Advanced Breast Cancer Global Decade Report 2.0 2015–2025

Knowledge in Motion
A Decade Reviewed, a Decade Defined

November 2025

This report is dedicated to the patients around the world who are facing, will face, or have already lost their lives to advanced breast cancer far too soon, as well as to all those who have worked with the ABC Global Alliance and are no longer with us.

It is our promise to you and your loved ones that we will continue working and fighting on your behalf.

This is an interactive report PDF.
The menu and arrow buttons are clickable to help you navigate quickly and efficiently to your desired sections.

Our 10 GOALS

Foreword

Ten years ago, the Advanced Breast Cancer (ABC) Global Alliance was created, building on the work of the ABC Consensus Conference and Guidelines, to confront one of the most persistent and overlooked challenges in breast cancer: how to ensure that every person living with advanced or metastatic disease could live not only longer, but better. We knew progress was possible, but only if clinicians, patients, advocates, researchers, policymakers, and industry acted together with a shared purpose.

In the decade since, we have seen what that collective commitment can achieve:

- Survival has significantly improved for two of the three main ABC subtypes.
- The first truly international ABC consensus guidelines have been embedded in practice across multiple regions.
- Registries and real-world data systems have begun to make the invisible visible.
- Conversations around quality of life, stigma, workplace rights, and psychosocial support have moved closer to the center of cancer policy.

These gains prove that progress is not theoretical, it is real, and it changes lives. But progress only happens when evidence, innovation, and advocacy move together. We call this "Knowledge in Motion": knowledge that does not sit on a page but is transformed into action.

Yet progress brings new realities. Living longer with ABC brings new challenges: managing long-term treatment side-effects and their impact on quality of life, ensuring equitable access to biomarker testing and biomarker-driven therapies, addressing financial toxicity, safeguarding employment and legal rights for both patients and their informal caregivers, and closing persistent (and increasing) survival gaps between and within countries. We have raised the bar for what is possible; now we must ensure that every person living with ABC has the chance to reach it.

The ABC Global Decade Report 2.0 (2015–2025) captures this pivotal moment. It is both a reflection on ten years of collective effort, the progress, the setbacks, the lessons, and a springboard for the next decade. It shows where proven potential must become standard practice everywhere.

Alongside this report, we launch the ABC Global Charter 2025–2035: ten renewed goals shaped by patients, clinicians, advocates, industry, and policy leaders worldwide. These goals challenge all of us to keep momentum, confront inequities that remain, and ensure that "as long as possible" also means "as well as possible" for every person living with ABC, irrespective of geography or circumstance, leaving nobody behind. Through these goals, we strive to change the course of advanced/metastatic breast cancer, transforming it into a manageable chronic disease and, ultimately, one that is potentially curable in the foreseeable future.

This second Global Decade Report would not exist without the courage of the patients who shared their experiences, the dedication of the researchers and healthcare professionals who contributed data and insight, and the tireless work of our Steering Committee, advisors, partners, and member organizations in more than 120 countries.

To all of you, I offer my deepest gratitude.

The last decade has shown that progress is possible.
The next decade must prove that progress can be equal for all.

With the Global Decade Report 2.0 and the new ABC Global Charter, we begin this new chapter—determined to make the gains of the past ten years count for every person, in every region, in the decade ahead.

Dr Fatima Cardoso,
President, ABC Global Alliance
November 2025

Introduction

UNDERSTANDING ADVANCED BREAST CANCER

Breast cancer is one of the world's most pressing health challenges, with approximately 2.3 million new cases and 666,000 deaths every year.[1] Advanced breast cancer (ABC), also known as metastatic, stage IV, or secondary breast cancer, occurs when the cancer spreads to other parts of the body such as the bones, liver, lungs, or lymph nodes. While survival for early-stage breast cancer has improved dramatically, outcomes for ABC remain poor: just 32% of women and 20% of men live five years beyond diagnosis.[2]

THE ABC GLOBAL ALLIANCE

The ABC Global Alliance was initially founded in 2016 as a global multi-stakeholder platform or federation (since its members are organizations, not individuals) dedicated to advanced/metastatic breast cancer. Originally established as an initiative of the European School of Oncology (ESO), it is now an independent non-profit organization headquartered in Portugal, uniting over 300 organizations across more than 120 countries. Its mission is bold: 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.

A DECADE REVIEWED, A DECADE DEFINED

In 2016, the Global Status of ABC/MBC Decade Report was published, providing an in-depth assessment of the global ABC landscape during 2005–2015.[3] This report identified critical gaps in patient care, policy, society and community impact, and the scientific landscape. It laid the foundation for the first ABC Global Charter, which introduced 10 ambitious goals to drive progress in ABC in the following decade, from 2015 to 2025.[4]

As the 2015–2025 decade comes to an end, the ABC Global Alliance has produced the Global Decade Report 2.0 (2015–2025), which evaluates progress made against the 10 goals of the original ABC Global Charter. This report reflects on advances and celebrates successes, but also highlights the significant challenges that persist in ABC care today. Based on the findings of this report—and following intense discussion among patients, patient advocates, industry, HCPs, and policymakers—the ABC Global Alliance has updated the ABC Global Charter, outlining a new set of 10 goals for the next decade, from 2025 to 2035.

TERMINOLOGY AND CONSIDERATIONS

Throughout the report there are some nuances in use of terminology that should be considered:

- The terms ABC (advanced breast cancer) and MBC (metastatic breast cancer) are most commonly used in the literature to describe this disease. In this report, we use the term 'ABC,' but our research includes studies referring to 'advanced breast cancer,' 'metastatic breast cancer,' 'secondary breast cancer,' and 'stage IV breast cancer' to ensure a comprehensive review of all relevant evidence.
- Approximately 99% of breast cancer cases occur in women, and data on men with ABC remain scarce. Male breast cancer is rare with a lifetime risk of 1 in 726, significantly lower than the 1 in 8 risk for women.[5] This rarity presents unique challenges, including limited research and awareness among people with ABC, clinicians, and the general public, contributing to disparities in outcomes. A 2019 analysis of over 1.8 million women and 16,025 men found that males with breast cancer had a 19% higher mortality rate than women.[6] Moreover, a 2023 study revealed that, unlike in women, male breast cancer survival rates have not significantly improved over the past 30 years.[7] While many insights in this report may apply to men, dedicated research is essential to address the distinct needs of males with breast cancer and improve their outcomes. For inclusivity, this report will refer to 'people with ABC,' except when referring to issues exclusively related to women.

RESEARCH METHODS AND INSIGHTS

Both this report and the new ABC Global Charter (2025–2035) have been informed by extensive primary and secondary research conducted throughout 2023–2024, and expert consensus to capture the current landscape of care in ABC.

Mapping the Global Landscape: Literature, Guidelines, and Country-level Analysis

To gain a comprehensive understanding of the current landscape of ABC care and define ambitious goals for the next decade, a variety of secondary research was conducted, alongside primary research interviews (**Table 1**). Detailed information on all research approaches is included in the appendices.

Secondary research conducted for this report focused on 14 countries, selected by the ABC Global Alliance Steering and Advisory Committees to provide a truly global perspective on ABC care. These countries, including a mix of high-, middle-, and low-income nations across all continents, offer a snapshot of diverse healthcare systems and sociodemographic contexts. They include Australia, Brazil, China, Colombia, France, India, Japan, Mexico, Nigeria, Poland, Portugal, South Africa, the United Kingdom, and the United States. While these 14 countries were the primary focus, insights from other countries were also welcomed and integrated throughout this report.

This selection of countries provides a broad global view, but it should be noted that most published data originate from high-income countries and significant information gaps persist in low- and middle-income regions. While many challenges faced by people with ABC are shared worldwide, country of residence continues to influence diagnosis, treatment, access to support, and overall quality of life.

Table 1: Overview of research methodologies employed throughout the report

Research methodology	Appendix	Related goal(s)
Clinical Targeted Literature Review	Appendix I	**Goal 1** Survival outcomes
Interviews with Global Registries	Appendix II	**Goal 2** High-quality data
Quality of Life Instrument Conversion	Appendix III	**Goal 3** Quality of life
Humanistic Targeted Literature Review	Appendix IV	**Goal 3** Quality of life
Analysis of Multidisciplinary Team Integration in ABC Care	Appendix V	**Goal 4** Multidisciplinary care
Global Audit of Communication Skills Training	Appendix VI	**Goal 5** HCP-patient communication
ABC Global Alliance Member Questionnaires	Appendix VII	**Goal 6** Informational needs **Goal 7** Support services **Goal 8** Stigma, isolation, and understanding
Support Service Policy and Funding Analysis	Appendix VIII	**Goal 7** Support services
Social Listening Analysis	Appendix IX	**Goal 8** Stigma, isolation, and understanding
Economic Targeted Literature Review	Appendix X	**Goal 9** Access to comprehensive care
McCabe Centre for Law and Cancer Analysis	Appendix XI	**Goal 10** Legal and workplace rights

Capturing Real-World Experiences: Patient and Healthcare Professional Perspectives

Primary research for this report was conducted through two global quantitative surveys targeting HCPs and people with ABC between April and June 2024.

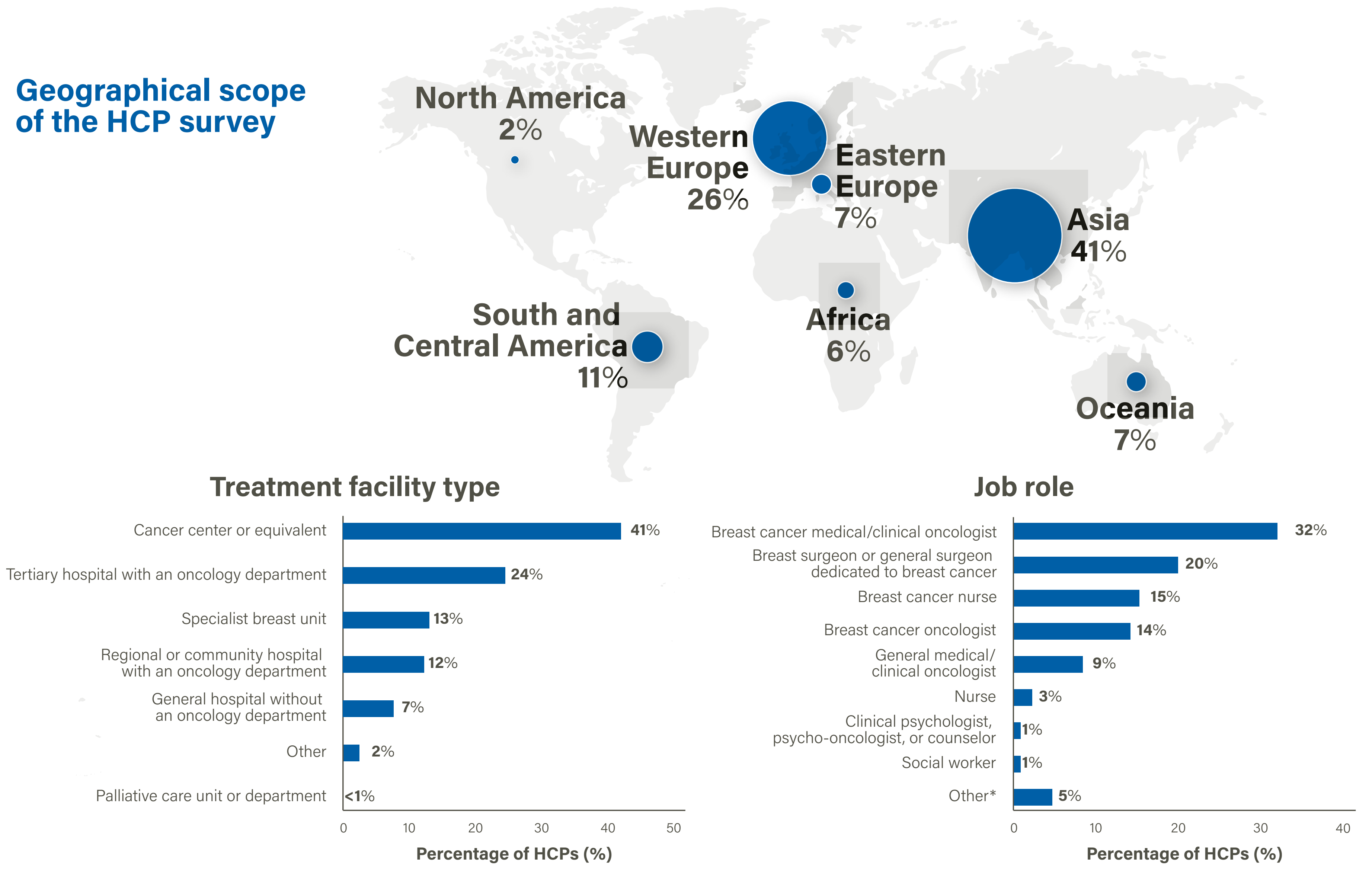
Surveys were disseminated online, so findings are influenced by local internet access. As responses are self-reported, there is a risk of recall or social desirability bias; HCPs may answer in line with perceived professional norms, while patients may participate due to personal motivations, potentially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

Healthcare Professional Survey

The ABC Global Alliance 2024 HCP survey collected 461 responses from 78 countries; exploring ABC care delivery, communication, access to treatments and support services, treatment beliefs, and providing a comprehensive overview of current practices (**Figure 1**). More than half (62%) of respondents had over 11 years of experience in treating ABC, offering valuable insight into longstanding practices and evolving standards of care.

Results of the survey should be considered in the context of its limitations. The regional representation of respondents was uneven, with 41% of respondents from Asia compared to only 2% from North America, which may skew the findings. Additionally, certain specialties, such as dieticians and pharmacists, were underrepresented, with very few responses from these groups, making it difficult to draw definitive conclusions about their roles in ABC care.

