

# Section 2

## Policy, Society and Community Impact



# Introduction

In reviewing the status of the metastatic breast cancer (mBC) landscape, through a truly holistic lens, consideration of the societal 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 political, societal and community factors that influence the mBC landscape.

As outlined in the introduction to this report, research into the policy, society and community impact has been designed to broadly assess the current status of mBC. Five core areas have been researched: Impact of mBC on Caregivers and Social Relationships, Workplace Perspectives, Policy Perspectives & Economic Burden, Societal Experience & Public Understanding, and the Impact of Patient Support and Advocacy Organizations in mBC.



Left to right: mBC patients Jen Sturtevant Meus, "CJ" (Dian) Corneliussen-James and Marlene King. Jen Sturtevant Meus, deceased. CJ was diagnosed in 2006. Both she and Marlene are living with the disease.

This section of the report shares key findings from primary research conducted in 2015 (methodologies are outlined in each chapter), it includes:

- **Health Policy of mBC**
- **Economic Burden of mBC**
- **Public Understanding of mBC**
- **The Impact of Patient Support and Advocacy Organizations (PSOs)**
- **Workplace Perspectives in mBC**
- **The Impact of mBC on Patient Social Relationships and Caregivers**

Research describing the complex relationship between support and coping with cancer is discussed in the *The Impact of mBC on Patient Social Relationships and Caregivers* chapter. Patient and caregiver experiences are



detailed, using their own voices, to determine key themes and ongoing unmet needs in this regard.

Work remains important and relevant to patients with mBC. In many countries around the world, but not universally, patients with cancer are protected from discrimination in the workplace and are entitled to ask for reasonable accommodations to be able to fulfill their job roles. Despite this, evidence of discrimination exists. Data discussing critical factors which support return to work are discussed in the *Workplace Perspectives for mBC Patients* chapter.

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.



# Chapter 1: Health Policy for mBC

- Health policy has a far reaching impact on mBC care; development is shaped by numerous factors and many different perspectives
- There are important differences in cancer care performance between countries which can be attributed to differences in the health policy approach
- A national cancer plan (NCP) sets out a country's ambition to face the demands of cancer
  - Many countries do not yet have a published NCP. In these countries, much needs to be done to incorporate cancer control as a national priority before a focus on improving the care of those with breast cancer can be implemented
- Published plans tend to focus on prevention and screening; this will not address the needs of patients already diagnosed with mBC
- Government, professional societies, and patient support organizations have all played a critical role in developing health policy that has started to contribute to the better care of breast cancer patients, including mBC, over the last decade
- Policy decision makers are going to need to find ways to meet the rising burden of cancer as a whole and breast cancer in particular

The influence of health policy on the outcomes and experiences of patients with breast cancer, including mBC, is far reaching; most notably on access to the care and treatment that patients need. Priorities set by governments are shaped by numerous influences and can change the way that breast cancer care is delivered; in fact, public policy touches every aspect of breast cancer.

“Health policy refers to decisions, plans, and actions that are undertaken to achieve specific healthcare goals within a society. An explicit health policy can achieve several things: it defines a vision for the future which in turn helps to establish targets and points of reference for the short and medium term.” (WHO, Health Policy, 2015)



Before discussing health policy specifically in the context of breast cancer, it is helpful to understand the breadth of factors that influence decision-making at a population health level and how this impacts wider cancer health policy. As shown in Figure 2.1, numerous inter-related elements influence and shape the political and health policy environment which makes the healthcare landscape complicated for patients, practitioners and decision makers around the world to navigate.

Figure 2.1

### Factors Influencing Health Policy

Stevens, 1994

Population Healthcare Need	Demand for Services	Supply of Healthcare Services
Determinants of health	Media and publicity	Historical pattern
Effective technologies	Available technologies	Public and political pressure
Evidence	Health professionals	Evidence
Financial support	Social and educational influence	Cancer registries
		Resource limitations

The relevant perspectives that inform health policy creation are diverse and include; patients, healthcare professionals, budget holders, national and international organizations such as professional groups, society itself, and the government. To optimize management of a specific disease area for any patient, the factors influencing, driving, and shaping health policy must be explored at both a global and an individual country level.

### A Health policy has a critical role in improving cancer outcomes

It has been shown that successful health policy approaches lead to changes in the observed incidence, mortality and survival rates for individual cancers and, as a result, different policy approaches can be compared to identify those that create the greatest cancer health gains for any population of cancer patient. (OECD, 2013a) In an effort to answer the question “Do certain care policies lead to fewer deaths?”, the Secretary General of the Organization for Economic Co-operation and Development (OECD) reported the results of a study carried out in 35 countries to explore the policy trends in cancer care over a decade (2000 – 2009). (OECD, 2013a) The study found that there are important differences in cancer care performance between OECD countries which can be attributed to differences in the health policy approach in 3 main aspects of care:

- Access to resources including infrastructure, personnel and medicines
- Patient care practices including access to evidence-based care
- Governance including the development of national cancer plans

Of particular note, the report highlighted that breast cancer mortality declined across all OECD countries over the time period covered by the study. While the changes in outcomes are covered in detail in Section 3: *Scientific Landscape*, from a policy perspective, facilitation of early detection and access to treatments contributed to the observed decrease in breast cancer-related deaths. (OECD 2013a)



**Methodology:** Secondary research was undertaken; examining national cancer plans (NCPs) included on the European Partnership Action Against Cancer (EPAAC) website (<http://www.epaac.eu/national-cancer-plans>) and the World Health Organization (WHO) website (<http://www.who.int/cancer/nccp/en/>). While these sites are not comprehensive of all countries, this allowed for a high-level assessment of cancer plans around the world. Included in this review was an evaluation of the most recent (2014) NCPs for 25 countries in the European Union (EU) and 4 additional ex-EU countries (Austria, Belgium, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Slovenia, Spain, Sweden, United Kingdom, Colombia, India, South Korea, and South Australia (a southern state in Australia, as the health system is divided into regions)). All are accessible via <http://www.iccp-portal.org/cancer-plans>.

Increasingly, countries have set out their broad ambition to face the demands of cancer through a national cancer plan (NCP). The NCP is a public health program designed to reduce cancer incidence, morbidity, and mortality through “the systematic and equitable implementation of evidence-based strategies for: prevention, early detection, diagnosis, treatment, rehabilitation, palliation and research to search for innovative solutions and evaluate outcomes.” (EPAAC) The plan’s design aims to make the best use of available resources, promoting the most cost-effective measures that create the greatest benefit to the majority of the population. (EPAAC) The first plan was published in Germany in 1979 and, since then, NCPs have become increasingly prominent in many countries around the world. (OECD, 2013a) Even in high income countries, national targets captured within NCPs have traditionally focused more heavily on prevention and screening. However trends show that NCP targets are now maturing to include a broader focus on treatment, patient education and aftercare. (OECD, 2013a)

Across the 29 cancer plans reviewed in detail, the United Kingdom referred to mBC specifically. This NCP explicitly noted that a data gap existed regarding the proportion of breast cancer patients who had mBC. This in turn negatively impacted the national health systems ability to effectively plan for services. The cancer plan set out clear targets on a new approach to data collection in order to capture this information; with a stated aim to inform the collection of information on other types of metastatic cancer. (Department of Health, 2011) Despite this positive influence, outcomes for people diagnosed with breast cancer in the UK are lagging behind other countries in Europe. (Allemani, 2015; Macmillan, 2015) This suggests that in reality there can be a disparity between what is recommended in the NCP and what is implemented.

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The allocation of financial resource is also an important component considered in the development of national health policy. Decisions about achieving greatest benefit for the greatest number of the population can be quantified by methods including cost effectiveness analysis. A cost effectiveness comparison highlighted the impact of early vs. late mBC diagnosis in Africa/Asia vs. North America. The disability-adjusted life year (DALYs) recorded in this analysis included accounting for societal perspectives, and clearly underscores the economic drivers in the current climate of encouraging early detection and prompt treatment of breast cancer (Figure 2.2). (Groot, 2006) However, there will always be a population of patients who either progress to, or present with mBC, for which there is no cure currently identified. Irrespective of geography, this analysis also shows that the costs associated with treating mBC effectively are far greater than those incurred whilst managing early stages of breast cancer. (Groot, 2006)



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Figure 2.2

### Cost Effectiveness Comparison of Treating Breast Cancer: Intervention Cost-Effectiveness by Breast Cancer Stage

Groot, 2006

Disease Stage	Disability-adjusted life year (DALY) averted	
	Africa/Asia	North America
Stage I,II or III	<\$390	\$6,550
Stage IV	>\$3500	\$70,400

The incremental cost-effective ratios (ICERs) suggest that the priorities for national breast-cancer-control programs in these countries should be prevention or treatment of early stage breast cancer whenever possible. Results also indicate the high costs of treating mBC effectively.

### **B** Over the last decade, global organizations and initiatives have been formed to shape breast cancer policy development and support national level implementation

In 2013 the World Health Organization (WHO) published its Global Action Plan for the prevention and control of non-communicable diseases (NCDs) which identified cancer control as one of the major priorities. (WHO, 2013) In some low- and middle-income countries, prominent public

health threats such as communicable diseases (eg, HIV, malaria) have caused the greatest pressure on governments. (Anderson, 2006) However, signatories to the global plan have committed to aim to achieve: (WHO, 2013)

- A 25% relative reduction in premature mortality from NCDs
- An 80% availability of affordable basic technologies and essential medicines

In a major step forward for mBC patients, the essential medicines list includes chemotherapy, hormonal, and HER2 targeted medicines that are considered core to the treatment of all 3 subtypes of mBC. (WHO, 2015b)

Moreover, the European Parliament, backed by EUROPA DONNA – The European Breast Cancer Coalition, adopted a written declaration “On the Fight Against Breast Cancer in the EU” in 2015. This statement followed previous Resolutions on Breast Cancer, (European Parliament, 2003; European Parliament, 2006) and committed that “those [with mBC] should have access to, and be treated in, a [specialist breast unit (SBU)], and their ongoing needs for care and psychosocial services should be coordinated and supported by the SBU.” (European Parliament, 2015) This builds on preliminary steps taken following the European Parliamentary declaration in 2010, which called for the European Commission to develop a framework for accreditation for SBUs by 2011. Debate amongst the medical profession about the need for specialist rather than generalist services for women with breast cancer, has been implicated in delays in implementation in some countries. (Knox, 2015) However, the 2015 declaration has reiterated the call to implement multidisciplinary SBU’s by 2016 and has been followed with a manifesto from the European Breast Cancer Council (EBCC) which demands action from the top - politicians and policy makers, and the bottom - grass roots patient advocacy and health care professionals, to drive through required changes to make this happen. (EBCC, 2015; European Parliament, 2015)



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In recognition of the need to drive policy development in breast cancer around the world, organizations such as the Breast Health Global Initiative (BHGI), Union for International Cancer Control (UICC), Pan American Health Organization (PAHO), and WHO have developed knowledge summaries and 'calls-to-action' that make economically and structurally feasible recommendations for the care of patients with breast cancer. (UICC, Planning comprehensive breast cancer programs; UICC, Improving access to breast cancer care) By considering these resource-stratified, structured recommendations, countries can plan for cancer care as a whole and, ultimately, improve their provision of care for those with breast cancer including for those with mBC.

These guidelines stress the need for identifying needs and barriers, setting goals for outcomes and quantifying resources. Critical success factors include following a resource-stratified pathway that addresses:

- Structural barriers
- Sociocultural barriers
- Personal barriers
- Financial barriers

Such recommendations are helpful where the quality of cancer care as a whole requires improvement. In the majority of cases, however, recommendations focus on strategies to increase early detection of breast cancer. This is critically important but will not necessarily address the healthcare needs of patients who have already been diagnosed with mBC.

Over the last decade, many organizations have worked proactively to create progress in a number of key areas that influence health policy and which will result in better outcomes for patients with cancer, including breast cancer. Organizations include professional clinical bodies, non-governmental organizations and patient support organizations and some of the numerous examples of their work are described here.

**// Organizations working in breast health can, and should, learn from one another. It's important that we share promising practices, exchange information and insight, and promote knowledge sharing about systematic, evidence-based approaches to improve the lives of women living with MBC. Komen engages with 1000s of national and international partner organizations and alliances to leverage resources to make the biggest impact. //**

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



International professional societies such as the American Society of Clinical Oncology (ASCO), St Gallen breast cancer scientific committee and the European Society of Oncology (ESO) in collaboration with the European Society of Medical Oncology (ESMO) have spent considerable effort in influencing policy related to screening, diagnosis and treatment of breast cancer through publication of guidelines. These guidelines support a call to action for healthcare professionals to provide specific and tailored care to patients with mBC, as discussed in detail in Section 3: *Scientific Landscape*. (Coates, 2015; Partridge, 2014; Giordano, 2014; Ramakrishna, 2014; Van Poznak, 2011; Cardoso, 2014) This is important because such recommendations standardize approaches to treatment and promote the delivery of evidence-based cancer care. (OECD, 2013a)

In 2013, the European Society of Breast Cancer Specialists (EUSOMA) produced an update to their position paper, first published in 2000, (EUSOMA, 2000) identifying the minimum requirements to set up a specialist breast center. The 2000 iteration of the guidelines was widely acknowledged as best practice and informed the European Parliament Resolutions in Breast Cancer 2003 and 2006. (European Parliament, 2003; Wilson, 2013) In the 2013 update, which took into account recent advances in breast cancer diagnosis and treatment, EUSOMA recognized that the application of minimum standards and quality indicators would drive improvements in breast cancer care. As such, the position paper requires that specialist breast units must be able to provide continuity of care to patients with mBC through an integrated multidisciplinary team that includes access to a high quality palliative care service. (Wilson, 2013)

Furthermore, initiatives such as European School of Oncology (ESO) Breast Centers Network, and the Europe Against Cancer European Breast Cancer Network are a step forward in ensuring quality care for breast cancer patients through collaboration. (Breast Centres Network, 2014; EBCN) The efforts of both Networks aim to strengthen the evidence-base for

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cancer care. This will improve outcomes for all including those with mBC, and support policy makers in the development of their national plans for breast cancer.

In the US, the National Cancer Policy Forum, established by the Institute of Medicine, has brought together representatives from the government, industry, academia and consumers to debate critical policy issues in cancer care and research. (IOM, 2015) The reports created from these debates provide straightforward advice to decision-makers and the public about all aspects of cancer including issues critically relevant to those with mBC. Examples include access to affordable cancer therapies, biomarkers for molecularly targeted therapies and implementing a national clinical trials system for the 21st century. (IOM, 2015)

Additionally, the ASCO Institute for Quality is leading the development of CancerInq which will aggregate and analyze real-world cancer data in order to allow practices to benchmark, provide personalized insights into optimal care and uncover patterns that identify improved response to treatments. (cancerinq.org) Additional funding provided by Komen will support the implementation of breast cancer clinical decision support, a specific breast cancer patient portal and the development of breast cancer specific guidelines and measures within CancerInq. This will improve the quality of patient care and drive advances in clinical research



through greater communication and collaboration between breast care specialists. (ASCO, CCF, 2015) While it isn't clear how much of Cancerling resources will be targeted towards mBC, efforts like these are likely to improve the clinical management of breast cancer across all stages.

Furthermore, Patient Support Organizations (PSOs) have provided opportunities for patients to influence health policy themselves. Organizations such as Breast Cancer Network Australia (BCNA), Europa Donna, and Komen have contributed significantly in capturing the experiences of mBC patients and bringing them to the attention of policymakers. Further detail on the role of PSOs in shaping policy can be found in Chapter 4: *The Impact of Patient Support and Advocacy Organizations in mBC*.

### **C Country level implementation of BC policies has been variable and faces several challenges**

Despite the availability of global policies for cancer generally, and breast cancer specifically, adoption has been variable around the world. Based on data collected by WHO in 2013, approximately 40% (79/194) of all countries do not have, or did not report, the existence of an NCP. In Africa, the proportion is higher, with almost three-quarters (39/54) of countries on the continent without a well-defined plan to address cancer. (WHO, Policies, strategies and action plans) In these countries, much needs to be done to incorporate cancer control as a national priority, before a focus on improving the care of those with breast cancer can be

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implemented. Where cancer control planning is already more advanced, the focus for breast cancer continues to be limited to early detection and screening. (OECD, 2013a)

While the healthcare needs of a given population are a core contributor to shaping health policy, within or of itself, there are many layers to consider. There is significant variation in health policy for cancer-care between countries, (OECD, 2013a) with health priorities reflecting the most significant healthcare burden to the local population. Where funding is limited, interventions may be directed to areas where the most lives can be improved with the resources available. (Global Health Working Group, 2012)

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(OECD, 2013a; Global Health Working Group, 2012)

Variations in healthcare policy adoption may influence the differences observed between countries in important metrics such as breast cancer stage at diagnosis and mortality. As detailed in Section 3: *Scientific Landscape*, major differences in the rates of late diagnosis and breast cancer mortality leads to significantly decreased survival in lower income countries. (DeSantis, 2015; IARC, 2013; Unger-Saldana, 2014) Such disparities may be attributed to inequities in health service infrastructure and access to care, factors that could be impacted, at least partially, by national policies.

