Health Policy Partnership

Reducing inequalities in metastatic breast cancer care

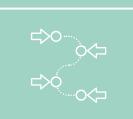
## **An overview**

### POLICY BRIEF

October 2024









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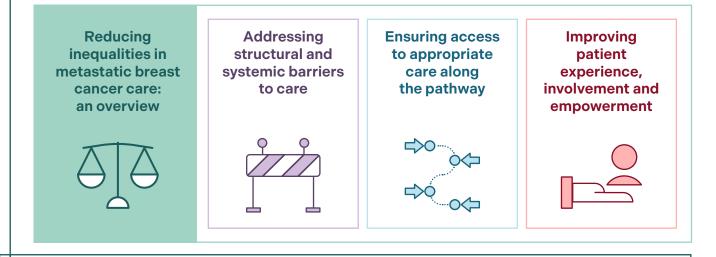


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## **About this policy brief**

This policy brief is part of a <u>set</u> 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.



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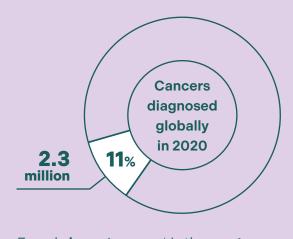
- Vicki Durston, Director of Policy, Advocacy & Support Services, Breast Cancer Network Australia
- Dr Beverley M. Essue, Associate Professor of Global Health Systems, Institute of Health Policy, Management and Evaluation, Dalla Lana School of Public Health, University of Toronto, Canada
- Veronica Foote,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

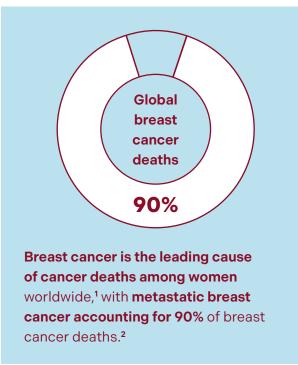
The authors recognise that these policy briefs do not highlight all inequalities experienced by people with metastatic breast cancer, nor do they identify every initiative aimed at addressing these inequalities.

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.

## The global scale and impact of metastatic breast cancer



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>1</sup>

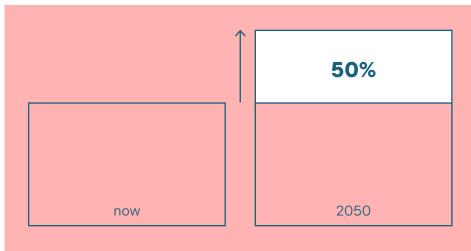


## Metastatic breast cancer (MBC) affects millions of people across the globe and accounts for the vast majority of breast cancer deaths.

MBC – also known as secondary, stage IV or advanced breast cancer<sup>3</sup> – occurs when cancerous cells from a tumour in the breast spread into a different area or areas of the body,<sup>4</sup> most commonly the lymph nodes, bones, lungs, liver and brain.<sup>56</sup> In most high-income countries, less than 30% of newly diagnosed breast cancer patients present with metastatic disease; the proportion is substantially larger (50–80%) in most low- and middle-income countries.<sup>78</sup> And globally around 25–30% of women diagnosed with early-stage breast cancer go on to develop MBC.<sup>57</sup>

The outcomes for people diagnosed with MBC are considerably poorer than for those with breast cancer detected at an early stage. While five-year survival rates for early-stage breast cancer can be up to 99%, for people with MBC they are only around 30%.<sup>79</sup> The rising incidence of breast cancer has led the World Health Organization (WHO) to project a nearly 60% increase in breast-cancer-related deaths among women between 2022 and 2045.<sup>10</sup>

\* Around 99% of the total incidence of breast cancer occurs in women.<sup>11</sup>



An **increase in breast cancer incidence of over 50%** among women is projected by 2050.<sup>10</sup>

There is no cure for the vast majority of MBC cases, but ensuring universal access to existing and emerging treatments can extend and improve quality of life. New and ever-improving treatment options allow many people with MBC to live longer, fulfilling lives, despite the absence of a cure for nearly all patients.<sup>5</sup> However, not all people with MBC are able to access best-practice care and achieve good outcomes.<sup>12</sup> Health inequalities are experienced by many people with MBC and are amplified among underserved populations.<sup>13</sup> Underserved communities often face additional barriers in accessing healthcare due to factors such as socioeconomic position, race and/or ethnicity, geographic location, religion, education level, gender identity, sexual orientation and/or other needs (disabilities, language barriers, age, country of origin).<sup>14 15</sup> These challenges add to the complex treatment landscape that people with MBC, their loved ones and carers must navigate alongside the physical, emotional and financial burden of the disease.<sup>16</sup>

