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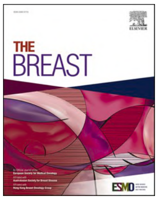

Knowledge in Motion: A decade reviewed, a future defined – The ABC Global Alliance 2015–2025 Decade Report and 2025–2035 Global Charter

Fatima Cardoso [a,*], Roberta Ventura [a], Georgia Attfield [b], Alexandra Lewis [b], Karen Gelmon [c]

[a] *Advanced Breast Cancer (ABC) Global Alliance, Lisbon, Portugal*
[b] *VML Health, London, United Kingdom*
[c] *BC Cancer, Vancouver, Canada*

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ABSTRACT

Breast cancer remains one of the most significant global health challenges, with approximately 2.3 million new cases diagnosed and 666,000 deaths every year. Advanced breast cancer (ABC) – encompassing locally advanced and metastatic disease – represents the leading cause of breast cancer-related mortality and morbidity worldwide. While early-stage breast cancer has seen remarkable improvements in survival rates in the past decade, outcomes for individuals with ABC remain sobering: only 32 % of women diagnosed with ABC survive five years post-diagnosis, and this figure drops to just 20 % for men.

The ABC Global Alliance was established in 2016 as a multi-stakeholder platform dedicated to advanced/metastatic breast cancer. Its vision: to improve and extend the lives of women and men living with ABC in all countries worldwide and to fight for a cure.

This special edition of *The Breast* is both a reflection on the past decade of progress across the ABC landscape, and a forward-looking roadmap for the future. It summarizes findings from the ABC Global Alliance's Global Decade Report 2.0 (2015–2025) and the newly defined ten goals set out in the 2025–2035 ABC Global Charter 2.0, signaling a renewed commitment to advancing ABC care globally over the next decade.

1. Introduction

Breast cancer remains one of the most significant global health challenges, with approximately 2.3 million new cases diagnosed and 666,000 deaths every year [1]. The 5-year prevalence (the number of people diagnosed in the last 5 years and still alive) is over 8 million [2]. Advanced breast cancer (ABC) – encompassing locally advanced and metastatic disease [3] – represents the leading cause of breast cancer-related mortality and morbidity worldwide [4]. While early-stage breast cancer has seen remarkable improvements in survival rates in the past decade, outcomes for individuals with ABC remain sobering: only 32 % of women diagnosed with ABC survive five years post-diagnosis [5], and this figure drops to just 20 % for men [5].

The Advanced Breast Cancer (ABC) Global Alliance was established in 2016 as a global multi-stakeholder platform or federation (since its members are organizations, not individuals) dedicated to advanced/metastatic breast cancer [6]. Originally established as an initiative of the European School of Oncology (ESO), it is now an independent non-profit organization headquartered in Portugal. The ABC Global Alliance unites over 300 member organizations across more than 120 countries. It has a clear vision: to improve and extend the lives of women and men living with ABC in all countries worldwide and to fight for a cure. By bringing together key stakeholders involved in ABC care, including patients, advocates, healthcare professionals (HCPs), policymakers, the pharmaceutical industry and diagnostic companies, the ABC Global Alliance co-creates and shares meaningful, practical solutions that reflect diverse perspectives. Through this shared purpose, the ABC Global Alliance is reshaping the future of ABC care worldwide.

This special edition of *The Breast* is both a reflection on the past decade of progress across the ABC landscape, and a forward-looking roadmap for the future. It summarizes findings from the ABC Global Alliance's Global Decade Report 2.0 (2015–2025) [7] and the goals set out in the 2025–2035 ABC Global Charter 2.0 [8], signaling a renewed commitment to advancing ABC care globally.

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* Corresponding author.

E-mail address: fcardoso@abcglobalalliance.org (F. Cardoso).

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1.1. The Global Decade Report (2005–2015) and ABC Global Charter (2015–2025): A catalyst for change

The publication of the Global Status of ABC/MBC Decade Report 2005–2015 [9] marked a turning point in the global understanding of ABC. This comprehensive report highlighted critical gaps in patient care, societal support, and scientific research, as well as the need for coordinated action to address issues such as limited access to diagnostics and treatment, inadequate data collection, and the stigma faced by ABC patients [9].

Based on these insights, the 2015–2025 ABC Global Charter introduced ten ambitious goals aimed at transforming ABC care. These goals encompassed a wide range of priorities, from improving survival outcomes and quality of life to enhancing communication between HCPs and patients [10]. Over the past decade, the ABC Global Charter has served as a rallying cry for stakeholders worldwide, inspiring innovative programs, policy changes, and research initiatives.

1.2. Why update the Global Decade Report and ABC Global Charter?

As the decade 2015–2025 draws to a close, there is a need to assess the reality facing people with ABC in 2025. The conclusion? Progress over the last decade has been meaningful, but uneven. While some patients now live longer and better, many still lack access to basic diagnostics, treatment, coordinated care, and workplace protections. The world has also changed, with new treatments, technologies, and shifting societal attitudes transforming the healthcare landscape. Inequities have become impossible to ignore and have widened, both between and within countries. We have demonstrated that progress is possible, but a new decade demands a new vision.

2. The Global Decade Report 2.0: methodologies used to assess a decade of progress

The development of the Global Decade Report 2.0 2015–2025 and the 2025–2035 ABC Global Charter 2.0 was informed by extensive primary and secondary research conducted throughout 2023–2024, and expert consensus to capture the current landscape of care in ABC. While this manuscript outlines a brief overview of the methodologies used to measure progress against each goal, comprehensive details can be found in the appendices of the Global Decade Report 2.0 [7].

The ABC Global Alliance Steering and Advisory Committees selected 14 countries of interest for in-depth analysis throughout the research, which provided a balanced global representation of ABC care. Countries were chosen to reflect a diverse mix of high-, middle-, and low-income nations, encompassing various healthcare systems and sociodemographic contexts across all continents. The selected countries were the United States, Mexico, the United Kingdom, Portugal, France, Poland, Australia, India, China, Japan, Brazil, Colombia, South Africa, and Nigeria. While these countries represented much of the research focus, insights from other countries were actively encouraged and included.

2.1. ABC Global Alliance 2024 surveys

The report, and subsequently the manuscripts in this special edition, draw upon insights from two global surveys targeting HCPs and patients conducted between 04/03/2024–30/06/2024. The surveys aimed to better understand both the achievements and persistent challenges of the past decade from the perspectives of different stakeholders.

The HCP survey, with 461 responses from 78 countries, explored topics such as ABC care delivery, communication, the impact of ABC on quality of life, and beliefs surrounding ABC treatment, providing a comprehensive overview of current ABC practices. More than half (62 %) of respondents had over 11 years of experience in treating ABC, with 66 % working primarily in the public sector, 21 % in private practice, and 13 % in both.

The patient survey, which gathered 1254 responses from 59 countries, sheds light on the lived experiences of people with ABC, examining treatment, daily life, access to care, decision-making, information availability, emotional impact, and effects on work and daily activities. Most respondents (>99 %) were female, with 50 % diagnosed *de novo*, 44 % experiencing recurrent ABC, and 6 % unknown.

Surveys were disseminated online, so findings are influenced by local internet access. Because responses are self-reported, there is a risk of recall or social desirability bias; HCPs may answer in line with perceived professional norms, while patients may participate due to personal motivations, potentially skewing results. These limitations highlight the ongoing need for further research, particularly in underrepresented regions and specialties, and for qualitative follow-ups to deepen insights.

2.2. Clinical targeted literature review

A clinical targeted literature review aimed to evaluate the clinical efficacy of ABC treatments in randomized controlled trials (RCTs) over the past decade and assess their impact on survival outcomes.

A systematic search on EMBASE was conducted using specific terms related to ABC (including metastatic breast cancer, and locally advanced breast cancer), treatment types, RCTs, and survival outcomes. The search was limited to studies published between 2015 and 2024 with abstracts available. Inclusion criteria focused on ABC patients, licensed pharmacological treatments, and Phase III RCTs reporting efficacy outcomes like overall survival and progression-free survival. Exclusion criteria included non-pharmacological treatments, observational studies, and publications before 2015. A total of 50 studies were included in the review.

2.3. Interviews with global registries

A series of virtual discussions with the International Agency for Research on Cancer (IARC) from the World Health Organization (WHO) were held in 2024 to better understand the evaluation of population-based cancer registries across the globe. In addition, five virtual structured interviews were conducted in 2024 with registry representatives from New Zealand (Te Rēhita Mate Ūtaetae), France (Epidemiological Strategy and Medical Economics, ESME), the Netherlands (Netherlands Cancer Registry), the UK (National Audit of Metastatic Breast Cancer, NaOMe) and Germany (OPAL registry). These interviews aimed to gather insights from national cancer registries and understand best practices, challenges, and opportunities for improving ABC data collection. In 2025, an additional virtual interview was conducted with representatives from Cancer Focus Northern Ireland and the Northern Ireland Cancer Registry (NICR) to discuss progress in ABC data collection in the country.

Interview discussions were focused on current data collection methods, challenges in registering relapse data, barriers to data collection, and suggestions for future improvement.

2.4. Humanistic targeted literature review

A targeted literature review aimed to evaluate studies reporting the humanistic burden (e.g., health-related quality of life (HRQoL), caregiver burden) associated with ABC.

A systematic search of EMBASE was conducted to identify studies evaluating HRQoL, patient-reported outcomes (PROs), and caregiver burden in the context of ABC. The search was restricted to publications from 2015 to 2024 with available abstracts. Studies were included if they focused on ABC patients and were either RCTs or observational in design. Studies examining only a single pharmacological intervention were excluded, as they were not considered to provide a comprehensive or holistic view of quality of life (QoL). Publications prior to 2015 were also excluded. A total of 122 studies were included in the review.

2.5. Analysis of multidisciplinary team integration in ABC care

To evaluate how multidisciplinary team (MDT) approaches are recommended and implemented in ABC care across diverse healthcare systems, 200 documents (e.g., guidelines or policies) from 12 countries (Australia, Brazil, China, Colombia, France, India, Japan, Mexico, Nigeria, Poland, Portugal, South Africa, the UK, and the US), focusing on local, national, and regional levels were analyzed. Analysis focused on the composition of MDTs, regional differences in MDT recommendations, and any evidence of implementation of MDT practices. Sources included international consensus guidelines, national cancer plans, and peer-reviewed publications.

2.6. Global analysis of communication skills training

To effectively understand the provision of communication skills training (CST), this research identified CST courses for both medical and nursing students, and HCPs working with ABC patients.

CST courses were reviewed by top academic institutions across 12 countries, including the US, Mexico, Colombia, Brazil, the UK, Portugal, Spain, France, Poland, Nigeria, South Africa, India, China, Japan, and Australia (48 courses in total). In addition, courses were reviewed from 35 professional oncology organizations (e.g., European Society of Medical Oncology). Countries and CST courses were compared according to the target audience, thematic focus, accreditation, and any available metrics to measure engagement. The analysis focused on training that was specific to ABC where possible, however it also included breast cancer, and general cancer courses.

2.7. ABC Global Alliance member questionnaire

To examine ABC-associated advocacy activities, which included patient resources and awareness campaigns, a structured questionnaire was distributed to 95 member organizations of the ABC Global Alliance to identify informational gaps and areas of saturation.

The questionnaire collected data on: organizational information ($n = 26$ responses received), patient information resources developed since 2015 ($n = 28$ responses), and public awareness campaigns developed since 2015 ($n = 33$ responses). Some organizations provided information on multiple resources or awareness campaigns. A thematic analysis identified high and low content availability in submitted resources and campaigns.

2.8. Policy and funding analysis of support services

To evaluate the integration of seven critical support services (palliative and end-of-life care, social support, peer support, complementary and integrative medicines, wellness and lifestyle support, genetic counselling, and survivorship programs) national cancer control plans, government-led policies and cancer strategies from six countries (Brazil, France, Japan, South Africa, the UK, and the US) were analyzed for support service-related recommendations, specific to ABC, breast-cancer, and general cancer.

Funding for these services was analyzed using literature, claims data, and governmental reports where possible. This research focused on cross-country comparisons of service provision and funding mechanisms.

2.9. Social listening analysis

A social listening exercise was conducted to analyze online conversations about ABC to understand visibility, sentiment, and key themes in English-speaking countries. Brandwatch was used to monitor public online discussions from 2016 to 2024. Search queries targeted disease terminology (advanced breast cancer, metastatic breast cancer, secondary breast cancer, locally advanced breast cancer), advocacy groups, and comparative framing of ABC. The analysis was used to review conversation volume, sentiment, and recurring themes. It excluded private or restricted platforms and non-English content.

2.10. Economic targeted literature review

A targeted literature review aimed to understand the economic burden (e.g., out-of-pocket costs, direct/indirect costs) of ABC and evaluate economic analyses of ABC treatments over the last decade.

A systematic search on EMBASE was conducted using specific terms related to metastatic breast cancer, treatment types, and cost effectiveness outcomes. The search was limited to studies published between 2015 and 2024 with abstracts available. Inclusion criteria focused on studies reporting economic outcomes (e.g., cost-effectiveness, financial burden) in ABC patients. Exclusion criteria included case reports, editorials, non-economic studies, and publications before 2015. A total of 219 studies were included in the review.

2.11. Legal landscape analysis

The McCabe Centre for Law and Cancer conducted doctrinal legal research using publicly available information, legislation, and relevant case law, supplemented with input from local legal experts via a tailored survey. The research assessed key workplace protections for people living with ABC and their caregivers across 25 countries. Fourteen of these were priority countries identified by ABC Global Alliance, with the remaining 11 selected by the McCabe Centre aiming to represent a spread of different regions and income levels. India was excluded from detailed analysis due to ongoing legal reforms.

3. Looking ahead: A call to action

As we embark on the next chapter of the ABC Global Alliance's journey, the importance of collective global action cannot be overstated. ABC remains a challenge that is too complex for any single organization or country to tackle alone. Success will require sustained collaboration across sectors, from governments and healthcare providers to patient advocates and industry partners.

This special edition of *The Breast* delves deeply into the themes and findings of the Global Decade Report 2.0 (2015–2025) and 2025–2035 ABC Global Charter 2.0. Each article offers a unique perspective on the progress made and the work that lies ahead, representing each of the 10 goals of the new ABC Global Charter (Fig. 1). The ABC Global Charter 2.0 will guide the work of the ABC community in the next decade, aiming at further improving the lives of all people living with this disease worldwide and their families.

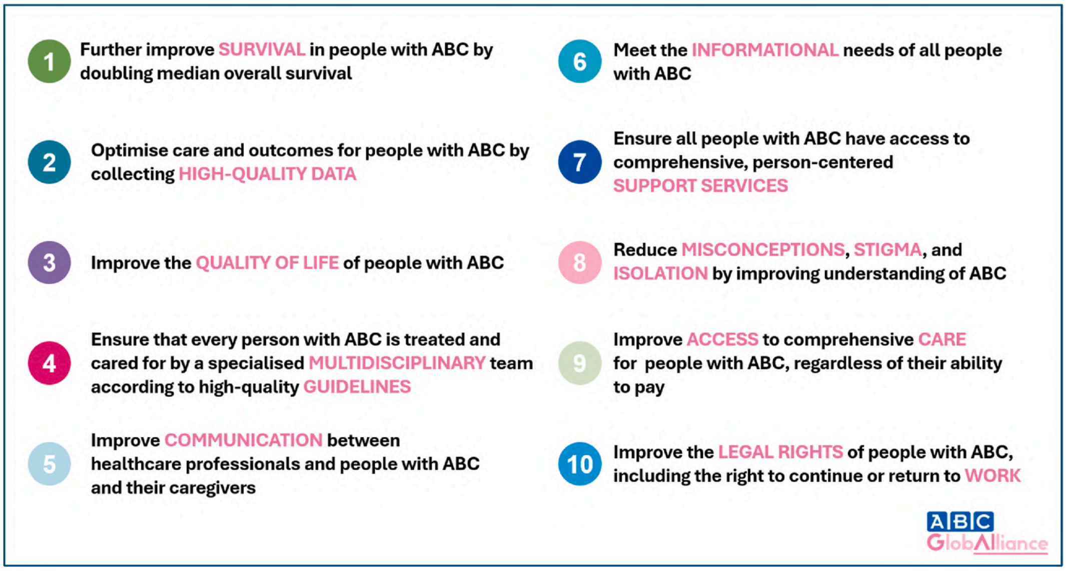
For more detail, comprehensive methodologies, and further insights across the ABC landscape, please refer to the full Global Decade Report 2.0 (2015–2025) and ABC Global Charter 2.0 (2025–2035), available on the ABC Global Alliance website [11].

In closing, the ABC Global Alliance community and *The Breast* reaffirm their unwavering commitment to transforming the landscape of ABC care through implementation of the ABC Global Charter 2.0 goals.

Through collaboration, advocacy, and evidence-based strategies, we can create a future where every person living with ABC can live longer and better lives. Together, we can turn the tide against advanced breast cancer – one goal, one patient, and one decade at a time.

CRediT authorship contribution statement

Fatima Cardoso: Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Methodology, Funding acquisition, Formal analysis, Conceptualization. **Roberta Ventura:** Writing – review & editing, Project administration, Funding acquisition, Conceptualization. **Georgia Attfield:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration,



1 Further improve SURVIVAL in people with ABC by doubling median overall survival

2 Optimise care and outcomes for people with ABC by collecting HIGH-QUALITY DATA

3 Improve the QUALITY OF LIFE of people with ABC

4 Ensure that every person with ABC is treated and cared for by a specialised MULTIDISCIPLINARY team according to high-quality GUIDELINES

5 Improve COMMUNICATION between healthcare professionals and people with ABC and their caregivers

6 Meet the INFORMATIONAL needs of all people with ABC

7 Ensure all people with ABC have access to comprehensive, person-centered SUPPORT SERVICES

8 Reduce MISCONCEPTIONS, STIGMA, and ISOLATION by improving understanding of ABC

9 Improve ACCESS to comprehensive CARE for people with ABC, regardless of their ability to pay

10 Improve the LEGAL RIGHTS of people with ABC, including the right to continue or return to WORK

Fig. 1. The ten goals of the ABC Global Charter 2.0 (2025–2035) [8].

Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Alexandra Lewis:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Karen Gelmon:** Writing – review & editing, Validation, Conceptualization.

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Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Given their role as author, [Editor-in-Chief] Fatima Cardoso and [Deputy Editor] Karen Gelmon had no involvement in the peer review of this article and had no access to information regarding its peer review. Full responsibility for the editorial process for this article was delegated to another journal editor.

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Improving survival outcomes of people with ABC: a global expert review and call-to-action for 2025–2035 (Goal 1)

Mariana Chavez-MacGregor [a], Joseph Gligorov [b], João Mouta [c], Matthijs Van Meerveld [d], Zsofia Wolkensdorfer [e], Georgia Attfield [f], Alexandra Lewis [f], Fatima Cardoso [g,*]

[a] *Departments of Breast Medical Oncology and Health Services Research, MD Anderson Cancer Center, Houston, TX, United States*
[b] *Medical Oncology Department, Sorbonne University, Paris, France*
[c] *Product Development Medical Affairs Oncology, Roche Farmacêutica Química, Amadora, Portugal*
[d] *Menarini Stemline, Zurich, Switzerland*
[e] *VML Health, Manchester, United Kingdom*
[f] *VML Health, London, United Kingdom*
[g] *Advanced Breast Cancer (ABC) Global Alliance, Lisbon, Portugal*

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ABSTRACT

Advanced breast cancer (ABC) remains a significant public health challenge, accounting for the majority of the ~670,000 breast cancer deaths globally in 2022. In the past decade, significant improvements in survival were seen across all ABC subtypes and patient populations, but disparities remain and ABC continues to be an incurable disease for most people.

This manuscript provides an overview of the survival improvements reported for each ABC subtype in clinical trials and in real-world studies since 2015. It highlights where disparities remain and outlines recommendations for the ABC community over the next decade to further improve survival. It summarizes findings from reviews conducted for the ABC Global Alliance's Global Decade Report 2.0. The main findings are: a) Clinical trials showed significant survival gains for ABC in 2015–2025, particularly for hormone receptor-positive and human epidermal growth factor 2 receptor (HER2)-positive subtypes; b) Real-world data mirrors survival trends seen in ABC clinical trials; c) Biomarker-driven treatments offer benefits in ABC, but testing is inconsistent from healthcare professionals; d) Survival disparities remain between ABC subtypes; e) Survival in ABC remains poor compared to early breast cancer.

The findings from the ABC Global Alliance's Global Decade Report 2.0 have informed the development of a new ABC Global Charter. The ABC Global Charter 2.0 defines ten new achievable and measurable goals for the decade 2025–2035, aiming at improving the lives of people living with ABC worldwide.

1. Introduction

Advanced breast cancer (ABC) remains a significant public health challenge, accounting for the majority of the ~670,000 breast cancer deaths globally in 2022 [1,2]. In the past decade, significant improvements in survival were seen across all ABC subtypes and patient populations, but disparities remain and ABC continues to be an incurable disease for most people [3].

This manuscript includes findings from a targeted literature review of clinical trials spanning 2015–2024 and a review of recent real-world evidence conducted for the development of the ABC Global Alliance's Global Decade Report 2.0. For more detail on the research methodologies, please refer to the Global Decade Report 2.0 [4].

2. Status in 2005–2015

The 2005–2015 Global Decade Report highlighted minimal survival gains for people with ABC, with a 5-year survival rate of around 25 % and a median overall survival (OS) around 2–3 years [5]. The report emphasized the need for improved understanding of ABC disease biology and the importance of identifying predictive biomarkers. It also highlighted the need for novel treatments with improved efficacy and

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* Corresponding author.
E-mail address: fcardoso@abcglobalalliance.org (F. Cardoso).

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tolerability, and comprehensive, international guidelines that are specific to ABC [5]. Based on the findings of the Global Decade Report, one of the ten 'Actions for Change' in the 2015–2025 ABC Global Charter was to double the median survival for people with ABC [6].

3. A decade in review (2015–2025)

In the last decade, the landscape of ABC has been transformed by new treatment options, a deeper biological understanding of ABC and its biomarkers, and the development of ABC-specific international and national guidelines [3,7–13]. In the clinical trial setting, survival improvements have been reported across all ABC subtypes [3].

3.1. Continued research on predictive biomarkers for targeted treatment has proven essential to survival gains

Although ABC subtype still guides most treatment decisions, biomarker-driven therapies – which offer a more personalized approach and potentially survival benefits – are already in use in many countries and are on the horizon in others. However, biomarker testing is not always performed in clinical practice and access is restricted by high costs, limited funding, and lack of infrastructure [14]. For example, in a survey of physicians in France, Italy, Spain, and the United Kingdom (UK), 59 % of these surveyed physicians reported to test for mutations in the *BRCA1/2* gene and 27 % tested for phosphatidylinositol-4, 5-bisphosphate 3-kinase catalytic subunit alpha (*PIK3CA*) in first-line, while about half of the surveyed physicians said to test estrogen receptor 1 (*ESR1*) mutations routinely in second-line [15]. To achieve the best possible survival, it is essential that these barriers are overcome so that all people with ABC can benefit from biomarker testing.

3.2. In the last decade, the greatest development has been seen in HR-positive HER2-negative ABC, including the introduction of CDK4/6 inhibitors

In the last decade, cyclin-dependent kinase 4/6 (CDK4/6) inhibitors in combination with endocrine therapy (ET) in first-line demonstrated important progression-free survival (PFS) benefits compared to standard-of-care therapies in the PALOMA-2, PADMA, and MONARCH-3, and RIGHT Choice trials for people with hormone receptor (HR)-positive human epidermal growth factor receptor 2 (HER2)-negative ABC [16–19]. Moreover, for this subtype, the MONALEESA-2, MONALEESA-3, and MONALEESA-7 trials demonstrated PFS and OS improvement with the CDK4/6 inhibitor ribociclib (Fig. 1) [20–24]. Based on these results, CDK4/6 inhibitors with ET are now recommended as gold standard treatments in first-line for HR-positive HER2-negative ABC [9].

For patients whose tumors progressed on first-line ET, PI3KCA/AKT/PTEN pathway inhibitors in combination with ET have shown PFS benefit in the SOLAR-1 and CAPItello-291 trials, while in the INAVO-120 trial a significant PFS and OS benefit for a PI3KCA inhibitor was demonstrated for the first time in the first-line setting (Fig. 1) [25–28]. For patients whose tumors have progressed on ET and also have an *ESR1* mutation, oral selective estrogen receptor degraders (SERDs) have shown to provide benefits [29,30]. These treatments showed PFS improvements compared to physician's choice therapies in the EMERALD, and EMBER-3 trials [29,30]. Elacestrant also showed a numerical OS improvement, however a significant OS benefit is not yet reported [29,30]. For patients with *ESR1* mutations the proteolysis targeting chimera (PROTAC) estrogen receptor degrader vepdegestrant showed significant PFS benefit compared with fulvestrant in the VERITAC-2 trial [31]. Other treatment options for patients with HR-positive HER2-negative ABC include antibody−drug conjugates (ADCs) such as trastuzumab deruxtecan (T-DXd), sacituzumab govitecan and datopotamab deruxtecan, with T-DXd demonstrating OS benefit for people with HR-positive HER2-low ABC [7,8,32–34]. In addition, for patients with pathogenic mutations in the *BRCA1/2* gene, treatment with poly (ADP-ribose) polymerase (PARP) inhibitors olaparib and talazoparib provides PFS benefits (Fig. 1) [35,36].

In real-world clinical practice, a recent study analyzing the OS of patients with ABC initiating antineoplastic treatments between 2011 and 2022, using the United States (US) Flatiron Health database, reported that the median OS for patients with HR-positive, HER2-negative ABC improved from 31.7 months in 2011–2013 to 39.2 months in 2020–2022, an overall gain of 7.5 months during this period [48]. Overall, patients with HR-positive ABC now have the broadest range of treatment options of all subtypes, however access to these therapies is not universal. ABC guidelines recommend that patients should receive

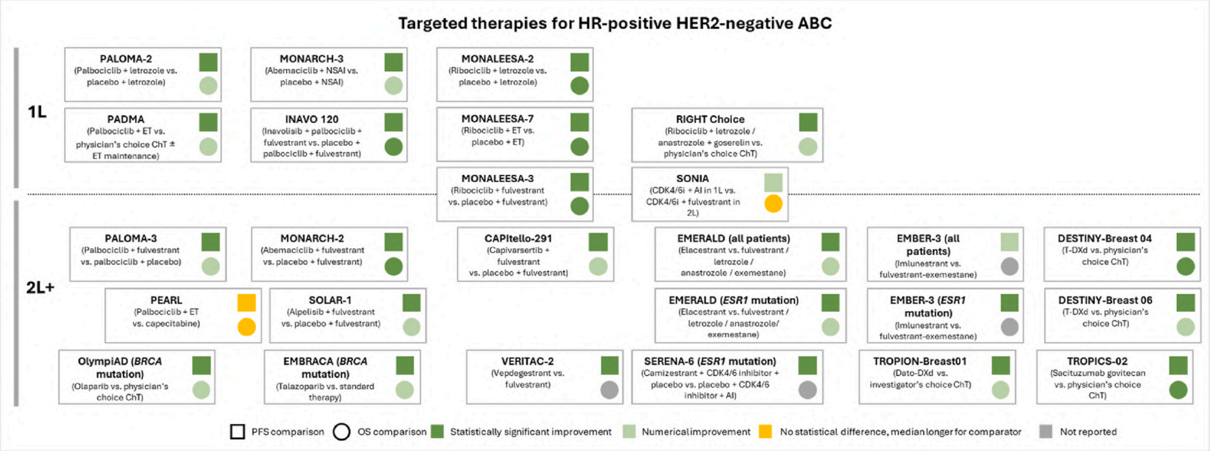

Fig. 1. PFS and OS results from key randomized controlled trials of new targeted therapies for HR-positive ABC in 2015−2025 [7,8,16–47]
This figure summarizes trials assessing new targeted therapies for HR-positive HER2-negative ABC in the last decade. Most of these new targeted therapies should be given in combination with endocrine agents, which remain the backbone of therapy for this subtype. These advances had great impact on the treatment pathway for these patients. However, eventually all patients will need to be treated with traditional chemotherapy, which remains essential for the care of people with this ABC subtype.
1L = first-line; 2L = second-line; 2L+ = second and later lines; ABC = advanced breast cancer; ADC = antibody−drug conjugate; CDK4/6i = cyclin-dependent kinase 4 and 6 inhibitor; *ESR1* = estrogen receptor 1; ET = endocrine therapy; HER2 = human epidermal growth factor receptor; HR = hormone receptor; NSAI = non-steroidal aromatase inhibitor; OS = overall survival; PARP = poly(ADP-ribose) polymerase; PFS = progression-free survival; PI3KCA/AKT/PTEN = phosphatidylinositol-4,5-bisphosphate 3-kinase catalytic subunit alpha/AKT/phosphatase and tensin homolog; SERD = selective estrogen receptor degrader.

treatment with ET backbone for as many lines as possible [9]. Patients for whom ET is no longer an option should be treated with chemotherapy- or ADC-based regimens [9].

3.3. *Targeted therapies have revolutionized HER2-positive ABC care*

In previous decades, trastuzumab transformed the care of HER2-positive ABC, becoming the gold standard treatment option for this subtype [9]. The introduction of trastuzumab also led to a paradigm shift in oncology, demonstrating the importance of continued HER2-pathway blockade in ABC, even following disease progression [9]. While access to trastuzumab in combination with a cytotoxic or endocrine agent beyond progression is crucial for better disease control, its access is limited in many countries [49,50]. Over the last decade, further significant improvements have been reported across multiple studies, including ADCs such as T-DXd and T-DM1(trastuzumab bound to a chemotherapeutic agent), tyrosine kinase inhibitors (TKIs), such as lapatinib, tucatinib and others, and for HR-positive HER2-positive patients, the CDK4/6 inhibitor palbociclib (Fig. 2) [51–68]. Based on the OS benefit demonstrated in the DESTINY-Breast trials, T-DXd is now recommended as standard of care in second-line HER2-positive ABC [9], and is even challenging the current first-line standard of care [52]. T-DXd has also shown promise among people with brain metastases, a subpopulation with significantly poorer clinical outcomes, in the DESTINY-Breast 12 study [53,69]. For people with brain metastases, the tyrosine kinase inhibitor tucatinib also provided OS benefit, as seen in the HER2CLIMB-01 trial [60,61].

