

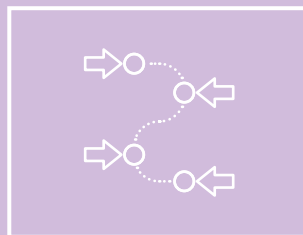
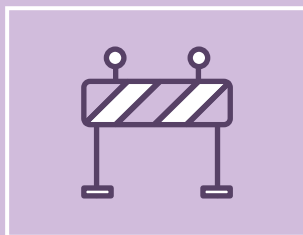
The  
**Health Policy  
Partnership**

Reducing inequalities  
in metastatic  
breast cancer care

# Addressing structural and systemic barriers to care

POLICY BRIEF

November 2024



This policy brief is part of a project initiated and funded by Gilead Sciences Europe, working in collaboration with Harwood Levitt Consulting. Funding was provided to The Health Policy Partnership (HPP) for project preparation and management, research, drafting and coordination. This work was guided by a multidisciplinary Steering Committee and interviews with expert stakeholders. Steering Committee members and expert interviewees were not compensated for their time financially or through any other transfer of value. HPP worked to deliver project outputs that represent a consensus position from the Steering Committee but retained editorial control. All outputs are non-promotional and not specific or biased to any particular treatment or therapy.

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.

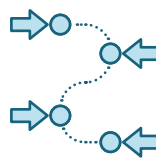
**Reducing inequalities in metastatic breast cancer care: an overview**



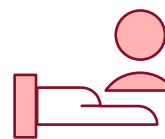
**Addressing structural and systemic barriers to care**



**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:



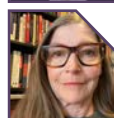
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Dr Dario Trapani, Assistant Professor at the Department of Oncology and Haemato-Oncology, University of Milan, Italy

HPP is also grateful to the experts who volunteered their time to contribute to this policy brief via interview:

- Vicki Durston, Director of Policy, Advocacy & Support Services, Breast Cancer Network Australia
- Dr Beverley M. Essue, Associate Professor of Global Health Systems, Institute of Health Policy, Management and Evaluation, Dalla Lana School of Public Health, University of Toronto, Canada
- 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

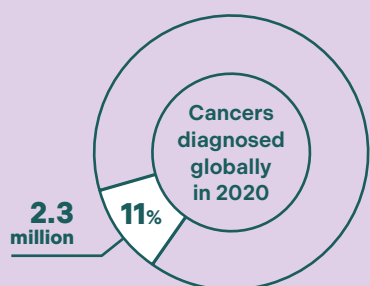
The authors recognise that these policy briefs do not highlight all inequalities experienced by people with metastatic breast cancer, nor do they identify every initiative aimed at addressing these inequalities.

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.

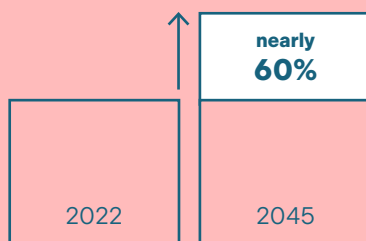
# Inequalities in metastatic breast cancer care

**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.<sup>1</sup> MBC is also known as **secondary** breast cancer, **stage IV** breast cancer or **advanced** breast cancer.<sup>2</sup>

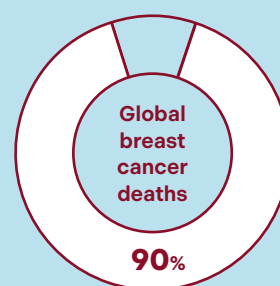
Female **breast cancer\*** is the **most commonly diagnosed cancer**, with an estimated 2.3 million new cases globally in 2020, accounting for over 11% of all cancers diagnosed.<sup>3</sup>



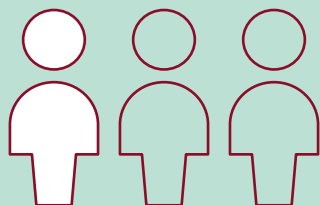
The World Health Organization (WHO) **projects a nearly 60% increase in breast cancer-related deaths** among women between 2022 and 2045.<sup>4</sup>



