

ADVOCACY SLIDE DECK • **SERIES 3**

Challenges of MBC, Big Issues that Could Change Lives “Cheat Sheet”

This cheat sheet is intended to draw your attention to points within the presentation slides. Additional information and more detailed support for selected slides follows.

Please use these links and the information they supply to support you — consider using them as you are preparing your presentation since they will allow you to address issues that you consider most important to your audience and will make answering any questions easier.

All sources listed have information that is extensive and reputable. Please take some time to look at the documents as you plan your presentation.

> You can also visit mbcalliance.org for additional support, if needed.

> **SLIDE 2: HOW MANY PEOPLE IN THE US LIVE WITH MBC?**

Source: [Metastatic Breast Cancer Network](#)

What is SEER Data?

SEER is part of the National Cancer Institute and stands for Surveillance, Epidemiology and End Results (SEER) Program, a premier source for cancer statistics in the United States.

The SEER program collects information on incidence, prevalence and survival from specific geographic areas representing 28 percent of the US population and compiles reports on all of these plus cancer mortality for the entire country.

The SEER database tracks 5-year relative survival rates for breast cancer in the United States, based on how far the cancer has spread. The SEER database, however, does not group cancers by AJCC TNM stages (stage 1, stage 2, stage 3, etc.). Instead, it groups cancers into localized, regional, and distant stages:

- Localized: There is no sign that the cancer has spread outside of the breast.
- Regional: The cancer has spread outside the breast to nearby structures or lymph nodes.
- Distant: The cancer has spread to distant parts of the body such as the lungs, liver or bones.
- These numbers apply only to the stage of the cancer when it is first diagnosed. They do not apply later on if the cancer grows, spreads, or comes back after treatment.

As you will learn, however, many statistics for metastatic breast cancer are NOT collected. This is a major problem for the metastatic breast cancer community because if we are not counted, do we still matter? How can we expect to have adequate attention and funding directed to the

needs of the metastatic patient for support, treatment, and research, if we lack fundamental statistics like incidence and prevalence?

SEER also does not parse out the subtypes of breast cancer. Therefore, Triple Negative and Inflammatory BC have different statistics regarding survival rates.

If we're NOT counted, do we still 'count'?

Statistics do not capture those with metastatic recurrence!

- The NCI/SEER (National Cancer Institute/Surveillance Epidemiology and End Results) databases record when a person is diagnosed with breast cancer and when a person dies. **It does not record a metastatic recurrence for someone who had early-stage breast cancer.** Therefore, the SEER databases collect only those with an initial Stage IV diagnosis (de novo), which represents only a small portion of the population living with metastatic breast cancer.
- **If you were first diagnosed with an earlier stage cancer, you are not excluded from breast cancer statistics, but you are not counted as being metastatic.**
We want SEER, CDC and all cancer registries to stop ignoring metastatic recurrences and start counting ALL people living with metastatic breast cancer. We can't remain uncounted and invisible.

For historical information about an effort to change this, see [MBC Alliance 2016 Change.org petition](#) that further articulates the issue and explains what we, as Alliance members, hope to accomplish.

A five-year grant was awarded in 2017 by the National Institutes of Health (NIH) to [Dr. Ruth Etzioni](#) of the Fred Hutch Cancer Institute to advance the science of cancer surveillance by developing, validating and deploying a scalable, automated approach for identifying cancer recurrence.

SLIDE 4: THE IMPROVEMENT IN BREAST CANCER SURVIVAL RATES HAS SLOWED

Source: [Cancer.org](#)

The overall breast cancer death rate increased by 0.4% per year from 1975 to 1989. It is estimated that 42,250 women died from breast cancer in 2024. Breast cancer death rates have been decreasing steadily since 1989, for an overall decline of 44% through 2022. The decrease in death rates is believed to be the result of finding breast cancer earlier through screening and increased awareness, as well as better treatments.

Disparities in death rates by ethnicity:

Some variations in breast cancer can be seen in racial and ethnic groups. For example:

- Black women have the highest death rate from breast cancer. This is thought to be partially because Black women have a higher risk of [triple-negative breast cancer](#), more than any

- other racial or ethnic group.
- At every age, Black women are more likely to die from breast cancer than any other race or ethnic group.
- White, Asian, and Pacific Islander women are more likely to be diagnosed with localized breast cancer than Black, Hispanic, American Indian, and Alaska Native women.
- Asian and Pacific Islander women have the lowest death rate from breast cancer.