In low- and middle-income countries, variability observed in policy planning and implementation arise from access to both the financial and physical resources required to implement effective cancer care.



Here there is a link between the quality of cancer care and the state of healthcare delivery. Inherent limitations in the health system impede its ability to deliver improved outcomes for patients with mBC. (Anyanwu, 2011; Chalkidou, 2014; de Souza, 2015) Poor cancer outcomes have been linked to insufficient numbers of an appropriately trained healthcare workforce, limited access to screening and treatment facilities, inadequate supply of necessary drugs and timeliness of treatment after diagnosis. (Harford, 2011)

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### Real-world Spotlight: Malaysia

A 2012 study from Malaysia described a low-cost program that combined healthcare worker training in cancer detection with measures to increase public awareness. The program improved identification of cancers of the cervix and breast, with a reduction in the diagnosis of advanced stages (III and IV) of both by approximately 50%. (Devi, 2007) Opportunities exist to raise public and primary care awareness and improve attitudes towards cancer diagnosis and treatment. (Erniah, 2012) It is clear that increasing breast cancer awareness in healthcare workers and the general population as a whole is imperative to address late diagnosis.

In realization of these issues, guidelines have been created that account for country-level differences. For example, the BHGI consensus statements provide guidance on resource allocation for supportive and palliative care for patients with breast cancer in low-income and middle-income countries. (Distelhorst, 2015; Anderson, 2006) Moreover, the clinical management recommendations included in the ABC guidelines were developed with consideration to their relevance to all countries around the world. (Cardoso, 2014) Despite these aims, implementation of some recommendations may still be impractical in low resource settings. (UCCI, Planning comprehensive breast cancer programs; Anderson, 2006)

Even among high income countries there are differences in outcomes for cancer including breast cancer. Factors such as socioeconomic status and access to healthcare services, contribute to disparities in cancer care in the US. (de Souza, 2015) Significant differences have been observed in the incidence rates, and mortality rates for breast cancer by race and ethnicity. (CDC, 2015) Therefore, it remains important for cancer initiatives to be designed to ensure equity of access to cancer care for minority populations. (de Souza, 2015) Moreover, in the UK, where outcomes for breast cancer lag behind that of other European countries, (Allemani, 2015; Macmillan, 2015) a new, independent cancer taskforce has identified 6 strategic priorities to improve cancer outcomes and transform patient experience. These priorities include a focus on improvements in public health, early diagnosis, patient experience, resource / infrastructure and commissioning. (NHS England, 2015) While these imperatives are a positive step, they continue to focus on early diagnosis and screening, and hence benefit patients with early-stage disease to the greatest extent; but targets to ensure better access to end-of-life care, clinical nurse specialists and improved technology will also begin to address the needs of mBC patients too.



**“Each community, here in the US and across the globe, has unique needs when it comes to breast cancer. It is important to understand these needs, as well as the strengths and assets of the communities we serve, so that we can design evidence-based plans to reduce breast cancer mortality in each of these communities in the US and across the globe. To guide our programming, we work in partnership with local organizations and agencies to conduct health system assessments and community profiles that assess key breast cancer statistics, available infrastructure and quality of public health services, the factors that determine why women enter the breast cancer continuum of care, and the barriers that prevent women from completing the continuum.”**

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

**There is a lack of reliable data on mBC.** Localized public health data is critical when decision makers are prioritizing healthcare expenditure. Although there are multiple data sources providing global and national breast cancer figures on prevalence of eBC, there are limited reliable global figures on prevalence of mBC. Some national data sets can be considered though, such as data from Australia estimating mBC prevalence to be 3 to 4 times the number of annual deaths from breast cancer. (Clements, 2012) As mentioned previously, policymakers in the United Kingdom recognised that the lack of data on the number of breast cancer patients with metastatic disease was impacting effective planning of services for these patients. Following an audit of the data available from existing sources, a recommendation was made to expand an existing mandatory data collection tool so that it specifically included information on patients with recurrent and metastatic BC. (NCIN, 2012) Low- and middle-income countries often do not have the capacity or tools to collect this type of data in a systematic way across disease states. (UICC,

Planning comprehensive breast cancer programs) Although there are exceptions which show that it is possible. In Kenya, for example, data for the single national cancer registry are collected from medical facilities in and around Nairobi. While this is a step in the right direction, information from the rest of the country is still absent. (Muthoni, 2010)

Despite clinical and technological advancements such as electronic health records (EHRs), disease registries and surveillance systems, even policy makers in high-income countries still lack reliable data regarding the burden of mBC. The data sets that are available suggest that the population of patients with mBC is continuing to grow. (Ferlay, 2010; Ferlay, 2015) However, without access to accurate numbers, policy makers cannot make informed policy decisions that will address the burden of disease in their communities. As such, policy makers may not sufficiently recognize the needs of many sub-populations, including those with mBC, which in turn creates challenges to the prioritization of resources.



**The rising cancer burden increases pressure on constrained national health budgets.** A detailed discussion of the economic aspects of mBC is included separately in Chapter 2: *Economic Burden of mBC*. However, in the context of health policy, the available health budget can influence policy development and adoption. (OECD, 2013b) Each country has its own priorities when financing healthcare and, as such, budgets vary considerably between nations.

The global burden of cancer continues to increase largely because of the growing and aging world population, alongside an increased uptake of cancer-causing behaviors, particularly smoking, in economically developing countries. (Jemal, 2011) Across the world, there has been a rapid growth in the direct costs of cancer treatment combined with an increasing constraint of healthcare budgets. (Kudrin, 2012) These factors combined show that the growth in healthcare spend has been driven by increasing prevalence of disease and growing costs of technologies and treatments.

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Budget holders are increasingly scrutinizing the cost of new therapies. Approaches which focus on a measurement of the cost effectiveness of treatments and interventions have gained greater prominence, even in countries such as France and Japan where Health Technology Appraisal (HTA) has historically focused on clinical efficacy. (Lim, 2014; Massetti, 2015; Kobayashi; 2012; Kudrin, 2012) The acceptable threshold at which new medicines are considered as cost effective differs between countries. (Kudrin, 2012)

Not all countries have established HTA processes. Those without an official, national HTA body may, or may not, complete some review based on cost before a drug is allowed to be used in the country. In this case, reimbursement is dependent on individual budget holders within that country. (Kudrin, 2012) However, this approach can lack transparency. Leading cancer centers and academic institutions in the US have urged for an evaluation and rating process similar to EU and other HTA countries to be applied prior to insurance coverage decisions and price negotiations. (Tefferi, 2015)

As a result of the different approaches employed around the world, the decision to fund any treatment can differ by country or region. One such example is Africa where there is variability in the national reimbursement of cancer treatments across the continent. In South Africa, best-practice cancer treatment is available at little cost to breast cancer patients within the public health system. (Dickens, 2014) In contrast, in Nigeria, patients personally bear the cost of cancer treatment, a formidable task for the majority. (Adisa, 2011) In one study, financial difficulties resulted in nonadherence to chemotherapy schedules in 45% of patients in the sub-Saharan region and also attributed to the infrequent use of new biological agents and subsequent lines of chemotherapy. (Adisa, 2011)



In one study, financial difficulties resulted in nonadherence to chemotherapy schedules in 45% of patients in the sub-Saharan region and also attributed to the infrequent use of new biological agents and subsequent lines of chemotherapy. (Adisa, 2011)

In conclusion, it is increasingly important for policy decision makers to find ways to meet the rising burden of cancer as a whole and mBC in particular. The resources required to meet this need are many and include, healthcare infrastructure such as access to hospitals, access to appropriately trained staff, radiotherapy, supportive care and cancer medicines. In breast cancer, while many of the treatments considered as standard-of-care are now available as generic products, (NIH, 2015) patients may still not have access to them as a result of other barriers in the health system.

Every opportunity to understand both the experience and needs of patients as well as the effective management of mBC through scientific research are invaluable. Such findings must be publicized and promoted

to national level health planners and policy makers to best inform health decision-making and could be applied in other countries around the world. Organizations such as the ABC Patient Advocacy Committee, Metavivor, UICC and Susan G Komen provide a forum to aggregate learnings to maximize steps-forward in mBC care. More in-depth research is needed to understand why current policy approaches haven't improved mBC survival and to identify the critical steps that need to be taken to create this step change.



"CJ" (Dian) Corneliussen-James was diagnosed in 2006. She is living with the disease.

**// We question whether we've done everything possible to provide for and prepare our children, spouses and parents for the end that is coming - knowing it can happen suddenly. We push for equality... in support, in research...in survival; and many become activists. So much is going on with us...but what the public sees is our smiling face...just like every other smiling face out there. //**

*"CJ" (Dian) Corneliussen-James, Co-Founder, President, and Director of Advocacy, METAvivor Research & Support, 2015*



## Chapter 2: Economic Burden of mBC

- mBC has been associated with a significant economic burden to society and healthcare systems around the world
- Direct costs of mBC constitute mainly hospitalizations, emergency care, drugs and palliative care
- However, economic burden goes beyond direct costs of care and include lost productivity
  - For patients under 65 years of age, the indirect costs of mBC arising from lost wages for patients and caregivers and productivity losses for society through work absences and early retirement, can account for more than 50% of the total cost of care (Lidgren, 2007)
- Patients, families, and caregivers are bearing the increasing financial and humanistic burden of mBC
  - Indirect costs result in a decrease in household incomes for families and add to financial distress (Sorensen, 2012)
  - The impact of mBC on families and caregivers is often overlooked
- Broader understanding of the cost of BC is required to inform policy decision-making broadly (Lidgren, 2007)

### Economic burden of mBC comprises direct and indirect costs.

The economic burden of cancer is significant, and continues to rise around the world. As our current review is focused on the economic burden of mBC, particular consideration must be drawn to the prevalence of this disease primarily in women, which exhibits additional unique societal challenges compared to other, less gender-defined, metastatic diseases. With women playing important roles both within and outside of the home, the impact of an mBC diagnosis is far-reaching. In addition, as women can often live for several years with mBC, they not only face the unpredictability of the ongoing and cumulative financial burden of living with the disease, but also the impact of the disease on their quality of life and ability to be productive members of society.

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**Methodology:** In order to present a comprehensive overview of the economic burden of mBC from a patient, healthcare system and societal perspective, a literature review was conducted on the economic burden and cost of illness of mBC, reported over the last 10 years. See Appendix 2.2 for more details on literature search methodology. Within this report, the direct costs associated with treatment of metastatic disease are discussed at a population level, rather than at an individual level.

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In considering the economic burden of any disease state, there are 2 main components 1) the direct costs of the treatment and management approach and 2) the indirect costs associated with the impact of the disease on the patient, caregivers and society. Figure 2.3 further defines what could be classified within each of the cost components and who bears these costs.



Figure 2.3

### Classification of Direct and Indirect Cost Components

Sorensen, 2012; Lidgren, 2007; Broekx, 2011; Wan, 2013; Here & Now, Novartis, 2013

	Direct Costs:	Indirect Costs
Cost components	<p>Direct medical costs are those directly associated with disease treatment and resources used for medical care, eg,</p> <ul style="list-style-type: none"> <li>• Hospitalizations</li> <li>• Surgery</li> <li>• Physician visits</li> <li>• Radiation therapy</li> <li>• Chemotherapy/immunotherapy</li> <li>• Oral drugs</li> <li>• Emergency care</li> </ul>	<p>Indirect costs are the monetary losses associated with time lost due to disease or time spent receiving medical care</p> <ul style="list-style-type: none"> <li>• Work departure (early retirement/temporary work absence) or time lost from other usual activities</li> <li>• Lost productivity due to premature death</li> <li>• Additional childcare needed while receiving medical care</li> <li>• Transport to and from medical care</li> </ul>
Who bears the cost	<ul style="list-style-type: none"> <li>• Health systems – governments, insurers, employers (insurance coverage for employees)</li> <li>• Patients and families (through individual/private insurance, and contributions such as copays)</li> </ul>	<ul style="list-style-type: none"> <li>• Patients, caregivers, families and more broadly, society</li> </ul>



While the literature review provided some published evidence describing the economic burden of mBC on individual patients and their families or caregivers, there were limitations in the depth and breadth of the data available. In addition, there were challenges in comparing data between sources, as summarized below:

- Most of the data regarding costs of mBC examines the direct costs relating to medical resource utilization at a healthcare system, rather than individual patient level. This is because most studies have been in countries where a national health system or system of health insurance pays for healthcare costs and not in countries where individuals bear these costs
- The majority of data available for patients with mBC is from higher income countries and is likely to underestimate the economic burden, since cancer registries are not always designed to provide complete information and disease progression is not always documented (Remak, 2004)
- There is a lack of data from middle-low income countries where extremely diverse socio-political and economic realities hinder prospective data collection and analysis, making extrapolation unreliable (World Breast Cancer Report, 2012)

- Comparative costs between high income countries have been difficult to make due to variations in healthcare systems and the definition of cost components examined
- Drug costs may vary depending on the year of analysis. For example, aromatase inhibitors which are the standard of care for HR+/HER2-mBC, the largest subtype comprising more than 60% of mBC, became generic in the US in 2010/2011. (Orange Book) Hence drug costs in this breast cancer subtype would likely be much lower after Loss of Exclusivity. Furthermore, trastuzumab, an innovative treatment for HER 2+ mBC, was approved in 1998 in the US, and significantly improved outcomes but also contributed to the increase in costs (CenterWatch; Eiermann, 2001)

### **A** There is increased economic burden of mBC on healthcare systems and society

The direct cost of BC has increased and metastatic disease is a significant contributor to the costs. In Belgium, the average annual healthcare costs for women with breast cancer across all stages of disease, measured over a period of 6 years, was compared with those of the general population. Results from this study showed that the excess annual healthcare costs for patients with mBC were €23,280; greater than for patients with less advanced disease. (Broekx, 2011) (See Figure 2.4)

Figure 2.4

### Excess Healthcare Costs per Breast Cancer Patient Over 6 Years According to Breast Cancer Stage from 1997-2004

Broekx, 2011

Disease Stage (n=4,975)	Average Healthcare Costs per Breast Care Patient in the Sample (€)	Average healthcare costs of general population (€)	Difference (Discounted difference at 4%)* (€)
I	19,827	10,610	9,217 (8,799)
II	24,927	10,610	14,318 (13,461)
III	32,606	10,610	21,996 (20,597)
IV (mBC)	35,201	10,610	24,591 (23,280)

\*Given the 6 year time period, the net present value of costs in 1998 was calculated using an annual discounted rate of 4%



Cost comparisons between high-income countries have been difficult to make due to variations in patient cohorts and healthcare system funding. As an example, total direct costs which calculate the total medical and resource costs, measured by hospital use per patient, (both mBC and relapsed BC) range from €30,000 to €48,000 in Belgium, the Netherlands, France and the UK. (Frederix, Breast Cancer Research and Treatment, 2013; Bonastre, 2012; Thomas, 2009)