# Inequalities in metastatic breast cancer care

People with MBC have specific needs that are often not met, and the policy response to these challenges varies widely. MBC encompasses a spectrum ranging from disease that has spread to a small number of sites to widespread disease with a poor prognosis, no effective treatments and very short life expectancy.<sup>17</sup> This complex picture – alongside significant gaps in MBC data, knowledge and available support<sup>12161819</sup> – does not help reduce the disparities some people face in accessing and receiving optimal care.<sup>13</sup> Access to innovative treatments, palliative support and coordinated care remains a particularly significant challenge for many people with MBC.<sup>20</sup> While some local and national initiatives support improvement in these areas,<sup>13</sup> there are substantial variations in how different countries address the unmet needs of people with MBC.<sup>16</sup>

#### Current policies insufficiently address the unique challenges

**faced by people with MBC.** Breast cancer policy around the world is skewed towards the early stages of the care pathway.<sup>20</sup> This focus understandably aims to deliver the best outcomes for patients, prevent many from developing metastatic disease, and maximise cost efficiency for the health system.<sup>16 20</sup> But it misses an opportunity to embed MBC care in broader cancer control plans .<sup>16 20</sup> The result is a significant emphasis on prevention, screening, and early diagnosis and treatment; consequently, the needs of many people with late-stage diagnoses or advanced disease are not effectively met throughout their care.<sup>16</sup>



'It is vital to understand that investing in resources for MBC benefits overall cancer control. Countries must embed MBC in cancer plans to avoid siloed cancer care delivery.'

#### Dr Dario Trapani, University of Milan, Italy<sup>21</sup>

## How can policymakers and health system decision-makers work towards reducing inequalities in metastatic breast cancer care?

Addressing the inequalities many people experience in incidence and treatment can improve MBC care and outcomes. From the individual to the global level, disparities in MBC vary significantly.<sup>20</sup> For example, rates of MBC are higher among Black women than White women in the US, even when taking into account their age and the stage of disease at diagnosis.<sup>22</sup> Inequalities are also apparent in diagnosis and treatment outcomes;<sup>2324</sup> there is a strong link between survival rates and country income.<sup>18</sup> Factors contributing to these disparities include structural and systemic barriers to care, unequal access along the care pathway, and inadequate focus on improving patients' experiences and involvement in research and policy.<sup>1116</sup> These obstacles must be comprehensively addressed to improve outcomes and ultimately reduce the burden of MBC on individuals, health systems and society.

#### BOX 1

Action to improve breast cancer outcomes at a global level

In 2021, the **Lancet Breast Cancer Commission** brought together a multidisciplinary group of international experts committed to raising the standard of breast cancer care and improving equity between and within countries.<sup>11</sup> It has established a 'roadmap for change' to address urgent breast cancer challenges, including those unique to people with MBC.<sup>11</sup>

In 2023, the WHO published the **Global Breast Cancer Initiative** Implementation Framework; its goal is to save 2.5 million lives from breast cancer by 2040.<sup>25</sup> The framework acknowledges that access to MBC treatment is fundamental to ensuring equitable healthcare and reducing stigma.<sup>25</sup>

Although steps have been taken in recent years, further global-level commitments and adequate resources are needed to achieve equity in

**MBC care.** Recognition of the exceptionally high global incidence of breast cancer<sup>1</sup> has led to concerted action at an international level (*Box 1*). For MBC specifically, consortia such as the US MBC Alliance and ABC Global Alliance have brought together people with MBC and other leading stakeholders committed to developing, promoting and supporting tangible improvements

in the care of people living with the disease globally.<sup>26 27</sup> For example, the ABC Global Charter outlines evidence-based actions to address the most urgent gaps in care and defines achievable goals for different geographies and health system capacities.<sup>28</sup> These efforts sit alongside broader governmental commitments to further invest in cancer control and reduce inequalities.<sup>29</sup>

**Effective focus on MBC at a national level is also required to address disparities in care.** Health system decision-makers and policymakers must consider priority areas for improvement at the structural level, along the care pathway and in terms of individual patient experience (*Figure 1*). This should inform action to improve current practice to deliver high-quality MBC care that is accessible to all.