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



**Nearly 30% of women diagnosed with early-stage breast cancer will develop MBC.**<sup>1</sup>



The most common sites of breast cancer metastasis are the lymph nodes, bones, lungs, liver and brain.<sup>1,6</sup>



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



**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.<sup>1</sup> However:**

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

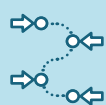
Current policies often fail to recognise or address the unique challenges faced by people with MBC.<sup>8</sup>

**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.<sup>7</sup>**

**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**



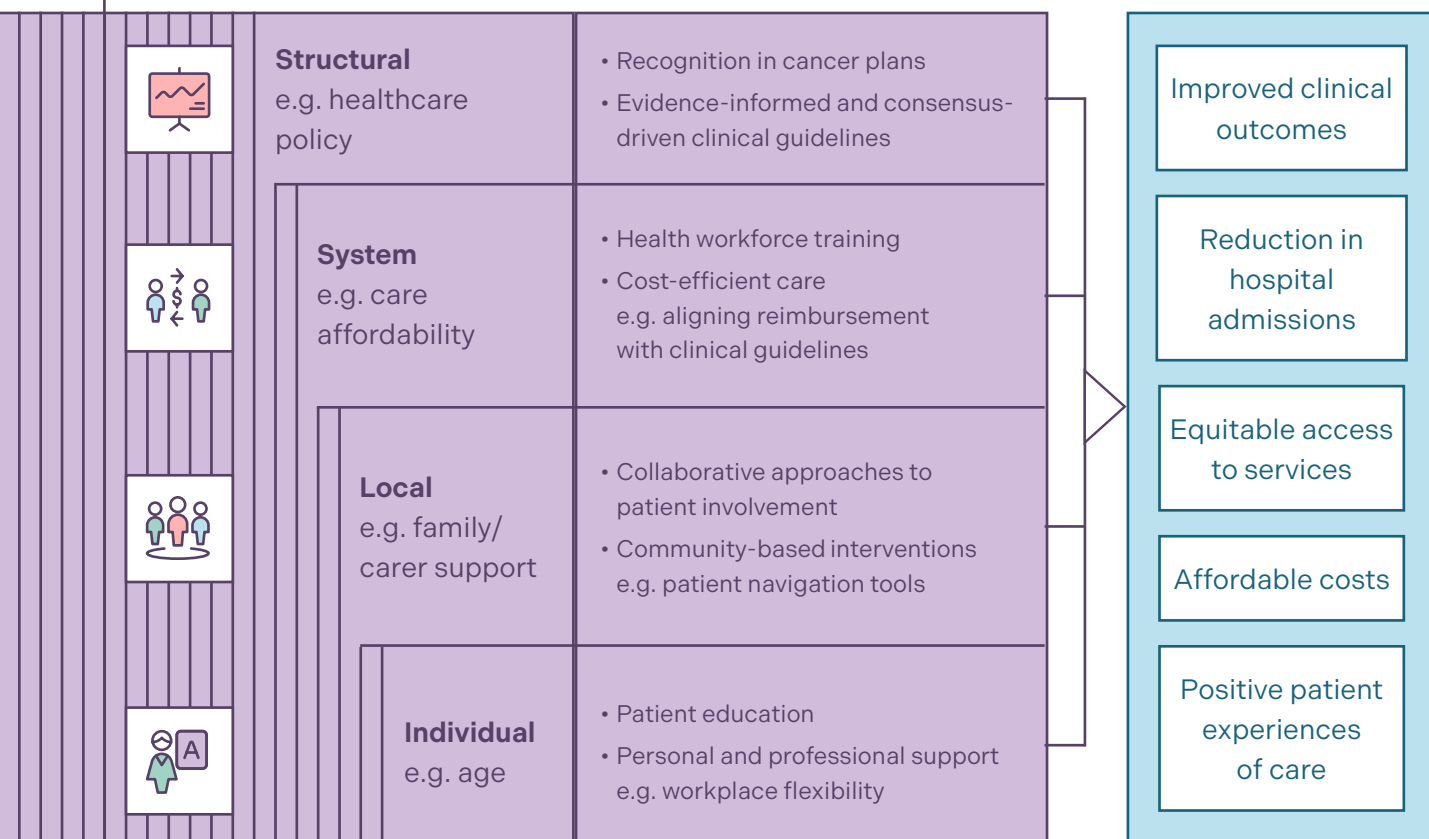
**improve patient experience, involvement and empowerment**

