

Policy brief

The power of data to transform metastatic breast cancer care

October 2026

About this policy brief

This policy brief was developed by Jessica Hooper and Eleanor Wheeler, and edited by Lisa Hillman, at The Health Policy Partnership (HPP). The brief is part of a project on strengthening data collection and insights for metastatic breast cancer; it is an extension of work that took place in 2024 and 2025, exploring the importance of reducing inequalities in metastatic breast cancer care.

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- Dr Fatima Cardoso, President, Advanced Breast Cancer Global Alliance; Head of Clinical Trials, Scientific Affairs and International Development in Breast Oncology, Centre Antoine Lacassagne, France
- Professor Charlotte Coles, Chair of The *Lancet* Breast Cancer Commission; Deputy Head of Department of Oncology and Professor of Breast Clinical Oncology, University of Cambridge, UK
- Dr Christine Delon, Data Scientist, National Audit of Metastatic Breast Cancer (NAoMe), National Cancer Audit Collaborating Centre (NATCAN), UK
- Vicki Durston, Director, Policy, Advocacy & Support Services, Breast Cancer Network Australia; President General Assembly, Advanced Breast Cancer Global Alliance
- Professor Helena Earl, Professor Emeritus of Clinical Cancer Medicine, Department of Oncology, University of Cambridge, UK
- Colleen Foran, patient representative, Canada
- Adèle Gautier, Lead, Programmes, Advanced Breast Cancer Global Alliance, Portugal
- Dr Karen Gelmon, Professor of Medicine, University of British Columbia and BC Cancer Agency, Canada
- Jenny Gilchrist, Nurse Practitioner – Breast Oncology, Macquarie University, Australia
- Karen Graham, Head of Data Improvement, National Disease Registration Service, UK
- Dr Thomas Hofmarcher, Research Director, The Swedish Institute for Health Economics, Sweden
- Emma Lavelle, Policy Manager, Breast Cancer Now, UK
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- Barbara Wilson, Founder and CEO, Working With Cancer, UK

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Metastatic breast cancer can affect people of all genders. The vast majority of breast cancers occur in females.

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Executive summary

Many people with metastatic breast cancer (MBC) are invisible in health systems due to insufficient data infrastructure, management and policy prioritisation. And without sufficient data, their experiences, needs and challenges remain unseen.¹ Understanding how many people are living with MBC is not just a scientific necessity but a matter of dignity, equity and ensuring that everyone receives the care they deserve.¹² Progress has been made, such as a mandate from the European Society of Breast Cancer Specialists for specialist centres to collect data on all people with breast cancer (including those with MBC), and recommendations developed by experts (including representatives from the International Agency for Research on Cancer) on the standardised collection of cancer recurrence data to support comprehensive evaluation of MBC.^{3,4} But significant data gaps persist.¹² These gaps make it harder for health systems to allocate resources effectively, leaving people living with MBC without the care and support they need, while reinforcing stigma and widening existing inequities.¹

Proactive, multidisciplinary stakeholder engagement, strengthened data systems and implementation of the latest innovations are required to address current disparities in MBC data collection.

The Advanced Breast Cancer (ABC) Global Alliance underscored this in its *Global Decade Report 2.0* and *Global Charter 2.0*, identifying high-quality data collection as one of ten essential goals to improve MBC care and outcomes.²⁵ This ongoing focus on strengthening MBC data has been reinforced by advocacy and policy action, including the launch of the *Advancing Global Visibility for Metastatic Breast Cancer* pledge and dedicated commitments to improve MBC data collection by governments.⁶⁻⁸ By leveraging this momentum – as well as innovations in data linkage methodologies, self-reporting patient data capture and digital health technologies – it is possible to work towards more comprehensive MBC data collection to optimise care, reduce costs and improve outcomes.

To support policymakers, health system decision-makers, national cancer registries and data teams in strengthening MBC data completeness and quality, we recommend the following actions:



Enhance policy commitments and collaboration

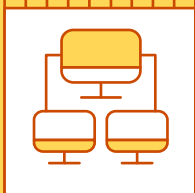
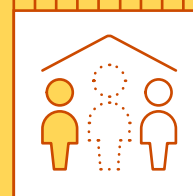
Embed targets and quality assurance measures for comprehensive MBC data collection in national cancer control plans and strategies, informed by global standards, and support the development and implementation of an International Classification of Diseases code for MBC in clinical settings.

Use international best practice examples and guidance to inform local and national collaborative efforts to improve MBC data collection.

Strengthen registry development and coverage

Build capacity across cancer registries – supported by adequate funding and infrastructure, and available initiatives and targets – to comprehensively and efficiently capture cancer stage at diagnosis and recurrence data.

Address challenges faced by MBC-specific registries, data platforms and audits, and establish quality improvement measures.



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, and enhance data on patient characteristics and outcomes, always applying adequate data privacy measures while enabling necessary waivers for official bodies such as cancer registries.

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, including teleradiology and electronic pathology reporting, to streamline data collection and sharing.

