

# Advancing Global Visibility for Metastatic Breast Cancer

**A joint update from Breast Cancer Network Australia, Breast Cancer Now (UK), and Rethink Breast Cancer (Canada) on progress since the July 2025 Pledge.**

In July 2025, our three organisations signed a joint pledge to advance global visibility for metastatic breast cancer (MBC). We promised to push for data that counts every person living with MBC, to call for policies that reflect the reality of metastatic disease and challenge outdated narratives, and to work in partnership with people with lived experience to drive the change we want to see. Since then, at national and global levels, we have built more evidence, created more political will, and continued to advocate for improved treatment and support. But the agenda remains unfinished until being counted is the same as being cared for.



**One year on | Progress report, May 2026**

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.

## Progress: Counting the invisible

Australia is the first country to deliver a national picture of how many people are living with MBC – the result of a four-year targeted advocacy program by Breast Cancer Network Australia (BCNA) to lead sector-wide momentum for change and cooperation. In November 2025, the Australian Institute of Health and Welfare (AIHW) announced that approximately **20,950 people (20,800 women and 150 men) were living with MBC as at 31 December 2024** – more than double the 2020 estimate of 10,553. The AIHW used world-first linked-data methods that built on new data models from New South Wales, Queensland and Victoria, combining state-based cancer registry data and hospital records with national pharmaceutical subsidy data and health service information.

Breast Cancer Now has funded a new study building on the ground-breaking work published by the Northern Ireland Cancer Registry in 2025, which will **better understand health inequalities and better support people living with MBC** in Northern Ireland. Across the UK, Breast Cancer Now continues to make the case for better recurrence data. In December 2025, it brought together an expert group of patient representatives, patient organisations, clinicians and data experts to develop actionable solutions on breast cancer recurrence (including metastatic recurrence) data. It also organised an ‘I don’t count?’ installation outside the Scottish parliament in November 2025 to hold the Scottish Government to account on delivering its commitment to improve data collection on metastatic breast cancer patients.

In Canada, Rethink Breast Cancer continues to build meaningful momentum. Together with two leading oncologists, Rethink completed a **pan-Canadian environmental scan to better understand current data gaps, provincial differences and system readiness**. This work identified where meaningful progress is most feasible and which provinces have data infrastructure best positioned to pilot a more comprehensive approach to capturing MBC data.

“This national estimate marks an important milestone in Australia’s cancer data reform and visibility for people living with metastatic breast cancer.”

– The Hon Mark Butler  
MP, Minister for Health,  
Disability and Ageing,  
Australian Government

## Securing government commitments

In Australia, the **Australian Cancer Data Alliance**, led by AIHW, is driving national accountability and consistency to improve the quality of MBC data and invest in sustainable data systems. The Alliance brings together government health and data agencies, researchers, sector experts, and consumers to deliver better data standards and build capacity across population-based cancer registries in other states and territories. Through the Alliance, MBC data initiatives are now being integrated into Australia’s *National Cancer Data Framework* implementation plan to improve reporting on priority needs, treatment and care, equity, access to medicines, and patient outcomes and experiences.

In February 2026, the UK Government’s *National Cancer Plan for England* committed to **define and count recurrent cancers, starting with MBC in 2026**. This marks a significant milestone to improve data needed for the National Audit of Metastatic Breast Cancer (NAoMe).

In Canada, Rethink is advancing discussions with provincial health system and data leaders, including Ontario Health and the British Columbia Cancer Agency, to explore how MBC data collection could be prioritised and more rapidly implemented. Federally, Rethink continues to engage the Ministry of Health about **how MBC data aligns with other national priorities**. For example, ensuring that MBC data is embedded within broader efforts to strengthen health data systems across Canada including e-health data and data harmonisation, and to elevate MBC data as part of national women’s health initiatives.

“We are encouraged by the momentum building across Canada, including healthcare leaders stepping forward as champions in some provinces. We appreciate the learnings from the UK and Australia, which have been instrumental in shaping our approach. Together, this progress brings us closer to identifying a lead province that will be the first to make those living with metastatic breast cancer count.”

– MJ DeCoteau, Founder  
& Executive Director,  
Rethink Breast Cancer

## Increasing global influence

In September 2025, BCNA influenced amendments to the United Nations' *Political Declaration on Non-Communicable Diseases* to **reinforce global commitments to improve breast cancer care including for those living with MBC**. In the UK, Breast Cancer Now continues to promote partnerships with government, clinicians, and patient advocates to put pressure on decision-makers to improve cancer data. In Canada, Rethink's Make Me Count campaign is gaining traction across the country to advance improvements to MBC data and care.