\*Around 99% of the total incidence of breast cancer occurs in women.<sup>9</sup>

# How can we address structural and systemic barriers to care?

To ensure equity in the delivery of care for MBC, it is essential to take a person-centred approach that addresses the structural and systemic barriers to best-practice care. A variety of factors – at an individual, local, system or structural level – disproportionately affect certain population groups and influence disparities in access to care and quality of healthcare services.<sup>10</sup> To improve health equity, governments are being urged to address structural and systemic barriers to accessing cost-efficient and patient-centred cancer care.<sup>11</sup> Such action is paramount to support MBC patients from underserved populations, who are less likely than other MBC patients to receive quality healthcare (Figure 1).<sup>7</sup> Patient-centred policies, systems, environments and practices can improve care by facilitating equitable access to high-quality care and research, reducing structural barriers, and increasing awareness and action.<sup>12</sup>

**FIGURE 1** Factors that influence disparities in access to care and quality of healthcare services<sup>10 13</sup>



# What must policymakers and health system decision-makers do?

**Integrate metastatic breast cancer into all cancer policies and ensure that guidelines offer evidence-based recommendations**



‘Equity is a major issue in MBC care. It’s not just about access to treatments, but supportive care as well. Health policy and guidelines must include recommendations that recognise the diverse needs of all patients to ensure equitable access to care and, ultimately, improve outcomes.’

**Jenny Gilchrist,  
Macquarie University,  
Australia<sup>16</sup>**

## KEY ACTIONS



**Ensure that all national, regional and global cancer plans/strategies recognise the needs of people with MBC and are designed to address disparities in care**



**Continue to develop evidence-informed and consensus-driven clinical guidelines on MBC, for all countries and contexts, to support consistent and tailored care delivery**

**A lack of clarity on how to provide timely and equitable access to care is contributing to poor outcomes for people with MBC.** There is evidence that consistent and comprehensive policies on cancer lead to improvements in survival,<sup>14</sup> but, compared with early-stage cancer, there is little focus on metastatic cancer in national, regional and global cancer policy, guidelines and awareness campaigns.<sup>8</sup> Breast cancer has the third highest economic costs of any cancer type globally,<sup>15</sup> and the majority (90%) of breast-cancer-related deaths are due to MBC.<sup>5</sup> However, National Cancer Control Plans (NCCPs) often fail to provide specifically for metastatic cancer; and where they do, they often lack clear recommendations on how to achieve timely and equitable access to care.<sup>8</sup> Policymakers must expand their priorities to ensure that all people with MBC are recognised and receive personalised care.<sup>9</sup>

**Clinical guidelines for MBC should be established for all contexts to facilitate consistent care and respond to local-level challenges.** The Advanced Breast Cancer (ABC) Global Alliance has developed

guidelines for MBC based on international consensus, with the latest version published in 2024.<sup>17</sup> Recognising the need for consistent and tailored information at the regional level, these guidelines have been adapted for use in Latin America.<sup>18</sup> By contrast, national MBC-specific guidelines are not commonplace, despite most countries having national clinical guidelines that are specific to breast cancer.<sup>19</sup> In addition, for countries where there are MBC-specific guidelines (e.g. Australia<sup>20</sup> and the UK<sup>21</sup>), they are not updated with sufficient frequency to ensure they remain relevant to clinical and practice developments, restricting the delivery of care informed by the latest evidence. Where consensus-driven national guidelines do not exist, they must be developed and updated regularly, based on high-quality international guidelines and adapted to the local resources. The establishment of international standards for adapting clinical guidelines could greatly assist this process, as well as helping harmonise and update existing guidelines. But more research is needed to streamline current practices.<sup>22</sup>