#### FIGURE 1 Priority areas for improvement in MBC care<sup>1116</sup>

Evidence-based policies and implementation of best-practice guidelines are needed to address inequalities in access to the best available care for people with MBC, and to reduce variations in care that exist within and between countries. Data completeness and quality improvements will inform effective health policy development by indicating whether people with MBC receive adequate support, treatment and services. Ultimately, this will help shape advances in care and address associated stigma and inequalities.

#### Ensure access to appropriate care along the pathway

Address structural and systemic barriers to care



A patient-centred approach will better deliver individualised care and address disparities. Optimal care delivery depends on numerous patient-centred factors determined by both tumour biology and the characteristics and preferences of the person with MBC. Establishing and evaluating best practices will help deliver widespread multidisciplinary, specialist care and address significant knowledge gaps and variations in adherence to clinical guidelines. This will improve the quality of available care and, in turn, the health outcomes of people with MBC.

#### Improve patient experience, involvement and empowerment



Tailored information and flexible systems will help people with MBC live fulfilling lives. Such systems can also address knowledge gaps across communities in the diagnosis and management of the disease, and establish among patients a sense of ownership over their care. Patient involvement in MBC research and policy will help address inequalities. Understanding the lived experience of people with MBC will help promote person-centred care at every stage of the care pathway and ultimately improve outcomes.

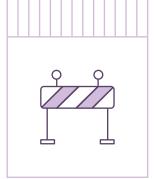
### Address structural and systemic barriers to care

Evidence-based policies and implementation of best-practice guidelines are needed to address inequalities in access to the best available care

National and regional cancer policies do not prioritise metastatic disease, and this hinders progress in providing optimal MBC care.

Cancer control plans at a regional level (such as Europe's Beating Cancer Plan<sup>30</sup>) and at a national level often fail to recognise and address the specific needs of people with metastatic cancer, and do not prioritise metastatic cancers to the same degree as early-stage disease.<sup>20</sup> For example, France, Germany and Italy have had national cancer control plans (NCCPs) in place for over a decade, but these do not incorporate MBC objectives.<sup>31</sup> Such limited recognition of MBC in cancer policy – alongside system-level challenges, such as the absence of a highly skilled, multidisciplinary workforce for MBC in nearly all settings<sup>16</sup> – forms significant barriers to ensuring that MBC care is tailored to individuals' needs.

Existing international and regional clinical guidelines for MBC have yet to be adapted for all countries and contexts, preventing inequalities from being comprehensively addressed. Since its formation, the ABC Global Alliance has developed guidelines for MBC based on international consensus, which have been widely endorsed.<sup>32</sup> The latest version notes that inequalities in access to care are leading to substantially different outcomes for people with MBC, both within and between countries.<sup>32 33</sup> Earlier ABC Global Alliance guidelines were adapted for use in certain contexts (for example, Latin America<sup>34</sup>), while regional and national organisations<sup>35 36</sup> have also developed their own guidelines (*Case study 1*). However, only a very small number of national MBC-specific guidelines address country-level inequalities,<sup>37 38</sup> and these guidelines are not frequently updated.



#### **CASE STUDY 1** The value of stakeholder collaboration in guideline development, Spain



In 2015, the Spanish Society of Medical Oncology (SEOM) published national clinical guidelines for MBC diagnosis and multidisciplinary treatment.<sup>39</sup> The guidelines were developed with the consensus of ten breast cancer oncologists from the Spanish Breast Cancer Research Group (GEICAM) and the Spanish Collaborative Group for the Study, Treatment and Other Experimental Strategies in Solid Tumours (SOLTI).<sup>39</sup>

In 2023, SEOM published national clinical guidelines for the management of advanced breast cancer; these were developed with the consensus of GEICAM and SOLTI representatives.<sup>40</sup> Many of the

#### CASE STUDY 1 continued

recommendations made in these guidelines are applicable to people with MBC, including those relating to the management of brain metastases.<sup>40</sup>

SEOM has had a medical agreement with the European Society for Medical Oncology (ESMO) since 2012,<sup>41</sup> and will therefore seek to align its national guidelines with the latest ESMO recommendations.