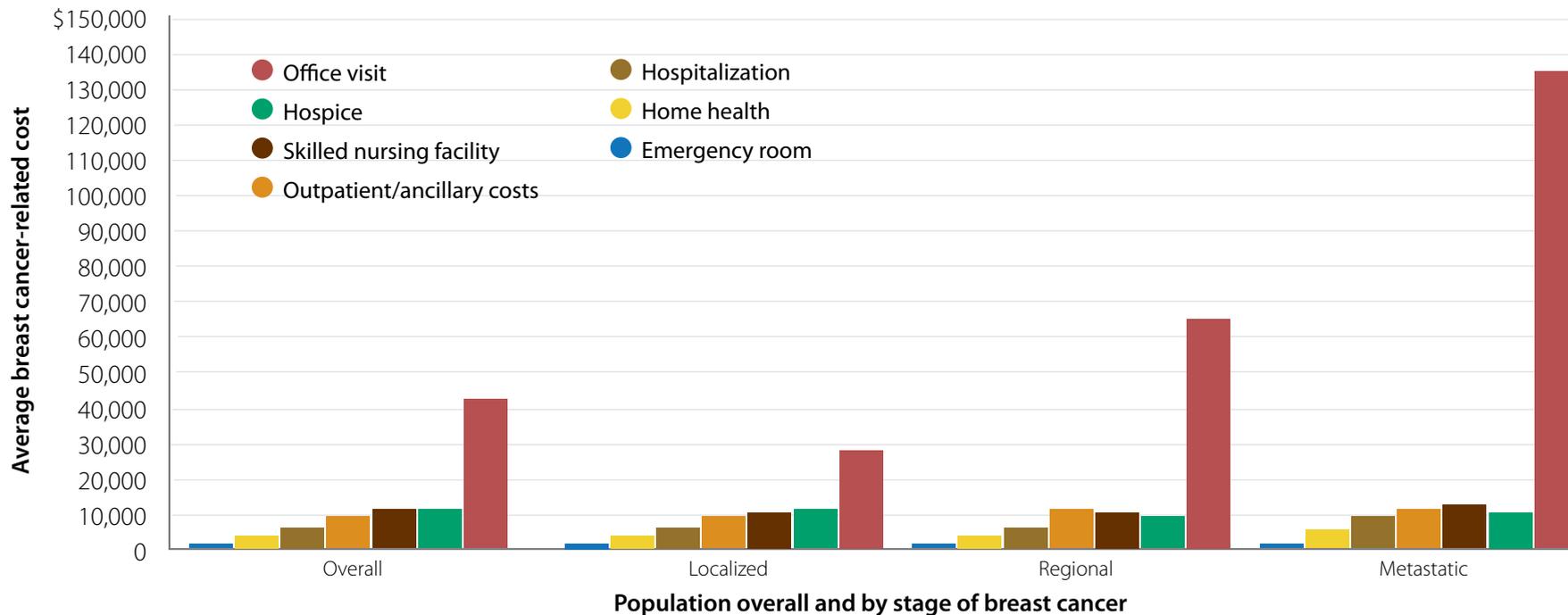
In the US, the cost per patient of mBC treatment to the healthcare economy is increasing. Medicare coverage is provided to people age 65 or older, people under the age of 65 with certain disabilities, and people

of all ages with End-Stage Renal Disease. (CMS, Medicare Program) Estimates in 1997-99, which included costs associated with inpatient hospital visits, skilled nursing facilities, physician/professional services, outpatient hospital clinics, diagnostic testing, home health, hospice care payments as well as payments for covered drugs, durable medical equipment, transport and supplies, show that the mean cost of treating a Medicare mBC patient in the US over an average of 16.2 months was \$35,164. (Rao, 2004) Using Bureau of Labor Statistics (BLS) published medical inflation data, this is equivalent to approximately \$52,700 in 2009. Davis et al analyzed the Medicare-SEER linked data to estimate costs, including

Figure 2.5

### Average Adjusted Cost by Breast Cancer Stage and Category for Patients Diagnosed between 2000 and 2005

Davis, 2010



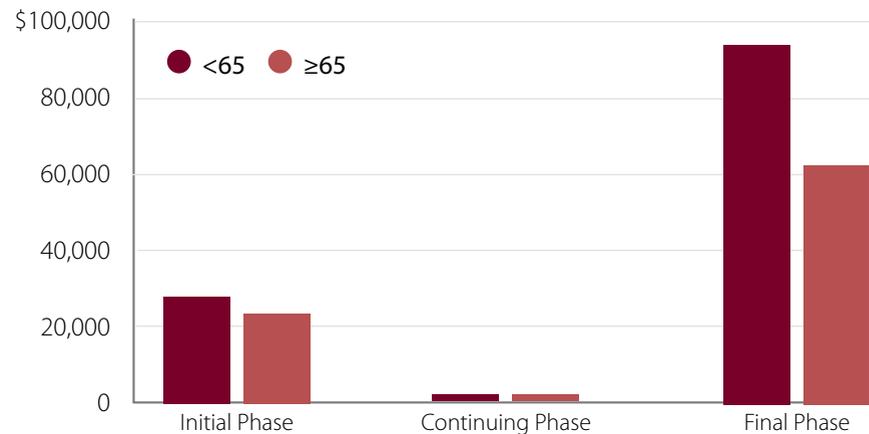
breast cancer-related surgery, radiotherapy, chemotherapy, and other medical encounters carrying a breast cancer diagnosis, and predictors of costs in elderly ( $\geq 65$  years) patients diagnosed with breast cancer between Jan 2000 and Dec 2005 (see Figure 2.5). Cancer-related adjusted costs (2009 US \$) per mBC patient were reported to be \$153,421 over a median follow up period of 26 months (median time between diagnosis and death). Metastatic stage at diagnosis, amongst other factors, was found to be a significant ( $p < 0.001$ ) predictor of higher costs. (Davis, 2010) Of note, based on an analysis including laboratory tests and diagnostics, surgeries and procedures, treatments, outpatient visits, hospitalizations including emergency department (ED) visits, and prescription fills factoring in the amount paid by the insurance plan, patient co-pays, deductibles, coinsurance amounts and out of pocket expenses, the cost of mBC per privately insured patient was on average, \$250,000 for an average life expectancy of 2.2 years in 2009. (Montero, 2012)

Cost of BC is the greatest in the final year of life. Mariotto et al (2011) published a projection of the costs of BC care in the United States, using SEER-Medicare linkage data, considered according to phase of care which they defined as initial (within the first 12 months from diagnosis), continuing (the period between initial and final phases) and final (last 12 months of life). This analysis of the direct medical cost estimates by phase of care, found that the average cost of treating breast cancer is greatest in the patient's final year of life (See Figure 2.6). Similar results were reported in a study from a Brazilian public healthcare system perspective. The analysis found that, even in the metastatic setting, progression of disease was associated with rising healthcare costs, with an increase from Brazilian Real (BRL) 308 in the pre-progression phase to BRL 731 post progression over one year. Furthermore, end-of-life costs were in excess of 5 times greater than in the post progression phase of mBC BRL 4,164 vs BRL 731 respectively (over the same time period). (Haas, 2013) These examples show how effective management at the end-of-life could have a substantial impact on the direct cost of cancer care in mBC patients.

Figure 2.6

### Annualized Treatment Cost Trend for Managing BC in 2010 (USD)

Mariotto, 2011



Initial Phase = 12 months following diagnosis; continuing phase = the period between initial and final phase shown as cost per year; final phase = last 12 months of life

**Indirect costs for mBC are significant to society.** Indirect costs of mBC arise from lost wages for time off work (for the patient and their caregiver), unpaid caregiver time, and productivity losses for society. Ignoring these costs could lead to suboptimal policy decision making from a societal perspective and prevent women from comprehending the true financial burden of their disease. (Lidgren, 2007)

A large percentage of breast cancer patients leave employment due to their disease, and for breast cancer survivors, returning to work full-time can be a major challenge. (Meadows, 2010; de Boer, 2009) A 2015 retrospective US study demonstrated that breast cancer disease progression is associated with greater work hour loss in the work place. Results show that on average, non-mBC survivors miss 77-83 hours of work per quarter. In contrast, mBC patients during the end-of-life period, lose on average, 126 work hours per quarter (a 66% increase compared



to non-metastatic patients). The same study also confirmed that breast cancer progression contributed directly to an increased dropout rate from employment. (Yin, *J Clin Oncol*, 2015) A separate study found that mBC imposes a significant financial burden on patients through short-term disability costs (approximately \$6,000 USD in total) vs matched controls. (Wan, 2013)

Unfortunately the economic burden to caregivers is often overlooked and poorly understood. (Wan, 2013) More detail on insights gained into the experiences of caregivers in the work place is discussed in Section 2, Chapter 6: *The Impact of mBC on Patient Social Relationships and Caregivers*.

Sorensen estimated the annual US societal costs associated with treatment of mBC patients, using an incidence-based cost-of-illness (COI) model framework. An incident cohort of mBC patients was followed over 5 years, from diagnosis of metastatic disease, through active treatment (for eligible patients) and subsequently to end-of-life care and death. The incident cohort included both de novo patients and patients who had progressed to mBC from earlier stages of breast cancer and captured both direct and indirect costs. (Sorensen, 2012)

The model estimated additional economic burden of mBC in the US associated with loss of productivity of patients and caregivers to total nearly \$3 billion over a 5-year span, with the total discounted cost (ie, adjusted for inflation) to society being over \$12 billion (Figure 2.7). This represents a 3-fold increase in the cost of mBC to the healthcare system compared with data from the 1990s. The analysis included both direct and indirect cost estimates: utilization of cancer therapies and other medical care resources, treatment-related adverse events, diagnostic costs, lost income, and caregiver costs. (Sorensen, 2012)

Several studies suggest that the cost to society of mBC care is dependent on patient age, with the cost being higher for younger vs. older patients, specifically if indirect costs are also included. (Lidgren, 2007; Gordon, 2007; Broekx, 2011) One Swedish study demonstrated that for patients younger than 65

years of age, the annual total cost (ie, direct and indirect costs) associated with mBC was estimated as 334,000 SEK (\$46,500) vs 122,000 SEK (\$17,000) for those over 65 years. This large contrast in total costs was attributed to higher indirect costs for younger patients caused by absence from work and early retirement, accounting for more than 50 percent of the total cost. (Lidgren, 2007) The same study showed that mBC was associated with the highest rate of early retirement compared with the other disease states in women under 64 years of age. This results in a substantial decrease in work capacity in women advancing to metastatic disease. (Lidgren, 2007) Replacing the unpaid labor of European women in the grey economy would cost in excess of €880 billion. (Here and Now, Novartis, 2013)

Figure 2.7

### The Estimated US Economic Burden of mBC\*

Sorensen, 2012

Group	Cost
Lost productivity of mBC patients and caregivers	\$2.9 billion indirect costs over 5 years = \$23,157 per patient-year = 23.5% of total direct and indirect mBC costs
Discounted cost (direct and indirect) to society of mBC (ie, adjusted for inflation)	\$12.2 billion accrued over 5 years = \$2.4 billion per year = \$98,571 per patient-year

\* An incidence based cost-of-illness model was developed in which an incident cohort of mBC patients are followed over 5 years, from diagnosis of metastatic disease and assessment of management course, through active treatment (for eligible patients) and subsequently to terminal care and death.



Annual total cost associated with mBC are higher in younger (<65) compared to older (>65) patients. The indirect costs of mBC can account for more than 50% of the total cost of care. (Lidgren, 2007)

### **B** mBC imposes an increasing financial burden on families and caregivers

When evaluating the financial burden directly to the patient, their families and caregivers, there can be variation in how this impact is qualified and measured. As detailed previously in Figure 2.16, financial burden can constitute both direct costs, such as out-of-pocket payments related to the care that patients receive or cost of transportation to receive medical care, and indirect costs, such as the cost of childcare or home help needed to support family while receiving medical care.

Studies have highlighted a greater financial burden for patients with mBC than those with non-metastatic disease; this likely reflects increased disease severity, co-morbidities and side-effects associated with increasingly complex treatment strategies. (Zafar, 2013; Wan, 2013) Several surveys and publications describe the financial need and related concerns of mBC on the individual from an Australian, European and US perspective. For example, in a primary research survey, with breast cancer center healthcare professionals, 31% of respondents identified financial support as a top 5 unmet need for patients with mBC. (Breast Cancer Center Survey, Pfizer, 2015)

In an Australian survey of 579 women and 3 men with mBC, one-fifth of respondents identified financial assistance as an unmet need. (BCNA Survey, 2015) 49% of respondents were treated in the private health system and 44% treated in the public health system (7% of individuals asked did not respond). The survey found that 60% of respondents reported acute financial difficulty. For women in the public system, loss of income (37%) and out-of-pocket expenses (28%) were most frequently reported as the reason for these financial difficulties. (BCNA Survey, 2015) Women in the Australian survey were asked to provide estimates of their mBC related out-of-pocket costs incurred in the previous month. The values given ranged from \$0 - \$25,000 for women treated in the private health setting and \$0 - \$10,500 for women treated in the public health system; with an average total monthly out-of-pocket cost of \$687.17 for all women. Figure 2.8 demonstrates the breakdown of cost drivers contributing towards these out-of-pocket expenses. (BCNA Survey, 2015)

**“The cost of treatment meant I used all my life savings... this is tough and has resulted in uncertainty... Am I going to have enough money to see me out? How does all of this affect my standard of living and therefore my relationships with family and friends?”**

*BCNA Survey Respondent, 2015*



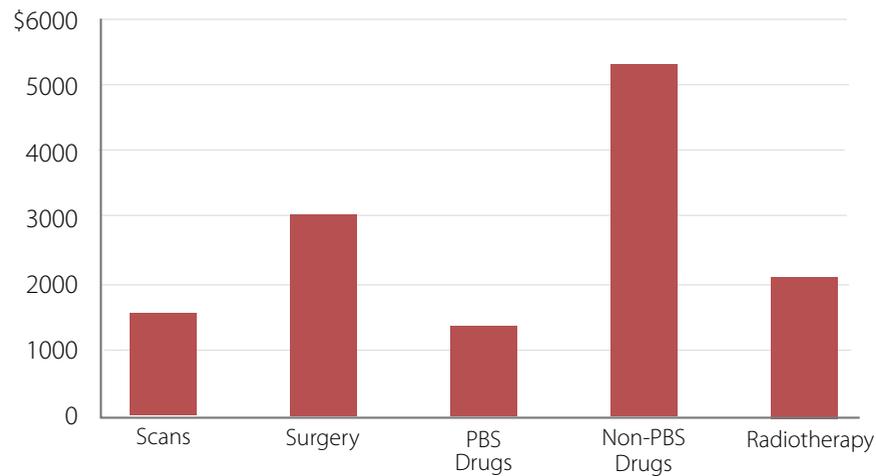
In an Australian survey, 60% of respondents reported they had experienced financial difficulty (within the previous week).

(BCNA Survey, 2015)

Figure 2.8

### Aspects of Treatment that Have Incurred the Most Significant Total Out-of-Pocket Cost, Based on Data Collected from August-September 2014

BCNA Survey, 2015



PBS = Pharmaceutical Benefit Scheme

Based on an Australian survey of women with secondary (metastatic) BC (n=420)

Q: Which parts of your secondary breast cancer treatment have the most significant out-of-pocket costs, and how much has this cost you?

Respondents also identified other-out-of-pocket costs; including, travelling for treatment (eg, petrol, flights, accommodation and parking), associated treatment and care, such as second opinion appointments; complementary and alternative treatments, including vitamins, massage, naturopathy, Chinese medicine and practical assistance such as employing home help. (BCNA Survey, 2015)

**“We are not on the poverty line, but I have lost half my wage and we relied on that to live.”**

*BCNA Survey Respondent, 2015*

In the US, greater out-of-pocket expenses reflect a shift of some of the cost burden of cancer treatment from insurers to patients. Out-of-pocket expenses could include direct payments to providers, prescription drugs, as well as unpaid liabilities such as travel costs and lost wages. There is evidence that the related out-of-pocket expenses are particularly high for cancer care, (Zafar, 2013; Davidoff, 2013) and the associated financial hardship has negative consequences on care choices, quality of life, and disease outcomes. (Irwin, 2014)

Patients with mBC face greater financial burden and have higher per patient costs than for those with non-metastatic disease.

(Zafar, 2013; Wan, 2013; Davidoff, 2013)



European patients describe experiencing financial burdens arising from increased living costs and adverse changes in their financial situation. (Here and Now, Novartis, 2013) Additional living costs occur from travel expenses or check-ups, supplementary treatments, help around the house, or from special dietary needs. As a result, many women with mBC reported reducing expenditures on non-healthcare related items. Patients report that they are struggling to manage expenses (38% of women surveyed) including the mortgage (15% of women surveyed). In a European survey, the majority of women living with advanced breast cancer report a decline in household income as a direct result of their cancer, with 87% reporting an increase in living costs. The majority of women recognize a need for financial support. (Here & Now, Novartis, 2013)

Reductions in income can be significant, with one in 10 women describing a 50% fall in household earnings in one study across 11 European countries (Austria, Denmark, France, Germany, Greece, Italy, Netherlands, Poland, Spain, Sweden, UK). 62% of study respondents stated that they need improved financial support. Approximately 40% experience psychological and physical problems as a direct result of the change to financial circumstances. (Here & Now, Novartis, 2013)

In a US survey of 134 breast cancer patients, nearly one-third of which had mBC, financial distress was detrimental to patient well-being and response to medical care. Financial hardship included difficulty in paying for basic necessities (16%) and exhausting a patient's savings (19%). (Irwin, 2014)

Approximately 40% of women with mBC experience psychological and physical problems as a direct result of the change to financial circumstances. (Here & Now, Novartis, 2013)



**“Travelling to hospital every day for treatment is incurring high petrol and parking expenses. Buying painkillers and other medication puts a big strain on our pension.”**

*BCNA Survey Respondent, 2015*

A diagnosis of mBC brings with it a high degree of uncertainty about the future and the consequences of diagnosis on patient lifestyle, family, work and friends. In addition to the emotional and physical impact of diagnosis, there are financial considerations that patients must manage throughout the course of their disease. U.S. data shows the families of patients with mBC incurred nearly 40% higher indirect costs compared with those families of patients with eBC. (Wan, 2013)

#### Patient Concerns Following the Diagnosis of mBC

- What will be the financial impact of treatment?
- Who will continue to fulfill the role of homemaker, caregiver or breadwinner?
- How will the demands or consequences of treatment impact the way roles are managed and responsibilities completed?
- How will the loss of income and costs of care and treatment impact the family's financial resources?

