

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.

SLIDES 4, 5 & 6

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.

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

[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?

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 uncared 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.

SLIDES 7 & 8

Source: [American Cancer Society: Facts and Figures 2019-2020](#)

The overall breast cancer death rate increased by 0.4% per year from 1975 to 1989, but has since decreased rapidly, for a total decline of 40% through 2017. As a result, 375,900 breast cancer deaths were averted in US women from 1989 to 2017.

However, the decline in breast cancer mortality has slowed slightly in the most recent time period, from an annual decrease of 1.9% during 1988-2011 to 1.3% during 2011-2017. By race/ethnicity, the breast cancer death rate during 2013-2017 declined annually by 2.1% in Hispanics, 1.5% in NH blacks, 1.0% in NH whites, and 0.8% in Asian Pacific Islanders (APIs), but was stable in American Indian/Alaskan Natives (AIANs).

The decline in breast cancer mortality has been attributed to both improvements in treatment and earlier detection. However, not all women have benefited equally from these advances, as indicated by the striking divergence in mortality trends between Black and white women beginning in the early 1980s. 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 9

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. \$1.0 Billion invested since 2000 in research grants specifically focused on MBC was identified, or only 7% of the \$15 billion invested in breast cancer research grants included in our study. The majority of that 7% focused on understanding the key processes of metastasis.
- 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).
- 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.

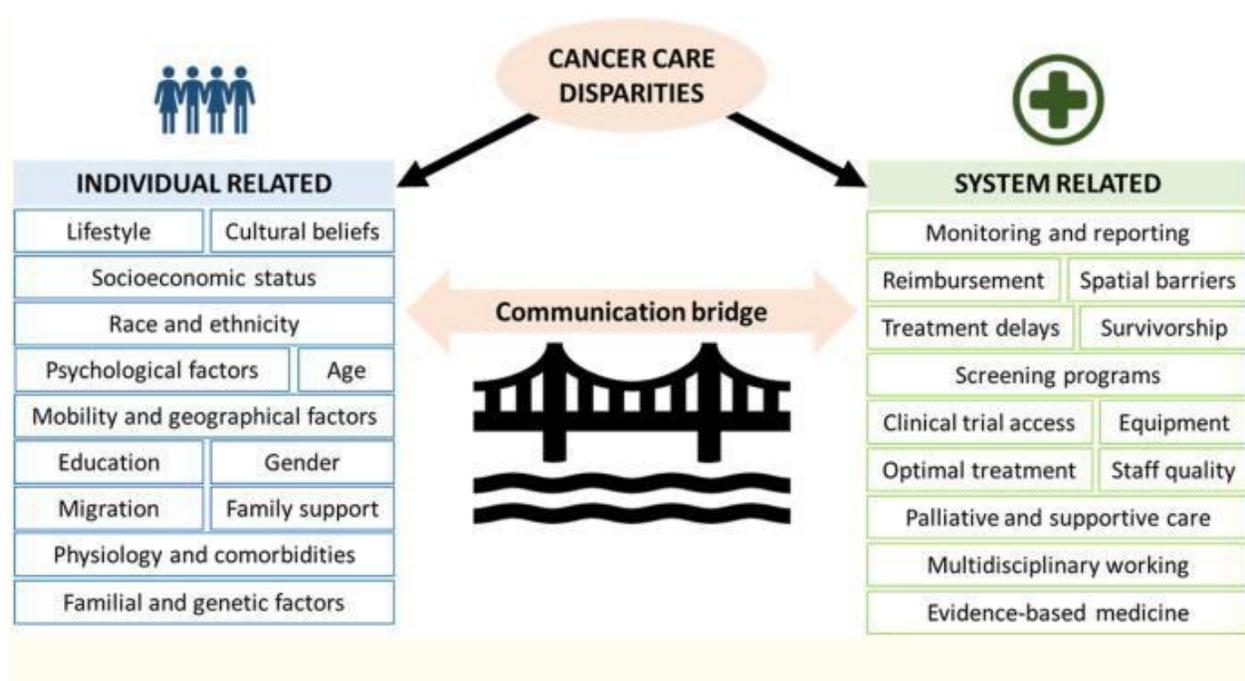
NOTE: Research funding numbers can differ between organizations depending on their own unique metastasis coding policy for research grants. Analyses do not always differentiate between research focused solely or largely on metastasis and research where metastasis was a smaller or adjacent interest.

SLIDE 12

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](#)).

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](#).