Breast
Cancer
Network
Australia

FROM INVISIBILITY TO INFLUENCE:

Progress on MBC data reforms in Australia

FOREWORD

WHILE THESE ACHIEVEMENTS IN CANCER DATA ARE WORTH CELEBRATING, IT IS ESSENTIAL TO SUSTAIN MOMENTUM. WE NEED CONTINUED COLLABORATION AND NATIONAL COORDINATION TO BUILD REGISTRY CAPACITY AND ENSURE EMERGING DATA MODELS TRANSLATE INTO EQUITABLE, PERSON-CENTRED CARE.

BCNA's advocacy has ensured people living with metastatic breast cancer (MBC) are now recognised and counted in national data – a milestone achieved through sector-wide collaboration.

The successful reporting of national metastatic breast cancer data marks a significant step forward in Australia's commitment to improving cancer outcomes. It demonstrates how far we have come in recognising and responding to the needs of people living with metastatic disease.

This Report, which aligns with the *Australian Cancer Plan* and the recently launched *National Data Cancer Framework*, highlights the progress achieved since the launch of BCNA's 2023 Roadmap. It underscores the importance of high-quality, integrated data and equitable cancer outcomes for all Australians.

Data will continue to be vital to achieving equity in cancer outcomes. Comprehensive cancer data enables more inclusive, person-centred care and supports evidence-based policy and planning.

Finally, I would like to acknowledge that this progress has been made possible through strong partnerships across the sector. I would also like to pay tribute to the late Peta Murphy MP, and all advocates, whose advocacy and vision helped advance metastatic cancer data collection. By building on these foundations, we can ensure that every person living with metastatic breast cancer is visible, supported and represented in shaping the future of Australian cancer care.

Professor Dorothy Keefe
CEO, Cancer Australia

For 27 years, Breast Cancer Network Australia (BCNA) has supported Australians impacted by breast cancer, ensuring their voices shape better care, stronger policy, and greater understanding.

Australia's progress has been driven by the leadership of New South Wales, Queensland, and Victoria, who each demonstrated extraordinary commitment following BCNA's 2023 National Roundtable. They undertook the work to develop new linked data methodologies to identify people living with metastatic breast cancer, setting the national benchmark for innovation. Their combined effort enabled the Australian Institute of Health and Welfare (AIHW) to leverage this knowledge and deliver Australia's first-ever national estimates of MBC prevalence, supported by Cancer Australia and the Department of Health, Disability and Ageing.

This moment will stand as one of BCNA's legacies, but there is still much work to do. We remain committed to standing with all Australians living with MBC to ensure their voices create meaningful change. We will expand our information and supportive care to create more opportunities to feel connected and a sense of belonging to a Network that understands. We will continue to build national and international partnerships that bring about real change. Australia is now shaping the future of global cancer data and redefining what collaboration can deliver for health reform – BCNA will continue to play a key role by driving global leadership and action in breast cancer care.

Vicki Durston
Director, Policy, Advocacy & Support Services, BCNA

> OUR ADVOCACY OVER THE LAST THREE YEARS HAS FOCUSED ON COUNTING THOSE LIVING WITH METASTATIC BREAST CANCER AND OUR ATTENTION AND DETERMINATION HAS LED TO THIS DEFINING MOMENT. THROUGH STRONG COLLABORATION WITH GOVERNMENTS, RESEARCHERS, DATA EXPERTS, AND CONSUMER ADVOCATES, WE HAVE ACHIEVED WHAT ONCE SEEMED IMPOSSIBLE – VISIBILITY FOR PEOPLE LIVING WITH METASTATIC BREAST CANCER (MBC) IN OUR NATIONAL DATA SYSTEMS. THIS OUTCOME IS THE RESULT OF THE COLLECTIVE STRENGTH OF A SECTOR DETERMINED TO TRANSFORM INVISIBILITY INTO INSIGHT, AND INSIGHT INTO INFLUENCE.

Toni, 42
Living with metastatic
breast cancer since 2021

SUMMARY

For the first time, an estimated 20,950 Australians (20,800 women and 150 men) living with metastatic breast cancer (MBC)* can say "I count". This emerging national picture exposes the scale of underestimation from previous MBC estimates of 10,553 in 2020, the chronic underinvestment in specialised healthcare, and historical inequities faced by people with MBC and their families and carers. Until now, efforts to understand this population have relied on small-scale or time-limited research projects rather than consistent national data collection.

