Section 2

Environmental Landscape
Introduction

In reviewing the status of the metastatic breast cancer (mBC) landscape, through a truly holistic lens, consideration of the environmental factors impacting patient care is vital to understanding the complete picture.

Section 1: Patient Care Perspectives focused on discussing patient care and support needs along the care continuum, highlighting the extent to which they are currently being addressed globally and key emerging recommendations that could progress mBC patient care.

While direct clinical management and support for patients with mBC is crucial, it is not the sole aspect of how patients manage and live with their disease. The patient experience is also largely shaped by the surrounding environment, that both directly and indirectly affects patients with mBC. This section explores the breadth of environmental factors that influence the mBC landscape.

As outlined in the introduction to this preliminary report, research into the environmental landscape has been designed to broadly assess the current status of mBC. Three core areas have been researched (or are part of ongoing work); Policy Perspectives & Economic Burden, Societal Experience & Public Understanding and the Impact of Patient Support and Advocacy Organizations in mBC.

While this Preliminary Report captures some of these areas, efforts continue to assess additional factors not captured in this report such as policy and economic impact, as well as the societal experience of patients with mBC. These additional analyses will be included in subsequent updates to this report.

This section of the report shares key findings from new primary research surveys (methodologies are outlined in each chapter), it includes:

- **Public Understanding of mBC**
- **The Impact of Patient Support and Advocacy Organizations (PSOs)**

One of the most important factors affecting public understanding of mBC is the stigma associated with the disease. This is explored further within the Public Understanding of mBC chapter. In addition, as a key information source for the general population, traditional and online media are discussed and analyzed to provide an overview of their influence. It is of note, however, that an in-depth review of the impact of and information available via social media, and its impact, is required.

The role of PSOs in meeting support needs of mBC patients is also discussed in the Impact of Patient Support and Advocacy Organizations chapter, with a call for further secondary research to identify more ways in which these are and can be addressed by PSOs.
While public understanding of early breast cancer (eBC) has risen in recent years, it is generally thought that understanding of mBC specifically is inadequate. (MBC Alliance, 2014, Executive Summary) Although public understanding may not directly impact how a patient with mBC is treated, inaccurate perception from others in society, matters greatly to a patient or caregiver. Inaccurate perception of disease implications, stigmatization, and cultural attitudes, influence the social and emotional experience for all affected by an mBC diagnosis, whether they are patients, caregivers or families. There is much work to be done to improve societal understanding of mBC, with media likely to play a role given the positive effect seen in educating the general public on eBC.
Methodology: To better understand the general public’s awareness, understanding, and perceptions of ABC/mBC globally, a general population survey was conducted during June 3 - July 30, 2015. In this survey, commissioned by Pfizer, a total of 14,315 adults aged 18+ from the general population (mBC patients and non-patients) participated. The 14 participating countries were: UK, France, Germany, Poland, Turkey, India, Taiwan, Japan, South Africa, Brazil, Mexico Argentina, Chile and Colombia. In all countries, respondents were sampled from internet consumer research panels and invited to complete a 15-minute self-administered questionnaire in local languages; in Argentina, Chile, and Colombia; internet panel samples were combined with face-to-face interviews. In some countries (Poland, Turkey, India, Taiwan, South Africa, Brazil, Mexico), samples may not be fully representative of the population segment without online access, due to lower Internet penetration among the general public and/or less developed Internet panels in those countries. A similar (but not identical) survey was conducted in the US in 2014; n=2090 and formed the basis of the report: Breast Cancer: A Story Half Told, findings and recommendations, 2014. Together, these studies represent the first, wide-reaching, global effort to assess public understanding and comprehension of both eBC and mBC. Results from these surveys provide a strong foundation for the findings within this chapter.

Public awareness and understanding of mBC is lacking in the context of global breast cancer awareness

Global awareness of breast cancer amongst the general public is high. In a recent international survey of over 14,000 members of the general public across 14 countries, on average 54% of respondents knew someone with breast cancer. It is also the cancer with which adults are most familiar in the majority of countries surveyed across the globe. (mBC General Population Survey, Pfizer, 2015) These results echo findings of a similar survey conducted with 2,000 members of the general public in North America in 2014. (A Story Half Told, Pfizer, 2014)

National and international breast health awareness and promotional campaigns have been fundamental in increasing awareness of breast cancer over the decades. In turn, the building of support communities, an increase in the availability of information, and a movement for patients encouraged to take ownership of the detection, diagnosis, and treatment of their disease has been observed. Such activity has mainly been in the context of eBC and its survivorship, with limited focus on patients with recurrent, advanced or metastatic BC. (mBC Alliance, 2014) This is reflected in a global lack of familiarity with the terms ‘advanced breast cancer’ or ‘metastatic breast cancer’ compared with ‘breast cancer’ by the general population across a range of countries. (mBC General Population Survey, Pfizer, 2015; A Story Half Told, Pfizer, 2014)

"For more than 160,000 women living in the U.S. with advanced, stage IV breast cancer, the situation is not one they can turn off on their TV sets, or avoid by skipping out from pink-decorated malls: they’re living and coping with the metastatic form of the disease, active treatments, side effects and, still, no known cure. Their outlook is tempered, maybe best portrayed in a spectrum of gray."

Huffington Post, 2010
We still have a long way to go and we are still losing too many women … but there is a lot more hope for many years of good quality life for a patient diagnosed with a metastatic recurrence now than there was two decades ago.

Dr. Julie Gralow, fredhutch.org, 2014

In October 2009, the US. Senate and House voted to support the designation of October 13 as a National MBC Awareness Day, as a result of the efforts of the Metastatic Breast Cancer Network. (Huffington Post, 2010; Metastatic Breast Cancer Awareness Day, 2012) Since 2010, this day has drawn attention to the unique needs and challenges of patients with mBC, across Europe and North America. (Metastatic Breast Cancer Network, 2010) While this is a positive step, the impact of this dedicated day has not been widespread and public knowledge remains limited, particularly regarding the distinction between early and mBC and the implications of these diagnoses.

