



Our role and voice

Breast Cancer Network Australia (BCNA) is Australia's largest breast cancer consumer organisation, representing over 180,000 people impacted by breast cancer. We provide specialist information, resources, and online peer support networks for the 21,000 people newly diagnosed each year and at least 15,000 individuals living with metastatic (advanced) breast cancer. We contribute to improved breast cancer care through collaboration and evidence-based advocacy that reflect the voice of our consumers and national and global strategic alliances. BCNA and our trained consumer representatives are well positioned to support the next phase of Australia's cancer care initiatives, promoting integrated and coordinated implementation centred around lived experience.

Introduction

Every day in Australia, 58 people are diagnosed with breast cancer and 9 lives are lost.

Despite many advances in research and treatment, it continues to be the most common cancer affecting Australian women and costs the Australian Government nearly \$1.8 billion annually. We call on the Australian Government to take further action to improve outcomes for all Australians affected by breast cancer and reduce the burden of disease on patients, their families and communities, and the healthcare system by:

1. **Reducing** the financial costs of breast cancer treatment
2. **Prioritising** risk-based stratification for early detection/breast screening programs
3. **Addressing** unmet supportive care needs for people impacted by breast cancer
4. **Investing** in a sustainable and comprehensive cancer data ecosystem.

1. Reduce the financial costs of breast cancer treatment

Why action is needed:

Women with breast cancer experience high out-of-pocket costs for healthcare as well as the indirect costs such as loss of income which results in substantial financial burden.¹ Rising cost of living pressures are exacerbating these inequities and barriers to accessing optimal breast cancer care. Costs are disproportionate for priority population groups and people living with metastatic breast cancer.

Australians endure an average wait of 466 days from the time a medicine is TGA-approved to when it becomes accessible through the Pharmaceutical Benefits Scheme (PBS).²

Without government subsidy, new breast cancer drugs that save or prolong lives can cost more than \$50,000 a year.³ Out-of-pocket costs are incurred throughout the cancer continuum. Expenses often

1. Duckett, S., Stobart, A., and Lin, L., 2022. Not so universal: How to reduce out-of-pocket healthcare payments. Grattan Institute.

2. Medicines Australia, Additional PBAC meeting announced so patients can access lifechanging medicines, 2024. <https://www.medicinesaustralia.com.au/media-release/additional-pbac-meeting-announced-so-patients-can-access-lifechanging-medicines/>

3. Enhertu (trastuzumab deruxtecan) is an innovative treatment for people with HER2-low metastatic breast cancer that cost between \$10,000 to \$15,000 every three months prior to being listed on the PBS in 2024.



range between \$7,000 to over \$20,000, even with private health insurance coverage. Insurance claims then contribute to rising premiums.

Nearly 40% of people diagnosed with breast cancer (over 8,000 each year) are of working age⁴ (between 20 to 59 years). Employment challenges due to short- and long-term impacts of treatment can negatively affect health outcomes and future economic participation.

What Government can do to reduce financial costs of breast cancer treatment:

- Simplify eligibility and application processes for early access to superannuation on compassionate grounds to pay for life-saving cancer treatment costs such as specialist diagnostic tests (e.g., MRI, contrast mammogram), surgery, chemotherapy, and radiation.
- Prioritise HTA Review recommendations that streamline assessment and approval processes for listing breast cancer-related therapies on the PBS and MBS.⁵
- Incentivise standardised private health fund rebates and transparent premium increases.⁶

2. Prioritise risk-based stratification for early detection/breast screening programs

Why action is needed:

Genetic conditions and breast density can significantly increase the risk of developing breast cancer. Access to specialist diagnostic and screening tests is limited due to restrictive eligibility criteria, cost, and workforce shortages, especially in regional areas.

Access to specialist screening and detection decreases the likelihood of advanced stage (metastatic) diagnoses that compromise survival outcomes and quality of life.

Despite extensive reviews of national breast screening programs, such as the Roadmap to Optimising Screening in Australia report (2023) and the current BreastScreen Australia National Policy and Funding Review, it remains unclear how recommendations will be implemented, monitored, and integrated with new genomic technologies.

What Government can do to prioritise risk-based improvements to early detection/breast screening:

- Invest in new research and technologies that detect breast cancer and improve referral pathways for high-risk people. For example, use Artificial Intelligence (AI) to standardise breast density classification and improve timeliness of breast screen reporting.
- In partnership with BCNA and other breast care organisations, develop a 2025 implementation plan to outline how screening improvements will incorporate risk stratified interventions, genomics and AI, and when legislative bans on genetic discrimination in life insurance will commence.⁷
- Address disparities in access to specialist screening technology and infrastructure (e.g., MRIs) through supplemental screening and reimbursements for people at high risk.
- Expand eligibility criteria for screening and predictive genetic tests that incorporate risk factors such as breast density and family history.
- Through Primary Health Networks (PHNs), educate GPs about appropriate risk-based assessment and prevention strategies for people at high risk of breast cancer including genetic testing, screening, and preventative surgery, particularly for younger women who are often overlooked.