Similarly to clinical trial findings, survival results from a recent study using patient data from the US Flatiron Health database show that the median OS for patients with HER2-positive ABC is the longest of all subtypes [48]. For those with HR-negative disease, OS improved from 33.4 months in 2011–2013 to 52.0 months in 2020–2022, an overall gain of 18.6 months during this period, demonstrating substantial improvement for this subtype [48]. For patients with HR-positive disease, the median OS increased from 42 months in 2011–2013 to 53.1 months in 2020–2022, showing an improvement of almost a year (11.1 months) [48].

3.4. *While new treatment options show promise, people with triple-negative ABC continue to have poorer outcomes compared to other ABC subtypes*

The treatment of triple-negative ABC continues to be largely based on traditional chemotherapy regimens and the OS of patients with this subtype continues to be poorer than HR-positive or HER-positive ABC [72]. However, in the last decade, the development of new targeted therapy options for specific subpopulations of patients showed, for the first time, survival improvements compared with chemotherapy (Fig. 3) [7,35,36,45,46,73–81].

The key new targeted therapies for this subtype include ADCs, in particular sacituzumab govitecan, immune checkpoint inhibitors (ICIs), especially pembrolizumab, and PARP inhibitors (Fig. 3) [7,35,36,45,46,73–81]. The ADCs sacituzumab govitecan and T-DXd showed significant benefit in both PFS and OS in later lines among patients with HER2-low tumors (Fig. 3), making these treatments the preferred option for people with triple-negative ABC after at least one previous line of therapy [9,73,74,81].

Another class of targeted therapies, ICIs may provide survival benefit for people with Programmed Death Ligand 1 (PD-L1)-positive tumors, as demonstrated for pembrolizumab in first-line in the KEYNOTE-355 trial [76]. For people with *BRCA1/2* mutation, PARP inhibitors olaparib and talazoparib showed PFS benefit, but no significant OS improvement compared with chemotherapy [35,36,45,46].

Whilst not as drastic as the survival increase seen in HR-positive HER2-negative and HER2-positive ABC, some improvements in this subtype have been observed in the real-world setting. According to data from the US Flatiron Health database study, the median OS for triple-negative ABC was found to increase from 11.2 months in 2011–2013 to 13.2 months in 2020–2022, indicating a small improvement and highlighting an unmet need for more effective treatment options for this subtype [48].

3.5. *Compared to the previous decade, survival has improved across all subtypes between 2015 and 2025, though the magnitude of this improvement varies*

In this decade, new treatment options have improved survival for people with ABC across all subtypes. The greatest improvement has been achieved for people with HR-positive HER2-negative ABC, with many new treatment approvals, including the major breakthrough of CDK4/6 inhibitors, substantially prolonging OS in the clinical-trial setting [17–19,21,23,24,37]. Currently, the HER2-positive subtype is associated with the longest survival, achieved by treatment with anti-HER2 agents [72]. With continued OS improvements in this subtype, people with HER2-positive ABC may reach similar life expectancy as those without metastatic disease in the future. However, to achieve this, access to several anti-HER2 agents and to trastuzumab beyond progression is crucial [50]. For triple-negative ABC, despite some improvement in OS, survival continues to be the lowest of all subtypes and an unmet need for more efficacious and better tolerated treatment options remains [72].

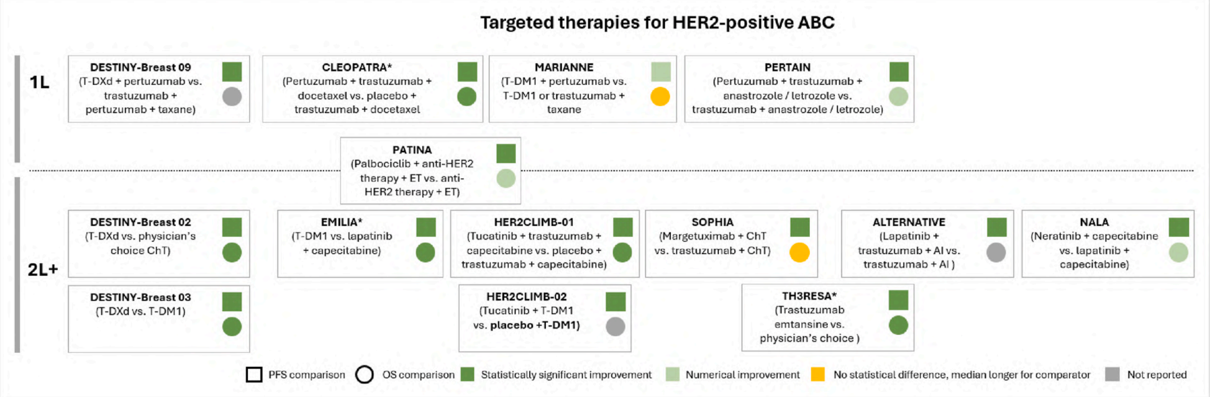

Fig. 2. PFS and OS results from key randomized controlled trials assessing targeted therapies in HER2-positive ABC in 2015–2025 [51–68,70,71]
*Findings from these key trials led to the approval of the assessed treatment option prior to 2015. 1L = first-line; 2L = second-line; ABC = advanced breast cancer; AI = aromatase inhibitor; ChT = chemotherapy; ET = endocrine therapy; HER2 = human epidermal growth factor receptor 2; OS = overall survival; PFS = progression-free survival; T-DM1 = trastuzumab emtansine; T-DXd = trastuzumab deruxtecan; TKI = tyrosine kinase inhibitor.

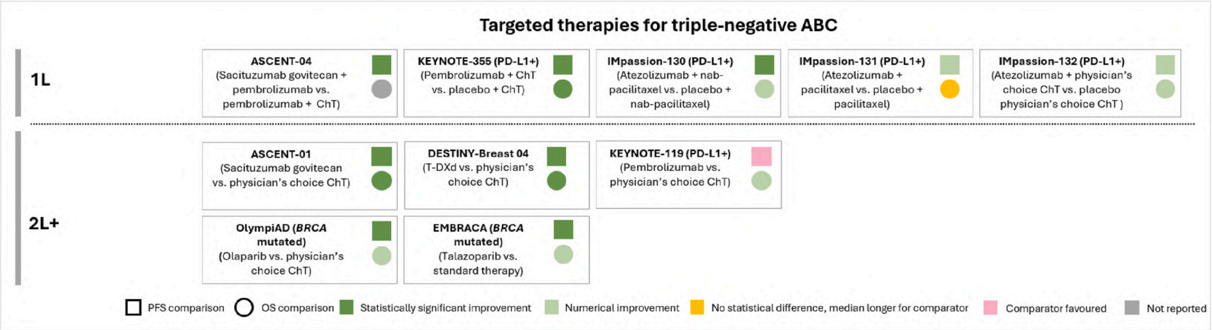

Fig. 3. PFS and OS results from key randomized controlled trials of targeted therapies in triple-negative ABC in 2015–2025 [7,35,36,45,46,73–81]
This figure summarizes the new targeted therapies assessed in key clinical trials in the last decade. It is important to note that ICIs and PARP inhibitors provide effective treatment options in specific subgroups of people with triple-negative ABC only. Moreover, traditional chemotherapy agents remain essential for the treatment of triple-negative ABC and the most commonly used treatment options for this subtype.
ABC = advanced breast cancer; ADC = antibody–drug conjugate; ChT = chemotherapy; ICI = immune checkpoint inhibitor; OS = overall survival; PARP = poly (adenosine diphosphate ribose) polymerase; PD-1 = programmed cell death protein 1; PD-L1 = programmed death-ligand 1; PFS = progression-free survival.

Based on publicly available data from the United States Surveillance, Epidemiology, and End Results (SEER) database, the 2005–2015 Global Decade Report noted minimal improvement in the 5-year OS rate for ABC, regardless of subtype, between 1992 and 1999 and 2005–2011 [5]. In this decade, based on data obtained from the SEER database, a more substantial survival increase is seen, with the 5-year OS rate improving from 26 % (2005–2011) to 33 % (2015–2021) [5,82]. Despite this, ABC survival still starkly contrasts with early breast cancer, where almost all patients survive for 5 years or more after diagnosis (Fig. 4) [82].

Moreover, in ABC, many critical questions remain unanswered: What is the optimal sequence of therapies tailored to each individual? How and when should biomarkers be used to guide treatment initiation? And, perhaps most challengingly, which patients can safely pause or discontinue therapy without compromising outcomes? These unanswered questions reflect the complexity of ABC and the urgent need for more personalized, evidence-driven care pathways.

3.6. With longer survival, there is a need for a holistic approach to ABC care

While new treatment options have resulted in prolonged survival throughout this decade, they are also associated with many side effects that may impact the quality of life (QoL) of people living with ABC [3]. For example, CDK4/6 inhibitors and PARP inhibitors are associated with hematological toxicity, ADCs are associated with interstitial lung disease, ocular and gastrointestinal toxicity, and peripheral neuropathy, and ICIs may cause immune-mediated adverse events (AEs) [3,83,84]. Therefore, it is essential that treatment efficacy is balanced with the impact on QoL when selecting the most appropriate therapy for people with ABC, requiring shared decision-making between healthcare professionals and patients to better understand preferences and treatment goals (discussed in more detail in Goal 5 of the Global Decade Report 2.0 [4]). Additionally, there remains a need to develop and implement tools that can more accurately assess QoL, as discussed in Goal 3 of the Global Decade Report 2.0 [4]. Finally, to ensure high-quality care, all patients with ABC should be treated by a multidisciplinary team that includes nutritional, psychological, financial, and spiritual support to address their holistic needs, as highlighted in Goal 4 of the Global Decade Report 2.0 [4].

3.7. In real-world settings, disparities persist both between different subgroups of people with ABC and across geographic regions

Despite great advancements in ABC, disparities in real-world

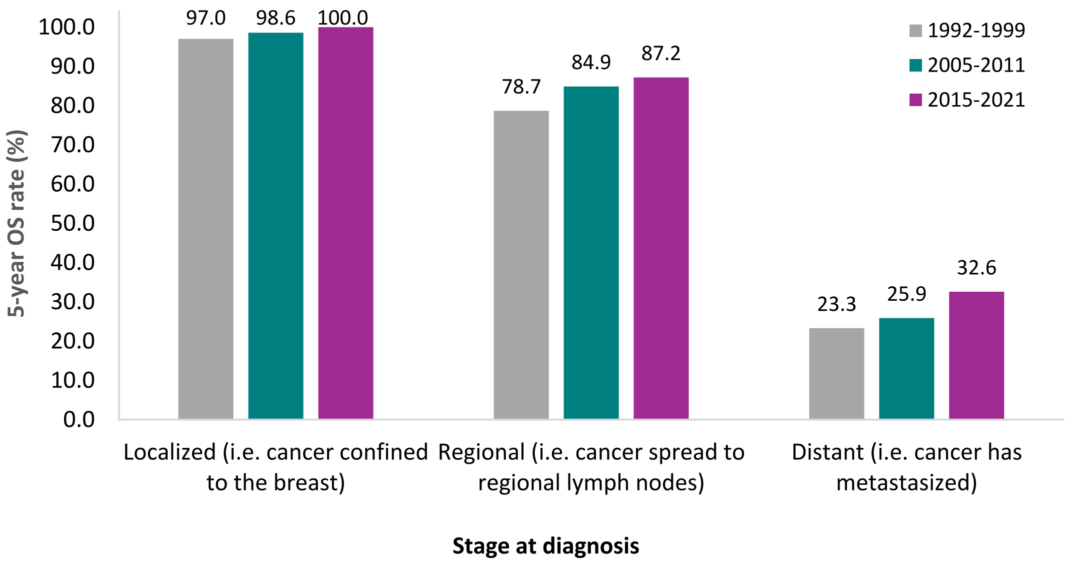

Fig. 4. 5-year OS rates by stage based on publicly available data for female breast cancer in the United States SEER database [5,82]
OS = overall survival; SEER = Surveillance, Epidemiology, and End Results.

survival outcomes remain, and have even increased, partly due to the high cost of newer drugs limiting access (discussed in more detail in Goal 9 of the Global Decade Report 2.0 [4]). A systematic evaluation of 224 real-world studies from 2010–2019 of drugs approved by the Food and Drug Administration (FDA) and European Medicines Agency (EMA) between 2010 and 2015 for solid tumors found that more than half (63 %) reported poorer survival compared with the pivotal trial [85]. Quality assessment using the Newcastle Ottawa Scale revealed that only 30 % of breast cancer studies met the threshold for moderate quality, while the remaining majority were low quality, highlighting a significant gap in robust real-world evidence [85].

In addition, clinical trials often have stringent inclusion criteria which limits the generalizability of the findings to real-world ABC populations [86]. Elderly people, those with clinically relevant comorbidities, men, and people with brain metastases are often excluded from trials, whereas people from ethnic minorities or members of the lesbian, gay, bisexual, transgender, queer, asexual, intersex + (LGBTQAI+) community may be underrepresented in trials due to historical bias [86–91]. Worse survival outcomes for these subgroups have been reported in multiple real-world studies. For example, a US study found that Black people were 40 % more likely to die from breast cancer than White people, while a SEER database study reported twice as long median OS among younger people aged <50 years (32 months) compared to elderly people aged >69 years (16 months) [92,93].

Disparities also remain between geographical regions, with people from low- and middle-income countries being 4−5-times more likely to receive a *de novo* ABC diagnosis than people from high-income countries [94]. To improve understanding of the differences in outcomes between regions, the collection of high-quality real-world evidence is essential. However, most real-world evidence studies are conducted in high-income regions, while the majority of breast cancer cases occur in low- and middle-income regions, including Africa, Asia, and South America [95]. Many countries in these regions lack national registries, which hinders the accurate assessment of the burden of ABC and limits understanding of the unmet needs of people living in these regions. Real-world evidence collection and national registries are described in detail in Goal 2 of the Global Decade Report 2.0 [4].

3.8. *ABC-specific treatment guidelines have set standards for quality care in ABC*

The 2005–2015 Global Decade Report highlighted the need for comprehensive ABC-specific treatment guidelines to improve care and survival. Over the past decade, significant progress has been made to overcome this unmet need, with the development of high-quality, ABC-specific international treatment guidelines, such as the ABC international consensus guidelines, the European Society for Medical Oncology (ESMO) ABC guidelines (2021), the American Society of Clinical Oncology (ASCO) resource-stratified guidelines (2024), and the National Comprehensive Cancer Network (NCCN) and African Cancer Coalition harmonized guidelines [9–11,13]. Country-specific guidelines, like the New Zealand Consensus Guidelines, further support localized decision-making [12]. While adherence to these guidelines has been shown to enhance survival rates, guideline recommendation uptake is varied [96–98]. Moreover, limited access and availability to treatments may hinder the uptake of guideline recommendations, especially in low- and middle-income regions. This highlights the urgent need for equitable access to treatment innovations in ABC care globally to ensure that all patients can benefit from these advancements and achieve longer survival, a topic further discussed in Goal 9 of the Global Decade Report 2.0 [4].

4. Conclusion and future directions

In the last decade, significant improvements in survival outcomes have been achieved in clinical trials across all ABC subtypes and there are now more options enabling more individualized and targeted treatment. Despite these improvements, patients with triple-negative ABC continue to experience worse outcomes than other subtypes. Moreover, it is essential that the outcomes seen in clinical-trial setting are translated to real-world improvements globally, and for all people, to truly improve survival in ABC.

To further improve patient outcomes in the next decade, new treatment options that prolong OS and/or improve QoL are critically needed. While PFS benefits are a good outcome, improvements in OS are essential to make greater advances on the course of the disease. Therefore, OS should be used as a primary or co-primary endpoint in clinical trials, or at minimum the statistical plan should be sufficiently powered to assess the impact of a treatment on OS. This recommendation remains important, even though factors such as crossover trial designs and differences in the availability of post-progression therapies can influence OS outcomes and have implications for trial participants.

Continued advancements of the understanding of ABC biology are needed for the development of new treatments and to identify better predictive biomarkers. Moreover, the best sequence of therapies for patients with ABC remains unanswered and should be further investigated, and better tools to accurately measure QoL in the metastatic setting are needed and being developed. As we are entering a new era of advanced technology, it is important that digital technologies are leveraged to further enhance patient care and improve outcomes for all.

We also call for efforts similar to the Early Breast Cancer Trialists' Collaborative Group (EBCTCG) meta-analysis of individual patient data that have existed for decades in the early breast cancer setting [99,100]. A centralized analysis of all clinical trials, pharma-led and academic, would allow us to answer some of the open questions in the metastatic setting.

Prolonging survival remains an essential goal for improving the lives of people living with ABC, therefore the ABC Global Alliance Community agreed to keep survival as one of the 10 key 'Actions for Change' in the 2025–2035 ABC Global Charter with the following updated wording: **Further improve survival in people with ABC by doubling median overall survival**.

To achieve this goal, future efforts must aim to.

- Improve median OS across all ABC subtypes, particularly for those with a poorer prognosis, by leveraging emerging biomarkers and driving research to better understand disease recurrence and progression
- Reduce survival disparities across geographies, ethnicities, and socioeconomic groups by expanding access to diagnostics, treatments, and clinical trials, and using resource-stratified guidelines, where appropriate
- Generate and standardize high-quality real-world evidence to support accurate assessment of global survival rates and data-driven decision-making in ABC
- For some subtypes, move towards considering ABC as a chronic condition where people live longer, fuller lives, enabling continued contribution to their families, communities, and economies

For further details and information please review the Global Decade Report 2.0 [4].

CRediT authorship contribution statement

Mariana Chavez-MacGregor: Writing – review & editing, Validation, Conceptualization. **Joseph Gligorov:** Writing – review & editing, Validation, Conceptualization. **João Mouta:** Writing – review & editing, Validation, Conceptualization. **Matthijs Van Meerveld:** Writing – review & editing, Validation, Conceptualization. **Zsofia Wolkensdorfer:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Georgia Attfield:** Writing –

review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Alexandra Lewis:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Fatima Cardoso:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Methodology, Funding acquisition, Formal analysis, Conceptualization.

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JM: Employment and stock ownership, F. Hoffmann-La Roche.

FC: Advisory role for Amgen, Astellas/Medivation, AstraZeneca, Bayer, Celgene, Daiichi Sankyo, Eisai, GE Oncology, Genentech, Gilead, GlaxoSmithKline, IQVIA, Macrogenics, Medscape, Merck Sharp & Dohme, Merus BV, Mylan, Mundipharma, Novartis, Pfizer, Pierre Fabre, prIME Oncology, Roche, Sanofi, Samsung Bioepis, Seagen, Teva, and TouchIME.

MVM, ZW, GA, AL: Authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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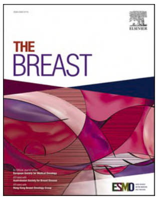

Collecting high-quality data for advanced breast cancer: a global expert review and call-to-action for 2025–2035 (Goal 2)

Vicki Durston [a], Charlotte E. Coles [b], Adele Gautier [c], Andrea L. Smith [d], Alexandra Lewis [e], Georgia Attfield [e], Fatima Cardoso [f,*]

[a] Breast Cancer Network Australia (BCNA), Melbourne, Australia
[b] Department of Oncology, University of Cambridge, Cambridge, United Kingdom
[c] Breast Cancer Foundation NZ, Auckland, New Zealand
[d] The Daffodil Centre, University of Sydney, a Joint Venture with Cancer Council NSW, Australia
[e] VML Health, London, United Kingdom
[f] Advanced Breast Cancer (ABC) Global Alliance, Lisbon, Portugal

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ABSTRACT

The systematic collection and analysis of high-quality advanced breast cancer (ABC) data is necessary to advance understanding, optimize care, and improve patient outcomes. High-quality data enables understanding of treatment effectiveness, thereby facilitating the development of innovative therapies. ABC data may also help to counter stigma, by demonstrating that many living with the disease continue to contribute meaningfully to society. Data is an essential tool in highlighting global inequities and advocating to overcome them, and prevalence data is key to determining the burden of ABC worldwide, informing healthcare policies and investment in ABC care.

This manuscript reviews global efforts to improve the collection and analysis of ABC data over the past decade. It highlights the advances and persistent challenges to high-quality data collection and proposes actions for the decade ahead. It summarizes research conducted for the ABC Global Alliance's Global Decade Report 2.0. The main findings are: a) New methodologies yield more accurate estimates of the number of people with ABC; b) Data linkage initiatives reveal ABC prevalence far higher than earlier projections; c) ABC-focused registries have advanced data collection globally over the decade; d) High-quality ABC data has been shown to drive treatment access and policy change; e) Persistent gaps in recurrence data and registries remain.

The findings from the ABC Global Alliance's Global Decade Report 2.0 have informed the development of a new ABC Global Charter. The ABC Global Charter 2.0 defines ten new achievable and measurable goals for the decade 2025–2035, aiming at improving the lives of people living with ABC worldwide.

1. Introduction

The systematic collection and analysis of high-quality advanced breast cancer (ABC) data is necessary to advance understanding, optimize care, and improve patient outcomes [1]. High-quality data enables understanding of treatment effectiveness, thereby facilitating the development of innovative therapies [1]. ABC data may also help to counter stigma, by demonstrating that many living with the disease continue to contribute meaningfully to society [2]. Data is an essential tool in highlighting global inequities and advocating to overcome them [3], and prevalence data is key to determining the burden of ABC worldwide, informing healthcare policies and investment in ABC care [1]. Data can come from a wide range of sources, from strictly controlled environments such as clinical trials to real-world contexts like social media, patient blogs, and online forums. Between these extremes lie other valuable sources, including cancer registries, real-world and epidemiological studies, claims databases, and electronic medical records, among others.

This manuscript reviews global efforts to improve the collection and analysis of ABC data over the past decade. It highlights the advances and

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* Corresponding author.

E-mail address: fcardoso@abcglobalalliance.org (F. Cardoso).

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persistent challenges to high-quality data collection and proposes actions for the decade ahead. It is informed by research conducted for the ABC Global Alliance's Global Decade Report 2.0, primarily interviews conducted in 2024 with national data registries from five countries, an assessment of the International Agency for Research on Cancer's (IARC) Cancer Incidence in Five Continents (CI5) publication, and a review of recent literature. For detailed information on the research methodologies and their limitations, please refer to the Global Decade Report 2.0 [4], in addition to the first manuscript of this special issue.

2. Status in 2005–2015

The 2005–2015 Global Decade Report highlighted significant gaps in the completeness and quality of data collected on ABC [3], and data on recurrence were severely lacking [5,6]. This gap stemmed from the fact that cancer registries typically recorded diagnoses (incidence) and deaths (mortality) but not recurrence, due to the fact that they do not actively follow the patient. As a result, the majority of people with ABC, with the exception of *de novo* cases for whom some registries collected stage at diagnosis, were not captured in national or global data sets [7]. Moreover, where data was available, it mostly came from high-income countries (HICs), contributing to disparities across geographies and underreporting in low- and middle-income countries (LMICs) [7].

In the 2015–2025 ABC Global Charter, the ABC Global Alliance included 'increasing the collection of high-quality data' as one of its ten 'Actions for Change' [8].

3. A decade in review (2015–2025)

3.1. The number of people living with ABC remains unknown

Complete and accurate ABC data collection is essential for understanding disease progression and improving outcomes [1]. The absence of data on breast cancer stage at diagnosis and recurrence has long hindered the identification of the number of people living with ABC globally, impacting health system administrators' ability to plan services and allocate resources [7]. That said, significant efforts have been made to address this issue in the past decade, leading to vastly improved prevalence estimates in certain countries and states [4]. The development of ABC-focused or population based registries that started to collect ABC data – such as The Netherlands Cancer Registry in 1989 [9], Épidémio-Stratégie Médico-Economique (ESME)-MBC Cohort in France in 2014 [10], the OPAL registry in Germany in 2017 (an evolution of the Munich Cancer Registry (MCR)/Tumor register München (TRM) established in 1978) [11], Te Rēhita Mate Ūtaetae – Breast Cancer Foundation National Register, New Zealand's (NZ) ABC analysis in 2018 [12], and National Audit of Metastatic Breast Cancer (NaoME) in the United Kingdom (UK) in 2022 [13] – paved the way for progress in ABC data collection.

In addition to registries, researchers have developed innovative methodologies to estimate the number of people living with ABC. In 2021, Macmillan Cancer Support and the National Disease Registration Service, Public Health England in the UK pioneered the use of linked data sets to estimate the number of people living with treatable but not curable cancer in England at the end of 2015 [14]. In 2022, Palmieri et al. used secondary care records extracted from the English Hospital Episode Statistics (HES) database to estimate that there were 57,215 people with ABC in England in the 2020/2021 financial year [15]. Building on this foundational work, University of Sydney researchers and the Cancer Institute of New South Wales (NSW) used a similar methodology to estimate the number of individuals living with ABC in NSW at 7900 in 2024 [16]. In 2025, underpinned by advocacy efforts by Breast Cancer Network Australia (BCNA), data linkage methods were again used by the Victorian Cancer Registry and Cancer Alliance Queensland to estimate the number of people living with ABC in Victoria (4,461) [17] and Queensland (3,863) [18]. In the same year, the Northern Ireland Cancer Registry (NICR) used data linkage methods to estimate there to be 911 people with ABC in Northern Ireland in 2020, increased from 587 in 2009 [19]. These breakthroughs not only provide clearer prevalence estimates but also gave visibility to a previously overlooked population.

Recent systematic analyses by Morgan et al., in 2024 highlight the diversity of approaches used to capture metastatic recurrence. These studies demonstrate that most population-based cancer registries (PBCRs) rely either on manual cohort reviews, which retrospectively check patient files from defined diagnosis years, or on data linkages that can detect recurrence irrespective of diagnosis date [20,21].

While this indicates progress since 2015, these efforts revealed significant underestimation of the burden of ABC based on previous figures. The 2022 research conducted by Palmieri et al. showed the number of people with ABC in England to be far higher than previous estimates for the whole of the UK [15]. Similarly, extrapolating the 2024 NSW estimates to the Australian population suggests that around 24,000 people are living with ABC in Australia, more than double the previous projections [16]. In addition, in 2025 most countries remain unable to generate reliable ABC prevalence estimates, underscoring the critical need for improved ABC data collection.

3.2. High-quality data is an essential tool in overcoming global disparities

Beyond prevalence, collection and analysis of high-quality ABC data is key to exposing and overcoming inequities in care. The Breast Cancer Foundation NZ's 2018 report 'I'm Still Here – Insights into Living and Dying with ABC in NZ' used data from Te Rēhita Mate Ūtaetae – Breast Cancer Foundation National Register to highlight disparities in ABC care for people in NZ [22] and was pivotal in driving national policy discussions [23]. The report resulted in meaningful change for people living with ABC in NZ, including public funding for three important ABC treatments [24], development of a digital patient-reported outcome tool for nurse-led ABC care [25], and production of the first ABC-NZ treatment guidelines [23], highlighting the transformative power of high-quality data.

Other countries are advocating for improved ABC data collection to address disparities. In Canada, Rethink Breast Cancer launched the 'Make MBC Count' campaign in 2020, which evolved to 'Make Me Count' in 2024 [26,27]. The campaign calls for robust, complete, and harmonized data that can be shared between provinces and regions across Canada, while highlighting the importance of data in overcoming ABC disparities [27].

3.3. ABC data collection is now a global priority, but registry quality continues to vary

The importance of collecting high-quality ABC data is increasingly being recognized as a global priority this decade, a change reflected in the setting of new standards and targets. The European Society of Breast Cancer Specialists' (EUSOMA) Requirements of a Specialist Breast Centre was updated in 2020 to mandate collection of data on all people with breast cancer, including those with ABC [28]. In 2023, the first set of quality indicators (QIs) for ABC were produced by EUSOMA and the ABC Global Alliance [29]. The QIs recommend the collection of ABC data, including that on pathological disease characterization, systemic therapy provision, and use of tumor markers [29].

In addition, the European Network of Cancer Registries (ENCR) published its Recommendations on Recording Recurrence, Progression, and Transformation of Cancer in 2025, providing detailed guidance for PBCRs on how to systematically collect and record recurrence data across all cancer types [30]. This represents a major effort by European cancer registries to improve the completeness and comparability of recurrence information, aligning with broader international initiatives to strengthen data collection on advanced and metastatic disease.

Furthermore, in 2024 the Lancet Breast Cancer Commission outlined a roadmap for breast cancer change that called for the collection of high-quality cancer registry data on cancer relapse worldwide, stating that a minimum of 70 % of global cancer registries should be registering people with metastatic disease [7], and aiming at reaching 100 % in the future. The report emphasizes that while ABC is leading the way, the goals are broadly applicable and all recurrences should be recorded regardless of cancer type [7]. These calls to action from leading international organizations demonstrate the enhanced global recognition of the importance of collecting high-quality ABC data and provide a benchmark to be realized over the coming years.

