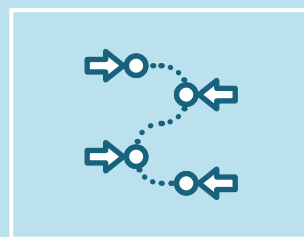


Reducing inequalities
in metastatic
breast cancer care

Ensuring access to appropriate care along the pathway

POLICY BRIEF

November 2024



**We would like to thank the following organisations
for their endorsement of this policy brief:**



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About this policy brief

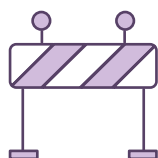
This policy brief is part of a [set](#) that explores opportunities and provides actionable policy recommendations to make care for metastatic breast cancer more equitable. The briefs look at opportunities for policymakers to improve care at a system level and along the care pathway, and to address the importance of enhancing patient

involvement in defining research, policy and care. The recommendations, generated under the guidance of a Steering Committee, aim to build on recent works, including the Lancet Breast Cancer Commission's 'roadmap for change' and the World Health Organization Global Breast Cancer Initiative Implementation Framework.

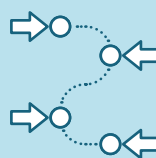
Reducing inequalities in metastatic breast cancer care: an overview



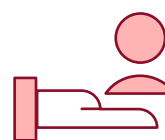
Addressing structural and systemic barriers to care



Ensuring access to appropriate care along the pathway



Improving patient experience, involvement and empowerment



These policy briefs were developed by Jessica Hooper, Helena Wilcox and Eleanor Wheeler at The Health Policy Partnership (HPP). HPP is grateful to the project's Steering Committee members, who guided the development of this policy brief and its recommendations:



Dr Fatima Cardoso, President, Advanced Breast Cancer Global Alliance and Director, Breast Unit, Champalimaud Foundation, Portugal



Dr Véronique Diéras, Head of the Breast Cancer Group, Department of Medical Oncology, Centre Eugène Marquis and member of UNICANCER French Breast Cancer Intergroup, France



Professor Helena Earl, Professor Emeritus of Clinical Cancer Medicine, Department of Oncology, University of Cambridge, UK



Colleen Foran, patient representative, Canada



Dr Dario Trapani, Assistant Professor at the Department of Oncology and Haemato-Oncology, University of Milan, Italy

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- Vicki Durston, Director of Policy, Advocacy & Support Services, Breast Cancer Network Australia
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- Veronica Foote, Head of Policy & Consulting, Working With Cancer, UK
- Jenny Gilchrist, Nurse Practitioner – Breast Oncology, Macquarie University, Australia
- Emma Lavelle, Policy Manager, Breast Cancer Now, UK
- Essie Mac Eyeson, Senior Policy Officer, Breast Cancer Now, UK
- Dr Mafalda Oliveira, Senior Consultant, Medical Oncology Department, Vall d'Hebron University Hospital, Spain
- Professor Frédérique Penault-Llorca, Professor of Pathology, University of Clermont Auvergne and Director General of Centre Jean Perrin, France
- Barbara Wilson, Founder & Director, Working With Cancer, UK

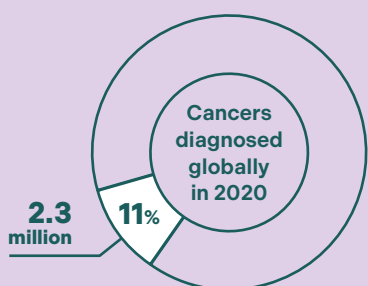
The authors recognise that these policy briefs do not highlight all inequalities experienced by people with metastatic breast cancer, nor do they identify every initiative aimed at addressing these inequalities.

Metastatic breast cancer can affect people of all genders. This policy brief uses the terms 'women' and 'men' if the research or data cited specifically describe people assigned female and male at birth.

