Advancing Global Visibility For Metastatic Breast Cancer

A pledge from Breast Cancer Network Australia, Breast Cancer Now (UK), and Rethink Breast Cancer (Canada) to continue advocating for people living with metastatic breast cancer to be counted and cared for

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Breast cancer continues to be the leading cancer among women globally. In 2022, there were over 2.3 million people newly diagnosed worldwide, and these numbers are expected to increase nearly 40% by 2050. In addition to new breast cancer cases, there is a growing group of people living with metastatic breast cancer (MBC). **MBC is the most serious form of breast cancer. It is treatable but not curable.**

People living with MBC are living longer due to better treatments, yet they have remained invisible in our health systems and policy frameworks for decades because cancer statistics have not counted them. There is an urgent need for better cancer data. New research methods have found that previous statistics significantly underestimated MBC prevalence due to historical gaps in how cancer data is collected and reported. Without accurate MBC prevalence data, governments cannot plan and invest in cancer research, workforce, and services to better support people living with MBC and their families.

Counting people with MBC ensures they get the care they need. This pledge shows our commitment as three leading breast cancer advocacy organisations in Australia, the United Kingdom, and Canada to work together and continue to call on governments to accurately count how many people are living with MBC. **Together with our global networks, we can drive faster improvements to cancer data for MBC and other cancers.**

Throughout this document, **metastatic breast cancer (MBC)** refers to breast cancer that has spread beyond the breast to other parts of the body. MBC is also known as stage IV, secondary breast cancer, or advanced breast cancer, and represents the most serious form of the disease.

Why metastatic breast cancer data matters

A history of being hidden in plain sight

For decades, people living with MBC have been ‘hidden in plain sight’ because they have not been included in cancer statistics. Cancer registries have instead focused on collecting data about how many people are diagnosed with breast cancer and how many people die. MBC leads to 90% of breast cancer deaths and is usually only recorded in mortality statistics.

But this approach no longer makes sense because it fails to recognise and support a growing population who are living longer with access to more effective treatments. It also prevents healthcare systems from understanding the full breast cancer picture, such as the impacts of delayed diagnosis, patterns of cancer recurrence and survival, how to address supportive care gaps, and whether innovative treatments are effective.

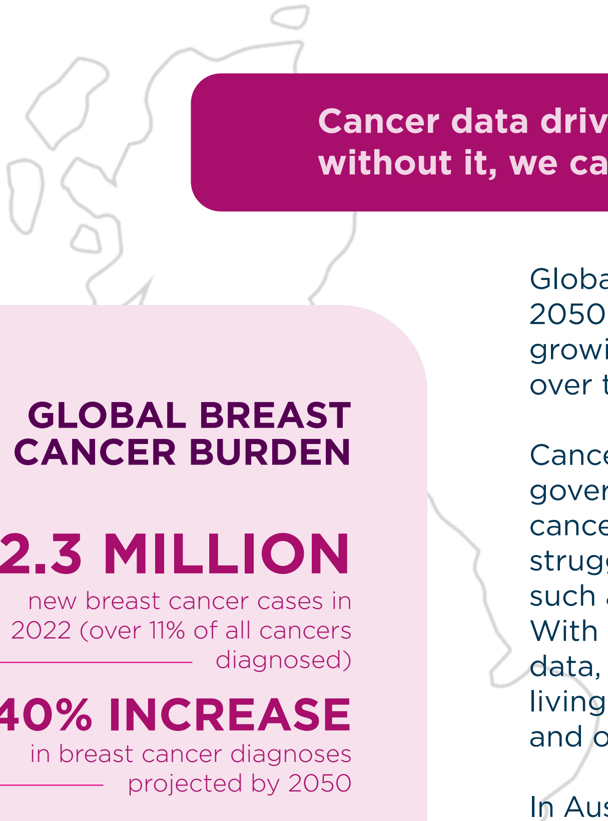
> “As someone living with metastatic breast cancer, I am now incredibly excited it is now possible to recognise those living with the disease. Until now we have been hidden in plain sight and vastly underestimated in numbers.”
> **- Lisa Rankin, Person living with metastatic breast cancer (Australia)**

People with metastatic breast cancer continue to experience significant gaps in care

While new treatments mean that people with MBC are living longer than before—on average five years instead of two or three years—they continue to face complex health challenges and need higher levels of support compared to people with early-stage breast cancer.

