representative of the whole region, especially given the widespread health inequalities both within and between countries in Latin America.[40]

*quote provided by Steering Committee

FIGURE 11: REGIONAL REPRESENTATION OF LOW MOTIVATION PATIENTS



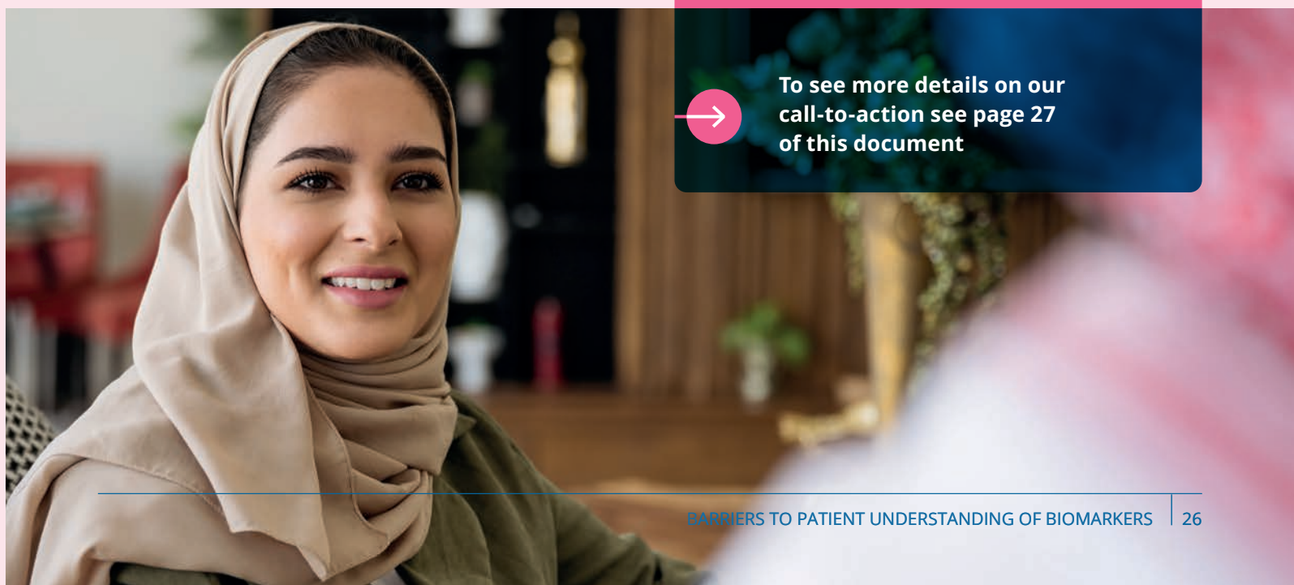
Percentage of patients from each region in the low motivation subgroup, defined by the proportion of patients in the low motivation subgroup from the region relative to the total number of patients from the region. Total number of patients in low motivation subgroup = 75; no patients from North America were in the low motivation subgroup

Steering Committee experts from the region noted that from experience many patients do not wish to know more information than necessary, beyond being told that they are receiving the recommended treatment. Several regional factors which may influence patients' motivation to find out more about their diagnosis were discussed:

- Patients receiving publicly funded healthcare lack access to testing, treatments, and consultation time with physicians. Lack of access to treatments, and associated biomarkers tests, and limited opportunity for in-depth discussions with HCPs can prevent patients from wanting to find out more about their diagnosis
- Some patients require interpretation for consultations. This can lead to information becoming lost in translation and can limit patients' motivation to learn more about the disease. A previous study focused on Latina patients diagnosed with cancer in the US also demonstrated that relatively few patients would like additional information on their diagnosis, and those with low English proficiency, or requiring translation were less likely to desire information.[37] This may be a particular challenge in multilingual or multiethnic countries, or communities
- Low average health literacy of levels of patients. The education level of patients in the region may limit their ability to understand complex information, and, in turn may prevent them from wanting to try and understand their diagnosis or taking responsibility for decisions as they rely on physicians to 'know best'[30,38]