Breast Cancer Network Australia (BCNA)'s ambitious goal to count people living with MBC, first set out in its 2023 roadmap report, *Time to Count People with Metastatic Breast Cancer - A Way Forward*, has been realised. This significant milestone has been achieved through strategic collaboration with government agencies, researchers, and data experts to improve cancer data so that people with MBC can live longer and live well.

Australia is leading national and international innovations in MBC data that can guide integrated responses for this growing group of people. Sustaining and evolving Australia's MBC data models will help close historical cancer data gaps and will support national commitments to improve breast cancer care. With continued investment, these pioneering approaches can be adapted to benefit people living with other advanced cancers.

ACHIEVING MOMENTUM REQUIRES:

> **Future support for the Australian Cancer Data Alliance to oversee the development of nationally consistent data, methods and reporting**
>
> **Building capacity across all state and territory cancer registries**
>
> **Accelerating investment in integrated health data initiatives that address the specific needs of metastatic cancers**

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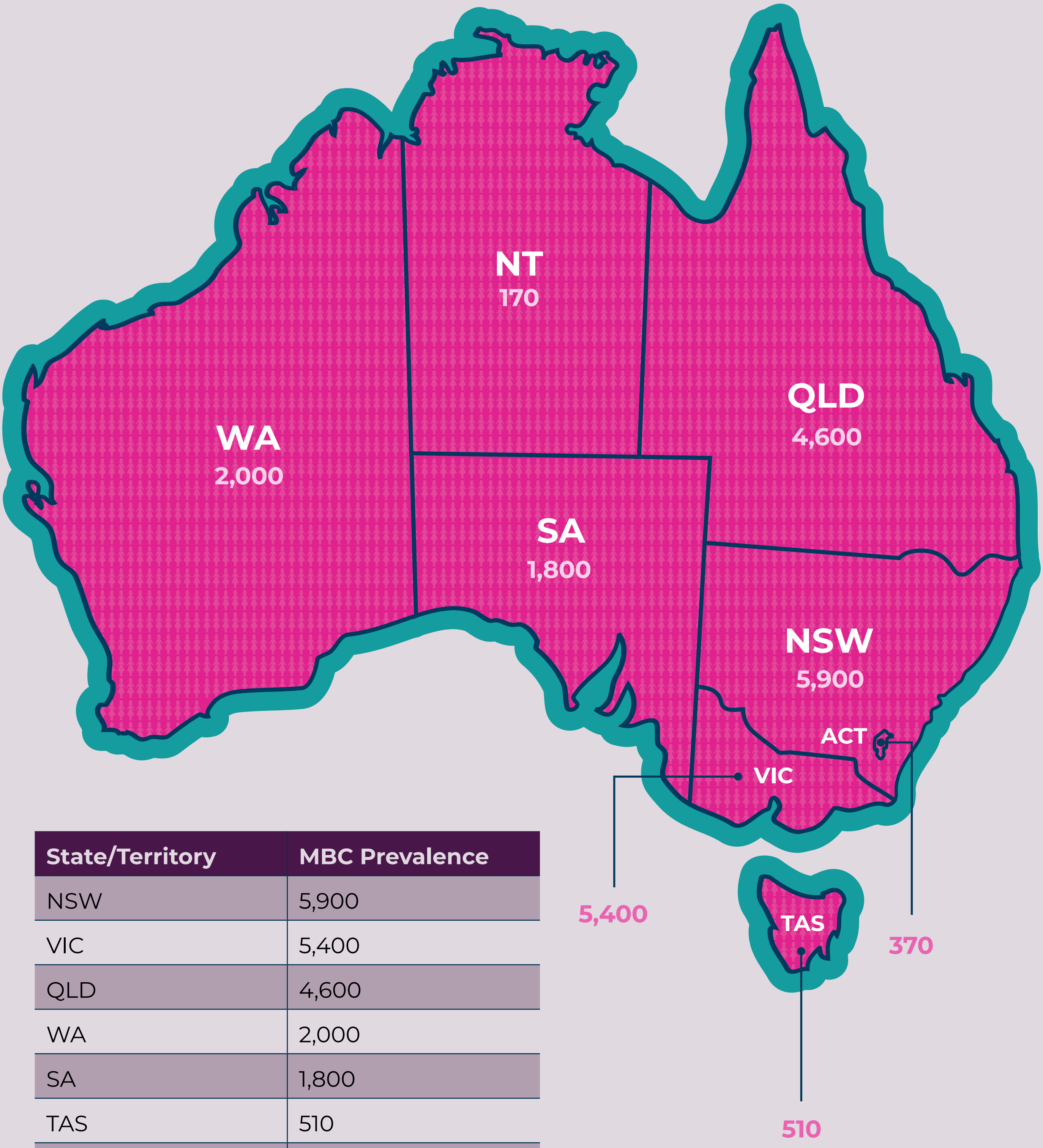
* Throughout this document, metastatic breast cancer (MBC) refers to breast cancer that has spread beyond the breast to other parts of the body. MBC is also known as stage IV, secondary breast cancer, or advanced breast cancer. It represents the most serious form of the disease because it is treatable but not curable.