Figure 1: Distribution of responses to the ABC Global Alliance 2024 HCP survey



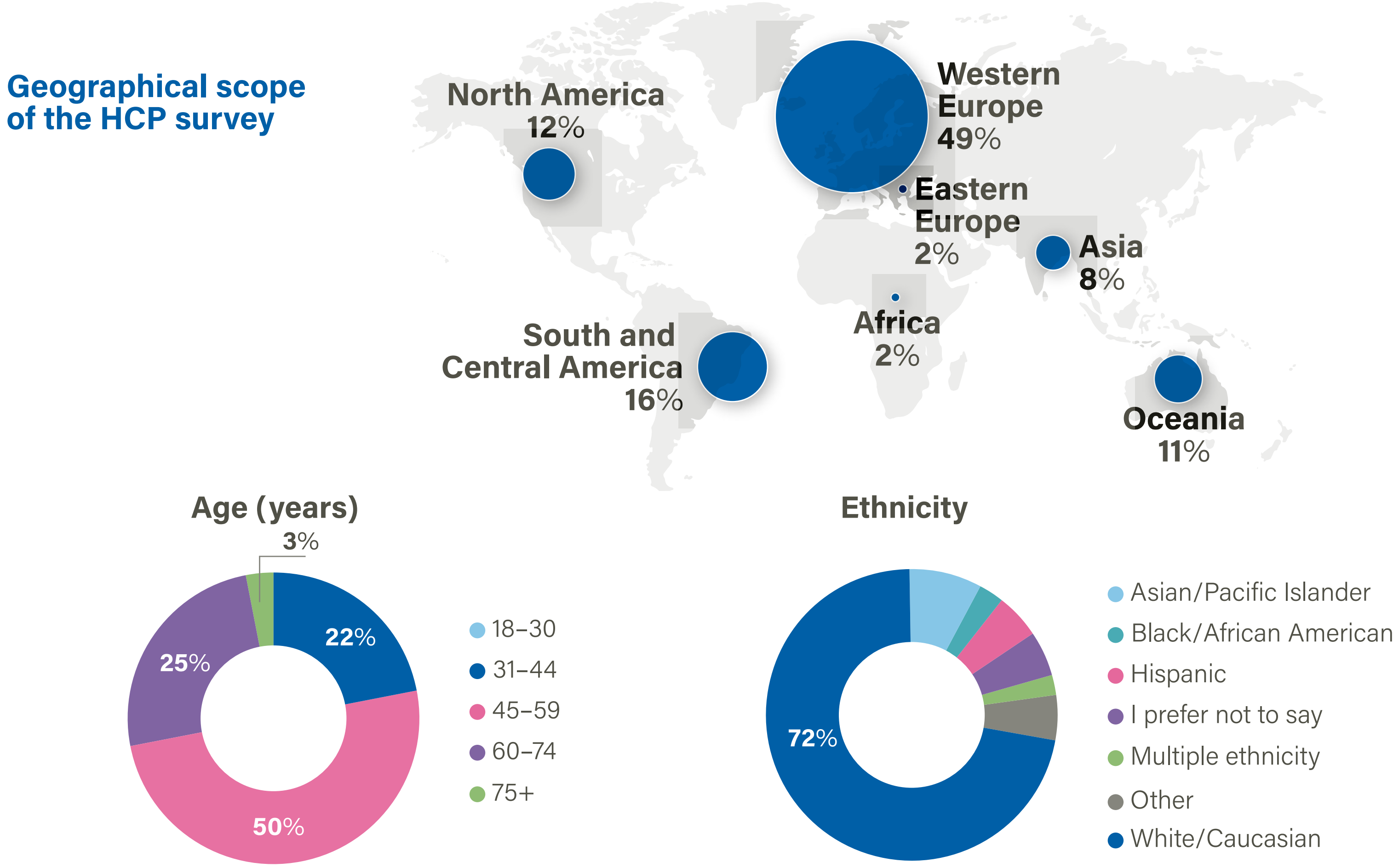
* Other HCPs include: breast data manager/administrative personnel, physical therapist/physiotherapist, breast pathologist, breast radiographer, breast radiologist, dietician or nutritionist, and oncology pharmacist.

Patient Survey

The ABC Global Alliance 2024 patient survey captured the lived experiences of 1,254 people with ABC across 59 countries, examining treatment, daily life, access to care, decision-making, information availability, emotional burden, and impact on work and daily activities (**Figure 2**).

The survey offers a strong dataset for analysis; however, around half of respondents (49%) were from Western Europe meaning results may reflect healthcare experiences from this region more strongly. Additionally, the predominance of White/Caucasian respondents (72%) means the findings may not fully represent the perspectives of different racial and ethnic groups.

Figure 2: Distribution of responses to the ABC Global Alliance 2024 patient survey



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This report could not have been produced without the generous guidance and feedback from the ABC Global Alliance Steering Committee and advisors. These global multi-stakeholder groups of experts, comprised of patients, patient advocates, HCPs, industry, and policy experts, provided valuable perspectives to shape the direction of the report.

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Acknowledgements

Funding Support

The ABC Global Decade Report 2.0 2015–2025 was funded by the ABC Global Alliance. The ABC Global Alliance received unrestricted educational grants from the Breast Cancer Research Foundation (BCRF), Gilead, Menarini, Novartis, Pfizer and Roche. These grants supported the research that shaped the report but none of the companies interfered in the scientific content. Some employees of the companies were invited to be members of the Steering or Advisory Committees but as individuals and not representing their employer.

Data Contributors

The ABC Global Alliance sincerely thanks all organizations and partners who contributed data to support the development of the ABC Global Alliance Decade Report 2.0, including AstraZeneca, Cankado, Daiichi Sankyo, Ecorys, Eli Lilly and Company, Epidemiological Strategy and Medical Economics (ESME) registry, the European Cancer Organization (ECO), Europa Donna – The European Breast Cancer Coalition, European Society of Breast Cancer Specialists (EUSOMA), Gilead Sciences, International Agency for Research on Cancer (IARC), International Psycho-Oncology Society (IPOS), McCabe Centre for Law and Cancer, Menarini Stemline, Merck, NaoME (the National Audit of Metastatic Breast Cancer), Novartis, the OPAL Registry, PLMJ, Pfizer, Rethink Breast Cancer, Roche, Susan G. Komen, Te Rēhita Mate Ūtaetae – Breast Cancer Foundation National Register, The Lancet Commission, Union for International Cancer Control (UICC), Working with Cancer, and Young Survival Coalition.

Other Acknowledgements

The ABC Global Alliance is deeply thankful to all who have contributed to the development of this report, by sharing experience and expertise, and both published and unpublished data, responding to surveys, and taking part in interviews.

A special thank you to the members of the ABC Global Decade Report Scientific Committee for their time, dedication and expertise, to the ABC Global Alliance Board of Directors, General Assembly leadership and Chief Operating Officer for their continuous support, and to the VML Health team, led by Sarah-Jane Barker, Alexandra Lewis, and Georgia Attfield, for outstanding research and coordination work.

The ABC Global Alliance acknowledges the significant contributions made to date by so many healthcare practitioners, patient support organizations, charitable groups, and experts worldwide, who have dedicated their time to publish, share experiences, and strengthen the foundation of ABC advocacy.

Structure of the Report

This report is divided into 10 chapters, each corresponding to one of the 10 goals of the original ABC Global Charter (2015–2025). Each chapter reflects on the status in 2015, critically analyzes progress made over the past decade, highlights remaining challenges, and offers insights into future opportunities for advancing care for people with ABC. It also provides the new wording for the respective goals of the new ABC Global Charter (2025–2035).

The structure is designed to facilitate easy navigation and to enable the reader to focus on specific goals and areas of interest:

- **GOAL 1: Survival** outcomes in people with ABC
- **GOAL 2:** Collection of **high-quality data** in ABC
- **GOAL 3: Quality of life** for people with ABC
- **GOAL 4:** Availability and access to care from a **multidisciplinary** ABC team
- **GOAL 5: Communication** between HCPs and people with ABC
- **GOAL 6: Informational** needs of people with ABC
- **GOAL 7: Support services** for people with ABC
- **GOAL 8: Stigma**, **isolation**, and **understanding** of ABC
- **GOAL 9: Access** to comprehensive ABC care
- **GOAL 10: Legal** and **workplace rights** for people with ABC

1 **Survival** outcomes in people with ABC

Survival outcomes in people with ABC

INTRODUCTION

Advanced breast cancer (ABC) represents a major public health challenge, with incidence and prevalence rates rising worldwide.[8] In 2022, an estimated 670,000 people died from breast cancer globally, with most of these deaths attributable to ABC.[9-10] While the past decade has brought significant advances that have extended the life expectancy of many people with ABC, the disease remains incurable in most cases.[8,11] Improvements in progression-free survival (PFS) and overall survival (OS) have been seen across all ABC subtypes; however, disparities in outcomes persist—both between subtypes and specific subpopulations of people with ABC.[11-12]

This chapter describes the key treatment advancements over the past decade that have contributed to improved survival outcomes, while examining the persistent disparities between and within countries, and among subpopulations. It draws on findings from a targeted literature review of clinical trials spanning 2015–2024 (see **Appendix I**), alongside a review of recent real-world evidence.

STATUS IN 2005-2015

The 2005–2015 Global Decade Report highlighted a sobering reality: despite advances in early breast cancer survival outcomes, progress for ABC remained minimal.[3] Between 2005 and 2015, gains in PFS and OS were modest, with 5-year survival rates stagnating at around 25%.[3]

Compared with other metastatic cancers, ABC had seen fewer novel therapy approvals, and the report emphasized the urgent need for more research to deepen disease understanding, particularly in biomarker identification, to enable the development of targeted therapies.[3] Outcomes for triple-negative ABC, a subtype that disproportionately affects Black people, were especially poor.[3] At the same time, global disparities in survival outcomes persisted, driven by unequal access to early detection, timely diagnosis, and comprehensive treatment, including surgery, radiation therapy, and systemic treatments.[3]

Before 2012, almost no global guidelines specific to ABC existed, leading to significant gaps in treatment recommendations, particularly for people with brain and bone metastases.[3] The report called for the development of high-quality, comprehensive, international guidelines for ABC, to establish a global standard of care, support physician decision-making, inform cancer control strategies, and reduce inequities globally.[3]

Based on the report findings, the 2015–2025 ABC Global Charter set the ambitious goal of doubling the median overall survival for people with ABC as one of its ten 'Actions For Change.'[4]

A DECADE IN REVIEW (2015-2025)

Evolving biomarker-driven treatments are transforming ABC disease understanding and outcomes

Historically, ABC has been categorized into three main subtypes based on hormone receptor (HR) and human epidermal growth factor receptor 2 (HER2) status: HR-positive and HER2-negative, HER2-positive regardless of HR status, and triple-negative (**Figure 3**).[3] Recent discoveries in ABC biology and biomarker research have enabled more precise and targeted treatment approaches within these subtypes.

A major breakthrough in the last decade was the identification of HER2-low tumors as potential candidates for a new generation of HER2-targeted antibody drug conjugates (ADCs).[13] HER2-low tumors have low HER2 receptor expression (immunohistochemical [IHC] score 1+ or 2+ with negative *in situ* hybridization [ISH] results) and span both HR-positive and triple-negative subtypes.[13] Prior to this recognition, HER2-low tumors were not treated with HER2-targeted treatments.[13]

This changed in 2022, with the DESTINY-Breast 04 trial demonstrating clinically meaningful and statistically significant survival improvements for people with HER2-low ABC, when treated with trastuzumab deruxtecan (T-DXd), a HER2-targeted ADC.[13] The trial included people with both HR-positive (90% of participants) and triple-negative (10%) HER2-low ABC and demonstrated significant PFS and OS improvements among all participants.[13] Building on these results, the DESTINY-Breast 06 trial evaluated T-DXd in people with HR-positive HER2-low ABC and also with HER2-ultralow ABC.[14] HER2-ultralow tumors have an even lower level of HER2 than HER2-low tumors and show a faint membrane staining in up to 10%

of tumor cells.[14] While the HER2-ultralow subgroup was small, T-DXd showed a numerical improvement in PFS compared with physician's choice chemotherapy.[14] With approximately 50% of ABC tumors classified as HER2-low and 10% as HER2-ultralow, these findings mark a pivotal shift in ABC treatment, expanding the reach of HER2-targeted therapy to a much broader patient population (**Figure 3**).[15-16]

Figure 3: Prevalence of ABC subtypes and the HER2-low and HER2-ultralow biomarkers

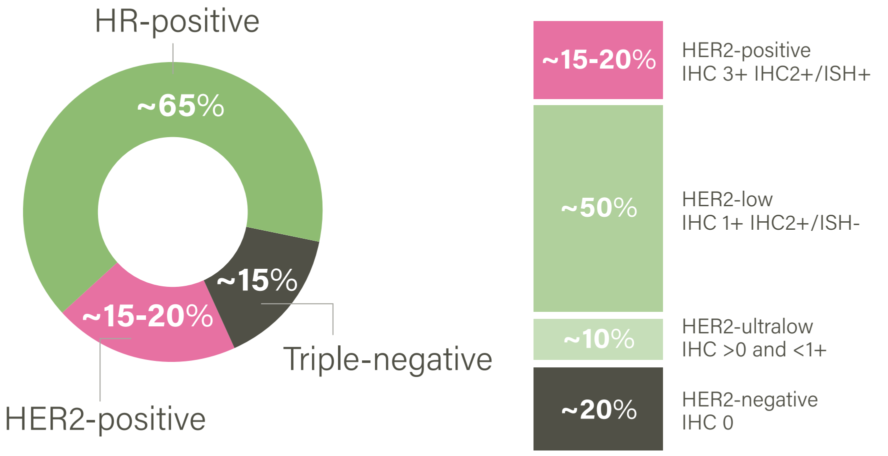
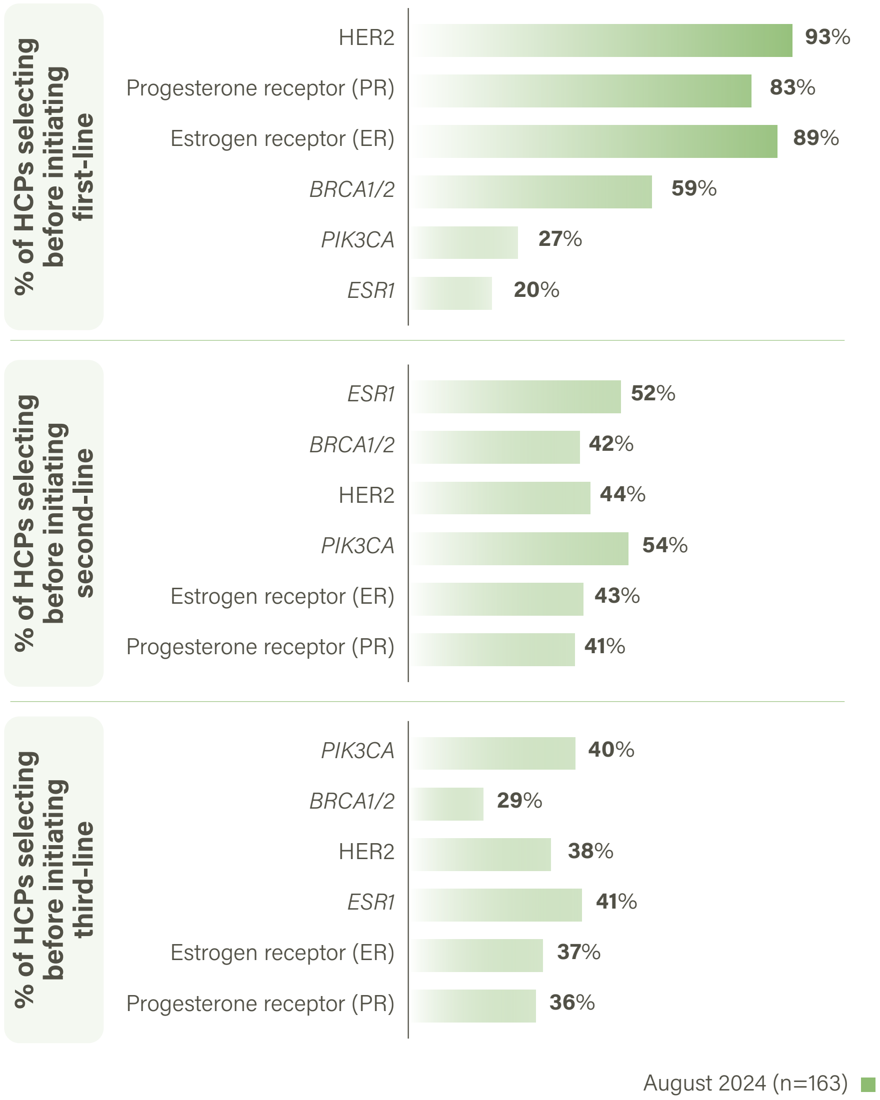


