



# Making Metastatic Breast Cancer Count

No Longer Hidden in Plain Sight



**In 2020, we estimate there were at least 10,553 people living with metastatic breast cancer in Australia.<sup>1,2</sup> We do not know for sure because they are not counted by our cancer registries.**

We call for national leadership and accountability to ensure those living with metastatic breast cancer are counted and made visible. We must have this visibility to plan for and invest in this growing population with complex needs.

## Our Voice

Breast Cancer Network Australia (BCNA) strives to be the sought-after voice on many topics relating to breast cancer policy, research and service or program development for government, health service providers, researchers and the broader community. We do so by building greater connection between decision making and lived experience, including in the area of metastatic breast cancer, which is one of our highest advocacy priorities. We utilise our network through insight-gathering and bringing metastatic breast cancer consumers to the table wherever possible.

**BCNA has long been calling for improvements to the collection and reporting of metastatic data as well as advocating for improved services to address the currently unmet needs of this population.**

People with metastatic breast cancer are living longer than ever before thanks to new medications and therapies that aim to slow the cancers' progression and control symptoms. However, health care goals extend beyond prolonging life and must also incorporate ways to define and live a quality life with metastatic cancer. Addressing the clinical, supportive and psychosocial needs of people with metastatic cancer requires a multi-disciplinary approach and yet these needs remain largely unmet by health and allied health providers.<sup>3,4</sup> Fear and anxiety, financial pressures, pain and symptom management, and assistance with daily living are some examples of the complex, chronic and often unpredictable needs that impact on the quality of life of the 'treatable but not curable' cancer population.<sup>3</sup>



**Supporting  
all Australians  
affected by  
breast cancer**

## Living with Metastatic Breast Cancer

We know through our work to date that appropriate care and support are essential for anyone with a cancer diagnosis. For people with metastatic breast cancer, the life-long nature of treatment, the complex care and the anxiety that accompanies the uncertain prognosis and disease trajectory can be physically and emotionally challenging.<sup>5</sup>

Our 2017 Member Survey Report demonstrated that people with metastatic breast cancer in Australia are not receiving the supportive care they need.<sup>4</sup> This is problematic from an equity perspective as people with metastatic breast cancer have significantly higher supportive care needs than people with non-metastatic breast cancer, yet our health and supportive care services are less likely to meet these needs.<sup>4</sup>

**Incomplete data means those living with metastatic breast cancer are ‘invisible’ to health systems and policymakers. This is because they are literally not being counted consistently by our cancer registries.**

This is not a new issue. BCNA, and other breast cancer consumer organisations around the world, have been advocating for increased and strengthened visibility of metastatic breast cancer for the best part of 10 years.<sup>6</sup> In 2022, despite significant progress across nearly all facets of cancer care in Australia, we are still no closer to shining a light on this population. With Australia’s first national cancer plan currently in development, there is an opportunity to strengthen the voice of not only those with metastatic breast cancer but all those living with metastatic disease.

In light of this, we are putting an estimated figure to those currently hidden in plain sight. Using modelling available to us, we estimate there were at least **10,553 people** living with metastatic breast cancer in Australia in 2020.<sup>1,2</sup> This is a conservative estimate and the figure is likely to be significantly higher. By 2025, it is estimated that this figure will increase to around **12,840 people** living with metastatic breast cancer.<sup>1,7</sup>

## Still hidden in plain sight

### **Not all Australian cancer registries report stage at diagnosis and none record or report on recurrence.<sup>8</sup>**

When our cancer registries were established in the 1970s their primary function was to report the type of cancer, the number of people diagnosed with cancer (incidence) and how many people died from cancer (mortality). However, 50 years later it is becoming increasingly clear that in addition to incidence and mortality data, we also need our cancer registries to collect and report how extensive the cancer is at diagnosis (stage), and when the cancer progresses or returns (recurrence). By combining these data, a more comprehensive picture of cancer in Australia can be drawn.

This current gap in cancer registry data has been recognised in Australia for many years. It was highlighted in Cancer Australia's National Cancer Data Strategy for Australia in 2008.<sup>8</sup> The report concluded that cancer registries should collect the stage and recurrence data needed to determine the number of people living with metastatic cancer in Australia. Despite this, nothing has been implemented on a national scale, and it is unclear where accountability is placed to progress this recommendation. The collection of these data is even more critical given improvements in breast cancer treatment mean metastatic survival has doubled in the past 20 years.<sup>9</sup>

### **Modelling and record linkage are a useful alternative but interim solutions**

In the absence of national cancer registry data, biostatisticians and epidemiologists can use modelling and record linkage to estimate how many people are living with metastatic breast cancer.<sup>1,7,10,11</sup> Modelling conducted by researchers in 2008, at

the request of breast cancer consumer advocates and the then National Breast and Ovarian Cancer Centre, indicated in 2004, there were 8,284 women living with metastatic breast cancer in Australia.<sup>1</sup>

BCNA has engaged with key health researchers to apply this same modelling to today's breast cancer population to estimate there were 10,553 people living with metastatic breast cancer in Australia in 2020.<sup>1,2</sup> However, the true number is not yet known.

