

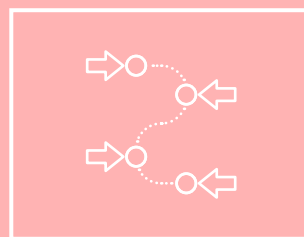
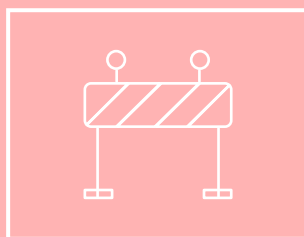
The  
**Health Policy  
Partnership**

Reducing inequalities  
in metastatic  
breast cancer care

# Improving patient experience, involvement and empowerment

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

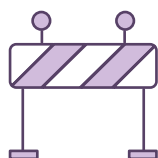
This policy brief is part of a [set](#) that explores opportunities and provides actionable policy recommendations to make care for metastatic breast cancer more equitable. The briefs look at opportunities for policymakers to improve care at a system level and along the care pathway, and to address the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

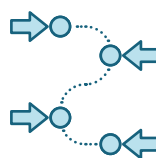
**Reducing inequalities in metastatic breast cancer care: an overview**



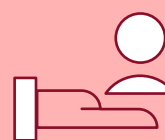
**Addressing structural and systemic barriers to care**



**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:



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

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

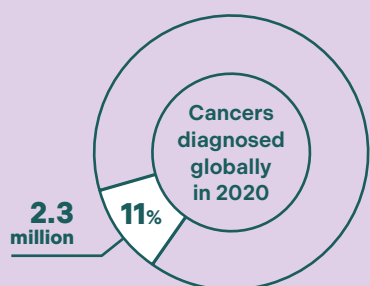
The authors recognise that these policy briefs do not highlight all inequalities experienced by people with metastatic breast cancer, nor do they identify every initiative aimed at addressing these inequalities.

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.

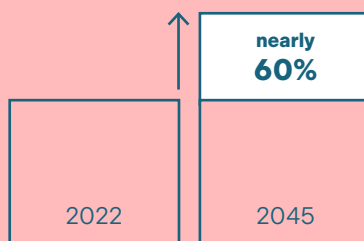
# Inequalities in metastatic breast cancer care

**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>

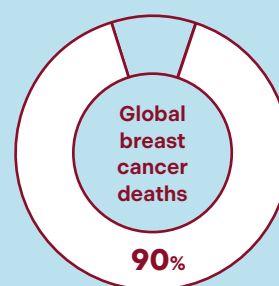
Female **breast cancer\*** is the **most commonly diagnosed cancer**, with an estimated 2.3 million new cases globally in 2020, accounting for over 11% of all cancers diagnosed.<sup>3</sup>



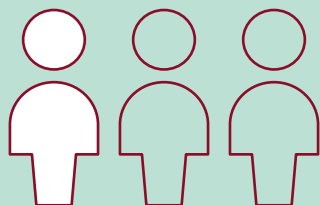
The World Health Organization (WHO) **projects a nearly 60% increase in breast cancer-related deaths** among women between 2022 and 2045.<sup>4</sup>



**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 patient experience, involvement and empowerment be improved?

## **The involvement of people with MBC in research, policy and health system processes is vital to improve equitable access to optimal care.**

While the perspectives of patients, carers and the general public are increasingly included in cancer research approaches,<sup>10</sup> the experiences of people with MBC vary greatly, and their needs change throughout the disease trajectory.<sup>11 12</sup> So their involvement in MBC research, policy and healthcare must improve so that these systems can be designed with their needs fully recognised and prioritised.<sup>13</sup> Involving people with MBC in care planning and delivery will also build trust and help counter the stigma that often prevents them from seeking advice, information and medical care.<sup>11</sup> Achieving widespread patient involvement will require the adequate allocation of resources, which is recognised as essential by the Lancet Breast Cancer Commission.<sup>9</sup>

## **Actively involving patients in MBC care helps healthcare professionals better understand their lived experiences, increases knowledge of the disease and improves care.**