Call-to-action areas of focus

- Leverage and expand existing care models and practices to facilitate effective two-way communication and information delivery across the patient pathway
- Activate the mBC patient community to self-advocate for better knowledge and engagement in decisions
- Improve accessibility of patient advocacy and support groups to accelerate education and patient empowerment
- Accelerate and expand access to peer-to-peer support groups leveraging learnings from the past decade to better serve patient understanding and empowerment



To see more details on our call-to-action see page 27 of this document

Call-to-action

People living with mBC deserve adequate access to support and care. Survey findings highlight that patients face many challenges in understanding their diagnosis with limitations in the information, education, and support provided to them, impeding their ability to self-advocate and engage effectively in shared decision-making. While the focus of the survey was on identifying challenges faced by patients globally, access to biomarker testing and targeted treatments is an underlying issue for patients in many countries which warrants additional research and separate interventions (Box 3). In addition, many of the identified challenges and opportunities for change may also be relevant to breast cancer more broadly. As such, the breast cancer community collectively has a critical role to play in galvanizing change for those diagnosed with mBC.

1 Elevate the effectiveness of communication between HCPs and patients

1. Standardise patient-focused terminology used to describe mBC biology and biomarkers to improve the clarity and consistency of information

- Create a patient-focused glossary of terms, developed by patient advocacy groups and HCPs, that can be used when speaking to patients to avoid inconsistencies that they can find confusing, particularly when seeing multiple HCPs or using different resources
  - Consider patients' health literacy levels and avoid jargon in standardised words or phrases
  - Adapt existing resources to focus on mBC and improve uptake (such as the Cancer Support Community Precision Medicine Lexicon – see **Box 2**)
- Develop accompanying guidelines for creating new patient education materials incorporating appropriate terminology, along with an accreditation process for new materials
  - Monitor the uptake and adherence of new materials and resources to guidelines through tracking accreditation
- Disseminate and translate glossary and guidelines into multiple regions and languages using local patient advocacy groups and medical professional organisations
- Engage multiple stakeholder groups in dissemination to ensure language is consistent in the dialogue between them (e.g., including industry and policy makers)

2. Leverage and expand existing care models and practices to facilitate effective two-way communication and information delivery across the patient pathway

- Create a policy framework to standardise the provision of information and support for patients as an integral component of care delivery
- Encourage the adoption of practices that enable effective two-way communication, particularly at initial diagnosis, including:
  - Flexible consultation models, especially for newly diagnosed patients, to allow for more time to educate patients, by both treating physicians and specialist nurses
  - Telehealth follow-up appointments to give patients an opportunity to ask additional questions, and provide additional information to consolidate their understanding, once they have had time to digest their diagnosis
  - Shared decision-making tools to ensure patients have adequate understanding of their diagnosis, its relevance, and the context as to why being engaged is important
- Expand the integration of models that leverage effective multi-disciplinary care, including specialist breast cancer nurses and patient navigators, to ensure consistency and continuity in information and support provision
- Establish metrics, encourage data capture, and evaluate data, to: 1) ensure effective introduction of educational and communication practices; 2) understand the impact on care and outcomes; and 3) encourage investment from policy makers for expansion

2 Empower patients with information and guidance for self-advocacy

3. Activate the mBC patient community to self-advocate for better knowledge and engagement in decisions

- Create campaigns from patient advocacy or support group networks which focus on empowering patients with knowledge on the disease and educating on why it is important for them to understand their diagnosis
  - Involve patients with lived experiences in campaigns to drive hope about outcomes with local adaptation depending on influencing cultural or socioeconomic factors
- Provide patients, and their carers or family members, with key questions (e.g., question prompt list) to ask about the disease, co-created by patients, caregivers, and HCPs, to ensure effective communication during limited consultation times and promote self-advocacy
- Develop self-advocacy guidance, including online or face-to-face sessions for self-advocacy building, for patients and their caregivers
  - Include information on understanding their rights as a patient to information and informed consent, how to communicate effectively and respond to physicians' decisions, guidance on challenging or questioning decisions, how to communicate issues important to them and their wellbeing, and navigation to key resources or support tools
- Empower patients to become patient navigators themselves through programmes held by patient-centred organisations, allowing patients to provide peer-to-peer support through the shock of initial diagnosis to living with the disease, empowering them with the right information and resources at the right time