### **Without these data we cannot advocate, plan or invest**

Cancer is Australia's leading burden of disease.<sup>12</sup> In 2019–2020, one in nine hospital admissions was related to cancer.<sup>12</sup> In Australia, more than \$20 billion is spent annually treating and managing cancer<sup>13</sup>. Given the increasing incidence of cancer, the earlier onset of cancers<sup>14</sup>, and Australia's growing and aging population, the demand on our health care system will only increase. Demand for chemotherapy and cancer physicians is expected to increase by 50 per cent in the next 20 years<sup>15</sup>.

Systematic capture and reporting of cancer stage and recurrence data is therefore essential if policymakers and health providers are to accurately predict Australia's future health service utilisation and workforce needs, as well as the costs related to delivering these services.

The ongoing and often complex nature of metastatic breast cancer care means it is particularly resource intensive and requires specialist support such as metastatic breast care nurses, psycho-oncology interventions and other allied health services and programs.

## People with metastatic breast cancer feel invisible

Breast cancer is renowned for galvanising patients, advocates, researchers, policymakers and health care providers, resulting in care that is often the envy of other cancers. However, within the breast cancer community, people with metastatic breast cancer often report feeling overlooked and even invisible.<sup>16-18</sup> The reasons for this are complex.

One reason is the celebration and dominance of the 'breast cancer survivor' narrative in society generally and also within our breast cancer consumer advocacy and research communities. While this celebration of improved breast cancer survival rightly acknowledges the incredible progress made in breast cancer treatment and care, it effectively shuts out the voices of those who will not survive, that is, those living with metastatic breast cancer. It could be said they are 'hidden in plain sight.'

Another reason is that surviving long-term with metastatic breast cancer is a relatively recent phenomenon driven by

continued improvements in treatment for metastatic breast cancer. Our current breast cancer care systems and breast cancer models of care, while successful in delivering clinical care and treatment to people with metastatic breast cancer, are not as well placed to deliver the much-needed holistic supportive care or metastatic survivorship care. This is critical to maintaining quality of life for these people.<sup>19-21</sup>

It has been recognised that the Australian cancer care continuum needs to evolve to include those people who are receiving treatment, not to cure or to palliate, but to prolong and improve quality of life. Progress has been made in Cancer Australia's Breast Cancer Optimal Care Pathways (2nd Ed), but more needs to be done.<sup>22</sup> We believe increased visibility through routine collecting and reporting of recurrence and stage data will change the way we view metastatic breast cancer and shine a light on the unmet needs of this group.

“

*The Clinical Oncology Society of Australia (COSA) supports the development of new systems to report recurrence of all cancers. Without this, we cannot plan services, ensure adequate resources, and learn how our treatments for cancer are working in the real world.*

– Prof Fran Boyle, COSA

”





“

*The lack of adequate epidemiological data about metastatic breast cancer is a major issue and has significant consequences in the quality of care of patients with this disease [...] Due to the fact that cancer registries only collect incidence and mortality data but not recurrence data, almost no country in the world has an accurate knowledge of how many patients live with [metastatic breast cancer] at any given moment. Not knowing how many patients exist, precludes the adequate allocation of resources, which in turn, precludes better short and long-term outcomes.*

*The ABC Global Alliance is fully supportive of the BCNA initiative “Making Metastatic Breast Cancer Count” and hopes it serves as an incentive to many other countries worldwide.*

”

– Dr Fatima Cardoso, Advanced Breast Cancer (ABC) Global Alliance

## Towards visibility

People living with metastatic breast cancer have significant health care needs. Metastatic breast cancer represents the most severe form of breast cancer and requires ongoing and often intensive treatment. Many groups, including consumer organisations such as BCNA, health services, researchers and clinicians are increasingly challenged by the lack of understanding about how many people are living with metastatic breast cancer in Australia.

BCNA believes it is imperative that Australia acts now. The US and UK have already acted. In the UK in 2021, National Health Service (NHS) England and NHS Wales announced they would be commissioning an audit on metastatic breast cancer. Breast Cancer Now, the UK's leading breast cancer advocacy organisation, estimates 35,000 people are living with metastatic breast cancer in the UK but are awaiting the audit for an accurate figure.<sup>23</sup>

The US Government is investigating costs through the National Institute of Health (NIH) and Centers for Disease Control and Prevention (CDC) to incorporate metastatic breast cancer progression into current cancer surveillance activities. There is also increasing pressure from breast cancer consumer organisations in the US for collection of recurrence data.

