

Rising to the metastatic breast cancer challenge

Current and future
policy responses



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About this report

Rising to the metastatic breast cancer challenge: current and future policy responses is a report by Economist Impact. It describes meaningful policy, infrastructure and research on metastatic breast cancer across several countries, providing an assessment of barriers, enablers and areas of opportunity in seven upper-middle and high-income countries: Brazil, France, Germany, Italy, Japan, the UK and the US. This report seeks to identify unique challenges faced by people with metastatic breast cancer, placing their needs at the centre of the policy conversation. The research was sponsored by Sanofi.

We performed a pragmatic literature review to assess the existing landscape, which was complemented by a search of grey literature to retrieve guidelines, policies and frameworks that were not listed in scientific databases. We also spoke to a range of global and regional experts—both over the phone and at meetings and conferences—including clinicians, academics, community experts, advocates and policymakers.



We would like to particularly thank the following experts (listed alphabetically by country) who contributed to this report through interviews:

Brazil

- Romualdo Barroso, clinical oncologist, head of research in oncology and National Leader of Breast Oncology - DASA Oncology
- Maira Caleffi, founder and president, FEMAMA and IMAMA (Brazil)
- Marianna de Camargo Cancela, head of the Surveillance and Situation Analysis Division, Coordination of Prevention and Surveillance at the National Cancer Institute of Brazil
- Luciana Holtz, Founder and President, Instituto Oncoguia

France

- Mario Campone, director, Institut de cancérologie de l'Ouest
- Benjamin Verret, medical oncologist, Gustave Roussy
- Maria Alice Franzoi, medical oncologist and researcher at Gustave Roussy, Villejuif

Germany

- Diana Lüftner, director of the Immanuel Hospital Märkische Schweiz & Medical University of Brandenburg Theodor Fontane, Campus Rüdersdorf

Italy

- Eugenio Paci, former director of the Clinical Epidemiology Unit, Oncological Network, Prevention and Research Institute (ISPRO)
- Dario Trapani, MD, medical oncologist, Dana-Farber Cancer Institute (advanced fellow) and European Institute of Oncology (IEO)

Japan

- Tamae Iwasawa, co-director of Kanagawa Federation of Cancer Patient Groups, co-representative of Breast Cancer Support "Maria Ribbon"
- Seigo Nakamura, professor of surgery and director of Breast Centre, Showa University Hospital; board chairman, Japanese Organization of Hereditary Breast and Ovarian Cancer (JOHBOC)
- Naomi Sakurai, president of Cancer Solutions, chief director of Project HOPE
- Midori Takahashi, advisor at Cancer Solutions, director of General Corporation CSR Project

UK

- Richard D. Baird, academic consultant in Experimental Cancer Therapeutics, Cancer Research UK Cambridge Centre
- David Cameron, professor of medical oncology, University of Edinburgh and chair of the Breast International Group (BIG)
- Jo Taylor, Founder of After Breast Cancer Diagnosis and METUPOK

US

- Christine Benjamin, Vice President, Patient Support and Education, SHARE Cancer Support
- Brittany Bychkovsky, MD MSc, instructor of medicine at Harvard Medical School, physician in the Department of Medical Oncology and Division of Cancer Genetics and Prevention at the Dana-Farber Cancer Institute, expert panellist at the Global Cancer Institute

- Nancy U. Lin, MD, associate chief, Division of Breast Oncology, Dana-Farber Cancer Institute
- Fran Visco, president, National Breast Cancer Coalition

Global

- Sawsan Abdul Salam Al Madhi, director-general, Friends of Cancer Patients (PAG)
- Kathi Apostolidis, president, European Cancer Patient Coalition-ECPC, president, Hellenic Cancer Federation-ELLOK

We would also like to thank the following individuals who participated in our expert panel:

- Benjamin Anderson, surgical director of the University of Washington Breast Health Clinic, chair of the Breast Health Global Initiative (BHGI), US
- Fatima Cardoso, president of the ABC Global Alliance, editor-in-chief of The Breast Journal, Portugal
- Susanne Cruickshank, strategic lead for applied health research at the Royal Marsden NHS Foundation Trust, honorary professor of nursing, University of Stirling, UK
- Maimah Karmo, founder and chief executive officer, Tigerlily Foundation, US
- Shani Paluch-Shimon, director of breast oncology at Hadassah Medical Organization, Israel

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Executive summary

Metastatic breast cancer (MBC) is a complex disease, and the course of the disease and experiences for people living with MBC vary widely. Most cases are incurable, although there are some long-term survivors. Advancements in the field have been made and many currently available treatments aim to slow disease progression and improve quality of life. Our research across seven countries shows that significant gaps exist in knowledge and approaches to addressing the needs of people with MBC and their caregivers.

This report highlights the diversity of challenges that people with MBC face around the world. It further identifies priorities for policymakers, advocacy organisations, health system administrators and other key stakeholders to improve the quality of life for individuals with MBC.



Key takeaways and priorities identified in this research include:

Support for people with MBC and caregivers is often inadequate. People with incurable diseases face numerous physical, emotional, psychosocial, family and financial hurdles, reducing their quality of life. Such conditions are made worse when they face stigma and discrimination within social groups or the workplace, compounded by limited knowledge about their disease in the general public. Policies and campaigns can help raise awareness, educate the public and enforce workplace flexibility (eg adapting the role and conditions) for individuals who want to work, but these actions vary across geographies. Underserved groups including racial and ethnic minorities, those of lower socioeconomic status, and other underrepresented populations report greater levels of adversity due to these challenges. It is critical to consider all these complex quality of life factors beyond the limits of symptoms and treatment reactions.

Optimal care delivery is dependent on numerous patient-centred factors. Best practices, such as multidisciplinary teams, shared decision-making and provision of comprehensive supportive and palliative care services, are universally recognised and adopted. However, access and quality of care vary by country and geographic location based on proximity to

specialist care centres. People with MBC frequently express frustration with the inconsistency and lack of continuity for meeting their needs as they move through health systems and the stages of treatment.

Lack of workforce expertise impacts the quality of available care. A shortage of qualified and specialised healthcare professionals with expertise and experience in MBC care means equal access to quality care is not guaranteed. Further disparity is seen in access to specialty care between urban and rural populations. Healthcare providers are often unequipped with the appropriate training or tools to meet the complex care needs of people with MBC. These challenges will become more acute as the population of people with MBC grows.

Existing policies create barriers to accessing best-available care. A spectrum of policies and health financing systems means that access to treatment and care is highly impacted by the individual's geography and economic situation. Particularly where there is no cost parity for oral medications, individuals' realistic treatment choices can be limited. Similarly, where health technology assessments (HTAs) are not routinely utilised, are methodologically inflexible or are subject to other delays, people with MBC may lack access to the latest and most novel therapeutics. Involving individuals with MBC in the policy development process and addressing quality of life needs for both people with MBC and their caregivers should be the priority.

Incomplete data limit advances in care for people with MBC and evidence-based policy. Clinical databases for people with MBC are often incomplete, and the full burden of MBC is obscured. National cancer registries often fail to capture information on when a person with early stage breast cancer develops recurrent MBC or if the person is newly diagnosed with metastatic disease. Other priority data gaps include individual

experience, quality of life and caregiver needs. Privacy and data sharing restrictions may limit collaboration between members of an individual's care team, and policy makers should act to facilitate data sharing needs for all stakeholders.

While this report presents several challenges encountered by those living with MBC, it is important to consider the actions necessary to change the status quo. Action will require purposeful multistakeholder involvement while putting those living with MBC at the centre of all decision-making. This will not be possible without the support of the MBC community.

Looking to the future, key areas of action are needed:

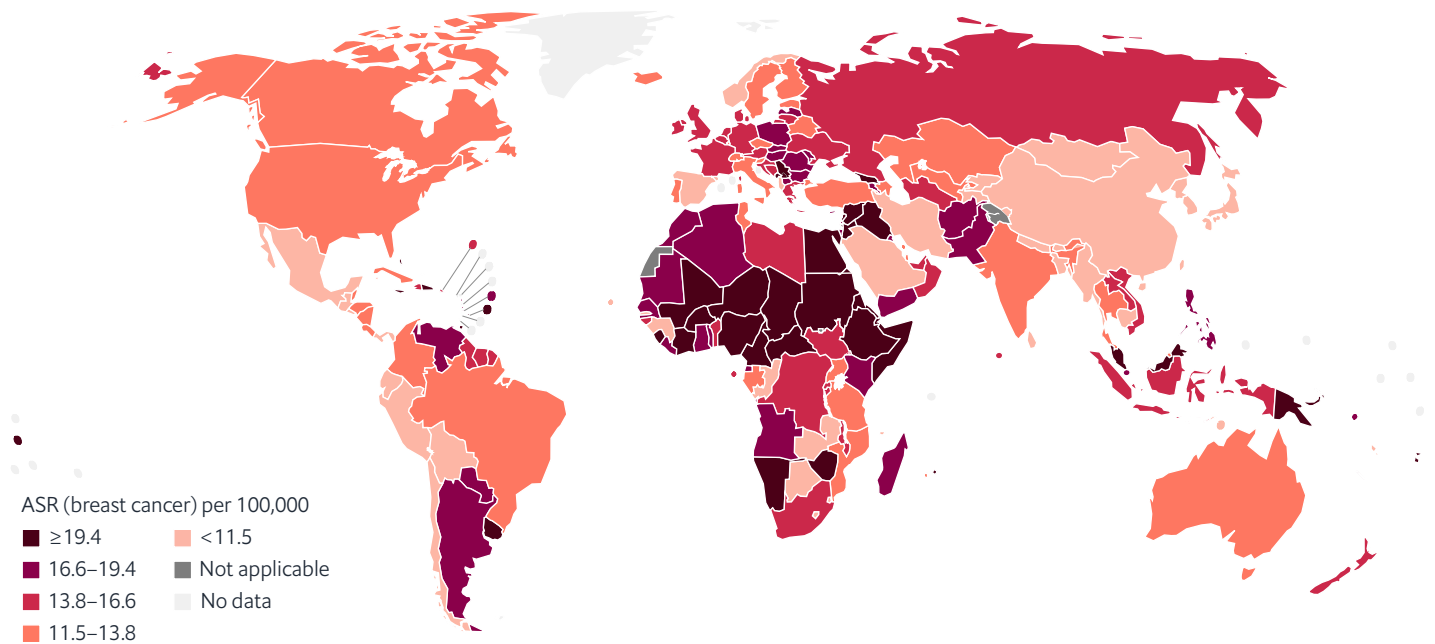
- Frame effective treatment as a long-term investment in patients and caregivers.
- Incentivise and align data collection initiatives.
- Commit to research and defining disparities and unmet needs for MBC patients.
- Improve quality of life for people with MBC and caregivers.
- Enhance education and knowledge transfer to prepare patients for the challenges of MBC.

The burden of metastatic breast cancer and gaps in research

Breast cancer is the most frequent cancer among women, representing nearly a quarter of cancer diagnoses and impacting an estimated 2.2m people globally.^{1,2} Metastatic breast cancer (MBC)—also called stage IV breast cancer*—is an advanced stage of disease in which cancerous cells that originated

in the breast tissue have spread—or metastasised—beyond the breast and locoregional lymph nodes to create new tumours at distant sites (ie in the liver, bone, lungs or brain).³ Nearly 30% of women diagnosed with early-stage breast cancer will develop metastatic disease.³

Figure 1. Estimated age-standardised mortality rates (ASR) for females with breast cancer, 2020



Source: World Health Organization. Estimated age-standardised mortality rates (world) in 2020, breast, all ages. GLOBOCAN, 2020.⁷

*Technically, *stage IV cancer* refers to de novo cases of metastatic disease, though the term is also used colloquially to refer to people with stage 0-III breast cancer who develop metastatic disease.