This disparity likely reflects a combination of factors that are difficult to parse, including later stage at diagnosis and other unfavorable tumor characteristics, higher prevalence of obesity and other health conditions, less access to high-quality prevention, early detection, and treatment. For example, Black women are more likely to be screened at lower resourced and nonaccredited facilities and also experience longer intervals between mammograms, and between abnormal results and follow-up. Although self-reported screening rates based on national surveys are similar between Black and white women, studies indicate that Black (and Hispanic) women are more likely than white women to overestimate their screening history. The Black-white disparity has grown as treatment for breast cancers has improved (particularly for HR+ breast cancers), but appears to have peaked in 2011, when rates in NH Black women were 44% higher than those in whites. In the most recent period (2013- 2017), the breast cancer death rate was 40% higher in Black women versus white women.

SLIDE 7: PROPOSED SOLUTIONS

Source: [Cancer.org](https://www.cancer.org)

- It can help to form support groups to share this information and gain strength in numbers to lobby for support for MBC.
- Investigate groups that do advocacy work on behalf of breast cancer patients such as MBCA, BCRF and the NCCA.
- Education is power, even when we want to have “non-cancer” days.

SLIDE 8: MBC NEEDS FOCUSED RESEARCH

Source: Key findings of the Metastatic Breast Cancer Alliance: *Changing the Landscape* report include:

- **Research:** More funds need to be directed to MBC-focused research. Previously (2000-2013), 7% of the \$15 billion in breast cancer research dollars was for MBC. In 2014-2020, 13% of all breast cancer research dollars was devoted to MBC. Therefore, investment in MBC as a percentage of breast cancer research nearly doubled for grants funded in 2014-2020 compared to 2000-2013. The annual investment in MBC research increased from \$249 million in 2014 to \$337 million in 2020, which is a 25% rise above the rate of inflation.

- Between 2012 and 2016, 24% of breast cancer awards internationally were either wholly or partly focused on MBC ([MBCA Fall Retreat Landscape Update Grants](#) M Hurlbert.pdf; slides 5 and 9).
- By 2020, people living with MBC identified treatment resistance as the area of primary importance for MBC research. The percent of MBC research dedicated to resistance increased from 15% (\$36.6 million) in 2014 to 26% (\$89.1 million) in 2020, an increase that was above inflation. This was the largest growing area of research from 2014-2020.
- The percentage of National Institutes of Health and Department of Defense/Breast Cancer Research Program MBC research in fiscal year 2016 was estimated to be approximately 20% (Feb 28, 2019 SABCS Poster [NBCC MBC Research Funding Analysis](#); Conclusions).
- Ongoing efforts by the MBC Alliance seek to understand the [current status](#) of funding for MBC research.

NOTE: Research funding numbers can differ between organizations depending on their own unique metastasis coding policy for research grants. Analyses do not always differentiate between research focused solely or largely on metastasis and research where metastasis was a smaller or adjacent interest.

SLIDE 9: ADDRESSING DISPARITIES IN MBC

Source: [ELSEVIER: The Breast, February 2021](#) (Based on statistics gathered in Europe)

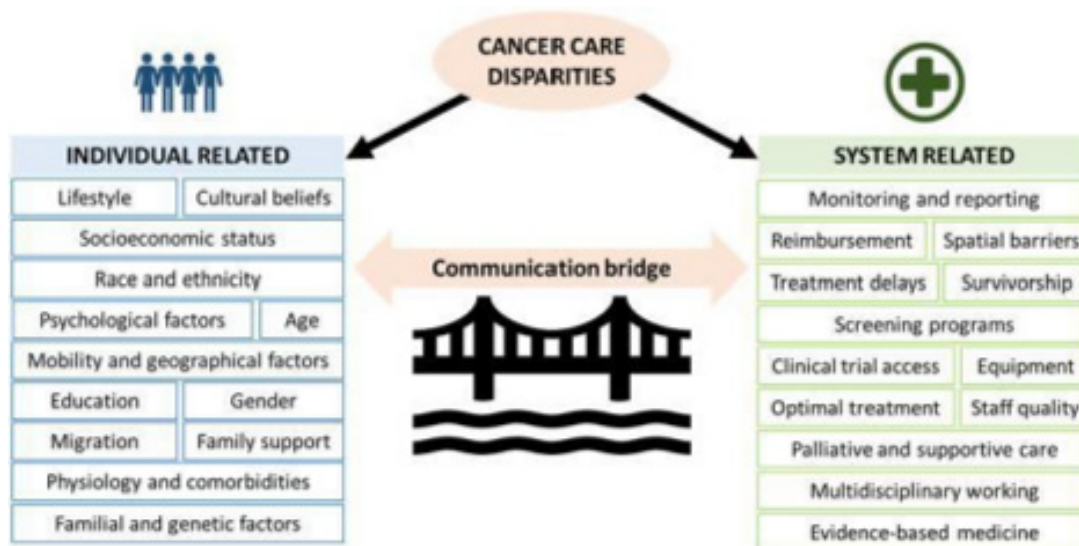
Disparities in cancer care can be classified as individual-related (e.g., age, socioeconomic status, etc.) or system-related (e.g. reimbursement, policy, etc.) (Fig. 1).