Despite this global prioritization and the vital role of registries in enhancing data collection, practices, and data completeness continue to vary across cancer registries. An analysis of IARC's Cancer Incidence in Five Continents (CI5) Volume XII, published in 2024, revealed a 28 % increase in the number of submitted PBCRs compared with Volume XI and a 25 % increase in those meeting IARC's data collection standards [31]. Submissions were highest in Asia, while acceptance rates were higher in Oceania, North America, and Europe [31], highlighting ongoing disparities. Unfortunately, when reviewing at a country-level, breast cancer stage at diagnosis was recorded by less than 20 % of IARC-accepted PBCRs in ABC Global Alliance analyzed countries (see introduction), with PBCRs in Brazil, Japan, Poland, and South Africa not collecting this data at all (Fig. 1) [31].

3.4. Progress in ABC data collection is restricted by universal hurdles

While the establishment of ABC-focused registries represents global progress in the collection of ABC data, ABC Global Alliance interviews conducted in 2024 revealed persistent challenges across registries that continue to hinder ABC data collection and analysis (Table 1).

Barriers to optimal data collection include high implementation costs, workforce shortages, and privacy law limitations that hinder data sharing and cross-referencing [32]. Challenges with tracking ABC at both *de novo* diagnosis and recurrence are compounded by fragmented healthcare systems, inconsistent record keeping, and the varying diagnostic and treatment options for advanced disease [32]. The effort and cost associated with active tracking of people with breast cancer represents a substantial barrier, resulting in those with recurrent ABC being lost to follow-up [7].

Database design is another issue, with many lacking standardized definitions of key terms such as 'line of treatment' and 'progression'. Furthermore, a lack of ABC-specific international coding standards used in clinical practice in electronic health records, can result in the requirement for manual recording and data extraction, [32], leading to substantial resource burden, particularly in countries with limited healthcare infrastructure. Even in countries where ABC data collection is mandatory and the correct systems are in place, a lack of healthcare professional (HCP) understanding, awareness, and incentive remains a barrier. In addition to these structural and operational challenges, data adjudication represents a further limitation. While adjudication can substantially improve the accuracy and reliability of registry data, it is resource-intensive and often not feasible in routine registry operations.

3.5. LMICs face additional barriers to ABC data collection

In LMICs, universal barriers are compounded by resource scarcity and systemic inequalities that lead to persistent and significant challenges in collecting high-quality ABC data [7]. A 2021 study in Sub-Saharan Africa (SSA) highlights this, with stage at diagnosis and hormone receptor status recorded for only 20 % of patients with breast cancer from across 11 urban registries [33]. In the same study, 51 % of those with curable breast cancer were found to receive inadequate or no cancer-directed therapy [33]. These findings reflect broader challenges documented in the region, including those from the African Breast

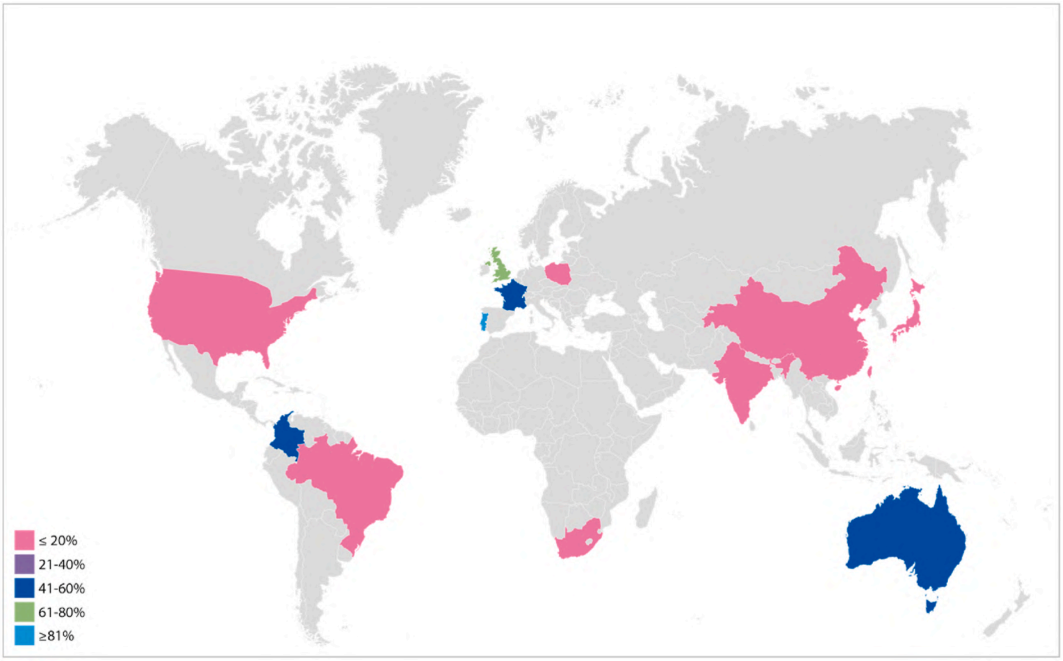

Fig. 1. PBCRs (by region) accepted by IARC C15 vol XII (Data from: 2013–2017) reporting to collect data on breast cancer stage at diagnosis from countries of interest*.

*The ABC Global Alliance Steering and Advisory Committees selected 14 countries of interest for in-depth analysis throughout the research, which provided a balanced global representation of ABC care. Countries were chosen to reflect a diverse mix of high-, middle-, and low-income nations, encompassing various healthcare systems and sociodemographic contexts across all continents. The selected countries were Australia, Brazil, China, Colombia, France, India, Japan, Mexico, Nigeria, Poland, Portugal, South Africa, United Kingdom, United States. Please note IARC do not collect data on Mexico or Nigeria, hence these countries were excluded. Countries in grey represent countries were data was not analyzed.

IARC = International Agency for Research on Cancer; PBCR = population-based cancer registry.

Table 1
Registry-reported challenges and barriers to ABC data collection.

Registry	Registry-reported challenges
Épidémio-Stratégie Médico-Economique (ESME), France	• Use of national hospital data means that some patients (i.e., those in clinical trials or private hospitals) are not captured. • The lack of standardized definitions for disease progression and quality-of-life measures presents challenges in maintaining an accurate registry, which is comparable between countries [20,21].
The OPAL Registry, Germany	• Private funding through pharmaceutical partnerships can enhance financial sustainability; however, research projects are largely guided by the strategic priorities of the sponsoring companies.
Te Rēhita Mate Ūtaetae – Breast Cancer Foundation National Register, NZ	• Maintaining real-time data is a challenge due to a growing number of long-term survivors to follow up, increasing number of data fields, and increasing the need for manual extraction. • Lines of treatment are not defined and differ between oncologists, hospitals, and countries, impacting accurate and comparable data collection [20,21].
The Netherlands Cancer Registry, The Netherlands	• Manual data gathering on recurrence (ABC) was performed retrospectively for selected cohorts (2003–2008 and Q1 2012) but was discontinued due to limited workforce capacity. • Accurate prediction of metastasis relies on linkage between NCR data and electronic health record (EHR) data, with algorithms applied to the combined dataset achieving ~80 % accuracy. • Data managers continue to play a key role in verifying and filling data gaps, and coding improvements are needed to address the lack of standardization across data EHR systems.
National Audit of Metastatic Breast Cancer (NAoME), The UK	• Inconsistencies in the use of International Classification of Diseases (ICD) codes to identify metastatic recurrence make the collection of high-quality relevant data difficult. • Balancing speed and quality of data: fast data collection may lack depth and completeness, while collection of high-quality data takes longer, risking reduced relevance

ABC = advanced breast cancer; NZ = New Zealand; UK = United Kingdom.

Cancer-Disparities in Outcomes (ABC-DO) study which emphasized the critical need for improved registration of cancer stage to enable accurate clinical research into survival and treatment outcomes [34]. These studies not only showcase inequities in care in LMICs, but also the role of data in highlighting these disparities.

Progress in establishing ABC registries has been largely limited to HICs, and expanding these efforts will be essential to improving ABC data collection in LMICs. The same 2021 SSA study showed that more than a third of people with breast cancer registered to PBCRs across 11 LMICs could not be traced to a treatment facility [33]. While some may never have initiated treatment, the widespread reliance on paper-based systems in LMICs makes it challenging to track people over time [33].

Gaps in ABC data in LMICs not only highlight ongoing inequalities, but also demonstrate the urgent need for more refined, standardized methodologies that can be implemented even in limited-resource settings. Unlike HICs that are using innovative methodologies to collect and report ABC data [11,16] LMICs require a different approach; one that is focused on improving infrastructure and technological frameworks, with financial and practical support from the global ABC community.

3.6. Innovation, collaboration and advocacy are key to advancing the future of ABC data collection

Global collaboration and advocacy are key to improving ABC data collection, as demonstrated most recently by researchers in Australia and Northern Ireland, who built on data linkage methodologies pioneered by researchers in the UK [15,16,19]. It is essential that the ABC community continues to build on the progress that has been made, but varying datasets and health systems make replicating successes across countries and regions challenging, which emphasizes the need for harmonization efforts.

Registries such as NAoMe have the opportunity to leverage a unique strength of the UK health system – the National Health System number – allowing consolidation of information from across various sources, including cancer registries, hospital records, chemotherapy and radiotherapy databases, and primary care prescription data. However, the NAoMe audit has a highlighted critical limitation: relapse and recurrence data remains significantly underreported. Recording recurrence has the potential to reduce the cost and accelerate the pace of clinical trials. It could also lead to more diverse, high-quality real-world data, better reflecting the general population, thereby accelerating the equitable introduction of new treatments into clinical practice [35]. However, many NHS trusts are still not capturing information on recurrence, despite it being mandatory since 2013, predominantly due to lack of time and resource [36].

Health technologies and artificial intelligence (AI) have the potential to transform ABC data collection and enhance completeness. One example is the Netherlands Cancer Registry, which is spearheading the use of algorithms on linked data form Dutch Hospital Data to predict relapse and this notification reduces the registration burden enormously [9]. Such approaches illustrate how technology can help identify underreported cases and improve the timeliness and accuracy of ABC incidence and prevalence data.

Looking ahead, AI-enabled tools could also facilitate more efficient data entry, automated case validation, and identification of disease progression from unstructured clinical data. In parallel, digital health innovations, such as those enabling real-time patient engagement and reporting, represent an opportunity to expand the scope of registries beyond traditional clinical data. While these developments, including patient-reported outcomes (PROs) initiatives like Germany's OPAL registry [11], are not yet central to ABC completeness efforts, they highlight how future systems could integrate patient input alongside clinical information [37]. As emphasized by the Lancet Breast Cancer Commission, the digital health era offers a unique opportunity to advance equity by breaking down barriers to patient engagement with healthcare systems, for example through better access to research and decentralized clinical trials [7].

In July 2025, Breast Cancer Now (UK), ReThink Breast Cancer (Canada), and BCNA (Australia) jointly call on governments to prioritize data collection and reporting for ABC, foster international collaboration, and integrate ABC into broader global health initiatives [38].

4. Conclusions and future directions

The last decade has seen growing global recognition of the importance of high-quality data collection for ABC. However, progress has been unequal, and persistent gaps remain that disproportionately affect people with recurrent ABC and those in LMICs.

As we look forward, it is important to build on the successes of this decade, whilst recognizing that there is no 'one-size-fits-all' approach to ABC data collection. Global collaboration and a commitment to obtain complete and accurate ABC data is essential. While this pledge signifies positive progress, it is just the beginning and much more can and will be achieved.

The ABC Global Alliance goal for 2025–2035 is clear: **Optimize care and outcomes for people with ABC by collecting high-quality data.**

To achieve this, the ABC Global Alliance community recommends several key actions.

- Ensure that every person living with ABC is recognized and recorded globally by 2035
- Define and implement worldwide minimum standards for ABC data capture, ensuring that all cancer registries include ‘stage at diagnosis’ as a fundamental data input
- Advocate for data privacy law waivers to enable accurate and ethical linkage of patient information across databases, to allow for better notification and collection of relapse data

For further information, please refer to the ABC Global Charter for 2025–2035 [39].

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Vicki Durston: Writing – review & editing, Validation, Conceptualization. **Charlotte E. Coles:** Writing – review & editing, Validation, Conceptualization. **Adele Gautier:** Writing – review & editing, Validation, Conceptualization. **Andrea L. Smith:** Writing – review & editing, Validation, Conceptualization. **Alexandra Lewis:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Georgia Attfield:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Fatima Cardoso:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization.

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Improving the quality of life of people with advanced breast cancer: a global expert review and call-to-action for 2025–2035 (goal 3)

Karen Gelmon [a], Cynthia Villarreal-Garza [b], Dawn Aubel [c], Hope S. Rugo [d], Julia Maués [e], Luzia Travado [f], Matthijs Van Meerveld [g], Runcie C.W. Chidebe [h], Bianca Patel [i], Georgia Attfield [i], Alexandra Lewis [i], Fatima Cardoso [j,*]

[a] BC Cancer, Vancouver, Canada
[b] Tecnologico de Monterrey, Breast Cancer Center, Hospital Zambrano Hellion, San Pedro Garza Garcia, Mexico
[c] Inflammatory Breast Cancer Research Foundation, Broadway, VA, United States
[d] City of Hope Comprehensive Cancer Center, San Francisco, CA, United States
[e] Guiding Researchers and Advocates to Scientific Partnerships (GRASP), Washington, DC, United States
[f] Champalimaud Clinical Centre, Lisbon, Portugal
[g] Menarini Stemline, Zurich, Switzerland
[h] Project PINK BLUE-Health & Psychological Trust Centre, Abuja, Nigeria
[i] VML Health, London, United Kingdom
[j] Advanced Breast Cancer (ABC) Global Alliance, Lisbon, Portugal

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ABSTRACT

Progress in the treatment landscape for advanced breast cancer (ABC) has significantly extended the survival of people with the disease. However, longevity alone is insufficient; maintaining and enhancing quality of life (QoL) is vital to ensure that people with ABC experience not only longer lives but fulfilling ones. Literature consistently highlights the unmet psychosocial needs of people with ABC, and its negative impact on QoL. Furthermore, many awareness and support programs disproportionately focus on early breast cancer, resulting in substantial gaps in information, resources, and medical and psychological support for people with ABC, which in turn can exacerbate feelings of isolation and stigma.

This manuscript explores the impact of ABC on QoL and draws on research conducted for the development of the ABC Global Alliance's Global Decade Report 2.0. The main findings are: a) QoL improvements over the last decade vary between ABC subtypes, with triple negative ABC patients having the lowest QoL; b) The impact of ABC on QoL remains unequal between populations; c) Low-grade side effects of ABC treatment have a profound impact on QoL; d) ABC has a substantial impact on caregiver QoL; e) Many QoL assessment tools currently fail to capture the specific needs of people with ABC.

The findings from the ABC Global Alliance's Global Decade Report 2.0 have informed the development of a new ABC Global Charter. The ABC Global Charter 2.0 defines ten new achievable and measurable goals for the decade 2025–2035, aiming at improving the lives of people living with ABC worldwide.

1. Introduction

Progress in the treatment landscape for advanced breast cancer (ABC) has significantly extended the survival of people with the disease [1]. However, longevity alone is insufficient; maintaining and enhancing quality of life (QoL) is vital to ensure that people with ABC experience not only longer lives but fulfilling ones. Literature consistently highlights the unmet psychosocial needs (encompassing emotional, spiritual, financial, and occupational factors) of people with ABC, and its negative impact on QoL [2–4]. Many awareness and support programs disproportionately focus on early breast cancer, resulting in substantial gaps in information, resources, and medical and psychological support for people with ABC, which in turn can exacerbate feelings of isolation and stigma [3,4] (discussed in Goal 8). Since disease

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* Corresponding author. Advanced Breast Cancer (ABC) Global Alliance, Lisbon, Portugal.
E-mail address: fcardoso@abcglobalalliance.org (F. Cardoso).

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progression with its associated symptoms and treatment-related toxicity affect the QoL of cancer patients, it is essential to consider the balance between efficacy and toxicity in shared decision-making for people living with ABC.

This manuscript explores the impact of ABC on QoL and draws on research conducted for the development of the ABC Global Alliance's Global Decade Report 2.0, predominantly patient and healthcare professional (HCP) surveys conducted in 2024 and a targeted literature review of QoL studies spanning 2015–2024. It provides an overview of the evolution of QoL in ABC over the last decade, highlighting notable advances while emphasizing the substantial work that remains in this field. For more details on research methodologies and limitations please refer to the Global Decade Report 2.0 [5], in addition to the first manuscript of this special issue.

2. Status in 2005–2015

The 2005–2015 Global Decade Report highlighted the profound impact of ABC on QoL, with eight in ten patients surveyed at the time identifying QoL as the most critical area for improvement in ABC care. Despite treatment advances over the decade, the QoL of people with ABC slightly declined, with the average EuroQoL (EQ)-5D score falling from 0.7021 in 2004 to 0.6313 in 2012 [2].

The report also revealed substantial variability in QoL assessment across countries and healthcare centers, leading to regional and global care inconsistencies. In some regions, general health instruments such as EQ-5D were used, while others relied on cancer-specific tools like Functional Assessment of Cancer Therapy questionnaire (FACT-G), often supplemented by breast cancer–specific modules. Most QoL data came from high-income countries (e.g., the United States, United Kingdom, and Australia), whereas studies from Asia, Latin America, and Africa frequently lacked standardized QoL reporting, limiting meaningful cross-regional comparisons.

While validated QoL tools existed and were used in clinical trials, their real-world effectiveness was limited due to poor integration into practice. Furthermore, all QoL tools at the time were for early breast cancer and no dedicated tool existed for ABC. The report called for a more structured definition of QoL, increased focus on influencing factors, and real-time, patient-centered assessment tools [5]. Recognizing these unmet needs, the 2015–2025 ABC Global Charter prioritized improving QoL for people with ABC as a key 'Action for Change' [6].

3. A decade in review (2015–2025)

3.1. New ABC treatments this decade have improved both survival and QoL outcomes

The previous Global Decade Report (2005–2015) highlighted a slight overall decrease in QoL for people with ABC, emphasizing the need for therapeutic advancements across all subtypes that are both effective and minimally toxic. In comparison, an ABC Global Alliance analysis of QoL scores reported in clinical trials from this decade (2015–2025) demonstrates an upward trend. Average EQ-5D scores increased from 0.6313 in 2012 to 0.7981 in 2024, indicating a positive shift in patient outcomes and experience (Fig. 1). This increase may be largely attributable to the advent of targeted therapies this decade, which have reduced the number of chemotherapy-related toxicities [7]. The most significant improvements in QoL have been in HER2-positive ABC, with modest improvements seen in the HR-positive subtype, and only marginal improvements for people with triple-negative ABC [8]. Across subtypes, it should be noted that those enrolled in first-line trials may typically report a higher baseline QoL, as seen in literature [9]. As such, traditional QoL assessments may fail to capture meaningful differences unless they consider the time until clinically relevant decline. Incorporating time to deterioration measurements could be a helpful indicator to accurately understand the true impact of treatment for ABC.

Despite the positive QoL outcomes observed in ABC clinical trials this decade, there is a need to understand the real-world impact of treatment. Clinical trials for ABC therapies often report QoL as 'tolerable' or 'maintained', which are nebulous terms that often do not reflect the individual experience. Additionally, trials often overlook the impact of persistent, low-grade side effects of ABC treatments on daily activities [10–12]. Unlike treatment for early-stage breast cancer where side effects are often temporary or the goal of treatment is curative, ABC requires a long-term treatment approach, where the cumulative burden of side effects can profoundly affect QoL [13]. Thus, optimizing the balance between treatment effectiveness and toxicity is vital to preserve patient QoL over time.

A 2024 survey by IQVIA and Menarini Stemline highlighted the impact of treatment toxicity on QoL. As patients progressed through successive lines of treatment, the number of respondents reporting '*poor*' or '*very poor*' QoL increased substantially [14]. The survey also found that those who reported more than 11 side effects were twice as likely to experience poor or very poor QoL compared to those who had fewer than 11 [14]. This treatment burden also impacts adherence, with almost half (43 %) of respondents to a 2024 survey of ABC patients in the

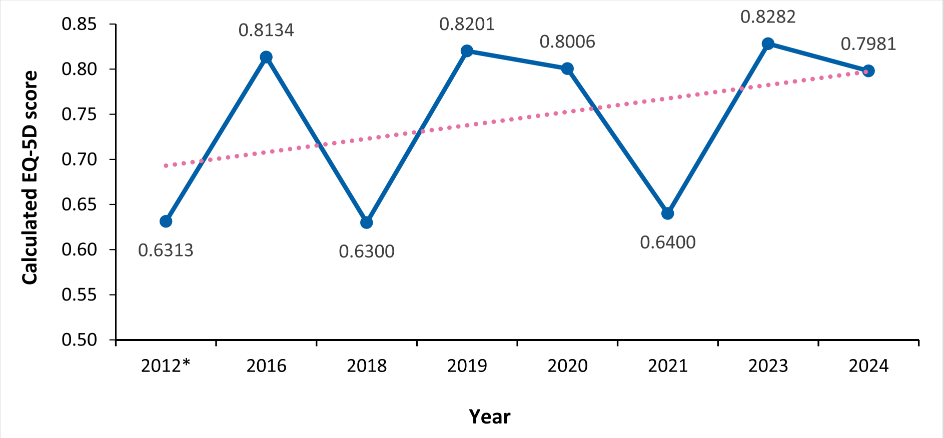

Fig. 1. Quality of life in people with ABC as assessed by EQ-5D, 2015–2024, Generic (non-cancer specific) Health Utility Score* [2,5]
* Data from 2012 was taken from the 2005–2015 Global Decade Report. For further details on methodology and its limitations, please refer to the Global Decade Report 2.0.
ABC = advanced breast cancer.

United States reporting missing at least one ABC treatment dose due to side effects, indicating a direct link between toxicity, adherence, and overall disease management [15].

Emerging evidence has shown that evolving treatment strategies that move away from 'maximum tolerated dosing' to 'minimum effective dosing' may help to limit toxicity while preserving efficacy [10,15]. This approach is particularly relevant in the setting of incurable disease, but not exclusively and is being evaluated in the early setting as well. Though this approach warrants further investigation, it could result in substantial QoL benefits for people with ABC and potentially better long-term adherence. This strategy could also help in low-resource settings, where access to standard treatments is costly [16].

3.2. ABC continues to have a profound impact on QoL, particularly for certain populations

The ABC Global Alliance 2024 patient survey (n = 1254) corroborated recent literature demonstrating the negative impact of ABC on QoL, with 65 % of respondents reporting a negative impact on their physical functioning and 79 % on their emotional and psychological wellbeing. This impact is greater for certain populations, including younger people with ABC, those with dependents, and those of a lower socioeconomic background [17–19].

The 2019 Survey of Health, Impact, Needs, and Experiences (SHINE) study found that people under the age of 50, those with limited financial resources, and those with additional responsibilities, experienced greater negative impact on QoL [17]. The QoL impact on younger patients was also highlighted by a global survey conducted by Young Survivor Coalition's Project 528, with 76 % of young people with ABC reporting disease-related anxiety, 88 % experiencing fatigue, and 51 % finding the management of side effects to be a major challenge [19].

Ethnicity, geography, and socioeconomic status also influence the impact of ABC on QoL. The ABC Global Alliance 2024 patient survey found the impact of ABC on emotional and psychological wellbeing to vary by ethnicity, with 84 % of white participants reporting a negative impact, compared to 67 % of those from non-white backgrounds. Furthermore, people from high income countries (HICs) reported ABC to have a greater negative impact on their QoL (66 %) compared to those from low-middle income countries (LMICs; 52 %). These disparities may reflect broader socioeconomic and cultural differences, which may shape how QoL is perceived and reported. In many HICs, better access to care and fewer lifestyle challenges may mean cancer can be prioritized in daily life, while in low-resource settings can be often one of many simultaneous challenges. These nuances highlight the need for further research and the development of context-sensitive QoL tools for ABC.

3.3. The impact of ABC is not only felt by patients, but also by their informal caregivers

ABC has a profound impact on the QoL of informal caregivers, which are often the partners or other relatives of the patients. Multiple studies this decade have demonstrated the physical and emotional strain of caring for someone with cancer [20–22]. One 2023 study reported that the psychosocial impact on advanced cancer informal caregivers was similar to the impact on patients themselves [22]. Another, published in 2022, found that caregiver QoL was correlated to patient QoL in breast cancer [23]. Though there is limited literature on caregiver QoL in ABC specifically, there is growing recognition of their needs, marking a substantial advance this decade. International guidelines and advocacy organizations now include dedicated resources for ABC informal caregivers [10,24–26], but caregiver support services are still lacking, and additional efforts are needed by healthcare systems and policymakers to improve this [10].

3.4. Tool limitations and implementation barriers make assessing QoL challenging

QoL assessment tools are integral to understanding how a disease and its treatment impact a person's life. Despite this, only a limited number of QoL tools have been developed this decade, and many of those used in clinical practice lack the specificity required to capture the unique and multifaceted experiences of people with ABC [5,27].

The dynamic nature of QoL in ABC necessitates regular and systematic assessment for effective monitoring. However, data from the ABC Global Alliance 2024 HCP survey (n = 461) highlighted that fewer than half of HCPs (46 %) reported regularly assessing QoL throughout ABC treatment. The same survey found that many HCPs assess QoL and psychosocial needs of their patients through informal discussions (82 %) or observation (57 %) rather than validated tools (11 %). This trend was also seen in a multi-country HCP and patient survey conducted in 2023, which found high rates (93 %) of verbal discussions to assess QoL in ABC [12]. Informal approaches to assessment may result in an incomplete understanding of patient QoL, highlighting the need for better implementation of QoL assessment tools in ABC.

In addition, findings from the ABC Global Alliance 2024 HCP survey highlighted multiple barriers to the comprehensive implementation of patient-reported outcome measures (PROMs) and QoL tools (Fig. 2). Limited uptake of these tools in clinical practice may mean the true impact of ABC on QoL is underestimated.

Across all HCP types, around a third (30 %) reported not having enough training on validated QoL assessment tools, and a quarter (25 %) not having adequate resources to use them (Fig. 2). These findings align with existing literature, with a third (32 %) of HCPs reporting not being familiar with any QoL tools in a 2021 study of QoL in HR-positive ABC patients [28]. In those who were familiar with QoL tools, fewer than one in five (15 %) were familiar with the EORTC QLQ-breast tools (BR-23 and BR-45) and only a third (33 %) recognized FACT-B, despite its wide use in breast cancer [28]. The study also highlighted limited consultation time as a major barrier to utilization of QoL tools, with only 19 % of HCPs reporting there to be enough appointment time dedicated to discussing QoL, leaving minimal opportunity for thorough QoL assessment [28].

Creation of a triage tool, similar to the well-established Distress Thermometer, which efficiently screens for psychological distress, ensuring timely, targeted referrals to psycho-oncology services, could help to address these systemic barriers. This quick QoL assessment could identify when a more comprehensive QoL assessment is warranted, triggering further evaluation by a specialist upon meeting a defined threshold. could help to address these systemic barriers. Such tools offer a straightforward method for identifying when more comprehensive QoL assessment is warranted [29]. When a patient meets a defined threshold, a full evaluation by a specialist (e.g., psycho-oncologist) may be triggered [29]. Implementation of strategies such as this could significantly alleviate resource burden on oncologists and healthcare systems and enable improved QoL assessment in ABC.

3.5. The next generation of QoL tools promise a deeper, holistic understanding of QoL in ABC

The last decade has seen more focused efforts on developing tools to help overcome barriers to assessing QoL in ABC, including the development of the European Organization for Research and Treatment of Cancer (EORTC) QLQ-BR45 tool and the first Core Outcomes Set (COS) for metastatic breast cancer [30,31]. Furthermore, novel approaches utilizing patient-reported outcome measures (PROMs) to monitor treatment side effects have been shown to improve therapy management. One example is the CANKADO PRO React tool, whose efficacy was demonstrated QoL benefits in the PRECYCLE trial [32,33]. This benefit has been further supported by findings from the SYMPHA and PRO-B trials, which highlight the potential of real-time, patient-led symptom

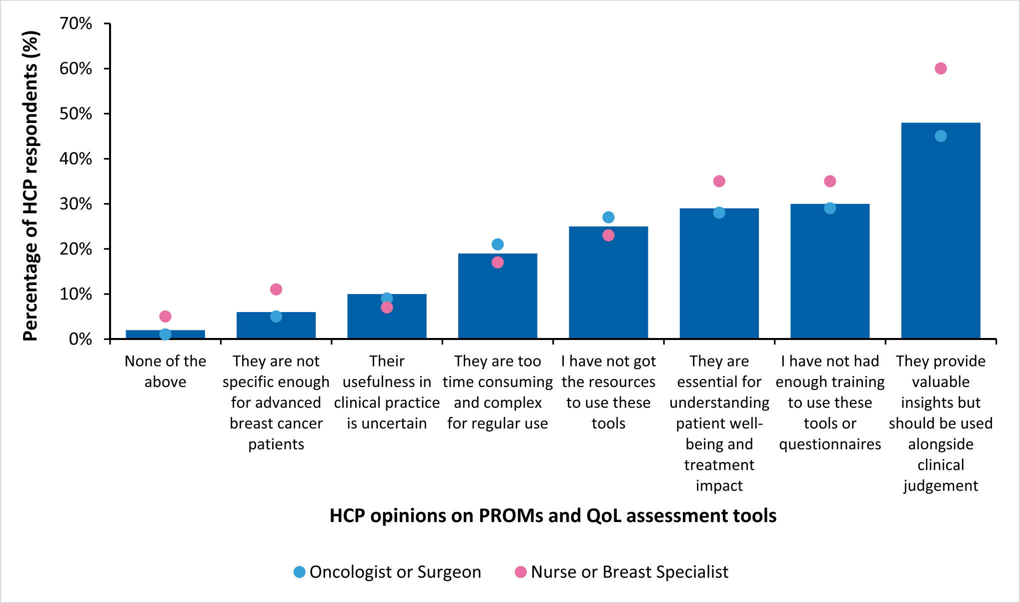

Fig. 2. HCP opinions on the use of PROMs and/or standard QoL assessment tools in clinical practice for people with ABC [5]
Data collected from the ABC Global Alliance 2024 HCP survey (n = 461). Survey question: What is your opinion on using PROMs and/or standardized quality-of-life assessment tools in clinical practice for patients with advanced breast cancer?
HCP = healthcare professional; PROM = patient-reported outcome measure; QoL = quality of life.

tracking to enhance QoL and, potentially, overall survival[34,35].