MBC accounts for 90% of all breast cancer deaths.⁴ On average, women with MBC survive just three years from diagnosis, with under a third (29%) surviving up to five years.^{*,5,6} The World Health Organization (WHO) projects a 43% increase in breast cancer–related deaths between 2015 and 2030, primarily due to cancer metastasis, and an upward trend in incidence and mortality in younger females aged 15–39 years through 2040.²

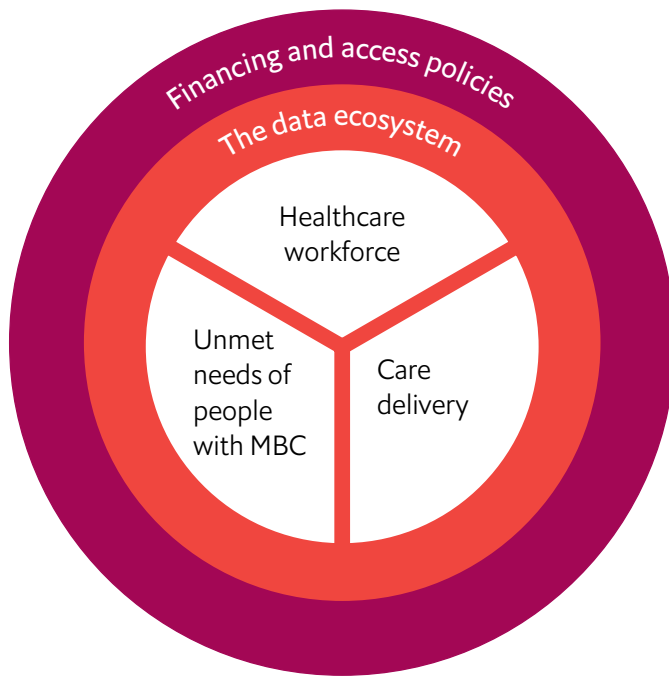
While MBC is incurable, individuals are treated to control the cancer’s spread, improve their quality of life and improve their survival.⁸ Treatment options for MBC have been historically limited, with individuals moving on to a new regimen when their current therapy stops working.³ Recent advances in our scientific understanding of breast cancer—in particular the genetic components from efforts in clinical trials, ongoing studies on breast tumours in vivo, and the Human Genome Project—have enabled new treatments to reach the market and facilitate a move from “one size fits all” to targeted therapy for each cancer subset.⁹

Despite the disease and mortality burden represented by MBC, it accounts for only 7% of all breast cancer research.¹⁰ Most research focuses primarily on diagnosis and treatment aimed at extending life, but generally lacks exploring individual experience, quality of life, access to advanced diagnosis and palliative care, access to information, financial support, or other areas of importance to people with MBC. This broad lack of information is a barrier to producing evidence-based policy. While progress is seen in provision for palliative care, training and facilities for multidisciplinary care, significant gaps and hurdles remain.

This report identifies five key categories representing challenges that must be explored to guide MBC policy towards areas with significant benefit for the impacted population, as shown in Figure 2 on the next page.

*These overall survival statistics vary by clinical subtype and may be even better now with advances in clinical research and treatment.

Figure 2. Metastatic breast cancer (MBC) framework



Financing and access policies
<ul style="list-style-type: none"> • Financing (insurance and oral parity) • Health technology assessment • National and regional MBC-specific policies
The data ecosystem
<ul style="list-style-type: none"> • Resources and infrastructure • Recurrence and quality standards • Data-informed guidelines
Healthcare workforce
<ul style="list-style-type: none"> • Needs (type of professionals, training, awareness and education) • Guidelines • Incentives
Unmet needs of people with MBC
<ul style="list-style-type: none"> • Support groups • Workplace flexibility • Quality of life considerations • Patient experience • Information and education
Care delivery
<ul style="list-style-type: none"> • Multidisciplinary care • Treatment (shared decision-making and personalised care) • Supportive care • Continuity and transition of care • Geographical distribution

Source: Economist Impact

Overarching challenges and unequal policy response:

Unmet needs of people with MBC

The basic tenets of the public health response to breast cancer focus on prevention, screening, early diagnosis and treatment. This response seeks to offer the best outcomes and cost-effectiveness for health systems. However, an unintended consequence of this prioritisation is that those with advanced disease or late-stage diagnoses can be left uninformed and unprepared for their prognosis. This is compounded by a complicated treatment landscape involving multiple sequential therapies and the need for individuals and caregivers to navigate the physical, emotional and financial toll

that comes with efforts to extend duration and quality of life.

Meeting these challenges requires detailed understanding of the needs of people with MBC and provision of support in healthcare settings and in the home and workplace. These aspects are commonly referred to as supportive care, and include any services to meet physical, educational, social, psychological or spiritual needs.¹¹ Here, significant variation is seen between different countries' responses to meeting these needs.



Table 1. Needs of people with MBC

Quality of life considerations (individual preference and symptom management)	
Brazil	Individual preferences in treatment are often taken into consideration before prescribing medications.
France	Doctors are required by law to incorporate individual preferences into treatment and can refer patients to palliative care.
Germany	Individuals have varying concerns depending on age. Young people with breast cancer show reduced social, emotional and cognitive functioning compared with older individuals.
Italy	A common measure of quality of life in Italy is pain as it relates to treatment, but other quality of life indicators are not widely collected because it is not a requirement.
Japan	Stress-related symptoms, in addition to other quality of life measures, should be taken into consideration when developing policies and legislation in addition to data collection.
UK	Individual preferences are considered as there is a culture in the country of being very open about treatment recommendations with people seeking care.
US	Chronic pain and side effects from treatment are not well understood or managed and may result in people with MBC having more pain than necessary. The opioid epidemic has led to policy that restricts prescriptions, making pain management especially difficult for people with MBC.
Support groups for people with MBC	
Brazil	Patient advocacy groups need to be mobilised to call for policy change. There is limited healthcare-associated financial support for people with MBC, and many are unaware of their rights under the national insurance programme.
France	There are support groups available to people with MBC, families and caregivers, such as the French League Against Cancer.
Germany	Numerous support groups are available for people with MBC. However, during the covid-19 pandemic many groups did not have capacity to accept new members, underscoring the need for increased online psychosocial support.
Italy	Various institutions, organisations and advocacy groups offer education, training and support to people with breast cancer, such as the Italian Association of Cancer Patients.
Japan	People with MBC seek support from patient groups, medical personnel and online, but stigma may be a barrier to access. Advocacy groups help with outreach and training at local hospitals.
UK	Many support groups are available to individuals through research, breast cancer information and support across the UK, such as METUP UK.
US	Numerous support groups are available both online and in person for people with MBC. Greater support for families and caregivers is needed.

Workplace flexibility	
Brazil	There is limited information about workplace flexibility for individuals with MBC in Brazil.
France	There are laws in place that give all employees the right to absences for medical treatment. The government will also temporarily supplement sick-leave benefits should the individual want to return to work part time. However, legislation is not comprehensive and makes returning to work more difficult than is necessary.
Germany	There are laws that protect time off for people with cancer and policies against discrimination due to cancer diagnosis.
Italy	Italy offers various protections for people with cancer seeking flexibility and return to work. Under Law 104/92, individuals can take different forms of leave for care for a person with over 50% disability. People with cancer can seek recognition of civil disability and can obtain work flexibility, which became especially significant during the covid-19 pandemic.
Japan	People with breast cancer have shown a higher level of absenteeism when compared to other types of cancer, and the government must take measures to ensure that individuals have the right to work and are protected from being fired for their absences.
UK	The 2010 Equality Act applies to people with, or who have previously had, cancer. All cancers are included, and the law offers job protection from the time of diagnosis.
US	There are several laws that prohibit discrimination the basis of disability; however, people with cancer in some cases must prove disability. It is federally mandated to make reasonable accommodations for disability in the workplace. There are also protections for caregivers (eg 12 weeks unpaid leave).
Individual experience: financing care	
Brazil	Medication modality is subject to different financial coverage. The length and complexity of the approval process can deter care.
France	Financial distress is not systematically studied in France as many consider it to be rare due to France's insurance scheme. However, external, patient-specific factors (eg unemployment) contribute to increased financial burden.
Germany	Financial toxicity is not a primary concern for German individuals seeking care. Minorities (eg black females, LGBTQ individuals) are less likely to receive cancer-directed and innovative treatments, and are underrepresented in clinical trials.
Italy	Financial toxicity is currently well controlled but is becoming more of a concern among individuals seeking care.
Japan	Financial toxicity is more severe among younger individuals because the Japanese government offers preferential treatment to elderly persons with breast cancer.
UK	Financial toxicity due to medical expenses is not a primary concern. However, covered medical treatments often undergo a lengthy approval process, which can restrict access due to delays.
US	Financial toxicity and racial disparities create systematic difficulties for the individual seeking care and barriers to innovative treatments and drugs. Reimbursements for treatments vary by type of insurance (eg public vs private).

Information and education for individuals with MBC	
Brazil	Care is guaranteed under the Sistema Único de Saúde (SUS), but many individuals are unaware of their rights in terms of benefits and often don't feel empowered to advocate for themselves.
France	Many patient advocacy organisations have developed educational materials that cover the care pathway in an effort to empower individuals seeking care in their care decisions.
Germany	Individuals seeking care need more education around each stage of the care pathway, from diagnosis to supportive care, including interpretation of results (eg genetic testing).
Italy	The ability of an individual seeking care to navigate the care continuum and partake in shared decision-making depends on health literacy and system integration.
Japan	Low medical literacy is a problem found among people with MBC, particularly older adults. Advocacy groups are critical in patient education and empowering individuals to participate in shared decision-making.
UK	While awareness of breast cancer is high in general, education on MBC is limited. Within the last five years, advocacy organisations and healthcare providers are offering more information to individuals.
US	People with MBC need more education around each stage of the care pathway, from diagnosis to supportive care, including clinical trials.

Quality of life considerations

Given that MBC is typically incurable, and individuals seeking care require ongoing treatment to manage disease, quality of life is an important component for MBC disease management and is considered to some extent in all countries studied. However, there are limited data describing the specific experience and quality of life needs for people with MBC. This has the impact of preventing high quality and effective care delivery, according to the expert interviewees. For example, chronic pain and treatment side effects are not well understood or managed, and may result in people with MBC living with more pain than is necessary. Where studies have been conducted they typically focus on breast cancer in general, and highlight gaps in our understanding rather than making concrete conclusions. High inter-patient

variability is also observed. A 2014 study on young people with breast cancer showed reduced social, emotional and cognitive functioning when compared with older people with breast cancer.¹²

Our experts identified two crucial areas for evaluating patient quality of life: firstly, listening to individuals about what matters to them; and secondly, developing tools that accurately measure their quality of life. These points are supported by a published study that investigated quality of life perceptions of people with MBC. Participants indicated that they value periods of time without disease progression, especially when coupled with improvements in quality of life. The study concluded that comprehensive quality of life measures should be considered in “the design and conduct of future clinical trials in MBC, as well as HTA and reimbursement decision-making.”¹³

There is limited research on caregivers' quality of life, but a few studies show that caregivers of people with breast cancer experience stress and a variety of difficulties at home and at work.¹⁴ The quality of life of caregivers was found to decrease with the time spent providing care.¹⁵ The same study discovered that caregivers also encounter significant emotional distress and financial worry. Fatigue, anxiety and the pressure to offer care were a few of the factors that directly contributed to lower quality of life. Recognising the impact that caregivers have on the wellbeing of people with MBC, one study proposed a four-part framework to support caregivers: 1) assess their needs, 2) offer a standardised skills training program, 3) empower caregivers not only in the employment context but also by feeling supported and 4) strengthen caregivers through a caregiver support program.¹⁶

Christine Benjamin, vice president, Patient Support and Education, SHARE Cancer Support, says this supportive framework for people with MBC, their families and caregivers could be achieved and have a positive impact on care quality. "We also know that patient navigation helps improve health disparities. If all metastatic patients received palliative care and patient navigation, we could improve outcomes. This would probably require federal policy to ensure patients receive this type of speciality care", she says.

People with MBC should be empowered to improve their emotional, physical and financial state—their overall quality of life. While the quality of life has

improved among people with MBC in the last decade, the search for effective treatments continues.¹⁷ Developing effective treatments with low toxicity is one way to reduce the burden on individuals.¹⁸ Long-term investment in research, treatment and care can lead to economic and societal benefits.¹⁹⁻²¹ It is critical to invest long-term in effective treatment, as well as care and support for people with MBC and caregivers to improve quality of life for all.²²

Stigma and support groups for people with MBC

People with MBC often seek help from support groups after diagnosis or during and after treatment. Some individuals suffer from an acute stress reaction after diagnosis and treatment—or are more susceptible to depression and other mental health conditions—which means ongoing support and access to mental health services is critical.²³ A 2018 study concluded insufficient resources and support to address these issues.²⁴

Support groups for MBC exist in some form in most countries. While many are local, several larger groups, such as the ABC Global Alliance and Europa Donna, have regional or international reach. The style and structure of this support can vary from websites and social networking sites to in-person meetings hosted by cancer organisations more typically in urban areas.²⁵ Regardless of the format, these groups share an underlying goal: to support individuals seeking care with increased access to information, capture the "patient voice" and meet other specific needs.

In some cases, such as in Japan, stigma may hinder engagement with support groups. "There really isn't a wide recognition of people with cancer in Japan and there is a lack of understanding and a lack of will to understand", says Naomi Sakurai, president of Cancer Solutions and chief director of Project HOPE. "There's a real sense of people

"Patient navigation helps improve health disparities. If all metastatic patients received palliative care and patient navigation, we could improve outcomes."

Christine Benjamin, SHARE Cancer Support, US

wanting to avoid the topic of death.” In addition, Midori Takahashi, director of General Corporation CSR Project (Japan) adds that Japan has minimal psychosocial and peer-to-peer support because “unlike the USA or European communities, we do not have a volunteer type of culture, but it’s growing.” She adds that it is rare to come by a patient group dedicated to MBC. “When it comes to patients with a more serious condition, it is hard for them to communicate or to interact with peers,” she says.

