

Metastatic Breast Cancer

Filling the Data Gap to Improve Research, Access and Patient Care

Metastatic breast cancer, also known as stage 4 breast cancer, occurs when the disease spreads beyond the breast to other parts of the body. It represents the most advanced stage of breast cancer.

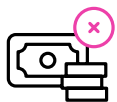
Yet, public health surveillance fails to track metastatic recurrence, leaving thousands of patients invisible in national datasets.

As a result, the true scope of metastatic breast cancer—and the needs of those living with it—remains poorly understood. Without a full understanding of the disease and the people living with it, policymakers may struggle to allocate resources effectively and to craft policies to improve outcomes.

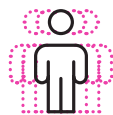


Why Data Matters for Metastatic Breast Cancer

Accurate, comprehensive data are essential to understanding the true impact of metastatic breast cancer and responding effectively to the needs of patients. Without it:



Funding is misaligned. When the true scope and burden of metastatic breast cancer is undercounted, funding decisions fail to match patient needs. 13% of global breast cancer research funding is dedicated to metastatic breast cancer, which includes both government and NGO funding. This leaves vast potential for treatment breakthroughs unexplored.



Research fails to reflect real-world populations. Without comprehensive data on who is living with metastatic breast cancer, scientists are left without an optimized foundation for their work, undermining investment and potentially weakening the relevance of research findings.



Patients miss out on critical discoveries. Incomplete data mean missed opportunities to invest in the full body of research needed to improve quality of life and reduce treatment burden.



Disparities in care remain hidden. Lack of detailed data by race, gender, geography, and insurance status hides critical inequities in diagnosis, treatment and outcomes. Without disaggregated data, these disparities remain invisible and unaddressed.

Closing the Data Gap: Improving Lives for People with Metastatic Breast Cancer

Patients living with metastatic breast cancer face distinct physical, emotional and financial challenges that differ significantly from those experienced in earlier stages of the disease.

Despite the critical need for accurate data, the federal public health system currently provides limited and incomplete information on metastatic breast cancer. Programs such as the National Cancer Institute's Surveillance, Epidemiology and End Results program and the Centers for Disease Control and Prevention National Program of Cancer Registries do not track metastatic recurrence following an early-stage diagnosis—even though this is the most common pathway to metastatic disease.

Only about 6% of cases of breast cancer in women are diagnosed at stage 4, often referred to as 'de novo.' This means that about 94% of those with MBC were diagnosed and likely treated at earlier stages—and then had a recurrence of metastatic disease.

Better data lead to better research—and better patient care.

As a result, the vast majority of people living with metastatic breast cancer remain missing from national datasets.

Closing the data gap is not just about improving statistics—it is about saving lives. Comprehensive, nationwide data will enable smarter research investments, more equitable health policies, and better access to treatments that reflect the realities of living with metastatic breast cancer.



ALLIANCE FOR BREAST CANCER POLICY

About the Alliance for Breast Cancer Policy

Launched in 2025 by Susan G. Komen, the Alliance for Breast Cancer Policy unites more than 30 advocacy organizations to transform breast care through policy innovation.