The focus on early detection combined with significant advances in treatments for eBC, resulted in a perception that breast cancer has been largely “cured”. The “breast cancer survivor” identity obscures the reality that approximately 20%-30% of women diagnosed with eBC will eventually progress to metastatic disease, (O’Shaugnessy, 2015; EBCTCG, 2015) which is incurable.

Perceptions about mBC in society can be seen as two extremes: those who are optimistic about prognosis of the disease, and those who think of it as hopeless. In most countries surveyed, 74–87% of respondents believed that early detection and/or treatment will prevent disease progression and 48–76% believed that advanced breast cancer is curable, suggesting that there is a lack of public knowledge of the prognosis for patients with mBC (Figure 2.1). (mBC General Population Survey, Pfizer, 2015) The public perception of a breast cancer “cure” may impact patients’ ability, both newly diagnosed with mBC or recurring from eBC, to adjust perception away from “curing” their breast cancer to “living” with metastatic disease.

Despite those who hold expectations of cure, globally, the terms ‘aBC/mBC’ and ‘breast cancer’ are associated with negative words by the general public. (mBC General Population Survey, Pfizer, 2015) There are also some perceptions of mBC as a hopeless disease and that the time and effort in treating and supporting mBC patients would be wasted, compared with eBC patients. (mBC Patient Support Organization Survey, Pfizer, 2015) These extremities in perspective highlight a lack of awareness and understanding about the disease and how it differs from early-stage breast cancer.

Breast cancer in this area [certain countries in Africa], is almost synonymous with stage IV, there are very little survivors. For these women a breast cancer diagnosis is a death sentence with little hope.

Dr. Olufunmilayo Olopade, Director of the Center for Clinical Cancer Genetics, University of Chicago, 2015
Figure 2.1

Percentage of the General Public Surveyed that Believe Advanced or mBC can be Cured

mBC General Population Survey, Pfizer, 2015; A Story Half Told, 2014, Pfizer

For all countries except the US, the percentage of respondents who either somewhat agree or agree strongly with the following question: “How much do you agree or disagree with the following statement about advanced or metastatic breast cancer? “Advanced or metastatic breast cancer is curable” (mBC General Population Survey, Pfizer, 2015). This research was not powered to draw comparisons between countries.

*US respondents totaled 2090. Responses were obtained via a separate survey asking whether respondents strongly agreed/agreed that patients with breast cancer can be cured if caught early with the right treatment.

“I think the minute you say metastatic or secondary [breast cancer], people just think they’re on their way out, why should we bother putting research money to it…and that makes it really difficult to research this group of patients separately.”

European Respondent, mBC PSO Survey, Pfizer, 2015
The lack of broader understanding of mBC negatively impacts mBC patients’ experience while living with their disease and adds to stigma, distress, and isolation.

Sadly, a significant proportion of the public believe that breast cancer progresses or recurs because patients do not take preventative measures, such as correctly taking medicine and attending appointments. (mBC General Population Survey, Pfizer, 2015; MBC Alliance Report, 2014) These findings were echoed in a similar survey of the public in the US. (A Story Half Told, Pfizer, 2014) Negative public perceptions of mBC impact the association that mBC patients have with the disease.

"People don’t understand the word metastatic to begin with…And when I’d tell them I was stage 4, they’d give me pity or stay away or see me a year later and think I was a ghost. They couldn’t believe I was alive."

US mBC patient, fredhutch.org, 2014

"Positive messages about early detection and lifestyle choices that might reduce breast cancer risk may in a subtle way reinforce the misperception that these things will be effective for everyone – and that if someone develops breast cancer or metastatic breast cancer, it must have been their fault."

Kimberly Sabelko, Managing Director, Strategic Partnerships and Programs, Susan G. Komen, 2015

Half of patients with mBC report feeling social rejection in the form of isolation, shame and feeling like outcasts, particularly within the breast cancer community. (MBC Alliance, 2014) These elements are characteristic of the mBC experience in the overall population as well, and influence patient behaviors such as their willingness to seek support or make treatment and quality of life decisions. It is notable that the feeling of isolation identified in mBC patient surveys from 2008-2009 are still present in later studies, highlighting the limited progress over time in changing perceptions of mBC. (Else-Quest, 2009; Faces of mBC, 2010; MBC Alliance, 2014)
“But dealing with an incurable illness and the side effects of its treatment aren’t the only burden MBC patients have to bear. Many also have to educate others about their disease, explaining over and over that no, the scans and blood tests and treatments will never come to end. No, the metastasized breast cancer in their lungs is neither lung cancer nor linked to smoking. No, staying positive and ‘just fighting hard’ isn’t going to beat back their late-stage disease.”

fredhutch.org, 2014

Results from a 2013 global survey of 1,273 women with mBC in 12 countries demonstrated that, regardless of country income level, most women with mBC felt that others do not empathize with their experience. Nearly two-thirds (63%) of women said they “often feel like no one understands what they are going through” while two in five women said they “feel isolated from the non-advanced breast cancer community” (see Figure 2.2). (Count Us, Know Us, Join Us, Novartis, 2013) This sense of isolation from the larger breast cancer community can be attributed to a lack of available resources to address their needs, appropriate messaging and the negative perceptions associated with a terminal diagnosis. This isolation is mirrored, globally, by the general public where, on average, 28% of people indicated that patients with mBC should keep it a secret and not discuss it with anyone other than their physician (Figure 2.3). This was most pronounced in India and Turkey, where almost half of people surveyed agreed with this statement (49% and 42%, respectively) (mBC General Population Survey, Pfizer, 2015).
While the majority of breast cancer patients are female, men also are diagnosed with both early and advanced disease; globally, an average of 69% of people are aware that breast cancer occurs in men as well as women. (mBC General Population Survey, Pfizer, 2015) Literature shows little information regarding men, and specific research is needed to understand how men’s needs differ from those of women.