## Data completeness and quality improvements will inform effective health policy development

Decisions about how to deliver equitable care for MBC are often impeded by limitations in data. The global number of people with MBC is unknown;<sup>11</sup> current MBC data do not sufficiently capture the entire patient population, and the data quality is very often inadequate.<sup>16</sup> The systematic compilation and analysis of high-quality data on people with MBC and their unmet needs would support policymakers and those planning MBC care to understand disparities in care, outcomes and experiences – and how to address these issues.<sup>42 43</sup> Yet data on MBC currently has many limitations, including:

- a lack of population-level data. Across the globe, population-based cancer registries do not adequately record data on metastatic cancers.<sup>11</sup> Only a few countries have registries to capture and track MBC cases at a national level<sup>31</sup>
- limited data on quality of life. There is a lack of data that describe the experiences and needs of people with MBC, particularly in relation to quality of life.<sup>16</sup> Most of the available tools to assess quality of life have been developed for early-stage breast cancer, making it difficult to monitor and improve quality of life for those living with MBC<sup>44</sup>
- inadequate data infrastructure. Gaps in MBC data collection and system connectivity are common, meaning many people experience disjointed care<sup>16</sup>
- low prioritisation of MBC in the collection of breast cancer data. Most NCCPs recommend that data be disaggregated by tumour type.<sup>20</sup> But the need to collect data relevant to MBC – namely stage at diagnosis, and recurrence – is often not prioritised by healthcare professionals, so the scale of MBC is not accurately captured<sup>16 20</sup>
- limited data on the economic impact of MBC. At present, the true economic cost of MBC is not accurately captured or understood.<sup>3145</sup> Consequently, progress towards optimal care for people with MBC is restricted owing to the lack of reliable data to inform resource allocation.

Limited understanding of the global MBC population prevents access to best-practice care and leaves people with the disease experiencing stigma and isolation. Lack of clarity around the prevalence of MBC prevents adequate allocation of resources and amplifies associated inequalities.<sup>11</sup> As a result, access to treatment and care for MBC is often challenging,<sup>16 46 47</sup> which can make people feel abandoned and stigmatised by policymakers, society and healthcare providers.<sup>11</sup> Without sufficient knowledge of the care required by people with MBC, policymaking will move too slowly to embrace innovation and enable equitable access to optimal care.<sup>48</sup> Locally relevant research and dedicated funding for MBC are required to develop a robust evidence base, address systemic barriers to care and ultimately improve outcomes. In England, for example, the number of people living with MBC was estimated for the first time in 2022, using secondary care records extracted from the NHS England Hospital Episode Statistics database - however, more systematic data collection and reporting on the prevalence of MBC will address important data gaps (Case study 2).49

#### **CASE STUDY 2** Campaign to improve MBC data collection, UK



As part of its 'Secondary. Not Second Rate' campaign, UK-based charity Breast Cancer Now (formerly Breast Cancer Care) found that only a third of National Health Service (NHS) trusts in England were collecting full data on their patients with MBC in 2016,<sup>50</sup> despite this being a requirement since 2013.<sup>51</sup>

It also found numerous systemic barriers that prevented the widespread and accurate recording of MBC data, including limited awareness of the requirement to collect data, confusion about the definition of MBC, and a lack of buy-in and leadership.<sup>52</sup>

In recognition of this, and of the need to increase consistency in access to care and stimulate improvements in outcomes, the National Audit of Metastatic Breast Cancer was launched to report on people diagnosed with MBC in NHS hospitals in England and Wales.<sup>53</sup>

The first quarterly report of the audit, published in April 2024, highlighted that data completeness continues to be an issue.<sup>54</sup> Moving forward, Breast Cancer Now hopes this type of reporting will lead to improved data collection to better inform decision-making around MBC care.<sup>55</sup>

## Ensure access to appropriate care along the pathway

A patient-centred approach will better deliver individualised care and address disparities

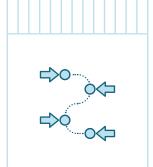
People with MBC have different care needs from those with earlierstage disease, and a better understanding of these needs can inform more optimal care provision. People with advanced cancer report high unmet needs in many areas: financial, health information, psychological, physical and daily life.<sup>56</sup> Many people with MBC express frustration with the transitions between stages of care.<sup>16</sup> Their clinical needs also differ from those of people with early-stage disease; for example, they are more likely to need urgent multidisciplinary care.