## Invest in systematic data collection as part of high-quality research into metastatic breast cancer

### KEY ACTIONS



**Increase MBC data collection by cancer registries to inform research and the organisation of care**



**Allocate funding for MBC research that reflects patients' needs, to address knowledge gaps and inform interventions**

**The compilation and analysis of real-world MBC data are essential to inform policy development that addresses disparities.** Systematic collection of data relevant to MBC – namely, the stage and extent of recurrence\* when diagnosed, as well as its impact on quality of life – is seldom recognised in policy (e.g. NCCPs)<sup>19</sup> or practice (e.g. cancer

\*It is important to distinguish between *de novo* MBC (i.e. the first occurrence of cancer in the body)<sup>24</sup> or recurrent MBC (i.e. when cancer comes back, or recurs, months or years after treatment).<sup>25</sup>



‘Data are essential to understanding and addressing the gaps in care for people living with metastatic breast cancer. By having accurate data, we can identify inequities, improve clinical care, and ensure that people affected by breast cancer receive the right support at the right time. These data will empower healthcare systems to make informed decisions and ultimately lead to better outcomes for all Australians affected by metastatic breast cancer.’

**Vicki Durston,  
Breast Cancer  
Network Australia<sup>23</sup>**



registries).<sup>26</sup> A key solution is to improve the currently limited global coverage and quality of population-based cancer registries.<sup>9</sup> The Lancet Breast Cancer Commission suggests targeting a ‘minimum of 70% (aiming at 100%) of cancer registries to record cancer stage and relapses’ for optimal inclusive management of MBC.<sup>9</sup> Some countries are aiming for these targets; for example, the Cancer Action Plan for Scotland 2023–2026 aims to improve data collection on metastatic cancers with an initial focus on MBC.<sup>27</sup> The establishment of dedicated MBC registries is another promising step forward in the commitment to collecting MBC data (*Case study 1*). As at least three quarters of new MBC diagnoses represent recurrent disease,<sup>28</sup> the routine collection of recurrence data by cancer registries is particularly important, and requires further refinement of data-collection standards.<sup>29</sup> Electronic data capture and dataset linkages offer promising avenues to assist in recording recurrence data,<sup>29</sup> as well as the development of international guidelines to support this data collection and inform healthcare providers and researchers of the impact of recurrence on long-term patient outcomes.<sup>30</sup>

### **CASE STUDY 1**

#### **Collection of MBC data to inform best-practice care in Québec, Canada**



Québec is the only province in Canada to establish a dedicated MBC registry; the Québec Metastatic Breast Cancer Registry launched in 2021.<sup>31</sup>

The registry supports the collection of standardised data for all types of breast cancer, promoting strong research practices and enhancing information-sharing.<sup>31</sup> To date, nearly 700 cases of MBC have been documented<sup>32</sup> and over 40 variables recorded for each individual, including stage and information about diagnosis and treatment.<sup>33</sup> The registry aims to lead to a better understanding of the disease and, ultimately, the optimisation of clinical practice.<sup>32</sup>

‘This Registry is a unique opportunity to both learn how patients with metastatic breast cancer are treated in Québec and to obtain concrete evidence of the effectiveness of new therapies. It will provide essential data for conducting new clinical trials and is a major step forward in improving breast cancer therapies in Québec.’

**Dr Sarkis Meterissian, quoted on the Canadian Cancer Society website<sup>34</sup>**

**Investment in research that reflects patients' needs is required to ensure that improvements in outcomes for people with MBC are achieved through evidence-based interventions.** From 2014 to 2020, the average annual investment in MBC globally was 13% of all breast cancer funding – an increase from the 2000–2013 average of 7%.<sup>35</sup> Most funding is directed towards studying MBC treatment resistance,<sup>35</sup> with the aim of developing more appropriate treatment options.<sup>36</sup> However, there is still not sufficient investment for the pace of research to match the demand for new treatments for MBC.<sup>35</sup> A collaborative approach is needed to ensure that research reflects patients' needs in different contexts in order for MBC care to be delivered equitably.<sup>9,37</sup> In support of this, a variety of approaches are being applied to the collection of MBC data (Figure 2).