Clear acknowledgement and communication of the economic burden of mBC and related financial concerns is required to inform policy decision-making and allow patients to have a clear picture of the potential financial burden to themselves and their families in order to adequately plan for the future. (Lidgren, 2007; Hunink, 2014)

## Chapter 3: Public Understanding of mBC

- Public awareness and understanding of mBC is still limited even though public understanding of eBC has risen
- Global misperceptions about mBC prognosis exist, such as 'mBC is curable' or 'mBC has no hope'
- Patients with mBC may feel isolated and helpless due to a lack of understanding and stigma associated with the disease
  - Limited progress has been made to address these issues over the last decade
- Globally, variations in cultural bias impact public understanding and perceptions of mBC
- Perceptions and health-related behaviors around mBC can be altered through wider, more accurate communication of information on experiences with the disease
- Public exposure to messages regarding mBC has been increasing steadily over time
- Media communication has the potential to elevate the patient voice, reverse stigma and create a supportive environment for patients with the disease

Stigmatization of mBC increases women's health risks, isolates them from relevant resources, and prevents patients from accessing the medical and social support that are key to survival and maintaining quality of life. Often this can lead to women delaying presentation to a clinician until they are exhibiting symptoms of the disease. (LIVESTRONG report, Beckjord, 2012; Tfayli, 2010)

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.

### **A 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 2015 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 2 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. (History of Metastatic Breast Cancer Awareness Day, 2013) 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 may eventually progress to metastatic disease, (O’Shaughnessy, 2015; EBCTGG, 2015) which is incurable.

Perceptions about mBC in society can be seen as 2 extremes: those who are optimistic about prognosis of the disease, and those who think of it as hopeless. In most countries surveyed, 47%-80% 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 2.9). (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 finding a 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 mBC patients would be wasted, compared with eBC patients. (mBC General Population 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. //**

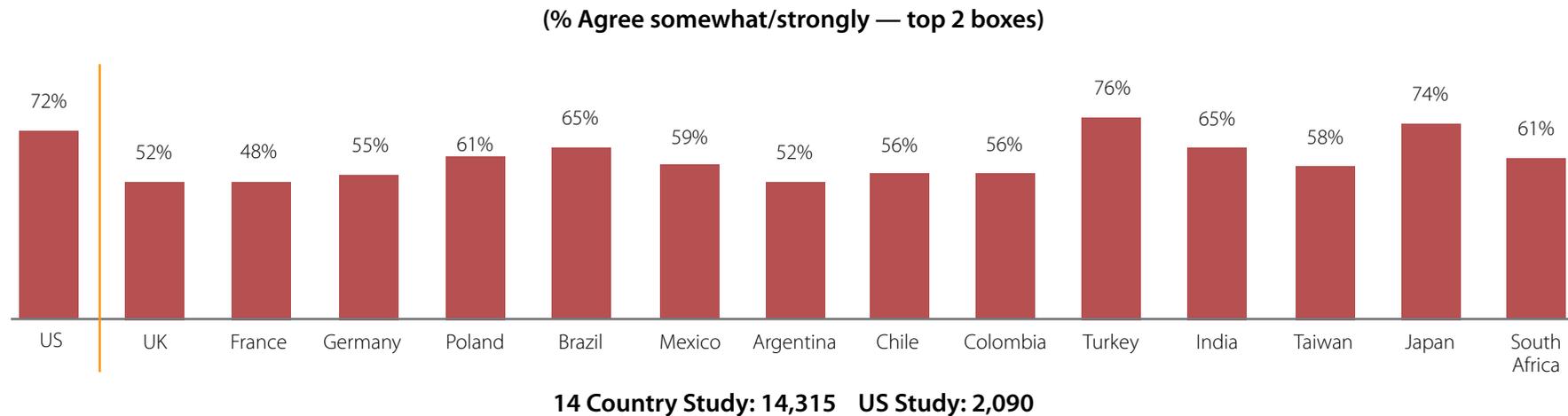
*Dr. Olufunmilayo Olopade, Director of the Center for Clinical Cancer Genetics, University of Chicago, 2015*



Figure 2.9

## Percentage of the General Public Surveyed that Believe Advanced or Metastatic Breast Cancer 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*



**B 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

**“People don’t understand the word metastatic to begin with...And when I’d tell them I was stage IV, 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*

progresses or recurs because patients do not take preventative measures, such as correctly taking medicine and attending appointments. (mBC General Population Survey, Pfizer, 2015) 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.

**“Positive messages about lifestyle choices that might reduce breast cancer risk or those that focus on early detection 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, PhD, Managing Director,  
Strategic Partnerships and Programs, Susan G. Komen, 2015*

Nearly 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. (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 2.10). (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 18%-49% of people indicated that patients with mBC should keep it a secret and not discuss it with anyone other than their physician (Figure 2.11). 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)

Figure 2.10

### Percentage of Women with mBC by Country Who Feel Their Experience is not Understood by Others and Feel Isolated from the Breast Cancer Community

Count Us, Know Us, Join Us, Novartis, 2013

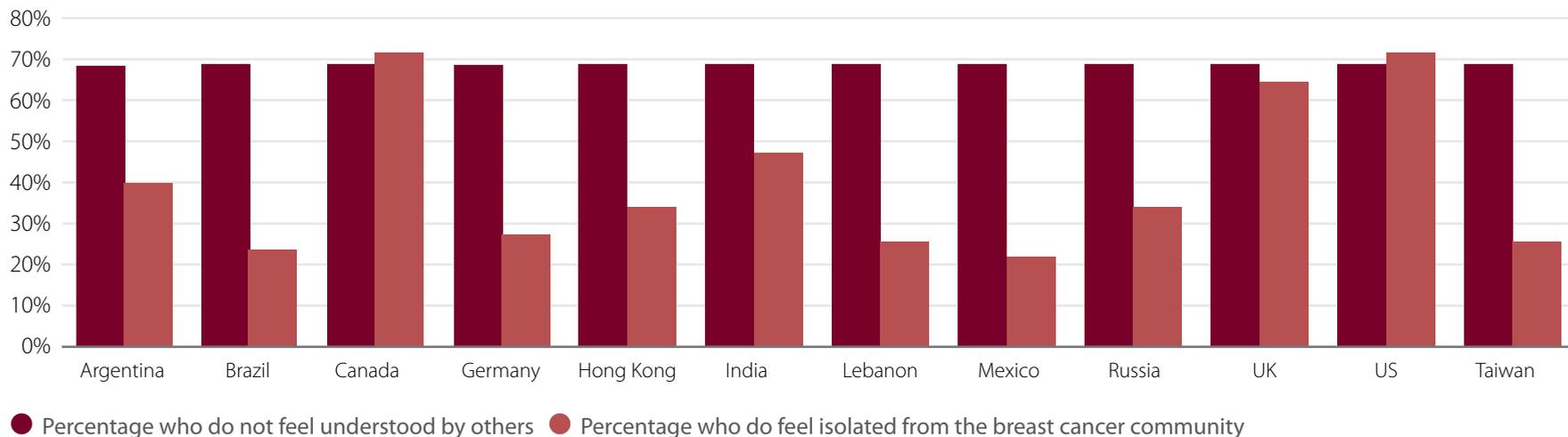
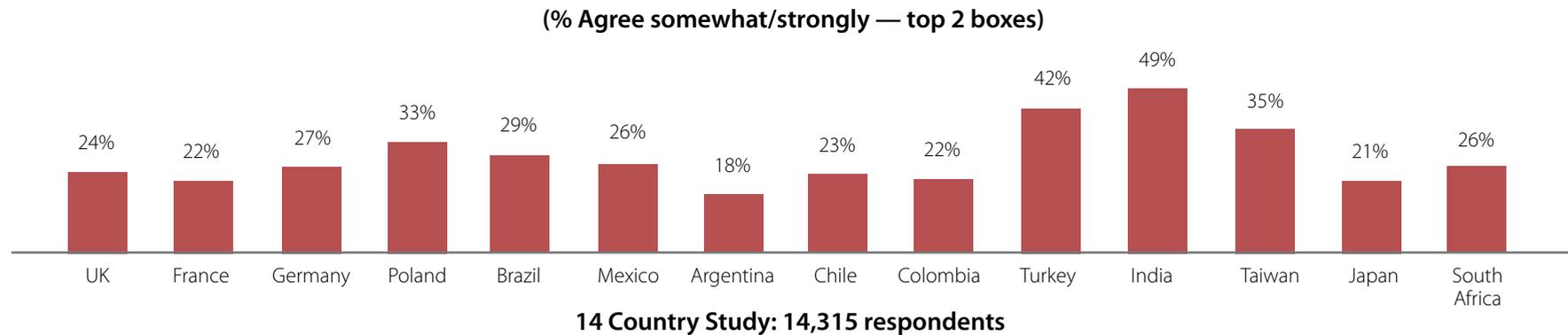


Figure 2.11

## Percentage of General Public Respondents Who Felt People With Advanced or Metastatic Breast Cancer Should not Talk About It With Anyone Other Than Their Physician

mBC General Population Survey, Pfizer, 2015



On average, 28% of the general population indicated that patients with mBC should keep it a secret and not discuss it with anyone other than their physician.

(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 2 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 4 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, PhD, Managing Director,  
Strategic Partnerships and Programs, Susan G. Komen, 2015*

The journey to change perceptions of eBC has taken many years and the level of success differs geographically. In the 1970s 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. (Ryan, 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. (Beckland, 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*



### **C 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 2.12). (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)

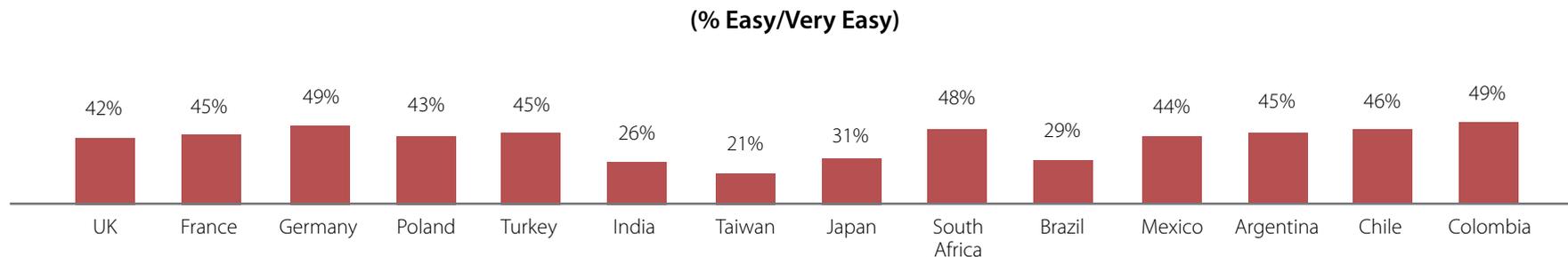
In a survey of 14 countries around the world, when considering specific information sources, those surveyed receive information on breast cancer through traditional media (TV, radio, newspapers etc.) as well as the internet; and approximately a third of participants rely on charitable organizations to 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 2 core articles reporting on the role of media (BRIDGE Metastatic Breast Cancer Patient Survey, 2010; 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 2.12

#### Access to Reliable Information on aBC/mBC

mBC General Population Survey, Pfizer, 2015



A 2010 analysis of cancer news reports from 8 large-readership newspapers and 5 national magazines 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 infrequently 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 2.3).

**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

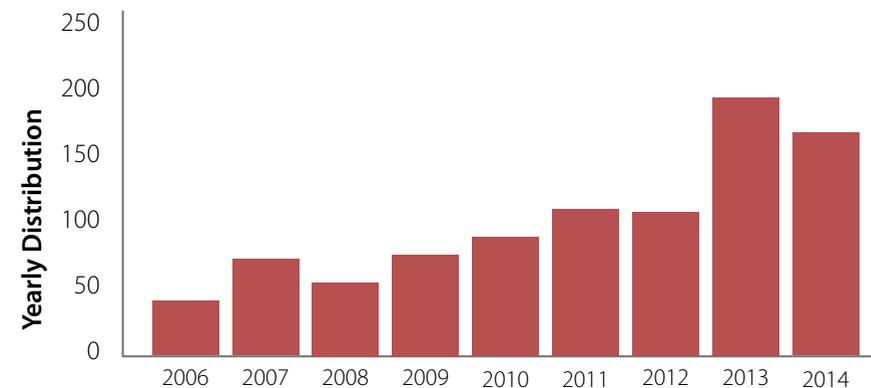
identified in each article. Initial text mining analyses rendered 13,824 word stems covering a broad range of subject areas. For the year 2005, data gaps existed within LexisNexis® and only limited results were found, therefore data from 2005 was omitted from the analysis. In addition, the time of analysis (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 2.3 for detailed methodology.

This analysis indicates that public exposure to messages regarding mBC has been increasing steadily over time (Figure 2.13).

Figure 2.13

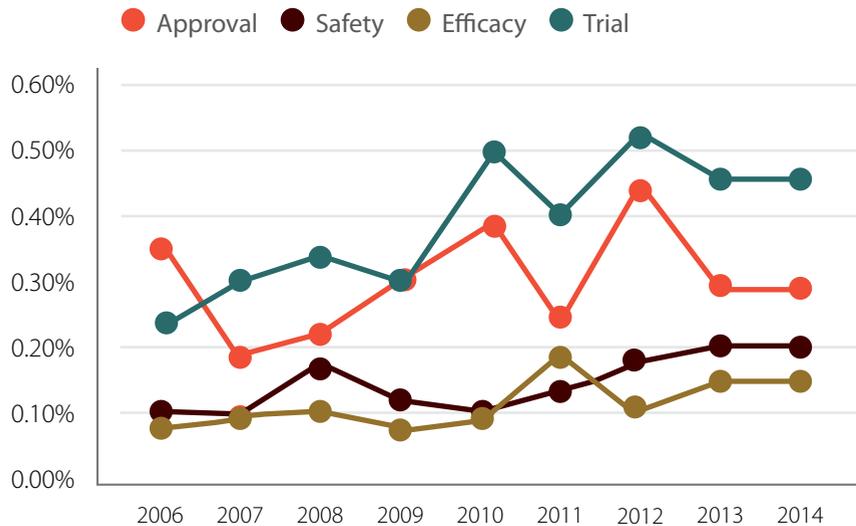
### Yearly Distribution of Newspaper Articles and Newswires on mBC Collected from 2006 through 2014

Research from Appendix 2.3



Further analysis of the media coverage on mBC (See Appendix 2.3) shows that the majority of mBC media content focuses on treatments, safety, efficacy and clinical studies (Figure 2.14); 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

Figure 2.14  
**Frequency of the Terms Approvals, Trials, Safety and Efficacy in mBC Media Coverage 2006 through 2014**  
 Research from Appendix 2.3



focusing on pain and suffering in the context of mBC (Figure 2.15) - this is a small but important step forward 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 2.16). These efforts have focused on the unique challenges that mBC patients face.