MBC treatment pathways can be complex, contributing to gaps in people's knowledge of the disease and in the support available.<sup>14 15</sup> Healthcare professionals have an important role in these processes, but sometimes assume patients already have a high level of knowledge about breast cancer.<sup>16</sup> This can lead to people feeling invisible in the health system, lacking access to vital services such as supportive care, and feeling less able to make educated choices about their healthcare and lifestyle.<sup>14 17</sup> For example, in a UK study of over 140 people with MBC, 47% said they still did not fully understand their illness, 67% said healthcare professionals did not address their emotional needs, and only 31% were offered palliative/supportive care.<sup>14 18 19</sup> The quality of life of people with MBC has been reported to be considerably lower than that of people with early-stage breast cancer.<sup>14</sup> To address this disparity, and increase uptake of services, it is essential that patients' needs are well understood and responded to appropriately by all involved in their support and care, and that these steps are tailored to the needs of individuals in their communities (*Case study 1*).



'The issue we have with metastatic breast cancer is that it's misunderstood. Many women think, "Oh, that's it, I'm going to die," whereas I've had the privilege to know women still living and working 15+ years post-metastatic diagnosis thanks to access to innovative treatments.'

**Veronica Foote,  
Working With  
Cancer, UK<sup>20</sup>**

## **CASE STUDY 1**

### **Patient-centric resources to reduce inequalities in breast cancer care for Aboriginal and Torres Strait Islander peoples, Australia**



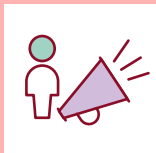
In Australia, First Nations women are more likely to be diagnosed with MBC than non-Indigenous women, and they are 1.2 times more likely to die from breast cancer.<sup>21</sup> Tailored resources aim to address these disparities:

- Breast Cancer Network Australia has established a private online network for First Nations people affected by breast cancer to share stories and support each other.<sup>22</sup>
- Cancer Councils in different states have developed resources and support services for Aboriginal and Torres Strait Islander peoples.<sup>23-26</sup>
- Patient information website ‘Our Mob and Cancer’, created in collaboration with Cancer Australia, provides culturally appropriate resources to guide best-practice care, including an optimal care pathway for Aboriginal and Torres Strait Islander people with cancer.<sup>27</sup>

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

**Support the active involvement of people with metastatic breast cancer in policy development, research and care**

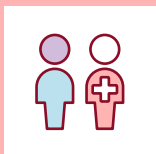
## KEY ACTIONS



**Recognise the needs of people with MBC in policy development at all levels to ensure that their priorities are reflected**



**Establish patient involvement as an essential component of research to develop relevant and high-quality care interventions for people with MBC**



**Foster meaningful relationships between people with MBC and healthcare professionals to help eliminate barriers in access to personalised care**

**Limited patient involvement is preventing the development of policy that reflects the needs and priorities of people with MBC.** Ensuring that patients are involved in policy development can help health services better respond to the needs of the population;<sup>28</sup> and this is the case for people with MBC.<sup>29</sup> Similarly, collecting outcomes data on metrics that are important to patients from all communities could enhance guidelines and care practices, but these data are often not gathered or, where they are, the data collection is not systematic.<sup>29-32</sup> Treatment and care guidelines can better meet people's needs by embedding patient-reported outcomes and patient voices into their development.<sup>29</sup>



'Living with MBC can be a time of profound depth in relationships. Many people do not have enough support, and the system doesn't seem equipped in any context – urban, rural etc. – to provide that missing support. And some healthcare providers I have encountered have not had the skills to even provide basic information about the future.'