The pledge is not only driving national leadership for change across Australia, UK and Canada, but is becoming **a collective voice for global change in other countries**. Advocacy action through the pledge is also strengthening international commitments such as the ABC Global Alliance, the WHO Global Breast Cancer Initiative and the Lancet Breast Cancer Commission. This ensures MBC-specific priorities are integrated into national cancer plans and sustainable technology investment.

## The unfinished agenda: looking ahead

Progress on MBC data must translate into progress on MBC care. **Prevalence data is still not systematically informing models of care, clinical research, workforce, and treatments**. Government commitments, existing and new, must now be matched by sustained delivery and funding. Health equity gaps also need to be addressed for Indigenous communities, people in regional and remote areas, culturally and linguistically diverse groups, and for other historically underserved populations.

### Australia

The Australian Cancer Data Alliance still lacks confirmed ongoing funding beyond its initial investment in late 2024. State and territory-based registries continue to operate with varying capability that limits their contribution to national prevalence reporting and evolving data methods.

#### BCNA will continue to advocate for:

- Sustained federal investment in the Alliance to maintain shared governance and accountability, national consistency, and prevent fragmented implementation of cancer care initiatives.
- Linked national cancer incidence data to the AIHW National Health Data Hub for more complete and reliable MBC estimates.
- Increased investment in registry capacity and data infrastructure across all states and territories and legislative/regulatory changes about data collection, sharing, and reporting.
- Extension of the linked-data methodology for MBC to other metastatic cancers, including lung and prostate.

### United Kingdom

In England, progress against commitments in earlier cancer strategies has moved too slowly. Despite legislation requiring NHS Trusts in England to record MBC data since 2013, compliance remains incomplete.

#### Breast Cancer Now will continue to advocate for:

- Implementation of the National Cancer Plan for England's 2026 commitment to define and count metastatic breast cancer, in partnership with government, clinicians and patient advocates.
- The next *Scottish Cancer Action Plan* to outline how it will deliver the existing commitment to improve data collection on MBC.
- The new Welsh government to develop a cancer strategy that includes a commitment to improve MBC data collection.
- The NHS to improve MBC data quality and coverage.
- Better understanding of health inequalities and support for people living with MBC through the Northern Ireland study.

### Canada

There is still no national MBC prevalence estimate in Canada because recurrence data is not collected consistently across 13 provincial and territorial health systems, and the 2023 *Canadian Cancer Data Strategy* did not specifically address it.

#### Rethink Breast Cancer will continue to advocate for:

- The launch of a provincial pilot in 2026 focused on thorough MBC data reporting, with the intention of creating a model that can be adapted and scaled across the country.
- Engagement with health ministers and government officials to further elevate MBC data improvements and embed it within national priorities for e-health, data harmonisation, and women's health.
- Recurrence data to be explicitly included in any future revision of the *Canadian Cancer Data Strategy*.

## OUR PLEDGE STANDS.

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

This is more than a record of progress – it is a global promise to every person living with MBC that we will continue to stand beside you and keep making you count. Our shared learnings and commitment to change will ensure we remain accountable to you and each other. Together, we will show the rest of the world how they can count you too and why it matters.

“I have been campaigning for over 10 years now on the need for accurate data collection, and with that true visibility of the needs of patients like me. I was really pleased to see this commitment from the UK government on data collection in the National Cancer Plan for England: ‘We will define and count recurrent breast cancers – starting with metastatic (secondary) breast cancer in 2026’. Now I would like to see that commitment being delivered and action on data being taken this year – then and only then will I really feel that we have achieved progress on this issue, with metastatic (secondary) breast cancer patients finally being properly counted and supported in our healthcare system.”

- Claire Myerson, person living with metastatic breast cancer (UK)

### 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.*



**Claire Rowney,**  
CEO, Breast Cancer Now



**MJ DeCoteau,**  
Founder and Executive Director,  
Rethink Breast Cancer



**Kirsten Pilatti,**  
CEO, Breast Cancer  
Network Australia



We're **Breast Cancer Now**, the UK's leading breast cancer charity. And we're combining the power of science and support to change breast cancer. We have a bold vision - that by 2050, everyone with breast cancer will live and live well. We can't do it on our own. But together, we can make change happen. Now.



**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.