Figure 2.15  
**mBC Media Coverage of Palliative Care, Pain, Suffering, Fear and Job Loss from 2006 to 2014**  
 Research from Appendix 2.3

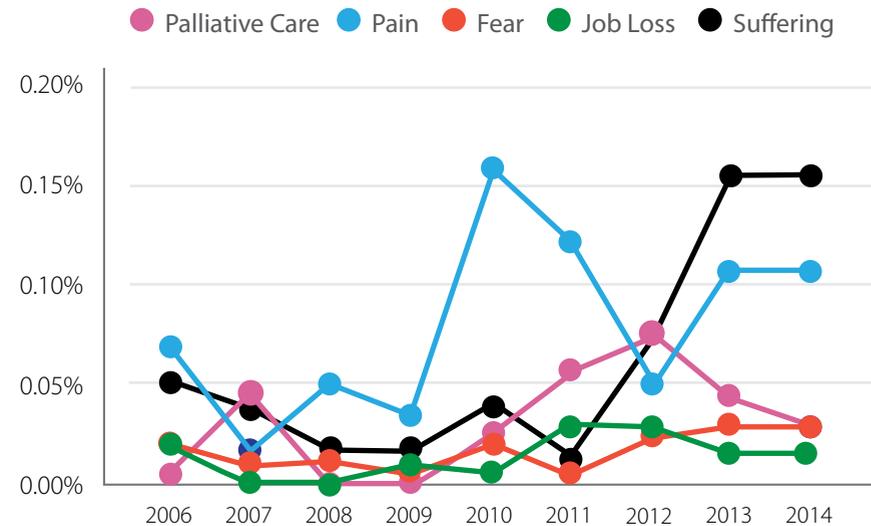


Figure 2.16

ADVANCEMENT	MILESTONE (examples shown; not a comprehensive review)
Recognition of mBC as distinct from early BC	<p>Creation of metastatic breast cancer day on Oct 13 (Huffington Post, 2009)</p> <p>First International Consensus Conference for Advanced Breast Cancer in 2011 (Cardoso, 2012a)</p> <p>Formation of the mBC Alliance in US (MBC Alliance, 2014)</p> <p>Launch of the mBC Alliance Landscape report (mBC Alliance Press Release, 2014)</p>
Launch of several high profile initiatives to educate the public and breast cancer community, and spur action on behalf of patients	<p>"Count Us, Know Us, Join Us" (Count Us, Know Us, Join Us, Novartis, 2013)</p> <p>"Here and Now" in Europe (Here and Now Report, Novartis, 2013)</p> <p>"Breast Cancer: A Story Half Told" in the US (A Story Half Told, Pfizer, 2014)</p>
High profile mBC patient perspectives and personal stories in the media	<p>As an example, Laurie Becklund, the late Pulitzer-Prize winning journalist, reported her frustrations at the lack of mBC attention, in particular from breast cancer awareness groups themselves . (Becklund, LA Times, 2014) She wrote of the inability to 'count' this patient group or access new treatments in a timely fashion, finally calling for a database to record as much data as possible about this group.</p>
Advances in science with positive phase III data or approval of new drugs for mBC patients	<p>New approvals (FDA Hematology/Oncology Approvals)</p> <p>Pertuzimab (NCI pertuzumab, 2015)</p> <p>Ado-trastuzumab emtansine (NCI Ado-trastuzumab emtansine, 2015)</p> <p>Everolimus (NCI Everolimus, 2015)</p>

**“ 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. ”**

*“CJ” (Dian) Corneliussen-James, Co-Founder, President, and Director of Advocacy, METAvivor 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.

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

***North American Respondent, mBC PSO Survey, Pfizer, 2015***

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.



## **D 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***

Regional and local cultural norms drive variations in the public perception of breast cancer and the creation of tailored resources can, in part, shape the public's perception towards mBC, positively affecting patient lives by reducing social stigma and enhancing community support networks. For example, Chinese women are not routinely inclined to check for breast cancer due to the cultural belief that cancer is a punishment and is contagious, and due to the desire to keep personal health matters private. (Beckjord, 2012) A focus group study evaluating attitudes among Chinese women demonstrated that women's attitudes towards breast cancer screening were significantly improved after watching a short video about the process that includes a soap opera and a segment with a physician. The authors argued that creating a culturally tailored video helped in increasing mammography use among Chinese women. (Wang, 2008)

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. (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)



**“[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*



Marie Pandeloglou, mBC patient, with her mother. Marie is living with the disease.

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.



## Chapter 4: 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 (eg, 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. 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; Metastatic Breast Cancer: Focus for Advocacy, Europa Donna, 2014)

Based on 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 continues 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 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 to 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)

Field interviews were conducted from June 15, 2015–August 3, 2015.

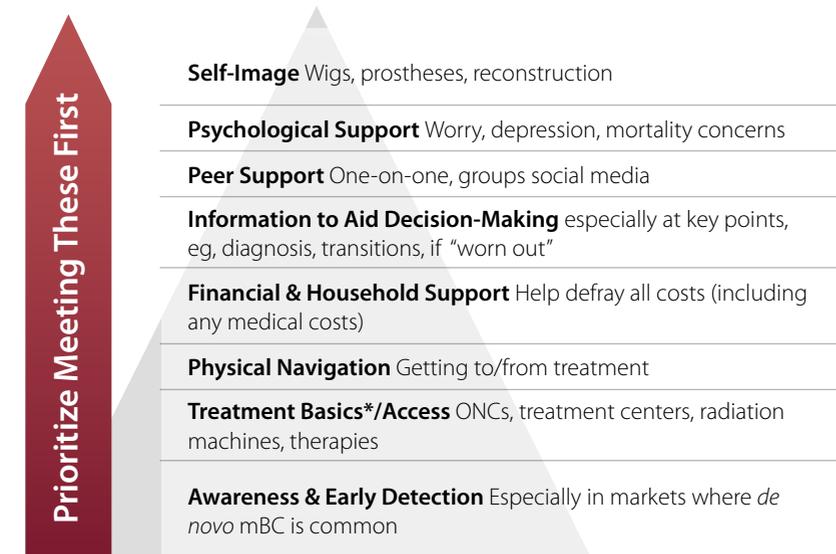
## A PSOs acknowledge the greater support needs of mBC patients, but prioritize them differently depending on available resources and local needs

The PSOs surveyed highlight a hierarchy of patient needs that exist for patients with breast cancer or mBC, and that more basic needs (awareness of breast cancer, self-examination, detection, access to treatment and availability of physicians to provide treatment) must be met before “higher-level” needs can be addressed (psychological support, aids to decision making, aids for improving self-image) (Figure 2.17).

Figure 2.17

### Hierarchy of Needs Across All Stages of Breast Cancer, as Perceived by PSOs

mBC Patient Support Organization Survey, Pfizer, 2015



\* In some countries, such as the US, reconstruction is considered as a basic treatment

\*\* The hierarchy does not suggest relative importance, provision of services, nor utilization of services, but instead provides an overlay that applies in context where needs are met as well as where they are not.



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. 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; perception of mBC patient population, 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)

PSOs report that patients with mBC have much greater needs in terms of psychological support, financial support and access to services, compared with those patients with earlier stage disease.

(mBC Patient Support Organization Survey, Pfizer, 2015)

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 2.18).

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 (>90% vs 60%-69%). 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)

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

**“ 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*



Figure 2.18

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

mBC Patient Support Organization Survey, Pfizer, 2015

■ Most frequently offered activities for patients with mBC by region

Activities Engaged in to Support mBC	US and Canada (n=11)	Europe (n=14)	Asia Pacific (n=7)	Latin America (n=10)	Africa and Middle East (n=8)
Awareness					
Patient Education					
Treatment Education					
Access Advocacy					
Peer Support					
Supporting Pts to Become Adv.					
Policy Advocacy					
Financial					
Data Generation					
Raising Awareness for Sci. Res.					
Clinical Trials/Registries					
Regulatory					
Legal					
Funding Scientific Research					

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.

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*



**B 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, as 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, a wish not to build their identity primarily on mBC, and a lessening of activity 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*



## C 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 levels. 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)
- Komen listed amongst its 2015 advocacy priorities the identification of expanded US federal funding for breast cancer research and policies that improve insurance coverage of breast cancer treatment; including, support for legislation that creates parity in insurance coverage for oral medicines compared with intravenous treatments (Susan G. Komen, National Public Policy)
- 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)

- Patient surveys carried out by the Breast Cancer Network Australia have identified both the support and information needs of patients with mBC and brought existing policy gaps to the attention of health decision-makers around workplace issues, access to superannuation, breast care nurses, and supportive care. (BCNA Survey, 2015) At the Georgetown University Lombardi Comprehensive Cancer Center in the US, the Georgetown Breast Cancer Advocates group are critically involved in research project decisions including grant approvals, ensuring all projects are patient-centered (Brundage, 2015)

For more information on PSO involvement with policy initiatives, please refer to Chapter 1: *Health Policy for mBC*.

Figure 2.19

### PSO Provision of Policy Advocacy Services by Region

mBC Patient Support Organization Survey, Pfizer, 2015

Region	BC general	mBC specific
North America	82%	45%
EU	86%	57%
Latin America	70%	70%
Africa/Middle East	29%	38%
Asia/Australia	75%	0%

When comparing the PSO's perceived needs of mBC patients vs reported activities, policy was identified by PSOs as an area where there is a gap in activity.

(mBC Patient Organization Survey, Pfizer, 2015)



Provision of policy advocacy services by PSOs also varies according to region (Figure 2.19). 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. Where although between 70-89% of PSOs engage in breast cancer policy support, less than 60% engage in the same activities specifically for mBC patients. (mBC Patient Support Organization Survey, Pfizer, 2015)

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. For example, a framework piloted in Japan and South Africa has been designed to assist advocacy organizations in effecting change for patients with cancer in general and indicated that immediate support through advocacy groups and patient forums are just as essential as long-term effects on policy. (Scheer, 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 Support 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*



## Chapter 5: Workplace Perspectives for mBC Patients

- **Issues affecting work and employment remain relevant to patients with mBC and their caregivers**
  - There are financial and psychological advantages to returning to work after a diagnosis of mBC, but staying in work can be difficult
  - Fatigue, persistent treatment-related adverse effects, and emotional ill-health can also increase the risk of not being able or allowed to work
- **In some countries, employees with cancer are protected in the workplace by disability equality legislation**
  - Where such legislation exists, employers are required to make reasonable accommodations to the work environment that prevent discrimination against employees with cancer
- Individualized accommodations as well as the support of colleagues and co-workers are important factors in facilitating return to work
- Despite this, the employment experiences of patients with mBC are variable
- Line managers need more training, support, and resources to facilitate return to work and employment retention for employees with cancer
- **More research is required to identify the specific needs of employees with mBC**

People continue to live their lives during all the events that surround a diagnosis of mBC, the demands of treatment, and the eventual preparations for the end-of-life. A diagnosis of mBC may occur when patients are active in the workplace and this brings specific challenges to both employees and employers.

All cancer survivors have a significantly increased risk of unemployment and are less likely to be re-employed than those without cancer. (Mehnert, Cancer, 2010) Cancer patients described worrying about the effect of their diagnosis on career opportunities and losing their job. (Cancer Council, Victoria, 2013) Attendance at doctors' appointments or the side effects of treatment necessitate workplace absence. However, the need to take

time off is associated with communication and relationship difficulties between employer and employee. (Cancer Council, Victoria, 2013) In a UK survey of 370 line managers from public sector, private and small-to-medium enterprises, respondents tended to be ambivalent about hiring and retaining people with cancer; a finding that brings significant implications for those wanting to return to work with the same or a different employer. (Amir, 2010) Also in the UK, the creation of the Health and Work Assessment and Advisory Service, working in conjunction with the Department of Work and Pensions, is anticipated to support return to work for people with cancer by providing occupational health advice to employers and employees. (Taskila, 2013)



**Methodology:** To understand the workplace experiences of mBC from the perspectives of both the employee and employer, a literature review was conducted on research into the impact of mBC, on work published within the past 10 years. See Appendix 2.4 for more details on the literature search methodology. Additionally, a 90-day snapshot of online sources was analyzed for discussion about employment matters for patients diagnosed with mBC. See Appendix 2.5 for details on the LexisNexis® search.

Note that the majority of published data on the impact of cancer on work generally, and mBC specifically, has been collected from Europe and the United States; data from low- and middle-income countries is scarce. Therefore, more research is required to understand the impact of mBC on employment in these countries as it would be incorrect to assume that experiences are the same in other regions. (Islam, 2014) Additionally, while the rates of return to work are relatively well documented, few studies have shed light on keeping a job, absences, and the workplace experience from the perspective of the patient, caregiver, or other stakeholders such as employers and co-workers. (Nitkin, 2011) Existing data does show that access to paid employment remains relevant to those with mBC. (Corneliussen-James, 2011)

### **A** Work and employment

Work outside of the home has variable importance in countries and cultures around the world. Gender equality, including participation, remuneration and advancement in work, has a positive correlation with per capita GDP, and female participation in the global workforce has increased over the past decade. (Schwab, 2015; OECD.stat) Having more women in the workforce benefits the social status and economic opportunities of the next generation of women; they invest a large proportion of household income into the education of their children. (Aguirre, 2012)

A survey of an international population of patients with mBC found that half of all respondents with mBC who returned to work made the decision to leave within one year.

(Corneliussen-James, 2011)

A diagnosis of mBC occurs in adults of all ages, including those of working age. (SEER.cancer.gov) The increasing number of treatment options available means that patients with mBC can receive medication for a prolonged period of time. Many with mBC who are in employment choose to return to work after their diagnosis. This can be for financial and emotional reasons. Despite a desire to continue working, challenges remain for employees with mBC and staying in work can be difficult. A survey of an international population of patients with mBC found that half of all respondents with mBC who returned to work made the decision to leave within one year. (Corneliussen-James, 2011)

### **B** Maintaining employment provides psychological, economic and societal benefits to patients with cancer and their caregivers

The (re-)integration of people living with cancer into working life is an important aspect of social functioning, according to the International Classification of Functioning, Disability and Health. (WHO.com) Return to work is associated with a return to normal activities, social recovery and rehabilitation after cancer treatment, improved well-being and a reconnection to normal life. (Islam, 2014; CBCN, 2010; Yoon-Jung, 2013) Work can also provide a distraction from illness or treatment, by keeping busy and occupying the mind. (Appendix 2.5; CBCN, 2010). Moreover, employees with mBC recognize their colleagues and co-workers as a source of support. (Appendix 2.5, Nassau Guardian, 2015)



In those with advanced cancer, employment has been associated with an improvement in well-being compared with unemployment. (Zimmerman, 2011) Employment may also improve adherence with cancer therapy. Adherence to treatment such as radiotherapy has been shown to be greater in those who are employed than the unemployed or retired, although the reasons are unclear. (Fyffe, 2010)

In those with advanced cancer, employment or retirement has been associated with an improvement in well-being compared with unemployment. (Zimmerman, 2011)

There are studies into the needs of caregivers of patients with advanced, serious illnesses, including cancer, respiratory disease, motor neuron disease, heart failure, and end-stage renal failure. They have found that while some caregivers would like to give up work and provide full-time support to a relative with serious illness, others find that continuing to work provides an important coping strategy. (Gysels, 2009) Furthermore, unemployment in caregivers can significantly increase family strain when caring for patients at the end-of-life, compared with being employed. (Yoon-Jung, 2013; CBCN, 2010)

**“The girls at work made a rota (schedule) take turns in picking me up from work as dad (my husband) was working late.”**

*90 Day Social Media Snapshot (See Appendix 2.5)*



### **© Financial burden of treatment or medical insecurity can often drive patients with mBC to return to work**

In countries where there is no national health system or a mixed public/private health service, being out of work may leave patients financially vulnerable to treatment costs. (Corneliussen-James, 2011; Timmons 2013) Although not specific to cancer, a systematic review of the direct and indirect costs of illness in low- and middle-income countries found the total economic cost of illness for households was frequently above 10% of household income, a threshold defined as “catastrophic” to the maintenance of the home; and occurring precisely at a time when domestic income is reduced. In situations like this, the family may engage in a number of coping strategies including: taking on additional employment, selling assets such as land or livestock, reducing the use of resources, including food, and borrowing money from friends, family or moneylenders. (McIntyre, 2005) In high income countries, health insurance and money worries are among the top sources of distress in patients with mBC. (Buzaglo, 2014; Breast Cancer Center Survey, Pfizer, 2015) In a systematic review of studies from 11 countries in Europe, Southeast Asia, USA and Canada, access to employer health insurance coverage or other work-related benefits, including extended sick leave or disability pensions, were identified as important influences in the decision to return to work. This finding highlights the impact of support, financial burden or fear of being unable to access affordable medical treatment in employment-related decision making. (Islam, 2014) In a separate Canadian study of 446 patients with breast cancer, one-fifth reported returning to work before they were ready, as a result of financial pressures. (CBCN, 2010)

In a Canadian study of 446 patients with breast cancer, one-fifth reported returning to work before they were ready, as a result of financial pressures. (CBCN, 2010)

Breast cancer, at any stage of diagnosis, has a serious impact on working for those who are self-employed. A lack of job security, access to employer benefits, or being unable to meet contractual commitments causes great stress. Better support is required for those who are self-employed, through, for example, extending social security or disability benefits currently available only to employees. Alternatively, it has been suggested that work-related insurance suitable for self-employed workers should be in place. (CBCN, 2010)

In many countries around the world, once employee sick leave benefits have ended, some mBC patients face the challenge of maintaining their financial contribution to the household through social security. These national benefits are mostly set at a significantly lower level than their salary. (OECD, 2011) In Canada, some patients also describe experiencing poor advice, or unrealistic expectations from social security staff. (CBCN, 2010) The situation for those patients who had a fulltime role as a homemaker prior to their diagnosis is often just as difficult. The impact of mBC may impair a patient's ability to fulfill their usual roles and responsibilities at home and require home help to be hired. As the patient is not employed, they are unlikely to be eligible for work related benefits, for example early employment insurance support, and therefore be put at a further financial disadvantage. (CBCN, 2010)

**Families and caregivers of patients with mBC are also directly affected.** Caregiving increases the risk of unemployment. (Girgis, 2013) For those caregivers who continue to work, the demands of caring for a loved one with mBC may require periods of time away from the job, giving up education or taking on overtime or part-time employment to maintain the household income. (Wan, 2012; Mazanec, 2011; CBCN, 2010; Mayer, 2015) Any reduction in paid work contributes towards caregiver social isolation and, beyond the immediate economic impact to the household, also has long-term financial consequences arising through a loss of savings for retirement. (Girgis, 2013)

### **D Employees with mBC face specific challenges arising from their cancer and treatment when considering return to work**

Significant differences in the experience of returning to work have been described by those with eBC compared with mBC. In a multicenter US survey of 730 patients aged less than 40 years, most young women with eBC remained in employment at one year following their diagnosis. Many reported that if an accommodation to their work environment was required, their employers were, on the whole, happy to make such an adjustment. Their disease did not limit their ability to work, and 74% were satisfied with their employment. (Rosenberg, 2015) In contrast, patients with mBC from many other regions around the world described their advanced disease as a barrier to returning to work. This was particularly the case when their role was manual, stressful or they considered it of low importance. (Islam, 2014; Tevaarwerk, 2010; Mehnert, Cancer, 2013) The research did not identify specific reasons why advanced disease negatively impacts return to work, but they are likely to arise from the consequences of treatment, as well as individual- and job-related factors.