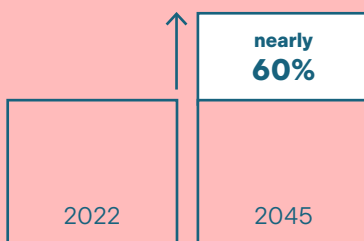
Inequalities in metastatic breast cancer care

Metastatic breast cancer (MBC) occurs when cancerous cells from a tumour that developed in the breast spread and grow in a different area or areas of the body.¹ MBC is also known as **secondary** breast cancer, **stage IV** breast cancer or **advanced** breast cancer.²

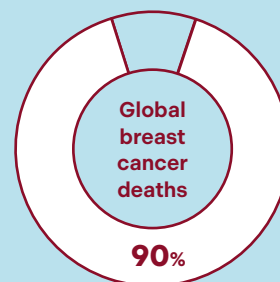
Female **breast cancer*** is the **most commonly diagnosed cancer**, with an estimated 2.3 million new cases globally in 2020, accounting for over 11% of all cancers diagnosed.³



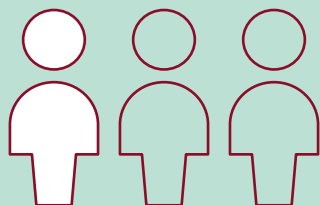
The World Health Organization (WHO) **projects a nearly 60% increase in breast cancer-related deaths** among women between 2022 and 2045.⁴



Breast cancer is the leading cause of cancer deaths among women worldwide,³ with **MBC accounting for 90%** of these deaths.⁵



Nearly 30% of women diagnosed with early-stage breast cancer will develop MBC.¹



The most common sites of breast cancer metastasis are the lymph nodes, bones, lungs, liver and brain.^{1,6}



Between 2022 and 2050, incidence of breast cancer among women is projected to increase by more than 50%.⁴



While there is no cure for MBC in the vast majority of cases, current treatment options enable many people to live longer, more fulfilling lives with the disease.¹ However:

Health inequalities are experienced by many people with MBC and intensified in underserved populations.⁷

Current policies often fail to recognise or address the unique challenges faced by people with MBC.⁸

Action is needed at the health system and local level to reduce the wide-ranging and varied inequalities in access to high-quality MBC care.⁷

To reduce inequalities in MBC care, health system decision-makers and policymakers should:



address structural and systemic barriers to care



ensure access to appropriate care along the pathway



improve patient experience, involvement and empowerment

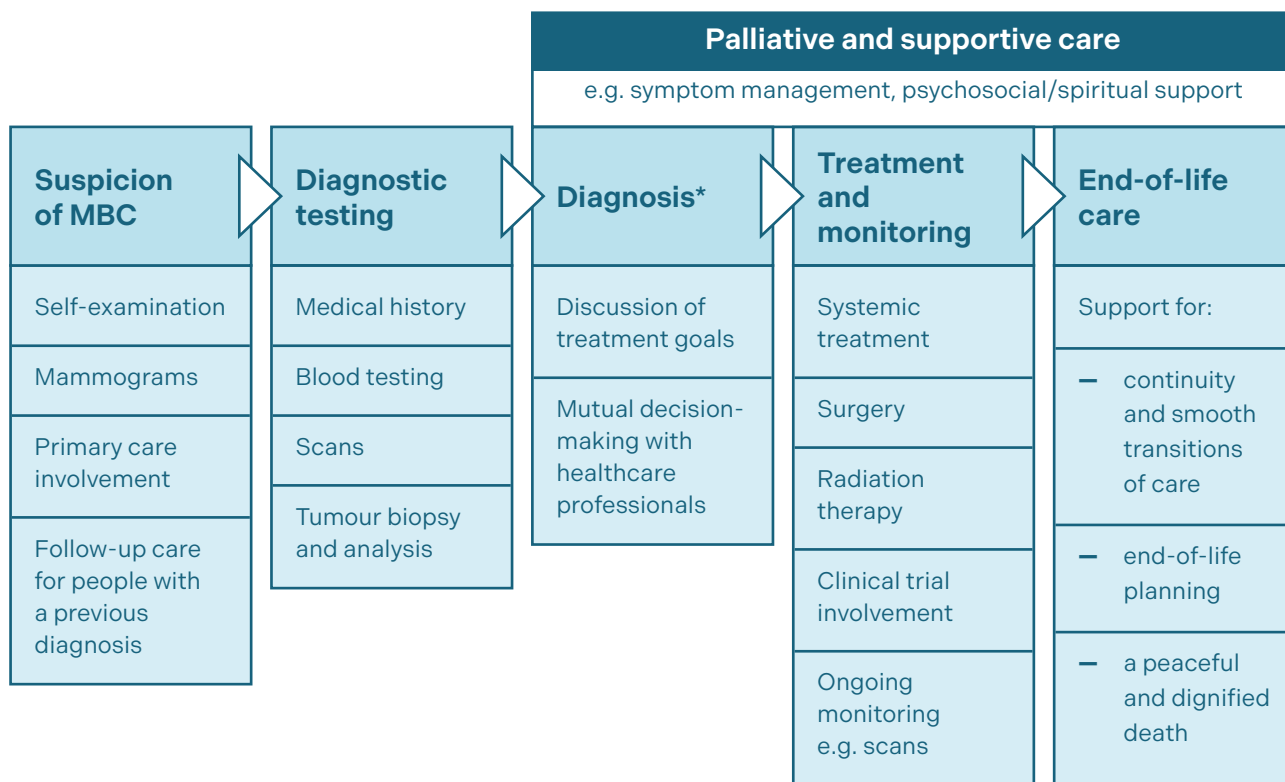
*Around 99% of the total incidence of breast cancer occurs in women.⁹

