

Making Metastatic Breast Cancer Count

– A way forward

Breast Cancer Network Australia is calling for people with metastatic breast cancer to be consistently counted on our cancer registries in order to better plan for health and supportive services.

If you are not counted you are not seen, which means you are ‘invisible’ when health service providers and policymakers plan cancer services and support.

Metastatic breast cancer is the most advanced form of breast cancer. Having spread to other parts of the body, it often requires ongoing and intensive treatment.

BCNA’s 2022 Issues Paper, *Making Metastatic Breast Cancer Count*, highlighted the need for more breast cancer data to understand how many people are living with metastatic breast cancer in Australia, as we currently only have modelling estimates. Our state and territory cancer registries collect and store limited breast cancer information, which currently does not include how advanced the disease is and whether the cancer has come back after an initial cancer diagnosis. This information would tell us how many people are living with metastatic breast cancer, variations in breast cancer experiences, and inequities in care and in turn inform planning of our health services and address the specific unmet needs of this group.

This issue is not unique to Australia, but many comparable countries have this information or have made a commitment to address it. The United Kingdom, for example, has committed to auditing their information to determine how many people live with metastatic breast cancer across England.

Did you know there are over **10,000 people** living with incurable and life-limiting metastatic breast cancer?

This is an estimate because they are not counted consistently by our cancer registries.

National Roundtable

To address this issue, in August 2023, BCNA held a National Roundtable in Canberra. The roundtable was a structured, all-day workshop which brought together over thirty leading experts including cancer organisations, policy makers, health care professionals and people with early and metastatic breast cancer. After a number of presentations, which discussed international initiatives and innovative ideas, a range of approaches for including more breast cancer information in cancer registries were discussed and workshopped across 2, 5 and 10 year timelines to align with the Australian Cancer Plan.

“The critical message is that we have the capacity, the knowledge, and the tools to improve cancer outcomes today [...] I think equity is probably the most important rationale for changing the data system.”

– Professor Sanchia Aranda

Towards Change

Round table attendees agreed that the time is now to improve breast cancer information in our cancer registries! There was consensus that this is vital information which could improve the care and experience of breast cancer consumers, and cancer consumers more broadly. Attendees stressed that it is vital to know how many people live with metastatic breast cancer in Australia for resource allocation, health system planning, incentivising clinical trials, medication subsidy and supportive care.

Key short-term recommendations from the roundtable include:

1. Increasing the funding of resources and staffing at state and territory cancer registries where needed to increase their capacity to collect breast cancer stage and recurrence data
2. Improving the ability of cancer registries to continually collect the number of people with metastatic breast cancer through improved data linkages with health providers
3. Trialling new approaches to understanding the number of people diagnosed with metastatic breast cancer using the different data sources already provided to State and Territory cancer registries

Looking to the mid to longer term timeframe, attendees agreed on:

1. Dedicated registry funding for the improved collection of more information about all stages of breast cancer diagnoses, including recurrence
2. A national framework centralising leadership and accountability and standards for collection of data
3. Minimum standards for the registries which includes routine collection of more breast cancer data
4. National leadership and accountability to oversee this work

What's Next

The time is now! BCNA is calling for more breast cancer information to be provided to, and used by, our cancer registries to ensure those living with metastatic breast cancer are counted, made visible and have access to the treatment and supports to help them live as well as possible. BCNA will be driving this advocacy and seeking commitment from key stakeholders. A formal report outlining detailed next steps will be released in coming months.

As noted by one attendee, ‘breast cancer has a long history of leading the way.’ This highlights the opportunity to trial new approaches for breast cancer data collection and then apply these insights to other cancers to improve equity in care and outcomes.

To read our full Issues Paper and find out how to get involved, visit bcna.org.au