The overwhelming focus on eBC in messages conveyed by the media, breast cancer awareness campaigns and the association between early disease and survival, generates the perception of two distinct breast cancer patient groups: those who survive and those who die as a result of their disease. The treatable, yet incurable nature of mBC means patients with advanced disease do not fall distinctly into either of these groups. This “gray area” impacts patients with metastatic disease with respect to their quality of life and their level of distress along disease continuum. These patients are considered to be “without a voice” in the general breast cancer community. (Count Us, Know Us, Join Us, 2013; Inside Vandy: Vanderbilt University, 2013; Metastatic Breast Cancer Network, 2015; History of Metastatic Breast Cancer Awareness Day, 2013)
"The way we [in the US] talk about breast cancer has fundamentally changed over the past four decades. Prior to the 1970s, breast cancer was a taboo subject -- many did not dare to say the words "breast cancer" aloud. We've overcome that stigma, and now, across the globe, we need to do the same for mBC."

Kimberly Sabelko, Managing Director, Strategic Partnerships and Programs, Susan G. Komen

The journey to change perceptions of eBC has taken many years and the level of success differs geographically. In the 1970's the journalist Rose Kushner shared with the public, not only her experience but also the science behind her breast cancer. She successfully combined her own story with the basics of cell biology, using everyday language to reach her audience (LA Times, 2014). Over the years, public figures willing to take a similar plunge and share their experiences have helped make conversations about breast cancer more acceptable. (LA Times, 2014)

In some developing countries, there still remains a need to overcome a stigma associated with breast cancer, overall, before strategies to change the perception of mBC, specifically, can take effect. Local culture and beliefs that can discourage patients from seeking care early-on, include the physical implications of treatment (especially mastectomy), lack of access to knowledge about breast health, and family/community rejection following a breast cancer diagnosis. The lack of options for early detection due to limited access to routine care and examinations, as well as lack of access to affordable, high-quality treatment options contribute to the poor outcomes for patients with breast cancer and perpetuate the negative image of breast cancer in these communities. (Shulman, 2010)

"Because it is such a devastating diagnosis, women (in some sub-Saharan African countries) feel that they cannot let anyone know that they have cancer, isolating them from help and support from friends and family. The stigma is so high that women stay under the radar. By the time they come out, the breast is fungating and smelling, leading to them being ostracized from society furthering hindering them from getting help at the time they need it the most."

Dr. Olufunmilayo Olopade, Director of the Center for Clinical Cancer Genetics, University of Chicago, 2015
Enhanced media attention (traditional and online) towards mBC has the potential to shape public perceptions and create a supportive environment for mBC patients

The availability of accurate, relevant information on mBC is essential to create a uniform cultural understanding of the disease, that will in turn help stimulate a sense of community and provide a supportive environment for mBC patients. Currently, there is a lack of specific, robust public information from sources felt to be trusted. Globally, less than half of the general population feels that reliable information on advanced or metastatic BC is easy to access (Figure 2.4). (mBC General Population Survey, Pfizer, 2015) Perhaps reflective of this lack of available information, a US survey highlighted that 61% of the general population knew little to nothing about mBC. (A Story Half Told, Pfizer, 2014)

When considering specific information sources, those surveyed receive information on breast cancer through traditional media (TV, radio, newspapers etc.) as well as the internet; and approximately a third of participants rely on charitable organizations to provide relevant information. (mBC General Population Survey, Pfizer, 2015)

Given the reliance on media as a source of mBC information, a deeper analysis of media coverage on mBC was conducted. The analysis began with assessment of two core articles reporting on the role of media (The BRIDGE survey, 2009 and Cancer and the Media Report, Fishman, 2010) The BRIDGE survey results revealed that over 50% of patients felt that BC received too little public attention; 73% of those surveyed wanted increased public awareness of mBC, including a greater level of media attention for people living with the disease (60 %) and more recognition of public figures with the disease (55%). (BRIDGE Metastatic Breast Cancer Patient Survey, 2010)

Figure 2.4
Access to reliable information on aBC/mBC
mBC General Population Survey, Pfizer, 2015

(% Easy/Very Easy)

<table>
<thead>
<tr>
<th>Country</th>
<th>UK</th>
<th>France</th>
<th>Germany</th>
<th>Poland</th>
<th>Turkey</th>
<th>India</th>
<th>Taiwan</th>
<th>Japan</th>
<th>South Africa</th>
<th>Brazil</th>
<th>Mexico</th>
<th>Argentina</th>
<th>Chile</th>
<th>Columbia</th>
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<tbody>
<tr>
<td>% Easy/Very</td>
<td>42%</td>
<td>45%</td>
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<td>43%</td>
<td>45%</td>
<td>26%</td>
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A 2010 analysis of news reports from the US highlight the limited focus on mBC; only 13.1% of 436 articles reported that aggressive cancer treatments can fail to cure or extend life, or that certain cancers are incurable (Fishman, 2010). Reports on cancer treatments and outcomes have included information on aggressive treatment options and patient survival, with seemingly little focus or discussion on the prognosis and treatment outcomes for late-stage cancers or terminal diagnoses, such as mBC. (Fishman, 2010). This may have portrayed a view of treatment for advanced disease that is inappropriately optimistic, leading to an unrealistic perception of the mBC patient experience. Furthermore, articles rarely discussed treatment side effects, such as neuropathy, pain, hair loss and nausea, which are common to cancer treatments. (Fishman, 2010).

Since these findings were reported in 2010, some progress has been made in increasing public exposure to mBC. To compliment these surveys, an analysis of yearly distribution of collected newspaper articles and newswires between 2006 and 2014 was conducted (see Appendix 2.1).

**Methodology:** In order to gain an understanding of public exposure to information on mBC, a qualitative literature review was conducted using secondary source data restricted between the years of 2005 to 2015 from LexisNexis®. Key word searches were conducted in LexisNexis® and were restricted to the years of 2005-2015 resulting in 998 abstracts. A standard TF-IDF text mining method was used to assign weight to the word stems identified in each article. Initial text mining analyses rendered 13,824 word stems covering a broad range of subject areas. For the year 2005, data gaps existed within LexisNexis® and only limited results were found, therefore data from 2005 was omitted from the analysis. In addition, the time of analysis (June 2015) resulted in only 6 months of data for 2015, this year was therefore also omitted from the analysis as it was not representative of a complete year. Please see Appendix 2.1 for detailed methodology.