Figure adapted from Miglietta et al. 2022;[11] Lv et al. 2025.[16]

The emergence of HER2-low and HER2-ultralow as clinically relevant biomarkers emphasizes the critical importance of understanding tumor biology and continuing to identify novel biomarkers to guide treatment strategies and improve survival outcomes for people with ABC.[13] Beyond HER2 status, several other biomarkers have played a role in informing systemic treatment decisions in ABC over the last decade, including mutations in phosphatidylinositol-4,5-bisphosphate 3-kinase catalytic subunit alpha (*PIK3CA*) and Ak strain transforming 1 (*AKT1*), phosphatase and TENsin homolog (*PTEN*) alterations, germline breast cancer gene 1 (*BRCA1*) or breast cancer gene 2 (*BRCA2*) mutations, partner and localizer of *BRCA2* (*PALB2*) mutations, neurotrophic tyrosine receptor kinase (*NTRK*) fusions, estrogen receptor 1 (*ESR1*) mutations, programmed death-ligand 1 (PD-L1) expression, and trophoblastic cell surface antigen 2 (TROP2) expression.[17-18]

Today, ABC treatment decisions remain largely driven by subtype,[19] but many countries are transitioning toward biomarker-guided treatment strategies. However, to fully realize this shift, biomarker testing must be integrated into standard ABC care practices, which is not yet the case. In a recent global survey conducted by Young Survival Coalition's (YSC) Project 528, 1 in 10 young adults with ABC reported never having undergone genetic testing.[20] Similarly, a survey of healthcare professionals (HCPs) in France, Italy, Spain, and the United Kingdom (UK) found that while HR and HER2 testing is routinely carried out for people with ABC prior to first-line treatment, testing rates for other key biomarkers were much lower: germline *BRCA 1/2* mutations were assessed in only 59% of patients, *PIK3CA* mutations in 27%, and *ESR1* mutations in just 20% (**Figure 4**).[21] Consistent with the current treatment algorithms, uptake of *PIK3CA* and *ESR1* mutation testing was higher before initiating second-line therapy compared with first-line.[21] By third-line treatment, biomarker testing was least frequently performed (**Figure 4**).[21] These findings highlight a clear need to increase the uptake and consistency of biomarker testing to ensure that all people with ABC have access to the most appropriate, personalized treatment options.

Figure 4: HCP-reported frequency of biomarker testing based on a survey conducted among physicians in France, Italy, Spain, and the UK



Based on findings from the Menarini Stemline Oncology survey. 2024.[21] When applying molecular testing, which biomarkers are you routinely testing for ER-positive/HER2-negative advanced/metastatic breast cancer prior to initiating the following therapy lines?'

While advances in targeted therapies offer great potential to improve survival outcomes in ABC, equitable access to biomarker testing, such as next-generation sequencing (NGS) or germline testing, remains a major challenge. High costs, limited funding, and inadequate infrastructure continue to restrict availability, particularly in low- and middle-income countries (LMICs).[22-23] For example, in parts of Eastern Europe, NGS technologies are available in fewer than 75% of laboratories, while in Brazil, testing is often covered only by private insurance and in specific circumstances, leaving many patients to bear the cost themselves.[22,24] Addressing these barriers will require reviewing regulatory frameworks, expanding infrastructure, and ensuring sustainable funding to make biomarker testing widely accessible (see Goal 9). Without these measures, the full potential of personalized treatment strategies in ABC will remain unrealized.

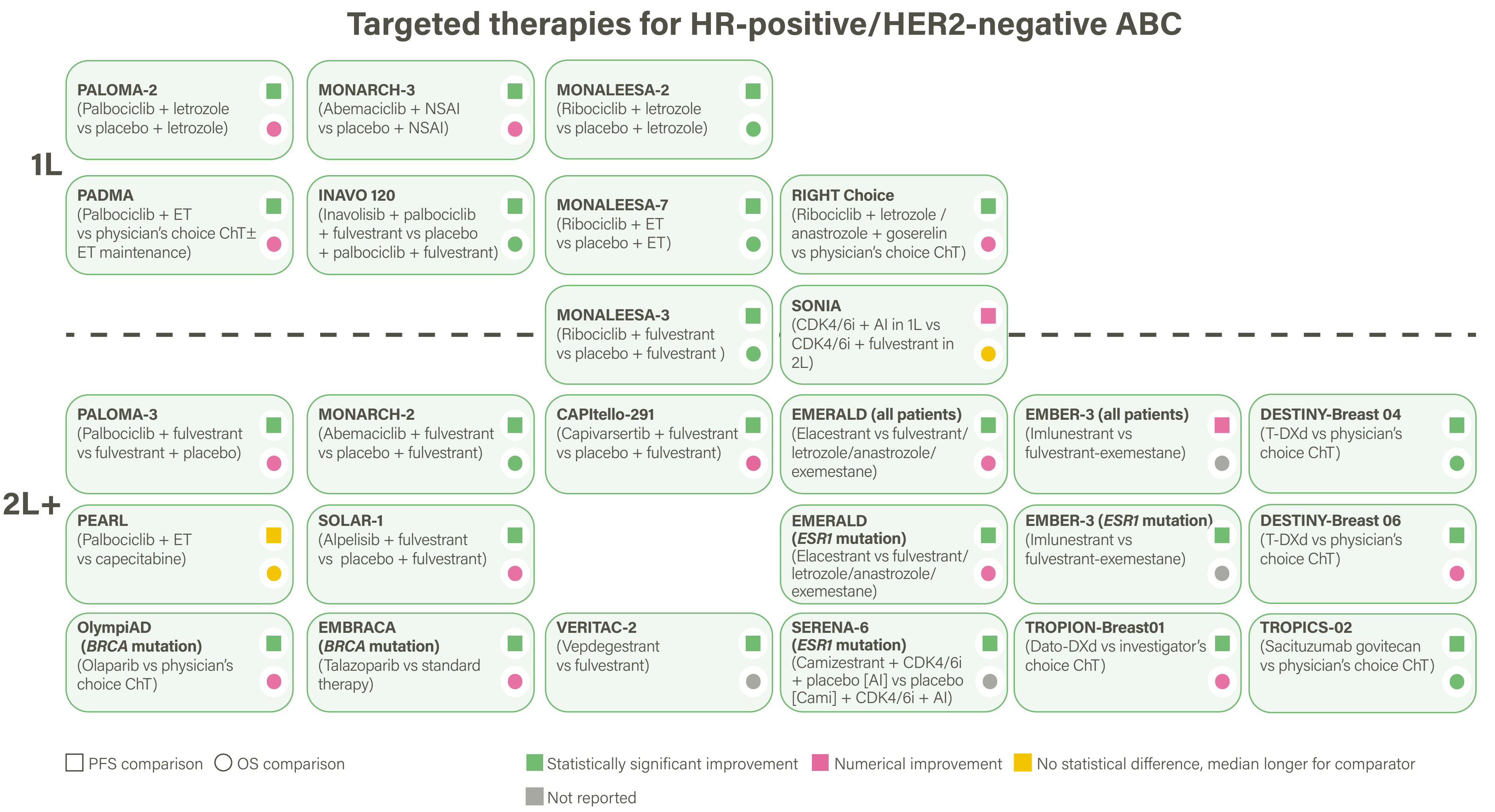
Advances in ABC treatment options have significantly improved survival across ABC subtypes

In 2024, the ABC Global Alliance conducted a targeted literature review to examine progress in PFS and OS outcomes reported in ABC clinical trials for new treatments approved over the past decade (see **Appendix I** for methodology). The sections below summarize key trials from this review, with a focus on approved treatment regimens from the past decade. For completeness, the figures in these sections also include important outcomes published prior to 2015.

HR-positive ABC

Over the past decade, survival outcomes for people with HR-positive HER2-negative ABC have improved substantially. Landmark advances include the introduction of cyclin-dependent kinase 4/6 (CDK4/6) inhibitors, inhibitors of the *PIK3CA/AKT/PTEN* pathway, selective estrogen receptor degraders (SERDs), poly(ADP-ribose) polymerase (PARP) inhibitors, and ADCs (**Figure 5**).[11] Many of these therapies not only extend PFS and OS but may also offer quality of life (QoL) benefits over more traditional chemotherapy agents (see Goal 3).[11] With multiple treatment options now available, individualized treatment has become increasingly possible for people with HR-positive HER2-negative ABC, optimizing outcomes for people who relapse on prior therapies and enabling more tailored patient-centered care.

Figure 5: PFS and OS outcomes from key clinical trials assessing targeted therapies for HR-positive/HER2-negative ABC between 2015–2025



Targeted therapies for HR-positive/HER2-negative ABC

1L

- **PALOMA-2** (Palbociclib + letrozole vs placebo + letrozole) 🟩 🟣
- **MONARCH-3** (Abemaciclib + NSAI vs placebo + NSAI) 🟩 🟣
- **MONALEESA-2** (Ribociclib + letrozole vs placebo + letrozole) 🟩 🟢
- **PADMA** (Palbociclib + ET vs physician's choice ChT± ET maintenance) 🟩 🟣
- **INAVO 120** (Inavolisib + palbociclib + fulvestrant vs placebo + palbociclib + fulvestrant) 🟩 🟢
- **MONALEESA-7** (Ribociclib + ET vs placebo + ET) 🟩 🟢
- **RIGHT Choice** (Ribociclib + letrozole / anastrozole + goserelin vs physician's choice ChT) 🟩 🟣
- **MONALEESA-3** (Ribociclib + fulvestrant vs placebo + fulvestrant) 🟩 🟢
- **SONIA** (CDK4/6i + AI in 1L vs CDK4/6i + fulvestrant in 2L) 🟪 🟡

2L+

- **PALOMA-3** (Palbociclib + fulvestrant vs fulvestrant + placebo) 🟩 🟣
- **MONARCH-2** (Abemaciclib + fulvestrant vs placebo + fulvestrant) 🟩 🟢
- **CAPItello-291** (Capivarsertib + fulvestrant vs placebo + fulvestrant) 🟩 🟣
- **EMERALD (all patients)** (Elacestrant vs fulvestrant/ letrozole/anastrozole/ exemestane) 🟩 🟣
- **EMBER-3 (all patients)** (Imlunestrant vs fulvestrant-exemestane) 🟪 ⚪
- **DESTINY-Breast 04** (T-DXd vs physician's choice ChT) 🟩 🟢
- **PEARL** (Palbociclib + ET vs capecitabine) 🟨 🟡
- **SOLAR-1** (Alpelisib + fulvestrant vs placebo + fulvestrant) 🟩 🟣
- **EMERALD (*ESR1* mutation)** (Elacestrant vs fulvestrant/ letrozole/anastrozole/ exemestane) 🟩 🟣
- **EMBER-3 (*ESR1* mutation)** (Imlunestrant vs fulvestrant-exemestane) 🟩 ⚪
- **DESTINY-Breast 06** (T-DXd vs physician's choice ChT) 🟩 🟣
- **OlympiAD (*BRCA* mutation)** (Olaparib vs physician's choice ChT) 🟩 🟣
- **EMBRACA (*BRCA* mutation)** (Talazoparib vs standard therapy) 🟩 🟣
- **VERITAC-2** (Vepdegestrant vs fulvestrant) 🟩 ⚪
- **SERENA-6 (*ESR1* mutation)** (Camizestrant + CDK4/6i + placebo [AI] vs placebo [Cami] + CDK4/6i + AI) 🟩 ⚪
- **TROPION-Breast01** (Dato-DXd vs investigator's choice ChT) 🟩 🟣
- **TROPICS-02** (Sacituzumab govitecan vs physician's choice ChT) 🟩 🟢

☐ PFS comparison ○ OS comparison 🟩 Statistically significant improvement 🟪 Numerical improvement 🟨 No statistical difference, median longer for comparator ⬜ Not reported

Based on data from: Andre et al. 2019;[25] Andre et al. 2021;[26] Arvinas 2025;[27] Bardia et al. 2024a;[28] Bardia et al. 2024b;[14] Bidard et al. 2022;[29] Bidard et al. 2025;[30] Cristofanilli et al. 2016;[31] Goetz et al. 2024;[32] Finn et al. 2016;[33] Hortobagyi et al. 2018;[34] Hortobagyi et al. 2022;[35] Jhaveri et al. 2024;[36] Johnston et al. 2019;[37] Martin 2021;[38] Martin 2022;[39] Modi et al. 2022;[13] Neven et al. 2023;[40] Litton et al. 2020;[41] Loibl et al. 2025;[42] Lu et al. 2022;[43] Lu et al. 2024;[44] Robson et al. 2017;[45] Robson et al. 2020;[46] Rugo et al. 2022;[47] Rugo et al. 2023;[48] Slamon et al. 2018;[49] Slamon et al. 2024;[50] Sledge et al. 2017;[51] Sledge et al. 2020;[52] Sonke et al. 2023;[53] Sonke et al. 2024;[54] Turner et al. 2018;[55] Turner et al. 2023;[56] Turner et al. 2024;[57] Turner et al. 2025.[58]

1L= first-line; **2L=** second-line; **AI=** aromatase inhibitor; **Cami=** camizestrant; **CDK4/6i=** cyclin-dependent kinase 4/6 inhibitor; **ChT=** chemotherapy; **Dato-DXd=** datopotamab deruxtecan; **ET=** endocrine therapy; **NSAI=** nonsteroidal aromatase inhibitor; **T-DXd=** trastuzumab deruxtecan.