**FIGURE 2** Examples of approaches to improve MBC data collection



## Determine the economic cost of metastatic breast cancer and maximise the cost-efficiency of care

### KEY ACTIONS



**Establish reliable data on the economic cost of MBC to inform efforts to improve the cost-efficiency of care**








**Embed flexible health technology assessment and evaluation processes that accommodate the reality of MBC care and inform decision-making**

**To appropriately allocate funding and resources, the costs of MBC to society and health systems must be determined.** It is predicted that cancer will cost the global economy over \$25 trillion<sup>†</sup> between 2020 and 2050, and that breast cancer will account for 7.7% of this expenditure.<sup>15</sup> While the exact economic costs of MBC are not known,<sup>41</sup> they are likely to be much higher than for early-stage breast cancer due to the more complex and longer clinical care required to manage metastatic disease.<sup>42-44</sup> Advances in treatment mean that people with MBC can lead increasingly long lives with the condition,<sup>1</sup> but this reality has not been matched by increased health system spending or allocation of resources to support lifelong treatment.<sup>19</sup> More comprehensive economic data are required to inform these much-needed changes.

**Tackling variations in treatment reimbursement will allow more people access to comprehensive, best-practice MBC care.** Often, financial structures determine how treatment is reimbursed, and there are disparities in the distribution of medicines, including misalignment with clinical guidelines and recommendations.<sup>45</sup> These variations exist not only between countries, but also within countries, regions and institutions.<sup>45</sup> For example, in many European countries, palliative care – which is essential to improve the quality of life of people with MBC – is not reimbursed.<sup>45</sup> Aligning treatment reimbursement with clinical guidelines will allow more people with breast cancer to be treated according to best-practice guidance, and will be cost-effective.<sup>45 46</sup>

<sup>†</sup> Estimates use international dollars.

**FIGURE 3** Examples of patient input into HTA processes for treatment and care

Country	National HTA body	Patient involvement in the HTA process
 <p>France</p>	<p><b>Transparency Committee of the French National Authority for Health (Haute Autorité de Santé)</b></p>	<p>Since 2019, patient advocacy groups have provided input to the HTA process via an online questionnaire, which includes a quality-of-life assessment.<sup>47</sup></p>
 <p>Germany</p>	<p><b>Federal Joint Committee (Gemeinsamer Bundesausschuss; G-BA)</b></p>	<p>Patient representatives attend all G-BA meetings during the value assessment of a new intervention,<sup>48</sup> but are not allowed to vote during these processes.<sup>49</sup></p> <p>The patient organisation Breast Cancer Germany (Brustkrebs Deutschland) delivered a petition to demand progression-free survival be recognised as a therapeutic goal for breast cancer.<sup>50</sup></p>
 <p>Italy</p>	<p><b>National Agency for Regional Healthcare Services (AGENAS)</b></p>	<p>Patients' perspectives are included in current HTA processes, which are overseen by AGENAS via an online consultation.<sup>51</sup></p> <p>Even though the impact of an intervention on quality of life is assessed,<sup>51</sup> stakeholders agree that a more structured and meaningful increase in patient involvement is needed.<sup>41</sup></p>
 <p>Spain</p>	<p><b>Spanish Network of Agencies for Health Technology Assessment and Services for the National Health System (RedETS)</b></p>	<p>Patient involvement in HTA processes has been limited historically.<sup>52</sup></p> <p>To enhance patient participation, the RedETS Patient Interest Group was established in 2017,<sup>53</sup> and a strategy to involve patients in national HTA processes was developed in 2019.<sup>54</sup></p>
 <p>UK</p>	<p><b>National Institute for Health and Care Excellence (NICE)</b></p>	<p>The Public Involvement Programme (PIP) supports patient, service user, carer and public involvement in the development of NICE guidance, advice and quality standards, as well as their implementation.<sup>55</sup> PIP support ranges from informal telephone/email advice to training workshops.<sup>55</sup></p> <p>An independent group, Patients Involved in NICE (PIN), also exists to provide a system of mutual support and information-sharing for patient organisations and NICE.<sup>55</sup></p>

