

Strengthening metastatic breast cancer data: a policy imperative for better care

The reality of living with the disease is largely unmeasured, and therefore unseen.

Metastatic breast cancer (MBC) is breast cancer that has spread to other parts of the body.¹ Thanks to treatment advances, people are living longer with it than ever before.¹⁻⁴

However, MBC is still a life-limiting disease, and average survival varies across subtypes.²⁻⁴ Limited data mean that differences in outcomes and quality of life among patient groups are poorly understood.⁵

Robust data are essential to understand the needs of people with MBC, measure outcomes and design evidence-based services. Yet major data gaps persist: critically, we still do not know how many people are living with MBC.⁵

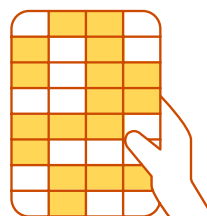
‘We cannot fully understand or meet the needs of people living with MBC if we do not know how many people are affected, the challenges they face, and how the disease impacts their daily lives.’

Rachel White,
Macmillan Cancer
Support, UK

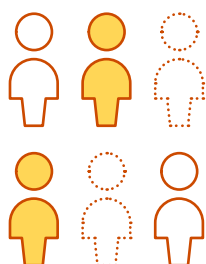
Where are the gaps?



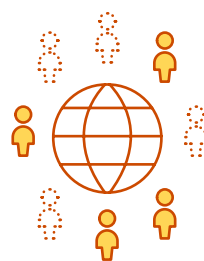
The number of people living with MBC is consistently underestimated because most MBC diagnoses are recurrences of an earlier cancer and are not routinely recorded in registries.^{2,5}



Even people initially diagnosed with MBC (de novo MBC) are being missed, as not all cancer registries collect data on stage at diagnosis.⁶



There are major disparities in the availability of reliable information on the day-to-day experiences, quality of life and wider impact of MBC on patients, families and carers.¹



Current care provision is not fit for purpose because, without adequate data on people with MBC, there are persistent inequities in access to treatment, personalised and supportive care between and within countries.^{6,7}

Better data can transform care

Better data on MBC will help health systems:

- plan services, allocate resources and prioritise specialist, coordinated care to improve quality and length of life^{6,8}
- provide equitable access to clinical trials¹ and plan effectively for newly funded therapies by enabling informed value assessment and decision-making⁹
- capture demographics, therapies and outcomes of people with MBC, transforming the evaluation and optimisation of treatment and care¹

Better data will also help ensure that people living with MBC are:

- able to access appropriate care and support services, with resources and information that better meet their needs and those of their families⁸
- more visible in health systems – with stage at diagnosis, recurrence, and clinical and demographic data included in national or global data sets – allowing their lives and experiences to inform policy, funding and care decisions⁵
- asked about their lived experiences, helping tackle stigma, employment barriers, social exclusion and poor mental health outcomes¹⁰

Positive change is emerging

In some countries, improved MBC data collection, analysis and sharing are driving policy change and better outcomes.

- The Épidémio-Stratégie Médico-Économique (ESME) MBC database in France collects hospital data; these support research on real-world treatment and disease progression, and inform decision-making by national health authorities.¹
- Te Rēhita Mate Ūtaetae – Breast Cancer Foundation National Register in Aotearoa New Zealand captures over 99% of breast cancer diagnoses, including MBC.¹¹ Combined with insights from patient and healthcare professional surveys, the register's data have facilitated improvements in care and survival equity, and the development of a patient-reported outcomes tool and national MBC guidelines.¹¹⁻¹³

International initiatives – such as the *Lancet* Breast Cancer Commission and the Advanced Breast Cancer Global Alliance's *Global Decade Report 2.0* and *Global Charter 2.0* – also provide a framework to strengthen MBC data completeness and quality.^{6,14}

‘For us patients, collecting more and better data on metastatic cancers needs to be a political matter of focus and concern.’

Colleen Foran, patient representative, Canada

Policymakers, health system decision-makers, and national cancer registries and data teams can learn from these developments and build stronger, fairer MBC data systems so that everyone with the disease is counted and cared for. This requires four key actions:¹⁵



Enhance policy commitments and collaboration

Embed targets and quality assurance measures for comprehensive MBC data collection in national cancer control plans and strategies

Use international best-practice examples and guidance to inform collaborative efforts to improve MBC data collection



Strengthen registry development and coverage

Build capacity across cancer registries to comprehensively and efficiently capture cancer stage at diagnosis and recurrence data

Address challenges faced by MBC-specific registries, data platforms and audits



Improve data linkage and increase the capture of patient-reported data

Refine and embed data linkage methodologies in national policy to create sustainable linked data sets that improve the accuracy and availability of incidence and prevalence estimates

Explore the feasibility, acceptability and associated costs of the systematic collection of patient-reported data



Expand the use of digital technology

Invest in digital health innovations to streamline data collection and sharing

Expand research into data models to better capture the MBC population

References

1. Advanced Breast Cancer Global Alliance. 2025. *Advanced Breast Cancer Global Decade Report 2.0 (2015–2025)*
2. Lord SJ, Bahlmann K, O'Connell DL, et al. 2022. *eClinicalMedicine* 44: 101282
3. Grinda T, Antoine A, Jacot W, et al. 2021. *ESMO Open* 6(3): 100114
4. Chavez-MacGregor M, Gligorov J, Mouta J, et al. 2025. *Breast* 84: 104607
5. Durston V, Coles CE, Gautier A, et al. 2025. *Breast* 84: 104608
6. Coles CE, Earl H, Anderson BO, et al. 2024. *Lancet* 403(10439): 1895–950
7. Eniu A, Chidebe RCW, Vuylsteke P, et al. 2025. *Breast* 84: 104612
8. Breast Cancer Now, Rethink Breast Cancer, Breast Cancer Network Australia. 2025. *Advancing Global Visibility for Metastatic Breast Cancer*
9. Hogervorst MA, Vreman RA, Mantel-Teeuwisse AK, et al. 2022. *Value Health* 25(6): 992–1001
10. Kaur R, Azmi RA, Nyagabona SK, et al. 2025. *Breast* 84: 104602
11. Breast Cancer Foundation NZ. 2026. *Rethinking Advanced Breast Cancer: Evidence, experience and opportunities in Aotearoa New Zealand*
12. Breast Cancer Foundation NZ. <https://www.breastcancerfoundation.org.nz/news-articles/article/abcpro-making-a-difference-for-kiwis-with-advanced-breast-cancer/391> [Accessed 13/08/26]
13. Breast Cancer Foundation NZ. 2025. *3rd New Zealand Consensus Guidelines for Advanced Breast Cancer (ABC-NZ3)*
14. Advanced Breast Cancer Global Alliance. <https://www.abcgloballiance.org/abc-global-charter-report> [Accessed 13/08/26]
15. The Health Policy Partnership. 2026. *The power of data to transform metastatic breast cancer care*