SLIDE 10: PROPOSED SOLUTIONS

Telehealth Extension and Evaluation Act update

<https://strohscheinlawgroup.com/medicare-coverage-for-telehealth-services-in-2025-and-beyond/> - :~:text=For example, the Telehealth Extension and Evaluation,evaluate which services should be permanently covered.

The chart below delineates disparities related to the individual and those related to various aspects of systems (hospitals, oncology practices, insurance, government, etc.)



Access information regarding Susan G. Komen's **Stand for H.E.R.** (Health Equity Revolution) program: <https://www.komen.org/about-komen/our-impact/breast-cancer/stand-for-h-e-r/>

A significant effort is underway by ASCO to address making a difference in disparities in cancer care: [ASCO's EDI Action Plan](#).

➤ SLIDE 11: ACCESS TO PALLIATIVE CARE FOR MBC

Access to palliative care for women with metastatic breast cancer (MBC) is often limited, with studies showing that a significant proportion of women with MBC do not receive palliative care, despite strong recommendations from medical organizations to integrate it early in their treatment journey; factors contributing to this include misconceptions about palliative care, geographic limitations, and disparities based on race and socioeconomic status. Elderly breast cancer patients have a poorer prognosis and potentially more physical symptoms as well as lower access to palliative care and other healthcare services often due to physical or social isolation.

According to NIH

(<https://pmc.ncbi.nlm.nih.gov/articles/PMC10653207/#:~:text=Conclusions,barriers%20to%20palliative%20care%20utilization.2023>) only 25% of women with MBC received palliative care between 2010 and 2017, highlighting a significant gap in access.

- **Misconceptions about palliative care:** Some patients may perceive palliative care as only for end-of-life situations, delaying access.
- **Geographic limitations:** Access to specialized palliative care providers can be limited in rural areas.
- **Socioeconomic factors:** Financial constraints and lack of insurance coverage for palliative care can hinder access to palliative care.

- **Cultural barriers:** Cultural beliefs and attitudes towards illness can impact the willingness to seek palliative care.
- While palliative care has significantly increased for all racial/ethnic groups, Hispanic White, Black, and Asian/Pacific Islander women with MBC still receive significantly less palliative care than non-Hispanic White women.
- **Early integration is key:** Medical guidelines strongly advocate for early integration of palliative care into the management of MBC to optimize quality of life and symptom control.
- **Importance of patient-provider communication:** Open communication between patients and their healthcare providers is crucial to identify the need for palliative care and facilitate appropriate referrals.
- **Patient Navigator programs** will help get patients to palliative care providers.

<https://pmc.ncbi.nlm.nih.gov/articles/PMC10410954/>

<https://pmc.ncbi.nlm.nih.gov/articles/PMC8798146/#:~:text=Conclusions,suffering%20of%20this%20patient%20population.>

What can be done to improve access to palliative care for women with MBC:

- **Educate healthcare providers and patients:** Raising awareness about the benefits of early palliative care integration for patients with MBC.
- **Develop patient navigation programs:** Assisting patients in navigating the healthcare system to access palliative care services.
- **Expand telehealth options:** Utilize telemedicine to improve access to palliative care in underserved areas.
- **Advocate for policy changes:** Support policies that improve insurance coverage for palliative care services.