#Estimated prevalence of metastatic breast cancer in Australian women at the end of 2024, by state of residence at the time of MBC diagnosis.



State/Territory	MBC Prevalence
NSW	5,900
VIC	5,400
QLD	4,600
WA	2,000
SA	1,800
TAS	510
ACT	370
NT	170
Total	**20,800**

IN THE NEXT 25 YEARS, PEOPLE IMPACTED BY BREAST CANCER WILL NEARLY DOUBLE.

Breast cancer remains the most common cancer and a leading cause of cancer-related death for women in Australia and worldwide. Diagnoses rise each year, and global cases are expected to almost double by 2050. International studies show that approximately 20 to 30 per cent of people with early breast cancer will later develop MBC (referred to as a 'recurrence' or 'relapse'). In some cases, people are diagnosed with de novo MBC, meaning their cancer is already spread beyond the breast to other parts of the body when it is first detected.

For too long, people living with MBC have been 'hidden in plain sight' within health systems and policy frameworks, with cancer data focused solely on incidence and mortality that overlook stage at diagnosis and recurrence. Incomplete data and inconsistent collection methods have limited estimates of Australia's MBC population. Where efforts have been made to understand the true size and needs of this population, they have largely relied on isolated, time-limited research projects rather than sustained, system-wide data collection. These challenges are not unique to Australia. For example, the United Kingdom's estimates remain unreliable due to poor compliance with MBC data reporting legislation, and Canada's MBC data gaps have prevented any modelling from being undertaken at all.

The impact of MBC extends far beyond a person's health outcomes – it affects both quality of life and the national economy. National productivity losses attributed to breast cancer are projected to reach $3.3 billion over a ten-year-period,[1] primarily due to reduced workforce participation and early retirement. These societal costs and financial challenges are magnified for people living with MBC. Lifelong treatment-related side effects and unpredictability of disease progression can limit people's capacity to work. Accessing life-prolonging treatments that are not subsidised can exceed hundreds of thousands of dollars, with further financial burdens across insurance, personal debt, and superannuation. These costs are in addition to Australia's estimated $1.84 billion annual spending (in 2023-24) on breast cancer.

Growing pressure on health system budgets, particularly since the COVID-19 pandemic, has exposed how people living with MBC remain absent from health planning and funding models. Harmonised methods and accurate data systems are essential to quantify need, guide resource allocation, and deliver sustainable, person-centred care focused on wellbeing and living well.

> *High -quality MBC data is both powerful and empowering. These data are essential to adequately plan, treat and support people with MBC. But the power of these data goes much further: it breaks down stigma by demonstrating to the world that millions of people with MBC globally are essential to the fabric of society. It also shows their rich contribution to families, communities, and the economy through paid and unpaid work.*
>
> *The Lancet Breast Cancer Commission calls for cancer registeries globally to record relapses for all cancers. The outstanding advocacy work by Breast Cancer Network Australia has catalysed this process and will provide a blueprint for the rest of the world to follow.*
>
> – Professor Charlotte Coles,
> Chair of the Lancet Breast
> Cancer Commission

Sam, 50
Living with metastatic
breast cancer since 2019

VISIBILITY OF METASTATIC BREAST CANCER HAS BEEN LED BY CONSUMER ADVOCACY.