How can access to appropriate care be ensured along the pathway?

Persistent inequalities in access to high-quality breast cancer care contribute to poor outcomes, especially for traditionally underserved communities. Timely and appropriate care must be delivered throughout the care pathway for MBC,⁸ with care delivery and experiences tailored to the unique circumstances of the individual.¹⁰ Disparities in breast cancer care and outcomes affect a number of underserved communities and patient populations (*Figure 1*), with those experiencing suboptimal care more likely to develop metastatic disease.^{11,12}

Ensuring equitable access along the care pathway requires a multidisciplinary and comprehensive approach to MBC care. Many people with MBC have expressed frustration over the inconsistencies and lack of continuity they experience as they navigate the health system and each stage of care.^{10,13} For example, in four regions of Italy, a recent survey by Europa Donna (also known as the European Breast Cancer Coalition) has identified a lack of standardised and structured MBC treatment pathways, challenging the provision of equal treatment opportunities for all patients.¹⁴ Such issues are often the result of barriers created by existing policies, lack of clear treatment guidelines for MBC, a shortage of skilled healthcare professionals, and insufficient MBC data to inform decision-making.¹³ Equitable access to diagnostic services, clinical trial opportunities, and palliative and supportive care – among other interventions – can help ensure that timely and appropriate care is delivered along the care pathway.^{9,15} For example, delays in diagnosis and treatment can influence MBC detection rates and survival outcomes.¹⁶ Better awareness and understanding of the signs and symptoms of MBC are needed, alongside the development and implementation of clear referral pathways.¹⁷⁻¹⁹ Comprehensive support for healthcare professionals, informed by the experiences of people with MBC, will help achieve this goal (*Case study 1*).

FIGURE 1 Examples of disparities experienced along the MBC care pathway



EXAMPLE	EXAMPLE	EXAMPLE	EXAMPLE	EXAMPLE
In the majority of low- and middle-income countries, 30–80% of people with breast cancer are diagnosed at stages III and IV , in contrast with fewer than 30% in high-income countries. ²⁰	For people with physical and intellectual disabilities, there is a greater likelihood of presenting with stage III or IV breast cancer by undue delays to screening and diagnostic services. ²¹⁻²³	Tumour subtypes associated with a high risk of metastatic disease are significantly more common among younger women (≤ 45 years) ²⁴ and women from certain minority ethnic groups (e.g. Black women in the US). ²⁵	Younger women, White women and women of higher socioeconomic position are more likely to receive timely systemic anti-cancer therapies. ²⁶	In the UK, underserved populations, including LGBTQ+ people, people of a lower socioeconomic position and people living with learning disabilities, are generally less likely to receive high-quality end-of-life care. ²⁷

*Diagnosis refers to *de novo* MBC (i.e. the first occurrence of cancer in the body)²⁸ or recurrent MBC (i.e. when cancer comes back, or recurs, months or years after treatment).²⁹

Adapted from: Pfizer Oncology (2019).¹⁰ The authors of this policy brief acknowledge the care available at each stage can vary.