**Flexible processes to evaluate health technologies that recognise patient experiences, including health technology assessment (HTA), are crucial to accommodate new evidence and treatments for MBC and support the financing of best-practice care.** HTAs that focus solely on overall survival when assessing a healthcare intervention may delay access to the latest non-curative interventions.<sup>19</sup> HTAs or similar processes should be adapted to reflect the reality of MBC care – namely, that many people with MBC are living longer with a diagnosis that may be incurable<sup>56</sup> and need several lines of treatment to overcome tumour resistance.<sup>36</sup> To do this, a stepwise approach – or an approach that includes other relevant endpoints, such as progression-free survival – should also be considered for initial approval, alongside health-related quality of life,<sup>41</sup> while maintaining the need to show overall survival benefit at a later stage, since it is the most relevant endpoint for patients with MBC.<sup>57</sup> But there are limited tools that effectively measure quality of life in MBC treatment settings.<sup>41</sup> New projects are emerging that are relevant to MBC, including the European Organisation for Research and Treatment of Cancer questionnaire for assessing health-related quality of life.<sup>58</sup> And national HTA agencies are increasingly incorporating patient voices in their approval processes for treatment and care (Figure 3).<sup>19</sup> These developments will help increase the flexibility of health technology evaluation processes – ensuring they reflect clinical guidance and the lived experiences of people with MBC – to provide comprehensive evidence that can inform the financial considerations for the integration of new treatments.

## Ensure a sufficient, skilled workforce for metastatic breast cancer care

### KEY ACTIONS



**Prioritise expansion of the healthcare workforce to ensure the widespread delivery of multidisciplinary, holistic care for people with MBC**



**Invest in training a diverse and representative workforce for MBC care, to enhance cultural competence and ensure optimal care delivery**

**Shortages of skilled healthcare professionals hinder the delivery of care, contributing to disparities experienced by people with MBC.**

The insufficient size and unequal distribution of the global oncology workforce contribute to significant disparities in care.<sup>59</sup> The COVID-19 pandemic exacerbated this situation, placing additional strain on healthcare workers around the world.<sup>60</sup> For example, in Poland, the pandemic exacerbated the already limited availability of and access to mammography services, and this contributed to a greater proportion of late-stage diagnoses and poorer survival outcomes for people with breast cancer.<sup>61,62</sup> Although the pandemic made the impact of workforce shortages particularly acute, the availability of a highly skilled, multidisciplinary workforce for MBC care remains challenging in nearly all settings.<sup>19</sup>

**To recognise and respond to the multifactorial needs of people with MBC, policies must prioritise access to multidisciplinary care.**

Healthcare skill shortages limit opportunities for people with MBC and healthcare professionals to develop meaningful relationships – which are crucial to address patients’ needs holistically.<sup>63</sup> The impact of this can exacerbate existing inequalities. For example, there is a lack of qualified personnel to manage MBC in Italy; almost half of the country’s Specialist Breast Units are in the north, while 29% are in the centre and 26% are in the south, so access to multidisciplinary MBC care is inequitable.<sup>61</sup> Multidisciplinary care is regarded as essential, and its recognition in national cancer plans will help increase access to, and the availability and coordination of, this care for people with MBC.<sup>64</sup> For example, the Cancer Strategy for Northern Ireland 2022–2032 emphasises the need to develop regional multidisciplinary teams for people with metastatic disease to ensure evidence-based, optimal treatment and care, and to enable access to clinical trials.<sup>65</sup>