The EORTC QoL questionnaire for metastatic breast cancer (MBR44), currently in Phase 3 trial development, offers a promising future for assessing QoL specifically in those with ABC [36]. Developed in collaboration with leading breast cancer organizations, it covers a comprehensive range of experiences, from the physical effects of the disease and treatments to the psychosocial issues impacting patients' lives [36]. This tool represents a significant step forward in enhancing the understanding and assessment of QoL in ABC.

4. Conclusion and future directions

Despite widespread recognition of the importance of QoL assessment and PROMs in ABC, their impact and implementation remain inconsistent globally. Critical gaps in addressing the psychosocial and physical needs of individuals with ABC persist, emphasizing the urgent need for enhanced QoL integration across clinical practice.

To truly understand and address the impact of ABC on QoL, the ABC Global Alliance community has agreed upon the goal for 2025–2035: **improve the QoL of people with ABC**. To achieve this, future efforts must focus on several key actions.

- Develop and integrate ABC-specific QoL assessment tools into clinical trials and routine practice to guide decision-making
- Establish a triage tool to overcome systematic barriers to QoL assessment in clinical practice
- Improve how PROMs are systemically collected, analyzed, and reported to allow for meaningful change in clinical practice
- Optimize treatment strategies to improve QoL while maintaining or improving efficacy
- Deliver patient-centered care across the ABC pathway, from diagnosis of metastasis until end of life, to meaningfully improve QoL

These advancements will pave the way for a more patient-centered approach to ABC care, ensuring that QoL is effectively monitored and managed throughout the entire journey.

For further information, please see the Global Decade Report 2.0 [5].

CRediT authorship contribution statement

Karen Gelmon: Writing – review & editing, Validation, Conceptualization. **Cynthia Villarreal-Garza:** Writing – review & editing, Validation, Conceptualization. **Dawn Aubel:** Writing – review & editing, Validation, Conceptualization. **Hope S. Rugo:** Writing – review & editing, Validation, Conceptualization. **Julia Maués:** Writing – review & editing, Validation, Conceptualization. **Luzia Travado:** Writing – review & editing, Validation, Conceptualization. **Matthijs Van Meerveld:** Writing – review & editing, Validation, Conceptualization. **Runcie C.W. Chidebe:** Writing – review & editing, Validation, Conceptualization. **Bianca Patel:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Georgia Attfield:** Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Alexandra Lewis:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Fatima Cardoso:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization.

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Declaration of competing interest

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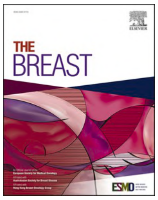

Ensuring access to multidisciplinary care in advanced breast cancer: a global expert review and call-to-action for 2025–2035 (Goal 4)

Shani Paluch-Shimon [a], Laura Biganzoli [b], Julie Torode [c], Ginny Mason [d], Sung-Bae Kim [e], Runcie C.W. Chidebe [f], Merel van Klinken [g], Georgia Attfield [h], Alexandra Lewis [h], Fatima Cardoso [i,*]

[a] *Hadassah University Hospital & Faculty of Medicine, Hebrew University, Jerusalem, Israel*
[b] *Hospital of Prati, Rome, Italy*
[c] *Institute of Cancer Policy, King's College London, London, United Kingdom*
[d] *Inflammatory Breast Cancer Research Foundation, Broadway, VA, United States*
[e] *Asan Medical Centre, University of Ulsan College of Medicine, Seoul, Republic of Korea*
[f] *Project PINK BLUE – Health & Psychological Trust Centre, Abuja, Nigeria*
[g] *European Oncology Nursing Society, Brussels, Belgium*
[h] *VML Health, London, United Kingdom*
[i] *Advanced Breast Cancer (ABC) Global Alliance, Lisbon, Portugal*

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ABSTRACT

Despite remarkable advances in the management of advanced breast cancer (ABC), profound disparities persist in outcomes and access to quality care globally. A multidisciplinary approach, where specialists collaborate on diagnosis, treatment planning, care continuity, and timely referrals, is widely recognized as the gold standard in ABC management and has been shown to lead to more accurate diagnoses, individualized treatment plans, and improved patient outcomes. Depending on the healthcare system, a multidisciplinary team (MDT) may include a medical oncologist, a radiation/clinical oncologist, radiologist, pathologist, surgeon, specialist nurse, allied healthcare professionals, and administrative staff. A multidisciplinary approach to ABC care is recommended by international guidelines and endorsed by leading bodies such as the European Society of Breast Cancer Specialists (EUSOMA).

This manuscript explores the current multidisciplinary care landscape in ABC, highlighting progress made, persistent challenges, and future directions. It summarizes research conducted for the ABC Global Alliance's Global Decade Report 2.0. The main findings are: a) New EUSOMA quality indicators set benchmarks for multidisciplinary ABC care; b) Most national guidelines now recommend multidisciplinary care for ABC; c) Surveys reveal uneven multidisciplinary team access, notably in low-income settings; d) Telemedicine and virtual MDTs expand access to ABC expertise; e) Palliative care remains poorly integrated in many MDTs globally.

The findings from the ABC Global Alliance's Global Decade Report 2.0 have informed the development of a new ABC Global Charter. The ABC Global Charter 2.0 defines ten new achievable and measurable goals for the decade 2025–2035, aiming at improving the lives of people living with ABC worldwide.

1. Introduction

Despite remarkable advances in the management of advanced breast cancer (ABC), profound disparities persist in outcomes and access to quality care globally. A multidisciplinary approach, where specialists collaborate on diagnosis, treatment planning, care continuity, and timely referrals [1,2], is widely recognized as the gold standard in ABC management and has been shown to lead to more accurate diagnoses, individualized treatment plans, and improved patient outcomes [3,4]. Depending on the healthcare system, a multidisciplinary team (MDT) may include a medical oncologist, a radiation/clinical oncologist, radiologist, pathologist, surgeon, specialist nurse, allied healthcare

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* Corresponding author.

E-mail address: fcardoso@abcglobalalliance.org (F. Cardoso).

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professionals, and administrative staff [3]. A multidisciplinary approach to ABC care is recommended by international guidelines, and endorsed by leading bodies such as the European Society of Breast Cancer Specialists (EUSOMA) [3,5,6].

This manuscript explores the current multidisciplinary care landscape in ABC, highlighting progress made, persistent challenges, and future directions. It draws on findings from the ABC Global Alliance's Global Decade Report 2.0, which includes an analysis of multidisciplinary care recommendations in cancer guidelines, policies, and plans from 12 countries and 5 regions, compared to EUSOMA standards. It also includes insights from patient and healthcare professional (HCP) surveys conducted in 2024. Detailed methodology and limitations can be found in the Global Decade Report 2.0 [7], in addition to the first manuscript of this special issue.

2. Status in 2005–2015

In the 2005–2015 decade, increasing emphasis was placed on the importance of MDT care in ABC, including access to palliative care [8]. In 2011, the first edition of the ABC International Consensus Guidelines were the first guidelines to call for multidisciplinary care in ABC [6]. Following this, EUSOMA's 2013 position paper, EUROPA DONNA's 2015 declaration, and the 2016 European Breast Cancer Council manifesto all supported multidisciplinary ABC care [8]. However, the 2005–2015 Global Decade Report revealed significant disparities in MDT implementation, with high-income countries (HICs) and urban areas progressing more than low-to middle-income countries (LMICs) and rural areas [8]. Global access to supportive and palliative care remained limited, especially outside of high-resource settings [8]. In response, the 2015–2025 ABC Global Charter made expanding access to ABC MDTs one of its ten 'Actions For Change' [9].

3. A decade in review (2015–2025)

3.1. Multidisciplinary ABC care is now embedded in major guidelines and accreditation systems

EUSOMA's 2020 position paper outlined core and extended members of the ABC MDT and recommended that specialist breast centers discuss at least 50 % of ABC cases in weekly MDT meetings, with the goal of achieving 100 % case discussion [3]. In 2023, EUSOMA introduced its first set of quality indicators for ABC, establishing a minimum standard that at least 50 % of ABC patients should be discussed at least once in an MDT meeting [5]. As of mid-2024, 44 centers across Europe and China were accredited according to EUSOMA standards [10]. However, accreditation to date has been primarily focused on quality indicators for early breast cancer, and full integration of the new ABC-specific standards into the certification process remains a work in progress [11–14].

Multidisciplinary ABC care is now recommended by national and regional guidelines, with 83 % of countries evaluated in the Global Decade Report 2.0 analysis recommending MDT care approaches. In addition, the analysis showed that all major international oncology guidelines (ABC Global Alliance [15], National Comprehensive Cancer Network (NCCN) [16], European Society for Medical Oncology (ESMO) [17], American Society of Clinical Oncology (ASCO) [18], and Pan-Asian adapted ESMO guidelines [19]) include MDT care, highlighting global prioritization and marking significant improvement since the last decade, where almost no ABC guidelines recommended multidisciplinary care [8].

3.2. Despite advances in recommendations, real-world access to an MDT remains uneven globally

The ABC Global Alliance 2024 HCP survey (n = 461) revealed that just over half of HCPs globally report taking part in weekly MDT meetings, dropping to 37 % in Asia and lower still in many LMICs. Specialist breast units demonstrate higher adherence to EUSOMA standards, with 58 % of HCPs reporting partaking in MDT meetings at least weekly, compared with only a third of HCPs in general hospitals without oncology departments ($p < 0.05$).

Crucially, according to HCPs in the survey, many MDTs include only a selection of core members (oncologists, surgeons, pathologists, nurses, palliative care specialists, and data management personnel), with limited participation from extended team members such as nutritionists, physiotherapists, and psycho-oncologists (Fig. 1).

3.3. Telemedicine and virtual MDT meetings are emerging as effective solutions to bridge gaps in specialist access

In many LMICs, access to high-quality multidisciplinary care for ABC is limited by a shortage of specialists, resource constraints, and fragmented health systems [20], with challenges intensified by late-stage diagnoses due to inadequate screening [21]. Global system-level innovations are advancing multidisciplinary care, including telemedicine and virtual MDT meetings, which offer scalable solutions to workforce shortages and geographic barriers. One example of this is in Mongolia, where a virtual tumor board connected local providers with international experts, enhancing decision-making for complex ABC cases [22]. This virtual MDT made recommendations across systemic therapy (40 %), surgical management (33 %), pathology re-evaluation (13 %), and the need for additional imaging (13 %) [22], highlighting key areas of ABC management where specialist expertise is most valued. In Ghana, the success of virtual MDT meetings, piloted during the COVID-19 pandemic, further emphasized the importance of digital tools in expanding access to specialist input [23].

Global initiatives are increasingly demonstrating the value of multidisciplinary approaches to improving ABC care in LMICs. For example, the City Cancer Challenge in collaboration with ASCO has piloted multidisciplinary care models in cities across Colombia, Paraguay, Myanmar, and Ghana, fostering city-wide, consensus-based treatment guidelines, and offering institutional support to embed MDT meetings into routine care [23]. Complementing these efforts, the Breast Health Global Initiative calls for a phased multidisciplinary service implementation model tailored to resource-limited settings. This strategy balances the centralization of complex services like palliative care with decentralized delivery to enhance access [20]. As many LMICs strive to scale up cancer services without a proportional increase in specialist capacity, structured MDT referral pathways offer a critical mechanism for ensuring coordinated, high-quality ABC care.

3.4. Palliative care is an integral part of ABC management, yet its integration into clinical practice is limited

EUSOMA's Requirements of a Specialist Breast Centre emphasize the necessity of early and continuous palliative care for people with ABC [3]. Over the past decade, palliative care has become more commonly included in clinical guidelines, with 58 % of sources included in the ABC Global Alliance's 2024 analysis now incorporating it.

Despite these advances, global implementation remains inconsistent, with less than half (45 %) of HCPs who responded to the ABC Global Alliance 2024 HCP survey reporting routine integration of palliative care into MDTs, a figure that is even lower in non-specialist settings. In many LMICs, limited workforce capacity means palliative care is often provided through referrals rather than direct MDT participation. This approach may limit access for certain populations, such as those in rural areas, and highlights the need for scalable strategies to enhance accessibility [20]. These gaps in implementation risk undermining the holistic intent of MDT care and may negatively impact patients' quality of life and outcomes [24].

Fig. 1. HCP-reported inclusion of different specialties in ABC MDT meetings [7]
Data collected from the ABC Global Alliance 2024 HCP survey (n = 461). Survey question: Are the following healthcare professionals part of your MDT meeting? [Please select the most appropriate option for each row.]. ABC = advanced breast cancer; HCP = healthcare professional; MDT = multidisciplinary team.

3.5. In clinical practice, HCPs report multidisciplinary ABC care more frequently than patients

The ABC Global Alliance 2024 patient (n = 1254) and HCP surveys highlight a notable discrepancy: while 87 % of HCPs report working within an MDT, only 67 % of people with ABC believe their case has been discussed by one. This gap likely reflects a combination of patient misunderstanding, limited communication, and systemic barriers. The divide is even more pronounced in certain regions, with patients in HICs 30 % more likely to report that their case was discussed by an MDT than those in LMICs (73 % vs. 43 % respectively). Increasing awareness of multidisciplinary care among people with ABC, including the understanding that their cases are reviewed by an expert MDT, may support patients to feel reassured and improve their care experience.

3.6. Barriers to effective implementation of multidisciplinary care persist globally

Despite growing recognition of the importance of multidisciplinary care, persistent challenges continue to hinder its effective implementation (Table 1), with these barriers being particularly pronounced in LMICs.

These issues are further illustrated by findings from the ABC Global Alliance 2024 HCP survey, where respondents highlighted significant gaps in the integration of non-physician roles within MDTs (Fig. 2). Nutritionist input was the most poorly integrated aspect of MDT care, followed by physiotherapy, and psychological input. Regional variation was demonstrated, with HCPs in Oceania most frequently citing inadequate nutritional input, while those in North America reported poor audit and analysis processes. In addition, less than half of HCPs surveyed rated nursing integration as '*good*' or '*very good*,' emphasizing the need for a cultural shift toward truly multidisciplinary, patient-centered care in ABC.

Table 1
Key barriers to effective ABC multidisciplinary care.

Barrier	Description
Resource limitations	Staff shortages, inadequate infrastructure, and underfunding are common, especially in LMICs [25–27]
Time and workload pressures	Increasing case volume puts strain on MDT capacity, risking superficial discussions [25,28]
Incomplete team composition	Non-physician professionals (nurses, psychologists, physiotherapists) remain underrepresented and undervalued in many MDTs [28]
Socioeconomic and regional disparities	Compared to HICs, fewer patients in LMICs report that their case has been discussed by an MDT [25]
Lack of standardized protocols and referral pathways	Non-specialist or rural hospitals lack ABC care pathways, leading to fragmented care [25]

ABC = advanced breast cancer; HIC = high-income country; LMIC = low-middle income country; MDT = multidisciplinary team.

Although many aspects of MDT care are still considered inadequate by HCPs (Fig. 2), there are some signs of progress. More than half (57 %) of HCP survey respondents rated overall multidisciplinary care in their network as '*good*' or '*very good*,' and fewer than 10 % described it as '*poor*' or '*very poor*.' Qualitative studies have shown successful enablers of multidisciplinary care to include strong organizational support, investment in technology (e.g., videoconferencing), clear guidelines, and a culture of collegiality and mutual respect [25].

3.7. Measuring the impact of multidisciplinary care is challenging, and routine evaluation remains limited

Implementation of multidisciplinary approaches alone does not guarantee effectiveness. Few systems routinely audit MDT decision quality, adherence to plans, or patient outcomes [29]. A prospective study from an Australian Metropolitan Breast Cancer Centre showed that almost a third (28 %) of ABC cases are impacted by MDT recommendations [29]. However, the quality of decisions in studies like these are often not evaluated. Broader adoption of structured quality indicators and regular audits are still needed to ensure MDTs deliver meaningful improvements in care and patient experience [30].

A layered system for evaluating and auditing MDT input in ABC provides a practical way to strengthen cancer care in LMICs, accounting for resource constraints and varying health systems. It starts simply by supporting the integration of MDTs with universal quality measures such as the frequency of tumor board discussions and adherence to clinical guidelines [31]. While this example is applicable to LMICs, embedding such quality reviews, could support continual improvement of multidisciplinary processes and optimize patient outcomes more broadly across countries.

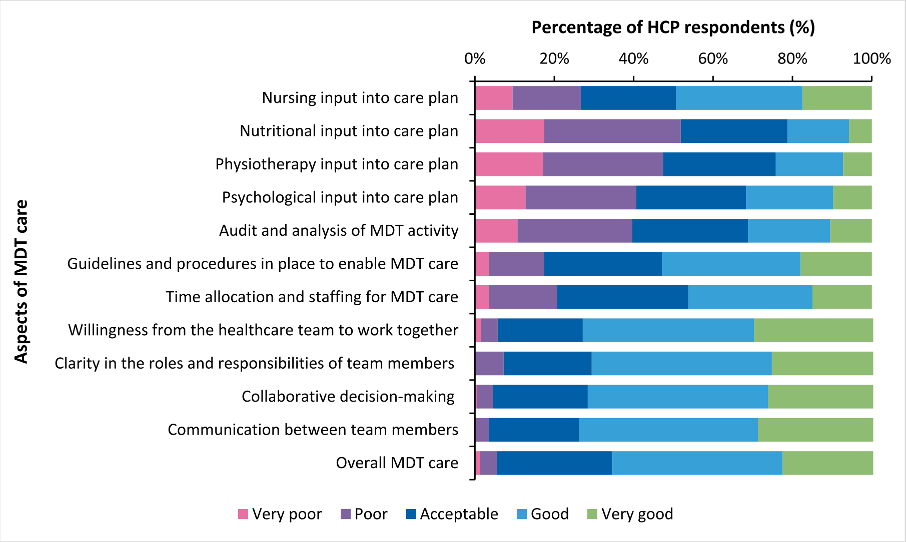

Fig. 2. HCP-reported rating of key aspects of multidisciplinary ABC care [7]
Data collected from the ABC Global Alliance 2024 HCP survey (n = 461). Survey question: Please rate the quality of the following aspects of multidisciplinary team care for patients with advanced breast cancer at your center [Very poor; Poor; Acceptable; Good; Very good].

4. Conclusions and future directions

The last decade has seen important strides in embedding multidisciplinary care within ABC management. Yet, progress is uneven and fragile, threatened by persistent resource, structural, and cultural barriers.

As we enter a new decade, the imperative is clear: Every person with ABC deserves access to high-quality, guideline-driven care delivered by a fully integrated and specialized MDT, with all key decisions made through collaborative MDT discussion. Achieving this will require policy commitment, innovative delivery models, holistic MDT composition that includes palliative and psychological care, and continuous measurement and accountability. By prioritizing access to multidisciplinary care as a global standard, we can narrow disparities, elevate quality, and transform the care experience for people with ABC.

For these reasons, the ABC community decided to keep this goal in the ABC Global Charter for 2025–2035, with the following wording: **Ensure that every person with ABC is treated and cared for by a specialized multidisciplinary team according to high-quality guidelines**.

To deliver against this goal, key actions need to be considered:

- Advocate for all people with ABC to be managed by a specialized breast cancer team, in line with international standards like EUSOMA
- Ensure ABC multidisciplinary teams have the necessary resources and support to function effectively
- Promote adoption of evidence-based, resource-stratified guidelines tailored to local resources and healthcare needs
- Ensure continuity and evolution of multidisciplinary care across the ABC care pathway, including early integrated palliative care
- Develop quality assurance measures that audit and measure utilization and application of MDT specifically for patients with ABC

For further details please see the Global Decade Report 2.0 [7].

CRediT authorship contribution statement

Shani Paluch-Shimon: Writing – review & editing, Validation, Conceptualization. **Laura Biganzoli:** Writing – review & editing, Validation, Conceptualization. **Julie Torode:** Writing – review & editing, Validation, Conceptualization. **Ginny Mason:** Writing – review & editing, Validation, Conceptualization. **Sung-Bae Kim:** Writing – review & editing, Validation, Conceptualization. **Runcie C.W. Chidebe:** Writing – review & editing, Validation, Conceptualization. **Merel van Klinken:** Writing – review & editing, Validation, Conceptualization. **Georgia Attfield:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Alexandra Lewis:** Writing – review & editing, Writing – original draft, Validation, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Fatima Cardoso:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization.

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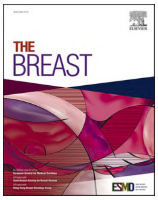

Improving communication between healthcare professionals and patients living with advanced breast cancer: a global expert review and call-to-action for 2025–2035 (Goal 5)

Lesley Fallowfield [a], Fran Boyle [b,c], Renate Haidinger [d], Kara Magsanoc-Alikpala [e,f,g], Luzia Travado [h], Matti Aapro [i], Zsofia Wolkensdorfer [j], Alexandra Lewis [k], Georgia Attfield [k], Fatima Cardoso [l,*]

[a] *Sussex Health Outcomes Research and Education in Cancer (SHORE-C), Brighton and Sussex Medical School, University of Sussex, Brighton, United Kingdom*
[b] *Mater Hospital, Sydney, Australia*
[c] *University of Sydney, Sydney, Australia*
[d] *German Breast Cancer Association, Munich, Germany*
[e] *ICanServe Foundation, Manila, Philippines*
[f] *Informal Technical Working Group of the World Health Organization's Global Breast Cancer Initiative, Manila, Philippines*
[g] *Lancet Commission on Women and Cancer Patient Advocacy Committee, Manila, Philippines*
[h] *Champalimaud Clinical & Research Centre, Champalimaud Foundation, Lisbon, Portugal*
[i] *Breast Center, Genolier Cancer Center, Genolier, Switzerland*
[j] *VML Health, Manchester, United Kingdom*
[k] *VML Health, London, United Kingdom*
[l] *Advanced Breast Cancer (ABC) Global Alliance, Lisbon, Portugal*

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ABSTRACT

The complexity of advanced breast cancer (ABC) and its treatment landscape makes communication between healthcare professionals (HCPs) and patients particularly challenging. It is essential that all HCPs receive comprehensive communication skills training starting at medical or nursing school and continuing throughout their careers. Effective communication can improve trust, treatment adherence, and ultimately, outcomes; it also facilitates shared and educated decision-making, all of which is crucial to ensure patients receive the most appropriate treatment and care.

This manuscript explores the global landscape of communication skills training, highlights remaining communication gaps, and assesses the preference for, and implementation of, shared decision-making in clinical practice. It draws on research conducted for the ABC Global Alliance's Global Decade Report 2.0. The main findings are: a) Communication skills trainings now cover a broader range of topics; b) People with ABC report their broader communication needs are often not met; c) Doctors and patients differ in their preferences for shared decision-making in ABC; d) Improving ABC care requires patients to feel supported in expressing their needs.

The findings from the ABC Global Alliance's Global Decade Report 2.0 have informed the development of a new ABC Global Charter. The ABC Global Charter 2.0 defines ten new achievable and measurable goals for the decade 2025–2035, aiming at improving the lives of people living with ABC worldwide.

1. Introduction

The complexity of advanced breast cancer (ABC) and its treatment landscape makes communication between healthcare professionals (HCPs) and patients particularly challenging [1]. It is essential that all HCPs receive comprehensive communication skills training (CST) starting at medical or nursing school and continuing throughout their careers [2–4]. The American Society of Clinical Oncology (ASCO) and

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[*] Corresponding author.

E-mail address: fcardoso@abcglobalalliance.org (F. Cardoso).

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the European Society for Medical Oncology (ESMO) recommend that HCPs provide detailed explanations about prognosis and treatment options that are tailored to the needs and preferences of patients [5,6].

Effective communication can improve trust, treatment adherence, and ultimately, outcomes [7–10]; it also facilitates shared and educated decision-making, all of which is crucial to ensure patients receive the most appropriate treatment and care [5,6]. However, despite recognition of its importance, significant gaps remain. Patients with ABC frequently report feeling unheard or inadequately informed about prognosis, treatment options, and available support services [1,11]. Research also shows that empathic communication by HCPs improves patient satisfaction [7,8], yet there is limited evidence on how best to implement and sustain these skills in busy clinical settings.

This manuscript explores progress that has been made in CST and shared decision-making for ABC in the past decade, and highlights challenges that remain. It draws on research conducted for the ABC Global Alliance's Global Decade Report 2.0, primarily, global HCP and patient surveys, and an analysis of CST courses from 48 top-ranking global academic institutions and 35 professional organizations conducted in 2024. Further details on methodologies and limitations can be found in the Global Decade Report 2.0 [11], in addition to the first manuscript of this special issue.

2. Status in 2005–2015

The 2005–2015 Global Decade Report highlighted various limitations in HCP communication expressed by people with ABC, including a desire for enhanced empathy and improved listening skills [12]. As a result of poor communication with HCPs, many patients felt that they lacked an adequate understanding of ABC, their treatment options, and potential prognostic outcomes [12]. While most HCPs (83 %) identified training on communicating 'bad news' as a key need, less than half (43 %) reported having received training on this, highlighting a need for better HCP education [12].

Based on the findings from the 2005–2015 Global Decade Report, the goal to 'improve communication between HCPs and people with ABC through the provision of communication skills training for HCPs' was added to the 2015–2025 ABC Global Charter as one of its ten 'Actions for Change' [13].

3. A decade in review (2015–2025)

3.1. ABC communication skills training has expanded, but quality and uptake vary

An analysis conducted by the ABC Global Alliance in 2024 showed that CST is now well-integrated into many nursing school curricula, but less commonly features in medical school curricula. The analysis identified large geographical disparities, with medical schools in North America and Europe (France, Poland, Spain, the United Kingdom) offering CST more frequently than other regions.

CST remains an important part of education as HCPs progress through training, and the 2023 update to the ESMO/ASCO Recommendations for a Global Curriculum in Medical Oncology features an enhanced focus on CST compared with previous years, indicating progress in this area [14]. Professional organizations play a vital role in continuing medical education for oncology-focused HCPs. However, only 40 % of the 35 professional organizations across 6 continents assessed by the ABC Global Alliance in 2024 offered CST, and those that did were predominantly located in Europe, North America, and Oceania. Of these, five (36 %) were on general oncology, six (43 %) were breast cancer-specific, and only three (21 %) were ABC-specific. These findings demonstrate that CST focused on the specific communication challenges between HCPs and people with ABC is often limited. Efforts to respond to this in the past decade include The European Oncology Society (EONS) 2020 ABC4Nurses Project, a bespoke online ABC curriculum for nurses, and a series of e-learning modules developed by the McGrath Foundation in Australia, launched in 2019 [15,16]. It should be noted that many CST courses are funded through charitable grants or industry support [17,18] and were therefore not captured by the ABC Global Alliance, indicating potentially better progress in this area than the analysis suggests.

Despite efforts to increase the number of courses available, the quality of CST varies with many programs lacking sound methodology, evidence-based content, and robust evaluation approaches [19]. Moreover, CST has historically not been a mandatory part of continuous medical education, limiting uptake among HCPs [20]. In Europe, in an effort to overcome this, both the European Commission Initiative on Breast Cancer's Quality Assurance Scheme for Breast Cancer Services and the European Society of Breast Cancer Specialists (EUSOMA) now require evidence of continuous HCP CST for accreditation [21,22].

3.2. Communication skills training now covers a broader range of topics, but is not perceived as useful by all

The ABC Global Alliance 2024 HCP survey ($n = 461$) showed that CST has expanded in the last decade to cover a wider range of communication topics beyond 'breaking bad news'. Around half (47 %) of those trained on 'breaking bad news' also attended courses on other important and relevant areas of communication (Fig. 1). While this demonstrates progress since 2015, it is important to note that 37 % of survey respondents reported to have no access to ABC-specific CST, further highlighting the persistent lack of tailored training available.

Overall, the HCP survey revealed that oncology CST is regarded as useful, with the topic 'breaking bad news' ranking highest in perceived usefulness. Compared with doctors, nurses consistently rated communication training to be more useful across all topics, particularly on issues related to psychosocial support and patient-centered care. This aligns with the differences in the roles between nurses and doctors, with the former often spending more time with patients and providing more emotional and psychosocial support.

3.3. People with ABC continue to express the need for better HCP communication

Despite improvements in CST, the ABC Global Alliance 2024 patient survey ($n = 1254$) found that many people with ABC continue to experience gaps in communication with their healthcare team. The lowest-rated communication area among doctors was 'addressing emotional and psychosocial needs', with less than half (46 %) of patients reporting that their doctor 'always' addresses this. This was followed by 'discussing all treatment options' (56 %) and 'understanding patient goals, values, and preferences for decision-making' (59 %). Respondents to the patient survey generally rated communication with nurses higher than with doctors, including in aspects such as addressing emotional and psychosocial concerns and trustworthiness. Doctors, on the other hand, excelled in discussing treatment options, reflecting their differing roles in ABC care. Interestingly, patient education level did not impact communication experiences, indicating the need to consider a range of patient characteristics when tailoring communication strategies.

Communication gaps may arise from a lack of information sharing between members of multidisciplinary healthcare teams or limited HCP understanding of their colleagues' roles in sharing information with patients. These can lead to HCPs not disclosing specific pieces of information, as they believe another team member has already shared them with the patient [23]. Meanwhile, patients may ask questions to various members of their healthcare team, or repeat the same questions to different HCPs, highlighting the importance of all team members being well-informed and confident in answering patient concerns [19,23,24].