More research is needed to understand the factors that influence disparities in access to care for people with MBC. Inequalities in breast cancer incidence and outcomes are driven by a complex interplay of demographic and social factors.<sup>16 57</sup> For example, in England, late-stage diagnosis and breast cancer deaths are more common among Black women<sup>58</sup> and those living in the most economically deprived areas,<sup>16 59</sup> with regional-level differences also determined by age, socioeconomic position and local service provision.<sup>60</sup> Innovative, cross-disciplinary research exploring the factors influencing MBC outcomes can help to identify and eliminate disparities.<sup>24</sup>

Establishing and evaluating best practices will help deliver widespread multidisciplinary, specialist care

**Rigorous monitoring and evaluation of standards, and sharing of best practices, are essential to enable access to the highest-quality care for people with MBC.** In 2000, the European Society of Breast Cancer Specialists (EUSOMA) set out standards for establishing high-quality, multidisciplinary Specialist Breast Units (SBUs) across Europe.<sup>61</sup> These standards are not yet met at every centre, and SBUs lack effective coordination.<sup>16</sup> As of 2022, for example, only approximately one quarter of breast units in Italy were reporting to the Breast Centres Network<sup>16 62</sup> (an international collaboration aiming to promote synergy among breast cancer units<sup>63</sup>), and fewer than one in eight breast units in the country had EUSOMA certification.<sup>64</sup> To help promote the widespread, routine measurement and evaluation of SBU practice, EUSOMA and the ABC Global Alliance jointly established a set of quality indicators for MBC care in 2023, with the aim of making them part of the standards for SBUs.<sup>65</sup>

Innovative solutions are required to ensure that people with MBC have access to multidisciplinary care in line with national and international guidelines. The ABC Global Charter recommends that people with MBC receive guideline-recommended treatment from a multidisciplinary,



specialised team.<sup>28</sup> There has been significant progress in establishing high-quality care in SBUs and sharing best practice, but many people with MBC cannot access SBUs.<sup>766</sup> In Europe, universal access to specialist services has yet to be achieved despite numerous resolutions and declarations issued in the past two decades; consequently, many people living with MBC do not receive optimal care.<sup>66</sup> To support the ambition of the ABC Global Charter, ESMO published the *Metastatic Breast Cancer Living Guideline*<sup>67</sup> in 2023 to enable healthcare professionals to access reference materials and updates to guidelines in real time.<sup>16</sup>

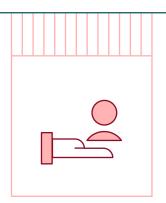
#### Improve patient experience, involvement and empowerment

Tailored information and flexible systems will help people with metastatic breast cancer live fulfilling lives

Educational materials and information should be tailored to relevant populations, to ensure that people with MBC have access to them.

People with MBC, especially those from underserved populations, often lack in information about, and understanding of, their condition.<sup>12 68 69</sup> To address this, resources and initiatives must be developed that reflect the needs of people with MBC; for example, in the US, an original graphic novel was published in Spanish about the diagnostic journey of a person with MBC, to raise awareness of the importance of genetic/biomarker testing among Spanish-speaking communites.<sup>70</sup>

Supportive interventions and resources available to people with MBC are often inadequate. At present, supportive care needs – needs that are specific to people living with a life-limiting prognosis – are not routinely or systematically documented .<sup>71</sup> Consequently, there is limited development of evidence-based interventions and resources that address these needs and optimise quality of life and wellbeing.<sup>71</sup> To drive collaboration and ultimately enhance access to supportive care for the global MBC community, the ABC Global Alliance has developed a toolkit of best-practice summary documents and relevant initiatives for remote and traditionally underserved communities.<sup>72</sup> *Figure 2* highlights other examples of successful initiatives that support the care of people with MBC.