4. Improve the accessibility of patient advocacy and support groups to accelerate education and patient empowerment

- Harness and evolve existing educational information, assets, and tools from patient advocacy groups to drive standardised adoption of terminology and tailored information dependent on health literacy levels
  - Ensure resources can be easily adapted by local patient-centred and medical professional organisations according to individual needs
- Enhance effective signposting of patient organisations to make information available more accessible to patients
  - Invest in existing online platforms, social media, and search engine advertising to increase visibility of support groups and patient advocacy groups and associated information
  - Accelerate signposting to patient advocacy and support groups by HCPs through outreach programmes to healthcare practices to improve awareness of such groups and the role they play

5. Accelerate and expand access to peer-to-peer support groups leveraging learnings from the past decade to better serve patient understanding and empowerment

- Create frameworks for peer-to-peer support groups designed for those with mBC and their unique experiences, to enable validated information and resources to be shared by peer-to-peer dissemination
- Facilitate and promote the use of frameworks by in-person and online support groups within existing patient advocacy groups
- Introduce new support groups in regions where they are not available using frameworks

3 Activate local patient advocacy groups to drive change and advocacy

6. Promote and translate best-practice initiatives between geographies that empower patients with information and support using existing advocacy networks

- Collect successful examples of initiatives (both within and beyond breast cancer) through a call for submission from country-level patient organisations, or targeted research into the activities and policies of specific regions based on findings (e.g., North America) to help identify learnings that can be applied elsewhere
- Develop a standardised template for collecting key information on initiatives including the process for implementation, costs, time-frame, and outcomes
- Categories could include:
  - Patient friendly communication of diagnostic information
  - Patient navigation training and programmes
  - Peer-to-peer support groups or platforms
  - Shared decision-making tools
  - Diversity and inclusion in clinical trials, by geography
  - Lobbying policy makers for access to targeted treatments
  - Effective multi-disciplinary care, including the integration of breast cancer nurses