In recent years, the introduction of telemedicine has changed some aspects of HCP−patient communication. While telemedicine provides an opportunity for HCPs to reach more patients regardless of geography,

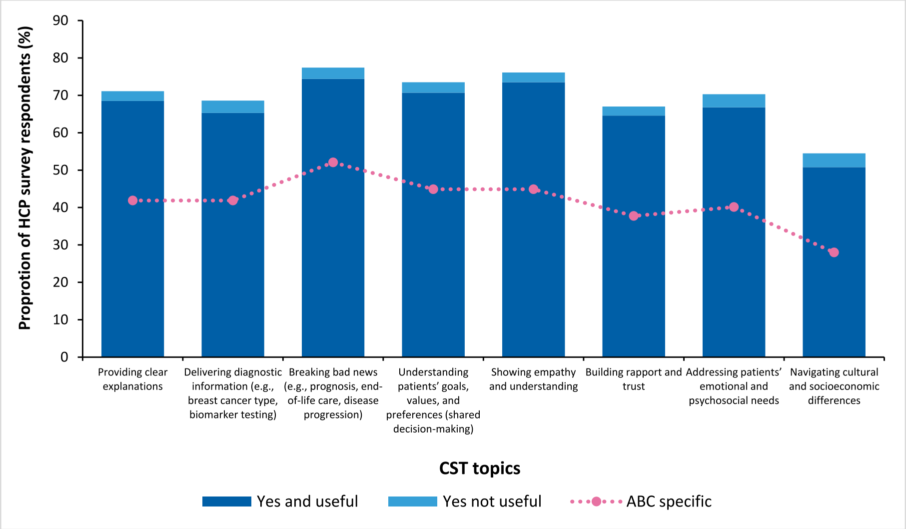

Fig. 1. CST topics received by HCPs treating people with ABC [11]. Data collected in the ABC Global Alliance 2024 HCP survey (n = 461). Survey question: 'Have you ever received any of the following communication skills training related to general cancer? If so, how useful was it?'; 'Have you received any of the following communication skills training specific to patients with advanced breast cancer?'. ABC = advanced breast cancer; CST = communication skills training; HCP = healthcare professional.

and can increase the convenience and efficiency of HCP–patient interactions, many patients prefer to receive bad news in person [25]. Despite this, a global survey by the Young Survival Coalition's (YSC) Project 528 found that almost half (44 %) of young women with ABC reported that their breast cancer diagnosis was first communicated to them over the telephone [26]. These findings highlight the need to evaluate the suitability of telemedicine in different scenarios, even when accounting for its associated benefits.

3.4. Patient treatment preferences are unique and impacted by a variety of factors

The ABC Global Alliance 2024 HCP and patient surveys found interesting differences in drivers of treatment decision-making. While both HCPs and people with ABC considered treatment efficacy and quality of life to be of higher importance than other aspects of treatment, HCPs prioritized quality of life and people with ABC showed a slight preference for efficacy. These somewhat surprising findings might be driven by the survey methodology, which required respondents to rank treatment aspects and did not offer the option to rank two or more as

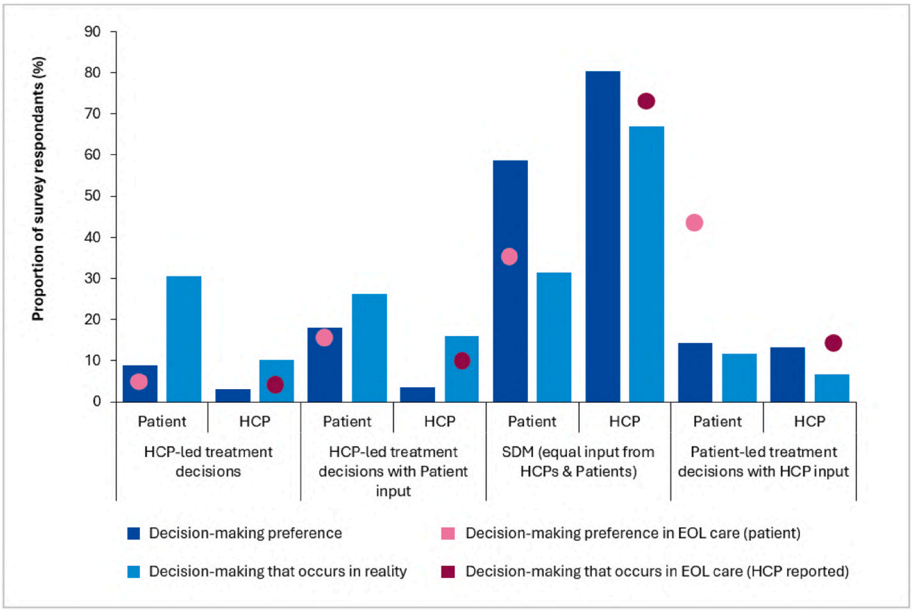

Fig. 2. Patient and HCP preference for treatment and EoL decision-making vs reality [11]. Data collected in the ABC Global Alliance 2024 patient survey (n = 1254 for treatment-decisions, n = 1058 for EOL care*) and the ABC Global Alliance 2024 HCP survey (n = 461). **Patients answering 'Prefer not to say/This does not apply to me' were excluded from the EOL analysis. Patient survey question: 'How would you prefer decisions about your advanced breast cancer treatment to be made?' and 'In reality, how are decisions about your advanced breast cancer treatment made?'; HCP survey question 'How would you prefer treatment decisions to be made for patients with advanced breast cancer?' and 'In reality, how are treatment decisions for patients with advanced breast cancer actually made?'. EoL = end of life; HCP = healthcare professional.

equally important. It should also be noted that these findings do not account for the potential influence of line of therapy, prognosis, and other confounding factors. They also contradict literature on the topic, much of which suggests that HCPs consider efficacy to be the most important aspect of treatment and that patients prioritize quality of life [27,28]. Regardless, differences between HCP and patient perspectives demonstrate the complexity of treatment decision-making in ABC, and may lead to misaligned treatment goals and potential dissatisfaction with care. These results emphasize the importance of shared decision-making in ABC treatment decisions.

3.5. Despite HCP and patient preference for shared decision-making, implementation remains limited

The ABC Global Alliance 2024 HCP and patient surveys found that many people with ABC (59 %) and an even higher proportion of HCPs (80 %) prefer shared decision-making, whereby both parties equally contribute to treatment decisions (Fig. 2). However, the findings revealed a difference between preference and clinical practice, where shared decision-making is less commonly implemented in favor of HCP-led decision-making. The surveys also highlight a stark contrast between HCP and patient perceived use of shared decision-making in clinical practice, with 67 % of HCPs reporting that shared decision-making occurs during consultations compared with only 31 % of people with ABC (Fig. 2). This demonstrates a disconnect between patient experience and HCP perception, highlighting the need for enhanced HCP−patient communication in ABC. While empathic and clear HCP communication has been shown to improve shared decision-making [29], barriers to its implementation into clinical practice include ineffective HCP−patient communication, lack of trust, and short consultation times [29,30].

Patient preference for shared decision-making also varied by region, with 75 % of respondents from North America preferring shared decision-making compared with only 36 % in Eastern Europe. Differences were also observed between people with college-level education and those with lower education levels, with 63 % and 48 % preferring shared decision-making, respectively. While in many instances higher education level is associated with better health literacy and improved participation in shared decision-making, this is not always the case and HCPs should not make assumptions about the preferences of patients based on their educational background [31].

Interestingly, while 59 % of patients preferred shared decision-making for treatment decisions, only 35 % felt the same way about end-of-life care. Despite this, 72 % of HCPs reported that shared decision-making is used for end-of-life care decisions during consultations (Fig. 2). At end-of-life, 43 % of patients reported a preference for patient-led decisions with HCP input, however, only 14 % of HCPs reported that this occurs. These findings highlight the critical importance of open conversations between HCPs and patients with ABC, to ensure awareness of available end-of-life options and alignment of care with values and expectations.

Family also plays a role in treatment decisions for people with ABC [32], and more than half (61 %) of respondents to the patient survey reported wanting family input into decisions about their care. However, the role of family in ABC decision-making is complex, and 37 % reported wanting to make all decisions without family input, while 1 % wanted their families make decisions on their behalf. It is important to note that family involvement in care decisions is influenced by cultural, social, and healthcare system factors [32], and HCP CST must be tailored to local contexts to ensure the best outcomes.

4. Conclusions and future directions

The last decade has seen enhanced recognition of the importance of HCP communication and shared decision-making in ABC, demonstrated by the expansion of CST in some medical and nursing school curricula and continuing medical education. However, people with ABC continue to express unmet communication needs, and implementation of shared decision-making remains limited, despite a long-standing consensus that all cancer care should be patient-centered.

As we look to the next decade, it is essential that communication remains a key focus for advancing ABC care. For 2025–2035, the goal is clear: **Improve communication between HCPs and people with ABC and their caregivers**.

To achieve this, future efforts must aim to.

- Integrate continuous, accredited, evidence-based communication skills training specific to advanced cancers into oncology curricula
- Embed the ABC patient voice into communication skills training materials to ensure it aligns with their unique needs
- Increase HCP use of shared decision-making resources across the ABC treatment pathway, including early and ongoing end-of-life discussions, to ensure alignment to patient preferences
- Support people with ABC and informal caregivers in expression of their goals, fears, and preferences

For further information, please see the Global Decade Report 2.0 [11].

CRediT authorship contribution statement

Lesley Fallowfield: Writing – review & editing, Validation, Conceptualization. **Fran Boyle:** Writing – review & editing, Writing – original draft, Validation, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Renate Haidinger:** Writing – review & editing, Validation, Conceptualization. **Kara Magsanoc-Alikpala:** Writing – review & editing, Validation, Conceptualization. **Luzia Travado:** Writing – review & editing, Validation, Conceptualization. **Matti Aapro:** Writing – review & editing, Validation, Conceptualization. **Zsofia Wolkensdorfer:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Alexandra Lewis:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Georgia Attfield:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Fatima Cardoso:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Resources, Methodology, Funding acquisition, Formal analysis, Conceptualization.

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Meeting the informational needs of people with advanced breast cancer: a global expert review and call-to-action for 2025–2035 (Goal 6)

Anna Cabanes [a], Jenny Gilchrist [b], Marzia Zambon [c], Maya Gilbert [d], Alexandra Lewis [d], Georgia Attfield [d], Fatima Cardoso [e,*]

[a] *ATOM Coalition, Union for International Cancer Control, Washington, DC, United States*
[b] *Macquarie University Hospital, Sydney, Australia*
[c] *Europa Donna – The European Breast Cancer Coalition, Milan, Italy*
[d] *VML Health, London, United Kingdom*
[e] *Advanced Breast Cancer (ABC) Global Alliance, Lisbon, Portugal*

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ABSTRACT

For people living with advanced breast cancer (ABC), the complexities of making treatment decisions, adhering to medication regimens, and balancing the social and personal aspects of the disease can be overwhelming. People with ABC need comprehensive information and resources to understand their disease, prognosis, and treatment options. However, this information is often difficult to access, interpret or navigate, leaving many feeling confused, frustrated and helpless.

This manuscript evaluates the global ABC information landscape and its evolution since 2015, it analyzes the ongoing challenges faced by people with ABC, and outlines recommendations for the ABC community over the next decade. It summarizes research conducted for the ABC Global Alliance's Global Decade Report 2.0. The main findings are: a) The availability of ABC information has increased, but topics remain limited; b) ABC information from healthcare professionals is often limited to clinical topics; c) Patient advocacy groups are now crucial, trusted sources of ABC information; d) Online ABC information presents both opportunities and challenges; e) Global disparities in access to some topics of ABC information persist.

The findings from the ABC Global Alliance's Global Decade Report 2.0 have informed the development of a new ABC Global Charter. The ABC Global Charter 2.0 defines ten new achievable and measurable goals for the decade 2025–2035, aiming at improving the lives of people living with ABC worldwide.

1. Introduction

For people living with advanced breast cancer (ABC), the complexities of making treatment decisions, adhering to medication regimens, and balancing the social and personal aspects of the disease can be overwhelming [1]. People with ABC need comprehensive information and resources to understand their disease, prognosis, and treatment options [2,3]. However, this information is often difficult to access, interpret or navigate, leaving many feeling confused, frustrated, and helpless [4].

This manuscript evaluates the global ABC information landscape and its evolution since 2015, it analyzes the ongoing challenges faced by people with ABC, and outlines recommendations for the ABC community over the next decade. The information presented draws upon research conducted for the ABC Global Alliance's Global Decade Report 2.0, primarily a global audit of 54 ABC resources submitted by ABC Global Alliance partner organizations, and insights from the ABC Global Alliance patient and healthcare professional (HCP) surveys conducted in 2024. Detailed methodology with limitations can be found in the Global Decade Report 2.0 [5], in addition to the first manuscript of this special issue.

2. Status in 2005–2015

The 2005–2015 Global Decade Report showed ABC-specific information and resources to be limited in scope, leaving the needs of people

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* Corresponding author.

E-mail address: fcardoso@abcglobalalliance.org (F. Cardoso).

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with ABC and their caregivers largely unmet [6]. For example, 78 % of people with ABC surveyed in 2015 had never been provided with clinical trial information by their HCP, resulting in inadequate knowledge and understanding of trials and subsequent low enrollment [6].

In 2015, the ABC Global Alliance outlined 'improved availability of and access to information for people with ABC' as one of its ten 'Actions For Change' for 2015–2025 [7].

3. A decade in review (2015–2025)

3.1. The availability of ABC information has increased dramatically, but topics remain limited

The availability of ABC information has improved in the past decade, with an increasing number of resources developed since 2015. While this reflects a positive shift in focus towards meeting the informational needs of people with ABC, there is an imbalance in the topics addressed. For example, the ABC Global Alliance resource audit (n = 54) found that 81 % of patient resources related to symptoms, treatments or side effects, compared with only 9 % that addressed the employment rights of people with ABC (Fig. 1). The ABC Global Alliance 2024 patient survey (n = 1254) further reiterated this, with almost all (93 %) respondents receiving information about treatments and potential side effects. However, less than half received information on crucial topics such as social support (48 %), financial assistance (44 %), and employment rights (47 %). These unmet informational needs can have profound consequences, impacting financial stability, quality of life, and even overall survival [8–11].

Concerningly, information on ABC clinical trials remains inaccessible to many patients, with only half (52 %) of survey respondents reporting receiving this information. Low clinical trial enrollment can limit the applicability of results and potentially impact trial outcomes [12]. It is vital that people with ABC receive information on this topic to enable them to make informed decisions on clinical trial participation [12–14].

3.2. HCPs are the primary source of information for people with ABC, yet their focus remains narrow

Despite the ABC Global Alliance 2024 patient survey identifying HCPs as the primary, trusted source of information for people with ABC (providing essential guidance on diagnosis, treatment options, and disease progression), a disconnect exists between HCP perception and patient experience (Fig. 2). While 90 % of HCPs surveyed in the ABC Global Alliance 2024 HCP survey (n = 461) reported providing information to patients across all topics, only 41 % of patients indicated receiving this information from their doctor or nurse. Unsurprisingly, results from the patient survey indicated that HCPs prioritized information covering clinical topics such as treatment and side effects (77 %) and diagnostic information (72 %), but many people with ABC reported wanting to learn more about non-clinical topics – such as practical guidance on navigating the non-clinical aspects of living with ABC, managing finances, accessing support services, and coping with the emotional toll of the disease. Unfortunately, these topics were only addressed by 18–43 % of HCPs. While HCPs should not be expected to provide such information and support directly to people with ABC, they should be suitably equipped and informed to guide people with ABC to relevant organizations or local resources.

3.3. Patient advocacy groups (PAGs) have emerged as a crucial source of information for people with ABC

As HCPs cannot, nor should they be expected to, fulfil *all* the informational needs of people with ABC, PAGs play a crucial role in filling information gaps, and are increasingly recognized as a valuable and trusted source of support and information. For example, of respondents to the ABC Global Alliance 2024 patient survey who were informed about financial rights, over a third (36 %) received this information from

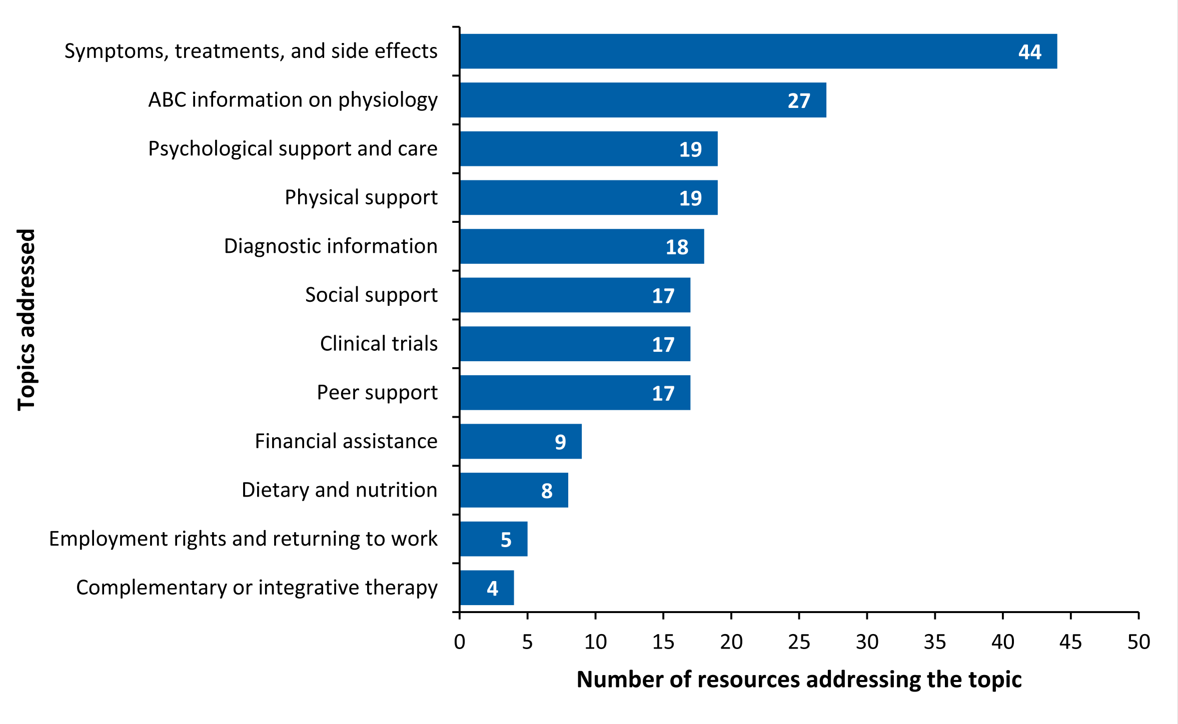

Fig. 1. Topics addressed in member-submitted ABC resources released from 2015–2025* [5]. Data collected from the ABC Global Alliance audit of 57 ABC resources submitted by ABC partner organizations. *Each resource was reviewed, and the topic(s) addressed tabulated. Some resources addressed more than one topic and have been counted accordingly. ABC = advanced breast cancer.

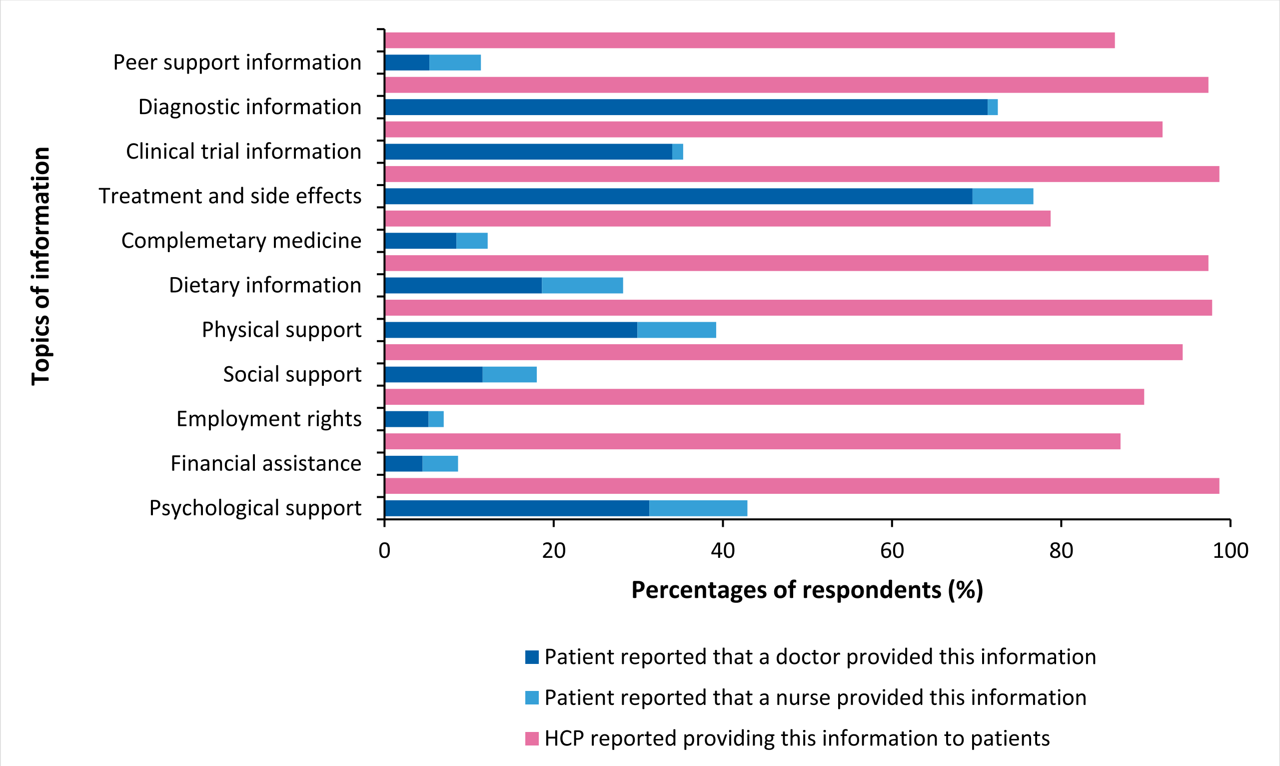

Fig. 2. Comparison of HCP- and patient-perceived provision of ABC information [5]. Data collected from the ABC Global Alliance 2024 patient (n = 1254) and HCP (n = 461) surveys. Survey question for HCPs: How often do you provide the following types of information to patients with advanced breast cancer? [Never; Rarely; Sometimes; Often; Always]. Survey question for people with ABC: What information have you received about advanced breast cancer and where did you get it from? [I have not had this information; My doctor; My nurse; The internet (e.g., Google); Patient or cancer organization; Another person diagnosed with breast cancer; Another source]. *Definitions for topics of information within the survey include: Psychological support & care information (e.g., psycho-oncology, counseling); Financial assistance information; Information on employment rights and returning to work; Social support information (e.g., transport, home care); Physical support (e.g., rehabilitation, lymphedema care); Dietary or nutritional information; Complementary or integrative therapy information (e.g., herbal medicine); Treatment and side effect information; Clinical trial information; Diagnostic information (e.g., breast cancer type, biomarkers); Peer support information (e.g., advocacy groups or organizations). HCP = healthcare professional.

patient or cancer organizations. A 2021 United Kingdom survey by MetUpUK found that around two-thirds of people with ABC reported moderate to high levels of trust in information disseminated by individuals and patient groups [15]. This represents a shift in mindset towards PAGs from 2015 when only 13 % of people with ABC regarded PAGs as a useful information source [16].

3.4. The ABC information landscape has evolved with the rise of digital resources

The majority (95 %) of people with ABC now rely mainly on digital sources of information, according to a 2023 survey of 246 people in Ireland and Northern Ireland [17], which presents both opportunities and challenges. The COVID-19 pandemic accelerated the use of online health information platforms, and this explosion of digital information has brought an increased risk of exposure to non-credible sources. The impact of this is vast, with one study identifying that 30−80 % of social media content relating to cancer contains misinformation [18]. Unsubstantiated claims and the promotion of potentially harmful alternative therapies pose a notable risk to people with incurable cancer, who have been found to be particularly vulnerable to misinformation [15,19]. Combating this misinformation requires a concerted effort to promote digital literacy, for example by developing credible online resources and digital literacy programs, to and empower patients to critically evaluate the information they find online.

The digital shift has the potential to both improve and exacerbate inequities among people with ABC. While online resources and platforms can provide much needed support and information to geographically isolated people, the rise of digital information may create a "digital divide" that disproportionately affects vulnerable populations. Low digital health literacy, limited access to reliable internet, and a lack of culturally appropriate online resources can create significant barriers for vulnerable populations, widening the gap in access to reliable and trustworthy information [20]. A 2022 study of 15,244 people with cancer in France, including 3798 with breast cancer, found that low digital health literacy was associated with poorer overall survival in patients with *de novo* metastatic disease, further highlighting the link between access to information and disease outcomes [21].

3.5. Disparities in access to ABC information remain a global challenge

Equitable access to ABC information remains a persistent and pressing challenge globally. Factors such as education level, geography, language proficiency, and cultural background all contribute to disparities in outcomes for people with ABC [22]. The ABC Global Alliance 2024 patient survey found that people with ABC who have lower education levels were less likely than their educated counterparts to find ABC information easily (21 % vs. 74 % respectively). This group was also less likely to receive information on support services than those with higher education (58 % vs. 75 %). This is a particular challenge as those with lower education levels may be less aware of available support programs, and consequently, more susceptible to financial toxicity [10]. In many low- and middle-income countries, access to specialized cancer centers is limited, and patients often rely on general practitioners who may not have the expertise or resources to provide comprehensive information about ABC [23]. Furthermore, language barriers can prevent patients from accessing information in their native language, which can exacerbate disparities within countries [24].

Addressing these disparities requires a tailored approach that considers the specific needs and circumstances of diverse populations, ensuring that information is accessible, culturally appropriate, and readily available to all. [25]

4. Conclusions and future directions

While the status of informational needs for people with ABC has improved in the last decade, challenges remain. With the correct information, people with ABC can be empowered to make informed decisions about their care and better navigate the complexities of the disease, ultimately improving quality of life and outcomes. Information that is evidence-based and tailored to different cultures and population groups, in a variety of formats, is needed to reduce global disparities in access to ABC information.

A multi-stakeholder, collaborative approach involving HCPs, PAGs, researchers, policymakers, and pharmaceutical companies is required to achieve the ABC Global Alliance's goal for 2025–2035: **Meet the informational needs of all people with ABC**.

To meet this goal, concerted, coordinated efforts are required to overcome persistent unmet needs, including the following key actions.

- Enhance access to reliable information for people with ABC, by making trusted, endorsed content more visible, helping people distinguish credible guidance from misinformation.
- Improve dissemination of information across the entire ABC disease continuum, ensuring people receive the right information at the right time.
- Evolve, adapt, and translate existing ABC resources to increase equitable access for people with ABC regardless of geography or circumstances.

For further information please refer to the ABC Global Decade Report 2.0 [5].

5. Discloures

FC: Advisory role for Amgen, Astellas/Medivation, AstraZeneca, Bayer, Celgene, Daiichi Sankyo, Eisai, GE Oncology, Genentech, Gilead, GlaxoSmithKline, IQVIA, Macrogenics, Medscape, Merck Sharp & Dohme, Merus BV, Mylan, Mundipharma, Novartis, Pfizer, Pierre Fabre, prIME Oncology, Roche, Sanofi, Samsung Bioepis, Seagen, Teva, and TouchIME.

AC, JG, MZ, MG, AL, GA: Authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Given her role as author, Fatima Cardoso had no involvement in the peer review of this article and had no access to information regarding its peer review. Full responsibility for the editorial process for this article was delegated to another journal editor.

CRediT authorship contribution statement

Anna Cabanes: Writing – review & editing, Validation, Conceptualization. **Jenny Gilchrist:** Writing – review & editing, Validation, Conceptualization. **Marzia Zambon:** Writing – review & editing, Validation, Conceptualization. **Maya Gilbert:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Alexandra Lewis:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Georgia Attfield:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Fatima Cardoso:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Methodology, Funding acquisition, Formal analysis, Conceptualization.

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Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Given their role as author, [Editor-in-Chief] Fatima Cardoso had no involvement in the peer review of this article and had no access to information regarding its peer review. Full responsibility for the editorial process for this article was delegated to another journal editor.

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Increasing awareness of and referral to support services in advanced breast cancer: a global expert review and call-to-action for 2025–2035 (Goal 7)

Belinda Kiely [a], Luzia Travado [b], Andrea L. Smith [c], Isabelle Aloi Timeus [d], Sung-Bae Kim [e], Renate Haidinger [f], Nampak N M Nanre [g], Hope Rugo [h], Georgia Attfield [i], Alexandra Lewis [i], Fatima Cardoso [j,*]

[a] *University of Sydney, Sydney, Australia*
[b] *Champalimaud Clinical & Research Centre, Champalimaud Foundation, Lisbon, Portugal*
[c] *The Daffodil Centre, University of Sydney, A Joint Venture with Cancer Council NSW, Australia*
[d] *Salvati Foundation, Mexico City, Mexico*
[e] *Asan Medical Centre, University of Ulsan College of Medicine, Seoul, Republic of Korea*
[f] *German Breast Cancer Association, Hohenbrunn, Germany*
[g] *Africa Medical Center of Excellence, Abuja, Nigeria*
[h] *City of Hope Comprehensive Cancer Center, San Francisco, USA*
[i] *VML Health, London, United Kingdom*
[j] *Advanced Breast Cancer (ABC) Global Alliance, Lisbon, Portugal*

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ABSTRACT

Advanced breast cancer (ABC) represents a significant global health challenge, not only due to its high mortality rates but also because of the profound physical, emotional, and social burden it imposes on patients. Support services – encompassing psychological, social and peer support, complementary and integrative therapies, wellness and lifestyle support, genetic counseling, survivorship programs, palliative and end-of-life care – are essential to addressing these challenges and ensuring that individuals with ABC receive holistic, person-centered care throughout their disease journey.