This analysis indicates that public exposure to messages regarding mBC has been increasing steadily over time (Figure 2.5).

**Figure 2.5**

**Yearly Distribution of Newspaper Articles and Newswires on mBC Collected from 2006 through 2014**

Research from Appendix 2.1
Further analysis of the media coverage on mBC (See Appendix 2.1) shows that the majority of mBC media content focuses on treatments, safety, efficacy and clinical studies (Figure 2.6); the volume of such content has increased slowly with time. Treatment guidelines and quality standards receive less media coverage compared with articles on specific therapies; however, since 2009, there has been an increase in media reports focusing on pain and suffering in the context of mBC (Figure 2.7) - this is a small but important step forwards in raising awareness.

In the time period of the media analysis conducted for mBC, several milestones have occurred that could have contributed to the increase in media coverage and built a positive momentum (Figure 2.8). These efforts have focused on the unique challenges that mBC patients face.
Contrary to what we often hear, death from breast cancer strikes all ages... from teens upward... This disease deserves strong public attention. It is not a disease of the elderly. It takes too many lives in their prime.

*Dian Corneliussen-James, Co-Founder, President, and Director of Advocacy, METAivor Research & Support, 2015*
Although these milestones represent a step forward for mBC, further efforts are required. Most of these activities have been restricted to North America and Europe. Public understanding of mBC remains limited (mBC General Population Survey, Pfizer, 2015, A Story Half Told, Pfizer, 2014); many mBC patients still experience isolation and stigma (MBC Alliance, 2014). Though mBC Awareness Day has brought more focus on mBC, it is one day in an entire month devoted to breast cancer where the emphasis remains on early-stage breast cancer and the need for self-examination and early detection. (National Breast Cancer Foundation, 2015) Further analysis is needed to understand the proportion of media coverage on mBC relative to overall breast cancer media coverage. Even if mBC coverage increases in absolute terms the impact of this difference may be limited if it remains a small fraction of the total media coverage for BC.

Honest, realistic and accurate representation in the media of the experience and outcomes of patients with mBC may enable the wider community to better support both patients and their caregivers. The communication of accurate information is essential in building a shared sense of empathy between patients with breast cancer, regardless of disease stage, as well as with the general public, and is especially important in destigmatizing metastatic disease. Charitable organizations and patient groups provide mBC patients with a global ‘voice’ through the sharing of personal stories and educational materials, which can contribute to enhanced public understanding of the disease and help reduce the isolation experienced by these patients.

In October 2015, the US based Metastatic Breast Cancer Alliance launched a social media campaign featuring real patients, #MetastaticSayIt, to educate the public about mBC. (MBC Alliance, 2015) More such efforts are needed across the world to highlight the mBC patient experience, within the appropriate cultural and social context.

Increased media coverage may mobilize public engagement and in turn help spur action amidst policymakers to advance the priorities for mBC. As an example, global research indicates that the extensive media coverage of AIDS and the gaping unmet need for treatments garnered the FDA to seek improved approval processes for these drugs, indicating that public engagement was a driving force to place AIDS treatments on the FDA priority list. (Carpenter, 2002)

Information presented in traditional and social media does influence public perception. However, not all available sources of information are evidence based and misinterpretation is possible. As such, information must be robustly supported by credible data, and communicated in a clear and consistent tone, to effect change in the perception of mBC.

“I think most people don’t want to know about metastatic disease because it’s scary.”

North American Respondent, mBC PSO Survey, Pfizer, 2015
Cultural perspectives impact the public understanding of mBC and associated health related behaviors

“People would rather have AIDS than cancer, they know that they can survive AIDS but do not think they can survive cancer… in Zambia, cancer equals death.”

Udie Soko, Co-founder and Executive Director at the Zambian Cancer Society, Zambia, 2015

Similarly, in South Africa, there is a reluctance to present with breast cancer symptoms and undergo physical examinations. There is a perceived invasion of privacy associated with the examination, due in part to the social opinion that private areas of the body should not be discussed. (LIVESTRONG Report, Beckjord, 2012)

In Pakistan, women with mBC often delayed telling their family that they had found a breast lump until it caused them significant pain and anxiety. (Banning, 2009) In Pakistan and Nepal, there is a widely held belief that breast cancer is a communicable disease that can be contracted by touch or contamination. This results in women concealing their diagnosis from their families and spouses, with some opting not to seek care at all. (Banning, 2012; Bhatt, 2011) This level of stigma associated with the disease not only has a negative impact on diagnosis and treatment, but also creates a heavy psychosocial burden on these women.

There is a division between those countries where discussion of the breast is permissible and those where it is not. Those countries, where communication around breast health and breast cancer is more acceptable, demonstrate an evolution in societal norms and culture over time. This evolution reflects ‘normalization’ of breast cancer through repeated communications. However, it is still necessary to minimize ongoing reluctance to communicate and educate about mBC. It is important to use sustainable community-based avenues, such as community health workers, women’s groups, churches, and health facilities to successfully reach women outside of urban areas where women have greater access to education. (Multhoni, 2010; Ford, 2003; Fernandez, 2009) Charities, such as the Uganda Women’s Cancer Support Organization (UWOCASO) aim to raise breast cancer awareness to give such a voice to Ugandan cancer survivors. (UWOCASO, 2015)
The use of fear-based messages is unlikely to motivate women to undertake early detection, and instead may intensify their anxiety about the disease (Cancer World, 2013). However a recognition of the severity of breast cancer could be beneficial if it brings about a reduction in stigma and reluctance to communicate about advanced-stage disease. (Cancer World, 2013)

Irrespective of socio-economic status, stigma unfortunately still exists for patients with mBC. More work must be done to help alleviate the burden of stigma on patients and ensure broader, community-wide support for patients with mBC to live with their disease.

“In some African countries, people did not even have a word for breast cancer. They did not know what breast cancer was…physicians would always diagnose infectious diseases first before they said the word cancer because it was not in their [vocabulary]. Since then, there has been increased awareness.”