CDK4/6 inhibitors have set a new standard of care

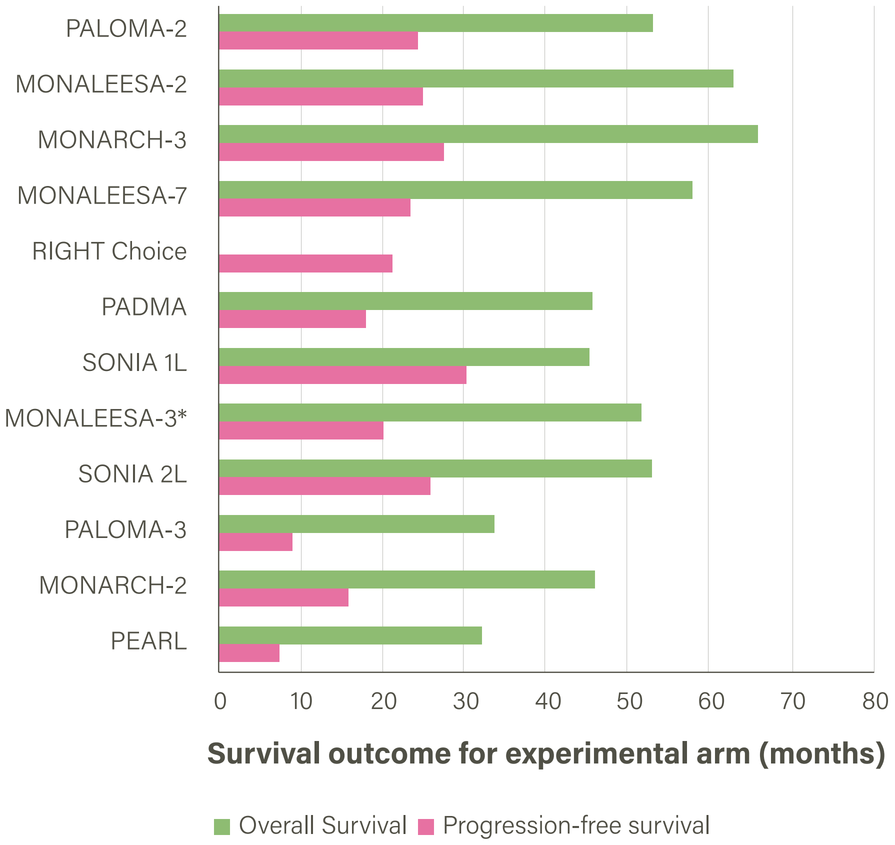
For people with HR-positive ABC, endocrine-based therapy (ET) is the preferred first-line treatment choice, except for those with true visceral crisis, as defined by the ABC guidelines.[19] Over the past decade, the introduction of CDK4/6 inhibitors—such as palbociclib, ribociclib, and abemaciclib—has been a major breakthrough, targeting key resistance pathways in HR-positive disease. Clinical trials have firmly established CDK4/6 inhibitors in combination with aromatase inhibitors (AIs) as the gold standard first-line treatment, demonstrating significant improvement in PFS and, in the case of ribociclib, OS benefit (**Figure 5**).[32-35,37,40,42-44,49-50,53] Across pivotal trials, patients have remained progression-free for 19–31 months and achieved a median OS of 46–67 months (**Figure 6**).[32-35,37,40,42-44,49-50,53]

In the second-line and later-line settings for ET-resistant tumors, the MONALEESA-3 and MONARCH-2 trials showed that combining CDK4/6 inhibitors with fulvestrant significantly improved PFS, with MONARCH-2 also showing significant OS benefit.[49,51-52] Across second-line CDK4/6 inhibitor trials conducted over the past decade, median PFS ranged from 7 to 28 months, and median OS ranged from 33 to 53 months (**Figure 6**).[31,38-40,51-55]

Several trials, including RIGHT Choice, PADMA, and ABIGAIL, have compared CDK4/6 inhibitors in combination with ET to monotherapy or combination chemotherapy in the first-line setting.[42,44,59] In all of these trials, the ET-based regimen was superior,[42,44,59] reinforcing the ABC guideline recommendation to treat HR-positive HER2-negative ABC with ET-based options instead of chemotherapy.[19] Despite this, real-world data show that many patients with HR-positive and HER2-negative ABC still receive chemotherapy inappropriately in the first-line setting, particularly outside of large academic or tertiary centers.[12]

The SONIA trial was an academic effort to determine the best line of therapy for CDK4/6 inhibitors, comparing them in both first- and second-line.[54] While no statistical difference in PFS after second-line (PFS2) was observed between the treatment arms, a trend favoring early administration was seen.[54] Due to the absence of OS data and other trial limitations, most ABC guidelines continue to recommend CDK4/6 inhibitors in combination with ET as the preferred first-line treatment for most patients.[60]

Figure 6: OS and PFS outcomes of people treated with CDK4/6 inhibitors in key clinical trials in 2015-2025



Based on data from: Cristofanilli et al. 2016;[31] Goetz et al. 2024;[32] Finn et al. 2016;[33] Hortobagyi et al. 2018;[34] Hortobagyi et al. 2022;[35] Johnston et al. 2019;[37] Martin 2021;[38] Martin 2022;[39] Neven et al. 2023;[40] Loibl et al. 2025;[42] Lu et al. 2022;[43] Lu et al. 2024;[44] Slamon et al. 2018;[49] Slamon et al. 2024;[50] Sledge et al. 2017;[51] Sledge et al. 2020;[52] Sonke et al. 2023;[53] Sonke et al. 2024;[54] Turner et al. 2018.[55]

* The MONALEESA-3 trial enrolled patients in both first-line and second-line. The data in the figure shows the PFS and OS outcomes reported for the overall trial population, including both first-line and second-line patients.

NB: This figure aims to provide an overview of the OS and PFS of people treated with CDK4/6 inhibitors reported across key trials. Naïve comparisons between the trial outcomes should not be made, differences in the included populations may impact the outcomes of the trials.

1L= first-line; **2L=** second line.

While CDK4/6 inhibitors have transformed the treatment pathway for HR-positive ABC and offer a chemotherapy-free option for many patients, they are still associated with adverse events (AEs) such as hematological toxicities, fatigue, nausea, diarrhea, and infections.[61] In most cases, these AEs are manageable and do not negatively impact patients' health-related quality of life (HRQoL).[62] That said, when selecting between agents, toxicity must be carefully considered to balance efficacy with potential HRQoL impact.

PIK3CA/AKT/PTEN pathway inhibitors can provide benefit following progression

Over the past decade, treatments that inhibit the *PIK3CA/AKT/PTEN* pathway, including alpelisib and capivasertib, have shown improvements in PFS among patients who progress on AIs, leading to their approval in several countries.[25,56,63-64] Recently, updated results from the INAVO-120 trial showed, for the first time, a significant OS benefit with first-line use of a *PIK3CA* inhibitor in a subgroup of patients with poor prognosis who had primary endocrine-resistant disease.[57-58] While these results are encouraging, this class of treatments are associated with notable toxicities, including hyperglycemia, dyslipidemia, rash and stomatitis, which can significantly impact HRQoL and require prophylactic measures and active management.[65-66]

Estrogen receptor degraders target key resistance mechanisms

ABC tumors treated with ET can develop resistance, often driven by mutation of the *ESR1* gene, reported in around 30–40% of people following first-line ET.[67-68] The emergence of oral SERDs marks an important advancement for this subpopulation. In the EMERALD and EMBER-3 trials, both elacestrant and imlunestrant showed improvements in PFS compared with standard of care (SoC) among patients with ESR1 mutation, despite differences in the baseline characteristics of participants.[29,36] Elacestrant also showed a numerical improvement in OS (**Figure 5**), although statistically significant OS benefits for oral SERDs have not yet been reported.[29,36]

For patients with ESR1 mutations, the oral proteolysis targeting chimera (PROTAC) ER degrader vepdegestrant has also shown promise, demonstrating significant PFS improvement over fulvestrant in the VERITAC-2 trial.[27] OS data from this trial are currently immature.[27]

PARP inhibitors can improve outcomes for people who have *BRCA* and HR-positive ABC

Germline mutations in the *BRCA1/2* genes are seen in about 3–4% of ABC cases.[69] For this subgroup, the introduction of PARP inhibitors, including olaparib and talazoparib, have shown improvements in PFS and numerical OS benefit compared with standard of care therapies in the first-line setting. These agents are generally well tolerated, with minimal negative impact on HRQoL, making them an important treatment option for eligible patients.[41,45-46,70]

TROP2-directed ADCs show promise in early trials

As described earlier in this chapter, the ADC T-DXd has demonstrated significant and clinically meaningful improvements in both PFS and OS for previously-treated patients with HR-positive HER2-low ABC.[13-14]

ADCs targeting the TROP2 transmembrane glycoprotein have also shown survival benefits. Sacituzumab govitecan demonstrated PFS gains and some OS improvement in the TROPICS-02 trial.[47,71] Similarly, datopotamab deruxtecan (Dato-DXd) showed significant PFS improvement over traditional chemotherapy in the TROPION-Breast 01 trial, among people with HR-positive and HER2-negative ABC who received 1–2 previous lines of chemotherapy and were unsuitable for further ET.[28] Unfortunately, the final analysis did not show improvement in OS, which is likely to limit its approval and clinical adoption in many countries.[72]

HER2-positive ABC

Since the approval of trastuzumab in 1998, survival outcomes for HER2-positive ABC have been the most improved among ABC subtypes, in countries where HER2-targeting agents are available.[12,73] Over the past decade, further significant gains have been reported across multiple studies, driven by the introduction of advanced treatment modalities. These include ADCs (trastuzumab bound to a chemotherapeutic agent) such as T-DXd and trastuzumab emtansine (T-DM1); tyrosine kinase inhibitors (TKIs) such as lapatinib, tucatinib and others; and, for HR-positive HER2-positive disease, the CDK4/6 inhibitor palbociclib (**Figure 7**).[11,74]

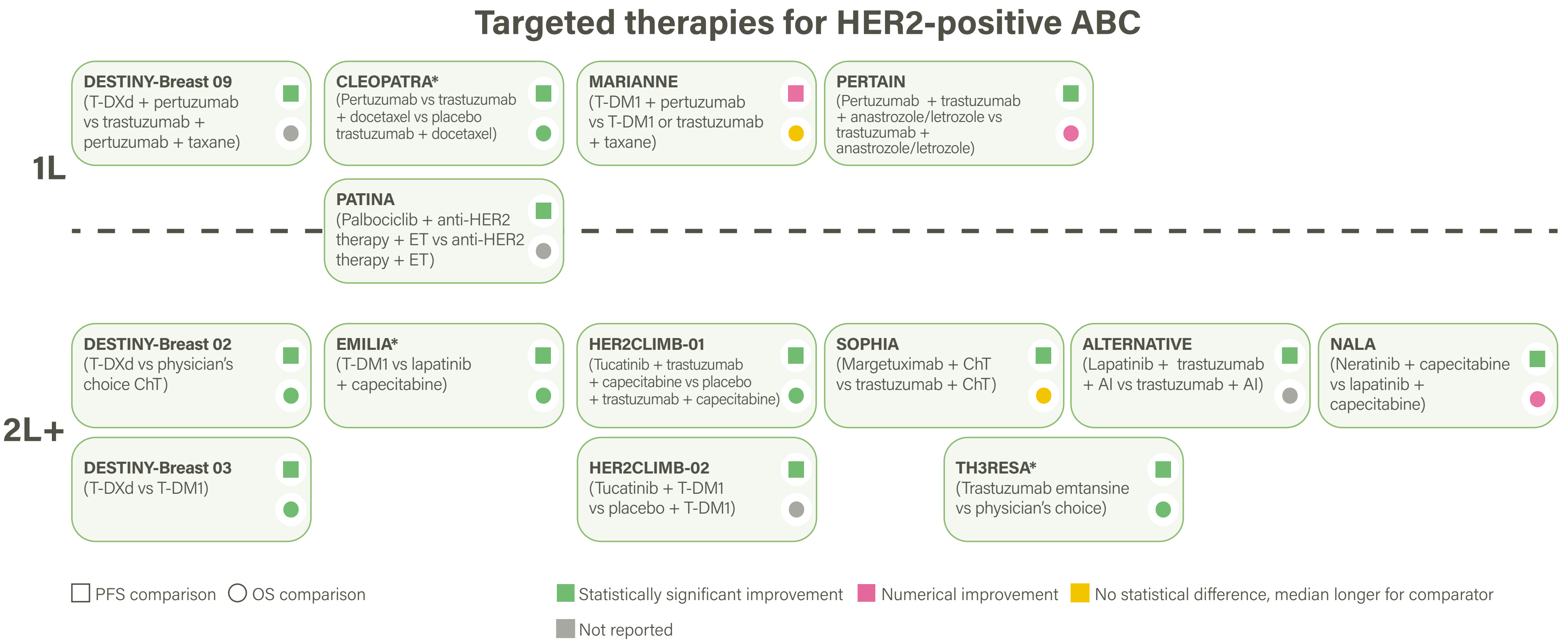


Figure 7: PFS and OS outcomes from key clinical trials assessing targeted therapies for HER2-positive ABC between 2015–2025

Based on data from: Andre et al. 2023;[75] Arpino et al. 2023;[76] Diéras et al. 2017;[77] Emery 2024;[78] Hurvitz et al. 2023;[79] Hurvitz 2024;[80] Johnston et al. 2020;[81] Kim et al. 2024;[82] Krop et al. 2017;[83] Metzger et al. 2017;[74] Murthy et al. 2020;[84] Perez et al. 2019;[85] Rugo et al. 2019;[86] Rugo et al. 2022;[87] Saura et al. 2020;[88] Swain et al. 2015;[89] Swain et al. 2020;[90] Tolaney et al. 2025.[91]

* 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; **T-DM1=** trastuzumab emtansine; **T-DXd=** trastuzumab deruxtecan.