CASE STUDY 1

Supporting earlier symptom recognition and referral in the UK



In the UK, a survey of people with MBC found that 23% of respondents visited their general practitioner (GP) at least three times before receiving a diagnosis.^{17,19} A survey of primary healthcare professionals found that 38% felt urgent referral criteria were too specific to primary breast cancer.¹⁸ And 24% of GPs and 37% of practice nurses also highlighted late identification of signs and symptoms by healthcare professionals as an issue.¹⁸

To address these gaps, UK-based charity Breast Cancer Now recommends more effective use of existing referral pathways for people with symptoms that may indicate MBC (such as direct GP referral back to the patient's multidisciplinary team).¹⁸ Where referral pathways are not available, Breast Cancer Now highlights the potential role of the non-specific symptom pathway (England) in fast-tracking referral.¹⁸ The charity also emphasises that the referral of people with MBC symptoms could be further supported by expanding the pathways' criteria to reflect the symptoms and medical history of people with MBC.¹⁸



'[Breast Cancer Now] found that a lot of the challenges in delivering a rapid [MBC] diagnosis largely centre around two key things: recognition of signs and symptoms of the disease – both from a healthcare professional angle and a patient angle – and knowing how best to refer patients or how to utilise referral pathways.'

Essie Mac Eyeson, Breast Cancer Now, UK¹⁹

To support the rapid diagnosis of MBC, Breast Cancer Now has several initiatives, resources and tools, including:

- digestible information for patients, to be disseminated by GPs, including leaflets on breast cancer recurrence³⁰
- awareness campaigns and an online hub, which has resources to support healthcare professionals to spot the signs and symptoms of MBC earlier³¹
- supporting the provision of a free course for primary care professionals, informed by patient consultation, to increase awareness of MBC symptoms and recurrence.³²

What must policymakers and health system decision-makers do?