Patients with mBC from many regions around the world described their advanced disease as a barrier to returning to work. This was particularly the case when their role was manual, stressful or they considered it of low importance.

(Islam, 2014; Tevaarwerk, 2010; Mehnert, Cancer, 2013)

In addition to the stage of disease, other factors that increase the risk of not being able, or allowed to work, include type of work, ethnicity, age >45, ongoing therapy, acute and delayed adverse effects of treatment, poorer



performance status, fatigue, lymphedema, mental and emotional health, and cognitive limitations. (Tevaarwerk, 2010; Mujahid, 2011; Nitkin, 2011; Islam, 2014; Valdivieso, 2012; Mehnert, Scand J Work Environ Heal, 2010; CBCN, 2010; Blinder, 2012) Some of these other factors are more commonly experienced by patients with mBC. (Yin, SABCS, 2015)

**“Undergoing treatment while working is challenging. I was the manager of an accounting department, and sometimes I’d be in the middle of something at work and would need to leave to get to the [hospital]. I was lucky that I had a very understanding supervisor.”**

***90 Day Social Media Snapshot (See Appendix 2.5)***

Indeed, breast cancer progression and treatment is associated with a lower probability of employment compared with those whose disease has not progressed, and may also result in reduced work productivity through more missed hours at work, compared with earlier stages of the disease. (Yin, SABCS, 2015) In a cohort of 2,013 Swedish and Dutch patients with breast cancer, nearly a quarter of whom had a diagnosis of mBC, 40%-41% and 69%-72% described absence from employment and reduced ability while at work respectively. (Frederix, Clinical Therapeutics, 2013) The consequences of cancer and its treatment include cognitive, physical and emotional challenges. (Feuerstein, 2006; CBCN, 2010) Furthermore, the type of therapy received also affects ability or confidence at work. Those taking hormonal therapies are more likely to be currently employed than those receiving chemotherapy. Treatment with chemotherapy is also more likely to result in caregivers taking time off from work. (CBCN, 2010) Moreover, the extent of surgery and consequences of radiotherapy may limit physical functioning and the ability to carry out some tasks at work. (Jerusalem, 2014; Mujahid, 2010; Islam, 2014)

## **E Experiences of returning to work following a cancer diagnosis are variable**

Employment law in some countries requires employers to make reasonable accommodations or adjustments for those with disabilities. (American Cancer Society, ADA; Macmillan, 2013; Chief directorate of labor relations – South Africa; Government of Canada; Rozman, 2009) The term disability can include cancer, but definitions are different between countries and do not always cover chronic illnesses. Implementation of legislation can also differ among countries and exemptions exist, for example, for small businesses employing few staff. (Association of European Cancer League, 2005; Government of Canada) The Association of the European Cancer League has proposed key areas for consideration that offer basic protection for workers with cancer when incorporated into legislation, policies and work-based tools. These key areas include recommendations for basic protection of employees (particularly vulnerable groups at greatest risk for work termination), maintaining employment and finding new work, the workplace, and caregivers or family members. (Association of European Cancer League, 2005)

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(Association of European Cancer League, 2005)



**The experiences of those returning to the workplace after a diagnosis of mBC are variable and suggest limited formal employer governance about managing employees with cancer.** In a UK survey of 219 Chartered Institute of Personnel and Development (CIPD) member organizations, only one-third reported having a good understanding of cancer and the impact of treatment in the workplace. Although cancer-specific policies may not be in place, as described by 73% of respondents, (Cancer Backup, CIPD and Working with Cancer, 2006) in many places they are instead covered by national or organizational policies and procedures designed to protect workers with long-term medical conditions. The UK National Health System provides advice to employers about supporting employees who have chronic health issues. (NHS Choices) In any case, some employees with a diagnosis of cancer describe being well supported by their employers/co-workers and describe examples of the supportive practices offered. (Cancer Council, Victoria, 2013; CBCN 2010; CEW, 2016) These include:

- Physical adjustments to the work environment
- Time off routinely granted for hospital appointments
- A supervisor who has discretion to allow an early finish on days where fatigue or other symptoms are causing a problem
- Discussion about the employee's preference for disclosure and communication with co-workers
- An annual leave bank where fellow employees can donate unused days off for use to employees going through major health or personal situations

In a UK survey of 219 Chartered Institute of Personnel and Development (CIPD) member organizations, 73% of respondents did not have a formal policy in place for managing employees affected by cancer.

(Cancer Backup, CIPD and Working with Cancer, 2006)

In Canada, patients with cancer say public services and large organizations offer greater assistance to those returning to work than smaller companies (defined as those employing less than 50 employees). (Nitkin, 2011) It has been proposed that a collaborative approach between medical personnel, employees and employers in preparation for reintegration into the workplace combined with employer accommodations may have a positive impact on return to work for people living with a cancer diagnosis. (Nitkin, 2011) The key adaptations which help people to return to work are (Nitkin, 2011; Cancer Council, Victoria, 2013; CBCN, 2010; Cancer+Careers.org):

- Flexibility and some discretion over working hours, duties, or location of work
- A gradual or step-wise return to usual working hours
- A supportive work environment including appropriate disclosure to colleagues
- Desk-based rather than manual or service jobs
- Counseling and rehabilitation
- Access and involvement of occupational health support



Note that the literature search did not identify any published research into the factors which support a return to work specifically for employees living with a diagnosis of mBC, but instead focused on cancer survivors, including those with earlier stages of breast cancer. However, data are still being generated. CanWork, a network of researchers from 10 institutions in the UK and Ireland, established in 2011, is coordinating and driving forward research into the employment experiences of patients with breast and other cancers. (Amir, 2011) In the USA, research is ongoing to explore any differences and similarities between the workplace issues experienced by patients with mBC and those with eBC. It is likely that given the differences in treatment goals and the care pathway, the situation for employees with mBC will be more complex. (Interview with Dr. Victoria Blinder, Memorial Sloan Kettering, 2016)

In recognition of unmet support needs for patients with breast cancer in Japan, psycho-oncologists in collaboration with nurses, medical social workers and a legal advisor created a “work ring”. This group provided advice on working status and practical work related issues to patients with breast cancer to ensure they were able to maintain their presence in the labor force. Following a successful pilot, this approach is being rolled out across Japan. (Yamauchi, 2013)

**Many employers and medical practitioners are not educated about the impact of mBC and its effects on work.** A UK survey found line managers need more training, support and resources to enable them to fulfill their duty of care to employees with cancer. (Nitkin, 2011; Yamauchi, 2013; Interview with Dr. Victoria Blinder, Memorial Sloan Kettering, 2016; Amir, 2010) It can be difficult for an employee to explain and predict the patient journey and timeframe associated with mBC to an employer, and indeed even an educated opinion, may prove inaccurate. Some with mBC may be able to work for many years, but the period of wellness is much shorter for most. (Interview with Dr. Victoria Blinder, Memorial Sloan Kettering, 2016) In periods where the demands of treatment are less obvious, those living with mBC can be

**“I wrote a letter to a patient’s supervisor explaining why she needed to sit instead of stand. It was a small thing. A stool. Now she can go to work and sit at the stool and be comfortable not have to worry about losing her job.”**

*Dr. Victoria Blinder, Memorial Sloan Kettering, 2016*

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(Nitkin, 2011; Yamauchi, 2013; Interview with Dr. Victoria Blinder, Memorial Sloan Kettering, 2016; Amir, 2010)



seen by their employers and colleagues as “normal now” and may find it challenging to have their needs for work accommodation or medical appointments accepted. (National Institutes of Health, 2014; Sortor, 2016)

In periods where the demands of treatment are less obvious, those living with mBC can be seen by their employers and colleagues as “normal now” and may find it challenging to have their needs for work accommodation or medical appointments accepted.

(National Institutes of Health, 2014; Sortor, 2016)

When an employee with mBC experiences disease progression that requires changes to their treatment plan, they may need their employer to consider changes to any accommodations that have already been made. For example, if an employee is taking an oral treatment for mBC they may only need one doctor visit per month. If their treatment then changes to a combination of intravenous chemotherapies they are likely to need more hospital visits. Despite limited understanding, employers will also need to be empathetic and consider that despite “looking well” employees with mBC may still be experiencing adverse effects of treatment. Symptoms such as peripheral neuropathy and fatigue, commonly caused by mBC therapy, are not visible but can be long lasting and will impact the daily lives of employees experiencing them. (Interview with Dr. Victoria Blinder, Memorial Sloan Kettering, 2016)

Employees say that patient information about access to work or disability benefits is often lacking. (Cancer Council, Victoria, 2013) In a pilot study in the Netherlands, half of occupational health physicians questioned reported that the provision of an educational leaflet with a treatment plan letter, given to the patient prior to their return to work, was helpful to both the patient and employer; the majority of employees living with cancer adhered to the steps of advice in the booklet. (Nieuwenhuijsen, 2006) Organizations such as Cancer and Careers and Workplace Transitions in the United States, Macmillan Cancer Support in the United Kingdom and the Danish Cancer Society have produced a series of resources to support employees, employers and co-workers in managing the consequences of living with a cancer diagnosis and treatment in the workplace. (Cancer+careers.org; workplacetransitions.org; macmillan.org.uk; Olgod, 2007) Such resources aim to provide practical, targeted support and are readily accessible online.

Despite limited understanding, employers will also need to be empathetic and consider that despite “looking well” employees with mBC may still be experiencing adverse effects of treatment.

(Interview with Dr. Victoria Blinder, Memorial Sloan Kettering, 2016)



Discrimination has also been described by employees with BC, such as reduced hours, changes to role, demotions and work termination. (Cancer Council, Victoria, 2013; Nitkin, 2011; CBCN, 2010) However, evidence from Australia suggests that cancer patients infrequently report discrimination. (Cancer Council, Victoria 2013) Unfortunately, the reaction of work colleagues can also be negative, with co-workers often unsure of how to approach and talk to their colleague with cancer. In one survey, about 25% of workers expressed concern that they would be expected to pick up the slack from a colleague returning from cancer treatment. (Nitkin, 2011)

In one survey, about 25% of workers expressed concern that they would be expected to pick up the slack from a colleague returning from cancer treatment.

(Nitkin, 2011)

In conclusion, patients with mBC choose to return to work for both financial and emotional reasons. (A Story Half Told, Pfizer, 2014) However, existing data is limited as to the specific employment needs of employees with mBC who intend to return to work. The consequences of treatment for mBC result in emotional, physical and cognitive changes that employers need to be aware of when supporting an employee with mBC returned to work.



## Chapter 6: The Impact of mBC on Patient Social Relationships and Caregivers

- Patients with mBC try to protect themselves from the societal opinions expressed by the general public about their disease, by limiting contact with or ignoring the views of those outside of their social network
- The dichotomous public opinion of mBC as either a hopeless diagnosis, or one which can be beaten and cured, leaves patients in despair with a diminished sense of hope, frustrated and inhibited to share their own fear
- Interpersonal relationships with caregivers and those close to patients with mBC are critical to the patient's sense of well-being
- Those with mBC describe friends, family, and their spouse or partner, as their best source of support and help with coping
- Caregivers feelings about the situation are complicated, and they find the role can be both positive, but also stressful
- However, caregiver support needs are often overlooked
- Strategies are needed to identify and meet the psychosocial, occupational and financial needs of caregivers surrounding the challenges of balancing work, commitments at home and caregiving

Patients with mBC experience a wide range of physical and emotional symptoms that require additional support, both directly and indirectly, as a consequence of the effect of cancer and its treatment. (Hasson-Ohayson, 2010; mBC Patient and Caregiver Qualitative Research, Pfizer, 2016) Although the interaction between support and coping is complex, the presence of a feeling of support is associated with hope among adults with advanced cancer. (Hasson-Ohayson, 2010; Hasson-Ohayson, 2014) Patients want to maintain their identity for as long as possible and are concerned about the financial, emotional, and practical burdens arising from prolonged treatment for mBC. They describe that, emotionally, the best support boosts their moral; it helps them to stay positive but realistic, keep strong, and doesn't deny their struggles but allows them to express the emotions that they are feeling. The demands of caregiving are far-reaching and must not be underestimated, as spouses, families, and friends feel the repercussions of a diagnosis of mBC in a loved-one. Family caregivers are known to provide a vital role in caring

for patients with mBC, but their understanding of the disease is often fairly limited at the time of diagnosis. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016)

Qualitative interviews with 28 patients and caregivers were carried out to inform this chapter. The aim of this primary research was to explore the interactions between patients with mBC and members of the general public. The results showed that the quality of interpersonal relationships with caregivers and those close to patients with mBC are critical to the patient's sense of wellbeing. Furthermore, the research confirmed that attitudes about mBC, particularly in developing countries, are still extreme; the diagnosis is seen as either a hopeless situation or something that can be beaten and cured. As a result, patients with mBC either ignore the views of the general public or limit contact with people outside of their support network in an attempt to avoid thoughtless comments or misperceptions about the disease. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016)



**Methodology:** To obtain a greater understanding of the personal experiences and perspectives of mBC patients and their caregivers, before and after a diagnosis, 28 individual, 60-minute telephone or face-to-face interviews were conducted from January 6 to 29, 2016. Responses were sought from 14 patients and 14 caregivers from US, UK, Turkey, India, Egypt, Brazil, and Mexico. Findings were analyzed qualitatively to identify key themes and differences across these 7 countries. Additionally, a qualitative review of published research on the support needs of patients and caregivers was undertaken. Full details of the search strategy can be found in the Primary Research Appendices.

### **A The Impact of mBC on Patient Social Relationships**

Some patients feel the need to withdraw from their social network during cancer treatment, resulting in feelings of loneliness. Alternatively, friends and family may choose to refrain from contact as they are concerned about exposing the patient to infection while their immune system is suppressed. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016; mBC Patient and Caregiver Qualitative Research, Pfizer, 2016; Leadbeater, 2008) Social withdrawal can be a particular problem during treatment with chemotherapy, and has been attributed to treatment-adverse effects causing patients to feel unwell, inability to maintain the household or offer hospitality, or to cope with changes in body image. Isolation can also occur if an existing relationship with a partner breaks down, or for those who are single. Patients in this situation describe not wanting to burden a new partner with the demands of cancer and its treatment, concerns about changes in body image, and what the future holds. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016)

**“She was hostile, did not want to see anybody, and did not want anybody to see her. She was really beautiful... She did not want people see her like that. Bald, swollen.”**

#### **Caregiver of patient with mBC, Mexico, 2016**

The general public can be intentionally and unintentionally less supportive to patients with mBC. In some low- and middle-income countries, particularly among rural populations, some respondents in two surveys reported that breast cancer should not be openly discussed. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016; mBC General Population Survey, Pfizer, 2015) They believe that mBC is contagious and ostracize patients by avoiding or refusing to eat with them. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016) As discussed in detail in Section 2, Chapter 3, *Public Understanding of mBC*, public understanding of mBC is limited, which has exacerbated the mBC patients' feelings of isolation and stigmatization. Some of the general public either refer to mBC in terms of an imminent death sentence, or do not differentiate between mBC and eBC and, hence, are overly optimistic. In this case, they minimize or misunderstand the seriousness of the situation by telling the patient that they are going to be fine, or that mBC can be cured (Figure 2.20). These two extremes of popular opinion regarding the severity of mBC leave patients either

Some of the general public either refer to mBC in terms of an imminent death sentence, or do not differentiate between mBC and eBC and, hence, are overly optimistic.