HER2-targeted treatments have reshaped care for those with HER2-positive disease

The introduction of trastuzumab revolutionized the treatment of HER2-positive ABC, establishing a new gold standard of care and earning its place on the World Health Organization (WHO) Essential Medicines List.[92] Trastuzumab also marked a paradigm change in oncology by demonstrating the value of continuing to block the HER2 pathway beyond disease progression.[93] While the high cost of anti-HER2 agents remains a barrier in some countries, maintaining trastuzumab in combination with a different cytotoxic or endocrine agent beyond progression is crucial for optimizing disease control and outcomes.[93]

In 2012, pertuzumab was approved[94] after demonstrating improved PFS and OS in combination with trastuzumab and chemotherapy (docetaxel) in the CLEOPATRA trial.[89-90] The following year, the first ADC T-DM1 was approved for HER2-positive ABC based on the EMILIA and TH3RESA trials.[77,83,95]

The past decade has brought further advances, with the development of new efficacious anti-HER2 therapies. The ADC T-DXd showed positive outcomes in the single-arm DESTINY-Breast 01 trial,[96] later confirmed in the randomized DESTINY-Breast 02 trial, leading to accelerated United States (US) Food and Drug Administration (FDA) approval in 2019 for patients previously treated with two or more anti-HER2-based ABC therapies.[75,82,97] In 2024, T-DXd was further approved for second-line use after the DESTINY-Breast 03 trial showed significantly longer PFS and OS compared with T-DM1 in this setting.[79,98] Based on these findings, T-DXd is now considered the second-line standard of care for HER2-positive ABC.[19]

More recently, the DESTINY-Breast 09 trial found that T-DXd in combination with pertuzumab improved PFS compared with standard of care trastuzumab, pertuzumab, and taxane, in the first-line. Discussions are ongoing on how to best incorporate these findings into the treatment pathway, while balancing efficacy and HRQoL.[99] T-DXd has also shown promise in people with brain metastases, with the non-comparative DESTINY-Breast 12 study reporting a median PFS of 17 months and a 12-month OS rate of 90%.[100]

For people with HR-positive HER2-positive ABC, the PATINA trial demonstrated that adding palbociclib to standard of care anti-HER2 therapy and ET significantly prolonged PFS in first-line, with a 15 month difference reported between the treatment arms (44 months vs. 29 months).[78] These results suggest that blocking CDK4/6 can delay resistance to HER2-targeting therapy, highlighting an exciting area for development: the use of HER2-targeting agents in combination with other targeted therapies (chemotherapy-free combinations) for some specific subgroups.[78]

TKIs are essential in managing brain metastases

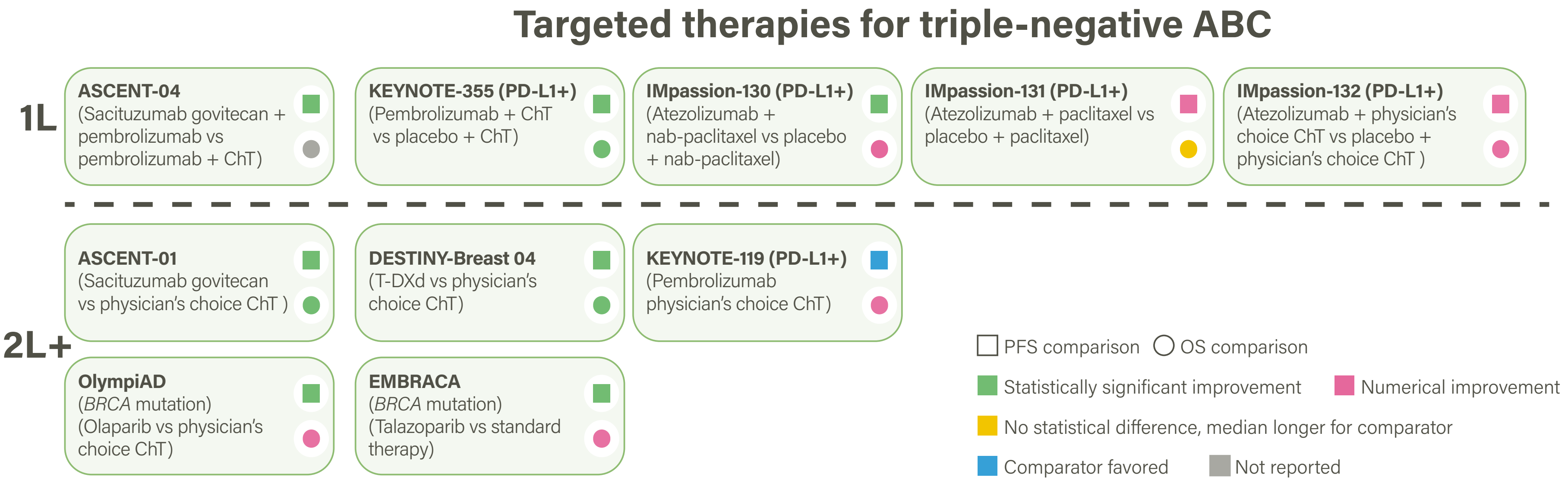
TKIs have shown promising PFS and OS outcomes in HER2-positive ABC and play a pivotal role in the treatment of central nervous system metastases, which occur in a high percentage of people with HER2-positive disease.[101] These small molecules have the ability to cross the blood-brain barrier and have shown survival improvements in people with brain metastases, an often underserved subgroup.[102]

Tucatinib received approval in 2020 for patients previously treated with anti-HER2 therapy, after the HER2CLIMB-01 trial demonstrated significant PFS and OS improvements, and the HER2CLIMB-02 trial confirmed a significant PFS benefit in previously treated patients, including those with active brain metastases.[80,103-104] In contrast, neratinib has not achieved widespread recommendation. In the NALA trial, safety concerns, including diarrhea, hand-foot syndrome, nausea, and vomiting, outweighed the modest OS benefit of just 1.7 months at 2-year follow-up.[105]

Triple-negative ABC

Triple-negative ABC has historically been associated with poorer outcomes than other subtypes.[11] For many years, chemotherapy was the only available treatment option, and it remains the backbone of therapy for this group today.[19] Over the past decade, however, three classes of targeted agents have transformed the treatment landscape for triple-negative ABC: ADCs, immune checkpoint inhibitors (ICIs), and PARP inhibitors for people with pathogenic *BRCA1/2* mutations.[11] For the first time in this subtype, these therapies have demonstrated survival improvements over chemotherapy, marking a significant advance in both treatment and care.[13,106] As shown in **Figure 8**, clinical trials assessing these targeted therapies over the past decade report varying survival outcomes.

Figure 8: PFS and OS outcomes from key clinical trials of targeted therapies for triple-negative ABC between 2015–2025



Targeted therapies for triple-negative ABC

	Trial	PFS	OS
1L	**ASCENT-04** (Sacituzumab govitecan + pembrolizumab vs pembrolizumab + ChT)	🟩	⚫
1L	**KEYNOTE-355 (PD-L1+)** (Pembrolizumab + ChT vs placebo + ChT)	🟩	🟢
1L	**IMpassion-130 (PD-L1+)** (Atezolizumab + nab-paclitaxel vs placebo + nab-paclitaxel)	🟩	🔴
1L	**IMpassion-131 (PD-L1+)** (Atezolizumab + paclitaxel vs placebo + paclitaxel)	🟥	🟡
1L	**IMpassion-132 (PD-L1+)** (Atezolizumab + physician's choice ChT vs placebo + physician's choice ChT)	🟥	🔴
2L+	**ASCENT-01** (Sacituzumab govitecan vs physician's choice ChT)	🟩	🟢
2L+	**DESTINY-Breast 04** (T-DXd vs physician's choice ChT)	🟩	🟢
2L+	**KEYNOTE-119 (PD-L1+)** (Pembrolizumab physician's choice ChT)	🟦	🔴
2L+	**OlympiAD** (*BRCA* mutation) (Olaparib vs physician's choice ChT)	🟩	🔴
2L+	**EMBRACA** (*BRCA* mutation) (Talazoparib vs standard therapy)	🟩	🔴

☐ PFS comparison ○ OS comparison

🟩 Statistically significant improvement 🟥 Numerical improvement

🟨 No statistical difference, median longer for comparator

🟦 Comparator favored ⬛ Not reported

Based on data from: Bardia et al. 2021;[106] Cortes et al. 2019;[107] Cortes et al. 2022;[108] Dent et al. 2024;[109] Emens et al. 2021;[110] Litton et al. 2018;[70] Litton et al. 2020;[41] Miles et al. 2021;[111] Modi et al. 2022;[13] Robson et al. 2017;[45] Robson et al. 2023;[46] Schmid et al. 2018;[112] Tolaney et al. 2025.[113]

* In the OlympiAD study, half of the participants had HR-positive ABC, and half had triple-negative ABC. OS comparison is reported for all patients in both treatment arms, data is not specific to people with triple-negative ABC.

NB: 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. Traditional chemotherapy agents remain essential for the treatment of triple-negative ABC, and are the most commonly used treatment options for this subtype.

1L= first-line; **2L=** second-line; **ChT=** chemotherapy; **PD-L1=** programmed death-ligand 1.

ADCs have improved survival, but their optimal treatment sequence is yet to be determined

In the ASCENT 01 trial, the ADC sacituzumab govitecan improved survival of people with triple-negative ABC without brain metastases, compared with single agent chemotherapy in later lines of treatment.[106] It demonstrated significantly longer median PFS (5.6 months vs. 1.7 months) and nearly doubled median OS (12.1 months vs. 6.7 months), with a generally manageable safety profile.[106] Based on these results, sacituzumab govitecan is now recommended as the preferred treatment option for this subtype in patients who have received at least one prior line of therapy.[19] More recently, sacituzumab govitecan combined with pembrolizumab showed significant PFS improvement over chemotherapy and pembrolizumab in first-line setting for people with PD-L1-positive tumors, although OS data remain immature.[113]

The ADC T-DXd has also shown promise in this space, demonstrating a significant OS benefit in patients with HR-negative HER2-low ABC in an exploratory subgroup analysis of the DESTINY Breast 04 trial, with a median OS of 18.2 months.[13]

Importantly, no head-to-head comparisons of sacituzumab govitecan and T-DXd have been performed yet, and the optimal sequencing of these agents remains to be defined.[19]

ICIs demonstrate varying impact on survival outcomes

In the KEYNOTE-355 trial, the ICI pembrolizumab demonstrated significant OS benefit in patients whose tumors had high PD-L1 expression.[108] However, this was not observed for groups with lower PD-L1 expression, highlighting the importance of PD-L1 testing to guide treatment selection in this subtype.[108]

Another ICI, atezolizumab, in combination with nab-paclitaxel, showed significant PFS benefit, but not OS improvement, in the first-line for patients with PD-L1+ tumors (SP142 staining ≥1% on immune cells), in the IMpassion-130 trial.[112] However, subsequent trials (IMpassion-131 and IMpassion-132), failed to demonstrate either OS or PFS benefit in the first-line setting.[109,111] These results led to the withdrawal of atezolizumab's approval for this indication in the US, although it remains available in Europe.[114-115]

PARP inhibitors delay disease progression in germline *BRCA*-mutated ABC

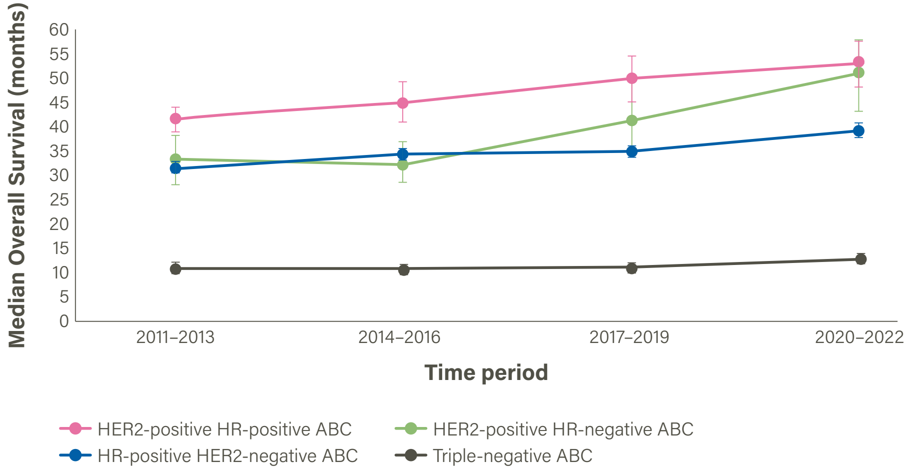
The PARP inhibitors olaparib and talazoparib showed a significant benefit in PFS and improved HRQoL for people with germline *BRCA1/2* mutations in later-lines of therapy, compared with standard of care chemotherapy regimens, in the OlympiAD and EMBRACA trials.[45,70] Although OS improvement was not statistically significant (as the trials were not sufficiently powered to show OS benefit), the gains in HRQoL and PFS were sufficient to support approval of both agents, addressing a high unmet need in the ABC subtype with the fewest treatment options.[46,70,116-117]

Real-world survival has improved across all ABC subtypes, but people with triple-negative ABC continue to have poorer outcomes

Real-world survival improvements differ across ABC subtypes

Consistent with clinical trial findings, a recent large-scale real-world data analysis of over 60,000 people with ABC from the US Flatiron Health database (unpublished data, manuscript in preparation) reported meaningful OS improvements from 2011 to 2025 across all subtypes. The greatest gains were seen in HER2-positive disease, where median OS increased by more than 10 months, reaching over 50 months in 2020–2022 (**Figure 9**). HR-positive HER2-negative ABC showed more modest improvement, from 32 months in 2011–2013 to 40 months in 2020–2022. In contrast, triple-negative ABC saw minimal progress, with survival increasing by less than 3 months over the study period to a median OS of just 13 months in 2020–2022 (**Figure 9**).

Figure 9: Median OS of people with ABC based on data from more than 60,000 patients in the US Flatiron Health database



Based on unpublished data from the US Flatiron Health database, manuscript in preparation.

The analysis also indicated an increasing proportion of patients presenting with *de novo* metastatic disease in the HER2-positive subtype—potentially reflecting reduced recurrence rates from early-stage disease due to therapeutic advances, although a biological explanation cannot be excluded. The temporal alignment between OS improvements and the introduction of novel therapies suggests a possible, though not yet proven, causal relationship between treatment evolution and improved survival outcomes in ABC. These findings complement clinical trial data and provide valuable insight into how the approval and adoption of therapeutic innovations may translate into meaningful improvements in patient outcomes across community and academic practices.

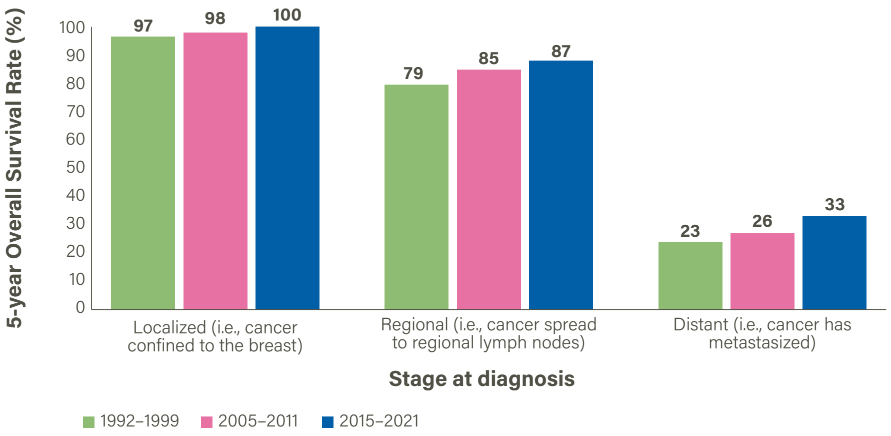
The Flatiron Health analysis shows that HER2-positive ABC is associated with the longest survival, and with continued advancements some patients may approach the life expectancy of those without metastatic disease, particularly if long-term complete responses to treatment can be achieved. That said, achieving this goal will require equitable access to anti-HER2 therapies, including trastuzumab beyond progression, and sustained efforts to make these treatments affordable worldwide.[93]

Meanwhile, the persistently poor outcomes in triple-negative ABC shown in the study highlight an urgent unmet need for more effective and better tolerated treatment options for this subtype.