Workplace flexibility

The workplace can be challenging for those suffering disease, and people with breast cancer generally report difficulty with employment. These challenges include difficulty with continued employment, underemployment and stunted career progression. Cancer can impact physical,

cognitive and psychological function, which affects work productivity and leads to work-related anxiety and distress.²⁶ Even when the ability to work has not declined, people with cancer often require time off for medical appointments, treatment and recovery, creating further productivity challenges that can result in discrimination from managers and colleagues. Perhaps unsurprisingly, those with MBC report greater employment challenges.²⁷ One study from the UK comparing people with early breast cancer and MBC found that individuals with MBC reported lower health utility, were more often unemployed and worked fewer hours.²⁸

An MBC diagnosis can also compound workplace disadvantages faced by underprivileged groups. According to one US study, racial and ethnic minority females with MBC were more likely to report adverse changes to their employment status due to the burden of cancer care, such as stopping work completely, reducing hours and taking unpaid leave.²⁹ Caregivers are also more likely to report similar impacts.³⁰

Ensuring individuals can continue to work is important. Not only is work associated with value and purpose, but in many countries work is linked to payment for healthcare—making hostile, inflexible work environments particularly alarming. This is particularly important for breast cancer which impacts younger females. More than 55% of breast cancer survivors in Japan are of working age; but younger age at diagnosis, lower education level and taking sick leave were identified as predictors of resignation after breast cancer diagnoses.³¹

In countries with employment-based private insurance, companies and insurers may not want to adopt the costs associated with cancer care. According to experts, a treatment regimen sometimes requires a person with MBC to retire. In the US, this leaves individuals looking beyond their employer for health insurance, often relying on Social Security Disability Insurance (SSDI)



To ensure workers' jobs are protected, and to ensure the workplace is responsive to individuals' changing health needs, the adoption of "flexible work policies" is critical.



and government-subsidised health insurance (Medicare). However, there's a two-year waiting period after qualifying for SSDI before one can qualify for Medicare, representing a potential gap in coverage should employment end. The Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) allows for the continuation of medical insurance coverage for 18 to 36 months for people at firms with 20 or more employees, which represents just 22% of employment firms.^{32,33} Exceptions depend on state-level law. Unfortunately, once there is a lapse in coverage, the disease may progress and in some cases individuals die during this time.

To ensure workers' jobs are protected, and to ensure the workplace is responsive to individuals' changing health needs, the adoption of "flexible work policies" is critical.

In Germany, laws guarantee time off for individuals seeking care and protect against discrimination due to cancer diagnosis. An example of comprehensive protection is found in Italy, where "the cancer patient has the right to be assigned to tasks appropriate to their changed working capacity, being able to be assigned to tasks equivalent to or even lower than those previously performed, as long as they are compatible with his conditions, maintaining in any case the salary treatment corresponding to the previous duties."³⁴

In the US, every state has laws that regulate and protect against disability-based employment discrimination, but these may vary by state.³⁵ These laws can also be conflicting. The federal Americans with Disabilities Act (ADA) prohibits some forms of job discrimination against people who have or have had cancer (among other conditions). However, cancer is not always considered a disability, and may not always qualify under the ADA. In 2008 amendments passed to help people with cancer meet the definition of disability.³⁶

The UK's Equality Act 2010 offers similar protections to the ADA, with the key difference that an individual is protected as soon as they are diagnosed with cancer without having to prove a disability.³⁷

Treatment and care experience

There is no standard or universal care pathway for individuals with MBC, and needs evolve throughout the care journey. This means health systems must consider individual nuances and must provide for numerous possibilities. While some health systems can excel in specific areas of care, the needs of people with MBC are not consistently met. Issues are compounded by unequal access to treatment and socioeconomic factors that make navigating care pathways difficult. These may include language needs, education, racial disparities, financial barriers and geographic disparities.



Our expert interviewees identified several categories of experiences for people with MBC that are of concern and often represent areas of data gaps that should be addressed. These are also aligned with results from national and regional patient surveys:

- Poor awareness and understanding of MBC among the wider public: given the emphasis placed on early-stage cancer, people with MBC often feel isolated, invisible and stigmatised.
- Insufficient psychosocial support: people with MBC require supportive care at all stages of their care journey, though the type of supportive care may vary. Typically, newly diagnosed individuals with MBC may require more psychosocial support, whereas people further along in the journey may need more input from specialist palliative care teams. During the covid-19 pandemic, people with MBC experienced additional social isolation which compounded psychological challenges. Support for family members also remains lacking.
- Inadequate health system resources: a shortage of doctors and oncological

specialists hinders care. In Brazil, this is particularly true of rural regions. There is a huge divide in terms of quality and access to care. This can lead to delayed treatment and worsening symptoms.^{38,39}

- Low rates of reimbursement for medications: insurance coverage is not always comprehensive enough to fully account for the range of treatments needed. Notably in the US, some individuals—particularly people of racial and ethnic minorities—have inadequate insurance coverage, which is compounded by low health literacy and substantial transportation challenges.
- Inadequate data infrastructure: gaps in data collection and system connectivity result in disjointed care that can feel impersonal. People with MBC report needing better communication with healthcare providers.
- Poor access to personalised treatment: a lack of universal access to tumour, genomic or hereditary genetic testing mutations for all people with MBC leads to less effective treatments. Results from these tests can help doctors predict whether certain regimens will be successful for an individual.
- Navigating investigational therapies: people with MBC do not have universal access to the newest treatment options. For individuals who live longer and exhaust commonly available treatment options, understanding investigational treatments and navigating access to clinical trials can be a burden.

Information and education

Across countries, MBC experts we spoke with agree that better patient information and education is needed. Ideally, education should cover each stage in the MBC journey, from diagnosis onwards, as individuals often feel blindsided when discussions

surface around palliative care or supportive care. Better education empowers people with MBC to engage in decisions around their care, and can improve health outcomes.⁴⁰ An Italian study found that 88% of individuals with advanced breast cancer who participated in patient education and empowerment activities were more interested in clinical trials when attending oncology consultations that had decision support services.

Even the best efforts to educate individuals are limited by incomplete knowledge around MBC. Among MBC communities, there is a lack of information about symptoms of metastases, availability of treatment options and side effects. Even among healthcare providers, conflicting clinical recommendations from both the public and private sector bodies can limit the choice of drugs for MBC.²⁵

Particular attention must be paid to underserved or disadvantaged groups to ensure equity in care. Studies show people of racial and ethnic minorities

are more often unaware of and less involved in MBC research. In the US, among the Latina population there is low awareness and limited data and availability of information about MBC.⁴¹ Similarly, black women in the US face the highest burden of breast cancer mortality in comparison to other ethnic groups, and this could be attributed to gaps in knowledge about clinical trials and awareness of screening and treatment options.⁴²⁻⁴⁴ Another US study found that Mexican-born people with MBC had a higher risk of being unaware of the disease when compared to those who had been born in the US.⁴⁵ In Europe, black women have been reported to be less likely “to receive cancer-directed surgery, radiation therapy, and hormonal therapy, are underrepresented in clinical trials, and have poorer access to trial-based innovations in cancer care compared with white women.”⁴⁶ The European LGBTQ+ community has also reported a lack of tailored support and representation for its MBC population.⁴⁷

Future trends for the needs of people with MBC:

- Certain countries, like Japan, are experiencing an ageing population, which can present unique needs for health systems and individuals, in addition to significant challenges in screening and access to quality care as breast cancer incidence increases.^{48,49}
- Health systems will need to be prepared to respond to future disruptions, including pandemics and other system-wide shocks, on treatment and support services for people with MBC.^{50,51}
- Digital clinical trials could help improve treatment by including more diverse populations that are currently underrepresented.^{52,53}
- Technology will encompass more areas and new aspects of individuals’ lives, increasing the creation of new data on quality of life and faster early breast cancer detection and allowing for improvements in machine learning and personalised treatments.^{54,55}



Care delivery

Not every individual seeking care is fortunate enough to live in proximity to a comprehensive breast cancer treatment centre that insurance covers and is fully staffed by highly educated health professionals. Short of such an ideal scenario, the

ways and means by which people with MBC receive treatment and support—and the hurdles they encounter along the way—vary widely between countries.

Table 2. Care delivery

Multidisciplinary care (including SBUs*)	
Brazil	Brazil has 13 breast units that report to the Breast Centres Network,** and all Brazilian states have at least one hospital qualified in oncology, where individuals can access a range of services.
France	In France, there is no official label for specialised breast centres. Private facilities typically have multidisciplinary breast centres, though many are not officially reported. Three breast units report to the Breast Centres Network.
Germany	As of January 2017, there were 1,200 certified Organ Cancer Centres, 109 Oncology Centres, and 15 Comprehensive Cancer Centres. There are over 200 certified breast centres in Germany, and eight report to the Breast Centres Network.
Italy	Italy has 52 breast units that report to the Breast Centres Network, offering multidisciplinary care, adopted by the government as a result of the Conferenza Stato-Regioni.
Japan	Japan has three breast cancer units that report to the Breast Centres Network.
UK	The UK has three breast units that report to the Breast Centres Network. Multidisciplinary team-driven cancer care is mandatory under national policy.
US	The US has 575 accredited breast centres. There are two certified American Breast Units with membership in the Breast Centres Network.

*SBUs refer to specialist breast units.
 **The Breast Centres Network is an international collaborative effort to exchange information and promote synergy among breast units.

Shared decision-making	
Brazil	Healthcare professionals generally take individuals' preferences into consideration for treatment.
France	The Law on Democracy in healthcare (2002) in France protects the right to shared decision-making based on feedback. Individuals are also allowed by law to obtain a second opinion.
Germany	There is a culture of shared decision-making in German clinical practice.
Italy	The Italian National Health Plan, in addition to regional health authorities, recognises the importance of shared decision-making, but this is still at an early stage in Italy.
Japan	Clinical practice guidelines recommend shared decision-making, but sociocultural factors and low medical literacy lead to hesitation toward patient participation.
UK	There is a model and a culture in the UK of being open about treatment recommendations with individuals seeking care.
US	Shared decision-making is recommended by the American Cancer Society, but the nuance of needs at different stages of MBC care are often not considered.
Palliative care access	
Brazil	Although the provision of palliative care is mandatory for a facility to be accredited as a CACON (Centre for High Complexity in Oncology Care), there is no regulation for the operation of care outside the hospital.
France	Little is known about access to palliative care in France, but studies show that there are differences in access to palliative and social services based on geographic and socioeconomic disparities.
Germany	Palliative care is mostly provided as home care by general practitioners (GPs) with support from other nursing and hospice care and is received by most individuals. People with MBC may require more specialised palliative services, which are not as easily available.
Italy	Under the Italian public health system, palliative care is widely available, a consequence of the expansion of facilities since the mid-2000s. Palliative care is offered through inpatient care as well as advanced home care.
Japan	Japanese national insurance covers various types of palliative care services, ranging from specialised hospital palliative care teams to nursing care services at home. There is a national Japanese palliative care registry under the Japanese Society for Palliative Medicine that tracks the number of people using the services.
UK	There are no reliable figures on the number of people in receipt of generalist palliative care services, delivered by GPs, district and community nurses, or health and social care assistants. However, estimates suggest only 50% of those who need generalist palliative care receive it.
US	The American Society of Clinical Oncology recommends that all individuals with advanced cancer receive palliative care.

Geographical distribution	
Brazil	The rural–urban divide is highly visible; there are severe disparities and fragmentation of services dividing the wealthy south and the developing north. Unequal access leads to delays in seeking breast cancer screening and life-saving care.
France	Services are concentrated in cities; people in rural areas may have to travel long distances to access specialised care.
Germany	Though access is generally good, geographical disparities are present in Germany.
Italy	Italy faces significant geographical disparities. Southern Italy offers fewer opportunities for high-quality, integrated care in comparison to the northern provinces.
Japan	There are significant geographical disparities in access to breast cancer treatment. While the urban–rural divide is evident, Japan faces a unique geographical challenge in offering care to residents of its hundreds of inhabited islands.
UK	In England, breast cancer deaths are more common in females in the most deprived areas; however, differences emerge depending on which part of the UK is examined.
US	Individuals in rural communities have greater financial burdens and longer commutes/wait times compared to those in urban areas. This has led to lower screening levels and poorer access to treatment, which impacts incidence and mortality data, especially among older individuals seeking care.

Multidisciplinary care

Multidisciplinary teams (MDTs) comprise differently skilled professionals who coordinate and deliver all services needed to meet an individual’s clinical and supportive care needs. As MBC is a particularly complex disease, the increased use of MDTs is particularly important for delivery of continuous care and improving the patient experience. Figure 3 demonstrates the different components that might constitute an MDT. To facilitate this multidisciplinary care, many countries have certified specialist breast units which provide comprehensive care, including genetics and supportive services, to people with breast cancer. In some countries, specialised breast centres are not explicitly named, but comprehensive services are often available in private settings.