Expand research into data models to better capture the MBC population, which in time could enable health systems to provide more proactive and personalised care, leading to improved cancer outcomes.



The number of people with metastatic breast cancer is unknown



'You can't fix a problem when you don't have an idea of the size of the problem.'

Jenny Gilchrist,
Macquarie
University, Australia

The number of people living with metastatic breast cancer (MBC) is increasing, as is overall breast cancer incidence, but current care is not sufficient. Advances in treatment mean the number of people with a history of breast cancer, including people with MBC (*Box 1*), is increasing alongside survival from MBC.⁹⁻¹⁵ However, MBC remains more complex and lengthy to manage than early-stage disease (also known as primary breast cancer).^{8,16} And because people with MBC are now generally living longer, the impacts on health systems and people are much greater and current care provision is no longer fit for purpose.^{8,10,17}

BOX 1

What is metastatic breast cancer?

MBC – also known as stage IV, advanced or secondary breast cancer – occurs when cancerous cells from a tumour in the breast spread and grow in a different area or areas of the body.^{18,19}

MBC is a spectrum of disease, ranging from lasting remission or stabilisation to more rapid disease progression.¹ For some people, MBC is a long-term condition requiring continuous treatment, characterised by an extended period of uncertainty around the progression of their cancer.¹

Broadly, people diagnosed with MBC fall into one of two groups:^{20,21}

- **de novo** metastatic disease (i.e. the first occurrence in the body)
- **recurrent** metastatic disease (i.e. when cancer comes back, or recurs, months or years after initial treatment).

Despite the impact of MBC, it is not clear how many people are living with the disease because long-term follow-up and recurrence data have rarely been captured at scale. Most countries do not routinely collect data on cancer stage at diagnosis, and even fewer collect data on recurrence.^{22,23} So the prevalence of MBC is unknown and consistently underestimated.^{18,9,11} People with de novo MBC have a better prognosis and a higher chance of longer survival than people with recurrent MBC, but long-term evidence for MBC survival is limited and conflicting.^{22,24}
²⁵ High-income countries that collect data on cancer stage at diagnosis report that around 5–10% of breast cancers are metastatic at first

diagnosis, with low- and middle-income countries reporting higher proportions.^{1,26} And up to 30% of people treated for early-stage disease are estimated to experience MBC as part of disease recurrence – although this estimate is only well defined in subgroups with long-term follow-up.^{119 27}



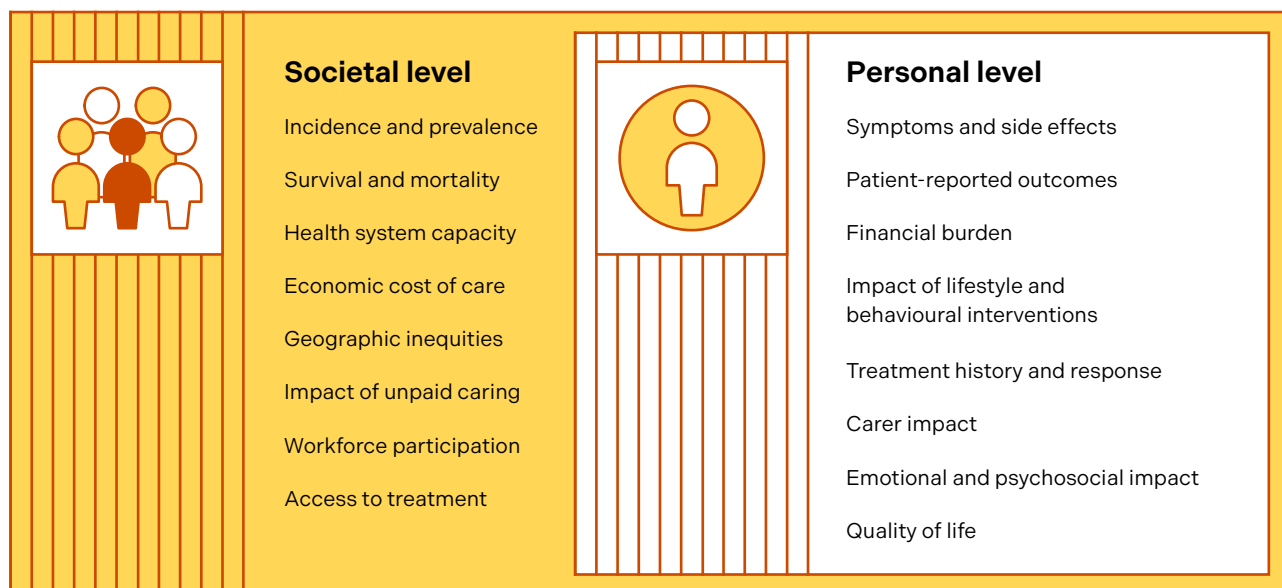
‘When I was diagnosed, I became aware that we are not being counted. For me, working as a public health researcher, it was very clear that the people delivering services, even in the health system, don’t fully understand who we are and that our supportive care needs are very different from those treated with curative intent.’