This manuscript outlines the need for universal access to comprehensive, tailored support services to transform the landscape of ABC care, improve quality of life, and promote health equity globally. It summarizes research conducted for the ABC Global Alliance's Global Decade Report 2.0. The main findings are: a) More than half of people with ABC report never being offered support services; b) Global disparities in ABC support services persist despite policy recommendations from national cancer care plans; c) Global survey data show major gaps in ABC support service referral and utilization; d) Palliative care remains underutilized and often introduced too late in ABC care; e) Despite growth of ABC advocacy groups, healthcare provider referrals are limited.

The findings from the ABC Global Alliance's Global Decade Report 2.0 have informed the development of a new ABC Global Charter. The ABC Global Charter 2.0 defines ten new achievable and measurable goals for the decade 2025–2035, aiming at improving the lives of people living with ABC worldwide.

1. Introduction

Advanced breast cancer (ABC) represents a significant global health challenge, not only due to its high mortality rates but also because of the profound physical, emotional, and social burden it imposes on patients [1]. Support services – encompassing psychological, social and peer support, complementary and integrative therapies, wellness and lifestyle support, genetic counseling, survivorship programs, palliative and end-of-life (EoL) care – are essential to addressing these challenges and ensuring that individuals with ABC receive holistic, person-centered care throughout their disease journey [1–4].

This manuscript outlines the need for universal access to comprehensive, tailored support services to transform the landscape of ABC care, improve quality of life (QoL), and promote health equity globally. It draws on findings from the ABC Global Alliance's Global Decade Report 2.0, which includes an analysis of funding and availability of

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* Corresponding author.
E-mail address: fcardoso@abcglobalalliance.org (F. Cardoso).

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various support services across 6 countries (Brazil, France, Japan, United Kingdom, United States and South Africa). It also includes insights from the ABC Global Alliance patient and healthcare professional (HCP) surveys conducted in 2024. Detailed methodology with limitations can be found in the Global Decade Report 2.0 [5], in addition to the first manuscript of this special issue.

2. Status in 2005–2015

Since 2002, the World Health Organization (WHO) and major clinical guidelines (e.g., ABC consensus guidelines, National Comprehensive Cancer Network (NCCN), and National Institute for Health and Care Excellence (NICE) guidelines) have emphasized the importance of integrating support services such as psychosocial care, survivorship support, and palliative care, into national cancer control plans (NCCPs) [6–9]. Despite these longstanding recommendations, implementation has remained inconsistent across countries [10]. The 2005–2015 Global Decade Report outlined the underutilization of psychological services in ABC and delays in initiating discussions around palliative and EoL care. Notably, 79 % of people with ABC identified supportive care as a key unmet need [10]. In response, the ABC Global Charter included improved awareness and referrals to support services among its 10 recommended “Actions for Change” for 2015–2025 [5,11].

3. A decade in review (2015–2025)

3.1. *Inconsistent integration of ABC support services into NCCPs amplifies disparities globally*

Despite growing recognition of the importance of support services for people with ABC, persistent gaps in access remain worldwide. Many NCCPs fail to include comprehensive recommendations for ABC-specific support services, leaving patients underserved and vulnerable (Table 1).

Many national policies fall short of translating supportive care recommendations into actionable frameworks. An analysis of NCCPs across six countries (Brazil, France, Japan, United Kingdom, United States, and South Africa) conducted by the ABC Global Alliance in 2024 revealed notable disparities: all support services analyzed were available in the UK [12–15], whereas other countries’ NCCPs included far fewer support services, and Brazil’s only referenced palliative care [16]. This variation mirrors broader global trends, with a 2021 review of 237 NCCPs revealing that fewer than half (41 %) referenced psycho-oncology or survivorship support for cancer survivors [17]. Together, these findings highlight ongoing disparities in the availability and prioritization of oncology support services worldwide.

3.2. *Challenges with implementation and uptake of ABC support services persist globally*

Even when policies exist, implementation of support services is inconsistent. For example, while the UK has robust policy recommendations for peer support groups, actual delivery often relies on *ad-hoc* initiatives by individual healthcare providers or charities [18]. Differences in support service uptake between countries may reflect differing perceptions on the importance of these services, with countries like Japan more focused on integrative or complementary medicine services such as kampo, compared to western countries [19,20]. Disparities may be especially pronounced in resource-limited settings, where insufficient funding and specialist expertise may result in a deprioritization of supportive care in favor of ensuring access to fundamental treatment, or stratification of supportive care into ‘essential’ (i.e., palliative care) and ‘non-essential’ (i.e., nutritional support) services [21,22]. These findings emphasize the need for stronger policy enforcement mechanisms and greater investment in supportive care infrastructure.

3.3. *Although uptake of psychological support has improved, many services remain underutilized*

Where ABC support services are available, they may not be offered to those who need them. According to the ABC Global Alliance 2024 patient survey (n = 1254), more than half (55 %) of people with ABC reported not being offered any support services at all, highlighting gaps in referral and access. However, when services are offered very few decline them, and most people report them to be useful (Fig. 1). Importantly, the survey also revealed that those in low-middle-income countries (LMICs) were significantly more likely not to be offered any support services than those from high-income countries (HICs) ($p < 0.05$). Such findings highlight the negative impact of restricted funding and limited policy-level recommendations on the availability of support services to people with ABC.

The ABC Global Alliance 2024 patient survey found psychological (64 %) and physical (54 %) support to be the most commonly used ABC support services, showing a positive shift since 2015. In contrast, lower numbers of patients reported using social support (27 %) or nutritional support (30 %), possibly due to out-of-pocket (OOP) costs. Even fewer accessed clinical trials (21 %) and palliative care or EoL services (15 %).

3.4. *HCP referral to some ABC support services remains low*

HCP referral patterns may further impact ABC support service utilization. While many of the HCPs who responded to the ABC Global Alliance 2024 HCP survey (n = 461) reported ‘*always*’ or ‘*often*’ referring patients to palliative care (68 %) and psychological support (53 %), only 10 % did so for complementary or integrative therapies, highlighting

Table 1

Funding coverage for key support services across six countries [5].

Support service	Japan [39,40]	Brazil [41–43]		South Africa [44,45]	US [46–49]		UK [50–53]	France [54,55]
		PUBLIC	PRIVATE[a]		PUBLIC	PRIVATE		
Psychological support	✔	✔	✔	✔	✔	✔	✔✔	✔✔
Palliative care and end-of-life services	✔✔	✔✔	✔✔	✔	✔✔	✔✔	✔✔	✔✔
Social support	●	✔✔	✔✔	●	✔	✔	✔✔	✔
Survivorship programs	X	X	✔	✔	✔	✔	✔✔	X
Support groups	X	✔	X	X	X	X	X	X
Genetic counseling	X	✔	✔✔	✔	✔	✔✔	✔✔	●
Complementary and integrative therapies	X	✔	✔✔	●	✔	✔	X	X
Wellness support[b]	X	●	✔	X	✔	✔	✔✔	✔

✔✔ = Service fully funded; ✔ = Service funded with limitations; ● = No information available; X = Service not funded. Data from the ABC Global Alliance ABC support services funding analysis.

UK = United Kingdom; US = United States.

[a] Coverage of services by health insurance differs substantially between providers.

[b] Wellness support includes services designed to improve a person’s overall well-being including their emotional, physical and mental health.

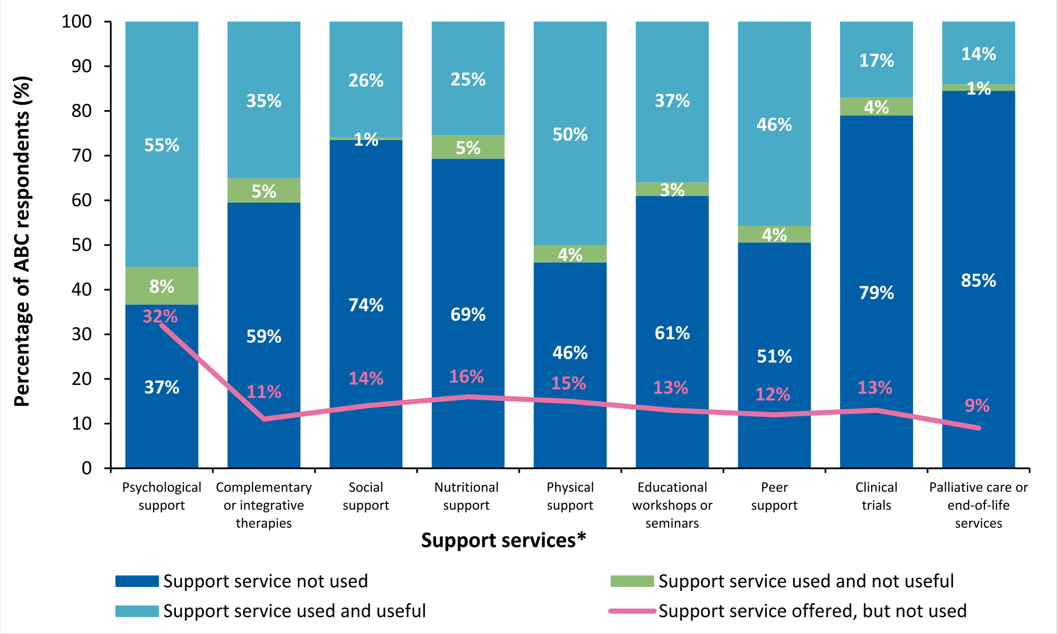

Fig. 1. Patient-reported utilization rates and usefulness of ABC support services [5]
Data collected from the ABC Global Alliance 2024 patient survey (n = 1254). Survey questions: Have you used any of the following services during your care for advanced breast cancer? If so, how useful were they? [No, I didn't use; Yes, it was useful; Yes, it was not useful]; Have you been offered any of the following support services, but not used them? [Yes; No]
* The survey defined support services as: psychological support (e.g., psycho-oncology, counseling); complementary or integrative therapies (e.g., herbal medicine); social support (e.g., transport, home care); nutritional support programs; physical support programs (e.g., exercise, rehabilitation, lymphedema care); educational workshops or seminars; peer support services (e.g., advocacy groups or organizations); clinical trials; palliative care or end-of-life services. Clinical trial information and financial assistance programs are discussed in more detail in Goal 6 (informational needs for people with ABC), and Goal 9 (access to comprehensive ABC care), respectively.
Values rounded to the nearest whole number, which may result in totals not equaling 100 %.
ABC = advanced breast cancer.

disparities likely driven by perceived value and accessibility of such services. Furthermore, the surveys revealed a notable discrepancy between HCPs and patients: while high numbers of HCPs reported offering their patients services such as palliative care and EoL support (Fig. 2), patient-reported rates of using the same services were comparatively low (Fig. 1). Overcoming these gaps calls for targeted education for both HCPs and patients, alongside better integration of support services into standard oncology practice.

It is also critical to address the unique support needs of younger adults with ABC, such as fertility preservation. A global survey by Young Survival Coalition's (YSC) Project 528 found that only 44 % of young women with ABC had discussed fertility preservation with their HCP [23]. While fertility has traditionally been a concern for women with early breast cancer, in recent years it has also become important for women with ABC [24]. This is possibly due to improved ABC survival [25] and the increased number of patients experiencing long-term complete remissions, especially those with HER-2-positive ABC [26]. These findings highlight the need for HCPs to discuss the individual support needs of their patients and connect them with the appropriate services.

3.5. *Palliative care is an essential support service for people with ABC, but is often integrated late in the disease trajectory*

Palliative care is a cornerstone of supportive care for people with ABC, offering benefits such as symptom management, improved QoL, and reduced caregiver burden [27,28]. Yet, access to palliative care often occurs too late in the course of the disease. The 2005–2015 Global Decade Report found that 65 % of palliative care discussions began only after active treatment ended [10]. While the ABC consensus and American Society of Clinical Oncology (ASCO) guidelines now recommend early palliative care [27,29], this still does not always happen in practice. A 2024 French study showed only 31 % of palliative care interventions for people with ABC occurred more than three months before death [30], while a 2018 US study reported late palliative care referrals for 40 % of people with ABC [31].

The definition of 'early integration' of palliative care in cancer remains challenging. Both the oncology and palliative care communities agree that palliative care should not be reserved solely for EoL and instead be introduced much earlier in the disease course. However, determining the optimal time for referral is complex and highly dependent on individual clinical factors, including the patient's symptoms, disease trajectory, and cancer subtype. Some guidelines recommend integration within 12 weeks of a metastatic diagnosis [27,32,33], while others define "early" as more than three months prior to death [34]. Despite these benchmarks, there is no universally accepted definition, and effective integration ultimately requires a personalized, patient-centered approach.

Furthermore, perception of palliative care is evolving: from being viewed solely as EoL care to encompassing early symptom management and support throughout the cancer pathway. The past decade has seen increased awareness of the importance of palliative care, with a 2020 study of 51 countries demonstrating growing availability of palliative care services between 2005 and 2019 across 82 % of countries [35]. In 2021, The WHO introduced palliative care indicators for use across disease areas, and several European countries now register palliative care outcomes [36,37]. Despite this progress, the 2020 International Cancer Control Partnership's Global Atlas of Palliative Care highlights persistent inequalities in palliative care services, particularly between Western and Eastern Europe and between HIC and LMICs, where investment remains uneven [38].

Cultural and psychological barriers may also play a role, with many

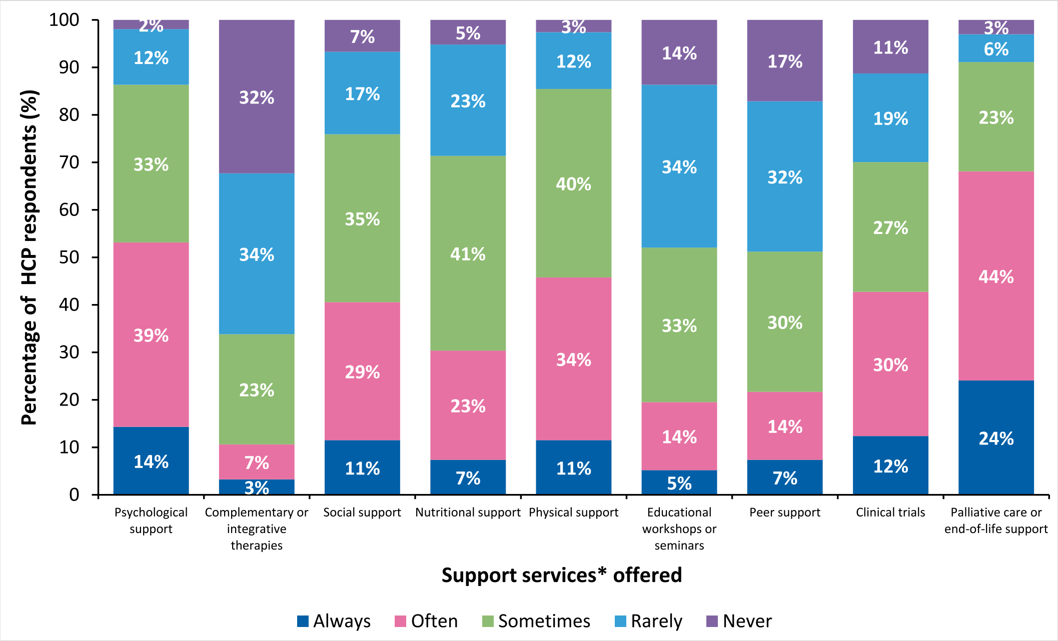

Fig. 2. HCP-reported frequency of patient referral to ABC support services [5]
Data collected from the ABC Global Alliance 2024 HCP survey (n = 461). Survey question: How frequently do you refer patients with advanced breast cancer to the following services? [Always; Sometimes; Often; Rarely; Never]
* The survey defined support services as: psychological support (e.g., psycho-oncology, counseling); complementary or integrative therapies (e.g., herbal medicine); social support (e.g., transport, home care); nutritional support programs; physical support programs (e.g., exercise, rehabilitation, lymphedema care); educational workshops or seminars; peer support services (e.g., advocacy groups or organizations); clinical trials; palliative care or end-of-life services. Clinical trial information and financial assistance programs are discussed in more detail in Goal 6 (informational needs for people with ABC) and Goal 9 (access to comprehensive ABC care), respectively.
Values rounded to the nearest whole number, which may result in totals not equaling 100 %.
HCP = healthcare professional.

still associating palliative care with EoL, leading to reluctance in accepting these services early in the treatment pathway. Addressing these misconceptions and reframing palliative care as an integral part of comprehensive cancer care is crucial to improve QoL and enhance care in ABC.

3.6. *Underfunding and resource constraints limit support services for people with ABC*

ABC support services are highly dependent on funding, which varies between countries and healthcare systems. Often support services for ABC are underfunded, relying heavily on OOP payments or charitable contributions. The 2024 ABC Global Alliance analysis of funding models across six countries found that public coverage for services like genetic counseling, wellness programs, and peer support was inconsistent, even in HICs (Table 1).

In addition to financial barriers, workforce shortages and inadequate infrastructure limit the availability of support services [56,57]. A German survey published in 2017 identified a lack of access to psychotherapists as a major barrier to psychosocial support, particularly in rural areas [56]. Innovative web-based solutions like "Finding My Way-Advanced" that is currently being evaluated in women with ABC may help to bridge these gaps and provide an alternative to peer-to-peer support [57], but broader systemic changes are needed to ensure equitable access [56,57].

3.7. *Patient advocacy groups are increasingly recognized as a vital ABC support service*

Patient advocacy groups (PAGs) have emerged as vital stakeholders in the ABC care ecosystem, playing an important role in providing peer support, directing to patient resources and services, and amplifying patient voices. Analysis conducted for the Global Decade Report 2.0 showed that the number of breast cancer and ABC PAGs has grown year-on-year between 2015 (8 PAGs) and 2023 (19 PAGs). ABC-specific groups increased their membership by a total of 92 %, indicating an increased focus on ABC in the oncology patient advocacy space.

However, engagement with PAGs remains uneven. Only half (49 %) of respondents to the ABC Global Alliance 2024 patient survey reported participating in peer support programs, though nearly all who do participate find them beneficial. In a global survey of young women with ABC (YSC Project 528), many respondents expressed a desire for emotional and informational support, with 77 % seeking connection with another survivor, 44 % wanting more information about their diagnosis, 69 % looking for guidance on daily life and practical issues, and 79 % requesting content specifically related to ABC [23]. These findings outline the critical role of peer-to-peer support and community-based services for those with ABC.

Limited HCP referral to PAGs may also be a barrier to engagement with these services, with only 21 % of HCPs reporting to '*always*' or '*often*' refer people with ABC to peer support services (Fig. 2). Strengthening collaborations between HCPs and PAGs could enhance awareness and utilization of these critical resources.

4. Conclusion and future directions

ABC support services can improve QoL, enhance treatment adherence, and reduce healthcare costs by mitigating complications and hospitalizations. Yet referral and access to, and utilization of, ABC support services remain suboptimal. The next decade offers an opportunity to redefine the standard of care for people with ABC. By prioritizing access to comprehensive, tailored and fully covered support services, we can address longstanding inequities and empower patients to navigate their ABC journey with dignity and resilience. Potential solutions include embedding a consistent referral process within multidisciplinary teams—such as involving nurses, social workers, and palliative care experts in routine clinic workflows and team meetings—to ensure timely and equitable access without overburdening oncologists. In addition, integrative models that bring oncologic and palliative care together, rather than operating in silos, could improve coordination and outcomes. The ABC Global Alliance community proposes inclusion of this goal in the 2025–2035 ABC Global Charter, with the following wording: **Ensure all people with ABC have access to comprehensive, person-centered support services**.

To activate against this goal the ABC community must.

- Ensure support services are both available and accessible to all people with ABC by establishing policy guidelines, securing sustainable funding, and addressing geographic and resource barriers
- Ensure all people with ABC are informed of and referred to appropriate support services by their HCPs, supported by clear communication and integrated care pathways
- Expand the reach of support services with a focus on equitable access for underserved populations
- Promote the establishment of ABC PAGs in countries where they do not yet exist and improve patient referral pathways through enhanced PAG−HCP trust and collaboration

For further details please see the Global Decade Report 2.0 [5].

CRediT authorship contribution statement

Belinda Kiely: Writing – review & editing, Validation, Conceptualization. **Luzia Travado:** Writing – review & editing, Validation, Conceptualization. **Andrea L. Smith:** Writing – review & editing, Validation, Conceptualization. **Isabelle Aloi Timeus:** Writing – review & editing, Validation, Conceptualization. **Sung-Bae Kim:** Writing – review & editing, Validation, Conceptualization. **Renate Haidinger:** Writing – review & editing, Validation, Conceptualization. **Nampak N M Nanre:** Writing – review & editing, Validation, Conceptualization. **Hope Rugo:** Writing – review & editing, Validation, Conceptualization. **Georgia Attfield:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Alexandra Lewis:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Fatima Cardoso:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Methodology, Funding acquisition, Formal analysis, Conceptualization.

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Declaration of competing interest

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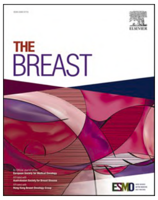

Reducing stigma, isolation, and misconceptions in advanced breast cancer: a global expert review and call-to-action for 2025–2035 (Goal 8)

Ranjit Kaur [a], Rania A. Azmi [b], Sarah Kutika Nyagabona [c,d], Eva Schumacher-Wulf [e], Stacy Lewis [f,g], Daniel Egbase [h], Alexandra Lewis [h], Georgia Attfield [h], Fatima Cardoso [i,*]

[a] *National Cancer Society Malaysia, Kuala Lumpur, Malaysia*
[b] *Fadia Survive & Thrive, Salmiya, Kuwait*
[c] *Muhimbili National Hospital, Dar es Salaam, Tanzania*
[d] *Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania*
[e] *Mamma Mia! Magazine, Cologne, Germany*
[f] *Young Survival Coalition, New York, NY, United States*
[g] *Metastatic Breast Cancer Alliance, New York, NY, United States*
[h] *VML Health, London, United Kingdom*
[i] *Advanced Breast Cancer (ABC) Global Alliance, Lisbon, Portugal*

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ABSTRACT

Despite significant advances in the diagnosis and treatment of advanced breast cancer (ABC), people living with the disease continue to experience profound social isolation on a global scale. The multifaceted physical, financial, and emotional challenges inherent to ABC are frequently misunderstood or underestimated, resulting in persistent stigma, social exclusion, and an elevated risk of adverse mental health outcomes for affected individuals. Misconceptions regarding ABC among healthcare professionals (HCPs) or the public exacerbate these challenges and further compound the overall disease burden.

This manuscript examines how stigma, social isolation, and misconceptions surrounding ABC have evolved globally since 2015. It summarizes research conducted for the ABC Global Alliance's Global Decade Report 2.0. The main findings are: a) Online mentions of ABC are increasing, but remain lower than general breast cancer; b) Despite progress, social and workplace stigma still impacts people with ABC; c) Stigma and isolation associated with ABC varies by geography and income level; d) Awareness of ABC has improved, but misconceptions persist.

The findings from the ABC Global Alliance's Global Decade Report 2.0 have informed the development of a new ABC Global Charter. The ABC Global Charter 2.0 defines ten new achievable and measurable goals for the decade 2025–2035, aiming at improving the lives of people living with ABC worldwide.

1. Introduction

Despite significant advances in the diagnosis and treatment of advanced breast cancer (ABC), people living with the disease continue to experience profound social isolation on a global scale [1,2]. The multifaceted physical, financial, and emotional challenges inherent to ABC are frequently misunderstood or underestimated, resulting in persistent stigma, social exclusion, and an elevated risk of adverse mental health outcomes for affected individuals [3,4]. Misconceptions regarding ABC among healthcare professionals (HCPs) or the public exacerbate these challenges and further compound the overall disease burden [5].

This manuscript examines how stigma, social isolation, and misconceptions surrounding ABC have evolved globally since 2015. It draws on findings from the ABC Global Alliance's Global Decade Report 2.0, primarily from patient and HCP surveys carried out in 2024, a social listening analysis conducted in 2024 for the period between 2016 and 2024, and a structured awareness campaign questionnaire distributed to 95 ABC Global Alliance partner organizations. For further details on methodologies and limitations, please refer to the Global Decade Report 2.0 [6], in addition to the first manuscript of this special issue.

This article is part of a special issue entitled: ABC Decade Report 2015-25 - ABC Global Charter 2025-35 published in The Breast.

[*] Corresponding author.
E-mail address: fcardoso@abcglobalalliance.org (F. Cardoso).

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2. Status in 2005–2015

Despite growing ABC awareness efforts since 2009, the 2005–2015 Global Decade Report described the designation of October 13th as National ABC Awareness Day as having only modest impact on public understanding of the differences between early-stage breast cancer and ABC, and the broader implications of an ABC diagnosis [1]. Nearly half of individuals with ABC surveyed at that time reported experiencing feelings of social rejection, including isolation, shame, and marginalization. Persistent misconceptions, such as the belief that disease progression was due to patient noncompliance, reinforced stigma and blame [1].

Recognizing these challenges, the 2015–2025 ABC Global Charter included the need to 'counteract the stigma and isolation associated with living with ABC by increasing public understanding of the condition' as one if its ten 'Actions For Change' [7].

3. A decade in review (2015–2025)

3.1. The number of ABC awareness campaigns has increased since 2015

In an analysis of 101 public awareness campaigns submitted by ABC Global Alliance partner organizations, around half (51 %) were found to focus specifically on ABC, reflecting notable progress compared to the scarcity of such initiatives reported in the previous decade [1]. Despite this encouraging trend, data on the actual reach and effectiveness of these campaigns remains limited, and changes in public attitudes are difficult to quantify. This analysis showed that campaigns led by pharmaceutical companies have tended to focus on navigation, symptoms, and screening, while other organizations have led the way in dispelling myths and reducing stigma.

ABC Global Alliance awareness efforts this decade go beyond treatment to focus on the lived experience and psychological impact of ABC through campaigns such as '*I Am Advanced Breast Cancer*', which uses personal storytelling to confront stigma; '*The Truth About Working with ABC*', which addresses employment-related challenges and advocates for supportive workplace policies; and '*The Other Victims of ABC*', which highlights the wider emotional and social burden of ABC on families, caregivers, and communities [8]. In addition, Europa Donna's '*Cancer Currency*' campaign brought visibility to the societal undervaluation of people with ABC, successfully influencing European policy and securing recognition of ABC for the first time in Europe's Beating Cancer Plan [9].

3.2. Online conversation on ABC is increasing, but continues to lag behind general breast cancer

Despite increasing recognition of the isolating and stigmatizing effects of ABC, research into its social and emotional challenges remains limited. The ABC Global Alliance 2024 patient survey found that nearly half of respondents felt misunderstood (47 %) or different from others (46 %), consistent with broader evidence of public misconceptions and lack of awareness across Europe [10].

The ABC Global Alliance 2024 social listening analysis indicates that digital discourse around ABC has grown steadily, with annual online mentions rising from approximately 270,000 in 2016 to 600,000 in 2024. However, no increase was observed during October, suggesting that the public may not associate Breast Cancer Awareness Month with ABC, and possibly reflecting waning focus on the month and the decline of traditional "pinkwashing" campaigns [11]. The analysis also found that the share of voice (i.e., the proportion of ABC mentions relative to overall breast cancer) for ABC had slightly declined year over year, dropping from 15 % between May and November 2023 to 13 % during the same period in 2024.

Further exploring the relationship between online sentiment and experiences of stigma and isolation, the analysis found that sadness (30 %) and fear (25 %), were the most commonly expressed negative emotions among people with ABC, while joy (28 %), often linked to survivor stories and treatment milestones, was also frequently observed. Anger (4 %) appeared less often, typically in response to survival rate concerns and lack of ABC awareness (Fig. 1). While these findings may indicate a nuanced emotional landscape within the online ABC community, it is important to note that sentiment analysis is based solely on publicly shared content and may not fully capture the lived reality of people with ABC. Additionally, it should be noted that social listening analyses inherently capture sentiments expressed in online spaces only; perspectives shared in face-to-face or peer support groups, where feelings of stigma and isolation may manifest differently, fall outside the scope of this research. Understanding whether such in-person support mitigates isolation among people with ABC therefore warrants further investigation.

3.3. Stigma and isolation associated with ABC varies by geography and country income level

The ABC Global Alliance 2024 patient survey (n = 1254) demonstrated significant geographical variation in stigma and isolation associated with ABC, with higher rates of isolation reported in the United States (US; 62 %) and United Kingdom (UK; 64 %) compared to Argentina (20 %) and Portugal (30 %) ($p < 0.05$). Additionally, feelings of being different were most prevalent in France (30 %) and Germany (25 %) (Fig. 2). Notably, these trends persist despite a high volume of public awareness campaigns in the US and UK, suggesting that these alone are insufficient to address social isolation and highlighting the need for more targeted support strategies.

Furthermore, individuals with ABC in high-income countries (HICs) reported significantly greater feelings of isolation (52 %) and difference (52 %) than those in low- and middle-income countries (LMICs) (29 % and 21 %, respectively; $p < 0.05$) (Fig. 2). Higher reported isolation among people with ABC in HICs compared to LMICs may reflect greater awareness and openness to express emotional challenges, partly due to visibility of awareness campaigns. In contrast, in LMICs, immediate survival needs, caregiving duties, limited autonomy, and financial barriers to treatment may lead to underreporting of psychosocial challenges and reinforce perceptions of incurability, thereby intensifying stigma and isolation.

It is also important to acknowledge that the COVID-19 pandemic occurred during this decade and imposed widespread social restrictions. Although this study examined isolation specifically in the context of ABC, the extent to which pandemic-related social distancing compounded patients' experiences of isolation has not yet been systematically explored within the literature.