While the countries we studied appear to accept the concept of MDTs, their approaches and availability of services varies. European countries are particularly advanced. MDT-driven cancer care is UK national policy. In fact, the UK was one of the first countries to establish the value of MDTs for a cancer type, which, together with defined care pathways, have been instrumental in addressing variations in outcomes among breast units and regions in the country.⁵⁷⁻⁶⁰

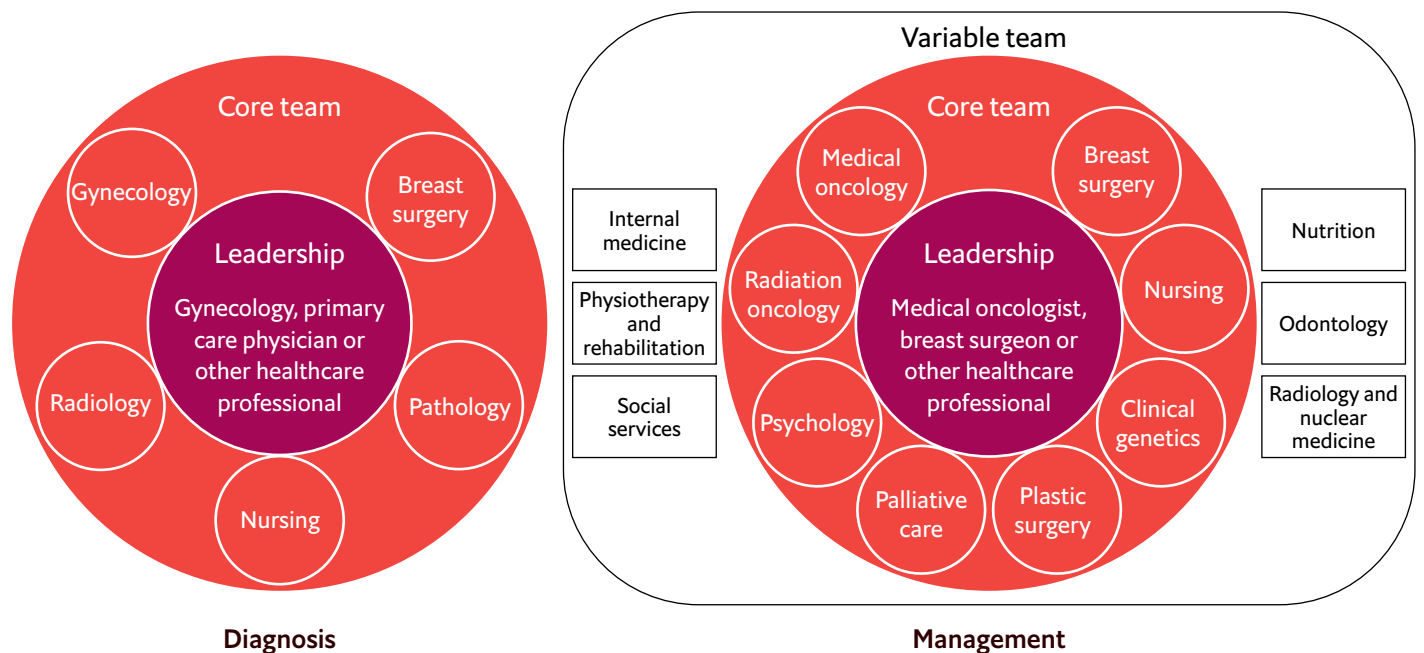
In Germany, a nationwide collaborative network of multidisciplinary breast centres was established in the early 2000s, with over 200 certified breast units in 2010. By January 2017, there were 109 oncology centres and 15 comprehensive cancer centres.⁶¹ The certification programme has led to several paradigm shifts in the structure of cancer care in

Germany.⁶² Concurrently, the number of specialised breast units in Italy increased from 84 in 2012 to 173 in 2020.⁶³

In Italy, multidisciplinary breast care is increasingly available across its regions.⁶⁴ According to Eugenio Paci, former director of the clinical epidemiology unit at ISPRO (Oncological Network, Prevention and Research Institute), “we have a regional and national law for breast cancer units: each region, in principle, is expected to have breast clinics working to respond to all the phases of the disease. From the prevention, screening, diagnosis, treatment, follow-up and end of life.” The Italian government now requires its regions to have a multidisciplinary breast care centre for every 250,000 inhabitants, with a core team consisting of “six dedicated professionals, a radiologist, surgeon, pathologist, oncologist, radiotherapist and data manager.”⁶³

Outside of Europe, challenges emerge in adapting to a multidisciplinary care delivery system. In Brazil, geographic challenges impact multidisciplinary care delivery. Our experts explain that all Brazilian states have at least one hospital qualified in oncology, where the person seeking care will find everything from an exam to more complex surgeries. In total, there are currently 317 units and care centres qualified for the treatment of cancer. The devolved system allows states and municipal health departments to organise care and decide to which hospital individuals—who need to enter the public health system through the Primary Care Network—should be referred.⁶⁵

Figure 3. Proposed composition of multidisciplinary care teams according to the management stage



Source: Barrios et al., 2022⁵⁶

Caregivers

In most cases, the primary caregiver of a person with MBC is a family member (eg a spouse, partner, parent, adult, child).⁶⁶ Their care is crucial to individuals' wellbeing—and they often sacrifice a great deal of their own wellbeing to provide it. Because every individual's journey with MBC is different, so are the types of support required of caregivers. This can range from providing transportation, helping with household chores, filing paperwork for insurance, keeping track of medical appointments, regularly updating healthcare teams and offering emotional support.⁶⁷

Caregivers can also face significant financial tolls while performing their role. A Brazilian analysis of caregivers of people with MBC estimated an economic impact of BRL1.7bn (US\$324m), resulting from a total of more than 115m hours of a national loss in productivity over a one-year period.⁶⁸ Another study argues that caregiver burden contributes significantly to indirect costs of MBC.³⁰ As many individuals must stop working, the burden on caregivers is likely greater as the condition worsens.³⁰

Many countries have patient organisations that support and advise caregivers. However, research that could inform future policies and programmes of support for caregivers' most pressing needs and quality of life is lacking globally.

Shared decision-making

Shared decision-making—where physicians discuss and agree on a treatment plan with an informed and empowered individual—is a vital tool for MBC where dozens of treatment regimens can be considered “guideline recommended” but will have different impacts on individuals. Clinicians and individuals seeking care are broadly aligned in prioritising the efficacy and side effect profile of a

treatment, but people with MBC have additional contextual considerations, including the logistics of treatment and being able to arrange medical care around important life events, familial responsibilities and others.⁶⁹

Shared decision-making is practised in all of the countries studied here, but with different levels of uptake. The European Society of Medical Oncology (ESMO) and the American Society of Clinical Oncology (ASCO) recommend the training of physicians in medical oncology, including standard care, diagnostic and therapeutic innovations, and personalised care.⁷⁰ The American Cancer Society also recommends shared decision-making.⁷¹ The Italian National Health Plan and many regional and local health authorities explicitly recognise the importance of patient participation in healthcare decisions.⁷² And in the UK, according to local experts, efforts are shifting away from a more paternalistic style in terms of a doctor–patient relationship.

In Japan, shared decision-making is nationally recommended.⁷³ According to Ms Takahashi, many people seem to get involved with decision-making, but it really depends on how much medical literacy



the individual has: “If the patient is 70 or 80, it is not easy to understand the suggested treatment plan in detail. So it’s more likely they let the doctor decide what they think is best.” Adoption of shared decision-making is particularly lacking in France, where the involvement of individuals seeking care in decision-making is typically not seen as a requirement by either the medical profession or individuals themselves.⁷⁴

Many barriers exist across countries in implementing shared decision-making, with the most-often cited being lack of time and resources.⁷⁵ Another issue is the lack of tools that can be used in clinical settings. Numerous aids have been developed that support patient education on choices before meeting with a doctor, but this is not enough to guarantee shared decision-making.⁷⁶ Such tools exist for early breast cancer, but further, up-to-date research is needed to develop these tools for MBC and to understand how to overcome barriers to implementing these aids.

Many barriers exist across countries in implementing shared decision-making, with the most-often cited being lack of time and resources.

Cultural and gender roles can represent obstacles to effective shared decision-making. Ms Sakurai reports, “I think for those patients who have a very clear view on what they want, there is now increasingly the kind of shared decision-making around treatment that is absolutely possible in Japan. However, if you look at the larger cultural context of patriarchy in Japan, there is a very big tendency, especially in the rural areas with older patients, where patients would have just listened to what the doctor might say or would just allow the doctors or their spouse to make the decision for them.”

Palliative care

As there is no cure for MBC, palliative care remains a crucial service for individuals to optimise their quality of life and mitigate suffering. Previously reserved for end-of-life care, palliative care has evolved to become an interprofessional discipline that focuses on ensuring the best quality of life for individuals.^{77,78} The goal is to help support individuals in all aspects of their lives when encountering psychological, social, spiritual and physical challenges.⁷⁹ Along with supportive care, palliative care forms a key aspect of individual treatment plans.

Our research finds that in the countries studied, there has been a significant increase in the availability of palliative care services in the past decades. For example, in Japan, palliative care was established in 1973, and the number of palliative care units has increased gradually. Today, the ratio of units per million inhabitants is comparable to that in Western countries.⁸⁰ In Italy, the number of palliative care units has grown continuously since the mid-2000s.⁸¹ In the US, where ASCO recommends that all people with advanced cancer receive palliative care, growth figures are impressive: in 2019, 72% of US hospitals with 50 or more beds reported a palliative care team, up from 7% in 2001.^{82,83}

Although palliative care services have expanded in many countries, the global demand still exceeds the supply. The data collected do not specifically capture the breast cancer or MBC population. In Germany, most individuals receive primary palliative care—mainly in the form of homecare—by general practitioners with support from nursing or hospice services.⁸⁴ But, according to Diane Lüftner, senior consultant in the Department of Oncology and Haematology at the Charité Central Campus, “we have more patients who need palliative care than specialists in palliative care and palliative institutions, which means that the waiting

time can be long, and that is a problem for such an institution.”

Progress is also needed in Brazil because, despite a significant growth in services over the past two decades, one report shows 80% of people who should be in palliative care service are treated in hospitals.^{85,86} Meanwhile, palliative care is not readily available to most people seeking care in France, and more palliative care professionals are needed, especially in rural areas.⁸⁷ Better data collection is essential to define the proportion of people with cancer who have access to palliative care.

As there is no cure for MBC, palliative care remains a crucial service for individuals to optimise their quality of life and mitigate suffering.

Continuity and transition of care

While the use of MDTs contributes to care continuity, many individuals report frustration with the transitions between stages of care, and can feel they are being passed along the health system with little support and abrupt transitions. One German patient representative commented that information sharing within a clinic or care setting does not always work properly. “The same goes for every referral. The right information doesn’t always make it back to the doctor who initially requested it. I think this is something that really must be improved.”

These issues have been compounded by the covid-19 pandemic, with many treatments and surgeries delayed as hospitals prioritised covid-19

care. As another patient representative reported, “patients felt like doctors forgot about them. On one side the doctor would tell you it’s important to start cancer treatment as soon as possible, then on the other hand they’d say we can’t do it because of covid. When decisions like this are made, patients and advocacy organisations need to be included.” While these anecdotal accounts offer some insight, high-quality qualitative data on continuity and transition of care for people with MBC are lacking and such research must be prioritised.

Geographic distribution

Cancer knows no borders, but medical services are often so concentrated in urban, affluent areas, and rural and poorer populations suffer from access issues. All countries studied here experience challenges in providing comprehensive cancer services geographically co-located with individuals seeking care. Rural–urban differences in access remain a universal problem.

The hundreds of remote inhabited islands in Japan present a unique geographical access challenge. The urban–rural divide on- and off-island have stoked complaints about the distance and time required to access care, as well as the availability of medical screening tools, which have led to low breast cancer screening and treatment rates.⁸⁸⁻⁹⁰ While the Ministry of Health, Labour and Welfare promotes the equalisation of cancer medical services, through the Cancer Control Act of 2006 nearly one-quarter of people seeking care are estimated to travel more than 45 minutes to access cancer treatment in Japan.⁸⁸

Sprawling Brazil faces similar challenges. Severe disparities and fragmentation of specialised services are seen for people with MBC, dividing the wealthy south and the developing north regions. This has led to an increase in premature death, particularly in the northern part of the country.^{38,39}

Barroso says the issue is straightforward: “If you have better access to the health system, you will have a better prognosis... in Brazil, there are ‘islands’ of very good service. Even in the public service, depending on where you are, the treatment is very different.”

In the US, one ASCO report estimated that 66% of rural counties have no oncologist, and most oncologists are concentrated in urban centres. Therefore, it is not surprising that the United States’ rural care-seeking population tends to have a more significant financial burden throughout the cancer care continuum due to higher costs and longer

travel times. “We need to enhance access to clinical trials for patients in rural areas who might not have access to those interventions”, suggests Brittany Bychkovsky, faculty at Harvard Medical School and physician at the Dana-Farber Cancer Institute in the US. In Europe, population growth relative to care centres represents another important barrier to access.