Substantial OS improvement has been demonstrated for all people with ABC

Overall, the current decade has seen far greater survival gains for people with ABC compared with the previous decade. The 2005–2015 Global Decade Report noted only modest improvement in the 5-year OS rate for ABC, from 23% to 26%, between 1992–1999 and 2005–2011, based on publicly available real-world data obtained from the US States Surveillance, Epidemiology, and End Results (SEER) database.[3] In contrast, more recent SEER data show a substantial rise in the 5-year OS rate for ABC to 33% in 2015–2021 (**Figure 10**).[118] Despite these advances, ABC survival remains markedly lower than for early breast cancer, where nearly all patients survive at least 5 years after diagnosis (**Figure 10**).[3,118] This stark disparity highlights the ongoing and urgent need to further improve survival outcomes for people with ABC.

Figure 10: 5-year OS rates by disease stage based on publicly available data for female breast cancer in the US SEER database



Based on data from the ABC Global Decade Report 2005–2015[3] and National Cancer Institute SEER Program 2022.[118]

ABC care goes beyond survival outcomes

In this decade, new treatment options have improved survival across all subtypes of ABC,[11] but this progress alone is not enough. Significant disparities in real-world survival outcomes persist, and in some cases have widened, partly due to the high cost of newer drugs limiting access (see Goal 9).

Treatments leading to an OS benefit are more likely to alter the natural history of the disease than those that impact only PFS. While PFS gains are valuable, without a significant impact on OS, advances in patient outcomes are much slower. To meaningfully change the trajectory of ABC over the next decade, research must prioritize therapies that extend OS and/or improve HRQoL. This requires that ABC clinical trials use OS as a primary or co-primary endpoint, or at minimum be sufficiently powered to assess OS impact. In parallel, better tools for measuring HRQoL in the metastatic setting must be developed and implemented (see Goal 3).

Many new therapies offer more targeted and less toxic alternatives to traditional chemotherapy, improving not only survival but also QoL and convenience for patients.[11] However, each comes with unique side effects: CDK4/6 inhibitors and PARP inhibitors are associated with hematological toxicities, ICIs may lead to immune-mediated AEs (including dermatological, gastrointestinal, hepatic, or endocrine events), and ADCs can occasionally cause interstitial lung disease, intense fatigue, ocular, gastrointestinal toxicity, or peripheral neuropathy.[11,119-120] As innovation continues, treatment selection must balance efficacy with QoL, and ABC care must extend beyond treatment, to include nutritional, spiritual, and psychological support (see Goal 7), with input from a multidisciplinary team (see Goal 4).

Looking ahead, several critical questions remain unanswered: What is the optimal sequencing of therapies for each patient? How and when should biomarkers be used to guide treatment selection for all people with ABC? And which patients could safely discontinue treatment without compromising outcomes? Addressing these questions will be key to driving the next wave of progress in ABC care.

Disparities in ABC survival outcomes persist globally

While improvements in survival have been seen in both trial and real-world settings over the past decade, this does not always translate to improved outcomes for all patients. A systematic review of real-world studies evaluating drugs approved by the FDA and European Medicines Agency (EMA) between 2010–2015 for solid tumors found that in more than half of cases (63%), survival outcomes were poorer than those reported in the pivotal trials.[121] Quality assessment using the Newcastle–Ottawa Scale revealed that only around a third (30%) of breast cancer studies met the threshold for moderate quality, with the remainder rated as low quality, highlighting a significant gap in robust real-world evidence (RWE).[121] These findings suggest that clinical trial results may not be fully generalizable to the broader ABC population, which in part may be due to the highly selective inclusion criteria used in trials.[122]

ABC clinical trials frequently exclude key subgroups, including elderly and/or frail people with clinically relevant comorbidities, men, and people with brain metastases.[122-124] Ethnic minority groups and members of the lesbian, gay, bisexual, transgender, queer, asexual, intersex + (LGBTQAI+) community are also often underrepresented, partly due to historical bias.[123,125] These groups may respond differently to treatment than the populations typically studied, and their exclusion can contribute to real-world disparities in outcomes. For example, the 2018 "I'm Still Here" report by Breast Cancer Foundation NZ found significantly worse survival among Māori people with ABC compared with non-Māori people (5-year survival: 5% vs. 15%).[126] In the US, Black people are 40% more likely to die from breast cancer than White people.[127] Age-related disparities are also evident, with median OS for younger people with breast cancer (<50 years) at 32 months, compared with 25 months for those aged 50–69 years and 16 months for those over 69 years.[128] Interestingly, large database studies have reported similar survival outcomes between men and women,[129-130] although more research is needed to understand ABC in men and ensure treatment approaches account for hormonal differences.[129]

Despite more than half of all breast cancer diagnoses occurring in Africa, Asia, and South America, most studies are conducted in high-income regions such as North America and Europe, limiting their global applicability.[121,131] Limited access to screening, timely diagnosis, and innovative treatments in LMICs, combined with low ABC awareness and disease-related stigma (see Goal 8), result in significant disparities. As a result, people in these regions are more likely to be diagnosed at a later stage and with *de novo* disease than those in high income countries (HICs) (10–30% vs. 3–6%).[132] Expanding access to ABC care in LMICs is critical to improving both survival and QoL. High-quality RWE collection in these settings could improve understanding of poorer outcomes, inform national cancer control policies, and guide resource allocation. However, many LMICs lack national cancer registries (see Goal 2).

ABC guidelines now set the standard for quality care

The 2005–2015 Global Decade Report identified a critical need for more comprehensive, ABC-specific international guidelines.[3] Such guidelines synthesize the best available evidence, define optimal treatment strategies, and support the prioritization of access to innovative therapies. By providing a clear framework for clinical decision-making, they enable physicians to select the most appropriate treatment options for their patients, ultimately supporting best possible outcomes.

Over the past decade, substantial progress has been made in developing comprehensive, high-quality, ABC-specific guidelines that set the gold standard for ABC care. These include the ABC international consensus guidelines, the European Society for Medical Oncology (ESMO) guidelines (2021), the American Society of Clinical Oncology (ASCO) resource-stratified guidelines (2024), the National Comprehensive Cancer Network (NCCN) Middle and North Africa guidelines (2023), the pan-Asian guidelines (2023) developed by oncology societies from

10 Asian countries, and the NCCN and African Cancer Coalition harmonized guidelines for African countries.[19,133-137] Comprehensive national guidelines have also been introduced, such as the New Zealand ABC consensus guidelines (2020), updated in 2022 by the Breast Special Interest Group and Breast Cancer Foundation NZ.[138-139]

Treatment according to these guidelines has undoubtedly improved survival for people with ABC.[140-141] However, adherence to guidelines in reality can vary,[142] and implementation is often limited by treatment availability, particularly in LMICs. While global efforts to improve access remain essential, there is also a pressing need for the development and adoption of resource-stratified guidelines to ensure that recommendations are practical and applicable across diverse healthcare settings.

CONCLUSIONS AND FUTURE DIRECTIONS

Between 2015 and 2025, clinical trials have demonstrated significant improvements in PFS and OS across all ABC subtypes, most notably in HR-positive HER2-negative, and HER2-positive, disease. However, these gains are not always replicated in real-world settings, and substantial disparities persist between countries and among underserved groups. Future clinical trials must be designed to be more inclusive, ensuring representation of these subgroups so that advances benefit all patients.

A median OS of approximately 5 years remains unacceptably low, particularly for those diagnosed at a younger age. As discussed throughout this chapter, goals for efficacy and tolerability must be higher and more patient-centered to accelerate progress for people with ABC. The priority must be to develop therapies that meaningfully extend survival and/or improve HRQoL. To achieve this, ABC clinical trials should use OS as a primary or co-primary endpoint, or at minimum be sufficiently powered to determine OS impact.

Continued advances in understanding ABC biology will be essential to drive the development of new treatments and identify more accurate predictive biomarkers. The integration of emerging digital technologies also offers new opportunities to enhance patient care, optimize treatment pathways, and improve outcomes globally.

Finally, to address unanswered questions—such as the optimal sequencing of therapies and the most effective use of biomarkers—we call for a global, centralized analysis of all clinical trial data, both industry-led and academic. Similar to the Early Breast Cancer Trialists' Collaborative Group (EBCTCG) meta-analyses that have shaped early breast cancer care for decades,[143-144] such an initiative in ABC could transform our ability to generate definitive, practice-changing evidence and deliver the best possible outcomes for all people living with ABC.

Based on these findings, the ABC Global Alliance community has agreed that this goal should remain in the ABC Global Charter 2025–2035 with the following revised 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.

Our 10 **GOALS**

2 Collection of **high-quality data** in ABC

Collection of **high-quality data** in ABC

INTRODUCTION

Systematic data collection and analysis in advanced breast cancer (ABC) is critically important and provides a foundation for improving patient outcomes, advancing research, and optimizing healthcare delivery. High-quality ABC data enables a deeper understanding of disease progression and treatment effectiveness, thereby contributing to the development of innovative therapies and personalized approaches to care.[145] Data is an essential tool in ensuring equitable access to clinical trials and treatment for people with ABC, as well as identifying and addressing inequities globally.[145] Accurate prevalence data is critical for determining the true global burden of ABC, informing healthcare policies and priorities, workforce planning, and investment.[145] ABC data may also help to counter stigma, by demonstrating that people living with the disease continue to contribute meaningfully to society.[146]

This chapter reviews global efforts to advance the collection of ABC data over the past decade. It highlights initiatives that aim to improve the quality and comprehensiveness of data registries, as well as persistent challenges in high-quality data collection. It is informed by 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 (see **Appendix II**), and a review of recent literature.

STATUS IN 2005-2015

The 2005–2015 Global Decade Report highlighted a significant gap in the completeness and quality of ABC data. Despite recurrent ABC accounting for approximately two-thirds of the metastatic breast cancer (MBC) population[147-148] and being the main cause of breast cancer morbidity and mortality,[145] data on recurrence was severely lacking. This gap stemmed from the fact that cancer registries typically recorded diagnoses (incidence) and deaths (mortality) but not recurrence. As a result, most 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. This posed major challenges for researchers, clinicians, and policymakers, all of whom depend on robust epidemiological data to accurately assess disease burden, evaluate treatment effectiveness, and monitor long-term survival trends.

The absence of high-quality registry data meant that the true number of people living with ABC worldwide remained unknown, and reported outcomes likely inaccurate.[3] In addition, most available data originated from higher-income countries (HICs), leading to disparities in representation across geographies and likely underreporting of the disease burden in low- and middle-income countries (LMICs).[3] These gaps hindered efforts to develop equitable care strategies and allocate resources effectively, leaving many people with ABC feeling ignored, invisible, and unaccounted for.

Recognizing these challenges, the 2015–2025 ABC Global Charter listed 'increasing the collection of high-quality data', including detailed characterization of disease progression, recurrence, and survival, as one of its ten 'Actions for Change'.[4]

A DECADE IN REVIEW (2015-2025)

The number of people living with ABC globally remains unknown

Accurate and comprehensive cancer data collection is essential for understanding disease patterns, improving patient outcomes, and planning effective healthcare services.[145] However, persistent gaps and differences in how ABC data is collected and reported continue to hinder accurate estimation of global ABC prevalence and its impact.[149] The absence of key data on breast cancer stage at diagnosis and recurrence not only prevents identification of the total number of people living with ABC worldwide, but also limits understanding of critical factors such as where these individuals live, how their cancer has progressed, and how long they have been living with the disease. Without this foundational information, health systems are unable to effectively plan or allocate resources to meet the needs of people with ABC, whether in terms of access to treatment, supportive care, or broader system-level responses.[149] As treatment advances over the last decade allow people to live longer with ABC, these unmet needs are growing in both scale and complexity.

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. The development of ABC-focused registries—such as the Netherlands Cancer Registry in 1989,[150] Épidémio-Stratégie Médico-Economique (ESME)-MBC Cohort in France in 2014,[151] the OPAL registry in Germany in 2017 (an evolution of the Munich Cancer Registry (MCR)/Tumor register München (TRM) established in 1978),[152] Te Rēhita Mate Ūtaetae – Breast Cancer Foundation National Register, New Zealand's (NZ) ABC analysis in 2018,[153] and the National Audit of Metastatic Breast Cancer (NaoME) in the United Kingdom (UK) in 2022[154]—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.[155] 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.[156] 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 to be 7,900 in 2024.[157] 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),[158] and Queensland (3,863),[159] respectively (**Box 1**). In the same year, the Northern Ireland Cancer Registry (NICR) used linked datasets to estimate there to be 911 people with ABC in Northern Ireland in 2020, an increase from the 587 estimated in 2009 (**Box 2**).[160] These breakthroughs not only provide clearer ABC prevalence estimates but also gave visibility to a previously overlooked population. Furthermore, 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 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.[161,162]

While the progress that has been made since 2015 is clear, 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.[156] 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.[157] In 2025, most countries remain unable to generate reliable ABC prevalence estimates, emphasizing the critical and persistent need for improved ABC data collection.[23]

Box 1: Estimating the number of people living with ABC in Australia

For over 20 years, Australian cancer agencies, registries, researchers, and advocates have acknowledged ongoing gaps in the collection and reporting of stage at diagnosis and recurrence data for ABC and other cancers.[163]

In 2023, following nearly three years of targeted advocacy and collaboration with researchers, governments, Australian cancer agencies, and consumers, BCNA launched a roadmap for national ABC data reforms.[164] The roadmap generated bipartisan government support nationally, resulting in the establishment of the Australian Cancer Data Alliance and increased funding for cancer registries across Australia. National commitment was further reinforced by the development of Cancer Australia's national cancer data framework.[164]

BCNA are now working with states to harmonize methodologies and support other registries to leverage similar methods to count people with ABC. While this marks a milestone, it is only the beginning. The problem is far from solved, but this step signals a strong commitment to improving ABC data collection and reporting.

"Pinpointing how many people have metastatic breast cancer is more than just knowing a number. It's about giving a voice, options, and hope to people living with and beyond cancer and letting them know we see them and are here for them."
Professor Tracey O'Brien AM,
NSW Chief Cancer Officer and CEO Cancer Institute NSW

Box 2: 'Putting Seconds First' ABC research in Northern Ireland[160]

For the first time, Northern Ireland now has a clear picture of ABC, thanks to a 2025 study using population-based data from the Northern Ireland Cancer Registry. The research shows nearly 1,000 people are living with ABC, with around 250 new cases each year—a marked increase from 2009, reflecting advances in treatment.