3.4. Perceptions of ABC vary substantially among HCPs, which may hinder optimal patient treatment and care

HCPs play a critical role in shaping the treatment pathway for individuals with ABC; however, evidence indicates that life-prolonging therapies are not consistently prioritized [5]. The 2019 '*I Am Still Here*' report revealed that people with ABC in New Zealand received on average only one line of therapy, often due to HCP reluctance to pursue further options [12]. This trend was echoed years later by the 2024 Lancet Breast Cancer Commission, which attributed this to perceptions of ABC as an immediate death sentence, despite available survival-extending treatments [5].

The ABC Global Alliance 2024 HCP survey (n = 461) revealed significant variation in beliefs regarding ABC prognosis: over half of HCPs viewed ABC as virtually incurable, while roughly a third considered it potentially curable, and a similar proportion anticipated it could become a chronic disease within the next decade. Notably, optimism about curability was more common among ABC specialists than those in general hospitals or hospitals without specialist units, and was also higher among physicians than nurses. As professional perspectives

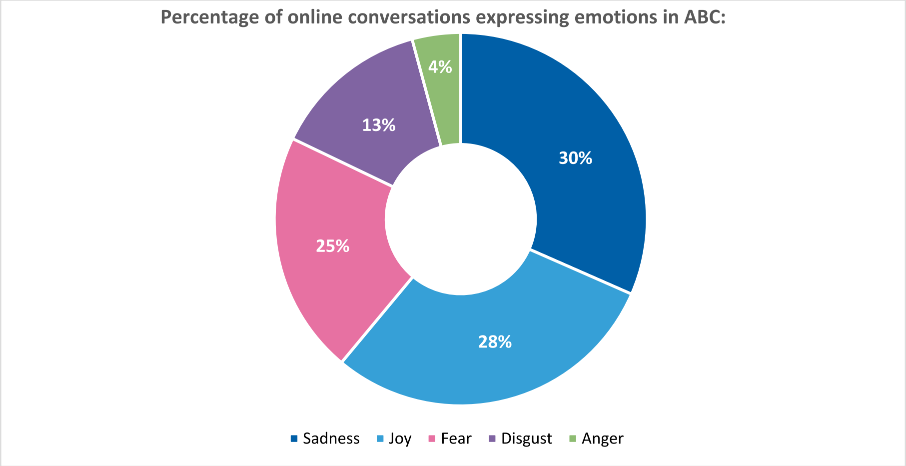

Fig. 1. Emotions expressed in social media discussions by people living with ABC between 2016 and 2024 [6]
Data collected from the ABC Global Alliance social listening, 2024.

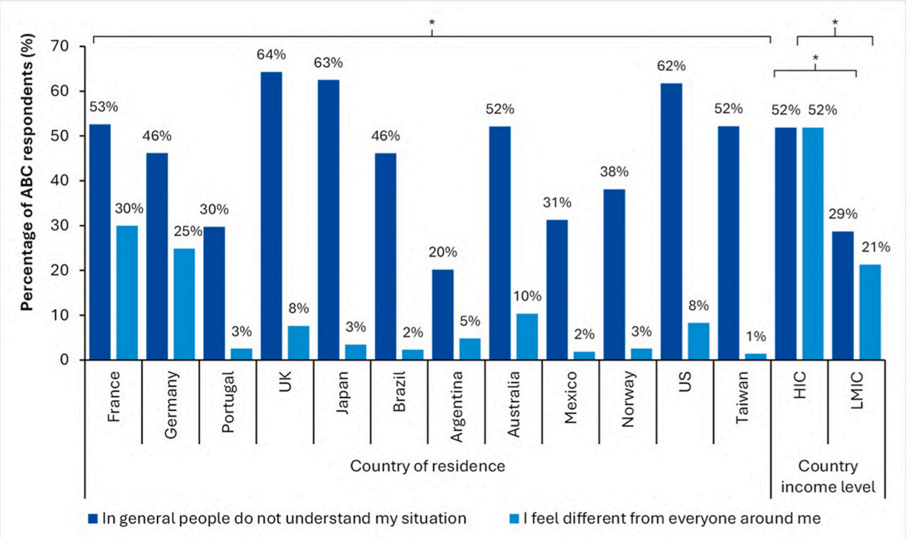

Fig. 2. Proportion of people with ABC reporting feelings of isolation and feeling different categorized by region [6]
Data collected from the ABC Global Alliance 2024 patient survey (n = 1254). Survey question: Which of the following have you experienced as a result of your advanced breast cancer diagnosis? [You may select more than one option. Please select all that apply.]
* Proportion of respondents who selected ‘In general people do not understand my situation’ and ‘I feel different from everyone around me’ categorized by geographic region; $p < 0.05$.
ABC = advanced breast cancer.

continue to evolve, coordinated clinical, advocacy, and societal efforts will be essential to reduce stigma and foster more hopeful narratives around ABC.

3.5. Misconceptions about ABC remain common but are declining compared to 2015

The 2005–2015 Global Decade Report revealed that a substantial portion of the public (47–80 %) mistakenly believed that early detection or treatment could prevent ABC progression or render it curable, highlighting widespread misunderstanding of ABC prognosis [1]. More recent data from the ABC Global Alliance 2024 patient survey suggest these misconceptions may be declining, with fewer people with ABC reporting hearing such beliefs. Less than half of respondents reported having heard that ABC could be prevented through early detection (45 %), or that the disease is curable (37 %). Surprisingly, these misconceptions are being heard more commonly by those with higher education levels. There is a clear opportunity to address misconceptions through targeted education, with a 2024 European survey by Daiichi Sankyo finding that 88 % of the public expressed interest in learning more about breast cancer, especially in relation to new treatments, life expectancy, and quality of life [10]. This strong appetite for information highlights the potential impact of well-designed awareness and educational initiatives that are sensitive to cultural contexts and tailored to public interests.

Geographic subgroup analysis revealed that misconceptions remain common in countries such as Taiwan (48 %) and Brazil (49 %). Limited public discussion regarding cancer in some regions has the potential to fuel misconceptions and deepen the isolation experienced by those living with ABC. For instance, in Taiwan, breast cancer remains a taboo subject, making open conversations difficult and potentially reinforcing stigma [13]. These cultural barriers, combined with general public misconceptions, contribute to persistent knowledge gaps around ABC.

3.6. *Despite progress, social and workplace stigma remains for people with ABC*

While previous research has demonstrated that individuals with ABC are subject to social and workplace stigma [14], around a third (36 %) of respondents to the ABC Global Alliance 2024 patient survey reported ‘not being treated differently by anyone after diagnosis’. However, when negative experiences were reported, these were most commonly with friends (31 %), colleagues (22 %), and partners or spouses (21 %) (Fig. 3). Notably, 15 % of respondents reported negative interactions with individuals diagnosed with early breast cancer, suggesting ongoing tensions between early and advanced disease groups. Moreover, 16 % of respondents identified their healthcare team as a source of negative experiences. Anticipated stigma in clinical settings can lead patients to hide their diagnosis or delay care, which may compromise treatment and outcomes [15,16].

These findings suggest that social and occupational settings remain significant sources of negative experiences for individuals with ABC, highlighting the need for targeted awareness and education. However, this analysis reflects absolute counts of negative interactions without adjusting for the frequency of contact with each group, which may bias interpretation.

4. Conclusion and future directions

The last decade has shown us that, despite growing efforts to raise awareness and shift public narratives around ABC, stigma and social isolation remain deeply entrenched and continue to impact the lives of those affected. Misconceptions and harmful stereotypes still persist, highlighting the need for sustained, strategic efforts across all levels of society.

As we look to the future, the goal for 2025–2035 is clear: Reduce misconceptions, stigma, and isolation by improving understanding of ABC.

To do this, we need to prioritize the following key actions.

- Improve understanding of ABC across all stakeholder groups by addressing misinformation and harmful stereotypes through targeted education and consistent, unbiased language.
- Expand the reach and impact of awareness campaigns by embedding inclusive, locally relevant, and culturally sensitive approaches that resonate with diverse communities.
- Influence policymaker perception and behavior through sustained advocacy that champions patient rights and ensures access to essential treatments, services, and opportunities for people with ABC.

By working together to dismantle misconceptions and foster more inclusive narratives, stakeholders can ensure that people living with ABC are seen, heard, and supported in every part of society. Achieving this vision will require long-term commitment, innovation, and collaboration across sectors.

For further information please refer to the ABC Global Decade Report 2.0 [6].

CRediT authorship contribution statement

Ranjit Kaur: Writing – review & editing, Validation, Conceptualization. **Rania A. Azmi:** Writing – review & editing, Supervision, Conceptualization. **Sarah Kutika Nyagabona:** Writing – review & editing, Validation, Conceptualization. **Eva Schumacher-Wulf:** Writing – review & editing, Validation, Conceptualization. **Stacy Lewis:** Writing – review & editing, Validation, Conceptualization. **Daniel Egbase:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Alexandra Lewis:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Georgia Attfield:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Fatima Cardoso:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Methodology, Funding acquisition, Formal analysis, Conceptualization.

Disclosures

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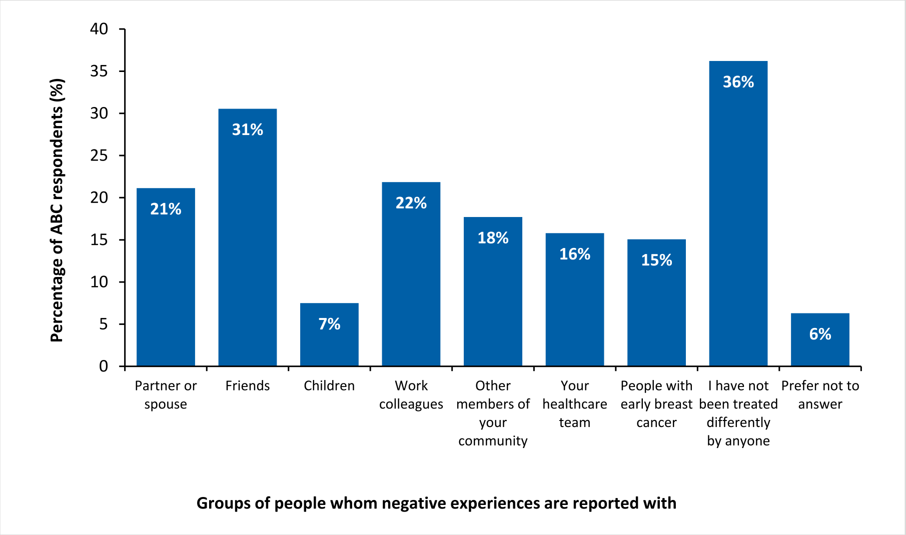

Fig. 3. Proportion of people with ABC reporting negative experiences with different groups of people following their ABC diagnosis [6]
Data collected from the ABC Global Alliance 2024 patient survey (n = 1254). Survey question: Have you had any negative experiences with any of the following people following your advanced breast cancer diagnosis? [You may select more than one option. Please select all that apply].
ABC = advanced breast cancer.

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Declaration of competing interest

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Improving equitable access to comprehensive care for people with advanced breast cancer: a global expert review and call-to-action for 2025–2035 (Goal 9)

Alexandru Eniu [a,b], Runcie C.W. Chidebe [c,d], Peter Vuylsteke [e,f], Mariana Chavez-MacGregor [g], Frederique Penault-Llorca [h], Gilberto Lopes [i], Matti Aapro [j,k], Silvia Neciosup [l,m], Nisha Pillay [n], Alexandra Lewis [n], Georgia Attfield [n], Fatima Cardoso [o,*]

[a] Medical Oncology, Genolier Cancer Center, Genolier, Switzerland
[b] European School of Oncology, Bellinzona, Switzerland
[c] Project PINK BLUE - Health & Psychological Trust Centre, Abuja, Nigeria
[d] Department of Sociology and Gerontology, Miami University, Oxford, OH, United States
[e] Department of Oncology, CHU Brugmann, Brussels, Belgium
[f] Department of Internal Medicine, University of Botswana, Gaborone, Botswana
[g] The University of Texas MD Anderson Cancer Center, Houston, TX, United States
[h] Department of Biopathology, Centre Jean Perrin, Université Clermont Auvergne, INSERM, U1240 Imagerie Moléculaire et Stratégies Théranostiques, F-63000, Clermont Ferrand, France
[i] Sylvester Comprehensive Cancer Center, University of Miami, Miami, FL, United States
[j] Breast Center, Genolier Cancer Center, Genolier, Switzerland
[k] SPCC Sharing Progress in Cancer Care, Bellinzona, Switzerland
[l] Department of Medical Oncology, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru
[m] Grupo de Estudios Clínicos Oncológicos del Perú (GECOPERU), Lima, Peru
[n] VML Health, London, United Kingdom
[o] Advanced Breast Cancer (ABC) Global Alliance, Lisbon, Portugal

A R T I C L E I N F O

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A B S T R A C T

Advanced breast cancer (ABC) remains an incurable yet treatable disease, requiring lifelong care. While treatment advancements have extended survival for many patients, access to these innovations is far from universal. There remains a critical need to ensure equitable access to proven and established interventions for all individuals with ABC, while continuing to drive progress in care and survival outcomes.

This manuscript assesses the evolving economic landscape for and access to comprehensive ABC care since 2015. It describes the persistent access barriers and inequities, and outlines recommendations for the ABC community over the next decade. It summarizes research conducted for the ABC Global Alliance's Global Decade Report 2.0. The main findings are: a) Disparities in access to ABC care are widening globally; b) Variable access to diagnostic services delays timely and adequate ABC treatment; c) Infrastructure, supply, and reimbursement barriers hinder ABC treatment access; d) High out-of-pocket costs drive severe financial toxicity across all income settings; e) In low-income contexts, multi-stakeholder efforts are improving access to ABC care.

The findings from the ABC Global Alliance's Global Decade Report 2.0 have informed the development of a new ABC Global Charter. The ABC Global Charter 2.0 defines ten new achievable and measurable goals for the decade 2025–2035, aiming at improving the lives of people living with ABC worldwide.

This article is part of a special issue entitled: ABC Decade Report 2015-25 - ABC Global Charter 2025-35 published in The Breast.

[*] Corresponding author.

E-mail address: fcardoso@abcglobalalliance.org (F. Cardoso).

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1. Introduction

Advanced breast cancer (ABC) remains an incurable yet treatable disease, requiring lifelong care. While treatment advancements have extended survival for many patients, access to these innovations is far from universal [1,2]. In high-income countries (HICs), well-established healthcare systems often provide advanced diagnostics and optimal treatments, although disparities persist for underserved populations [3]. In contrast, people in low-and-middle-income countries (LMICs) often face significant barriers at every stage of care, from diagnosis to treatment [3,4]. There is a critical need to ensure equitable access to proven and established interventions for all individuals with ABC, while continuing to drive progress in care and survival outcomes [3].

This manuscript explores the economic burden of ABC, and challenges in accessing diagnostics, treatments, and care, in an evolving treatment landscape. It highlights widening disparities both between and within countries and outlines actionable steps for the ABC community to improve equitable access to comprehensive care. Findings are based on research conducted for the ABC Global Alliance's Global Decade Report 2.0, primarily a targeted literature review, analysis of key studies from the ABC community, and patient and healthcare professional (HCP) surveys conducted in 2024. For detailed methodology with limitations please refer to the Global Decade Report 2.0 [5], in addition to the first manuscript of this special issue.

2. Status in 2005–2015

The 2005–2015 Global Decade Report highlighted the substantial economic burden of ABC on healthcare systems, patients, caregivers, communities, and society [6]. Access to comprehensive ABC care was directly linked to the ability of healthcare systems, or individual patients, to bear the associated cost [6–8]. This led to inequities in access between those who could afford care and those who could not, potentially leading to high levels of financial toxicity for patients and their families.

In 2015, the ABC Global Alliance outlined the goal to: 'Ensure that patients with ABC have access to treatment regardless of their ability to pay' as one of its ten 'Actions For Change' for 2015–2025 [8].

3. A decade in review (2015–2025)

3.1. *The total cost of ABC is rising, impacting access to care*

The total cost of ABC care continues to rise, placing an increasing financial strain across the ABC ecosystem [9–11]. In the United States (US) alone, total costs for ABC are projected to increase by 70 %, from $63.4 billion in 2015 to $107.8 billion by 2025 [9]. This is driven by increasing prevalence, as more individuals are diagnosed, and novel most-often expensive treatments that extend survival but require prolonged and often intensive treatment regimens, are becoming more common [9,10].

Treatment advances are also linked to rising drug costs [10,12]. While not the sole driver for constrained healthcare system budgets, drug prices may influence reimbursement decisions and increase out-of-pocket (OOP) expenses for patients [12–14]. Although the total costs for cancer care remain comparable to some other chronic diseases, per-patient costs for ABC are significantly higher due to its complex, long-term care needs [15–18]. In ABC, end-of-life care also adds substantial cost, with hospitalizations, emergency care, and intensive symptom management, often accompanied by costly interventions with minimal benefit [18–21]. This highlights the need for more effective management and integration of palliative and end-of-life care specialists to enhance patient-centricity and minimize financial burden.

Beyond direct medical costs, the economic impact of ABC on lost productivity, in both paid and unpaid work, is significant but often underestimated [9,11,22,23]. This is notable given ABC predominantly affects women, who often bear the responsibility for unpaid labor such as caregiving and household tasks [24,25]. A United Kingdom (UK) study estimated that lost productivity from unpaid work accounts for nearly one-third of the total indirect societal costs associated with breast cancer [23]. This highlights the broader societal implications of ABC, emphasizing the urgent need for strategies to improve access to comprehensive care and counteract this impact.

3.2. *Diagnostic barriers delay timely ABC diagnosis and optimal treatment*

Timely and accurate diagnosis, staging, and subtyping are essential to ensure that people with ABC receive optimal treatment [26]. However, in LMICs, these fundamental diagnostic capabilities are often unavailable due to a lack of imaging modalities, high-quality pathology facilities, and trained professionals including pathologists [27–31]. This not only leads to poorer outcomes but also increases the risk of inappropriate treatments being used, resulting in wasted resources [32].

Advanced biomarker testing for targets such as breast cancer susceptibility gene 1 and gene 2 (*BRCA1/2*), phosphatidylinositol-4,5-bisphosphate 3-kinase catalytic subunit alpha (*PIK3CA*), or programmed death-ligand 1 (*PDL-1*) remains inaccessible in most LMICs and inconsistently available in HICs [33,34]. Variability in testing and quality of pathology services between HIC facilities may also lead to disparities in the accuracy of tests and appropriate treatment [29,33]. Outdated reimbursement frameworks further compound the problem. Tests and treatments are often reimbursed separately, creating scenarios where a therapy is covered but its corresponding diagnostic test is not, limiting access to only those who can afford to pay OOP expenses [13].

3.3. *Geographic and socioeconomic disparities in treatment access are widening*

Access to ABC treatment remains deeply inequitable along geographic and socioeconomic lines. The ABC Global Alliance 2024 HCP survey (n = 461) demonstrated significantly higher access to all types of therapies (except surgical intervention) in HICs compared with LMICs (Fig. 1). The largest gaps were observed for targeted therapies, likely due to their reliance on advanced diagnostics and biomarker testing, as well as for palliative and supportive care medications, likely because they are often deprioritized by payers [35,36].

Where diagnostic capabilities exist in LMICs, barriers to accessing treatments remain significant, even for medicines listed on the World Health Organization (WHO) Essential Medicines List (EML) [1,37]. While availability of common generic WHO EML medicines has improved modestly worldwide, from 29–54% in 2009 to 38–68% in 2024, shortages persist [38]. In LMICs, preferential distribution to higher-profit markets and challenging economic operating conditions contribute to inefficient third-party distributor models, and inadequate and unreliable supply chains [38–40]. These factors drive up costs, limit supply, and encourage the production of substandard or falsified therapies [41]. In HICs, cheaper generics like tamoxifen and platinum agents also face shortages due to low production incentives, often resulting in prioritization of early breast cancer over ABC [42,43].

Pain and other palliative and supportive care medication, despite its relatively low cost, face similar issues with supply and procurement [36]. In 2021 more than 80 % of reported morphine consumption was in HICs [36]. Stigma and fear surrounding opioid use, more prevalent in regions outside of Western Europe and North America, are pervasive. This contributes to restrictive legislation, high taxation, and limited prescribing by HCPs, further reducing access for patients in need [36,44]. For women with ABC, these issues may be compounded by gender disparities in pain management, with evidence suggesting that female patients often receive less adequate pain relief interventions than their male counterparts [45]. As a result of these complex issues, many patients across geographies bear a high proportion of the cost for both pain

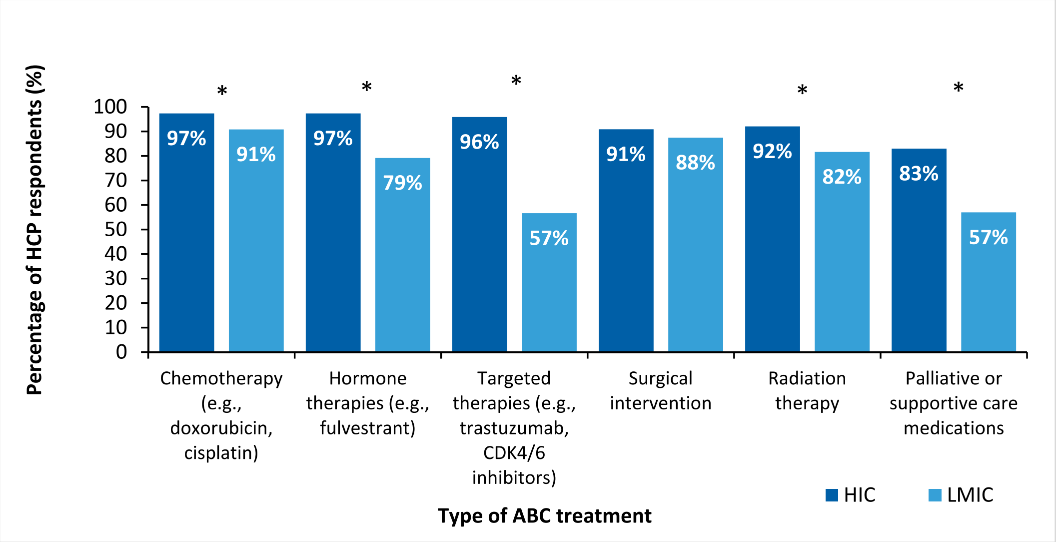

Fig. 1. HCP-reported access to ABC treatment by country income status
Data collected from the ABC Global Alliance 2024 HCP survey (n = 461). Survey question: Survey question: How accessible are the following treatments or interventions for patients with advanced breast cancer at your center? [Not accessible; Sometimes accessible; Easily accessible].
Countries classed by income group according to Word Bank classifications; *<0.05.
ABC = advanced breast cancer; CDK4/6 = cyclin-dependent kinase 4/6; HCP = healthcare professional; HIC = high-income country; LMIC = low-and-middle income country.

and other supportive medications [35,36]. Addressing inequities in access to such medications requires a comprehensive strategy that tackles stigma, reforms restrictive policies, increases payer awareness, and eliminates administrative barriers to ensure equitable pain and side effect management worldwide.

When ABC treatments are available, high OOP costs remain a major obstacle to access in LMICs [1]. Even essential and off-patent therapies like trastuzumab are often only accessible at the risk of catastrophic expenditure [37]. Additionally, evidence suggests prioritization of coverage for early breast cancer compared with ABC in LMICs. For example, in the 2023 European Society of Medical Oncology (ESMO) International Consortium study, 51 % of LMICs reported free access to trastuzumab for ABC compared with 59 % for early breast cancer [1]. Even in HICs, prioritization of early versus late-stage breast cancer is evident; ongoing platinum shortages in the US have prompted American Society of Clinical Oncology (ASCO) guidelines outlining that the use of platinum agents should be limited in the non-curative breast cancer setting in these contexts [42,43].

While HICs tend to offer coverage for a broader range of ABC treatments than LMICs, national reimbursement decisions based on local budget and health system policies drives heterogeneity and unequal access [1,46]. For instance, trastuzumab deruxtecan is reimbursed for HER2-low ABC in Scotland but not in England or Wales [47]. However, progress has been made in countries such as Poland, Romania, Kazakhstan, Australia, and New Zealand, where established treatments like pertuzumab and T-DM1 have become more widely reimbursed over time [1,48,49]. Kazakhstan in particular, demonstrates how expert-led policy reforms based on prioritization frameworks can improve access to valuable cancer treatments even within constrained budgets [50]. Despite the existence of prioritization tools, such as the ESMO Magnitude of Clinical Benefit Scale and ASCO Value Framework, they are often not used by decision-makers leading to inconsistency and confusion in how reimbursement decisions are made [51–53].

In countries lacking universal health coverage, the ability to afford care often depends on insurance status. Many HICs and LMICs transfer some treatment costs to patients, with only 60 % of HICs in the 2023 ESMO International Consortium study reporting that on average patients can access all recommended ABC medicines for free [1]. In the US, OOP costs for therapies like cyclin-dependent kinase 4/6 (CDK4/6) inhibitors can vary widely depending on coverage, though Medicaid expansion has improved timeliness of treatment and reduced racial disparities in ABC outcomes [54–56]. Meanwhile, recent updates to Medicare are expected to further limit OOP payments for patients, improving access for many [57]. By contrast, in Europe, regional differences in healthcare budgets can create a “postcode lottery”, where access to comprehensive ABC care varies widely depending on geographical location [58–60]. The ABC Global Alliance 2024 HCP survey outlined that various treatment types were more accessible in specialized hospitals and facilities, and given that socioeconomic and geographical factors often intersect, this likely contributes to disparities for patients in underserved communities.

3.4. *Radiation therapy resources and infrastructure fall short of growing demand*

Radiation therapy, a critical component of ABC care for bone and brain metastases, has received moderate global investment in recent years. Efforts from the International Atomic Energy Agency (IAEA) together with local patient advocate and government partners, have been instrumental in monitoring and driving changes, with radiation oncology capacity in Africa increasing from 294 to 430 megavoltage units (45 %) between 2012 and 2020 [61]. However, these facilities remain highly concentrated within specific countries and centers, limiting widespread access, and maintenance-related issues often lead to long periods where radiation therapy is not available [61,62]. While less pronounced, trends toward increased capacity have also been observed in Europe over the past decade [63].

Despite efforts, global capacity still falls short of growing demand [64]. In many regions, including some HICs, there is a lack of high-quality, up-to-date, facilities, equipment, and trained personnel [62,65]. Limited prioritization in national cancer control strategies has further constrained the necessary investments to meet these demands [66]. Hypofractionation schemes, which offer more cost-effective and patient-centered radiation therapy options, remain underutilized due to outdated fee-for-service reimbursement models, lack of education, and technical complexities that require specialized expertise [67,68]. These challenges are particularly acute in LMICs, and access remains highly inequitable, ranging from 9.44 to 0.07 machines per million inhabitants in HIC and LMICs respectively [69].

3.5. Access to innovative therapies through clinical trials remains limited

Clinical trials are a vital pathway for accessing innovative therapies in ABC, yet global participation remains persistently low. In the ABC Global Alliance 2024 patient survey (n = 1254), nearly 80 % globally reported no participation in clinical trials (Fig. 2), a figure unchanged from the previous decade [6]. When stratified by income status, participation was slightly lower in LMICs with 84 % of respondents reporting no trial involvement compared to 78 % in HICs. While regional differences in trial site distribution are well-documented, and some individuals may not be eligible or have been offered a trial, these findings suggest that overall uptake remains low regardless of geography [70]. Interestingly, the overall low levels of participation identified by the survey contrast with the ABC Global Alliance HCP survey, where half (51 %) of HCPs reported that clinical trials were easily accessible. This discrepancy suggests that barriers to participation are complex and multifaceted, even where trials are available.

Within countries, trial sites are often concentrated in specialized cancer centers, making them inaccessible to rural and underserved populations [71,72]. Geographical inequities are compounded by referral bias, particularly for marginalized communities [73]. Recent US research shows no difference in clinical trial discussion between HCPs and different ethnic groups and, when offered, patients are equally likely to participate regardless of ethnicity [74]. Nevertheless, while there have been efforts to improve diversity in trial participation, ethnic minorities remain underrepresented in ABC clinical trials globally [75,76]. In the ABC Global Alliance 2024 patient survey, 13 % of respondents reported that they had declined an offer for trial participation, underscoring the need for both improved awareness of the benefits of clinical trials and enhanced accessibility. Addressing referral bias, financial barriers, and geographic inequities is critical to ensuring that all patients can benefit from cutting-edge advancements in ABC care.

3.6. High OOP costs for comprehensive ABC care are increasing financial burden

High OOP expenses for comprehensive ABC care, spanning treatment, supportive services, travel, and sustenance, create a significant financial burden for patients and their families globally. A recent meta-analysis reported pooled financial toxicity rates for breast cancer medical care of 35 % for HIC and 79 % for LMIC [77]. Beyond medical costs, a 2022 US study found that over 20 % of people with breast cancer faced unexpectedly high costs for essentials such as food, travel, and supplements [78]. Additionally, up to 40 % of people with ABC in the US experience debt or bankruptcy due to their diagnosis, forcing many to make difficult trade-offs, including skipping treatments, reducing spending on necessities, or taking on debt [79,80].

The ABC Global Alliance 2024 patient survey further underscored this financial strain, with 60 % reporting a negative impact on their financial security (Fig. 3), worsened for those with dependents or lower household incomes. Interestingly, the survey found no clear correlation between financial insecurity and national income status, contrasting with other research showing widespread financial toxicity among people living with cancer in LMICs [81]. Furthermore, HICs with universal healthcare systems, such as the UK and Australia, reported relatively high levels of financial insecurity compared to the US (Fig. 3). Additional research suggests that this financial burden is worsening, with one European study finding that the negative impact of financial burden on patients' wellbeing has increased from 39 % to 69 % between 2013–2019 [82]. These findings highlight that access to comprehensive care for ABC comes with a cost that not everyone can afford.