Care delivery: future snapshot

Because of the incurable nature of metastatic disease, the care an individual receives is crucial to their ability to live well. Services need to be comprehensive, affordable and available to all individuals for every stage of the care continuum. Numerous care guidelines exist, and WHO is working to develop guidelines that can be stratified by country resource levels so clinicians can offer care that matches the realities of their environment. However, the care required for individuals with MBC is not restricted to the treatment of cancer metastasis.

The merits of multidisciplinary care are well known but are not yet accessible to everyone who would benefit from this care. For locations with such care, the European Commission Initiative on Breast Cancer is currently developing a quality assurance scheme to improve and standardise the care that individuals receive.⁹¹ Innovative aids such as the online Advance Care Appointment Companion communication tool are also emerging to assist individuals with planning for the future and defining their care goals by improving patient-provider communication.⁹² There is also a growing number of psychological interventions for individuals with breast cancer; however, these tools are not tailored to the MBC experience which presents a gap in research.⁹³

The future of care delivery for MBC will consist of robust quality assurance measures, improved communication between all involved stakeholders and adequate support to both health professionals and informal caregivers. Research must prioritise how to overcome barriers to implementing multidisciplinary care in geographically distant communities.



Healthcare workforce

The availability of a highly skilled, specialist workforce for delivering care for people with MBC remains a challenge in nearly all settings. Health systems globally must balance the recruitment,

training and retention of the healthcare workforce with the increasing burden and changing patterns of cancer in the population. Our experts and research highlight the following workforce needs as priority.

Table 3. Healthcare workforce

Needs (type of professionals, training, awareness and education)	
Brazil	Access to screening services is a major challenge. Public health campaigns, mobile screening units and more resources are needed. The Integrated Approach to Improving Oncology Care (IAIOCA) is a new health program that trains healthcare providers (HCPs) in breast cancer radiology and medical oncology to improve diagnosis and treatment.
France	Physical therapy and rehabilitation are an important part of MBC care and need to be provided across the care team.
Germany	From the onset of treatment, greater integration of services and involvement of allied health professionals is needed for holistic care. There are no national guidelines on integrative concepts in oncology; research is needed to evaluate the impact of integrative treatment and care.
Italy	More qualified professionals are needed to provide psychological support, particularly within national breast units.
Japan	Better awareness and training are critical for breakdown of cultural stigma surrounding breast cancer. Training should focus on digital literacy to help medical personnel improve data collection and sharing.
UK	Nurses should be included in training around MBC management and should play a role in decision-making as well as forming and advocating for MBC-specific policies.
US	Greater integration of services and involvement of allied health professionals is needed for holistic care. Care teams need to be trained on psychosocial support and other forms of supportive care.

Palliative care availability	
Brazil	Progress is needed for palliative care offerings, particularly in rural areas.
France	Palliative care is not readily accessible to most individuals seeking care. More palliative care professionals are needed, especially in rural areas.
Germany	Palliative care is readily accessible to all individuals seeking care.
Italy	Palliative care programs offer guidelines to train healthcare professionals, integrate palliative care services and increase awareness of quality of care.
Japan	Palliative care is widely available in government-designated cancer hospitals since it is a certification requirement by the Ministry of Health, Labour and Welfare.
UK	Palliative care is widely available to individuals seeking care in the UK; however, due to workforce shortages in some regions, access may vary.
US	Palliative care teams have grown 60% from 2001 to 2015. Now over 72% of hospitals in the US with 50+ beds have a palliative care team.
Incentives	
Note	This research attempted to examine the status of incentives for the MBC workforce but could not find sufficient evidence of incentives in any of the seven countries.

Quantity

It is estimated that 40,000 additional cancer physicians will be required to meet the increasing patient demand for all cancers in the coming two decades.⁹⁴ However, many countries do not have accurate estimates on their current number of clinical oncologists,⁹⁵ or a clear projection of their needs.

Regional disparities are also baked into workforce challenges. Figures for prevalence of medical professionals are generally reported in the form of average per 1,000 or 100,000 population and do not account for concentrations. Nearly all the studied countries confirm that physicians are concentrated in urban areas, and more are needed in rural areas to promote equity in access, screening, affordability and data collection.

The health workforce needed for MBC spans many medical disciplines and includes surgeons, radiologists, pathologists, radiotherapists, oncologists, plastic surgeons, nurses and lab technicians.⁹⁶ Another emerging role is that of the psycho-oncologist. These experts are often a critical element of comprehensive cancer care teams and can provide personalised psychological support to people with MBC through all stages of the disease.⁹⁷ Our experts also specify pain management doctors as a critical part of the care team to include early in the care pathway.

Other more recent roles include cancer clinical nurse specialists (CNSs) who are often referred to as “patient navigators” and are responsible for addressing individuals’ clinical needs as well as their emotional, psychological, financial and social needs.⁹⁷

Another evolving workforce requirement is for palliative care professionals. Over the last 20 years, palliative care teams have grown exponentially, particularly in the US, which saw a 60% growth from 2001 to 2015. To date, over 72% of hospitals in the US with 50+ beds have a palliative care team.⁸³ Policymakers in Europe have prioritised the role of palliative care professionals through dedicated training programmes, although additional efforts to improve the supply of palliative care professionals are still needed inside and outside of Europe.⁸⁸

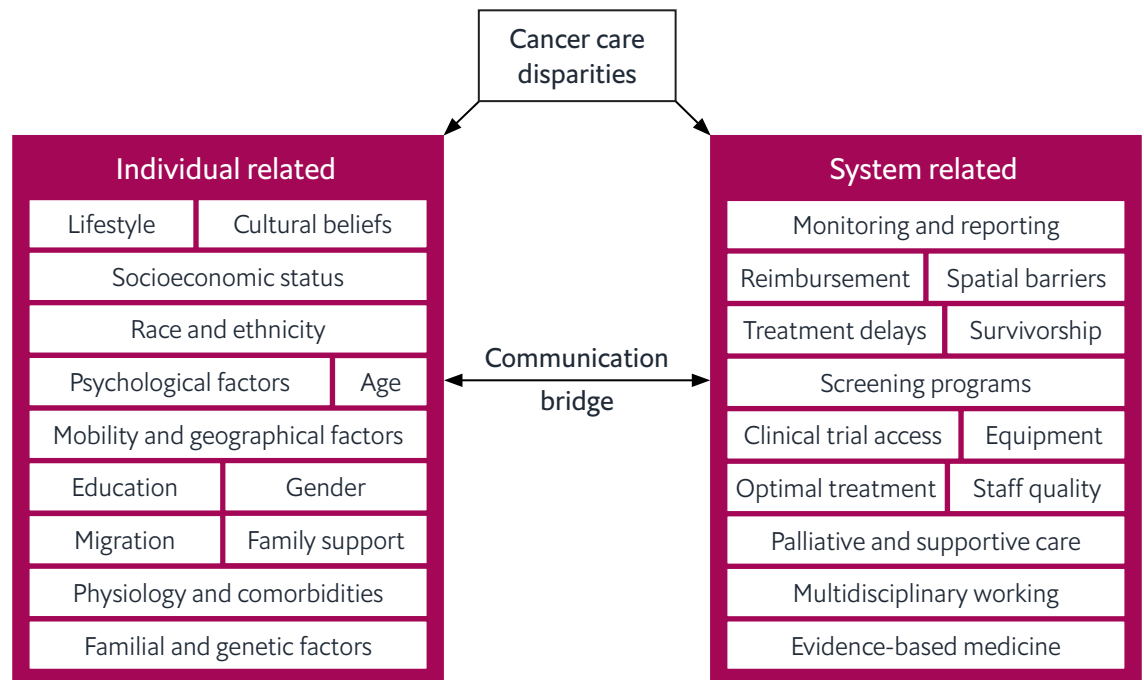
Training, awareness and education

Our experts were unanimous in voicing concern about the availability of well-informed, formally trained frontline healthcare providers for MBC care. Primary care doctors are often individuals’ most

common point of contact with the health system for information or advice on decision-making. However, these doctors rarely have the necessary information on MBC that they need to provide evidence-based referrals or recommendations.⁹⁷

“We need to have explicit training for healthcare professionals caring for MBC patients,” says Maimah Karmo, founder and CEO of Tigerlily in the US. “There’s not enough understanding (even in the healthcare system) about how to treat and talk to patients about their needs. There are still unmet needs in the MBC community that need support.” HCPs also need training on how to best communicate and engage with patients of different cultural backgrounds, as unconscious bias can affect the care and treatment that providers offer to MBC patients.⁹⁹

Figure 4. Cancer care disparities classified according to patient-related or system-related factors



Source: Vrdoljak et al., 2021¹⁰⁰

Patient organisations are attempting to address this gap by providing educational toolkits and training. Other sources of MBC training come from a mix of stakeholders, including efforts by hospitals, medical associations, government and universities. Typically, efforts to improve healthcare professional knowledge generally focus on early-stage breast cancer, with gaps in understanding MBC.⁹⁸

A successful example of a formal approach can be found in Germany, where professional cancer organisations developed a national certification programme for breast cancer specialty centres. Centres are required to maintain accreditation as assessed through a variety of metrics including continuing medical education for HCPs.¹⁰¹ Experts also mention that nurses—who typically provide care to individuals, especially at the primary stages—often lack specialised training around MBC, leading to inconsistent quality of care. It is important to expand MBC-specific training and include these HCPs in the decision-making and policy processes.

Guidelines

As noted in the previous section, all countries have national clinical guidelines specific to breast cancer, but most lack specific MBC guidelines. National guidelines provide doctors and caregivers evidence-based pathways to consider in the diagnosis and management of individuals, often specific for the care settings and health system limitations. Clinical recommendations should be regularly updated to reflect the latest science and learning, as well as nationally approved diagnostic, treatment and care options.

In October 2021, ESMO published the most up-to-date international clinical practice guidelines for the diagnosis, staging and treatment of people with MBC.¹⁰² ESMO noted that a “living” version of the guidelines will be published, “allowing

doctors to access treatment algorithms, important reference materials and regular updates as needed, in real time.”¹⁰³ It is unclear to what extent the countries in this analysis have adopted the ESMO guidelines. In addition, the Advanced Breast Cancer (ABC) European School of Oncology (ESO)–ESMO International Consensus Conference has established the international consensus guidelines for the management of ABC. It was developed jointly by ESO and ESMO and supported by several other international oncology organisations. These guidelines are based on the most up-to-date evidence and can be used and adapted to guide treatment decisions in many healthcare settings globally.¹⁰⁴

Incentives

There is, as previously discussed, a current and projected shortage of oncologists needed to treat the increasing population with cancer. This is compounded by a wave of retiring staff, a lack of incoming students to the profession, increasing



complexity of care and burnout. And even while bemoaning the lack of data collection on MBC, we must be mindful of the rising administrative burden on the workforce as well.¹⁰⁵

This research could find no evidence of incentive programmes for the workforce that would improve workplace satisfaction (eg salary,

training, wellbeing programmes and rewards) and encourage innovations to relieve some of the growing burdens. This may be due to a gap in published information, but it presents an opportunity for change.

Healthcare workforce: future snapshot

The future healthcare workforce in breast cancer will require optimised care pathways, integrated care and an increase of specialists for effective and efficient treatment of people with breast cancer.

Countries should consider innovative ways not only to maximise access and reduce the complexity of navigating care pathways for individuals, but to empower the health workforce in offering coordinated care. One example is found at the One-Stop Clinic at the Women's Reference Center at the Pérola Byington Hospital in São Paulo, where individuals have access to diagnosis and specialised services in the same location.^{106,107} If a person needs additional testing, for example, they can seek advanced services, schedule consults with oncologists and breast cancer surgeons, and begin neoadjuvant chemotherapy treatment in one place. Streamlined, integrated pathways in one-stop clinic models could potentially lead to a more optimised approach to care coordination.

Prioritising training and investments in the health workforce is also critical to addressing shortages of specialists that offer screening services and provide critical care to people with breast cancer. Countries should consider increasing the number of specialised breast cancer nurses and clinical nurse specialists to provide physical and psychosocial support, as evidence suggests that specialised breast cancer nurses can improve quality of life, anxiety, depression and satisfaction with care.¹⁰⁸⁻¹¹⁰ In addition, shortages of pathologists in countries like the US, Canada and Japan, as well as insufficient laboratories in Brazil, could hamper screening and diagnosis due to inadequate staffing and limited resources.¹¹¹⁻¹¹⁴

To improve the continuity and coordination of care, and increase the number of specialised medical personnel, the development and implementation of new strategies and policies should be at the forefront of future developments in the MBC space. Countries should consider re-evaluating care coordination models and reallocating resources towards the future of workforce development to ensure that people with breast cancer can receive the care they need.