Dr Andrea Smith,
University of Sydney,
Australia

Data gaps also persist at both personal and societal levels (Figure 1), leaving much of the impact of MBC unmeasured and unseen. There are widespread disparities in the availability of reliable information on the day-to-day experiences, quality of life and wider impact of MBC on people with the disease, and their families and carers.² As a consequence, the physical, financial and emotional challenges are often overlooked and underprioritised in policy, leading to persistent stigma, social exclusion and poor mental health outcomes.²⁸ Intergenerational social and financial disruptions are also severe. For example, the first global estimates of maternal orphanhood due to breast cancer found that over a quarter of a million children lost their mothers to the disease in 2020 alone.²⁹ All of these challenges are exacerbated by misconceptions about MBC among healthcare professionals and the public.²⁸

The lack of reliable data on people living with MBC has extensive consequences for health system planning and patient care. This matters because policymakers cannot effectively plan services they cannot quantify, nor can they allocate resources for a population they cannot accurately identify and characterise.¹² As a result, people living with MBC, whose needs differ significantly from those of people diagnosed at earlier stages, risk being overlooked in strategies, budgets and support programmes. This has a direct impact on the value assessment of treatments, where a lack of data prevents effective planning for the implementation of new therapies, resulting in limited access to innovative treatments.³⁰

FIGURE 1 MBC data gaps at the societal and personal levels, as defined by the expert advisory group guiding this policy brief



Capturing data on people with metastatic breast cancer is essential

High-quality data on the MBC population will improve awareness of the disease and its economic impact, helping drive better care and outcomes. Cancer is predicted to cost the global economy over US\$25 trillion between 2020 and 2050, and breast cancer accounts for almost 8% of this total.³¹ The costs of MBC are higher than for early-stage breast cancer because care is more complex and lifelong.³²⁻³⁴ But major gaps in how MBC data are collected, reported and tracked (including incomplete registry coverage, limited recurrence data and inconsistent reporting standards) prevent an accurate assessment of the disease and its social and economic implications.² These weaknesses create policy and system challenges that directly affect people's quality of life by making it harder to plan appropriate, cost-effective and sustainable care and research (Figure 2).

FIGURE 2 Improving MBC data collection has wide-ranging implications for policy and practice





‘People with MBC come from so many different backgrounds. We often don’t know which data are being collected on us, what to ask, or how to understand the information that is shared.’

Colleen Foran, patient representative, Canada

Better data on MBC are crucial for exposing inequities and supporting optimal care.

In the past decade, improvements in MBC data collection in some countries and states have shown what is possible; clearer estimates of how many people are living with MBC drive policy change and better outcomes (*Case study 1*).² But this progress must be accelerated to address widening global disparities in access to MBC care.⁴⁰ By learning from successful local examples and aligning with international efforts and commitments – including the World Health Organization (WHO) Global Breast Cancer Initiative, the European Breast Cancer Council 2024 manifesto, the *Lancet* Breast Cancer Commission and the work of the Advanced Breast Cancer (ABC) Global Alliance – countries can strengthen their data collection and ultimately deliver better outcomes for people with MBC.^{8,9,41}

CASE STUDY 1

Driving change through data for people with MBC in Aotearoa New Zealand

Te Rēhita Mate Ūtaetae – Breast Cancer Foundation National Register has collected data on both de novo and recurrent MBC for decades.⁴²

Using these data, a first-of-its-kind national overview of MBC was published in 2018 to inform policy discussions; the overview analysed incidence, treatment and survival data covering approximately 70% of annual breast cancer diagnoses.⁴³

As of 2026, the national register had captured over 99% of breast cancer diagnoses, including MBC, and care and outcomes have improved. Achievements include:⁴²

- no significant variations reported in overall MBC survival among women from Māori, Pacific and European backgrounds
- the development of a digital patient-reported outcomes tool to support nurse-led MBC care⁴⁴
- the publication of national consensus guidelines for MBC.⁴⁵

To continue this progress, Breast Cancer Foundation NZ recommends standardising and evaluating surveillance practices, and embedding the guidelines into routine practice.⁴²



‘The Breast Cancer Foundation NZ Register is over 25 years old, which is pretty rare. Having these data has opened up opportunities for change that wouldn’t have happened otherwise.’