3.7. Non-profit organization partnerships are key to improving ABC treatment access in LMICs

Addressing the multifaceted barriers to ABC treatment availability and affordability in LMICs requires a sustainable, multipronged approach involving collaboration with local stakeholders and policymakers. Non-profit organizations play a critical role in bridging gaps and facilitating access in these contexts. Notable examples include efforts led by the Union for International Cancer Control (UICC) and The Max Foundation. In 2022, the UICC, together with partners including the ABC Global Alliance, established the Access to Oncology Medicines (ATOM) Coalition to increase access to essential cancer medicines in LMICs [38,83]. The ATOM Coalition approach includes facilitation of licensing agreements for generics, enabling donation programs, providing a digital procurement platform for affordable medicines, and strengthening local healthcare systems through capacity-building

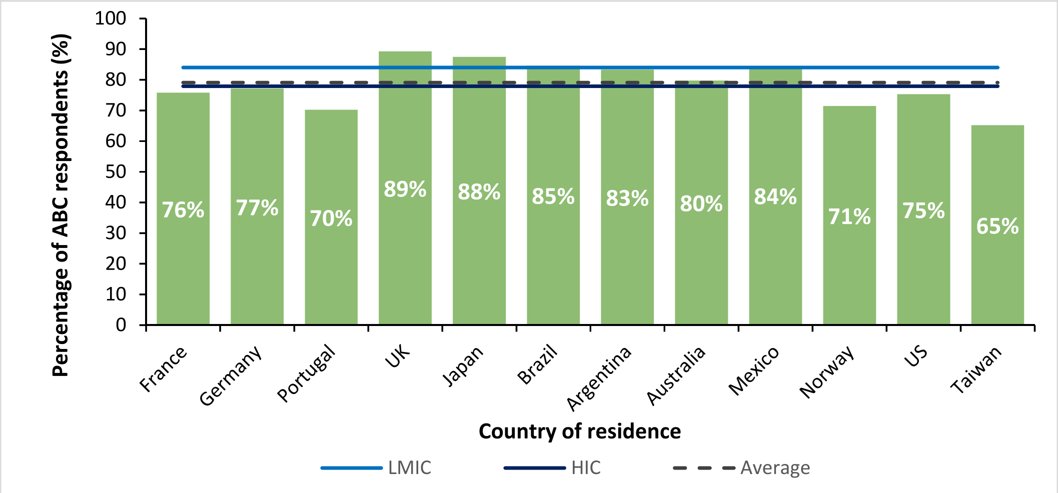

Fig. 2. Patient-reported participation in ABC clinical trials

Data collected from the ABC Global Alliance 2024 patient survey (n = 1254). Survey question: Have you used the following services during your care for advanced breast cancer? Responses 'No, I didn't use' to the option 'clinical trials' are indicated in the figure.

Countries classed by income group according to Word Bank classifications

ABC = advanced breast cancer; HIC = high-income country; LMIC = low-and-middle income country; UK = United Kingdom; US = United States.

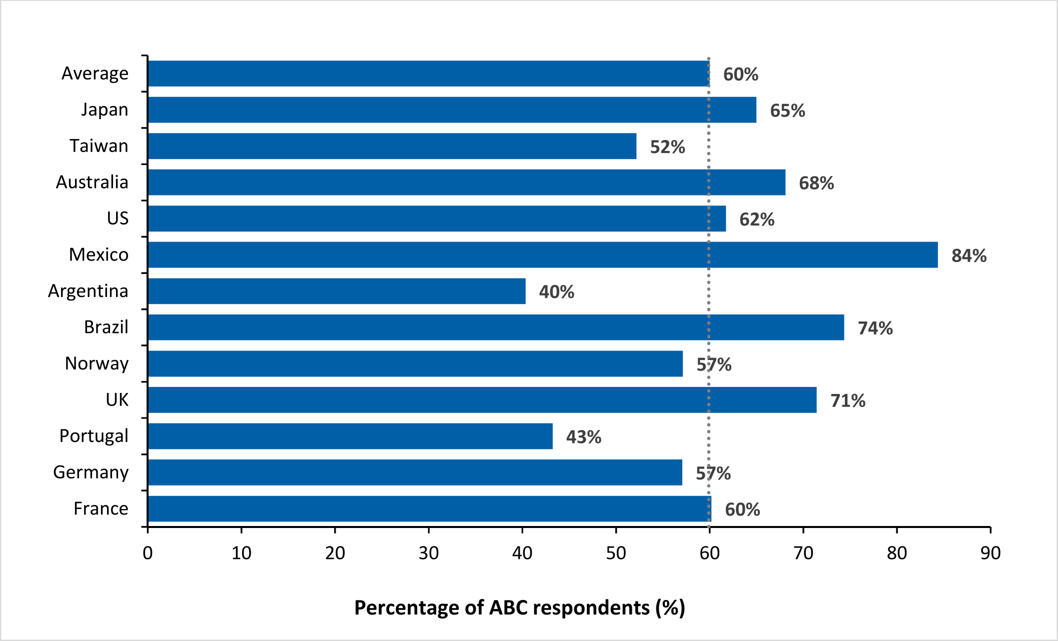

Fig. 3. Patient-reported negative impact on financial security
Data collected from the ABC Global Alliance 2024 HCP survey (n = 461). Survey question: How accessible are the following treatments or interventions for patients with advanced breast cancer at your center? [Not accessible; Sometimes accessible; Easily accessible]
Dotted line indicates the average for all patients answering the survey. Countries with >20 respondents are indicated on the graph.
ABC = advanced breast cancer; UK = United Kingdom; US = United States.

initiatives [38].

The Humanitarian Partnership for Access to Cancer Treatment (PACT), a partnership between The Max Foundation, the ABC Global Alliance, the American Society of Clinical Pathology, and pharmaceutical partners, was expanded in 2023 to provide free treatment to people with HR+/HER2- ABC [84,85]. In addition to supplying life-saving therapies, the program supports healthcare infrastructure, trains HCPs, and offers patient services to ensure sustainable and effective delivery of care [85]. These partnerships demonstrate the critical role of multi-stakeholder collaborations in facilitating access to ABC treatment in resource-constrained settings.

4. Conclusion & future directions

Over the past decade, progress in ABC treatment has been significant, yet the benefits remain unevenly distributed. The changing treatment landscape and increasing economic burden presents policymakers with difficult decisions. While some HICs face delays in adopting new therapies, many LMICs continue to lack reliable access to essential diagnostics and treatments. Meanwhile, clinical trial access, which can offer innovative treatment options and is linked to overall higher quality of care, remains limited for most people with ABC worldwide.

Financial toxicity is a growing global challenge, affecting patients in all settings and extending beyond OOP payment for medical costs to include travel, food, lifestyle adjustments, and lost income. These burdens fall disproportionately on underserved populations, compounding existing inequities.

Ensuring timely, affordable, and equitable access to comprehensive ABC care in an evolving treatment landscape requires sustained investment and coordinated efforts globally.

The ABC Global Alliance community has agreed that this goal should remain in the ABC Global Charter 2025–2035 with the following revised wording: **Improve ACCESS to comprehensive CARE for people with ABC, regardless of their ability to pay.**

Achieving this goal will require sustainable, innovative, and resource-tailored solutions to bridge the widening gaps, and concerted efforts to.

- Work with policymakers to ensure universal coverage and access for ABC diagnostics and treatments under public health systems
- Ensure access to high-quality pathology evaluation of the tumor biology, and effective imaging is available to and covered for all patients with ABC
- Improve continuous financial support for people with ABC by expanding financial assistance programs and navigation, and increasing awareness of financial rights and available services
- Improve access to diagnostics, treatments, and clinical trials by removing additional financial barriers, particularly across diverse ethnic, geographical, and socioeconomic groups
- Fight growing inequalities in access to ABC care by focusing on the needs of underserved groups, across and between countries

For further details and information please review the 2025–2035 ABC Global Charter [86].

CRediT authorship contribution statement

Alexandru Eniu: Writing – review & editing, Validation, Conceptualization. **Runcie C.W. Chidebe:** Writing – review & editing, Validation, Conceptualization. **Peter Vuylsteke:** Writing – review & editing, Validation, Conceptualization. **Mariana Chavez-MacGregor:** Writing – review & editing, Validation, Conceptualization. **Frederique Penault-Llorca:** Writing – review & editing, Validation, Conceptualization. **Gilberto Lopes:** Writing – review & editing, Validation, Conceptualization. **Matti Aapro:** Writing – review & editing, Validation, Conceptualization. **Silvia Neciosup:** Writing – review & editing, Validation, Conceptualization. **Nisha Pillay:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Alexandra Lewis:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Georgia**

Attfield: Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Fatima Cardoso:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Methodology, Funding acquisition, Formal analysis, Conceptualization.

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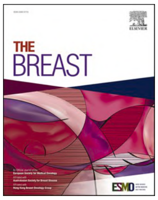

Advancing the legal rights of people with advanced breast cancer: a global expert review and call-to-action for 2025–2035 (Goal 10)

Sarah McHutchison [a], Tarishi Desai [a], Hayley Jones [a], Georgia Attfield [b], Alexandra Lewis [b], Fatima Cardoso [c,*]

[a] *The McCabe Centre for Law and Cancer, Melbourne, Australia*
[b] *VML Health, London, United Kingdom*
[c] *Advanced Breast Cancer (ABC) Global Alliance, Lisbon, Portugal*

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ABSTRACT

A diagnosis of advanced breast cancer (ABC) can be life-altering, presenting challenges that extend far beyond the clinical domain. Among these challenges is the ability to continue or return to work, a decision often influenced by financial necessity, social support, and the psychological desire for normalcy. Yet, systemic barriers such as treatment-related side effects, physical and cognitive impairments, and workplace stigma frequently hinders people with ABC from maintaining employment. The right to work is fundamental to dignity, independence, and quality of life, but for people with ABC this right is too often denied due to a lack of workplace support and insufficient legal protection.

This manuscript explores the current landscape and future opportunities to advance the legal rights of people with ABC. It summarizes research conducted for the ABC Global Alliance's Global Decade Report 2.0. The main findings are: a) ABC diagnosis severely limits work participation and employment retention; b) Legal protections for ABC patients and informal caregivers (often unpaid family members and friends) remain inconsistent globally; c) Flexible work policies can reduce economic loss and support workplace inclusion; d) ABC informal caregiver burden causes significant economic and social impact.

The findings from the ABC Global Alliance's Global Decade Report 2.0 have informed the development of a new ABC Global Charter. The ABC Global Charter 2.0 defines ten new achievable and measurable goals for the decade 2025–2035, aiming at improving the lives of people living with ABC worldwide.

1. Introduction

A diagnosis of advanced breast cancer (ABC) can be life-altering, presenting challenges that extend far beyond the clinical domain. Among these challenges is the ability to continue or return to work, a decision often influenced by financial necessity, social support, and the psychological desire for normalcy. Yet, systemic barriers such as treatment-related side effects, physical and cognitive impairments, and workplace stigma frequently prevent people with ABC from maintaining employment [1–4]. The right to work is fundamental to dignity, independence, and quality of life [1,3], but for people with ABC this right is too often denied due to a lack of workplace support and insufficient legal protection [2].

This manuscript explores the current landscape and future opportunities to advance the legal rights of people with ABC, drawing on findings from the ABC Global Alliance's Global Decade Report 2.0, which includes a legal analysis completed by the McCabe Centre for Law and Cancer, Australia. It also includes insights from the ABC Global Alliance patient survey conducted in 2024. Detailed methodology can be found in the Global Decade Report 2.0 [5].

2. Status in 2005–2015

The period between 2005 and 2015 marked a growing recognition of the challenges faced by people with ABC in the workplace [6]. Although, surveys conducted during this time revealed significant gaps in workplace policies and awareness. In a 2006 UK survey of 219 member organizations of the Chartered Institute of Personnel and Development, 73

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* Corresponding author. Advanced Breast Cancer (ABC) Global Alliance Lisbon, Portugal.
E-mail address: fcardoso@abcglobalalliance.org (F. Cardoso).

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% of respondents reported a lack of formal policies for managing employees with cancer [6]. In a Canadian study published in 2011, 25 % of co-workers expressed concern that they would be expected to 'pick up the slack' from a colleague returning from cancer treatment; feelings that contributed to workplace stigma and discrimination for people with ABC [6].

Disability laws offered limited legal protection, as chronic illnesses such as cancer were not always legally defined as a disability requiring workplace adjustments [6]. Moreover, self-employed individuals and informal ABC caregivers, often unpaid family members, faced economic hardships and social isolation due to the lack of structured benefits or support mechanisms [6].

3. A decade in review (2015–2025)

3.1. *Substantial barriers to employment exist for people with ABC*

The ability to participate in and retain employment is profoundly affected by an ABC diagnosis. According to the ABC Global Alliance 2024 patient survey (n = 1254), 73 % of people with ABC reported that their diagnosis negatively impacted their ability to work or pursue education, while 16 % lost their jobs directly due to ABC.

The challenges faced by individuals with ABC in the workplace are multifaceted. Treatment-related side effects such as fatigue, chronic pain, and cognitive impairment often make it difficult to meet job demands [4]. The emotional toll of living with a terminal illness, including anxiety, depression, and the psychological shock of diagnosis, further complicates workforce participation [4]. Frequent and complex hospital visits, often involving multiple departments, tests, and therapies, and spread across different days and locations, can consume substantial time, energy, and mental bandwidth for people with ABC [7]. Moreover, care regimens are rarely tailored to minimize disruption, and treatment guidelines typically overlook patients' capacity to manage this burden while working. For many, this cumulative time and stress make full-time work unfeasible [8]. Furthermore, informal caregivers, often working family members, can be forced to resign from their workplaces, compounding the overall impact on household economic stability [9]. Studies have shown that individuals diagnosed at more advanced stages of disease are particularly vulnerable to employment disruption [4,10], as are those in physically demanding roles or lower-income households, where workplace accommodations are less common [4,11].

Country-level analysis of the ABC Global Alliance 2024 patient survey revealed employment retention for people with ABC to vary significantly across the globe. Perhaps unsurprisingly, countries reporting higher return-to-work difficulty also had higher reported rates of job loss following an ABC diagnosis. Survey respondents from Japan reported the highest rates of job loss due to ABC (40 %), difficulty returning to work (58 %), and 'being treated differently by colleagues' (38 %) (Fig. 1). These findings could suggest that cultural factors, such as extended working days and rigid workplace expectations, exacerbate the challenges faced by individuals with ABC.

3.2. *Insufficient workplace support is rooted in limited awareness and inadequate policies*

Despite growing recognition of the challenges faced by employees with cancer, workplace accommodations for people with ABC remain inconsistent and often insufficient. The ABC Global Alliance 2024 patient survey revealed that nearly one-third (29 %) of people with ABC reported insufficient workplace support, with particularly high levels of unmet need in Portugal (46 %) and the US (38 %). These results are supported by a 2022 Portuguese survey, which found that 39 % of women with ABC left their work prematurely, largely for medical rather than personal reasons [10]. A 2021 UK-based study further supported results from the ABC Global Alliance 2024 patient survey, with approximately half of respondents with advanced cancer feeling that they would benefit from additional workplace accommodations, such as flexible working schedules, remote work options, or time off for medical appointments [1]. Notably, the study also found that individuals with advanced cancer were less likely to receive workplace support than those with early-stage disease [1].

One reason for this gap in workplace accommodations is employers' reluctance to formalize cancer-specific workplace policies. A 2024 UK study found that only 4 % of workplaces had cancer-specific policies, despite nearly half of human resource managers acknowledging their necessity [12]. Even when policies exist, they are often poorly communicated, leaving employees unaware of their rights and entitlements [13]. Furthermore, many employers lack the training needed to effectively support employees with ABC, creating a disconnect between policy intentions and practical implementation [13], and leaving people with ABC particularly vulnerable in the workplace.

Stigma and discrimination further compound these structural gaps. Misconceptions about the capabilities of individuals with ABC can fuel social exclusion, wrongful dismissal, and reluctance among employees

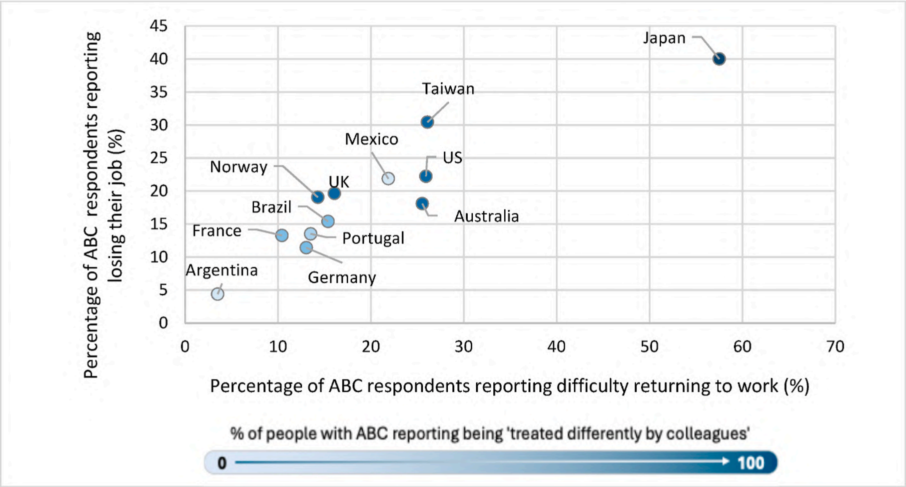

Fig. 1. Patient-reported impact of ABC on employment retention and returning to work [5] Data collected from the ABC Global Alliance 2024 patient survey (n = 1254). Survey questions: Which of the following have you experienced as a result of your advanced breast cancer diagnosis? [option to select: I lost my job]. Have you faced any difficulties from your employer in returning to work after undergoing treatment for advanced breast cancer? [Yes; No; I don't know or prefer not to answer]. ABC = advanced breast cancer; UK = United Kingdom; US = United States.

to disclose their diagnosis. Colleagues can often feel uncertain about how to support someone returning to work, particularly when sensitive topics like mortality are involved. This stigma disproportionately affects marginalized populations, including older adults and those from ethnic minority groups, worsening existing inequalities [4].

Flexible work accommodations are a critical part of overcoming these challenges and allowing people with ABC to maintain or return to work. In the Portuguese study spanning 2019–2021, using national prevalence estimates of 2151 working-aged women with ABC and average wage data, researchers modelled that disease-related nonemployment resulted in €28.7 million in lost productivity over three years. They projected that a subsidized part-time work scheme could halve these productivity losses (saving ≈ €14.3 million) and outweighing the extra €12 million in government subsidies, the scheme would deliver a net economic gain of €2.4 million [10]. This evidence highlights how well-designed flexible workplace policies can support people with ABC to remain employed, delivering benefits not only for people with ABC, but also for public finances and the broader economy.

3.3. National legislation plays a crucial role in safeguarding the rights of people with ABC

A 2024–2025 review of national legislation by the McCabe Centre for Law & Cancer (see Global Decade Report 2.0 for further detail [5]) highlights significant gaps in the extent of workplace protections across 24 countries from diverse regions and resource levels. This is despite all countries included in the review having international human rights law obligations to advance work rights and non-discrimination. While some progress has been made and several countries have laws in all key areas (Table 1), the review found that no country has national legal frameworks in place that are sufficiently comprehensive to fully uphold the rights of individuals with ABC and their informal caregivers.

3.3.1. Reasonable accommodations and flexible work

Of 24 countries surveyed by the McCabe Centre for Law & Cancer, 21 have laws mandating reasonable accommodations in the workplace, defined as adjustments to ensure that employees with disabilities can perform their job duties without undue hardship to the employer. However, whether these laws (and more general anti-discrimination

Table 1

Key workplace protections in national legislation across 24 countries* [5]

Country	Short-term employer-funded sick-leave	Paid long-term sickness	Paid leave (caregiver)	Flexible work request	Flexible work request (caregiver)	Reasonable accommodations
Australia	🟢	🔴	🟢	🟢	🟢	🟢
Brazil	🟢	🟢	🔵	🔴	🔴	🟢
Canada	🟢	🟢	🟢	🟢	🟢	🟢
China	🟢	🟢	🔴	🔴	🔴	🔴
Colombia	🟢	🟢	🔴	🟢	🟢	🟢
France	🟢	🟢	🟢	🟢	🟢	🟢
Indonesia	🟢	🔴	🔵	🔴	🔴	🟢
Iran	🟢	🟢	🔴	🔴	🔴	🔴
Japan	🔴	🟢	🟢	🔴	🟢	🟢
Kenya	🟢	🔴	🔴	🟢	🔴	🟢
Mexico	🟢	🟢	🔴	🔴	🔴	🟢
New Zealand	🟢	🔴	🟢	🟢	🟢	🟢
Nigeria	🟢	🔴	🔴	🔴	🔴	🔴
Norway	🟢	🟢	🟢	🟢	🟢	🟢
Philippines	🟢	🟢	🔴	🔴	🔴	🟢
Poland	🟢	🟢	🟢	🟢	🟢	🟢
Portugal	🟢	🟢	🟢	🟢	🟢	🟢
Samoa	🟢	🔴	🔴	🔵	🔵	🟢
South Africa	🟢	🟢	🔴	🟢	🔴	🟢
Spain	🟢	🟢	🟢	🟢	🟢	🟢
Sweden	🟢	🟢	🟢	🟢	🟢	🟢
Uganda	🟢	🔴	🔴	🟢	🔴	🟢
UK	🟢	🟢	🔴	🟢	🟢	🟢
USA	🔴	🔴	🔴	🟢	🔴	🟢

*Data from the McCabe Centre for Law and Cancer 2024–2025 analysis. All care was taken to ensure accuracy of the data at the time of legal analysis. The analysis should not be relied on as legal advice as laws may change. Results are based on the extent to which national legislation include key workplace protections, and do not address implementation in practice.

UK = United Kingdom; USA = United States of America.

Red: No national legislative entitlement found.

Blue: National legislative entitlement limited to certain employee groups (such as public servants).

Green: National legislative entitlement found.

protections) apply to individuals with ABC often depends on how "disability" is defined within national legislation. Only 12 countries explicitly include cancer or chronic illness as protected categories under anti-discrimination laws.

Flexible work arrangements are another critical area of need. Fifteen of the countries surveyed provide employees with the right to request flexible work, but these laws often lack substantive guarantees, leaving significant discretion to employers to take their business needs into account. In many cases, eligibility criteria, such as minimum employment duration, further limit access to these accommodations.

3.3.2. Employer-funded sick leave and job protection

Short-term employer-funded sick leave is available nationally in nearly all surveyed countries (22 of 24), but the duration (of particular importance in incurable diseases such as ABC), pay rate, payment funding source and eligibility criteria vary widely. For example, in Indonesia, employees are entitled to 12 months of sick leave (paid on a sliding scale) [14], while in New Zealand, the entitlement is just ten days at most per year [15]. Long-term leave options are even more limited, often forcing employees to exhaust other entitlements such as paid holiday leave. In some of the countries surveyed, employees who remain unable to return to work following the expiration of sick leave entitlements may qualify for social security or social insurance benefits. The variability in approach to paid sick leave and social security directly impacts job security including through influencing employer practices.

Dismissal protections are essential to ensure job security for individuals with ABC who need to take time off work. Most countries have federal laws prohibiting dismissal based on discriminatory grounds, or where the dismissal is without cause or otherwise unfair, but enforcement mechanisms are often weak. In some jurisdictions, the burden of proof lies with the employee, creating additional barriers to justice.

The majority of countries reviewed (22 of 24) had federal laws protecting individuals against employment discrimination based on disability or protected characteristics. These laws varied substantially by scope, type of discrimination considered unlawful, extent of employer responsibilities, complaint and enforcement avenues, and remedies. In only 12 countries, the laws clearly apply to individuals living with ABC. In other countries, cancer may be listed as a protected characteristic under some non-discrimination laws but considered as a disability under others. This nomenclature may influence whether anti-discrimination laws are likely to include people with ABC, depending upon how disability is defined under the relevant law. As such, determining whether a person is considered to have a disability for the purpose of discrimination protection is not always clear-cut and increases inequalities.

3.3.3. Informal caregiver protections

Caring for someone with ABC can have a substantial impact on employment, and informal ABC caregivers also require robust legal protections. A 2021 study found that one-third of ABC caregivers changed employment, with 13 % leaving work entirely. Many reduce working hours, switch to less demanding roles, or take formal leave, while some increase workloads to maintain financial stability [16]. In Brazil, informal caregivers of people with ABC lose more than 115 million hours annually [17], highlighting a substantial, yet often hidden, economic burden.

Furthermore, only 12 countries surveyed by the McCabe Centre for Law & Cancer extend flexible work rights to caregivers, and only 10 offer paid leave to all informal caregivers, with duration and eligibility criteria varying significantly. For example, France and Japan mandate that employers cannot generally refuse caregiver leave applications if requirements are met, while some countries provide only unpaid leave or no leave at all. Financial incentives, such as caregiver tax credits, are available in some countries, but these measures are not universally accessible.

3.4. Where legal protections exist, implementation and enforcement remain a significant challenge

Key barriers to implementation and enforcement of legal workplace protections for people with ABC span policy, organizational, and cultural areas (Table 2).

Opportunities to enact reform, include.

- Improving access to flexible work by reforming laws to limit the extent of employer discretion to refuse flexible work requests (while at the same time balancing employers' needs and, when necessary, consider compensation to the employer by the state)
- Advocating for the extension of paid and unpaid leave entitlements for people with ABC and their caregivers to ensure job security and a level of income protection
- Clarifying that discrimination protections apply to people with ABC and their carers by reforming laws as appropriate in each country
- Increasing social work, legal and financial advice programs to support people with ABC to navigate their work-related entitlements
- Advocating for legal reforms to give caregivers a similar level of protections as the people they care for
- Ensuring that all law reform efforts comply with international human rights obligations, including those established by the Convention on the Rights of Persons with Disabilities, and involve people with lived experience.
- Sharing examples of innovative legal and policy approaches promoting work rights for people with ABC to inform law reform efforts across the globe

4. Conclusion and future directions

Too often, a limited understanding of the lived experiences of people with cancer fuels stigma, weak support systems, and discriminatory practices, particularly in the workplace. Legislative and systemic gaps reveal persistent misconceptions about the value and capability of those living with incurable illnesses in employment settings. While some countries have implemented legislative protections in certain areas, none have introduced sufficient workplace entitlements to fully uphold the rights of individuals with ABC. There is a need to strengthen legal protections, while promoting workplace inclusion and challenging

Table 2

Key barriers to implementation and enforcement of legal workplace protections for people with ABC [5].

Challenge	Description
Ambiguity in legal definitions	Unclear definitions of "disability" create ambiguity about the applicability of laws to individuals with ABC
Inconsistent accommodations	Employer discretion regarding flexible work and the nature of reasonable accommodations means these arrangements often fail to meet employees' needs and/or expectations, particularly in smaller businesses with limited resources which are often exempt from legal requirements
Lack of awareness	Both employees and employers frequently lack knowledge of existing rights, entitlements, and obligations, limiting their ability to advocate for or provide necessary support
Barriers to legal recourse	High costs and lengthy delays associated with litigation, and the onus of proof on employees, deter individuals from pursuing claims of wrongful dismissal or discrimination
Insufficient prevention of discrimination	Insufficient proactive obligations on employers mean laws are often ineffective at preventing discrimination from occurring.
Weak enforcement mechanisms	Penalties for breaches of workplace rights are generally inadequate to encourage compliance

Based on findings from the ABC Global Alliance and McCabe Centre for Law and Cancer 2024–2025 analysis.

societal stigma, to empower individuals with ABC to maintain their dignity, independence, and quality of life. As we embark on the next decade, the ABC Global Alliance community has agreed upon the goal for 2025–2035: **to improve the legal rights of people with ABC, including the right to continue or return to work**. To achieve this, future efforts must focus on.

- Advocating for improved laws and policies providing social and financial protections for people with ABC and their informal caregivers, for example, through recognition of advanced cancers (including ABC) as a disability without reinforcing stigma
- Empowering people with ABC, their informal caregivers, and HCPs with clear, accessible information about legal rights and obligations
- Ensuring that supportive, flexible return-to-work entitlements and programs are available for people with ABC, enabling them to return to work, if they wish to do so
- Educating employers about ABC and their legal obligations to promote non-discrimination and the right to work for people with ABC and their informal caregivers
- Encouraging governments to review their work rights and anti-discrimination laws through the point of view of individuals with ABC and their informal caregivers

For further details and information please see the Global Decade Report 2.0 [18].

CRediT authorship contribution statement

Sarah McHutchison: Writing – review & editing, Writing – original draft, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Tarishi Desai:** Writing – review & editing, Writing – original draft, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Hayley Jones:** Writing – review & editing, Writing – original draft, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Georgia Attfield:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Alexandra Lewis:** Writing – review & editing, Writing – original draft, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Fatima Cardoso:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Methodology, Funding acquisition, Formal analysis, Conceptualization.

Declarations

FC: Paid advisory role for Amgen, Astellas/Medivation, AstraZeneca, Bayer, Celgene, Daiichi Sankyo, Eisai, GE Oncology, Genentech, Gilead, GlaxoSmithKline, IQVIA, Macrogenics, Medscape, Merck Sharp & Dohme, Merus BV, Mylan, Mundipharma, Novartis, Pfizer, Pierre Fabre, prIME Oncology, Roche, Sanofi, Samsung Bioepis, Seagen, Teva, and TouchIME.

HJ, SM, TD, GA, AL: Authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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