Dr. Olufunmilayo Olopade, Director of the Center for Clinical Cancer Genetics, University of Chicago, 2015
Chapter 2: The Impact of Patient Support and Advocacy Organizations in mBC

- A number of Patient Support Organizations (PSOs) have begun to focus more attention on supporting patients with mBC in recent years
- PSOs consider the hierarchical order of needs to be similar between eBC and mBC patients; however, they acknowledge the greater level of support needed for mBC patients
- PSOs spend a lower proportion of efforts on mBC due to several factors including limited resources, perception of relative size of mBC patient population, local needs, logistical and cultural barriers in accessing mBC patients
- Patient advocacy efforts in influencing health policy for breast cancer vary by region
- Peer support networks offered by PSOs are particularly important to mBC patients, but often challenging to implement

In this report the term Patient Support Organization (PSO) is used to describe organizations that offer a range of services to support patients directly (e.g. peer support groups, education, information), and/or advocate on their behalf to advance patient care, including policy changes, public education and raising research funding. PSOs are typically charitable or non-profit organizations and may differ widely in scope of operations. PSOs operate in many countries and strive to meet the needs they consider to be the highest priority to the patients and caregivers in their communities. (mBC Patient Support Organization Survey, Pfizer, 2015)

Patient Support Organizations (PSOs) play a vital role in supporting breast cancer patients and their families, providing a wide range of services to meet their evolving needs. (A Story Half Told, Pfizer, 2014) Collaborations developed by PSOs have helped to drive common agendas and initiatives to support the mBC community. Such collaborations include the Metastatic Breast Cancer Alliance in the US and the pan-European organization, Europa Donna, which offers specialist 'sub-groups' to address the unique needs of women with mBC. (mBC Alliance, 2014; europadonna.org; Metastatic Breast Cancer: Focus for Advocacy, Europa Donna, 2014)

Based on new primary research encouraging trends can be seen in the levels of support and advocacy for patients with mBC, however global variation exists. Although it is recognized that there continue to be issues surrounding appropriate and effective support for patients with mBC, some PSOs have employed concerted efforts in driving change and improvements have been made. In a 2014 survey conducted by a PSO with 17 of its mBC patient members, 11 said that they felt their local breast cancer support or advocacy group adequately met their needs for information and support. Despite a small representation of patients, this was recognized as an improvement on past surveys where a majority had not felt appropriately supported. (Metastatic Breast Cancer: Focus for Advocacy, Europa Donna, 2014)
**Methodology:** To improve understanding of the perceived needs of mBC patients, and the activities and contribution by PSOs in meeting these needs, a qualitative primary research project was commissioned by Pfizer, that included 50 in-depth telephone interviews, each 45-60 minutes in length (some were face-to-face interviews) with key members of PSOs. The countries included were Canada, US, Belgium, France, Germany, Greece, Ireland, Italy, Poland, Spain, Turkey, UK, Australia, China, Japan, South Korea, Argentina, Brazil, Colombia, Costa Rica, Dominican Republic, Mexico, Egypt, Kenya, Rwanda, Saudi Arabia, Uganda, and Zambia.

Respondents were PSO leaders (CEOs, Presidents, Directors, etc.) of charitable and non-profit organizations that focus on mBC, breast cancer, and/or cancer on a local, national, and global level. They were selected to participate in the survey on the basis of their strategic and/or program responsibilities and their involvement in directing, developing, and/or managing health education, outreach, evaluation, and/or outcomes for their organization. On average, the tenure of respondents within a specific PSO is 8 years, with a range of 1 to 20+ years.

The surveyed PSOs vary greatly in size, with the number of employees and volunteers ranging from 2 to 1500+; the average staff size was under 20. The number of years surveyed PSOs have been supporting the needs of the breast cancer community also vary, ranging from 1 to 50+ years with an average of 11.5 years. (mBC Patient Support Organization Survey, Pfizer, 2015)

Research was conducted from June 15, 2015–August 3, 2015
Generally, PSOs consider that relative to one another, eBC and mBC patient needs are similar. This is reflected by consistency in the hierarchical order of needs for both eBC and mBC patients. However, the extent of those needs does differ between early and metastatic disease. PSOs report that patients with mBC have much greater need in terms of psychological support, financial support and access to services, compared with those patients who have earlier stage disease. Although not spontaneously mentioned by many PSOs, some respondents acknowledge additional end of life (EOL) planning needs. While stage (especially eBC vs. mBC) is an important driver of needs, other factors also shape this; one crucial differentiator highlighted was de novo vs recurrent diagnosis of mBC. Others include diversity of patients in terms of personality, desire for information, and course of illness. (mBC Patient Organization Survey, Pfizer, 2015).

While acknowledging the needs of mBC patients, PSOs report that a lower proportion of their efforts are directed towards mBC within BC overall. A range of barriers impact PSOs ability to meet patient needs, especially in mBC; these include; limited resources, perspective on mBC needs, cultural factors, and logistics.

PSOs report that the proportion of funding between eBC and mBC is often dictated by the size of the patient population. PSOs perceive mBC as a smaller patient population and it therefore receives a proportionately smaller share of support. This perception of PSOs is challenged by the reality that in some parts of the world, such as developing countries,

50-80% of patients are being diagnosed with advanced disease. (Unger-Saldana, 2014)

PSO services specifically focused on mBC patients are not only dependent on the available funding, but also on local need and therefore regional variation in provision of support services can be seen (Figure 2.10). Awareness and education is frequently offered to both general BC and mBC patient populations, however awareness, though among the top services provided, is relatively less frequently offered for mBC. Most PSOs surveyed reported that they offer peer support for mBC patients. In North America, peer support is offered to the general BC population by approximately 50-75% of PSOs; however, this is not a frequently offered support service for mBC patients. (mBC Patient Support Organization Survey, Pfizer, 2015)

“"The women who are living with metastatic breast cancer are getting 100% of our programs, but the numbers are smaller. If we have 4500 callers and peer supporters, maybe we are talking about 70 women [who are mBC patients].”"

