Consumer engagement at every stage of research and policy development to achieve systemic change: making metastatic breast cancer count

Breast
Cancer
Network
Australia

Background

People living with metastatic breast cancer (MBC) in Australia and internationally report feeling invisible to health systems and policymakers because population-based cancer registries do not collect stage at diagnosis or recurrence data. Metastatic breast cancer is treatable but not curable. Advancements in treatment in recent years mean that people with MBC are on average living for up to five years instead of two to three years, but they often report higher unmet supportive care needs and poorer quality of life.

For two decades, Breast Cancer Network Australia (BCNA) has been advocating for increased visibility of people living with MBC. Improved MBC data is essential to ensure equitable access to care, inform research priorities and funding decisions, allocate healthcare resources appropriately and improve clinical trial access and design.

The absence of MBC data collection is a global challenge. For example, Canada has also reported gaps in recurrence data and incomplete and fragmented MBC data collection. Global initiatives and international calls to action are emerging to address the issue, such as through the Lancet Breast Cancer Commission, the Advanced Breast Cancer (ABC) Global Alliance, and the International Agency for Research on Cancer (IARC).

In late 2024, BCNA's advocacy work influenced innovative advancements in MBC data collection, leading to development in New South Wales (NSW) of a world-first methodology to accurately estimate MBC prevalence that can be applied across Australia.

Methodology

Consumer workshop Jul-22
Issues Paper Oct-22
National Roundtable Aug-23
Roundtable Report Nov-23

In 2022:

- Working group of BCNA staff and consumer representatives living with MBC discussed options to address Australia's long-term MBC data gaps.
- **Issues paper** was launched on International Breast Cancer Awareness Day in October highlighting MBC data gaps and research estimates indicating 10,553 people were living with MBC in Australia in 2020.

In 2023:

- Multiple stakeholders were consulted including people living with MBC, health professionals, researchers, and government health agencies.
- A two-day roundtable identified strategies to address legal, policy, technology, and system challenges that had remained unresolved for over 20 years.
- **Roadmap report** was published with outcomes from the national roundtable and recommendations for state and federal government action.

Consumers were involved throughout the process including as members of project groups, participating in media and stakeholder engagement activities, co-facilitating roundtable discussions, and co-developing policy recommendations.

> ***Recent improvements in breast cancer survival represent a great success of modern medicine. However, we can't ignore how many patients are being systematically left behind. By highlighting [current gaps] they can be addressed by health care professionals and policymakers in partnership with patients and the public around the world.***
>
> – Professor Charlotte Coles, The Lancet Breast Cancer Commission 2024

> ***As someone living with metastatic breast cancer, I am incredibly excited that it is now possible to recognise those living with the disease. Until now we have been hidden in plain sight and vastly underestimated in numbers.***
>
> – Lisa Rankin, BCNA Consumer Representative

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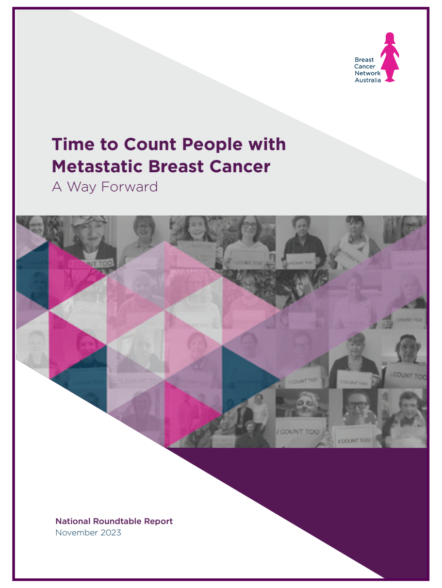
Results/Conclusion

Following nearly three years of targeted advocacy, BCNA's Roadmap received bipartisan government support. In late 2023, the **Prime Minister announced funding to establish an Australian Cancer Data Alliance** to lead national cancer data improvements.

Nearly 12 months later, the **Cancer Institute of New South Wales announced a methodology** using integrated and long-term health datasets to more accurately estimate prevalence. Informed by BCNA's Roadmap, the methodology combined state-based registry data with national health records to estimate there were 7,900 people living with MBC in NSW. The new systemic approach to data linkage identified limitations with previous modelling approaches and suggested significant underestimations in national prevalence data. Other states and territories are progressively adopting the methodology to reveal the true number of people living with MBC in Australia.

7,900 people living with MBC in NSW



Breast Cancer Network Australia

Time to Count People with Metastatic Breast Cancer
A Way Forward

National Roundtable Report
November 2023

> ***I know my colleagues around Australia and globally would also benefit from access to information like this, so I hope the methods NSW have developed are rolled out nationally and globally.***
>
> – Dr. Belinda Kiely, NSW Medical Oncologist

Impact

Accurate prevalence data is critical to better access to MBC treatment options, supportive care, and system-level responses including research funding for clinical trials. BCNA's consumer-led advocacy highlights the impact of lived experience to strategically influencing research, policy and service provision to inform systemic change in healthcare. This breakthrough can drive global commitments to improve responses for people living with MBC and provides a blueprint for counting other metastatic cancers nationally and internationally.

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