Address social and demographic barriers in access to treatment and care

KEY ACTIONS

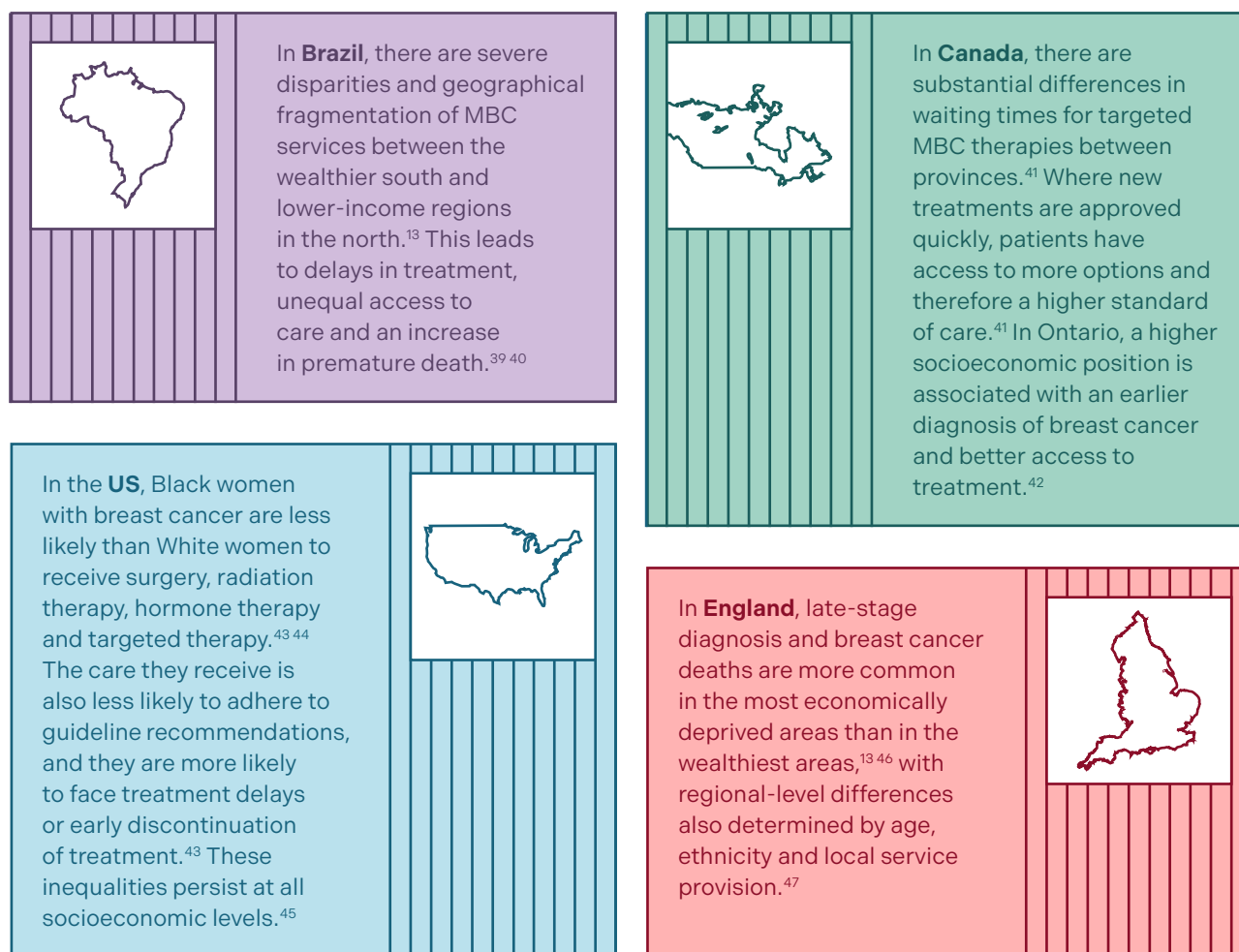


Accelerate research to understand the factors that create barriers to accessing MBC treatment and care, so that targeted interventions can be resourced and implemented equitably

Multiple social and demographic factors contribute to some populations with MBC experiencing poorer care and outcomes. Timely access to appropriate treatment remains a significant unmet need among people with MBC.¹³ People who face barriers to treatment and care access are more likely to be diagnosed with metastatic disease and less likely to receive best-practice care.^{33,34} The inequities in access to MBC treatment are determined by a number of demographic factors, including cultural norms, income level, geographic location and ethnicity (*Figure 2*), and social factors such as cultural norms or beliefs.^{13,26}

Understanding how different cultural factors might influence health-seeking behaviours is vital to address disparities in MBC presentation, treatment and care. The influence of cultural factors on breast cancer stage at diagnosis is increasingly recognised, with some cultural norms and/or beliefs found to be significant predictors of progression to MBC.³⁵ In Canada, for example, some South Asian women rely on their husbands or other family members as translators during visits to their doctors, hindering discussion about sensitive health issues (e.g. related to breast problems),³⁶ while many Syrian refugee women have expressed beliefs that cancer reflects God's will and associate breast cancer with a fear of losing social status, so they do not interact with the health system.³⁷ Similarly, among Latina groups in the US, cultural beliefs (such as that faith in God can protect people from breast cancer) have been found to contribute to later presentation to a physician, affecting onward treatment.³⁸ It is important to understand these factors, as they should also influence cancer care delivery.^{35,36}

FIGURE 2 Examples of inequalities in MBC diagnosis and treatment caused by demographic factors



Research is needed to understand the complex interplay of social and demographic factors affecting access to MBC care, and to better equip the health workforce to deliver appropriate services.

To offer optimal MBC care, there is a need to expand the workforce to reach all communities, train healthcare professionals in cultural awareness, and work to remove other community-level barriers to care (e.g. lack of financial resources, low awareness of self-examination).^{48,49} In addition, more research is needed to better inform the design and delivery of appropriate services. In the US, for example, one area of research is focused on enhancing the role of patient navigators (who guide patients through health systems) to help address racial disparities in MBC care.⁴³ And several organisations, including Susan G. Komen, are working to better inform underserved communities about how to access breast cancer treatment.^{50,51} The Komen Network helps people find treatment options that are local and low-cost,⁵² and the Stand for H.E.R. programme aims to remove barriers that prevent Black communities from accessing high-quality care by providing educational resources, financial assistance and training programmes.⁵¹

Enable access to innovative treatments

KEY ACTIONS



Ensure that all population groups affected by MBC are represented in clinical trials to increase equitable access to new interventions



Prioritise equitable access to innovative treatments for MBC informed by the latest research into the disease



'In the UK, certain ethnic groups lack information about how to access clinical trials; there is also fear and misinformation about trials. I think there is a huge area of opportunity to better communicate the potential benefits of clinical trials, because they can offer early access to treatment, especially in the metastatic phase of the disease.'

**Veronica Foote,
Working With
Cancer, UK⁵⁶**

Clinical trials can offer new treatments for MBC but do not fully represent the real patient population. Research and development has changed the treatment landscape and, as more treatment options have become available, improved outcomes for people with MBC.⁵³ However, real-world data indicate that these improvements are most likely driven by demographic groups that already have higher survival outcomes, such as people with a higher income level.^{13 54} When participants in clinical trials are not representative of the actual population living with a disease, the findings are less generalisable.⁵⁵