Adèle Gautier, ABC Global Alliance, Portugal

Opportunities for change in the current data landscape

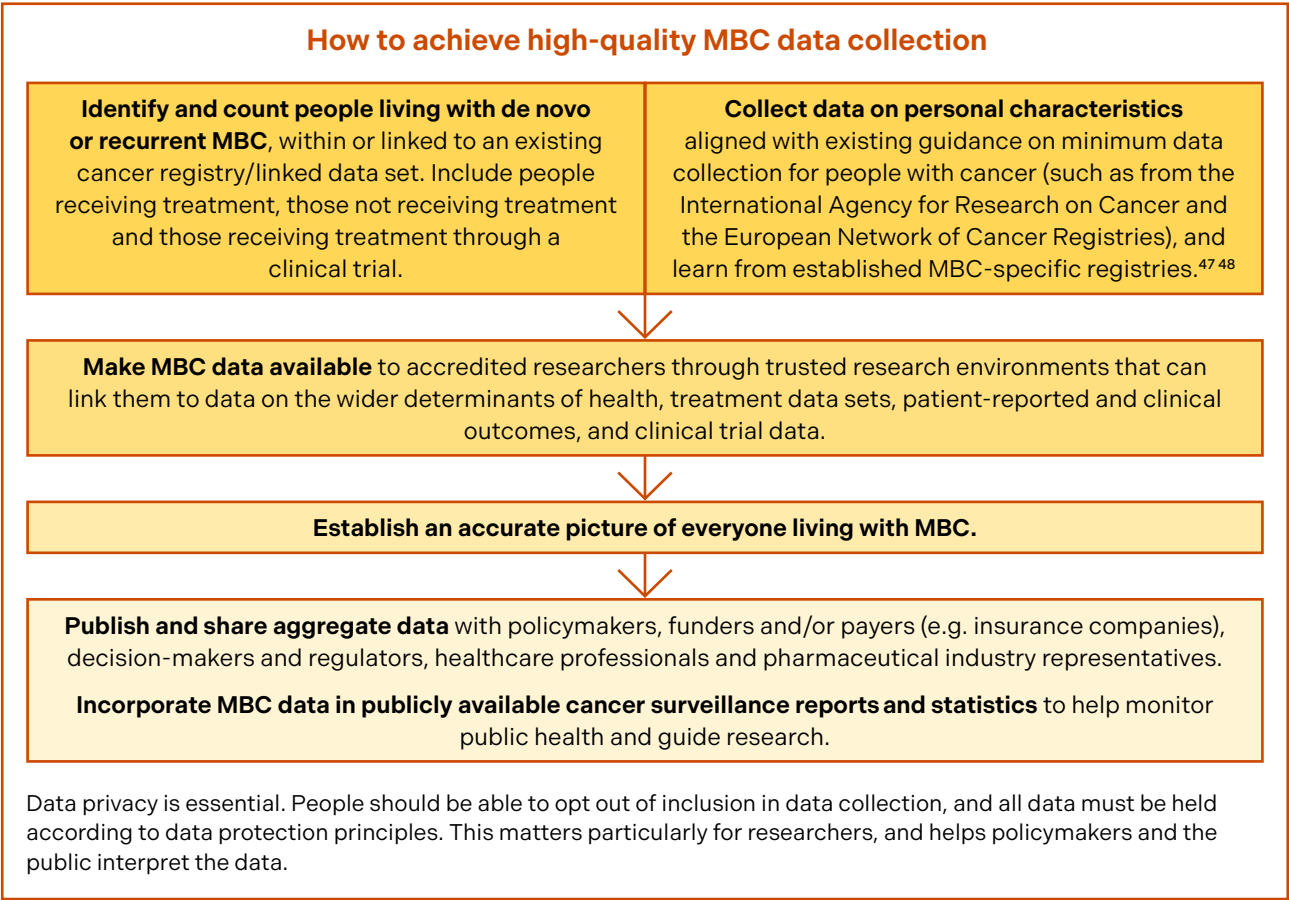


‘For us patients, data on MBC are not readily available. Data on metastatic cancers needs to be a matter of focus and concern.’

Colleen Foran,
patient
representative,
Canada

Understanding what causes gaps in MBC data collection is essential to identify meaningful opportunities for change, building on the efforts made to date. Robust data are increasingly recognised as essential for tracking health service capacity and performance, and improving care for people with cancer.⁴⁶ As poor MBC data collection is widespread, comprehensively identifying the underlying reasons is needed to inform policy and health system action.¹² The expert advisory group guiding this policy brief defines the key attributes of high-quality MBC data collection (*Figure 3*) and emphasises the need for clear data standards to measure performance and support improvement.

FIGURE 3 High-quality MBC data collection, as defined by the expert advisory group guiding this policy brief





Enhance policy commitments and collaboration

Policy and guidelines on collecting MBC data are insufficient and limit the delivery of high-quality care. Although guidance for MBC care has evolved, guidelines for MBC data collection are limited.^{9,49} And where guidelines do exist, MBC experts have called for improved adherence to guidelines, and stronger clinical and real-world data collection to support equitable access to treatment and care.⁵⁰ But realising this ambition is hindered by metastatic cancer often being absent from national cancer control plans, these plans not being in place in every country, and the widespread gaps in policy-level commitments to collect and report recurrence data.⁵¹⁻⁵³ There are also no international coding standards specific to MBC, meaning data often need to be manually recorded and extracted from patient notes, requiring significant time and resources.² To support more consistent and efficient data collection, the ABC Global Alliance is calling for the development and implementation of an International Classification of Diseases code for MBC in clinical settings.²