(mBC Patient and Caregiver Qualitative Research, Pfizer, 2016)



**“I have other friends that said, ‘You’re going to be fine,’ and I wanted to punch them. I thought, I’m not fine.”**

**Patient with mBC, US**

despairing, with a diminished sense of hope, or frustrated and inhibited to share their own fears. Furthermore, mBC patients highlighted examples of media campaigns in the UK and US that give a sense that they are to blame for their diagnosis by drinking alcohol, smoking, or not having children. Fundraising or awareness building efforts such as “no bra day” are considered by mBC patients to be insensitive, particularly to those who have had their breasts removed after breast cancer surgery. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016)

As a result of these experiences, patients ignore or reduce contact with those in the general public that they find less supportive or understanding. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016) However, respondents recognize that their close network of supporters remain there for them, despite the challenges of their diagnosis. In fact, experiences with their social network are on the whole positive. Interpersonal relationships frequently become stronger, with the support group becoming very protective of the person with mBC. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016)

Patients ignore or reduce contact with those in the general public that they find less supportive or understanding.  
(mBC Patient and Caregiver Qualitative Research, Pfizer, 2016)

Figure 2.20

**The Challenges of Extreme Societal Opinions Regarding mBC**

mBC Patient and Caregiver Qualitative Research, Pfizer, 2016

<b>mBC Attitudes</b>	
<i>Death sentence</i>	<i>Curable</i>
Some believe people with mBC will die very soon	Others are overly positive, thinking people can “beat” mBC
Driven by perception that all cancer is terrible / imminently fatal	Typically driven by visibility of success stories in eBC
Or by perception that once cancer spreads, end-of-life must be close	Patients themselves may believe their mBC can be cured – in some cases, the medical team appears to have painted an overly positive picture

**Spouses, friends, and family, play a critical role as a support network for those diagnosed with mBC.** In the mBC Patient and Caregiver research, a ranking of primary concerns illustrates the breadth of fundamental issues with which mBC patients struggle (Figure 2.21). (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016) Those with mBC describe friends, family, and their spouse or partner, as their best source of support and help with coping. (Hasson-Ohayson, 2010; mBC Patient and Caregiver Qualitative Research, Pfizer, 2016) However, at an individual level, the network of support can be much broader than this and could include, medical staff, neighbors, local store owners and, of course, other people receiving similar treatment either met face-to-face or through social media. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016) Those who are religiously engaged, find the ongoing support of their clergy or congregation has a positive effect on their mood. Maintaining spiritual support by meeting



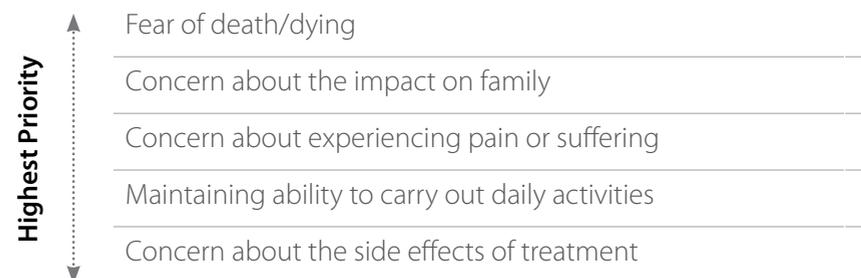
Those with mBC describe friends, family, and their spouse or partner as their best source of support and help with coping. (Hasson-Ohayson, 2010; mBC Patient and Caregiver Qualitative Research, Pfizer, 2016)

individual preferences for a faith leader or congregation contact, either at home or through assisted visits to the patient's place of worship, is associated with decreased depression during periods of serious ill health. (Hays, 2011)

Figure 2.21

### Primary Patient Concerns

mBC Patient and Caregiver Qualitative Research, Pfizer, 2016



Ultimately, any member of the support network may be the caregiver, but frequently this function is performed by the patient's spouse or children. (Feiten, 2013) The presence of a caregiver is important for the patient's feeling of social support. Women with mBC who had a caregiver were more likely to feel satisfied with the social support that they received from friends and family, compared with those women who did not. (Mertz, 2013)

The care needs of patients evolve over time, increasing as the consequences of mBC and its treatment limit physical abilities. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016) Support is required in practical, financial, and emotional ways. Patients describe how their supporters attend doctor or treatment appointments with them, provide personal care such as washing and feeding, are there to talk when they need them, and will comfort them when they feel emotional. Other practical acts of support include child care, cooking, cleaning, taking patients out, or running errands. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016) However, patients describe that the most helpful support they receive from caregivers is emotional. It boosts their morale, helps them to stay positive but realistic, keep strong, and doesn't deny their struggles but allows them to express the emotions that they are feeling. In many situations, caregivers will also provide financial support by paying for treatment and hospital visits. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016)

**“Then, my biggest worry was finding a way of telling my mother, who has a heart condition, and telling my children. I thought about them. I never thought: ‘I’m going to die.’ Frankly, I never thought about that. I thought: My God, how can I look after my family now? ”**

*Patient with mBC, Brazil, 2016*



**“They supported me in terms of everything.”**

*Patient with mBC, Egypt, 2016*

In some countries, the patient is protected by caregivers from the realities of an mBC diagnosis. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016) The mBC Patient and Caregiver Qualitative Research identified examples in some low- and middle-income countries, where patients are “protected” from their mBC diagnosis by their caregivers and doctors. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016) The reasons for this are sociocultural and reflect the contrast between a Western approach to informed consent and patient autonomy, and a family-centered approach to decision-making, which is still prevalent in some countries. (Aljubran, 2010; Chittem, 2015) Members of the family may request non-disclosure of mBC diagnosis due to the perception of hopelessness and concerns about the psychological impact on the patient. Some family members believe that patients, especially older women, would become overwhelmed by the bad news or weight of decision-making and, hence, these family members take over responsibility for this. (Aljubran, 2010)

**“We told her that she has a herniated disk, but that she can’t undergo surgery due to the presence of a tumor... [Family and friends] are not allowed to talk to her about it. I told them all to not mention the disease to her at all.”**

*Caregiver of patient with mBC, Egypt, 2016*

While patients in family-centered cultures accept that their family will take over some or all of their responsibilities, in other cultures, patients feel ambivalent or find it difficult to accept offers of help for a number of reasons. They want to maintain their identity for as long as possible and are concerned about the financial, emotional and practical burdens arising from prolonged treatment for mBC. Patients may also feel responsible for the disruption that their illness has caused to the lives of those close to them and, hence put on a brave face to protect their loved-ones as much as possible from the situation. (Sulik, 2007; mBC Patient and Caregiver Qualitative Research, Pfizer, 2016) In certain circumstances, patients with mBC might try to protect some members of their support network, especially close family, who find the situation difficult to handle. This can create a feeling of distance in the relationship as information about the disease and treatment is passed on, only on a “need to know basis.” (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016)

In certain circumstances, patients with mBC might try to protect some members of their support network, especially close family, who find the situation difficult to handle.

(mBC Patient and Caregiver Qualitative Research, Pfizer, 2016)



## B The Impact of mBC on Caregiver

**The responsibility of caregiving for someone with mBC has a significant effect on the caregiver.** In a 2015 public survey, respondents from the general public across 14 countries recognized that mBC puts a considerable emotional strain on family and friends. (mBC General Population Survey, Pfizer, 2015) Family caregiving for patients with end-stage medical conditions is potentially life changing. (Hasson-Ohayson, 2014) Caregiver's worries focus on their loved one's well-being, disease status, and ability to maintain life activities. (Mayer, 2015) Feelings about the situation are complicated, and caregivers may find the role can be positive, but also stressful. (Badr, Health Psychol, 2010) They describe the experience as both profound and overwhelming, and perceive any burden associated with caring increases as the functional status of their loved one declines. (Hasson-Ohayson, 2014; Mayer, 2015; Grunfeld, 2004) Some do feel unappreciated. (Mayer, 2015) However, in a survey of mBC caregivers in the US, while 50% felt that no one understood what he or she was going through, the majority agreed that they always try to maintain a positive outlook and many feel that their caregiving is a choice, not an obligation. (Mayer, 2015)

In a survey of mBC caregivers in the US, while 50% felt that no one understood what he or she was going through, the majority agreed that they always try to maintain a positive outlook and many feel that their caregiving is a choice, not an obligation. (Mayer, 2015)

A Canadian survey of 89 caregivers of patients with mBC found that approximately two-thirds reported some form of adverse impact on work.

(Grunfeld, 2004)

The literature search found research on the effects of caregiving on spouses. A diagnosis of mBC affects both members of a couple, and the patient and his/her partner often acts as a primary source of support for each other. (Badr, Health Psychol, 2010) The demands of providing care for a loved one extends beyond personal relationships; caregivers experience psychological and economic strain resulting in decreased well-being and symptoms of stress. (Grunfeld, 2004; Hasson-Ohayson, 2010; Hasson-Ohayson, 2014) Notably, the economic burden to caregivers is often overlooked and poorly understood. (Wan, 2013) A Canadian survey of 89 caregivers of patients with mBC found that approximately two-thirds reported some form of adverse impact on work. This included work-absence or the need to take annual or special leave as a result of caregiving responsibilities. In a small number of cases, caregivers had to give up work or decline opportunities for promotion. (Grunfeld, 2004)



**“It’s different. [Her husband] kind of distances himself a bit, like he wants to break down and cry and he’ll go out and drive, but he can’t handle it as much. He doesn’t know much detail about what’s going on because she knows he can’t really handle it so it’s distant in terms of that.”**

*Caregiver of patient with mBC, US, 2016*

When the caregiver is the spouse, the demands of caregiving can also result in marital strain. (CBCN, 2010) Emotional distance can be created as couples cope with cancer; potentially contributing to impairment in sexual relationships and decreased marital satisfaction. (Milbury 2013) Spouses of patients with breast cancer are known to be directly affected by the illness, with the impact being greatest in spouses of those with mBC. (Hasson-Ohayson, 2010; Badr, Health Psychol, 2010) Although the evidence is not clear-cut, some studies found that the distress experienced by spouses may be greater than that of the patient with mBC themselves. (Hasson-Ohayson, 2010) In fact, levels of anxiety and depression were higher in caregivers than patients during the terminal phase of mBC. (Grunfeld, 2004) Caregiver’s stress and the demands of caring may impair their ability to provide adequate support for their loved one, (Badr, Health Psychol, 2010) and can manifest as caregiver ill-health through the abandonment of his or her own self-care needs. (Blum, 2010)

Age and gender are relevant variables in the experiences of caregivers. In general, spouses report significantly lower levels of social support from friends and family. Younger spouses appear to experience greater distress than older spouses perhaps because of the need to juggle work and child care commitments resulting in feelings of being overwhelmed. (Hassan-Ohayson, 2010; Hassan-Ohayson, 2014) Furthermore, evidence suggests that this strain may be greater for men than women. Men, who are traditionally thought of as relying solely on their spouse for emotional support, might undergo a period of readjustment as they need to find another source of

such support. (Hasson-Ohayson, 2010) This readjustment can be challenging to the partner with mBC, and they may feel upset by the fact that they are no longer able to fulfill their responsibilities to their spouse. (mBC Patient and Caregiver Qualitative Research, Pfizer, 2016)

Caregiver’s stress and the demands of caring may impair their ability to provide adequate support for their loved one and can manifest as caregiver ill-health through the abandonment of his or her own self-care needs.

(Badr, Health Psychol, 2010; Blum, 2010)

**Addressing the needs of caregivers, particularly spouses, is important but not often considered.** Just as mBC patients need practical, emotional and financial support, so do caregivers. However, their support needs are often overlooked. Spousal distress may go unnoticed when spouses are seen as caregivers, not as individuals in need of care themselves. (Hasson-Ohayson, 2010) In fact, patients with breast cancer remain a significant source of support to their spouse despite having increased support needs of their own. Caregiver support networks are important in mitigating the distress caused by the disease to both patient and caregiver. The support from friends and family appears to provide



greater protection from psychological distress than the support the spousal partnership offers. (Hasson-Ohayson, 2010) Importantly, the beneficial impact of a social support system appears consistent over all stages of the disease. The support given to the spouse is of equal importance as the support given directly to the patient in determining the patient's level of distress. Spousal support provides a buffer against both the emergence of depression and anxiety amongst patients with mBC, and the psychological wellbeing of both the patient and spouse. (Hasson-Ohayson, 2010) It has been suggested that this is because, in the case of a female patient, spousal support allows her to relinquish her normative role as a care provider to her husband at a time when she needs to focus on her own wants and needs. (Hasson-Ohayson, 2010) This suggests a need for couple-focused interventions to ensure that both members of the couple can adaptively cope with cancer together. (Badr, Health Psychol, 2010)

In conclusion, primary research showed that patients with mBC may actively reduce the size of social networks to those who matter to them the most. In this regard, patients, on the whole, feel well supported by their spouse, family and friends. The support needs of caregivers are currently largely unmet. Caregivers described wanting access to support services or support groups but were unable to find such support at the time of their loved one's diagnosis. (Mayer, 2015) It is important to recognize that preferences for support vary with the age of the caregiver. While older spouses tend to look to the family for help, younger spouses are more likely to look to their friends. (Hasson-Ohayson, 2014) Strategies are needed to identify and meet the psychosocial, occupational and financial needs of caregivers given the challenges of balancing work, commitments at home and caregiving. (Grunfeld, 2004) Resources and sources of support are also required for family members and other members of the support network. (Mertz, 2013)



Angela Barker, mBC patient from the UK, with her daughter, Sarah-Jane. Angela was diagnosed in February 2016 and is living with mBC.



# Emerging Recommendations

This section discussed a broad scope of political, societal and community factors that impact mBC patient care. Although insight has been shared broadly around policy approaches and the economic burden associated with mBC, recommendations largely focus on continuing to educate and inform relevant stakeholders on the role of policy in mBC care and the economic impact of the disease. 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 Patient Support Organizations (PSOs), which are discussed in the recommendations below.

Ultimately, the following recommendations will 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.

## **Broaden the approach to health policy development beyond screening and early detection of breast cancer**

- Identify the elements of effective health policy that will positively influence mBC care
  - Emphasize that while screening and detection of eBC is important, it will not address the needs of those who are diagnosed with mBC
- Address inherent limitations in healthcare systems to improve outcomes for patients with mBC
- Accurately quantify the burden of mBC within a population to allow policy makers to make informed decisions about the needs of their communities
- Capture and promote the experience and needs of patients with mBC to national level health planners and policy makers

## **Increase understanding and awareness of the costs of mBC, from an individual perspective as well as from a health system or societal perspective**

- Recognize the excess financial impact and associated distress of mBC on patients and their families/caregivers, particularly at the end-of-life, compared to eBC
- Openly discuss costs of treatment options and potential reduced work productivity so patients are able to make appropriate financial plans for the future, this may be particularly impactful to younger patients
- Create financial support services that can help patients manage the acute financial difficulties many describe experiencing during mBC treatment

## **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 philanthropists, government officials, general public journalists, 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



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

- Further development of mBC-specific support services that address patient and family needs is critical, especially for younger women. These services could include peer-support networks, educational initiatives and financial support
- Increase proactive communication highlighting specific support services, including counseling and online support groups
- Enable the creation of financial support services and encourage appropriate financial planning
- Increase global accessibility to support services for all patients with mBC

**Development of a globally impactful alliance for mBC advocacy, replicating some of the successes seen by organizations such as the US mBC Alliance, which include policy efforts, patient and physician communications resources and disease awareness initiatives**

- Provide a platform for advocates to educate one another 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 PSOs to drive consistency of communication about mBC

**Advance 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 that which has been seen for eBC
- Provide mBC with a distinct identity separate from eBC
  - Globally leverage Metastatic Breast Cancer Awareness Day beyond the current reach to expand this initiative across more countries and with increased visibility

**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 regarding best practices in reporting mBC and advanced cancer generally



### Better attention should be given to the needs of patients with mBC in the workplace

- Exploration of employment rights in each country to determine how these currently meet the needs of employees with mBC and what changes are required to facilitate a return to work after a diagnosis of mBC
- Greater access to financial support for those without an employer or in self-employment
- Development of educational materials to create greater understanding among employers and primary care/occupational health staff about the pressures of an mBC diagnosis on working life
- Guidance for employers that support employees with mBC in their desire to return to work and where, particularly, their ability has been compromised

### The societal impact of mBC on patients with the disease and their caregivers needs to be understood

- Greater public understanding of a diagnosis of mBC is required to protect mBC patients from the need to withdraw from social networks that share extreme perceptions that the disease is an imminent death sentence or conversely that the patient will “just be fine”
- Greater recognition of the impact of mBC on caregivers
- A change in perspective on caregivers by health care professionals to recognize and address their care needs in a way that reflects age and gender preferences for support
- Educational materials specifically targeted at caregivers, which aims to bring them up to speed on the matters of greatest importance that informs the medical care of their loved one and treatment options
- Provide resources to services that can support caregivers practically, financially and emotionally



# Appendices and References

## Section 2: Appendix 2.1

### Policy Trends Research Methodology

**Purpose:** The purpose of this search was to understand global political actions on behalf of patients with mBC.

**Method:** For this search, a literature scan was conducted to better understand policy trends that may impact the mBC space. Although a formal systematic literature review was not conducted, this section was written based on a thorough search of literature around mBC and policy trends.