#### FIGURE 2 Examples of supportive interventions for people with MBC

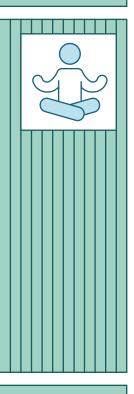


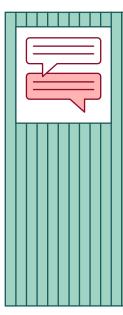
**Workplace adjustments**, such as temporary changes to working patterns, enable people with MBC to continue or return to work, and to take time off for medical appointments.<sup>73</sup> For example:

- Working With Cancer provides occupational and legal support to people living with cancer in the UK, including managing treatment side effects while looking for work.<sup>74</sup>
- Several patient organisations, including Breast Cancer Now and the Canadian Breast Cancer Network, signpost resources to support individuals seeking workplace adjustments, as well as other information.<sup>7375</sup>

To improve quality of life, **wellness programmes** have been developed to provide social, psychological, emotional and practical support for people with MBC. For example:

- In New Zealand, charity Sweet Louise provides a holistic programme of social, psychological, emotional, practical and financial support to enable people with MBC to live as well and as long as possible.<sup>76</sup> It delivers a five-fold social return on investment based on the improved physical and mental health of participants.<sup>76</sup>
- In India, the SATORI (II) initiative, launched in 2021, is a holistic wellness programme for women who have experienced breast cancer recurrence.<sup>77</sup> It provides training and tools to allow people to care for themselves in their own homes, with an initial impact study of 75 patients reporting substantial positive outcomes.<sup>77</sup>





**Community forums** provide an online platform for open discussion among patients, allowing them to ask questions, share their experiences and discuss topics of mutual interest.<sup>78</sup> For people with breast cancer, including MBC, several forums have been established to create social connections and a sense of community, including:

- a forum for people with stage IV breast cancer to share stories and coping mechanisms, set up by Breastcancer.org<sup>79</sup>
- monthly calls and social media groups offered by the Male
   Breast Cancer Global Alliance<sup>80</sup>
- a private group of First Peoples affected by breast cancer, established by Breast Cancer Network Australia.<sup>81</sup>

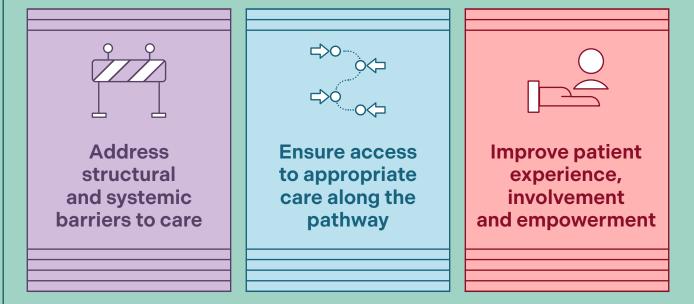
Patient involvement in metastatic breast cancer research and policy will help address inequalities

Despite growing recognition of the importance of patient involvement, many people with MBC are still not represented in the research and policymaking that define their care. Increasing attention has been paid to the importance of patient participation in health policy development at a local and national level,<sup>82</sup> and patient involvement in cancer research has expanded in recent years.<sup>83</sup> However, the insights of people with MBC are still not comprehensively included in policy decision-making.<sup>84</sup> Meanwhile, patient involvement in cancer research often does not include people from underserved communities (e.g. people of low socioeconomic position or low education level) and is skewed towards the earlier stages of the research process.<sup>83</sup>

**Communication between healthcare professionals and people with MBC has not always been prioritised, but there are now efforts to improve this.** The patient voice should be central to all aspects of MBC care delivery, to enhance experiences and ensure optimal care.<sup>85 86</sup> However, for people with MBC, patient-healthcare professional relationships are often overlooked, and many report a desire for better communication.<sup>12</sup> Experts are increasingly recognising this need; the latest oncology curriculum from the American Society of Clinical Oncology and ESMO included mandatory training in communications and improving preparedness for shared decision-making – a collaborative process in which healthcare professionals support patients to make decisions about their care.<sup>87</sup>

## Key actions to reduce inequalities in metastatic breast cancer care

To achieve equity in care and effectively address the unmet needs of people with MBC around the world, we have established three priority areas of action:



These topics are further explored in the three other policy briefs in this set. Together, the publications provide an overview of key opportunities at all levels to reduce inequalities in MBC care and improve patient experiences and outcomes. Policymakers must identify how to improve current practice and take immediate action to optimise MBC care that is accessible for all.

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