North American Respondent, mBC PSO Survey, Pfizer, 2015
One way for PSOs to effectively support the mBC population is in the specialization of services; a “complete, don’t compete” approach is taken, that yields complementary services rather than those that compete against other organizations. Each organization can vary in size, scope, reach, and mission, and as such the goal of overcoming barriers to meeting mBC needs should not be pursued at the expense of making PSOs homogeneous. (mBC Patient Support Organization Survey, Pfizer, 2015)

“If there are other organizations doing [something], we’re not going to recreate the wheel. We’d rather just direct them to other organizations that are… the best fit for their needs.”

North American Respondent, mBC PSO Survey, Pfizer, 2015

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### Most Frequent Activities Provided to Support Patients with mBC

**mBC Patient Support Organization Survey, Pfizer, 2015**

<table>
<thead>
<tr>
<th>Activities Engaged in to support mBC</th>
<th>US and Canada (n=11)</th>
<th>Europe (n=14)</th>
<th>Asia Pacific (n=7)</th>
<th>Latin America (n=10)</th>
<th>Africa and Middle East (n=8)</th>
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<tbody>
<tr>
<td>Awareness</td>
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<td>Patient Education</td>
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<td>Treatment Education</td>
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<td>Access Advocacy</td>
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<td>Peer Support</td>
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<td>Supporting Pts to Become Adv.</td>
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<tr>
<td>Policy Advocacy</td>
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<tr>
<td>Financial</td>
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<td>Data Generation</td>
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<td>Clinical Trials/Registries</td>
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<td>Regulatory</td>
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<tr>
<td>Legal</td>
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<tr>
<td>Funding Scientific Research</td>
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</table>

This table represents the most frequently provided services only. Activities not highlighted are still offered across regions based on survey responses with the exception of policy and regulatory support in Asia/Australia and funding for scientific research in the Africa/Middle East region. The criteria for which activities are classified as ‘most frequent’ varies by region.
Peer support networks offered by PSOs are particularly important to mBC patients, but often challenging to implement.

“There are many women who have to face the disease again as recurrent or with metastases in another part of the body. If they have a recurrence, we just lose them. We don’t know where they are. They feel that they are not the ‘winners’ anymore, so they withdraw from the whole group.”

*European Respondent, mBC PSO Survey, Pfizer, 2015*

One of the key services that PSOs provide BC patients is peer support networks. For mBC patients, peer support is of particular importance in the context of the emotional challenges and social isolation they experience, outlined in Section 1: Patient Care Perspectives. Evidence demonstrates that online support groups offer women with mBC the feeling of being supported by one another, even though they may not have met face-to-face. Online support groups also served as a place for information exchange, making women more active in their treatment decisions, and reducing ambiguity about new symptoms. Group cohesiveness benefits were seen in the women. Peer support groups directly alleviated their anxiety, helped them gain better medical care, reduced their need for social support, and increased their openness to others. Participation in such peer networks also reduced the sense of isolation that women feel, as they often feel partners, friends, and relatives are not able to completely understand what they are going through. (Vilhauer, 2009)

Studies have shown that stage-specific groups are more helpful to women with mBC than mixed-stage groups (ie those that include both eBC and mBC patients), also seen via online support groups. (Vilhauer, 2009; Vilhauer, 2011) This is often because of the unique experiences a patient with mBC is living through; mBC onset (de novo vs. recurrent), progression (indolent vs aggressive), symptoms experienced, and treatment goals are all individualized to a greater extent vs. eBC patients. Some PSOs also reported that eBC patients were reluctant to be in the same peer groups as mBC patients. (mBC Patient Organization Survey, Pfizer, 2015)

“Up until now [with the eBC patients] we were trying to break the stereotype or notion that ‘breast cancer means death.’ It took us a lot of time to deal with that. When it comes to metastases, everything is going back to the beginning—patients hear ‘metastases’ and they think it means painful death. That’s the way people here think about metastases.”

*European Respondent, mBC PSO Survey, Pfizer, 2015*

Despite the rationale and clear benefit of providing peer support for mBC patients, PSOs admit that true peer support is difficult to achieve. Barriers include a reluctance by mBC patients to participate, patients do not wish to build their identity primarily on mBC, and they may become less active overall. In addition mBC peer group members may find it traumatizing if their mBC peers progress or pass away. (mBC Patient Organization Survey, Pfizer, 2015)

“We are shutting down [our mBC group] after 7 years….because it is too painful when someone dies.”

*North American Respondent, mBC PSO Survey, Pfizer, 2015*
Patient advocacy efforts in influencing health policy for breast cancer vary by region

Patient advocacy can also have a significant influence on policy decision-making. (Lerner, 2002) In high-income countries, improvements in breast cancer care have been achieved as a result of efforts by patients and their supporters, as well as survivors, the healthcare industry and media. (UICC, Planning Comprehensive Breast Cancer Programs) In countries where patient advocacy groups devote attention to breast cancer, these efforts have successfully increased awareness of mBC and contributed to increased access to cancer screening, diagnosis, and treatment. (Here & Now, Novartis, 2013)

PSOs are involved in the development of health policy at both the local and national level. This involvement includes increasing policy-maker awareness of patient and caregiver needs through educational programs, receptions, and one-to-one meetings with specific government officials.