**Colleen Foran, patient representative, Canada<sup>33</sup>**



**People with MBC are increasingly involved in research, which is critical to developing relevant, high-quality treatments and interventions.**

Research underpins treatment and care innovation and improvements, and including patients' perspectives in this process can help address limitations in care delivery and support patient-centred care.<sup>34-36</sup> To be effective, involvement should be embedded in the entire research process, not just the earlier stages.<sup>10</sup> In the UK, the National Institute for Health and Care Research has established policies and guidelines that pave the way for patient involvement in cancer research, with research centres working to ensure voices from all backgrounds are heard.<sup>37-39</sup> Increasingly, dedicated funding is available to improve these strategies and resources in MBC research. For example, Against Breast Cancer has involved the public and patients as research advocates in its grant funding review process and to inform its research strategy, to provide insights from those living with all stages of breast cancer.<sup>40</sup>

**Various tools can help people with MBC become more involved in decisions about their care, ultimately improving outcomes.**

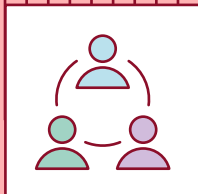
People who understand their condition and play an active role in decision-making are significantly more likely to experience better outcomes.<sup>15</sup> Many people with MBC express a wish to be more actively involved in their care decisions, and formalised tools can help patients communicate their treatment preferences, thereby reducing inequalities in care delivery.<sup>41,42</sup> This may be particularly significant for underserved communities: in the US, a shared decision-making treatment planning process for Black women with MBC has enabled patients to make their treatment preferences known.<sup>41</sup> Healthcare professionals should be supported to communicate more effectively in holistic, person-centred ways while fostering meaningful and trusting relationships with patients.<sup>15 32 36 43</sup> However, such relationships are often challenged by time constraints.<sup>43 44</sup> For example, the nurse-patient relationship is recognised as being hugely important in cancer care, but a 2019 UK survey of over 2,000 people with MBC found that fewer than a third saw a clinical nurse specialist regularly.<sup>44</sup> Tools and strategies such as shared decision-making and patient navigator roles can help meet this gap, and are critical to improving the experiences of people with MBC;<sup>17</sup> such tools should be commonplace, developed with patients and regularly updated (*Figure 1*).<sup>45</sup>



'Breast Cancer Network Australia recognises the importance of giving those with metastatic breast cancer a meaningful voice in shaping policies, research and care. Our digital platform, connecting over 200,000 people, facilitates peer-to-peer support and empowers individuals to actively participate in discussions that influence their care, treatment and support, driving better outcomes.'

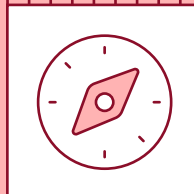
**Vicki Durston,**  
**Breast Cancer**  
**Network Australia**<sup>46</sup>

**FIGURE 1** Supporting active patient involvement in care through shared decision-making tools and navigators



### Shared decision-making

- The American Society of Clinical Oncology and the European Society for Medical Oncology have jointly developed a curriculum for oncology, which includes communications training to improve healthcare professionals' preparedness for shared decision-making.<sup>47</sup>
- The Dandelion Toolkit, developed in 2015 for people newly diagnosed with MBC, was based on research conducted in Australia, Mexico, Turkey and the US.<sup>48</sup> It aims to create opportunities for shared decision-making and support better communication between people with MBC and healthcare professionals by providing visual aids that guide discussions on diagnosis, pathology, staging, treatment options and quality of life.<sup>48</sup>

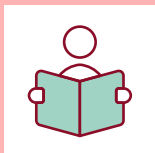


### Patient navigation programmes and tools

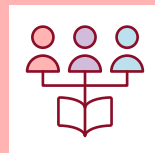
- The ABC Global Alliance's ABC Peer Navigation Program connects patients with Peer Navigators, who provide support and resources that can be personalised to patients' needs.<sup>49</sup> The programme is designed to meet the needs of underserved communities in particular, and aims to dismantle some of the barriers they face in accessing quality cancer care and support.<sup>49</sup>
- PatientPath, a digital navigation tool developed by the Canadian Breast Cancer Network, provides tailored information, resources, and a general treatment plan for all breast cancer patients.<sup>50</sup>