Financing and access policies

Healthcare policy sets the priorities and goals for how a health system provides for individuals. The countries we studied have a wide range of policy and financing systems, but with very few specific MBC policies.

Table 4. Financing and access policies

Financing (insurance and oral parity)	
Brazil	Public insurance is available through the Sistema Único de Saúde (SUS), though resources are often unavailable. Oral parity has not been achieved.
France	Public insurance guarantees access to certain treatments but excludes those deemed nonessential. Individuals must opt in for private insurance for additional coverage. Oral parity has not been achieved.
Germany	Public and private insurance is guaranteed by law. Oral parity has been achieved.
Italy	Public insurance is guaranteed, but not all new medications are 100% covered. Oral parity has not been achieved.
Japan	Public insurance is guaranteed through the universal health system. Information on oral parity is not clear, but oral chemotherapy is common.
UK	Public insurance is guaranteed through the NHS, but not all new medications are 100% covered. Information on oral parity is not clear, but cost and access to drugs vary among regions.
US	Public and private insurance are available but not guaranteed. Oral parity has not been achieved at the national level, but some states have passed parity legislation.

Health technology assessment (HTA)	
Brazil	National Commission for the Incorporation of Health Technology (CONITEC) plays an advisory role to the Ministry of Health for such decisions.
France	The Transparency Committee of the French HAS assesses the level of medical benefit. The current HTA process does not consider the use of surrogate endpoints.
Germany	AMNOG is the national HTA procedure that informs HTA processes of other EU countries. RCT data on overall survival serve as the primary endpoint.
Italy	The National Agency for Regional Healthcare Services (AGENAS) supports the HTA process and collaborates with the Italian Drug Agency (AIFA) and the Health Institute's national HTA centre.
Japan	HTA is not mandatory, and it applies only to selected pharmaceuticals and medical devices in Japan; it has no impact on reimbursement, only on price adjustment. As part of the Japanese Ministry of Health, Labour and Welfare, the Central Social Insurance Medical Council approves new drugs.
UK	HTA is mandatory through the National Institute for Health and Care Excellence (NICE). Overall survival serves as the primary endpoint in HTA, though progression-free survival is sometimes considered.
US	The Food and Drug Administration (FDA) approves medications, but there is no national HTA programme for evaluating health technologies and guiding coverage/drug prices.
National and regional MBC-specific policies	
Brazil	The National Policy for Cancer Prevention and Control (PNPCC) was established in 2013. No MBC-specific policy exists.
France	The stratégie décennale de lutte contre les cancers 2021-2030 is France's latest cancer strategy. No MBC-specific policy exists.
Germany	The National Cancer Plan has been available since 2008. No MBC-specific registries or plans are available.
Italy	The Ministry of Health has a Technical Policy Document on the Reduction of Cancer Disease Burden for 2010-13, later extended to 2016. No MBC-specific policy exists.
Japan	The Japanese Cancer Control Act requires that each prefecture develop the Plan to Promote Cancer Control Programs. No MBC-specific policy exists.
UK	The NHS Long-Term Plan (LTP) was published in January 2019. No MBC-specific policy exists.
US	National cancer control plan is available (since 1998) and national cancer registry system. No MBC-specific registry or plan is available.

Financing (insurance and oral parity)

The countries analysed here employ several different financing systems with variable insurance coverage, out-of-pocket costs and reimbursement structures. In most countries, individuals seeking care are covered under public or private insurance which provides comprehensive care for people with MBC. However, many insurance plans require deductibles, co-payments or coinsurance (specifically in the US) which result in high out-of-pocket costs.

Out-of-pocket costs to individuals seeking care vary considerably by therapy, insurance coverage and location. The complexity and variability in care may explain why this research found significant gaps in cost information available for MBC treatment.

A common theme seen across countries is a higher cost of care at more advanced, complex stages of MBC. According to one US study, median annual healthcare costs for people with MBC with advanced metastasis was \$112,402, compared with \$50,835 for those without advanced metastasis.¹¹⁵ Studies also show that higher medical spending places an increased financial burden on racially and ethnically diverse communities.¹¹⁶

Too often, financial structures that determine how treatment is reimbursed in the inpatient versus outpatient settings discourage the best treatment options. According to Bychkovsky, “when a patient is hospitalised with cancer, the way things are structured, if we want to start a cancer therapy in the hospital, certain diagnostics and treatments are not reimbursed the same way as if they were ordered or administered in the clinic, and this creates a barrier to inpatient treatments for patients newly diagnosed with cancer.”

Costs and coverage for oral chemotherapy drugs also vary between countries. According to expert interviewees, in select countries including Germany and the UK, oral medications have parity with other treatment options. But in others, such as the US and Brazil, they are more expensive and covered differently (generally resulting in more out-of-pocket costs for individuals). These policies have real implications for people seeking care and doctors. “If the medication is given intravenously, the process for reimbursement from insurance companies is automatic, but if given orally, coverage is not guaranteed and needs to be analysed and approved by an HTA process. Unfortunately, the HTA process is long, bureaucratic, not transparent and there are no clear rules”, says Luciana Holtz, founder and president of Instituto Oncoguia in Brazil.

In the US, Nancy Lin, associate chief for the Division of Breast Oncology at Dana-Farber Cancer Institute, describes a similar situation: “There is no parity in terms of IV and oral chemotherapy drug coverage. And that can be a consideration, unfortunately.” One patient advocacy group representative shared her own story of paying \$35/month out of pocket for oral medications through her corporate insurance but later transitioned her insurance coverage to Medicare and now pays over \$10,000 a year. Another patient representative put it bluntly: “You can create a



thousand different oral medications and it won't matter because many individuals won't be able to afford them."

Health technology assessment

To effectively utilise finite resources, countries have adopted various HTA* frameworks to determine the value that a new technology or treatment can offer and inform relevant policy, pricing and guidance. Overall survival is the traditional metric used in HTA calculations. Less frequently used, surrogate endpoints measuring progression-free survival and quality of life, are increasingly considered in advanced cancer settings. Some HTA agencies in the UK, Canada and Australia already recognise this importance and additionally incorporate patient voices in their approval processes. The extent to which individual experiences influence the HTA process and decisions in these countries is unclear.¹¹⁷

The adoption of HTA varies widely. The US, for example, does not have a national HTA programme.¹¹⁸ People with MBC and providers will often have to ask insurers to cover essential imaging and diagnostics (prior authorisations are frequently required) despite the fact that their role is established in care guidelines. US payers use internal processes that incorporate HTA elements to inform coverage decisions, but these processes lack transparency and can involve duplicated efforts across organisations, which can ultimately lead to delays in treatment and higher costs.¹¹⁸

In contrast, Brazil adopted HTA laws in 2011 laying out the criteria and time frame for the HTA process, while establishing the National Commission for the Incorporation of Health Technology (CONITEC).

This entity advises the Ministry of Health regarding decisions about the introduction, exclusion or alteration of new pharmaceuticals, products and procedures, including protocols and guidelines.¹¹⁹ CONITEC approval does not guarantee access in the public system due to fixed reimbursement fees. The private system also faces challenges, as the National Health Agency must grant a secondary approval for coverage, which leads to delays in reimbursement for individuals.¹²⁰

In France, the HTA process is systematic for all newly available medicines, including those receiving marketing authorisation nationally or at a centralised European level.¹²¹ The Transparency Committee of the French Haute Autorité de Santé (HAS) assesses the level of medical benefit based on clinical effectiveness and safety profile of the drug, considering other aspects such as disease severity and the drug's public health impact.¹²² However, the HTA process in France does not consider the use of surrogate endpoints such as progression-free survival of people with MBC and the different impact advanced stages have on quality of life.⁹⁷

The HTA process in the UK is also systematic for all newly available medicines.¹²³ The National Institute for Health and Care Excellence (NICE) recommends that HTAs be reviewed every three years or when new data emerge. New technology should be made available by local health authorities within three months. HTA has been highly successful in the UK due to the independence of the institutions involved, quality of work and the involvement of individuals seeking care and health professionals.¹¹⁹ However, if NICE does not deem a medication cost-effective, obtaining coverage for that treatment becomes very difficult.¹²⁴

*According to Health Technology Assessment International, "HTA is a multidisciplinary process that uses explicit methods to determine the value of a health technology at different points in its lifecycle. A health technology is an intervention developed to prevent, diagnose, or treat medical conditions; promote health; provide rehabilitation; or organize healthcare delivery; the intervention can be a test, device, medicine, vaccine, procedure, program, or system."

The German HTA system is highly influential in Europe, as it is considered detailed and scientifically based.¹²⁵ In Germany, France and the UK, mature data on overall survival have the strongest positive correlation to a medication's approval. However, overall survival data can take a long time to obtain, so experts recommend that surrogate endpoints that demonstrate clinical benefit be accepted to allow individuals quicker access to helpful medicines.¹²⁶

In Japan, the submission of cost-effectiveness evidence has been mandatory for selected pharmaceuticals and medical devices. The HTA programme requires the provision of incremental cost-effectiveness ratios as evidence, with quality-adjusted life years as the preferred outcome measure.¹²⁷ However, people seeking care have limited access to new pharmaceuticals. Naomi Sakurai and Midori Takahashi explain that Japan suffers from significant drug lag compared with other developed nations. It takes a long time for new pharmaceuticals to reach Japan and be approved for clinical use, possibly due to Japan's regulatory need to include Japanese patients in clinical development programmes.

Finally, Italy's National Agency for Regional Healthcare Services supports the HTA process across regions, in collaboration with the Italian Drug Agency and the Health Institute. Several Italian regions have additional regional laws or regulations to manage the HTA process.¹²⁸

National and regional specific policies

While policies to better address the burdens of cancer in general and guidelines specific to breast cancer are found in nearly all countries studied, those specific to MBC are not widely present. Most plans, such as in Japan, set high-level goals of reducing deaths from cancer in general (with emphasis on early screening and prevention) and

improving the quality of life for people with MBC and their families.¹²⁹

As for targets: France aims to reduce avoidable cancer cases by 60,000 per year.¹³⁰ The UK's NHS Long Term Plan, published in 2019, envisions that 55,000 more people will survive cancer each year by five years or more by 2028 and 75% of people with cancer will be diagnosed at an early stage.¹³¹ In Italy, geographic disparities in care are well documented. National plans aim to end those disparities and push for better integration of social, primary and secondary healthcare services.^{132,133}

And in Brazil, where wait times for treatment can be long, there is a national push to increase timely care.¹³⁴ Notably, Brazil's 60-day law stipulates that people with cancer have the right to start treatment in the public health system within 60 days of a diagnosis signed by a medical provider. However, there has been minimal enforcement, and only half (49.8%) of those diagnosed with cancer begin treatment within 60 days. Various



administrative and operational obstacles are to blame.^{135,136} “I believe that patients should be empowered to be better organised and fight for their rights”, says Romualdo Barroso, clinical oncologist and national leader of Breast Oncology at DASA Oncology. “Patients should be aware

how strong they are and how they can influence policymakers to change this scenario if they work together.”

Financing and access policy: future snapshot

Current breast cancer financing schemes and policies fail to recognise the unique differences in care pathways for individuals, which are compounded by a lack of specific MBC strategies. The future of MBC financing and care access depends on governments taking advantage of best practice initiatives and learning from experiences across countries.⁹⁸

One successful policy approach is the new Priority Medicines (PRIME) scheme, through the European Medicines Agency (EMA), which offers individuals early access to promising new medicines and enhanced scientific regulatory support, enabling better trial design and accelerating product development and evaluation.¹³⁷ Another innovative example is found in the UAE, which applies a fast-tracking mechanism for some innovative medicines that have received approval by the US Food and Drug Administration (FDA) and the EMA. These processes provide individuals with an opportunity to access treatment earlier, but countries that implement these regulations must ensure a balance between timely access and safety.^{98,138}

As new interventions are approved, a number of provisions can facilitate access to cancer care. The Canadian Agency for Drugs and Technologies in Health offers an example of a cost-effectiveness approach, since it has an integrated special cancer assessment agency (pan-Canadian Oncology Drug Review), which operates with input from cancer patient groups and is separate from the review of non-cancer drugs.¹³⁹ In Italy, the system regularly uses confidential agreements between manufacturers and the Italian Medicines Agency and the regional and local health authorities to make provisions from simple discounts to cost sharing, risk sharing, volume discounts, and pay-for-performance schemes. Future MBC policies can use these examples to support efficiency in improving strategies across all areas of the MBC ecosystem.¹⁴⁰

In most countries, governments have prioritised the implementation of national cancer policies or breast cancer screening programs. However, most do not include specific needs or strategies related to people with later-stage cancer. The future of MBC care will depend on countries implementing MBC-specific financing mechanisms and policies to foster overall prevention, early detection, and high-quality care.



The data ecosystem

The ability to collect and utilise data is vital to inform and improve care in MBC. Data collection is dependent on well-structured digital, legal and institutional systems that offer the necessary resources and legal scope to collect information, the pathway to report data, and the guidelines to process and use information.