For 27 years, BCNA has provided a voice for people affected by breast cancer, including those living with MBC, and their families. With its network connecting over 250,000 people, BCNA has driven MBC advocacy for more targeted research, subsidised life-prolonging medicines and precision diagnostics such as genomic profiling, and specialist nursing and survivorship care models.

To address the unique and complex care needs of people living with MBC, BCNA has developed tailored information and resources, supportive care services, collaborative research initiatives, and expanded opportunities for MBC-consumer partnerships and engagement.

BEING COUNTED IS FUNDAMENTAL TO BEING CARED FOR.

While treatable, MBC remains incurable and requires lifelong treatment. Significant advancements in medicines, technologies and research are now helping people live well with MBC for an average of five years.[2] With emerging and effective treatments, some people are living for more than a decade. However, equitable access to quality care and life-prolonging therapies varies widely, often shaped by social, economic and geographic factors that continue to influence survival outcomes.

People living with MBC have complex, lifelong care needs that are often misunderstood or overlooked. Historical gaps in MBC data have led to gaps in care experiences and health outcomes. There is still a shortage of coordinated multidisciplinary care that results in unmet financial, physical and psychological needs. Alongside specialised MBC clinical care, holistic and person-centred approaches that promote community and economic participation are fundamental to reducing stigma and isolation commonly reported by people living with MBC.

Cancer data registries are considered the 'bedrock of global cancer care'[3] because, when designed and used effectively, they can provide the evidence needed to inform every stage of the cancer continuum. Cancer registries are expected to collect and report comprehensive population-level data to guide prevention and screening programs, policy reform, research funding, clinical trials, and workforce and service planning. However, most registries are not yet equipped to capture the full patient experience - from diagnosis through to treatment and recurrence - leaving significant gaps in understanding disease burden, long-term outcomes, and survivorship needs.

> *After 13 years of invisibility living with metastatic breast cancer, I am finally being counted. For too long, it felt as though my life—and the lives of others with MBC—did not matter to the health system. Being counted is more than a statistic; it is an acknowledgment of our humanity, our resilience, and our worth. It's about dignity, visibility, and validation.*
>
> – Lisa Tobin

Emily, 31
Living with metastatic
breast cancer 2023

By strengthening Australia's cancer data, governments can better understand and respond to the experiences of people living with MBC through more accurate, timely, and actionable insights into cancer incidence, treatment, biomarkers, recurrence, and stage at diagnosis. Shifting from outdated research methodologies and theoretical models to real-world, linked data systems requires continued advances in digital infrastructure, artificial intelligence, and federated learning. Building Australia's data capability is essential to understanding the profile of people living with MBC and ensuring that tailored care and support are delivered where they are needed most.

TWO YEARS ON: TRANSFORMATION HAS BEEN MADE POSSIBLE.

National initiatives now prioritise integrated data and optimal cancer care.

In February 2024, the Prime Minister announced a $1.5 million investment to accelerate the collection of cancer stage and recurrence data. This included funding to establish the Australian Cancer Data Alliance (the Alliance) with bipartisan support to strengthen cancer registry systems, including improved MBC data. The Alliance is coordinated by the Australian Institute of Health and Welfare (AIHW), supported by Cancer Australia and the Department of Health, Disability and Ageing. It consists of state and territory cancer registries and sector experts to provide leadership and expert advice on national cancer data priorities outlined in the *Australian Cancer Plan*, focusing on improved access, consistency, and data integration across jurisdictions. The critical role of data in delivering optimal cancer care and improving outcomes for Australians affected by cancer is recognised in other recent health initiatives, including the *National Cancer Data Framework, National Framework for Genomics in Cancer Control*, and *Health Technology Assessment Review*.

State-based innovation is driving national reform in MBC data.

In late 2024, NSW implemented a world-first linked-data methodology to estimate the number of people living with MBC (prevalence) in NSW. By linking local cancer registry data and hospital data with national records about prescriptions and cancer services, the approach established the first accurate model for measuring MBC prevalence in Australia. By mid-2025, Queensland and Victoria had applied and refined the methodology within their own systems. Together, the three states are now informing national and international efforts to modernise cancer registries, strengthen data integration, and embed evidence-driven approaches to improve cancer care, research, and policy reform.

Australia is now building a clearer national picture of MBC prevalence.