## Provide clear and tailored information to people with metastatic breast cancer

### KEY ACTIONS



**Systematically address gaps in patient knowledge and the availability of patient-focused information by developing or adapting and disseminating relevant materials to enable people with MBC to make educated choices about their care**



**Consult people with MBC on their informational needs and ensure that educational resources are informed by, and designed to reach, all communities**

### **Gaps in patients' knowledge of MBC must be addressed through the development or adaptation and dissemination of tailored information.**

Educational resources about MBC must reflect the needs of patients from different communities and be made available to and accessible for all.<sup>51</sup> Yet campaigns for breast cancer often overlook MBC, meaning information is less widely available.<sup>52</sup> This is more acutely experienced by people from underserved communities, particularly those who face language barriers or have low health literacy.<sup>15</sup> Informational avoidance is associated with lower literacy levels and, in the US, is more prevalent in some communities (e.g. Latinos diagnosed with cancer) due to a lack of comprehension or to exert autonomy over their health.<sup>53</sup>

### **The active involvement of people with MBC in the development of informational resources can address gaps in knowledge, promote trust among people with MBC and reduce experiences of stigma and isolation.**

Access to treatment and care for MBC is often challenging,<sup>17 54 55</sup> which can make people feel abandoned and stigmatised by policymakers, society and healthcare providers.<sup>9</sup> Patient involvement – for example, by working collaboratively with patient groups to develop informational resources – is essential to raise awareness of MBC, tackle the stigma experienced by patients and improve access to care. Local patient advisory groups, cultural organisations and community-based healthcare professionals can also play a key role in advising health professionals and policymakers on proposed initiatives, and support tailored dissemination of information.<sup>13</sup> In recognition of this, alongside patients and other expert stakeholders, the ABC Global Alliance has highlighted how specific gaps in patient knowledge and patient-focused information on the diagnosis and management of MBC can be addressed (*Figure 2*).<sup>15</sup>

**FIGURE 2 Addressing gaps in MBC patient knowledge and information†**

Gaps and challenges	How can these be addressed?	Examples of solutions
<p><b>Limited awareness of recurrence, leading to unpreparedness for an MBC diagnosis.</b></p> <p>This can be exacerbated among people with limited time to source reliable information.</p>	<p>Consult with patients to develop patient-friendly language and develop clear communication on risk, treatment options and survival.</p>	 <p>Breast Cancer Network Australia has developed educational resources on MBC for men, First Peoples, LGBTIQ+ people, young people and people living rurally.<sup>56 57</sup></p>
<p><b>Terms to describe MBC are not consistent, leading to confusion.</b></p> <p>This can be worsened by low health literacy and difficulty understanding medical concepts and terminology.<sup>58</sup></p>	<p>Provide accurate and tailored information in an appropriate format, including in communication with healthcare professionals.<sup>59</sup></p>	 <p>A variety of patient organisations provide MBC information in different formats e.g. podcasts, videos, helplines and in collaboration with community forums.<sup>60-63</sup></p>
<p><b>Limited occupational, legal and financial advice and support.</b></p> <p>These limitations are more acutely felt by people in lower socioeconomic groups.<sup>64</sup></p>	<p>Signpost available resources, ensuring, via consultation with people affected by MBC, that they are relevant to the individuals' needs.</p>	 <p>Working With Cancer provides occupational and legal support to patients in the UK, including information on managing the side effects of treatment while looking for work.<sup>65</sup></p>
<p><b>Many educational materials are only available in one language.</b></p> <p>People whose primary language is not that of the place where they live are less able to access the resources they need.</p>	<p>Develop and direct people with MBC to resources in their primary language.</p>	 <p>The ABC Global Alliance and Susan G. Komen resources are available in several languages to broaden their accessibility.<sup>66 67</sup></p>

† The gaps and challenges in MBC patient knowledge and information, and ways these can be addressed, were identified during the 2019 ABC Global Alliance Annual Meeting.<sup>15</sup>

## Ensure that people with metastatic breast cancer are empowered to continue with daily life



### KEY ACTIONS



**Develop and expand the number and variety of interventions available to help all people with MBC live fulfilling lives**



**Establish flexible work environments, encourage greater understanding of the challenges of MBC among employers, and increase the availability of supportive resources that allow patients to work if they wish to**

'More people with metastatic breast cancer are living longer but, unfortunately, they often face prejudice in the workplace. Employers may find it challenging to accommodate their needs, which can lead to biased attitudes about their ability to continue working. People with metastatic breast cancer need flexibility in their working hours to attend appointments and chemotherapy, and ultimately to enable them to have a better quality of life.'