Increasing global momentum for policy change to strengthen MBC data capture creates a clearer path forward. In 2025, amendments to the United Nations (UN) political declaration on non-communicable diseases included a new target: to integrate breast cancer into national plans.⁵⁴ And over the past decade, the importance of collecting high-quality MBC data has increasingly been recognised in new standards, targets and priorities, in great part due to the persistent work of the members of the ABC Global Alliance, as highlighted in goal 2 of its *Global Charter 2.0*.⁵ For example, the European Society of Breast Cancer Specialists has mandated specialist centres to collect data on all people with breast cancer, including those with MBC.³ Initiatives such as the Breast Cancer Care Quality Index also guide national policy and accelerate progress in this space.⁵⁵ Policymakers and members of the cancer community should build on this momentum and commit to further harmonising MBC data standards across health systems, close long-standing gaps in recurrence reporting, and ensure that everyone living with MBC is counted and supported through evidence-based planning and investment (Case study 2).



‘Robust data collection is needed to ascertain both the direct and indirect costs of MBC. Without this, policymakers cannot make informed decisions.’

Dr Fatima Cardoso, ABC Global Alliance and Centre Antoine Lacassagne, France



‘The *Lancet* Breast Cancer Commission and most recent ABC Global Alliance work have emphasised that we must learn from the significant findings around data deficits. To do this we must work together in a joined-up way. There’s not just one solution.’

Professor Charlotte Coles, University of Cambridge, UK

CASE STUDY 2

Strengthening policy through partnerships to improve the global visibility of MBC

In July 2025, three leading patient organisations – Breast Cancer Network Australia, Breast Cancer Now and Rethink Breast Cancer – united with a shared mission: to ensure that people with MBC are counted and cared for.^{8 56} This mission built on other commitments, including Australia's AU\$1.5 million investment in 2024 to improve cancer stage and recurrence data.⁷

The organisations' pledge, supported by members of the WHO Global Breast Cancer Initiative, calls for sustained government funding for MBC data collection and stronger international collaboration to share best practice and align data improvement efforts.^{8 56}

Since the pledge was introduced:^{8 57}

- Australia published its first national estimate of MBC prevalence, and the Australian Cancer Data Alliance is driving national consistency and accountability to improve MBC data quality⁵⁸
- England's National Cancer Plan committed to counting all metastatic cancers, starting with MBC⁶
- Breast Cancer Now funded a study on health inequalities experienced by people with MBC in Northern Ireland, brought together an expert group to develop actionable solutions on breast cancer recurrence, and organised an 'I don't count?' installation to hold the Scottish government responsible for delivering its commitment to improve MBC data collection
- In Canada, Rethink Breast Cancer continues to advocate for policy prioritisation of MBC data collection, and the organisation completed a nationwide environmental scan to look at data gaps, provincial differences and system readiness.



'We're just getting started. We have several ideas of how to progress the promises made in the pledge to more countries – global advocacy and collaboration are essential to build on the momentum and milestones already reached. We are stronger together.'

Vicki Durston, Breast Cancer Network Australia



'Most cancer registries collect data when you're diagnosed with cancer and when you die from cancer, and nothing in between. There's nobody counting people who experience recurrence, and people are rightly blown away by that fact.'

Dr Andrea Smith,
University of Sydney,
Australia

Strengthen registry development and coverage

Identifying the MBC population requires cancer registries to obtain more data on people with metastatic cancer. MBC-relevant data are drawn from a wide range of sources, from clinical trials to cancer registries (Box 2) and electronic medical records.³⁵ While population-based cancer registries are important sources of data, most are not designed to capture the full patient experience.^{123 51 53} They usually record incidence and mortality, but not recurrence or stage beyond initial diagnosis, and there is wide variation in whether and how such data are collected.^{2 23} As a result, most people living with MBC are not captured in national or global data sets.¹ Strengthening registries through sustained investment – and establishing adequate infrastructure, clear guidelines and standardised definitions, particularly to support recurrence and progression data collection – would substantially enhance their value as tools for research and evidence-informed policymaking.^{9 51 59}

BOX 2

What are cancer registries?

Widely regarded as the 'bedrock of global cancer care', cancer registries are organised systems for collecting, analysing, curating and reporting data on people diagnosed with cancer.^{60 61}

Multiple cancer registry types – including population-based, hospital-based and breast cancer-specific – are used to capture MBC data.²

Gaps in global coverage and limited standardisation of cancer registries exacerbate MBC data gaps; active tracking and follow-up of people with breast cancer are also sparse in many settings.