Historically, ABC patients were often invisible in cancer statistics, limiting care planning. Patient advocates successfully campaigned for recognition, leading to this research and a commitment from the Northern Irish Health Minister to develop a dedicated ABC care pathway.

"We are no longer invisible; now we have the data to drive better outcomes for ABC patients."
Ann McBrien, Patient advocate living with ABC

High-quality data is key to overcoming ABC disparities

High-quality ABC data collection is essential to both uncovering global inequities and driving improvements in ABC care. Analysis of ABC data can reveal differences in access and outcomes across countries, ethnicities, or socioeconomic groups,[149] allowing for the development of tailored strategies to overcome inequities and enhance care.

The powerful impact of ABC data on exposing and overcoming inequities has been demonstrated by researchers in New Zealand this decade. A 2018 report by Breast Cancer Foundation NZ—"I'm Still Here – Insights into Living and Dying with ABC in New Zealand"—combined survey findings with the first comprehensive statistical analysis of ABC data from Te Rēhita Mate Ūtaetae – Breast Cancer Foundation National Register, to highlight disparities for people with ABC in New Zealand.[126] Their research showed that New Zealanders with ABC had poorer survival rates, received fewer treatment options, and faced systemic disadvantages in access to care, compared to those in other countries.[126]

This research not only highlighted ABC disparities but was pivotal in driving national-level policy discussions in New Zealand. The findings encouraged individual cancer centers to further investigate their data and identify which patients were missing out on treatment and why. The data added weight to advocacy efforts and ultimately led to the public funding of three important ABC treatments (palbociclib, trastuzumab, and fulvestrant).[165] In response to the report, the first ABC-NZ treatment guidelines were produced in 2020 (based on the ABC International Consensus guidelines),[166] and a digital patient-reported outcome measure (PROM) tool for nurse-led management of ABC symptoms was developed and implemented in 2021.[138] A 2024 ABC Global Alliance interview with the Te Rēhita Mate Ūtaetae – Breast Cancer Foundation National Register (see **Appendix II** for methodology) highlighted progress over the past decade (**Box 3**).

Box 3: Registry spotlight: Te Rēhita Mate Ūtaetae – Breast Cancer Foundation National Register, New Zealand[167-169]

Following the launch of the "I'm Still Here" campaign in 2018, the Te Rēhita Mate Ūtaetae register was consolidated into a national registry in 2020, achieving full population coverage across both public and private hospitals. As an opt-out registry, it aims to ensure that all people with breast cancer are tracked from diagnosis to death, capturing recurrence data through two-yearly reviews of patient clinical records.

Te Rēhita Mate Ūtaetae uses a robust, inclusive data system to ensure every person with ABC is acknowledged and tracked throughout their journey. Data is widely used to audit clinical practice, investigate epidemiology of both early and advanced breast cancer, and monitor outcomes.

The register plans to develop dashboards for clinicians, so that all data is searchable by location and hospital. In addition, New Zealand's new breast cancer quality performance indicators are being measured out of the register.

"To make widespread change we [Breast Cancer Foundation NZ] have been able to use the register to pick topics and say these are the gaps and move forward with a lot of those to improve care."
Adèle Gautier, Te Rēhita Mate Ūtaetae –
Breast Cancer Foundation National Register

The situation in New Zealand illustrates the transformative power of high-quality data for driving meaningful and tangible change for people with ABC. While similar outcomes are yet to be achieved in other countries, many are now advocating for improved data collection as a crucial step toward addressing inequities. In Canada, persistent challenges in ABC data collection led Rethink Breast Cancer to launch the "Make MBC Count" campaign in 2020,[170] which spotlighted the urgent need for more robust ABC registries.[170] The campaign evolved into "Make Me Count" in 2024, calling for robust and complete data that is harmonized and can be shared between provinces and regions across Canada.[171] It highlights the importance of quality data to overcome ABC disparities, specifically calling out the need for improved data on recurrence, race, and social determinants of health, to improve health equity and outcomes for all people with ABC in Canada.[172] As of June 2025, the campaign's petition has 960 signatures and Rethink Breast Cancer intend to take this to Canadian Federal and Provincial decision-makers to advocate for improved ABC data collection.[172]

In LMICs, registry data can be a powerful tool to highlight persistent inequities in access to adequate treatment and care. With most breast cancer data in Sub-Saharan Africa (SSA) coming from cancer referral centers, information on breast cancer survival outcomes and access to treatment is largely limited to those who live close to specialist centers, are covered by health insurance, or can afford to pay out of pocket.[173] A 2021 population-based cancer registry (PBCR) study aimed to understand access to treatment for the general breast cancer population, beyond those treated in specialist centers, in ten SSA countries. The study found that only a fifth (20%) of breast cancer patients randomly selected from 11 urban registries had stage at diagnosis and hormone receptor status recorded, making assessment of therapy according to the National Comprehensive Cancer Network (NCCN) Harmonized Guidelines for SSA challenging.[173] Furthermore, around half (51%) of those with curable breast cancer received inadequate or no cancer-directed therapy, with access to treatment varying by registry area.[173] Although not specific to ABC, studies such as these showcase the stark disparities that remain in many LMICs, despite the development of resource-stratified guidelines, and demonstrate the role of registry data in highlighting these inequities.

Improving ABC data collection is now a global priority with new standards and targets being set

The collection of high-quality ABC data is increasingly being recognized as a global priority—a change that is reflected in the new standards and targets that have been set over the past decade. In 2020, the European Society of Breast Cancer Specialists (EUSOMA) updated their Requirements of a Specialist Breast Centre, to include collection of data on all patients with early or advanced breast cancer.[174-175] The requirements also mandate that specialist breast centers must achieve the minimum standards outlined in EUSOMA's Quality Indicators for Breast Cancer Care.[174-175] In 2023, EUSOMA and the ABC Global Alliance collaborated on the first set of quality indicators (QIs) specifically for ABC, which recommend the collection of data including, among others, appropriate pathological characterization of disease, the proportion of patients receiving systemic therapies, and appropriate use of tumor markers.[175] The publication strongly suggests that specialist breast centers collect data on PROMs, *BRCA* (breast cancer gene) testing, and clinical outcome measures, all of which are anticipated to become formalized QIs in the future.[175] The latter will allow the identification of differences in outcomes between centers and countries, as well as providing a comparison between real-world data and that coming from clinical trials.[174-175]

In 2024, The Lancet Breast Cancer Commission—established in 2021 as a global multidisciplinary group dedicated to improving the lives of people with breast cancer—launched a report based on two years of primary and secondary research.[149] It outlined a roadmap for breast cancer change that included a call for the collection of high-quality registry data on cancer relapse worldwide.[149] Specifically, ABC data collection is one of five key proposed measurable indicators for improving the inclusive management of ABC. The Commission recommends that at least 70% of global cancer registries record people with metastatic disease, with a long-term goal of 100%.[149] Importantly, the recommendation for worldwide collection of relapse data includes not only those with ABC, but also with other metastatic cancers, and calls out ABC as a beacon of change for global healthcare systems.[149]

In addition, the European Network of Cancer Registries (ENCR) published in 2025 its Recommendations on Recording Recurrence, Progression, and Transformation of Cancer, providing detailed guidance for population-based cancer registries on how to systematically collect and record recurrence data across all cancer types.[176] 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. These initiatives demonstrate enhanced global recognition of the importance of high-quality cancer data collection, and ABC data specifically. Although this represents a positive shift in mindset globally, implementation of these recommendations is largely yet to be realized, and targets remain particularly challenging for LMICs.

Cancer registries are increasing in number, but quality varies globally

Cancer data is routinely collected through different types of registries that vary in their focus and drivers (**Table 2**). Despite growing global recognition of the importance of data collection and the critical role of registries, the scope and types of data they capture, such as stage at diagnosis, recurrence information, biomarkers, and survival data, still vary significantly across registries.

Table 2: Types of registries used for collection of ABC data

Type of Registry	Description	Drivers
Population-Based Cancer Registries (PBCRs)[150]	Collect data on all cancer cases within a defined geographic area (e.g., state, country).	Public health surveillance, epidemiology, tracking of incidence, and mortality.
Hospital-Based Cancer Registries	Focus on patients diagnosed and treated within a specific hospital or healthcare system.	Quality improvement, clinical care optimization, institutional benchmarking.
Breast Cancer-Specific Registries[168]	Dedicated to collecting detailed data specifically on breast cancer patients.	Research into breast cancer subtypes, treatment outcomes, personalized medicine.
Pharmaceutical / Drug Registries[177]	Monitor patients receiving specific drugs or therapies, often sponsored by pharmaceutical companies.	Post-marketing surveillance, real-world evidence, safety monitoring, regulatory compliance.

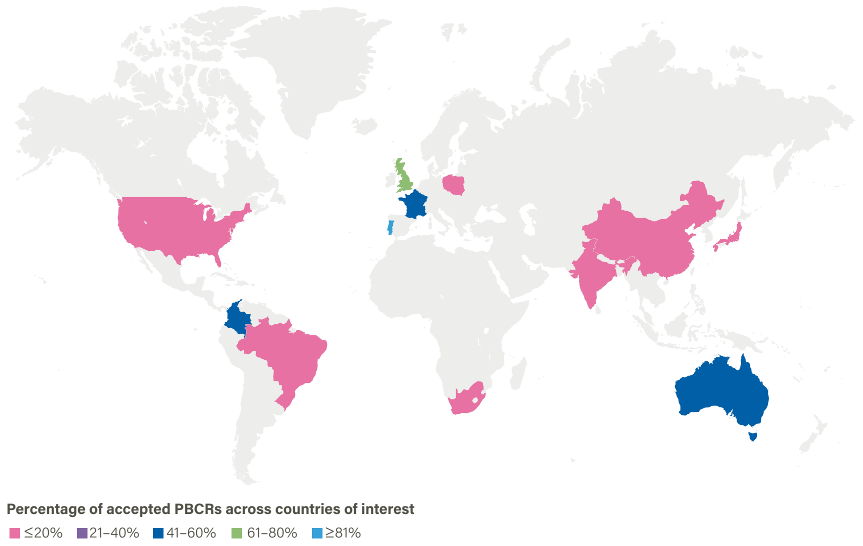
PBCRs record all new cancer cases in a defined population and are vital to assess disease burden, monitor trends, and evaluate progress over time.[178] IARC's Cancer Incidence in Five Continents (CI5) Volume XII provides a global view of cancer incidence from 2013–2017.[178] This volume saw a notable increase (28%) in PBCR submissions compared with the previous edition (Volume XI), with 675 submitted to IARC across 99 countries (**Figure 11**).[178] However, of these, only 460 PBCRs from 65 countries met IARC's data collection standards, which cover comparability, validity, timeliness, and completeness. While this represents a 25% increase compared with Volume XI, there is still room for data collection improvement globally. PBCR submissions were highest in Asia, while acceptance rates were higher in Oceania, North America, and Europe. This geographic pattern suggests that while Asia contributes the largest volume of data, driven by large populations and expanding cancer registration programs, registries in Oceania, North America, and Europe are more likely to meet IARC's quality standards, likely reflecting more mature infrastructure, consistent diagnostic systems, and greater resources for data validation.

Figure 11: PBCRs submitted to IARC's C15 Volumes XI (2008–2012) and XII (2013–2017)[178]

Although the rising number of accepted PBCRs signals progress, major gaps in data collection and completeness remain worldwide. Fewer than one in five IARC-accepted PBCRs in over half of the countries analyzed by the ABC Global Alliance record breast cancer stage at diagnosis—and none in Brazil, Japan, Poland, or South Africa capture this data (**Figure 12**). The number of PBCRs reporting stage at diagnosis has remained largely unchanged since the last IARC report, suggesting stagnation in many regions.[178]

Encouragingly, initiatives are underway to address these gaps and strengthen cancer data collection. Across Europe, registries have been incentivized to improve their data quality through a 2024 European Commission Direct Grant to Member State Authorities. With a dedicated budget of €13 million under the EU4Health Programme, the initiative seeks to improve the quality, completeness and timeliness of cancer registry data that feeds the European Cancer Information System.[179]

Figure 12: PBCRs accepted by IARC C15 Volume XII reporting to collect data on breast cancer stage at diagnosis[178]



Countries in grey were not included in the analysis

Progress in registry data collection is unequal worldwide

Numerous ABC-focused national and regional registries have been established in the past decade.[3] The ABC Global Alliance conducted interviews with several registries that collected ABC data in 2024 (see **Appendix II** for methodology), including ESME-MBC cohort in France, the NaoME in the UK (**Box 4**), and the OPAL registry in Germany (**Box 5**).

While initiatives such as these mark important advancements, the development of ABC-focused registries remains disproportionately concentrated in HICs. Expanding such efforts to LMICs will require substantial funding, but is essential for improving ABC data collection and analysis and addressing global disparities.[173] A 2021 PBCR study in SSA highlighted the substantial barriers to data collection in LMICs: of breast cancer patients registered to PBCRs across 10 SSA countries, records of more than a third (36%) could not be traced to a treatment facility.[173] While the authors assume that many never initiated therapy, they note that inadequate paper-based record systems and the absence of frameworks to facilitate record linkage could also be a reason for the lack of tracing.[173] These findings reflect broader challenges documented in the region, including those from the African Breast 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.[180] These studies highlight the need for strengthened health systems and enhanced data management infrastructure to improve patient tracking, disease surveillance, and outcomes for people with breast cancer in LMICs.[173]

Box 4: Registry spotlight: ABC-focused registries

Épidémio-Stratégie Médico-Economique (ESME)-MBC Cohort, France [151]

The ESME database, an independent academic initiative, collects retrospective hospital-based data from a national network of 18 hospitals in France, focusing on efficacy, progression, and treatments. Data is collected manually from electronic health records (eHR), then cross-checked with National Health System (NHS) and National Insurance System reimbursement data.

ESME enables research on real-world cancer treatment, complementary to data obtained from randomized controlled trials, with 35,000 ABC patients registered as of 2024. It has provided independent data to support the French health authorities in their health product evaluation missions.

> **“Most registries are quite good or somewhat good regarding early breast cancer. But we thought that there was a big lack of data regarding MBC and details of treatments in France.”**
>
> *Suzette Delaloge, Épidémio-Stratégie Médico-Economique*

National Audit of Metastatic Breast Cancer (NAoME), UK [155,181]

NAoMe, funded by the UK NHS, is an ambitious initiative designed to improve the understanding, visibility, and management of ABC by leveraging a unique strength of the UK health system: the NHS number.

Unlike many countries, the NHS uses a universal patient identifier, allowing NAoMe to consolidate information from across the health system including cancer registries, hospital records, chemotherapy and radiotherapy databases, and primary care prescription data. This integration enables NAoMe to map patient care pathways with an unparalleled degree of completeness—in theory.