Building on the success of state-based innovation and collaboration, Australia now has its first national estimate of how many people are living with MBC. Using linked national and state data, the AIHW, through the Alliance, has developed a new data model estimating that 20,950 Australians were living with MBC in 2024.

National cancer incidence (diagnosis) data is now planned to be linked to the AIHW's National Health Data Hub - AIHW's major national data linkage system for health and welfare research and analysis. This is expected to strengthen capacity and enable the production of more complete and reliable estimates that will guide future cancer plans and services for people living with MBC. It will also provide a pathway to accurately estimate the impact of other metastatic cancers, such as lung and prostate, helping build a more complete and equitable picture of cancer in Australia.

AUSTRALIA'S PROGRESS IS SETTING A NEW GLOBAL BENCHMARK.

MBC data has long been considered a global priority[4] including by the World Health Organisation and Advanced Breast Cancer (ABC) Global Alliance, yet few countries have successfully addressed it. As The Lancet Breast Cancer Commission stated, a minimum of 70 per cent of global cancer registries should now be registering people with metastatic disease, with the goal of reaching 100 per cent in the decade ahead.[5] Australia is the first to deliver MBC data reforms through linking and collaborating across state and national data systems.

Through BCNA's advocacy, Australia's MBC data achievements are being recognised globally and inspiring momentum to make people with MBC visible across global cancer data and healthcare systems. Together with Breast Cancer Now (UK) and Rethink Breast Cancer (Canada), BCNA launched *Advancing Global Visibility for Metastatic Breast Cancer* in July 2025 to showcase Australia's data innovation and pledge ongoing advocacy for governments to improve MBC data.

In September 2025, BCNA reinforced Australia's standing as a trusted and influential voice in global health policy by guiding amendments to the *United Nations Political Declaration on Non-Communicable Diseases* that ensured governments, including Australia, remain committed to breast cancer action that matches its global impact. By demonstrating what is possible when governments, researchers, cancer registries and consumer advocates work together, Australia is setting a new global standard that can be adopted by other countries. The Australian Cancer Data Alliance's role coordinating national cancer data strategies creates a unique position for Australia to continue influencing global initiatives.

FUTURE PRIORITIES: SUSTAINING MOMENTUM THROUGH COORDINATED ACTION AND INVESTMENT.

New South Wales, Queensland and Victoria have advanced state-based methodologies to estimate MBC prevalence, but cancer registries across Australia continue to operate with varying levels of capability, resourcing, and maturity. Multiple and incompatible data systems, inconsistent standards, and differing legislative frameworks create inequities and complexities, making it difficult for some registries to access and link state and national datasets required to accurately collect and report on their MBC populations.

Sustained action and investment are needed to improve the timely collection of national data on cancer stage at diagnosis and recurrence and link together with relevant data about treatment and mortality. Future priorities are to:

Sustain the Australian Cancer Data Alliance to oversee national consistency.

AIHW's Cancer and Treatment Linked Analysis Asset (CaT-Link), which includes national linked data on cancer diagnoses and deaths, and Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) data, has enabled Australia's first national estimate of MBC prevalence. The Alliance, however, lacks ongoing funding to coordinate and strengthen data system integration across Australia's cancer registries. Continued investment will prevent fragmented implementation of cancer initiatives and oversee consistency of national data quality standards and modelling methods.

The Alliance will also support enduring linkage of cancer-related data for all jurisdictions to the National Health Data Hub. This will drive more efficient access and strategic use of MBC data, enhanced and standardised reporting, and evidence-based cancer care and research priorities.

Build capacity across all cancer registries.

Every state and territory must have the capability to analyse their own linked cancer and treatment data to support local jurisdictional service needs, planning, and to contribute to an accurate national picture of MBC. Better data collection will also inform predictive models that identify emerging service gaps in priority groups, including MBC and cancer sub-types, forming a stronger evidence base for health and cancer policy, research, and funding. Ongoing investment in specialist cancer registry workforce, systems, infrastructure, and technology will ensure state and territory cancer registries can collaborate with the AIWH to develop harmonised methods of data collection. Leveraging health technology and AI to strengthen data completeness and accuracy will ensure sustainable, repeatable and replicable data reporting.

Accelerate investment in integrated health data initiatives that address the specific needs of metastatic cancers.