Addressing the barriers to inclusion in clinical trials, which often mirror those that people with MBC face in accessing care, can support more equitable participation. Access to MBC clinical trials is limited,^{55 57} and strict criteria preclude participation by certain individuals, such as older people.⁵⁸ And because many MBC trials take place at specialist centres, there can also be geographic limitations; for example, Canada's vast geography and centralised delivery of cancer care create barriers to clinical trial participation for people living in remote and rural areas.^{59 60} Other factors – including ethnicity, socioeconomic position and comorbidities – affect enrolment and ongoing participation in MBC clinical trials⁶⁰ (*Case study 2*), as do fear and misinformation.⁶² Lack of information about trials is also an issue (*Case study 3*). In the UK, for example, only around 32% of healthcare professionals discuss clinical trial participation with people in their care,⁶³ and fewer than 50% of people with MBC feel they have been given enough information about clinical trials.¹⁷

CASE STUDY 2

Understanding the barriers to clinical trial participation faced by Black women living with MBC in the US⁶⁴



The Black Experience of Clinical Trials and Opportunities for Meaningful Engagement (BECOME) initiative, sponsored by the US MBC Alliance, aims to understand the barriers to clinical trial participation experienced by Black women with MBC in the US. Only 40% of participants had discussed clinical trials with a member of their care team. Black women reported lower trust in receiving fair treatment in trials, compared with their White counterparts. Black participants were also more likely than participants from other groups to value receiving trial information from someone of the same racial/ethnic identity.

The project's recommendations include: addressing concerns about side effects, effectiveness and harm; providing messaging from people of shared racial/ethnic identity and health experience; and helping individuals identify and access relevant trials.

CASE STUDY 3

Raising awareness and providing information for people living with breast cancer in England⁶⁵



A pilot in England is aiming to raise awareness, improve communication and provide longer-term support to people with breast cancer from Black, Asian and minority ethnic groups. Supported by the NHS Race and Health Observatory, the project is designing ways for people with breast cancer to access clinical trials and better information processes. The project will also recruit two specialist nurses to provide individual support to participants.

The project will: create marketing materials targeted at minority communities; develop action plans to increase the diversity of clinical trial participants; and offer navigation support to connect patients with relevant clinical trials.

Innovative treatments are increasingly available for people with MBC, but their benefits are not fully realised due to limited access. The emergence of such treatments – including novel, targeted and precision medicines – provides more therapeutic options for cancer patients.⁶⁶ However, access to these innovative treatments remains limited,^{13 67 68} and is influenced by the availability of information, the affordability of care, health system infrastructure, and barriers to accessing the health system in general.^{69 70} Programmes such as the UK's Early Access to Medicines Scheme (EAMS) are supporting treatment access; over 1,200 people from across the country, with conditions including cancer, have benefited from early access to new treatments through EAMS since it launched in 2014.⁷¹ In addition to supporting access to innovative interventions, raising awareness of these treatments should be a key part of health system implementation planning (*Case study 4*).⁶⁹

CASE STUDY 4

A patient-centred approach to the implementation of innovative MBC treatment, Spain



The HOPE study allows people with MBC to share real-world data on the use of molecular information in the management of their condition (i.e. treatment based on genetic changes to tumour cells).^{72 73} These data will help the Spanish health system determine how precision medicines, in particular, may be used.^{72 73}

Alongside documenting their treatment and disease experiences, participants are invited to join a patient empowerment programme that includes educational workshops and videos about innovative MBC treatments.⁷²

Within a week of the study being launched by the Spanish Collaborative Group for the Study, Treatment and Other Experimental Strategies in Solid Tumours (SOLTI), over 300 participants had registered, underscoring the desire for patient involvement and improved access to innovative treatments.⁷³



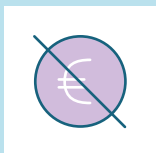
'Many of the newer medications significantly improve the quality of life for people with metastatic breast cancer. Although these treatments can be expensive, the cost of prolonged hospitalisation and managing complications is often much higher. Ensuring everyone has access to the latest treatments should be the focus of policymakers.'

