

Cancer Nurses  
Society of Australia



# elevate

## cancer nursing

innovate | integrate | educate | advocate

28th ANNUAL CONGRESS • 17-19 JUNE 2026  
Perth Convention and Exhibition Centre

## Counted at last: Australia's first national metastatic breast cancer prevalence estimate

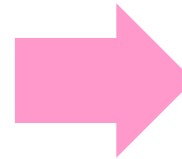
Vicki Durston

Director Policy, Advocacy & Support  
Services

Breast Cancer Network Australia (BCNA)



Until November last year,  
**no government in the  
world – including our own**  
– could tell you how many  
people were living with  
metastatic breast cancer.



**Cancer care decisions:**

- ✕ Policy priorities
- ✕ Research funding
- ✕ Workforce planning

# Hidden in plain sight

- 1970s cancer data systems = diagnosis and death
- Stage at diagnosis and recurrence is not routinely collected
- Cancer has changed enormously but our data systems have not kept pace

You cannot plan for those you **cannot see**

**25–30%**

of people with early breast  
cancer later develop  
metastatic disease

# Leading change through lived experience



- BCNA is the peak national consumer organisation for Australians affected by breast cancer
- Seat At The Table program trains consumers to influence change at a system level



**SATT**  
SEAT AT THE TABLE



# Advocacy into action: Counted at last



2022: BCNA consumer  
workshop & Issues  
paper

2023: BCNA national  
roundtable & roadmap  
report

Feb 2024: Funding for  
Australian Cancer Data  
Alliance

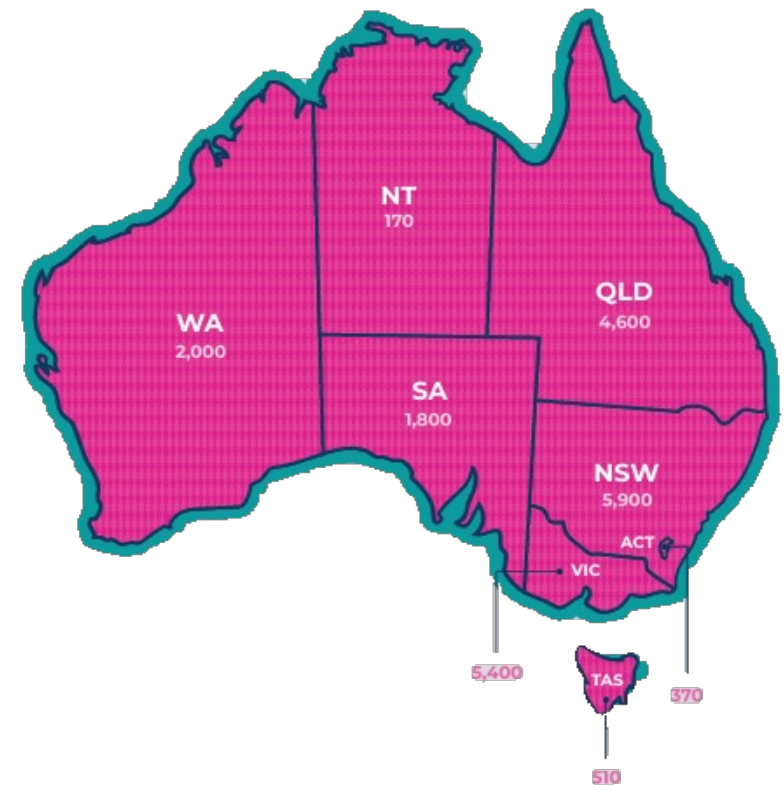
Late 2024: World-first  
cancer data linkage  
method (NSW)

Nov. 2025: Australia's  
first national MBC  
prevalence estimate

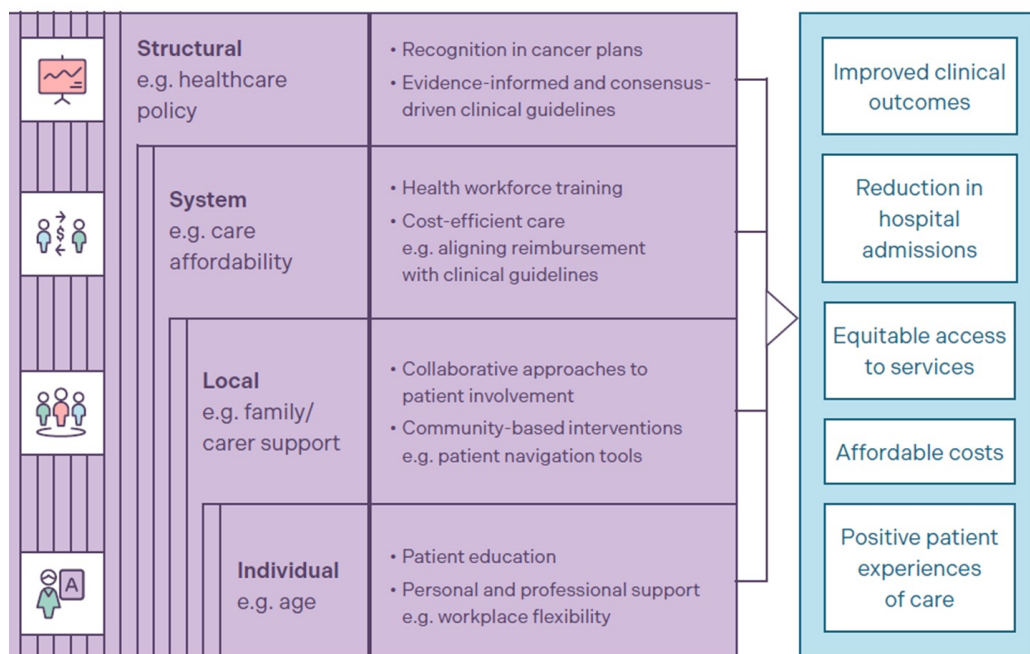
# 20,950

Approximately **20,800 women** and **150 men**  
estimated to be living with metastatic breast  
cancer as at 31 December 2024

**More than double** previous 2020  
estimate of 10,553



# Being counted = Being cared for



“If data registries were tracking metastatic breast cancer when I was first diagnosed in 2012, it would have made a big difference to me. If we can’t be counted, **how can we be looked after properly?**”

Lisa Tobin, BCNA Consumer Representative

Health Policy Partnership: Reducing Inequalities in Breast Cancer Care, Nov 2024

# A blueprint beyond breast cancer



Through the Australian Cancer Data Alliance:

- Extending the MBC data model to new tumour types – e.g., lung, melanoma
- Helping generate state-based estimates to guide cancer care planning – e.g., 2026 WA Cancer Plan
- Driving implementation of National Cancer Data Framework and the Australian Cancer Plan

## Our vision:

Metastatic disease – across all cancers – to be recognised as a priority population





# Patient advocacy is not over

People living with incurable disease can still feel invisible...

- At the bedside
- On the ward
- In the hospital
- In their local community
- In their state/territory

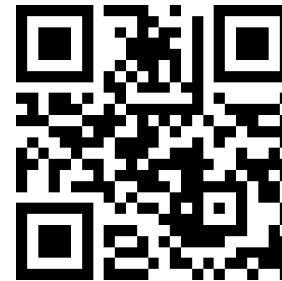
Advocacy – this is something **cancer nurses** understand deeply





# Thank you & Questions

For more information e: [policy@bcna.org.au](mailto:policy@bcna.org.au)



BCNA's *'From invisibility to Influence'* Report



AIHW MBC national prevalence estimates technical report (complimentary report)

Come and see us at BCNA's booth