Collecting MBC-specific data depends on several interconnected factors, involving different stakeholders within health systems. Common

barriers to data collection include whether there is a place within digital systems to input information (eg a field to input data on software or online platforms), awareness of the need to collect these data among medical personnel, resources and support to require the collection of this type of data, national standardisation in how to collect and process data, as well as the proper privacy protections that allow for collecting and sharing data within the health system and among stakeholders. These issues are addressed in the sections below.

Table 5. Data collection and use

Data-informed clinical practice guidelines	
Brazil	Guidelines produced by the Brazilian National Cancer Institute of the Ministry of Health, among others.
France	Guidelines produced by the French Ministry of Health and the French National Cancer Institute, among others.
Germany	Guidelines produced by the German Federal Ministry of Health, German Cancer Society, German Cancer Aid and the Association of the Scientific Medical Societies in Germany, among others.
Italy	Guidelines produced by the Italian Ministry of Health.
Japan	Guidelines produced by the Japanese Breast Cancer Society.
UK	Guidelines produced by the National Institute for Health and Care Excellence and, more broadly, the National Health Service–England, among others.
US	Guidelines produced by the National Cancer Institute, US Preventive Services Task Force and the American Cancer Society, among others.

Recurrence and quality standards	
Brazil	No national requirement to collect data on recurrence, but data are collected on stages.
France	No national requirement to collect data on recurrence.
Germany	No national requirement to collect data on recurrence.
Italy	No national requirement to collect data on recurrence, and data are not widely collected.
Japan	No national requirement to collect data on recurrence, but data are collected on stages.
UK	No national requirement to collect data on recurrence, but data are collected on stages.
US	No national requirement to collect data on recurrence, but data are collected on stages.
Resources and infrastructure	
Brazil	Hospital, population and specific cancer registries collect and report data individually to the Brazilian National Cancer Institutes.
France	Twenty-seven cancer registries report to a centralised database managed by a hospital. The database covers 24% of the French population.
Germany	A national registry was created in 2010. Beginning 2023, all registries will be required to report cancer cases to the national registry.
Italy	An association collects data from population-based and specialised registries, covering 70% of the Italian population. Regional authorities drive data collection.
Japan	A national registry was established in 2016 to collect, process and administer cancer data, including breast cancer.
UK	England, Wales, Northern Ireland and Scotland collect and report data individually.
US	All states are mandated to report cancer cases. Hospital, population and specific cancer registries collect and report data individually to the state, which sends data to national registries.

Registry resources, infrastructure and quality

Globally, much work is needed to improve the collection of MBC data. Health systems struggle to acquire and harmonise sufficient quality and quantity of data. And in the case of MBC-related data, the situation is dire. In the absence of comprehensive and high-quality data, countries rely on less concrete estimates and projections to inform policy response and clinical guidelines.

For countries without full coverage by population-based cancer registries (PBCRs) and limited resources, the recommendation is to have high-quality strategic PBCRs to make reliable cancer estimates. This has some limitations, according to Marianna de Camargo Cancela, head of the Surveillance and Situation Analysis Division, Coordination of Prevention and Surveillance at the National Cancer Institute of Brazil (INCA), as stage distribution is not currently estimated. Brazil, for

example, relies on hospital-based cancer registries to have information about stages.

Accurately measuring prevalence is a problem if low-income and geographically distant individuals seeking care are not counted. “How many people in the world today are living with and being treated for metastatic breast cancer? Actually, we do not know. Data collection is not as homogenous and as standardised as it should be”, says David Cameron, professor of medical oncology at the University of Edinburgh in the UK. As a result, efforts to improve access and policies will be ineffective and may not provide additional resources to the most needed areas. Limited data will lead to limited visibility.

Cancer registries exist in all seven countries included in this review. Many, such as the US, have multiple regional registries that exchange data with the national cancer registry, including the incidence and prevalence of MBC.¹⁴¹ In Japan, the Centre for Cancer Registries in the National Cancer Centre collects all population and hospital-based registries, as required by law.¹⁴² A national registry was established in 2016 to collect, process and administer cancer data.¹⁴³

However, a near-universal issue is the quality and standardisation of those registries, as well as the timing and enforcement of reporting—leading to fragmented and delayed data. For MBC, it is important to distinguish in registries between an individual diagnosed with *de novo* metastatic disease from those who initially had stage 0-III breast cancer and later developed recurrent metastatic breast cancer. This distinction needs to be prioritised in national cancer registries as it influences outcomes and can reflect differences in tumour biology if a patient develops metastases while on active treatment for early non-metastatic breast cancer.

MBC data tend to be primarily housed with high-level oncological data. Very few registries

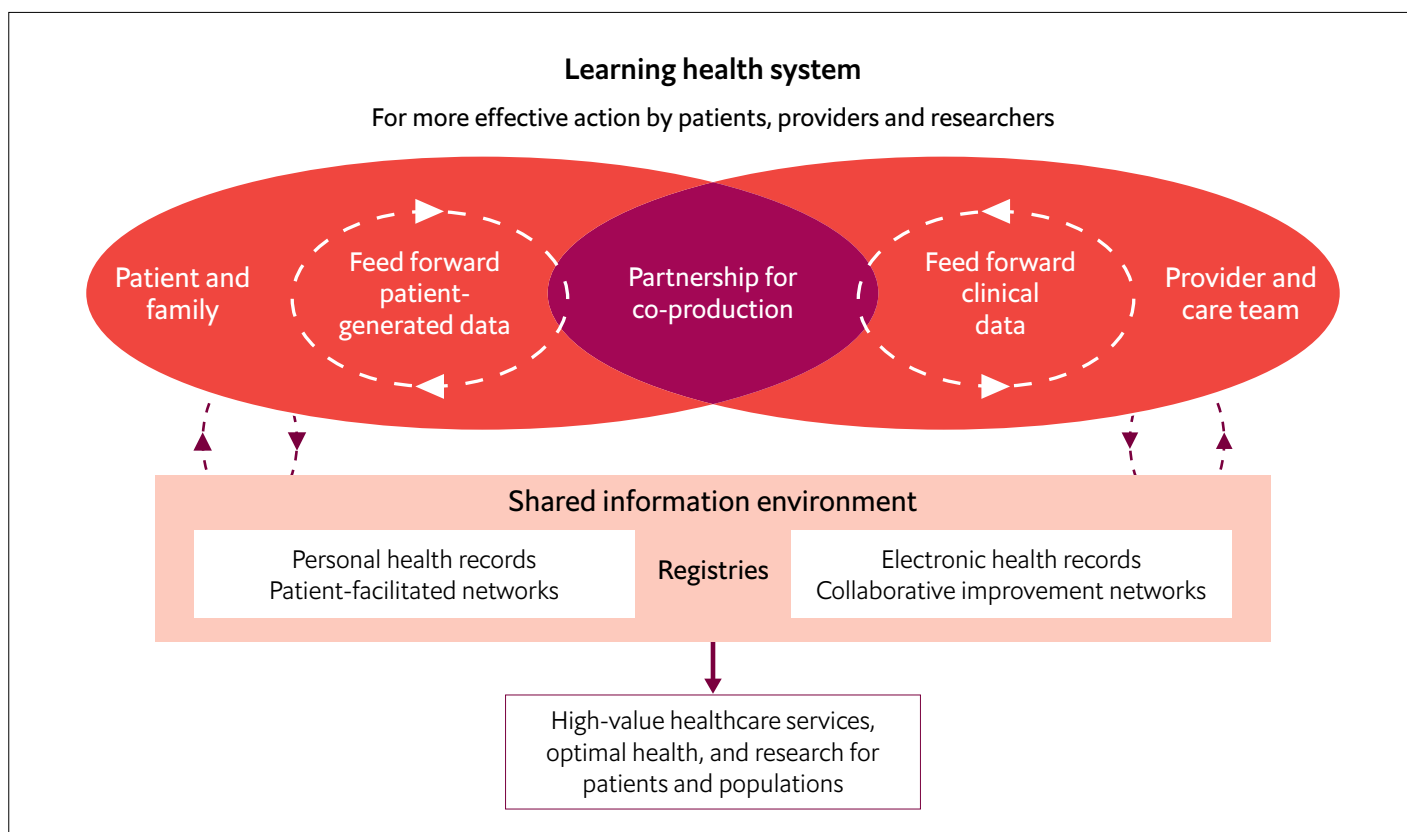
allow for the categorisation and filtering of MBC-specific data, a process contingent on various factors, including system infrastructure, cost and interoperability.¹⁴⁴ Figure 5 demonstrates what an effective data ecosystem could look like if registries were built in learning systems.

In Brazil, several registries exist, but data quality and integration challenges have been reported.^{146,147} Maira Caleffi says they have “an absurd lack of trustworthy data,” which means oncologists in Brazil may dismiss the information presented. There are also geographical disparities in the system capacity (resources and infrastructure) of cancer care that reflect the quality of data collection and sharing. For example, Mr Barroso and Ms Cancela indicate critical discrepancies between the southern and northern regions of Brazil, as well between urban and rural and low-income and high-income areas.

European countries tend to have better practices in data collection, leading to relatively robust and trustworthy data.¹⁴⁴ However, reports indicate a lack of standardisation across registries of what specific indicators are collected and how they are classified. This makes it difficult to obtain uniform, comparable information. Issues are compounded when data and reports are published in any of the numerous European languages.¹⁴⁸

“There are also issues with quality,” adds Diane Lüftner, senior consultant in the Department of Oncology and Haematology at the Charité Central Campus of Germany. “They hope that the data is recorded, but there is no obligation to register it. That is why there are differences in numbers when looking at registries.” France is notable in having a well-developed data collection system. They have “a very rich data set on what it is like to live with metastatic breast cancer, the treatments you get and so on and so forth,” reports David Cameron.

Figure 5. Model of registry-enabled care and learning health system



Source: Nelson et al., 2016¹⁴⁵

Incomplete recurrence data

Individuals with early non-metastatic breast cancer have a risk of recurrence and can develop metastatic disease despite curative therapy for non-metastatic disease, but there is a significant lack of data on how many people with MBC have developed recurrent MBC versus those with de novo metastatic disease.^{149,150} Obtaining data on recurrence is critical for our understanding of which treatments have the most significant impact. For example, obtaining data on neoadjuvant systemic therapy can help us understand the opportunities

and challenges of preventive, diagnostic and therapeutic interventions and their impact on MBC development at a later date, and cancer registries can play a significant role in this.¹⁵¹

Breast cancer recurrence data (including both locoregional recurrence* and metastatic recurrence) are not captured nationally in any of the studied markets of this report. However, Germany and the UK have been taking steps towards increasing the number of hospital-based registries that capture both the initial stage of breast cancer and recurrence information for

*Locoregional recurrence refers to recurrence in the breast tissue or regional lymph node rather than in a distant site.

people who have MBC. “Even in private practice, data on recurrence are not regularly collected”, says Barroso. “This information is not available, so you need to analyse the charts retrospectively and make some assumptions.”

In Japan, Naomi Sakurai shares frustration on the limited data collected: “Data entry in the Japanese Breast Cancer Society is voluntary, and at best captures 80% of cases.” The national registration “only records two things, which is when a patient is diagnosed with cancer and then when they die”, which means doctors have “absolutely no idea if the cancer recurred and if it led to a patient’s death or if a patient had actually died from something else like a car accident.”

Experts noted recurrence data capture is further complicated as individuals move around. For instance, if one person was diagnosed in Portugal and then immigrated to the UK, there would be no way to track the health status of that individual. Even within individual countries it is difficult to overcome these barriers. Financial incentives can be offered to providers for updating these data, but this still does not solve the issue of individuals moving.

Capturing recurrence data depends on the methodology used to obtain data, and depending on the selected strategy, it can lead to missing and biased data. Consider the US: among the global leaders in cancer data collection, the population-based Surveillance, Epidemiology and End Results (SEER) Program is considered the gold standard. Over recent years, the data collected between SEER, the National Cancer Institute, the CDC’s National Program of Cancer Registries (NPCR) and the North American Association of Central Cancer Registries (NAACCR) cover nearly 100% of the US population.¹⁵²⁻¹⁵⁴ Despite having an extensive data coverage network, SEER-Medicare reported that it has the ability to identify people with “treated recurrence” but does not collect this type of data because of data-quality challenges. Data can be captured if people with cancer seek additional treatments, but this method has been found to lead to a biased sample of data and a large amount of missing data.¹⁵⁵

While the need to capture data on breast cancer recurrence is widely recognised, there are still significant barriers to ensuring that health systems can collect, process and use such information. As a result, countries are experimenting with innovative technologies and different data-capturing methodologies to best protect people with breast cancer and obtain critical information to help with advancements in treatments and better quality of life decisions.