**Jenny Gilchrist,  
Macquarie  
University,  
Australia<sup>74</sup>**

**As more people with MBC are living longer with the condition, flexible support is needed to help them live fulfilling lives.** A cancer diagnosis at any stage, and regardless of outcome, can, in some locations, be formally considered a long-term disability, for example as recognised in the UK Equality Act 2010.<sup>68 69</sup> And, as the development of treatments means people with advanced cancer are living longer,<sup>12</sup> this gives rise to a number of emotional, practical and social challenges.<sup>20 62</sup> Among underserved communities, such challenges are exacerbated by disparities along the care pathway and the additional barriers to best-practice care they often already experience.<sup>70</sup> A variety of tools have been developed to enhance flexibility in managing MBC, and these may lessen the impact of such disparities (*Figure 3*).

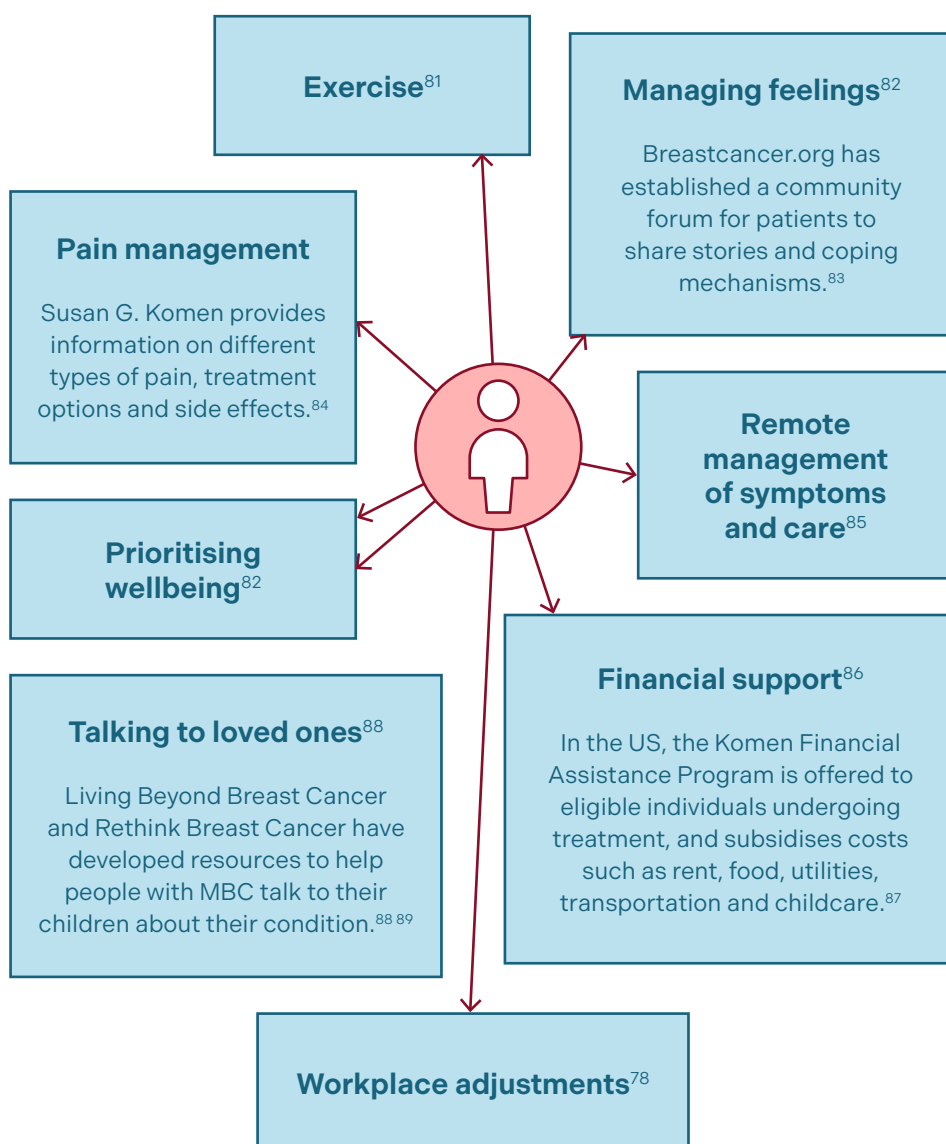
**Health system and work-related barriers should be addressed so that people with MBC can continue to work if they wish to.** Many people with MBC need or want to continue working, often due to financial constraints coupled with treatment expenses.<sup>20 71</sup> Being able to work also offers a sense of normality, purpose and identity.<sup>11</sup> Enabling people with MBC to continue working or return to work also benefits the economy, as the productivity losses associated with MBC are significant.<sup>72</sup> In many countries, however, workplace flexibility is not enshrined in law; people with MBC may face discrimination based on misconceptions about the disease, and few are offered appropriate legal protections at work.<sup>51</sup>  
<sup>73</sup> And, where legislation such as the UK Equality Act 2010 is in place,