**Comprehensive and tailored training for healthcare professionals is essential to ensure that people with MBC receive best-practice care.**

To address the increasing prevalence and changing patterns of cancer in the global population, health systems must step up workforce recruitment, training and retention.<sup>19</sup> For example, in Japan, an ageing population and rising rates of breast cancer – along with chronic workforce shortages – place significant demands on the health system.<sup>66,67</sup> To address these challenges, digital literacy training for medical personnel is proving critical to automate aspects of data collection and sharing, and therefore ease time constraints for healthcare professionals.<sup>19</sup> On a global level, the training and education of healthcare professionals is a key part of improving understanding of MBC (*Case study 2*).

## **CASE STUDY 2**

### **Global investment in MBC palliative care, advocacy and patient navigation training**



As of June 2023, the Seeding Progress and Resources for the Cancer Community (SPARC) MBC Challenge had reached over 1,176,000 people in 35 countries via its resources and awareness campaigns.<sup>5</sup> It had also trained 2,625 professionals in palliative care, advocacy and patient navigation. The initiative's support for advocacy groups, hospital networks and other non-for-profit organisations includes training, networking, mentoring and financial assistance.

One group receiving SPARC support is Prayas<sup>68</sup> – a non-profit organisation providing palliative care for people with advanced-stage cancer in West Bengal, India – which trained over 50 volunteers in 2016 and 2017. Prayas also provided training in basic care to the families and carers of MBC patients, and led awareness campaigns about social stigma and the early detection of cancer.

'As in many developing countries, West Bengal has a huge burden of metastatic breast cancer and patients come from rural areas where [there is little] access to palliative care...After we (Prayas) were awarded a SPARC grant, we gave proper training to caregivers, volunteers and social workers working with MBC patients, so that symptoms could be managed locally.'

**Aditya Manna, quoted on the Union for International Cancer Control website<sup>68</sup>**

**Establishing a diverse and representative workforce must be part of efforts to deliver more equitable care for people with MBC.** Increasing diversity, as well as supporting cultural competence via training, will help address health disparities experienced by people with cancer.<sup>69</sup> Policies and targeted interventions – such as providing mentorship or training to tackle bias – can help achieve this.<sup>70</sup> For example, the American Society of Clinical Oncology has developed a strategic plan to increase racial and ethnic diversity in the oncology workforce.<sup>71</sup> Cancer research training and career development opportunities for trainees and scientists from racial and ethnic minority groups are also important; to further this goal, the Center to Reduce Cancer Health Disparities, in the US, established the Continuing Umbrella of Research Experiences programme in 1997.<sup>69 72</sup> Such programmes help ensure better representation of the populations most affected by cancer, which, in turn, will create an environment for advancing health equity.

# Key actions to address structural and systemic barriers to equitable metastatic breast cancer care

## Integrate MBC into all cancer policies and ensure that guidelines offer evidence-based recommendations



Ensure that all national, regional and global cancer plans/ strategies recognise the needs of people with MBC and are designed to address disparities in care



Continue to develop evidence-informed and consensus-driven clinical guidelines on MBC, for all countries and contexts, to support consistent and tailored care delivery

## Invest in systematic data collection as part of high-quality research into MBC



Increase MBC data collection by cancer registries to inform research and the organisation of care



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## Determine the economic cost of MBC and maximise the cost-efficiency of care



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Embed flexible health technology assessment and evaluation processes that accommodate the reality of MBC care and inform decision-making

## Ensure a sufficient, skilled workforce for MBC care



Prioritise expansion of the healthcare workforce to ensure the widespread delivery of multidisciplinary, holistic care for people with MBC



Invest in training a diverse and representative workforce for MBC care, to enhance cultural competence and ensure optimal care delivery

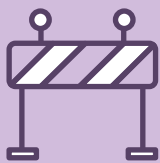


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Please cite as: Hooper J, Wilcox H, Wheeler E. 2024. *Reducing inequalities in metastatic breast cancer care: addressing structural and systemic barriers to care*. London: The Health Policy Partnership.