3. Address unmet supportive care needs for people impacted by breast cancer, including those living with metastatic (advanced) disease

Why action is needed:

Multidisciplinary meetings (MDMs) for patients with metastatic disease are recommended as best clinical practice.⁸ While research shows MDMs can have high impact treatment changes and improve clinical trial referrals and quality of life, current time and cost constraints within MBS structures limit MDM implementation.⁹

Advances in breast cancer treatment continue to improve survival rates, but the physical and emotional impacts of treatment are often complex, such as chronic pain, fear of recurrence or

4. Australian Institute of Health and Welfare, Cancer data in Australia, 2024. <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia>

5. For example, Health Technology Assessment (HTA) Policy and Methods Review recommendations 3-10; 32-43, and 44-47.

6. Duckett, S. and Moran, G. 2021. Stopping the death spiral: Creating a future for private health. Grattan Institute.

7. Ministers Treasury Portfolio, Total ban on the use of adverse genetic testing results in life insurance, 2024. <https://ministers.treasury.gov.au/ministers/stephen-jones-2022/media-releases/total-ban-use-adverse-genetic-testing-results-life>

8. Cancer Australia. Influencing best practice in metastatic breast cancer. Cancer Australia Statement; 2019.

9. The Breast, Evaluating the impact of a tertiary multidisciplinary meeting in metastatic breast cancer: A prospective study, 2024. DOI: 10.1016/j.breast.2024.103861

progression, and lymphoedema.

Supportive services are critical to optimal breast cancer experiences¹⁰ and need multi-disciplinary approaches (e.g., exercise, diet, emotional wellbeing). For example, supervised exercise programs for metastatic patients improve quality of life and contribute to public health and economic benefits.¹¹

Current Medicare-subsidised mental healthcare and chronic disease management plans do not meet long-term supportive care needs. Allied health sector shortages, limited service availability, and high service costs create additional barriers to accessing support (emphasised in the 2022 Better Access evaluation).¹²

What Government can do to address unmet supportive care needs:

- Amend MBS structures for multidisciplinary care meetings to support implementation of clinical best practices for metastatic disease.
- Amend Better Access prescribed mental health professionals to include registered counsellors who can deliver mental health treatment plans to address provider shortages.
- Amend Better Access program rules to permit individuals to reallocate the current annual threshold of 20 sessions (10 individual and 10 group) towards more individual sessions if needed. This reflects reported stigma, shame¹³, and cultural barriers experienced by people with breast cancer that prevent engagement with group-based mental health programs.
- Amend chronic disease management plan program rules to permit access up to 10 rebated services in a calendar year, instead of five, to facilitate holistic supportive care models.
- Maintain the Lymphoedema Compression Garment Scheme, initially funded in 2019 for five years, and publish national standards to improve equity and consistency of access.

4. Invest in a sustainable and comprehensive cancer data ecosystem to inform person-centred research, policy, and healthcare delivery.

Why action is needed:

The lack of comprehensive cancer data about stage and recurrence, including metastatic diagnoses, limits evidence-based healthcare planning and investments.

State-based cancer registries do not all have access to national health data, like Medicare and PBS, limiting a national estimate of how many people are living with metastatic disease.

A coordinated approach to data collection, reporting, and linkages, is critical to reducing service gaps and inequities and improving consumer experiences and health outcomes. But the proposed Australian Cancer Data Alliance, recommended by BCNA,¹⁴ does not have sustainable funding to implement and monitor the outcomes of cancer data reforms.

What Government can do to sustain a comprehensive cancer data ecosystem:

- Allocate long-term funding to the Australian Cancer Data Alliance to lead and coordinate cancer data reforms, improve health data integration, and streamline access to national health data sets to inform modelling methodologies.
- Establish a standardised system to collect and report on inherited risks of breast cancer to monitor access to preventative interventions including surgery and the efficacy of predictive genomic tests.
- Leverage state-based and national data sets to accurately estimate the number of people with metastatic disease in Australia and identify implications for cancer care services.

10. Cancer Council Victoria and Department of Health Victoria 2021, Optimal care pathway for people with breast cancer, 2nd edn, Cancer Council Victoria Melbourne.

11. Breast Cancer Network Australia (BCNA), Research shows exercise improves quality of life for people with metastatic breast cancer, 2025. <https://www.bcna.org.au/latest-news/bcna-news/research-shows-exercise-improves-quality-of-life-for-people-with-mbc/>

12. Australian Government-Department of Aged Care, Evaluation of the Better Access initiative – final report, 2023. <https://www.health.gov.au/resources/collections/evaluation-of-the-better-access-initiative-final-report>

13. Brennan ME, Bell K, Hamid G, Gilchrist J, Gillingham J. Consumer experiences of shame in clinical encounters for breast cancer treatment. "Who do you think you are- Angelina Jolie?". Breast. 2023 Dec; 72:103587.

14. Breast Cancer Network Australia (BCNA), Time to Count People with Metastatic Breast Cancer - A Way Forward, 2023. <https://www.bcna.org.au/resource-hub/research-reports/time-to-count-people-with-metastatic-breast-cancer-a-way-forward/>

