

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

TO THE EDITOR: Lord and colleagues' article¹ provides a much-needed snapshot of breast cancer distant recurrence and metastatic survival. As one of Australia's leading breast cancer advocacy organisations, Breast Cancer Network Australia (BCNA) has long been calling for reporting of recurrence data. Although we can justifiably celebrate a 5-year survival rate of 92%,² the long term data on distant recurrence reported by Lord and colleagues demonstrate the importance of looking beyond 5 years to understand the full burden of disease. In addition, Lord and colleagues' survival data after distant recurrence is a critical first step in understanding the survival experience of this important but neglected group.

In the associated Editorial, Redfern and Martin³ highlight that Australia's cancer registries do not systematically collect or report recurrence. The same applies for stage at diagnosis. Consequently, the number of Australians living with metastatic breast cancer is unknown. This is a fundamental problem. Without information to quantify this group of people we cannot adequately plan or deliver services.

The problem extends beyond breast cancer to cancers such as prostate, melanoma, colorectal and lung, where targeted therapies, immunotherapies, and antibody drug conjugates are driving improvements in survival for patients with metastatic disease.⁴ These patients often have long term, complex supportive

care needs yet have little visibility in our health care system. BCNA's 2017 national survey of 10318 people with breast cancer identified higher information and support needs among patients with metastatic compared with non-metastatic breast cancer.⁵ These information and support needs were also less likely to be met by services for people with metastatic compared with non-metastatic breast cancer.⁵

On 13 October 2022, which was Metastatic Breast Cancer Awareness Day, BCNA launched its *Making metastatic breast cancer count* Issues Paper to draw much-needed attention to these issues.⁶ In the absence of cancer registry data, we applied Australian modelling from 2008 to current breast cancer mortality data.^{2,7} We estimate that in 2020 there were at least 10553 Australians living with metastatic breast cancer. Data from the United States suggest this number will continue to grow.⁸

Collection of recurrence and stage at diagnosis data will require national leadership and accountability, including continued investment in Cancer Australia's Stage, Treatment and Recurrence Project. Critically, it will also require input from key stakeholders including data-management experts, cancer epidemiologists, cancer registries, clinicians and consumers. The time for action is now.

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