In the US, the National Breast Cancer Coalition (NBCC) launched ‘Breast Cancer Deadline 2020 - a call to action for policymakers, researchers, breast cancer advocates and other stakeholders to know how to end the disease by 2020.’ (Breast Cancer Deadline 2020) In Europe, Europa Donna is actively engaged in advocating for the European Parliament Written Declaration of Breast Cancer and other national parliamentary lobbying projects in EU member countries to raise awareness of the needs of mBC patients in policy and in BC guidelines. (EuropaDonna.org)

Provision of policy advocacy services by PSOs also varies according to region (Figure 2.11). When comparing the perceived needs of mBC patients and the reported PSO activities, policy was identified by PSOs as an area where there is a gap in activity in most regions. (mBC Patient Organization Survey, Pfizer, 2015)

Figure 2.11
PSO Provision of Policy Advocacy Services by Region

<table>
<thead>
<tr>
<th>Region</th>
<th>BC general</th>
<th>mBC specific</th>
</tr>
</thead>
<tbody>
<tr>
<td>North America</td>
<td>82%</td>
<td>45%</td>
</tr>
<tr>
<td>EU</td>
<td>86%</td>
<td>57%</td>
</tr>
<tr>
<td>Latin America</td>
<td>70%</td>
<td>70%</td>
</tr>
<tr>
<td>Africa/Middle East</td>
<td>29%</td>
<td>0%</td>
</tr>
<tr>
<td>Asia/Australia</td>
<td>75%</td>
<td>38%</td>
</tr>
</tbody>
</table>

The PSO advocacy efforts to influence health policy are tailored to region-specific or local challenges. In developing countries such as Africa, PSOs need to address basic infrastructural issues, such as access to radiotherapy and pain medications before specific mBC issues are approached.

When comparing the perceived needs of mBC patients and the reported PSO activities, policy was identified by PSOs as an area where there is a gap in activity. (mBC Patient Organization Survey, Pfizer, 2015)
Many PSOs are actively involved in supporting access to cancer medications and reimbursement coverage for all necessary tests and treatments. 

Many PSOs list “making the patient voice heard” as one of their principal goals (mBC Patient Organization Survey, Pfizer 2015). Despite being a key area of focus for many PSOs, creating opportunities for the elevation and vocalization of the patient voice to policy makers can be challenging, especially in low- and middle-income countries. Instability in the political infrastructure, a lack of fiscal or human resources available to lead advocacy efforts, socioeconomic or educational status can limit an individual’s ability to effectively advocate for themselves or others. (UICC, Planning Comprehensive Breast Cancer Programs) However, effective mBC advocacy is possible in low- and middle-income countries. For example, in Nigeria, a campaign was conducted to raise awareness at all levels of government, of the need to subsidize cancer treatment as a strategy to reduce the incidence of mBC. (Adisa, 2011)

A multi-stakeholder approach to developing advocacy efforts has demonstrated impact in raising awareness of breast cancer in high income countries. (UICC, Planning Comprehensive Breast Cancer Programs) Learnings can be taken from coordinated approaches to help guide policy makers towards implementing change. (UICC, Planning Comprehensive Breast Cancer Programs)

PSOs play a critical role in defining the mBC patient experience. While it is encouraging that progress has been made, and PSOs recognize the unique needs of mBC patients, barriers to providing optimal support remain. Through achieving a better understanding of the current disease state and the role of PSOs, further progress in the provision of tailored and compassionate support to mBC patients can be made.

“The goal of many PSOs is to make sure that the voices of women living with metastatic BC are heard during Breast Cancer Awareness Month because so much is going on and most of it relates to early-stage: ‘Let’s look for a cure.’ ‘Treatment is better.’ ‘Diagnosis is better.’ But there’s still a large number [of patients] who are becoming metastatic.”

North American Respondent, mBC PSO Survey, Pfizer, 2015
Emerging Recommendations

While negative perception and misunderstanding around mBC exists globally, approaches and strategies to address this will vary depending on each country and its resources. There are opportunities to drive change through improved education and awareness across both the general public and PSOs. These emerging recommendations focus heavily on changing the perception of mBC, prioritizing the unique needs of mBC patients and addressing these with tailored solutions. These recommendations need to be solidified through further dialogue and will require long term commitment across a broad range of stakeholders to see effective change for mBC patients across the world. In addition, further opportunities for action will emerge based on ongoing analysis of the policy and economic landscape as well as societal perspectives on mBC.

**Investment in education campaigns and outreach strategies is needed to grow awareness and action around mBC, in the same way that has been done for eBC**

- It is necessary to educate not only patients, caregivers and healthcare professionals, but the donor community, general public journalists, government officials and other key stakeholders, in order to harness a successful advocacy movement
- Emphasize with PSOs specifically the great need for long-term and often increasing assistance for mBC patients
- In limited-resource countries, appropriate advocacy and education should focus government attention on the growing burden of breast cancer including the untimely deaths due to mBC, and highlight the need for increasing national focus. (Koon 2013)

**Advanced widespread global awareness of mBC, with honest and accurate presentation of the realistic experience of patients, enabling the wider community to better support both patients and their caregivers in managing the impact of mBC on their lives**

- Encourage public figures with mBC to share their experiences, similar to what has been seen for eBC
- Provide mBC with a distinct identity separate from eBC - Leverage mBC day globally beyond the current geographies and potential expand to a longer duration than just a day

**Increased global access and availability of PSO support services specific to mBC**

- Development of more mBC-specific support services is critical with an increased emphasis on impact to patients families, especially for younger women
- Increase proactive communication highlighting specific support services, including counseling and online support groups.
- Increase global accessibility to support services for all patients with mBC

**Development of a global mBC alliance for advocacy, replicating some of the successes seen by organizations such as the US mBC Alliance**

- Provide a platform for advocates to educate each other on how to use stories, messages, the media, and social media to transform their society’s understanding of mBC
- Collectively drive the need for access to treatments and palliative care, and for research on mBC
- Develop a brief for patient support organizations to drive consistency of communication about mBC
Empower media (both traditional and social) to deliver tailored, evidence based approaches to mBC communication and education

- Engage key global experts to directly educate the media about mBC care globally and the need to drive change
- Utilize traditional media to guide the general public to appropriate sources of mBC information
- Develop a reporting brief for the media about best practice in reporting mBC and advanced cancer generally
Appendices and References

Section 2: Appendix 2.1
Public Understanding Literature Search (July 2015)

Purpose: The purpose of this search was to gain an understanding of the public perception of metastatic breast cancer and its potential impact on the patient experience, a literature review was conducted of media and newswire sources.

Method: For this search, we used a systematic search methodology in order to mitigate the risk of missing relevant content by incorporating all perspectives and by including content from trusted and revered sources.

Sources: In order to gain an understanding in the mBC societal experience, a qualitative literature review was conducted using secondary source data restricted between the years of 2005 to 2015 from Lexus Nexis.