Although the number of population-based cancer registries has increased substantially over the past two decades, these registries still cover only around one-fifth of the global population.^{60 62} Their creation and expansion are hindered by political instability and limited resources.⁶⁰ Registries do not track people throughout the care pathway, which prevents accurate recording of recurrence; important privacy considerations and data-sharing constraints further restrict follow-up.^{1 53 63} These challenges are particularly acute in low- and middle-income countries, where there are few national cancer registries, technological capacity to identify later-stage diagnosis is limited, and infrastructure is often insufficient for effective patient tracking.^{1 64 65} In sub-Saharan Africa, for example, a study of 11 countries found that more than a third

of people with breast cancer captured in registries could not be traced to a treatment facility, and reliance on paper-based systems made long-term follow-up difficult.⁶⁶

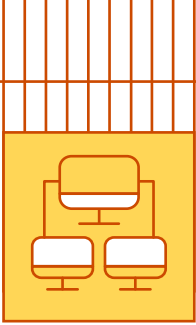
The creation of national MBC-specific registries is an important advance in data collection in high-income countries, but challenges persist. To support more comprehensive data collection, a few countries have established dedicated MBC registries, data platforms and audits.² They offer useful insights for policymaking, but have several limitations: not all are population-based or complete, and limited recurrence data and inconsistent definitions of disease progression persist.² A reliance on hospital data can also exclude patients receiving care in facilities not included in the registry, such as private healthcare providers (as experienced by the Épidémio-Stratégie Médico-Économique data platform for MBC in France). Limited awareness and engagement among healthcare professionals pose further challenges.² For example, the National Audit of Metastatic Breast Cancer (NAoMe) in England and Wales draws on multiple data sources, but recurrence is significantly underreported; this has prompted a strategic focus on improving recurrence recording, starting in 2026.⁶⁷

Policymakers, health system decision-makers and cancer registry teams must build on the standards and momentum already being driven by leading international organisations to close long-standing gaps in MBC data. Several global initiatives are already in place to help governments strengthen cancer registries and improve the completeness of MBC data. These include the International Agency for Research on Cancer and the Union for International Cancer Control's Global Initiative for Cancer Registries, and the *Lancet* Breast Cancer Commission's targets for expanding data collection based on the work of the ABC Global Alliance – including a minimum of 70% of global cancer registries capturing data on people with MBC, rising to 100% through improved stage and recurrence data collection.¹⁶⁸ And in 2025, the European Network of Cancer Registries published recommendations on how to systematically collect and record recurrence data in cancer registries; the organisation is now working with the American Joint Committee on Cancer to extend these standards beyond Europe, complementing existing standards for oncology registry entry published by the American College of Surgeons.⁶⁹⁻⁷¹



‘There is great variance in how different countries approach cancer registration. But these never take into account recurrent cases. Data collection throughout the care pathway is needed to ensure systems are better equipped to capture and support care delivery.’

**Dr Thomas Hofmarcher,
The Swedish Institute
for Health Economics,
Sweden**



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

Linking data sources is essential to improve MBC data capture at a national level and enable more accurate insights. To address long-standing data fragmentation, there is momentum across health systems to invest in data linkage, common data models and consistent terminology use.⁴⁶ For MBC, the lack of reliable recurrence data, wide variation in collection methods, and significant costs and practical challenges of collecting and quality-controlling data within a single registry have driven interest in alternative approaches to capturing data.²¹⁰⁷² Linked data systems, supported by national policy developments, are being built through established centres in some countries to track patient characteristics and outcomes, and generate MBC prevalence estimates (see *Appendix*).¹⁰¹³⁷³⁷⁴ However, limitations remain, including the exclusion of people receiving treatment through clinical trials in data sets and the lack of reference data to validate prevalence estimates.¹⁰ Sustained long-term funding and commitment are essential to ensure that data linkage occurs routinely and can support ongoing monitoring and planning. The ABC Global Alliance has also called for data privacy law waivers to enable the accurate and ethical linkage of patient information across databases.² In many low- and middle-income countries, however, limited data availability means that establishing basic infrastructure and technological frameworks must be prioritised before more innovative methodologies can be adopted.³⁵

Collecting and linking patient-reported outcome data can improve the utility of MBC data and extend the types of research questions that could be answered by these data sets. Self-reported information can help fill data gaps in the MBC care pathway and inform decision-making. Patient-reported outcomes (PROs)* are recognised by the ABC Global Alliance as essential for international data improvement.⁷⁵ Although patient experience studies have highlighted the wide-ranging challenges faced by the MBC population, these data are not routinely collected, and PRO measures are largely absent from population-based cancer registries.⁵⁹⁷⁶ Incorporating PROs into registry systems could enhance their relevance and accuracy, enabling them to better support research and reduce inequalities.⁷⁷⁷⁸ And patient-reported data collection through surveys, for example, could also help collect and validate information on recurrence and other aspects of the patient experience, informing prevalence estimates and awareness of the disease's impact.⁷⁷



'Data systems are complex, and they often do not speak to each other. Estimates of MBC prevalence, and the methodologies used to generate them, need to be established in countries that record relevant data. This would allow for extrapolation and provide useful insights for other settings.'

**Jenny Gilchrist,
Macquarie University,
Australia**

*PROs are 'any report of the status of a patient's health condition that comes directly from the patient without interpretation of the patient's response by a clinician or anyone else'.⁷⁹



'A few years ago, we had absolutely no national-level information on people living with MBC. So some information with caveats is better than none. And as data linkage methods evolve, we should always be working to collect the most accurate information to identify and understand this population.'