Healthcare models for MBC should prioritise living well and quality of life, yet most existing cancer initiatives and tools focus on early-stage breast cancer. Implementing and evaluating national cancer initiatives, such as the *Australian Cancer Plan* and *National Cancer Data Framework*, must address the specific needs of people with metastatic cancers, including MBC. Integrating and linking metastatic cancer data is critical to delivering person-centred care, improving detection, risk-stratified interventions, pathology and screening reporting, and care coordination. By streamlining and harmonising data methods and sharing insights about new technologies, governments can fast-track innovation and build stronger partnerships with researchers, healthcare professionals, and consumers to deliver projects that enhance healthcare experiences and quality of life.

> *This national estimate marks an important milestone in Australia's cancer data reform and visibility for people living with metastatic breast cancer.*
>
> *Delivered by the Australian Institute of Health and Welfare, with the support of Cancer Australia and the Department of Health, Disability and Ageing, this achievement has been driven by the leadership and advocacy of Breast Cancer Network Australia.*
>
> *For the first time, Australia has a clearer picture of how many people are living with metastatic breast cancer — data that will bring greater visibility to this population across planning, policy and service delivery nationwide.*
>
> – The Hon Mark Butler MP - Minister for Health, Disability and Ageing

Jessica, 41
Living with metastatic
breast cancer since 2024

ACKNOWLEDGEMENTS

We acknowledge the tireless work of those who have sought to put this issue on the national agenda and solve this complex challenge. Their vision, persistence, and technical leadership laid the foundations upon which this progress has been built. It is a testament to what is possible when people come together with shared purpose.

> **BCNA Metastatic Breast Cancer Lived Experience Reference Group – past and present members**
>
> **The Australian Government**
>
> **Australian Institute of Health and Welfare**
>
> **BCNA National Roundtable attendees (2023)**
>
> **Department of Health, Disability and Ageing**
>
> **Cancer Australia**
>
> **Members of the Australian Cancer Data Alliance**
>
> **Cancer registries from across Australia**
>
> **Researchers, epidemiologists and cancer-control policy experts whose work underpins this national breakthrough**
>
> **BCNA Board, staff, Consumer Representatives, and the Project 27 Working Group**
>
> **BCNA Consumer Representatives from the Seat at the Table Program**

We also honour the memory of those who have died from metastatic breast cancer.
Your strength and advocacy continue to inspire our work.

FOOTNOTES

1. Projections between 2022 to 2031 from productivity-adjusted life years lived and associated gross domestic product (GDP) costs in Australian females aged 20–64 years. Also quantified as $1.4 billion in lost wage earnings.
2. Rates are lower for certain MBC sub-types and population groups. MBC survival can range from 6 months to 15 years.
3. The Lancet. Cancer registries: the bedrock of global cancer care. *Lancet*. 2025 Feb 1;405(10476):353.
4. 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), Lancet Breast Cancer Commission, Advanced Breast Cancer (ABC) Global Alliance
5. Coles CE, Earl H, Anderson BO, Barrios CH, Bienz M, Bliss JM, Cameron DA, Cardoso F, et al. *Breast cancer: addressing inequities and improving outcomes worldwide*. Lancet. 2024;403(10439):1895–1950. doi:10.1016/S0140-6736(24)00747-500747-5)

#Source: AIHW analysis of CaT-Link data, and adjustment with reference to Cancer Institute NSW (CINSW), Cancer Council Victoria (CCV) and Cancer Alliance Queensland (CAQ).

For further details, refer to: Australian Institute of Health and Welfare (2025) Metastatic breast cancer - first national estimates, AIHW, Australian Government.

Notes:

1. Estimates have been rounded to the nearest 10 (for small numbers) or 100 (for large numbers).
2. Rows will not add to total due to rounding because for 50 out of the 20,800 cases, there was insufficient information to identify state of residence.
3. In addition to these prevalent women, approximately 150 Australian men diagnosed with MBC are also estimated to be prevalent at the end of 2024.
4. AIHW estimates for NSW, Victoria and Queensland will differ from the counts previously produced by CINSW, CCV and CAQ, reflecting differences in the available data and completeness of counts, the assumptions used to model national estimates, or interstate differences in treatment (if any).

Ilana, 57
Living with metastatic
breast cancer since 2011

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CONTACT US

Helpline: **1800 500 258**
bcna.org.au