7. 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

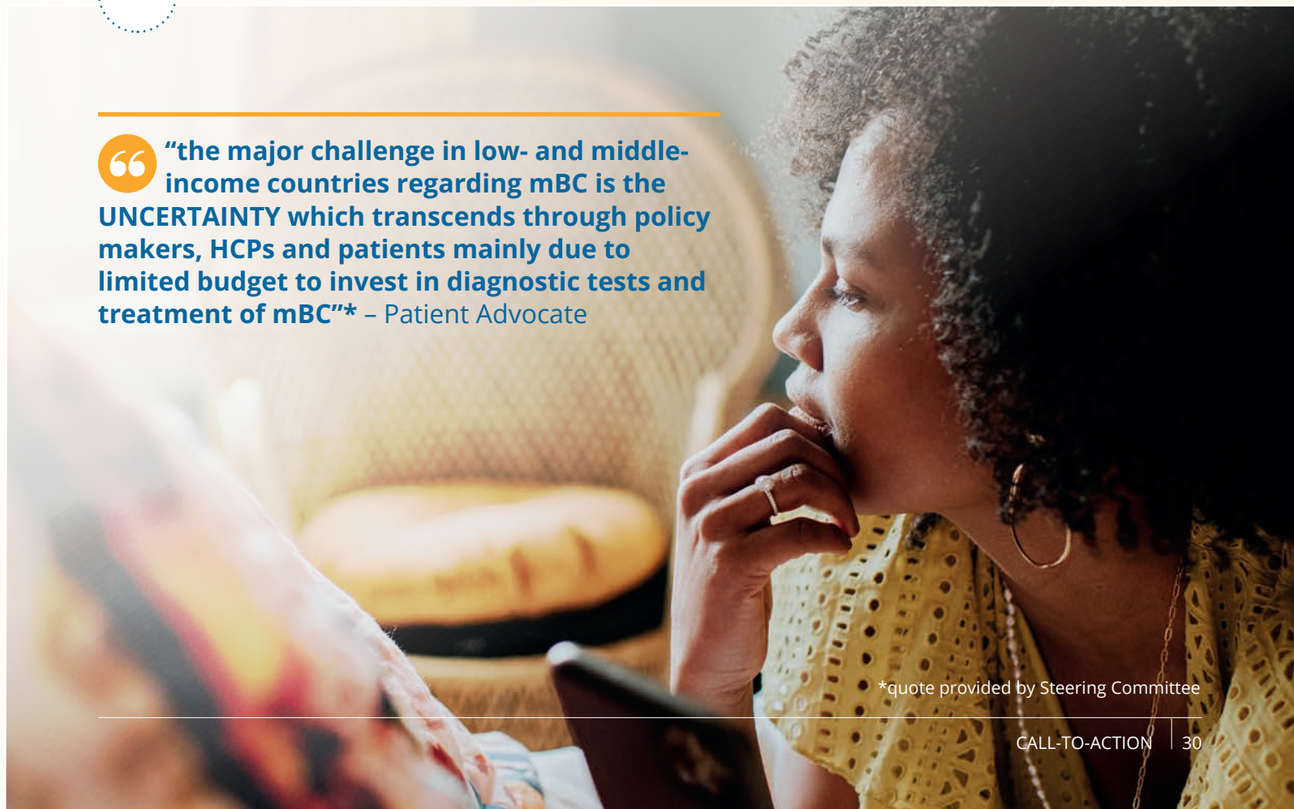
- Investigate the local challenges limiting patients' understanding of the type of breast cancer they have, driven by local organisations. Localised research may more easily identify the cultural or societal nuances and define specific challenges that may not be visible on a global scale
- Provide local, regional, or country-level organisations with a toolbox of questions to investigate in their region, to guide creation of tailored surveys by country or region, or to facilitate the gathering of existing research
- Leverage data to develop a series of mini-frameworks based on identified challenges to establish locally-driven initiatives, through collaboration between global and local patient organisations

BIOMARKERS AND INEQUITY OF ACCESS

BOX 03

Across geographies access to biomarker testing remains a major challenge for many patients. This is especially true for those in low-and-middle- income countries where there is a lack of infrastructure and funding for the implementation of biomarker testing. Note, that for some patients access to targeted treatments may be the primary challenge meaning that many biomarker tests are not used or needed. For these patients the following actions are needed:

- Introduce legislation and funding to support the local delivery of biomarker testing and associated targeted treatments from policy makers, and reimbursement from payers. This relies on first raising awareness of the unmet needs of those living with mBC and their contributions to society to persuade payers and policy makers of the importance of investment. Raising awareness relies on collaborative efforts from the metastatic breast cancer community to:
  1. Collect and share data as an evidence base via registries, surveys, and real-world evidence
  2. Advocate using platforms to gain attention from payers and policy makers, such as invitations to patient advocacy meetings, public awareness and media events, or leveraging the voice of high-profile public figures
- Expand globalisation of clinical trials for targeted treatments that rely on biomarker testing, both from the pharmaceutical industry and academic groups. By investing in local infrastructure and easy-to-use biomarker tests that may be used in lower resource, de-centralised settings there is potential for long-term impact on the uptake of biomarker tests in these environments. Involving lower income countries early on in treatment development may also help to raise the importance of investment in mBC to local policy makers



"the major challenge in low- and middle-income countries regarding mBC is the UNCERTAINTY which transcends through policy makers, HCPs and patients mainly due to limited budget to invest in diagnostic tests and treatment of mBC"* – Patient Advocate

*quote provided by Steering Committee

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ABC GlobAlliance

We, the authors, call on policy makers and their governments, healthcare professionals and their societies, patient advocates and their organisations, global health organisations, and pharmaceutical and diagnostic companies worldwide to work together to improve communication and understanding of biomarkers to patients with mBC. It is only through collaboration and concerted effort that change can be realised for the millions of people living with mBC today.

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