**Sources:** In order to gain an understanding of policy trends, a qualitative literature scan was conducted using secondary source articles. The search was restricted between the years of 2005 and 2015 using the peer reviewed journal *Health Affairs* to find relevant articles. Other supplemental sources were also obtained using PubMed.

**Search terms:** Search terms were chosen based on their relevance to policy and mBC.

Category	Key Terms
Disease	"metastatic breast cancer" OR "advanced breast cancer"
Category	"policy"

**Results:** In *Health Affairs*, the search "metastatic breast cancer' policy" yielded 19 search results. Similarly, "advanced breast cancer' policy" yielded 13 search results. These articles were reviewed for information on cost-effectiveness policy, coverage and reimbursement policy, distinct case studies, and general cancer care. Articles from these searches were fully reviewed for content and relevance, those that were most relevant to mBC policy for the purpose of this report were included in this section. In addition, other articles found from other database or general searches were included in this section to enhance understandings of policies around metastatic and advanced breast cancer.

**Limitations:** This search was not a systematic literature review and therefore may not scientifically reflect global political decisions on metastatic breast cancer. However, *Health Affairs*, as well as the other peer-reviewed sources used, are trusted sources for gleaning information about global political views in many therapeutic areas and therefore, we believe that this section accurately portrays general policy trends in mBC.



## Section 2: Appendix 2.2

### Economic Burden Literature Review Methodology (3/17/2015)

**Purpose:** The purpose of this literature search was to understand the economic challenges mBC patients and their families face from the point of diagnosis until end-of-life.

**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, particularly that of economic and financial hardships.

**Sources:** In order to gain an understanding of the economic burden of mBC, a literature review was conducted using secondary source data. The search was restricted between the years of 2005 to 2015 from 4 main databases: Medline, Medline In-Process, EMBASE, and Cochrane Library.

**Search terms:** Search terms were selected with the intent to ascertain all essential articles related to economic and financial experiences of mBC patients, caregivers, and their families. A complete list of search terms is provided in the table below.

Category	Key Terms
Disease	"metastatic breast cancer"
Category	"economic burden" OR "cost" OR "cost of illness"

#### EMBASE search conducted on the 17th March 2015:

	Searches	Results
1	"breast"/exp OR breast AND ("metastasis"/exp OR metastasis)	89,063
2	"breast metastasis"/exp OR "breast metastasis" AND [2005-2015]/py	
3	"breast"/exp OR breast AND ("metastasis"/exp OR metastasis) AND [2005-2015]/py	
4	#1 OR #2 OR #3	
10	economic AND burden	
12	"cost"/exp OR cost	
13	#10 OR #12	
14	#4 AND #13	



**MEDLINE search conducted on the 18th March 2015:**

	Searches	Results
1	Search metastatic breast cancer.mp Filters: published in the last 10 years	22639
2	Search (metastatic OR metastasis).mp breast (cancer OR tumour OR malignan* OR oncology OR carcinoma* OR neoplas* OR mass OR growth* OR cyst).mp; Filters: published in the last 10 years	29
3	#1 OR #2	22665
4	Search "Cost of Illness"[Majr] Filters: published in the last 10 years	5021
5	#3 AND #4 Published in the last 10 years	9
6	Search ("economic burden") OR "cost" Filters: published in the last 10 years	175154
7	#10 OR #12	455
8	#5 OR #7 Published in the last 10 years.	455

**Cochrane search conducted on the 18th March 2015:**

	Searches	Results
1	MeSH descriptor: [Breast Neoplasms] explode all trees	8904
2	(metastatic or metastasis).mp	453
3	#1 and #2	38
4	MeSH descriptor: [Cost of Illness] explode all trees	1167
5	#3 and #4 Publication Year from 2005 to 2015	3

**Cochrane search conducted on the 18th March 2015:**

	Searches	Results
1	breast (cancer or tumour or malignan* or oncology or carcinoma* or neoplas* or mass or growth* or cyst) .mp	574
2	(metastatic or metastasis) .mp	453
3	#1 and #2	179
4	(economic or burden or cost).mp	2207
5	#3 and #4 Publication Year from 2005 to 2015	93



**Results:** After the searches were completed and duplicates, a total of 526 abstracts were collected and recorded in an excel document, including relevant sources information and abstract text. Of After reviewing these articles for relevancy, 37 full text articles and 10 abstracts were assessed for eligibility. Articles were removed from the original collection due to differences in language, being therapy specific, demonstrating burden of skeletal events only, not pertaining to mBC, and not portraying cost data. A total of 26 articles and 3 abstracts were included in the quantitative synthesis.

These articles were then fully reviewed to glean key messages and information about the economic challenges of mBC patients. Thorough examination of all articles and abstracts allowed for the best selection of articles relevant to the economic burden piece; however, the writing does include references to other sources to add appropriate context.

**Limitations:** Despite this systematic approach, limitations to this search methodology exist. Specifically, articles irrelevant for this section 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 if the databases failed to capture all relevant articles in the space based on the search terms used. However, based on the credibility and number of databases, this limitation is unlikely to significantly impact the findings. Lastly, to add necessary context to research findings, articles from separate searches are included in this piece and therefore, for those articles, we cannot be certain that the articles represent all possible perspectives in this space.



## Section 2: Appendix 2.3

### Public Understanding Literature Search (July 2015)

**Purpose:** The purpose of this search was to gain an understanding of the public perception of mBC 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 LexisNexis®.

#### Search Terms:

Category	Key Terms
Therapies	Lapatinib, Trastuzumab OR T, Herceptin, Patritumab, Arimedex OR anastrozole, Aromasin OR exemestane, "aromatase inhibitor", BKM120, BYL719, Paclitaxel OR "Paclitaxel albumin" OR P-A OR Abraxane, Eribulin OR E, Halaven, Bevacizumab OR Bev, LEE011, Abemaciclib, Neratinib, "GnRH agonist", "LHRH agonist", "GnRH antagonist", "LHRH antagonist", Omnitarg, Everolimus OR RAD001 OR EVE OR Afinator, Buparlisib, Entinostat, Fulvestrant OR Falsodex, Femara OR Letrozole, Tamoxifen, Toremifene, Gemzar OR gemcitabine, kadcyla, Pertuzimab OR P, Perjeta, Palbociclib OR PD-0332991 OR IBRANCE OR Ibrance, Vintafolide OR V, Docetaxel, "End of life care" OR "end of life" OR EoL OR "EoL care", "supportive care", "palliative care", "radiation therapy", "CDK 4/6 inhibitor", "surgical therapy", "surgery", "mastectomy" "Lumpectomy", amoxifen, Anthracycline, Capecitabine OR C, Xeloda, "investigational", "radiotherapy", "chemotherapy", "hormone therapy", "endocrine therapy"
Disease	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-



(continued) **Search Terms:**

Category	Key Terms
Outcome Measure	OS OR "Overall survival", "survival rate", PFS OR "Progression free survival", "TTP" OR time to progression"
Trial	"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"
Metastases	"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
Patient Reported Outcome	"Patient reported outcomes" OR PRO OR "patient-reported outcomes", Efficacy
Tolerability	Tolerance OR Tolerability
Side Effects	"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
Value	"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"
Social	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"
Country	All country members of the United Nations



**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 LexisNexis® 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 section 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: Appendix 2.4

### Workplace and Community Literature Review

**Purpose:** The purpose of this search was to better understand the perspectives of patients, caregivers, and employers from patient diagnosis with mBC to final stages of life through a systematic literature search.

**Method:** As outlined in more detail below, a broad search strategy was employed 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 of patient's societal experience, a qualitative literature review was conducted using secondary source data. Five separate search strategies were used to capture the complete immediate societal impact on the patient. The search was conducted in EMBASE with the search terms listed below.

**Search Terms:** Search terms were selected with the intent to ascertain all essential articles to understand the patient's societal experience. A complete list of search terms are provided in the table below.

Category	Search Terms	Number of Articles
Advanced Cancer and Job Performance	(advance* or metastatic or metastat*) and (cancer* or neoplasm* or tumour* or tumor*) and (("job performance"/ exp or "job performance") or "job satisfaction")	2
Advanced Cancer and Work and Law	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-	3



(continued)

Category	Search Terms	Number of Articles
Advanced Cancer and Work	or ("unemployment"/exp or "unemployment") or ("unemployed"/exp or unemployed) or ("retirement"/exp or "retirement") or ("sick leave" or "sickness absence" or "absenteeism") or (vocational* or "work ability" or "work capacity" or "work activity" or "work disability" or "work rehabilitation" or "work status" or "work retention" or "workability" or "employability" or employable or employee) or ("occupation"/exp or "occupation") or ("vocational rehabilitation"/exp or "vocational rehabilitation") or ("work disability"/exp or "work disability") or "disability management") and (advance* or metastatic or metastat*) and (cancer* or neoplasm* or tumour* or tumor*) and (("policy"/exp or policy) or ("support group"/exp or "support group") or support or "policymakers")) and (1997:py or 2004:py or 2005:py or 2006:py or 2007:py or 2008:py or 2009:py or 2010:py or 2011:py or 2012:py or 2013:py or 2014:py or 2015:py)	18
Advanced Cancer Work and Patient Advocacy	((("work resumption"/exp or "work resumption") or ("return to work"/exp or "return to work") or ("employment"/exp or "employment") or ("employment status"/exp or "employment status") or ("unemployment"/exp or "unemployment") or ("unemployed"/exp or unemployed) or ("retirement"/exp or "retirement") or ("sick leave" or "sickness absence" or "absenteeism") or (vocational* or "work ability" or "work capacity" or "work activity" or "work disability" or "work rehabilitation" or "work status" or "work retention" or "workability" or "employability" or employable or employee) or ("occupation"/exp or "occupation") or ("vocational rehabilitation"/exp or "vocational rehabilitation") or ("work disability"/exp or "work disability") or "disability management") and (advance* or metastatic or metastat*) and (cancer* or neoplasm* or tumour* or tumor*)) and (advocacy or ("patient advocacy"/exp or "patient advocacy"))	3
mBC and the Wider Community	(((((advance* near/6 breast and ("cancer"/exp or cancer) or (advance* near/6 breast and ("neoplasm"/exp or "neoplasm")) or (advance* near/6 breast and carcinoma*) or (advance* near/6 breast and tumour*) or (advance* near/6 breast and tumor*) or (metastatic near/6 breast and ("cancer"/exp or cancer)) or (metastatic near/6 breast and ("neoplasm"/exp or "neoplasm")) or (metastatic near/6 breast and carcinoma*) or (metastatic near/6 breast and tumour*) or (metastatic near/6 breast and tumor*)) and (((("social environment"/exp or "social environment") or ("support group"/exp or "support group") or ("social isolation"/exp or "social isolation") or "community support" or "community attitude" or ("social support"/exp or "social support") or ("friend"/exp or "friend") or ("peer group"/exp or "peer group")) or "public awareness")) not "early stage") and (2004:py or 2005:py or 2006:py or 2007:py or 2008:py or 2009:py or 2010:py or 2011:py or 2012:py or 2013:py or 2014:py or 2015:py)	11



**Results:** A total of 37 articles were systematically recorded in an Excel document, including relevant source information and abstract text. These articles were fully reviewed and relevant content was highlighted as evidence in this section. Reasons for article exclusion included content being irrelevant for mBC patients or duplication in search results. As this section was not meant to be a systematic literature review, only the most relevant articles were included. Thorough examination of all abstracts allowed for the best selection of articles relevant to supportive care for patients living with mBC.

**Limitations:** Despite this systematic approach, limitations to this search methodology exist. Specifically, articles irrelevant for this section might have appeared in the search through selected search terms being used in different contexts. For example, if the search term was “mBC,” non-“mBC” 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 if the databases failed to capture all relevant articles in the space based on the search terms used. However, based on the credibility and number of databases, this limitation is unlikely to significantly impact the findings.

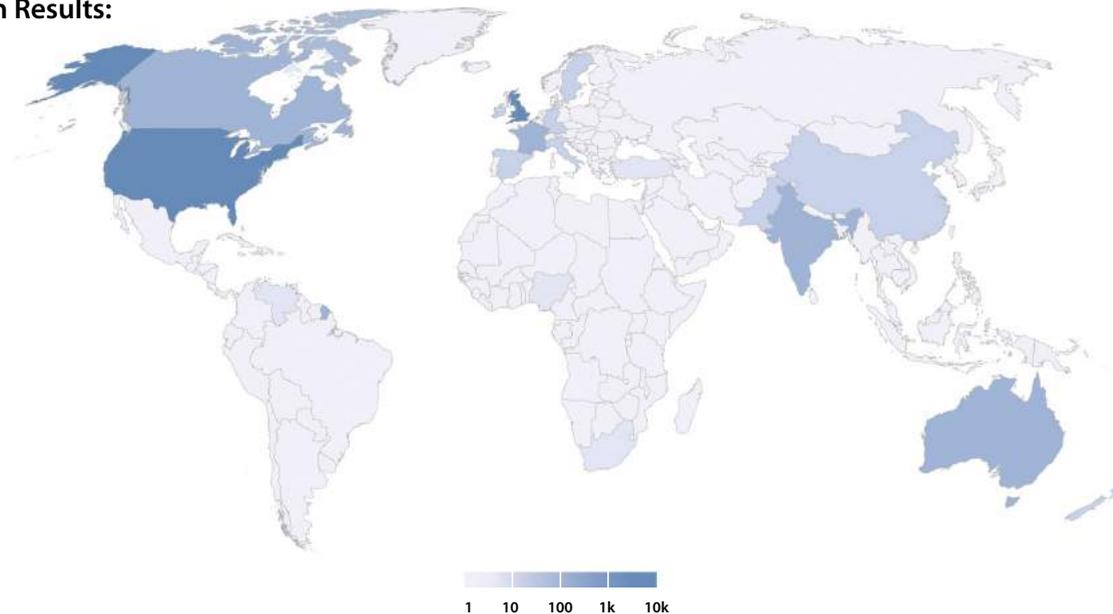


## Section 2: Appendix 2.5

### Online Media 90 Day Snapshot Methodology

To capture the online media environment for patients with mBC, a 90 day snapshot of media sites was analyzed through the LexisNexis® Newsdesk tool from September 7 through December 16, 2015. This tool monitors media from print news, online news, broadcasts, and social media sources from around the world, with the aim of understanding the current landscape around a certain organization or topic. Search terms were entered into the LexisNexis® system to reveal 113 media clips related to mBC. Of these, the perceptions varied greatly: 1 mixed, 1 neutral/positive, 39 positive, 17 negative, 1 neutral/negative, 54 neutral. The search terms used in the system were “metastatic breast cancer” OR “advanced breast cancer” OR “Stage IV breast cancer” OR “Stage 4 breast cancer” AND “mbc” AND “cancer”. Findings from this search were included in this chapter.

#### Map of LexisNexis® Search Results:



A breakdown of how many references came from each site and from where in the world are listed below.

Site	Number of Hits
Facebook	70
Reddit	30
The New Yorker	1
Buzzfeed	2
The Washington Post	1
Google Plus	1
Twitter	15
The Guardian	2



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