Search Terms:

<table>
<thead>
<tr>
<th>Category</th>
<th>Key Terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease</td>
<td>MBC OR “metastatic breast cancer”, “stage four” OR “stage 4” OR “stage IV”, LABC OR “locally advanced breast cancer”, ABC OR “advanced breast cancer”, HER2+ OR “HER2 positive” OR HER2-positive, HER2- OR “HER2 negative” OR HER2-negative, ER+ OR “estrogen receptor positive”, ER- OR “estrogen receptor negative”, ER OR “estrogen receptor”, “Hormone receptor negative”, “Hormone receptor positive”, ER+/HER2+ OR HER3+/ER+, ER+/HER2- OR HER2-/ER+, ER-/HER2+ OR HER2+/ER-, “pre menopausal” OR pre-menopausal, premenopausal, “post menopausal” OR post-menopausal, postmenopausal, “secondary breast cancer”, TNBC OR “triple negative breast cancer” OR ER-/HER- OR HER2-/ER-</td>
</tr>
</tbody>
</table>
### Search Terms:

<table>
<thead>
<tr>
<th>Category</th>
<th>Key Terms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Outcome Measure</strong></td>
<td>OS OR &quot;Overall survival&quot;, “survival rate”, PFS OR “Progression free survival”, “TTP” OR time to progression</td>
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<tr>
<td><strong>Trial</strong></td>
<td>“Phase I” OR “Phase 1” OR P1, “Phase II” OR “Phase 2” OR P2, “Phase III” OR “Phase 3” OR P3, “Phase IV” OR Phase 4” OR P4, “comparative effectiveness” OR “head-to-head” OR “head to head”</td>
</tr>
<tr>
<td><strong>Metastases</strong></td>
<td>“Brain metastases” OR “central nervous system metastases” OR “nervous system metastases” OR “CNS metastases” OR brain, “Liver metastases” OR Liver, “Skin metastases” OR “Epithelial metastases” OR Skin, “bone metastases” OR bone</td>
</tr>
<tr>
<td><strong>Patient Reported Outcome</strong></td>
<td>“Patient reported outcomes” OR PRO OR “patient-reported outcomes”, Efficacy</td>
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<tr>
<td><strong>Tolerability</strong></td>
<td>Tolerance OR Tolerability</td>
</tr>
<tr>
<td><strong>Side Effects</strong></td>
<td>“adverse effect” OR “adverse effects” OR “adverse reaction” OR “Adverse events” OR AE OR Aes OR PSE OR “Patient safety event” OR “side effects” OR SE OR “adverse reaction” OR “adverse drug reaction” OR “unexpected adverse drug reaction” OR “other adverse event” OR OAE”, drug-drug interaction” OR DDI, toxicity</td>
</tr>
<tr>
<td><strong>Value</strong></td>
<td>“cost effectiveness” OR “Cost effective,” OR “cost-effectiveness,” OR “beneficial value” OR “QALY” OR “economic value”, “value” OR “risk benefit”, Cost, efficiency OR “cost efficiency”</td>
</tr>
<tr>
<td><strong>Social</strong></td>
<td>discrimination OR prejudice, employment OR fired, insurance OR coverage OR reimbursement OR uninsured OR “employer-sponsored insurance” OR “employer sponsored insurance”, “family support” OR support OR family OR burden OR “family impact”, “in-home care” OR “in home care” OR “hospital care” OR hospital OR in-patient OR “in patient” OR “hospice care” OR “hospice”, prescription OR refill OR medication OR drug, “daily routine” OR lifestyle OR “daily activities”, Caregiver, “quality of life” OR QoL OR HRQoL OR “health-related quality of life”, Advocacy, Legislation, Awareness, “patient education”, “cancer fund”, “government aide”, “NGO”</td>
</tr>
<tr>
<td><strong>Country</strong></td>
<td>All country members of the United Nations</td>
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</table>
Results: Standard text mining method, TF-IDF approach, was used to assign weight to the word stems identified in each article. All media extractions are tokenized, non-letters removed, and stemmed to reduce complexity. Initial text mining analyses rendered 13,824 word stems covering a broad range of subject areas ranging from treatment to spiritual terms such as “god”. Key word searches were conducted in Lexus Nexis and were restricted to the years of 2005-2015 resulting in 998 abstracts. To review the trends of the selected terms, an analysis was performed using a modified version of the “bag-of-words” text mining concept. This method searches for binary outputs of absence or presence by disregarding word order and grammar. To perform this analysis abstract content all punctuation except for +, - and / was replaced with a space and content was scanned using the selected key terms. Results were marked with a “1” or “0” respectively if a term was present or absent.

Limitations: Despite this systematic approach, limitations to this search methodology exist. Specifically, articles irrelevant for this chapter might have appeared in the search through selected search terms being used in different contexts. For example, if the search term was “metastatic breast cancer,” non-“metastatic breast cancer” could also appear. To account for this challenge, each abstract was reviewed to determine relevance and inclusion criteria. In addition, there is a potential risk of missing articles due the fact that our research was restricted to newspaper articles only.
Section 2 References


Beishon M. Approval rating: how do the EMA and FDA compare? *Cancer World.* 2014;58:12-17. (Belshon, 2014)


Breast Cancer Center Survey, commissioned by Pfizer. August 2015. (Breast Cancer Center Survey, Pfizer, 2015)


EBCTCG. CTSU: Clinical Trial Service Unit and Epidemiology Studies Unit. http://www.ctsu.ox.ac.uk/research/meta-trials/ebctcg/. Accessed October 31, 2015. (EBCTCG.org)

Eichholz M, Pevar J, Bernthal T. Perspectives on the financial burden of cancer care: Concurrent surveys of patients (Pts), caregivers (CGs), and oncology social workers (OSWs). J Clin Oncol. 2010;28(suppl):abstract 9111. (Eichholz, 2010)


Inside Vandy: Vanderbilt University. 10.2.2013. Newspaper. (Inside Vandy, Vanderbilt University, 2013)