Associate Professor Sally Lord, University of Sydney, Australia

Policymakers should invest in research to establish the feasibility and acceptability of implementing standardised, validated PRO collection for people with MBC. Evidence has shown that people with MBC can accurately report disease characteristics, treatments and recurrence, and are willing to do so.⁷²⁻⁷⁸ However, as this evidence base is scarce and methodologically limited, clear standards and validated tools are needed for collecting MBC PRO data.⁸⁰⁻⁸¹ These should be informed by carefully designed and verified studies that assess real-world implementation, including recall bias, feasibility across diverse populations and respondent burden.⁷⁷⁻⁸² Strengthening PRO data would improve the visibility of patients' lived experiences, helping health system decision-makers understand the value of interventions in the context of recurrence and progression. Lessons from system analyses and other disease areas, such as the increasing use of PRO measures in diabetes care, demonstrate the value of patient-reported data to enhance cancer registry data, and support decision-making and treatment access.⁸³⁻⁸⁷



'Patient experience data for people with MBC is not systematically collected anywhere as far as I know. Yet it's so important.'

Adèle Gautier, ABC Global Alliance, Portugal



Expand the use of digital technology

Advances in digital health are creating new opportunities to transform how MBC data are captured.

In 2024, the *Lancet* Breast Cancer Commission showed how combining digital information from multiple sources supports personalised care, reduces costs and informs health policy.¹ A variety of technologies could help realise this vision and make MBC data collection and sharing more streamlined and complete. These could include teleradiology* as well as PRO collection using digital dashboards and tools to support more sustainable, person-centred care and self-management.¹⁸⁸ Additionally, wider use of electronic pathology reporting could help cancer registries identify recurrence more efficiently by drawing on existing electronic data.⁶³ Efforts such as the electronic pathology-reporting guidelines from the North American Association of Central Cancer Registries and The Pathology Network's use of governance, software and AI to coordinate the diagnostic pathway show how technology can make data more complete, consistent and useful.^{89 90}

*Teleradiology is 'the exchange of radiological images and patient-related data between geographically different locations for purposes of primary interpretation, expert consultation and/or clinical review by digital transmission'.⁹¹

Digital data modelling and analysis could transform how health systems capture data on and support people with MBC in the future.

In a number of settings, AI models have been developed to identify metastatic recurrence of breast cancer in health records to assist research and surveillance.⁹²⁻⁹⁵ Also emerging are AI models that predict recurrence to guide decision-making about ongoing care.^{96 97} Estimating future risk of breast cancer recurrence and survival using digital models could help personalise care and improve outcomes and quality of life.⁹⁸ ⁹⁹ However, ensuring readiness for implementing these technologies once the research is sufficiently advanced will require sustained investment in the data infrastructure – including data quality, linkage and interoperability – which governments should prioritise as part of long-term health system planning. Rigorous external validation of digital data models is needed to support reproducibility and pave the way for their safe and effective integration into clinical practice.^{98 99} To avoid exacerbating inequalities, algorithms must be trained on data sets that reflect real-world and local populations, underscoring the importance of improving breast cancer recurrence data collection.¹⁰⁰

Key actions for change

Improving the quality and completeness of MBC data requires countries and organisations to work together to strengthen health systems, recognise MBC in policy and develop shared standards.

Campaigns such as Rethink Breast Cancer's 'Make MBC Count' and 'Make Me Count' in Canada, and the *Advancing Global Visibility for Metastatic Breast Cancer* pledge, have shown how powerful advocacy can be – but these successes must be replicated and scaled.^{8 101}

Although differences in health systems and data standards make this challenging, global harmonisation efforts offer a clear path forward.²

It is time for stakeholders from different countries to work together, align practices and make better use of high-quality data in decision-making to ensure that everyone with MBC is counted and supported.



'I don't think we've made nearly enough progress in the last decade globally to advance visibility of MBC data. I understand that different countries are at different stages of what they are able to achieve, but we need cancer registries, governments, political will and investment in data systems to align if we want to see the change we are seeking.'

Vicki Durston, Breast Cancer Network Australia

We recommend that policymakers, health system decision-makers, national cancer registries and data teams:



Enhance policy commitments and collaboration

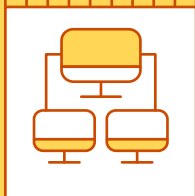
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Build capacity across cancer registries – supported by adequate funding and infrastructure, and available initiatives and targets – to comprehensively and efficiently capture cancer stage at diagnosis and recurrence data.

Address challenges faced by MBC-specific registries, data platforms and audits, and establish quality improvement measures.



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, and enhance data on patient characteristics and outcomes, always applying adequate data privacy measures while enabling necessary waivers for official bodies such as cancer registries.

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, including teleradiology and electronic pathology reporting, to streamline data collection and sharing.

Expand research into data models to better capture the MBC population, which in time could enable health systems to provide more proactive and personalised care, leading to improved cancer outcomes.