Jenny Gilchrist, Macquarie University, Australia⁷⁴

Ensure early access to comprehensive palliative and supportive care that is tailored to the needs of people with metastatic breast cancer



KEY ACTIONS



Establish tailored palliative and supportive care that is freely available from time of diagnosis to support the physical and psychosocial needs of people with MBC



Expand the number and variety of approaches to palliative and supportive care to increase accessibility around the globe

Palliative and supportive care is an essential part of a well-rounded treatment plan for people with MBC, but there is a widespread lack of availability and access. Such care involves a multidisciplinary approach, from diagnosis to end of life.⁷⁵ Embedding palliative and supportive care as early as possible in the pathway can inform planning and support people's physical and psychosocial needs, maintaining or improving survival as well as enhancing overall wellbeing and quality of life.⁷⁶⁻⁷⁹ These services have been expanded in many health systems, but their integration into cancer care is highly variable, and high-quality care is lacking in many countries.^{13 80} In the US, for example, fewer than 25% of women with MBC received palliative care between 2010 and 2017; and Hispanic White, Black, and Asian/Pacific Islander women with MBC received significantly less palliative care than non-Hispanic White women.⁸¹

Thorough planning and multidisciplinary involvement can enable the effective integration of palliative and supportive care into cancer services. Palliative and supportive care for MBC can be introduced at the time of diagnosis, to enable patients' active involvement in every stage of their care.^{75 83} For example, in France, a new program of multi-professional workshops has been co-created with patients; it includes a session on palliative care, and long-lasting positive outcomes have been reported.⁸⁴ Many resources required for this type of care delivery – including physicians, nurses, mental health specialists, social workers, spiritual carers, trained volunteers and other professionals – already exist in most health systems.⁷⁵ Tailored interventions have

'When I asked my GP about palliative support or resources, he just told me that we didn't need to worry about that now. When I persisted in asking how long he thought I might anticipate staying "healthy" and in what way my cancer might progress, what symptoms might develop, he asked me if I really wanted to know this as most of his patients don't. I want and expect my healthcare providers to be capable of walking alongside me, honestly and openly supporting me to face whatever I have coming.'

Colleen Foran, patient representative, Canada⁸²

been established in different healthcare settings to improve the palliative and supportive care offered to people with MBC (Figure 3). Efforts to raise awareness of available services must also increase; for example, expanded provision of non-medical patient navigators and care coordinators could help patients better understand the services available to them.⁸⁵

FIGURE 3 Improving palliative and supportive care for people with breast cancer around the world

 <p>Albania</p>	<p>An initiative led by the Integrated PAI Oncology Hospital aims to provide resources such as silicone prostheses and wigs to improve the psychological wellbeing and quality of life of people with breast cancer.⁸⁶ To date, the initiative has reached approximately 300 patients, all of whom have reported improved self-esteem and body image as a result.⁸⁶</p>
 <p>Ghana and Tanzania</p>	<p>This one-year initiative aimed to ensure that breast cancer survivorship is well understood and sensitively managed.⁸⁷ The initiative assessed the unmet needs of women following primary treatment for breast cancer, and determined the feasibility of implementing a recovery package (a holistic needs assessment, care plan and treatment summary).^{87 88}</p>
 <p>Peru</p>	<p>A 'School for Caregivers' curriculum trains healthcare professionals to educate families and carers in palliative care and home-based symptom management.⁸⁹ The training has been rolled out nationally using educational materials created by an expert working group of palliative care professionals alongside local advisers and nursing staff.⁸⁹</p>
 <p>Global</p>	<p>Europa Donna, along with several other organisations, recently shared strong evidence that people with MBC should be offered exercise as part of their care and treatment, due to findings from the PREFERABLE-EFFECT study.⁹⁰ The study, which included 357 people with MBC from six countries, split participants into two groups: 178 took part in a supervised exercise programme for nine months alongside their usual care, and the other 179 continued their usual care.⁹⁰ Those participating in the supervised exercise arm of the study experienced less pain, had better physical fitness, experienced less fatigue and reported better quality of life.⁹⁰</p>

Key actions to ensure equitable access to appropriate care along the pathway

Address social and demographic barriers in access to treatment and care



Accelerate research to understand the factors that create barriers to accessing MBC treatment and care, so that targeted interventions can be resourced and implemented equitably

Enable access to innovative treatments

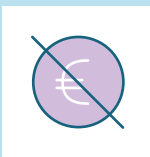


Ensure that all population groups affected by MBC are represented in clinical trials to increase equitable access to new interventions



Prioritise equitable access to innovative treatments for MBC informed by the latest research into the disease

Ensure early access to comprehensive palliative and supportive care that is tailored to the needs of people with MBC



Establish tailored palliative and supportive care that is freely available from time of diagnosis to support the physical and psychosocial needs of people with MBC



Expand the number and variety of approaches to palliative and supportive care to increase accessibility across the globe

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