Without better data, MBC remains invisible across the healthcare system. It has been impossible to know where people with MBC are living, their age, or other personal circumstances that should inform policy and funding decisions. Health system budgets and workforces remain under pressure, particularly since the COVID-19 pandemic. Better MBC data will help governments prioritise specialist care that improves the quality of life for people living with MBC and their families through coordinated and long-term support.

> "Recent improvements in breast cancer survival represent a great success of modern medicine. **However, we can't ignore how many patients are being systematically left behind.** By highlighting [current gaps] they can be addressed by health care professionals and policymakers in partnership with patients and the public around the world."
>
> **– Professor Charlotte Coles, The Lancet Breast Cancer Commission 2024**



Cancer data drives decisions – without it, we cannot plan for treatment and support

GLOBAL BREAST CANCER BURDEN

2.3 MILLION
new breast cancer cases in 2022 (over 11% of all cancers diagnosed)

40% INCREASE
in breast cancer diagnoses projected by 2050

90% OF DEATHS
percentage of breast cancer deaths due to MBC

NEARLY 70%
projected increase in breast cancer deaths for women by 2050

Globally, breast cancer diagnoses and deaths will rise by 2050. Improved MBC data is urgently needed to meet growing demand for MBC care and support services over the next 25 years.

Cancer registries collect and report data to help governments evaluate and understand the impact of cancer on different population groups. But they have struggled to include MBC data due to a range of issues such as limited workforce and outdated data systems. With these historical gaps and inconsistencies in cancer data, global estimates about how many people are living with MBC (prevalence) are considered inaccurate and outdated.

In Australia, previous modelling from 2020 estimated there were at least 10,553 people living with MBC. In England and Scotland, total estimates are around 61,000 people. Canada's lack of data has prevented any modelling of MBC prevalence being undertaken at all. Not only have researchers had to rely on inaccurate and incomplete data, but they have also used inconsistent methods to estimate the size of the MBC population without considering new treatments that prolong people's lives.

The gap between estimated and actual numbers increases existing challenges for health workforce, research funding, and cancer care services.

Extending global efforts to count people living with metastatic breast cancer

Building global momentum for change

International efforts are raising standards of breast cancer care and improving equity across countries.[1] For example, the Lancet Breast Cancer Commission, Advanced Breast Cancer (ABC) Global Alliance and the World Health Organisation (WHO) have all called for better cancer data, including for MBC. The United Nations is also leading work to improve breast cancer care and cancer registry practices to promote sustainable, coordinated approaches across nations.

MBC data gaps are not unique to a particular country. It is a global problem that has been the focus of advocacy action for decades, including from Breast Cancer Network Australia (BCNA), Breast Cancer Now in the UK, and Rethink Breast Cancer in Canada.

> “This is a turning point. For too long, governments have written off people with metastatic breast cancer simply because it is not curable—but incurable shouldn’t mean invisible. Thanks to decades of consumer-led advocacy, we are finally breaking through the data silence that kept this community overlooked and underserved.
>
> Today, we pledge to no longer accept gaps in data or care. We are counting every life, recognising every story, and reshaping the system for those living with metastatic breast cancer.”
>
> **– Vicki Durston, Director Policy, Advocacy and Support Services, BCNA**

Australia: New modelling research is uncovering the truth

Australia has achieved significant progress to accurately estimate MBC prevalence, driven by 20 years of consumer-led advocacy from BCNA. In 2023, BCNA published a national roadmap urging state and federal governments to reduce barriers to collecting and reporting MBC data. Later that year, the Australian Prime Minister announced the creation of the Australian Cancer Data Alliance to improve cancer registry systems, including for MBC data. This major victory was the result of three years of targeted action and engagement with people living with MBC, researchers, cancer registries, and government agencies.

By late 2024, the Cancer Institute of New South Wales (NSW) developed a world-first methodology that combined local cancer registry data and hospital data with national records about prescriptions and cancer services.

This new approach revealed 7,900 people in NSW were living with MBC, highlighting a much larger MBC population compared with earlier 2020 estimates.

State-based cancer registries are working to develop a clearer picture of MBC prevalence across Australia. In June 2025, Australia’s two other largest states announced updated estimates – Queensland reported over 3,800 cases, and Victoria has estimated over 4,400 cases. Together, these three states alone have identified more than 16,000 people living with MBC, confirming that previous national estimates of 10,553 people had significantly undercounted this community. Remaining cancer registries are working with researchers to harmonise data collection methodologies and close national MBC data gaps. Future research will explore ways to apply these methods to other metastatic cancers.