Appendix. Milestones in estimating prevalence of metastatic breast cancer and related policy developments in Australia and the UK

2006	Breast Cancer Care (now Breast Cancer Now) establishes the secondary breast cancer taskforce, leading the 'Stand Up and be Counted' campaign calling for UK governments to make the collection of data on MBC a requirement. ¹⁰²
2009	A consensus report by the MBC Advocacy Working Group calls for data collection on MBC prevalence and survival rates.¹⁰³ The National Cancer Intelligence Network (NCIN) announces that data on recurrent and/or metastatic breast cancer should be collected through mandatory monthly submissions to the National Cancer Waiting Times Monitoring Dataset.¹⁰⁴
2011	An MBC data collection pilot is mentioned in England's cancer strategy, to take place in 2012. ¹⁰⁵
2012	Driven by Australian breast cancer groups (including the National Breast and Ovarian Cancer Centre and researchers from Cancer Council New South Wales (NSW)), researchers validate a model that uses cancer registry data from 1980 to 2004 to estimate that there are three to four cases of MBC per breast cancer death in Australia.¹⁰⁶ The NCIN, the Association of Breast Surgery and Breast Cancer Care (now Breast Cancer Now) carry out a six-month pilot project to identify the extent to which information on recurrent and metastatic breast cancer is available through existing mandated data sources in the UK's National Health Service (NHS) and regional cancer registries.¹⁰⁴
2013–16	Data collection on breast cancer recurrence is made mandatory in England in 2013,¹⁰⁷ and the 2015 national cancer strategy acknowledges that more needs to be done to improve data collection on cancer recurrences.¹⁰⁸ Breast Cancer Care (now Breast Cancer Now) publishes a report as part of its 'Who's counting?' campaign, capturing the state of MBC data collection in the UK.¹⁰⁷ The Scottish government's cancer strategy – Beating Cancer: Ambition and Action – commits to improving data collection on secondary and recurrent cancers.¹⁰⁹
2019	A Breast Cancer Now report, <i>Until Things Change</i> , reiterates the need for action to improve MBC data. ¹¹⁰
2021	Macmillan Cancer Support, the National Disease Registration Service and Public Health England pioneer the use of linked data sets to estimate the number of people at the end of 2015 living with treatable but not curable cancer in England.⁷³ The NAOme begins in England and Wales, 12 years after the NCIN committed to delivering these data.¹¹¹
2022	Researchers use secondary care records extracted from the English Hospital Episode Statistics database to estimate the number of people with MBC in England from 2016 to 2021. ¹¹

2023	Breast Cancer Network Australia publishes a roadmap report, <i>Time to Count People with Metastatic Breast Cancer – A Way Forward</i>. The report follows a national roundtable that built consensus among government and cancer sector stakeholders on the requirements for routinely capturing and reporting breast cancer stage and recurrence data.¹¹² Retrospective estimates of MBC prevalence in NSW are presented by researchers from the University of Sydney at the Clinical Oncology Society of Australia, demonstrating that comprehensive population-level reporting of MBC is feasible using linked, routinely collected health data.^{113 114} NHS Wales publishes a cancer improvement plan for 2023–26, which includes a commitment for health boards and trusts to capture data required for national audits, including the NAOme.¹¹⁵ The Scottish government's <i>Cancer Action Plan for Scotland 2023–2026</i> commits to improving data collection on metastatic cancers, with an initial focus on MBC.¹¹⁶
2024	The first NAOme <i>State of the Nation</i> report is published, capturing 2019–21 data for England and Wales from multiple sources; it notes that recurrent MBC is likely to be significantly underreported.¹¹⁷ Cancer Institute NSW and University of Sydney researchers use linked data sets to estimate the number of people living with MBC in NSW in 2024.¹¹⁸
2025 onwards	The 2025 NAOme <i>State of the Nation</i> report captures data for England and Wales from 2020 to 2022 and highlights that the recorded number of people with recurrent MBC is still likely to be an underestimate.⁶⁷ In the first study of its kind in the UK, researchers use data linkage methods – combining cancer registry, hospital records and death records data – to estimate the number of people with MBC in Northern Ireland from 2009 to 2020.¹¹⁹ A retrospective study is published in 2025 that demonstrates the potential of using routinely collected data to identify breast cancer recurrences in England.¹²⁰ The 2026 National Cancer Plan for England commits to ensuring that all metastatic cancers, starting with breast cancer, are counted.⁶ Cancer Institute NSW and University of Sydney researchers publish further retrospective estimates of MBC prevalence in NSW.¹⁰ Data linkage methods are used by the Victorian Cancer Registry and Cancer Alliance Queensland to estimate the number of people with MBC in those states.^{121 122} The Australian Institute of Health and Welfare develops the first national prevalence estimate of MBC for 2024, with further refinement expected as linked data become available.⁵⁸ The Australian government's Data Governance Framework is established in 2025, supporting consistent data management across government and forming a blueprint for other countries.¹²³

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