### Coming to the table

In Australia, a national roundtable to bring together health agencies, cancer advocacy organisations, clinical and data experts, and consumers and policymakers will help identify an agreed long-term approach and interim measures to reporting stage and recurrence data and inform current policy commitments.

### Leadership

As the national cancer control agency, Cancer Australia has shown historical and ongoing commitments to strengthen record linkage and reporting of cancer stage, treatment and recurrence data at the national level.<sup>8,10</sup> We want to understand how it is placed to lead the establishment of an accurate national picture of metastatic breast cancer data, and all other metastatic and advanced cancers.

### Modernising cancer registries

Updating our cancer registries is integral to the sustainable reporting of recurrence data (not just for breast cancer but across all cancers). Prioritising this will require strong leadership, commitment, governance and funding to drive change across the health sector. Upgrading cancer registries will also require legislative changes to set minimum data requirements, funding and recruitment of specialist health data analysts and modellers, as well as further investment in technology.

## It's time for action

We strongly encourage interested stakeholders to contact BCNA's Policy & Advocacy team for more information on our work and advocacy for metastatic breast cancer. Please email [policy@bcna.org.au](mailto:policy@bcna.org.au) to get in touch.

**We are calling on relevant stakeholders working in government policy, research, consumer engagement, health care or supportive care to express their interest to be part of a roundtable, to be held in 2023, to discuss and progress the issues raised in this paper. Please contact BCNA's Policy & Advocacy team for more information.**

Researchers conducting work related to metastatic cancer are encouraged to involve consumers early in the development of their studies. BCNA's Consumer Representative program, Seat at the Table (SATT), provides trained Consumer Representatives who work with researchers, committees and decision-making bodies throughout Australia to represent the experience and views of all people affected by breast cancer in Australia. More information can be found on our website or by contacting BCNA's Policy & Advocacy team.

A background paper containing references, analysis and further exploration of the topics raised in this issues paper can be made available on request.



## Acknowledgements

Breast Cancer Network Australia wishes to acknowledge the following people for their contribution to this issues paper:

- **Vicki Durston**, BCNA
  - **Sam Mills**, BCNA
  - **Amanda Winiata**, BCNA
  - **Julie Rae**, BCNA
  - **Siobhán Dunne**, BCNA
- **Dr Andrea Smith**, The Daffodil Centre, a joint venture between Cancer Council NSW and University of Sydney
  - **Jodie Lydeker**, Head2Heart Worx Consulting
  - **Dr Sally Lord**, NHMRC Clinical Trials Centre, the University of Sydney
  - **Prof Dianne O’Connell**, The Daffodil Centre, a joint venture between Cancer Council NSW and University of Sydney
  - **BCNA’s Metastatic Breast Cancer Lived Experience Reference Group**