[1] For example, WHO Global Breast Cancer Initiative; WHO Global Initiative for Cancer Registry Development; International Agency for Research on Cancer (IARC); International consensus guidelines for the management of advanced breast cancer (ABC guidelines 6 and 7, Cardoso, Fatima et al., The Breast, Volume 76, 103756).

> “The groundbreaking work by NSW, Victoria and Queensland shows what’s possible when state and federal governments work together to ensure people with metastatic breast cancer are counted. **The Albanese Government stands with BCNA and their Commonwealth (UK and Canada) partners** as they pledge ongoing commitment to raise the visibility of metastatic breast cancer and drive global momentum for change.”
>
> **- The Hon Mark Butler MP, Australian Minister for Health and Ageing, Minister for Disability and the National Disability Insurance Scheme**

World-first research approaches are building a new national picture of how many people are living with MBC across Australia

7,900 **in New South Wales**

Over
3,800 **in Queensland**

Over
4,400 **in Victoria**

United Kingdom: Making metastatic breast cancer data collection mandatory

For nearly two decades, Breast Cancer Now has acted as a catalyst for change in the UK, resulting in National Health Service (NHS) Trusts in England being required to record MBC data since 2013. However, a 2016 review found that two-thirds of hospital trusts in England were still not recording complete data about MBC patients.

Research published in 2022 estimated that around 57,215 people were living with metastatic breast cancer in England in 2020/21 and showed that previous studies had grossly underestimated the true picture of MBC.[2] This new research demonstrates the value of the first *National Audit of Metastatic Breast Cancer for England and Wales* (NAoMe), launched in 2021, to assess and track the quality and delivery of care and outcomes for people with MBC including information about the profile of the MBC population. The *State of the Nation* report in 2024 identified ongoing gaps in recurrence data related to MBC and urged NHS organisations to prioritise data collection to better support people living with MBC.

Breast Cancer Now continues to work closely with the National Cancer Audit Collaborating Centre, members of the NAoMe Audit Advisory Group, and NHS teams in Wales and England to improve data quality and ensure all MBC cases are recorded.

Breast Cancer Now also successfully advocated for Scotland’s Government to improve data collection on MBC in its *Cancer Action Plan for Scotland 2023-2026* to drive service improvement. However, they are yet to deliver this commitment, with the current action plan ending in 2026.

Northern Ireland’s *A Cancer Strategy for Northern Ireland 2022-2032* recognises the need to improve data collection for people living with MBC and for this to be included within mandatory data sets for cancer. With the strategy also committing to reviewing cancer data and developing a cancer data framework to improve services, there is an opportunity for this to deliver impactful change for people with MBC in Northern Ireland.

> “Despite some steps in the right direction, it’s completely unacceptable that people living with metastatic (secondary) breast cancer are still not being consistently counted. **They are invisible in the health system, and in turn overlooked and denied the tailored treatment, services and support they so desperately need and deserve.** Collectively we can shout louder for the changes we need to see so that everyone living with metastatic breast cancer is seen, counted, and supported now.”
>
> **– Claire Rowney, CEO, Breast Cancer Now**

RECENT UK PROGRESS IN 2025:

- **UK researchers published new data methods that can be used to identify breast cancer recurrence in England that will also improve effectiveness of clinical trials.**
- **Funded by Cancer Focus Northern Ireland, researchers linked population-based cancer registry data with hospital admission and mortality records to estimate 911 people were living with MBC in 2020 in Northern Ireland, and approximately 250 new MBC diagnoses annually.**

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[2] Total estimates for England in 2020/21 (Palmieri, C., Owide, J., & Fryer, K. (2022). Estimated Prevalence of Metastatic Breast Cancer in England, 2016-2021. JAMA Network Open, 5(12), e2248069). Public Health Scotland (2022) estimates a further 3,945 people were living with secondary breast cancer in Scotland at the end of 2020.

> "For too long when it comes to secondary breast cancer, we've done a wonderful job of counting the dead, but not enough to count the living. I've been campaigning for over 10 years to change that - to make sure that data on secondary breast cancer is collected and then used effectively. As of today we still don't know how many people are living with the disease in the UK. People with secondary breast cancer do not have time to wait - we need action on data collection now."
>
> **- Claire Myerson, Person living with metastatic breast cancer (UK)**

Canada: Calls to harmonise, federate and liberate MBC data

After a decade of building a Canadian movement for young people with breast cancer, the urgent needs of the MBC community propelled Rethink Breast Cancer to formalise its MBC advocacy program in 2015. Canada has had long-term challenges accessing accurate data, including linking data between 13 provincial and territorial health ministries and Indigenous groups to count the number of people living with MBC. Rethink's MBC patient advisory board identified improving MBC epidemiology and outcomes data as the key advocacy priority – aligning with the ABC Global Alliance's Action for Change. Following this, Rethink rallied over 10,000 people to pledge to be MBC allies, standing with women living with metastatic breast cancer to #MakeMBCCount.