Absent quality of life data

Quality of life information is largely absent from breast cancer registries and clinical trials. Our experts say such data should be collected as part of the standard routine and would be very useful to understand how people with breast cancer are living. One study concluded that overall survival and quality of life are the most important outcomes, and that progression-free survival should also be incorporated “into the design and conduct of future clinical trials in MBC, as well as HTA and reimbursement decision-making . . . to better capture the potential value of a therapeutic innovation.”¹³ MBC-specific quality of life data could inform future intervention studies around supportive care, but funding for these types of analysis is limited.

As the MBC community pushes for the collection of and better access to quality of life data, high-income countries often do not collect necessary data to better understand these factors. For example, Public Health England, a respected health entity, has limited data and understanding of lifestyle factors that influence the incidence, mortality and quality of life of people with cancer.¹⁵⁶

According to Brittany Bychkovsky, “patients with metastatic breast cancer are being treated for months or years after their diagnosis, but the data doesn’t always capture how they feel... More data on quality of life is really important.” Seigo

“Patients with metastatic breast cancer are being treated for months or years after their diagnosis, but the data doesn’t always capture how they feel... More data on quality of life is really important.”

Brittany Bychkovsky, instructor of medicine at Harvard Medical School, US

Nakamura, professor of surgery and director of the breast centre at Showa University Hospital in Japan, adds a desire for innovative ways to measure quality of life, potentially bypassing the registry issues: “Ideally, if patients have specific feelings or conditions, they could enter [information and data] by themselves by using a cell phone or personal computer—this system would be important.”

Privacy and security

Privacy and data security are important considerations which can limit the collecting and sharing of data, affecting the opportunity to obtain MBC-specific data.

In Europe, the EU General Data Protection Regulation (GDPR) governs data collection and sharing, which have produced both opportunities and challenges. According to patient advocacy organisations, concern about how individual data are used poses a considerable problem for cancer registries that may be limited by legal privacy restrictions. GDPR rules have led to problems with data collection in Italy. According to Eugenio Paci, “[Italy] had a lot of problems in the implementation of population-based cancer registries with the privacy regulation that was an absolute block for more than 10 years. Because we were not able to manage [data] with the government and with the system, we were not nationally able to achieve the coverage and national standards as other countries of the European community. So, for many years, we have been working with some administrative pressure to stop [data collection] because it was considered dangerous.”

Japan encounters similar problems. A study reported the challenges of collecting data on cancer survival due to privacy restrictions under the Protection of Personal Information Act of 2005.¹⁵⁷ This act made it difficult for hospitals to follow up on registered cases once individuals

stop visiting their facilities. A survey of designated cancer care hospitals in Japan reported that only 27% of hospitals followed survival for individuals with cancer.¹⁵⁷ If these issues are not addressed by policymakers, many registries will continue to struggle with the ability to obtain high-quality data on MBC recurrence and will depend on estimated data.

Ultimately, policymakers, regulators and clinicians (particularly general practitioners) must rethink how these laws affect care. One patient advocate argues: “I know how difficult it is and we have millions of regulations on why this data cannot be

shared. Then private companies don’t want to share data because they own it. Universities don’t want to share because they want to have the publication. So, in the end, it doesn’t help us.” The future of MBC-specific data will depend on finding a balance between privacy and high-quality data for all stakeholders.

Data: future snapshot

A better future for MBC diagnostics and health technology development depends on capturing quality of life measures as well as data on de novo MBC and recurrence. Institutions are experimenting with different data-capturing methodologies with the goal of finding effective and efficient data reporting pathways. For example, the Southeast Netherlands Advanced Breast Cancer (SONABRE) Registry is conducting a prospective, observational cohort study to identify individuals with de novo or recurrent advanced breast cancer, using specially trained registration clerks to review medical charts.¹⁵⁸ The study is currently underway, and the estimated completion is in 2023.

In the US, the CDC is adopting a similar approach with a natural language processing (NLP) pilot program to automate data collection from medical records through dictionary-based software and machine-learning methods.¹⁵⁹ This pilot program aims to identify cancer-related data from unstructured and narrative text and automatically report data to the cancer registry. Research has shown promising results with NLP and other machine-learning tools, yet work is still needed to improve the sensitivity and accuracy of identifying relevant data.¹⁶⁰⁻¹⁶²

The future of cancer registry data will consist of the interconnectedness of data silos, the implementation of cutting-edge machine learning and NLP technologies, and a highly skilled informatics workforce to facilitate a rapid and high-quality data collecting, reporting and sharing among different databases, institutions and stakeholders. Therefore, the future of data for MBC will depend on investing in workforce development and technology infrastructure, as well as formulating robust data policies and guidelines.



Opportunities for improvement



Our research identifies several areas of focus to improve the care offered to people with MBC. Though country-specific priorities will differ, five overarching priorities should be considered for delivering comprehensive and effective MBC policy and care:

- Frame effective treatment as a long-term investment in individuals and caregivers.** Timely, effective care and side-effect management for people with MBC has impact beyond the individual, and can positively influence the often debilitating emotional, physical and financial impact on their family and friends. By enabling healthcare systems to better treat and support people with MBC, those individuals may lead longer and more productive lives. Beyond direct benefits to the individual, investing in care that improves the lives of people with MBC can yield long-term economic and societal benefits.
- Incentivise and align data collection initiatives.** Evidence-based policy relies on accurate and timely data, which are lacking in MBC. Particular attention is required to identify and address policy gaps related to data privacy and sharing to protect patient data while simultaneously facilitating clinical care and research. Multistakeholder and cross-disciplinary collaboration should be guided by national laws and international best practices. Stakeholders should collaborate on identifying and adopting novel methods to collect MBC-specific data and recurrence information, as well as ways to pilot strategies to integrate these methods within cancer registry systems.
- Commit to research and defining disparities and unmet needs for people with MBC.** The absence of data across all areas of MBC care significantly impacts understanding, policy and guidelines around



treatment, access and quality of life. Better quantity and quality of research and various MBC-related indicator data, including quality of life measures, will inform national plans and prioritise the most impactful changes for their population of people with MBC.

- Improve quality of life for people with MBC and caregivers.** To better understand the multidimensional impacts of treatments, it is essential for quality of life measures to be collected. This type of information consists of the collection of MBC progression data and concerns access to innovative medical treatments. It is also important to improve the quality of life for caregivers, who provide critical support throughout the entire experience for people with MBC. Therefore, programs should be developed to offer various forms of support to caregivers.
- Enhance education and knowledge transfer to prepare individuals for the challenges of MBC.** Health systems must provide better education for people with MBC to empower them in the shared decision-making process and in order to reduce the negative quality of life impacts associated with an MBC diagnosis. Physicians and nurses remain among the most powerful resources for educating individuals on their diagnosis and helping them to access proper information, but they require support to meet these needs. Additional resources are needed to overcome barriers such as language, health literacy and stigma.

Country-specific priorities

Brazil



In Brazil, the quality of information on epidemiological cancer surveillance needs to improve, with the establishment of public policies aimed at primary prevention and early diagnosis. The information obtained from many national health information systems is essential to support the demands of health management and identify the needs of the population. It is recommended that the information systems be formally and regularly evaluated to improve the completeness of data.¹⁶³ Administrative databases such as the APAC-SIA/SUS, Health Information System for Primary Care (SISAB), Individualised Ambulatory Production Bulletin (BPA-I), Cancer Information System (SISCAN), Decentralised Hospital Information System (SIHD) and Regional Electoral Court (TRE) can generate better-quality information, be less costly and improve health indicators.¹⁶⁴ It is also important to note that it can be difficult to get a cancer diagnosis and treatment in Brazil because equipment is concentrated in the south and southeast regions and much less available in the north and northeast regions. Public–private partnerships can be a strategy to expand access between regions and reduce any barriers in the country.¹⁶⁵

France



While France has made progress in organising the care of people with MBC, there is still much to be done to improve quality of life. Though the benefits of supportive care are known, many individuals with MBC in France do not utilise such services as it is not compulsory.⁶³ Surveys have demonstrated that for individuals who are not receiving supportive care, in over two-thirds of cases they were not offered such care from their physician.¹⁶⁶ In terms of treatment, effectiveness is still the primary goal. However, quality of life needs to be considered at both the research and consultation stages of care.⁶³ Access

to palliative care, which is often a crucial component of supportive care, also remains sparse. Only 2% of all cancer patients who are alive three years after diagnosis have access to inpatient palliative care.⁶⁷ France's positive efforts to raise awareness and secure rights for individuals with MBC cannot be overlooked, but solidifying access to supportive and palliative will be crucial moving forward.

Germany



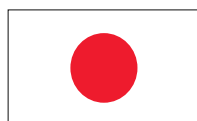
Germany is one of Europe's leaders in new forms of treatment. Dianne Lüftner says that it is one of the best-supplying countries as there are not many restrictions or delays in approvals. However, negotiations of drug prices between manufacturers and the Federal Joint Committee in the country are not the best, as there have been cases in which the manufacturer withdrew treatment medication for MBC, so price negotiations often do not end up in favour of people with MBC. Therefore, it is important to review this process and address this systemic error politically.⁶³ Overall survival is the primary clinical endpoint considered in Germany's HTA processes; however, to improve access to emerging therapies, consideration of surrogate endpoints is encouraged.¹²⁶

Italy



The stark differences caused by health care regionalisation in Italy have led to an increase in unbalanced investment, inequitable access and unequal infrastructure development between the northern and southern parts of the country.¹⁶⁷ The IMPACT study reported significant disparities between northern and southern Italy in the stage of diagnosis and conservative surgery in people with breast cancer.^{168,169} The differences were more related to diffusion of organised screening services than to treatment.¹⁷⁰ Eugenio Paci and Mario Campone confirm the significant impact of geographical disparities on breast cancer care and cancer registries. Italy must strategically address this imbalance, ensuring equitable access in the centre-south, ranging from screening to treatment and follow-up care through publicly organised programmes.¹⁷⁰

Japan



One of the core challenges expressed by experts is the sociocultural perception of MBC within the Japanese population. The perception of individuals, family members and caregivers impacts their willingness to access screening and treatment, participate in shared decision-making, and seek psychosocial support. While advocacy organisations are expanding training, patient support and education, a more collaborative effort between medical

institutions, advocacy groups and community leaders that targets sociocultural perceptions could improve screening rates and access to treatment. Additionally, Japan needs to improve its data collection process. To obtain data on MBC recurrence and improve the quality of survival data, Japan needs to revisit the Protection of Personal Information Act of 2005.¹⁵⁷ Policymakers should consider implementing mechanisms that allow hospital-based registries to follow up on MBC survival and require consistency and standardisation of collecting and reporting data at the national level on MBC recurrence while ensuring that privacy is upheld to the highest degree. Additionally, Japan should expand data collection outside of its network of designated cancer care hospitals while controlling for data quality. This will increase data coverage and offer a more comprehensive view of MBC in Japan.

UK



UK cancer registry systems are considered among the best in the world, yet there is still much to be done to improve MBC data coverage and quality. For example, one report concluded that approximately two-thirds of hospitals in England had issues collecting accurate data on people with MBC, and one-fifth of hospitals did not contain any MBC data.¹⁷¹ Furthermore, NCRAS of Public Health England did not collect treatment information six months after diagnosis, making it challenging to amend final registration data.¹⁵⁶ There is limited understanding of factors beyond epidemiological data. The UK's health system is spread across four countries (England, Wales, Scotland and Northern Ireland), presenting a challenge in ensuring collaboration to address several issues within the MBC community. Jo Taylor, founder of After Breast Cancer Diagnosis and METUPUK, asserts that the UK needs better coordination of strategies and accountability for established breast cancer goals and, most certainly, specifically focusing on increasing survival. One recommendation is collaboration among involved parties. Multistakeholder collaboration is critical to ensure that all aspects of care are considered throughout the care continuum. People with MBC must be at the centre when considering overall benefits during HTAs, endpoints of care, policy-making and quality of life decisions.¹¹⁷

US



The current payment structure of the US health system leads to high out-of-pocket costs that directly and indirectly impact people with MBC.^{172,173} Studies report that females with MBC have higher monthly costs than those with earlier-stage breast cancer, leading to greater unexpected healthcare expenses and financial toxicity.^{174,175} While healthcare is a point of contention in the US, policymakers should provide financial and labour

protections for families, caregivers and people with MBC. Additionally, the US is leading in integrating innovative technology through collaborative partnerships and has helped expand data coverage and quality. New technologies are also being implemented to improve quality and speed, such as cloud-based computing and natural language processing.¹⁷⁶ Countries should move towards the development of the necessary partnerships and further develop their infrastructure to expand data collection and sharing efforts, as seen in the US. Despite an advanced system, the US does not collect data on MBC recurrence versus the diagnosis of de novo metastatic disease, but does collect data on different stages at diagnosis. Collecting recurrence data should be prioritised as institutional stakeholders consider the next phase of improving cancer data collection.

“Patients should be aware of how strong they are, and how they can influence policymakers to change this scenario if they work together.”

Romualdo Barroso,
DASA Oncology

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