## References

1. Clements MS, Roder DM, Yu X, Egger S, O'Connell DL. Estimating prevalence of distant metastatic breast cancer: a means of filling a data gap. *Cancer Causes & Control*. 2012;23(10):1625-1634. doi:10.1007/s10552-012-0040-9
2. Australian Institute of Health and Welfare (AIHW). 2022 Cancer Data in Australia. Table S2a.1: Cancer mortality counts from the National Mortality Database; Canberra: AIHW. July 2022. Available at <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/data> (viewed Sept 2022).
3. Hart NH, Crawford-Williams F, Crichton M, et al. Unmet supportive care needs of people with advanced cancer and their caregivers: a systematic scoping review. *Crit Rev Oncol Hemat*. 2022;176:103728. doi:10.1016/j.critrevonc.2022.103728
4. Breast Cancer Network Australia (BCNA). BCNA Member Survey Report. BCNA: Melbourne; 2017. Published online 2017. <https://www.bcna.org.au/media/8806/bcna-member-survey-report-final-v3-08-nov-2017.pdf>
5. Shilling V, Starkings R, Jenkins V, Fallowfield L. The pervasive nature of uncertainty—a qualitative study of patients with advanced cancer and their informal caregivers. *J Cancer Surviv*. 2017;11(5):590-603. doi:10.1007/s11764-017-0628-x
6. Cardoso F, Spence D, Mertz S, et al. Global analysis of advanced/metastatic breast cancer: Decade report (2005–2015). *Breast*. 2018;39:131-138. doi:10.1016/j.breast.2018.03.002
7. Gallicchio L, Devasia TP, Tonorezos E, Mollica MA, Mariotto A. Estimation of the numbers of individuals living with metastatic cancer in the United States. *JNCI*. Published online 2022. doi:10.1093/jnci/djac158
8. Cancer Australia. A National Cancer Data Strategy for Australia. Cancer Australia, Australian Government: Canberra; 2008. [https://www.canceraustralia.gov.au/sites/default/files/publications/ncds\\_final\\_web1\\_504af02093a68.pdf](https://www.canceraustralia.gov.au/sites/default/files/publications/ncds_final_web1_504af02093a68.pdf)
9. Caswell-Jin JL, Sun L, Munoz D, et al. Contributions of screening, early-stage treatment, and metastatic treatment to breast cancer mortality reduction by molecular subtype in U.S. women, 2000-2017. *J Clin Oncol*. 2022;40(16\_suppl):1008-1008. doi:10.1200/jco.2022.40.16\_Suppl.1008
10. Cancer Australia. Stage, Treatment and Recurrence (STaR). Improving Cancer Data. <https://canceraustralia.gov.au/research-data/cancer-data/improving-cancer-data>
11. Lord SJ, Daniels B, Kiely BE, et al. Long term risk of distant metastasis in women with non - metastatic breast cancer and survival after metastasis detection: a population - based linked health records study. *Med J Australia*. Published online 2022. doi:10.5694/mja2.51687
12. Australian Institute of Health and Welfare (AIHW). Cancer in Australia 2021. Cancer Series No. 133. Cat. No. CAN144. AIHW: Canberra; 2021.
13. Australian Institute of Health and Welfare (AIHW). Disease Expenditure in Australia 2018-19. AIHW: Canberra; 2021. <https://www.aihw.gov.au/getmedia/9ce5ae2a-f574-4089-8d52-158abb4bdb09/Disease-expenditure-in-Australia-2018-19.pdf.aspx?inline=true>

## References

14. Ugai T, Sasamoto N, Lee HY, et al. Is early-onset cancer an emerging global epidemic? Current evidence and future implications. *Nat Rev Clin Oncol*. Published online 2022:1-18. doi:10.1038/s41571-022-00672-8
15. Wilson BE, Jacob S, Yap ML, Ferlay J, Bray F, Barton MB. Estimates of global chemotherapy demands and corresponding physician workforce requirements for 2018 and 2040: a population-based study. *Lancet Oncol*. 2019;20(6):769-780. doi:10.1016/s1470-2045(19)30163-9
16. Breast Cancer Foundation NZ. “I’m Still Here” Insights into Living - and Dying - with Advanced Breast Cancer in New Zealand. Breast Cancer Foundation NZ: Auckland; 2018. <https://breastcancerfoundation.org.nz/Images/Assets/21894/1/BCFNZ-ABC-Report-2018-Executive-Summary.pdf>
17. Breast Cancer Now. Until Things Change: The Unsurvivors Report. Breast Cancer Now: London; 2019. [https://breastcancer.org/sites/default/files/bcn\\_untilthingschange\\_final\\_30.09.20.pdf](https://breastcancer.org/sites/default/files/bcn_untilthingschange_final_30.09.20.pdf)
18. Breast Cancer Now. Secondary. Not second rate. Manifesto for change. Breast Care Now: London; Published online 2017. <https://breastcancer.org/get-involved/campaign-us/secondary>
19. Mollica MA, Smith AW, Tonorezos E, et al. Survivorship for individuals living with advanced and metastatic cancers: National Cancer Institute Meeting Report. *J National Cancer Inst*. Published online 2021. doi:10.1093/jnci/djab223
20. Smith AL, Hart NH, Jefford M, Chan RJ. Survivorship research for people with metastatic or advanced cancer: a time for action. *Asia-Pacific J Oncol Nurs*. Published online 2022. doi:10.1016/j.apjon.2022.02.001
21. Clinical Oncology Society of Australia (COSA). COSA Model of Survivorship Care: Critical Components of Cancer Survivorship in Australia Position Statement. COSA; 2016. <https://www.cosa.org.au/media/332340/cosa-model-of-survivorship-care-full-version-final-20161107.pdf>
22. Cancer Council Victoria; Department of Health, Victoria. Optimal care pathways for people with breast cancer: Second edition. Cancer Council Victoria: Melbourne, 2021.
23. Breast Cancer Now. Secondary counts - our secondary breast cancer campaign win. Breast Cancer Now: London; Published 2021. <https://breastcancer.org/about-us/news-personal-stories/secondary-counts-%E2%80%93-our-secondary-breast-cancer-campaign-win>



**Breast Cancer Network Australia**  
Level 1, 293 Camberwell Road,  
Camberwell Vic 3124

**HELPLINE 1800 500 258**  
**BCNA.ORG.AU**