Rethink's amplification of the unmet needs of Canada's MBC community has played a role in prioritisation of MBC research. There is now a dedicated MBC Registry in Quebec that collects standardised breast cancer data, supports research, and improves collaboration between healthcare providers and researchers. Rethink has also helped fund a model to identify recurrence of MBC in the province of Alberta.

While this is important progress, it was disappointing that the *Canadian Cancer Data Strategy* launched in 2023 did not specifically reference cancer recurrence data. Rethink will continue to advocate to Canadian federal and provincial governments to address cancer data gaps and prioritise MBC data collection, with the goal of improving evidence-based patient care and health equity.

> "We live in a digital age and a lot of detailed data is being collected. **Yet, when it comes to cancer data—when the stakes are high—we've fallen behind.** In Canada, breast cancer recurrence data is not collected in a consistent or harmonized way, leaving us without an understanding of the number of people whose cancer recurs or the number of people living with metastatic breast cancer. This information is foundational to improving patient outcomes."
>
> **– MJ DeCoteau, Founder and Executive Director, Rethink Breast Cancer**

> "Right now the data reports me as a "survivor" because I'm more than 5 years from my initial diagnosis [of early stage breast cancer], but I'm a survivor who is in treatment for the rest of my life. I have heavy side effects and I'm living on borrowed time. Some of us will have a metastatic recurrence, shouldn't the data reflect that?"
>
> **- Vesna Zic-Cote, Person living with metastatic breast cancer (Canada)**

Keturah – Caregiver and MBC advocate

OUR PLEDGE IS TO CONTINUE ADVOCATING FOR...

1. **Governments to prioritise MBC data collection and reporting:** Improve MBC data through dedicated, sustained funding in data infrastructure, data linkage capabilities, and skilled workforce development.
2. **International collaboration:** Governments, researchers and breast cancer advocacy organisations work together to share knowledge and best practice on MBC data.
3. **Integrating MBC across global initiatives:** Align MBC considerations with the ABC Global Alliance, the WHO's Global Breast Cancer Initiative and other international commitments to progress cancer data improvements.
4. **People living with MBC across the world:** Ensure people living with MBC are visible in health systems, at the table in research, policy and decision-making forums, and are cared for and supported.

OUR PROMISE TO PEOPLE LIVING WITH METASTATIC BREAST CANCER

We are coming together—across continents—for one shared reason:
to make metastatic breast cancer count.

In delivering this Pledge, we make this promise to you:

- *To push for data that counts every person living with metastatic breast cancer.*
- *To call for policies that support and reflect the reality of living with metastatic disease.*
- *To challenge outdated narratives and show the full spectrum of life with metastatic breast cancer.*
- *To work in partnership with you, because real change starts with those living with the disease.*

We will count you in.
We will make you count.
Because you always have.

MJ DeCoteau

Claire Rowney,
CEO, Breast Cancer Now

MJ DeCoteau,
Founder and Executive Director, Rethink Breast Cancer

Kirsten Pilatti,
CEO, Breast Cancer Network Australia

REFERENCES

Scan QR code for linked references

BREAST CANCER NOW The research & support charity

Breast Cancer Now *is the UK's largest breast cancer charity. We fund life-saving research, campaign for change and provide information and support to anyone affected by breast cancer. Why? Because our vision is that by 2050, everyone diagnosed with breast cancer will live, and be supported to live well. But to make that vision a reality, we need to act now.*

rethink BREAST CANCER

Rethink Breast Cancer Canada *educates, empowers and advocates for system changes to improve the experience and outcomes of those with breast cancer, focusing on historically underserved groups: women diagnosed at a younger age, those with metastatic breast cancer and people systemically marginalized due to other factors within the social determinants of health.*

Breast Cancer Network Australia

Breast Cancer Network Australia (BCNA) *is the peak national consumer organisation for Australians affected by breast cancer. We represent over 200,000 individual members and work to ensure that Australians diagnosed with breast cancer receive the very best care, treatment and support including those living with MBC.*