greater employer and employee awareness is needed so people with MBC can benefit. For example, in the UK, many employers do not know how to support employees with a diagnosis of MBC, and people living with metastatic cancer have reported receiving low levels of support and access to workplace adjustments.<sup>75 76</sup> In most countries, practical support and resources are available – including coaching for individuals and employers,<sup>77</sup> phased return to work,<sup>78</sup> work ability assessments<sup>79</sup> and online networks<sup>80</sup> – but they have limited impact if there is no flexibility in systems and structures. For instance, many people experience barriers such as immovable medical appointments that clash with inflexible working hours.<sup>1120</sup>

‘Returning to work is critical, but it can be aspirational... because the supports required don’t rely entirely on the health system. It requires seeing individuals holistically to understand the disease experience and trajectories of those who flow in and out of the health system, and understanding what they need to live and work effectively.’

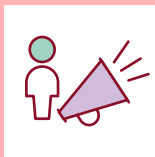
**Dr Beverley Essue,**  
**University of Toronto,**  
**Canada<sup>90</sup>**

**FIGURE 3** Supportive interventions for people with MBC



# Key actions to improve patient experience, involvement and empowerment

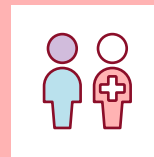
## Support the active involvement of people with MBC in policy development, research and care



Recognise the needs of people with MBC in policy development at all levels to ensure that their priorities are reflected



Establish patient involvement as an essential component of research to develop relevant and high-quality care interventions for people with MBC

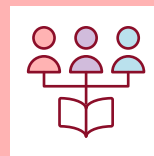


Foster meaningful relationships between people with MBC and healthcare professionals to help eliminate barriers in access to personalised care

## Provide clear and tailored information to people with MBC



Systematically address gaps in patient knowledge and the availability of patient-focused information by developing or adapting and disseminating relevant materials to enable people with MBC to make educated choices about their care

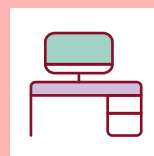


Consult people with MBC on their informational needs, and ensure that educational resources are informed by, and designed to reach, all communities

## Ensure that people with MBC are empowered to continue with daily life



Develop and expand the number and variety of interventions available to help all people with MBC live fulfilling lives



Establish flexible work environments, encourage greater understanding of the challenges of MBC among employers, and increase the availability of supportive resources that allow patients to work if they wish to

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