However, the audit has highlighted a critical limitation: recurrence data remains significantly under-reported. Although the National Disease Registration Service (NDRS) has collected recurrence data through the Cancer Outcomes and Services Dataset (COSD) since 2013, the reality is that many NHS trusts are still not capturing information on recurrence, despite it being mandatory to report. For example, 2021 data from the COSD shows that, on average, NHS trusts in England reported Breast Non-Primary Cancers (e.g., recurrences or progressions) in only 1.2% of all submitted primary cancers of any type.

Despite these challenges, NAoMe is catalyzing real progress and has invested in a dedicated research fellow to drive audit advancement over 2025 and beyond. In October 2024, NAoMe published its first “State of the Nation” report, providing a long-overdue snapshot of ABC in the UK. The report estimated that 11,132 people were living with *de novo* ABC and 5,923 with recurrent disease in 2019–2021—a number believed to significantly underestimate the true population.

> **“The truth is we simply do not know the incidence or the prevalence of metastatic breast cancer at the moment, and obviously that limits what can be done with national audits and epidemiological work significantly.”**
>
> *David Dodwell, National Audit of Metastatic Breast Cancer (NAoMe)*

Furthermore, some registries are using innovative technologies to enhance ABC data collection. One example is the OPAL Registry in Germany, which is pioneering real-time data collection to improve ABC outcomes (**Box 5**).[152] While registry innovation and improved data collection are not equal worldwide, the progress made by some should be leveraged where feasible to advance progress in countries where ABC data collection remains inadequate.

Box 5: Registry spotlight: The OPAL Registry, Germany [152]

The OPAL registry prospectively follows patients longitudinally from early to advanced breast cancer. It aims to complement Germany's National Cancer Registry, providing a snapshot of ABC cases across selected hospital and community oncology settings. This includes real-time, patient-reported outcome (PRO) capture with a >80% response rate.

Although not a nationwide view of ABC cases, OPAL's dynamic approach to prospective data capture tracks ABC treatment and patient outcomes using data administrator personnel. This is setting a precedent for real-time data collection, which allows for rapid integration and analysis of novel treatments and biomarkers compared to retrospective data registries, and has the potential to be scaled across national registries.

"We can track how quickly a new treatment or biomarker test is adopted and how many patients receive it, allowing us to spot gaps in care early and address them."

Martina Jänicke, The OPAL Registry

Barriers to optimal ABC data collection persist worldwide, even in HICs

Registries face an array of challenges that hinder optimal ABC data collection, including high implementation costs, limited funding, privacy law limitations, barriers to information sharing, and workforce capacity constraints.[182] Findings from virtual interviews conducted in 2024 by the ABC Global Alliance (see **Appendix II**) align with recent literature highlighting persistent issues in tracking both *de novo* and recurrent ABC. These challenges are compounded by fragmented healthcare systems, inconsistent record-keeping practices, and variability in diagnostic procedures and treatment options for advanced disease (**Table 3**).

According to interviews, a significant barrier to high-quality data collection is the effort and cost required for active tracking of people with breast cancer, which can result in those with recurrent ABC being lost to follow-up, and leave a substantial proportion undocumented. Additionally, database design can limit comprehensive data collection, with many databases lacking fields to capture reasons for treatment changes and, when they do exist, lacking standardized definitions for key terms such as 'line of treatment' and 'progression.'

The absence of international coding standards specific to ABC adds another layer of complexity, as manual recording and data extraction from patient notes are often required. This imposes a significant resource burden on countries, particularly those with limited healthcare infrastructure. It is crucial that an easy to find International Classification of Diseases (ICD) code for "metastatic breast cancer" is created and implemented in all clinical settings, worldwide. This would not only facilitate the correct identification of people with ABC at the hospital level, but also at a country level.

Table 3: 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.
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	• Real-time data collection is a challenge due to a growing number of long-term survivors to follow up and the increasing number of data fields to be completed (e.g., biomarkers). • Lines of treatment are not defined and differ between oncologists, hospitals, and countries, impacting accurate and comparable data collection.
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 still requires data managers to verify and fill in gaps, with the algorithms applied to the combined dataset achieving predicting ~80% accuracy. • Data managers continue to play a key role in verifying and filling data gaps, and coding improvements are needed to help address the lack of standardization across data recording in electronic health records EHR systems.
National Audit of Metastatic Breast Cancer (NAoME), The UK	• Inconsistencies in the use of ICD codes to identify metastatic recurrence make the collection of high-quality relevant data difficult. • Fast data collection may lack depth and completeness. The collection of high-quality data takes longer, but this risks reduced relevance.

The future of ABC data collection relies on continued innovation, collaboration and advocacy

Global collaboration and advocacy are key to improving ABC data collection, as demonstrated by recent work in Australia and Northern Ireland, which built on data linkage methodologies pioneered in the UK.[157-158,161] While the ABC community has made significant progress, differences in datasets, health systems, and registry structures make it challenging to replicate successes across countries and regions. This emphasizes the urgent need for harmonized methodologies that ensure consistency, comparability, and adaptability worldwide.

Although registry reform is widely recognized as a priority, recent research shows that predictive algorithms applied to existing datasets can help fill gaps in incomplete data.[183-184] These approaches offer a potentially less resource-intense, faster, and more accurate way to improve ABC data collection (**Box 6**).[183] While such methods rely on robust baseline health data—which may be a challenge in LMICs—their global application could provide an exciting opportunity to better understand ABC prevalence and patterns. That said, there is no 'one-size-fits-all' solution, and harmonization efforts must be flexible enough to accommodate local realities.

Over the past decade, ABC data has been increasingly leveraged to drive quality improvement and policy change. In New Zealand, registry data has been used to assess ABC treatment patterns against national guidelines and evaluate the impact of adherence on outcomes.[185] A recent study found that the registry captures data most ABC-NZ guideline measures and, with planned enhancements—such as improved completeness and inclusion of key biomarkers—will enable routine, prospective monitoring of adherence at national, hospital, and individual levels.[185] In Portugal, the ABC Global Alliance and Centre for Evidence Based Medicine used an original cumulative incidence model and observational data to estimate cost savings from a subsidized, part-time employment scheme for people with ABC. The findings were used to advocate for changes in labor laws to improve flexible working for people with metastatic cancers,[146] illustrating the power of data to influence policy.

As we enter an era increasingly shaped by health technologies and artificial intelligence (AI), the potential to transform ABC data collection, management, and application is growing rapidly. Some registries, such as the Netherlands Cancer Registry, already use algorithms to predict relapse (**Box 6**),[27,41] while in England, similar models have achieved 96.6% sensitivity.[186] The German OPAL registry (**Box 5**) has demonstrated the value of systematically capturing PROs, achieving >80%

response rates through manual collection—showing the willingness of people with ABC to share their experiences. Looking ahead, embedding technologies that enable real-time, automated PRO capture, as seen in platforms like Cankado,[187] could expand the volume of ABC data collected worldwide while directly supporting improved patient outcomes.

The Lancet Breast Cancer Commission has highlighted the opportunity for digital health to advance equity by reducing barriers to patient engagement, through improved access to research, decentralized clinical trials, and remote participation.[149] While real-world applications of AI and automation in ABC data registries remain limited as of 2025, momentum is rapidly building. In the coming years, a surge in AI-enabled tools is expected to support predictive analytics, patient stratification, and enhanced registry analytics.[188] Ensuring that registry infrastructure is future-ready will be essential to capitalizing on these innovations.

Finally, as technology advances, it is essential to ensure equitable application across settings, including LMICs. At a minimum, registry frameworks should capture core data on stage at diagnosis and recurrence. Achieving this will require partnerships, training, and scalable solutions tailored to local capacities and resources—ensuring that the digital transformation of ABC data collection narrows, rather than widens, the global data divide.

Box 6: Registry spotlight: the Netherlands Cancer Registry, The Netherlands[150]

The Netherlands Cancer Registry operates on an opt-out basis, with new cancer patients identified through pathology laboratory results. Patients are added to the database at diagnosis, with final registration occurring approximately 9–12 months later, once treatment data is available. Each year, the registry cross-references its records with the national hospital discharge database to reconcile incidence data for patients without pathology confirmation.

Recurrence data from pathology labs can be incomplete, as not all patients undergo biopsies. To address this, in 2019 the registry developed an algorithm to predict the development of metastases. This model draws on hospital discharge data, procedure histories, PET scan results, prescription codes, and eHR analysis, to estimate prevalence.

Because enrollment is automatic, participation rates are significantly higher than in opt-in systems, where patients must actively register. This registry demonstrates how technology-driven innovation can enhance the completeness and accuracy of ABC data, offering a model for how digital health solutions can strengthen cancer surveillance worldwide.

"The algorithm we built has been tested and validated with cohorts we actively followed for certain projects. Our data managers or registration clerks confirm data by looking in the files of these patients."

Sabine Siesling, the Netherlands Cancer Registry

CONCLUSIONS AND FUTURE DIRECTIONS

The past decade has shown the critical importance of high-quality data collection in addressing the global challenges associated with ABC. While significant strides have been made, persistent gaps in data collection, reporting, and harmonization continue to hinder a comprehensive understanding of ABC prevalence, progression, and outcomes worldwide. These limitations disproportionately affect LMICs, where resource constraints exacerbate disparities in care and outcomes for people living with ABC.

Global initiatives such as the Lancet Breast Cancer Commission's roadmap and the EUSOMA's ABC Quality Indicators, and innovative registry models like Germany's OPAL Registry, demonstrate the transformative potential of robust ABC data systems. These efforts highlight the power of collaboration, advocacy, and technology in driving progress. However, they also reveal the complexity of implementing scalable, equitable solutions across diverse healthcare systems and socioeconomic contexts. Moving forward, it is essential that we build on these advances by fostering global partnerships, standardizing methodologies, and leveraging emerging technologies, that are applicable to LMICs.

Ultimately, improving ABC data collection is not just about numbers, it is about visibility, equity, and advocacy. By illuminating the true burden of ABC and identifying disparities in care, high-quality data empowers stakeholders to design targeted interventions, allocate resources effectively, and improve outcomes for all people living with ABC.

As a result, the ABC Global Alliance community has agreed that this goal should remain in the ABC Global Charter 2025–2035 with the following wording:

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.

3 Quality of life for people with ABC

Quality of life for people with ABC

INTRODUCTION

Developments in the advanced breast cancer (ABC) treatment landscape are enabling people to live longer than ever before.[189] However, longevity alone is not enough: maintaining quality-of-life (QoL) is essential to ensure that people with ABC experience not only more years, but more fulfilling ones.

Quality of life encompasses physical and psychosocial (including emotional, spiritual, financial, and work-related) well-being, which naturally evolve as a person's priorities shift over time.[189-191] Literature shows that many psychosocial and spiritual needs of people with ABC remain unaddressed, negatively impacting their QoL.[191] Additionally, the focus on early disease in breast cancer awareness and support programs has left gaps in information, resources, and support for those with advanced disease (discussed further in Goals 6 and 7), often leading to feelings of isolation and stigma (Goal 8), and a reduced QoL.[190-191]

This chapter explores key factors shaping the QoL of people with ABC and their caregivers. It draws on findings from an analysis of QoL in ABC clinical trials, a targeted literature review (**Appendix III and IV**), and global healthcare professional (HCP) and patient surveys conducted in 2024.

STATUS IN 2005–2015

The 2005–2015 Global Decade Report highlighted the profound impact of ABC on QoL on both the physical and psychosocial wellbeing of people with the disease.[3] Despite significant advances in treatments, the QoL of people with ABC slightly declined over the decade, with the average EQ-5D score falling from 0.7201 in 2004 to 0.6313 in 2012.[3] At the time, eight in ten people with ABC identified QoL as the most critical area for improvement in ABC care.[3] The report also revealed significant disparities in disease management and financial support between early and advanced breast cancer, contributing to poorer psychosocial outcomes for those with advanced disease.[3]

Assessment of QoL was shown to vary substantially across healthcare centers, creating regional and global inconsistencies in care.[3] While standardized and validated QoL measurement tools existed for use in clinical trials, concerns remained regarding their real-world effectiveness due to poor integration into clinical practice.[3] The report called for a structured definition of QoL, with a greater focus on its influencing factors, and the development of clinical tools to assess QoL in real time at the patient level.[3]

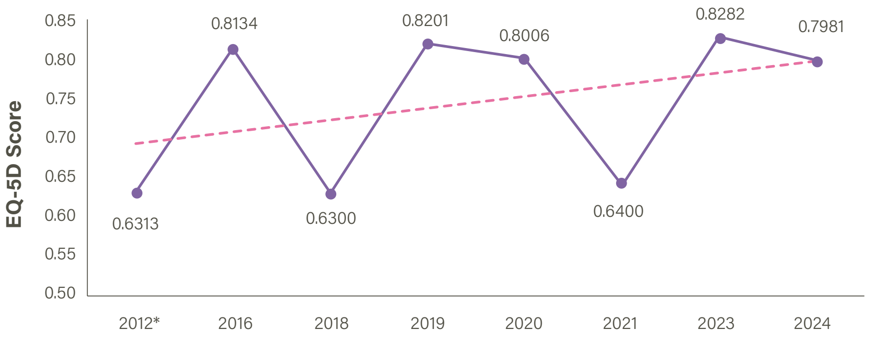
Recognizing this substantial unmet need, the 2015–2025 ABC Global Charter prioritized improving the QoL of people with ABC as one of its ten 'Actions for Change.'[4]

A DECADE IN REVIEW (2015-2025)

The QoL of people with ABC has marginally improved over the past decade

The past decade has shown improvements in QoL for people with ABC. A 2025 analysis of QoL outcomes reported in Phase 3 clinical trials between 2016–2024 (using the same methodology as the 2005–2015 Global Decade Report; see **Appendix III**) indicates a slight overall increase in QoL. While this general trend is positive, EQ-5D scores were still highly variable across subtypes and lines of therapy, and overall gains across the decade were marginal (**Figure 13**).[3]

Figure 13: QoL in people with ABC as assessed by EQ-5D, 2015-2024, Generic (non-Cancer specific) Health Utility Score



Data collected from: Rugo et al. 2018; Harbeck et al. 2016; Verma et al. 2018; Fasching et al. 2020; Harbeck et al. 2020; Kaufman et al. 2020; Goetz et al. 2020; Oliveira et al. 2024; Rugo et al. 2024; Schmidt et al. 2022; Fehm et al. 2024; Curigliano et al. 2023; Ueno et al. 2024; Curigliano et al. 2022; Saura et al. 2020; Pe et al. 2017; Schmid et al. 2023; Cescon et al. 2024; Lobil et al. 2023; Kahan et al. 2021; Senkus et al. 2023; Cortes et al. 2023.

* Data from 2012 is from the 2005–2015 Global Decade Report and is for comparison only.

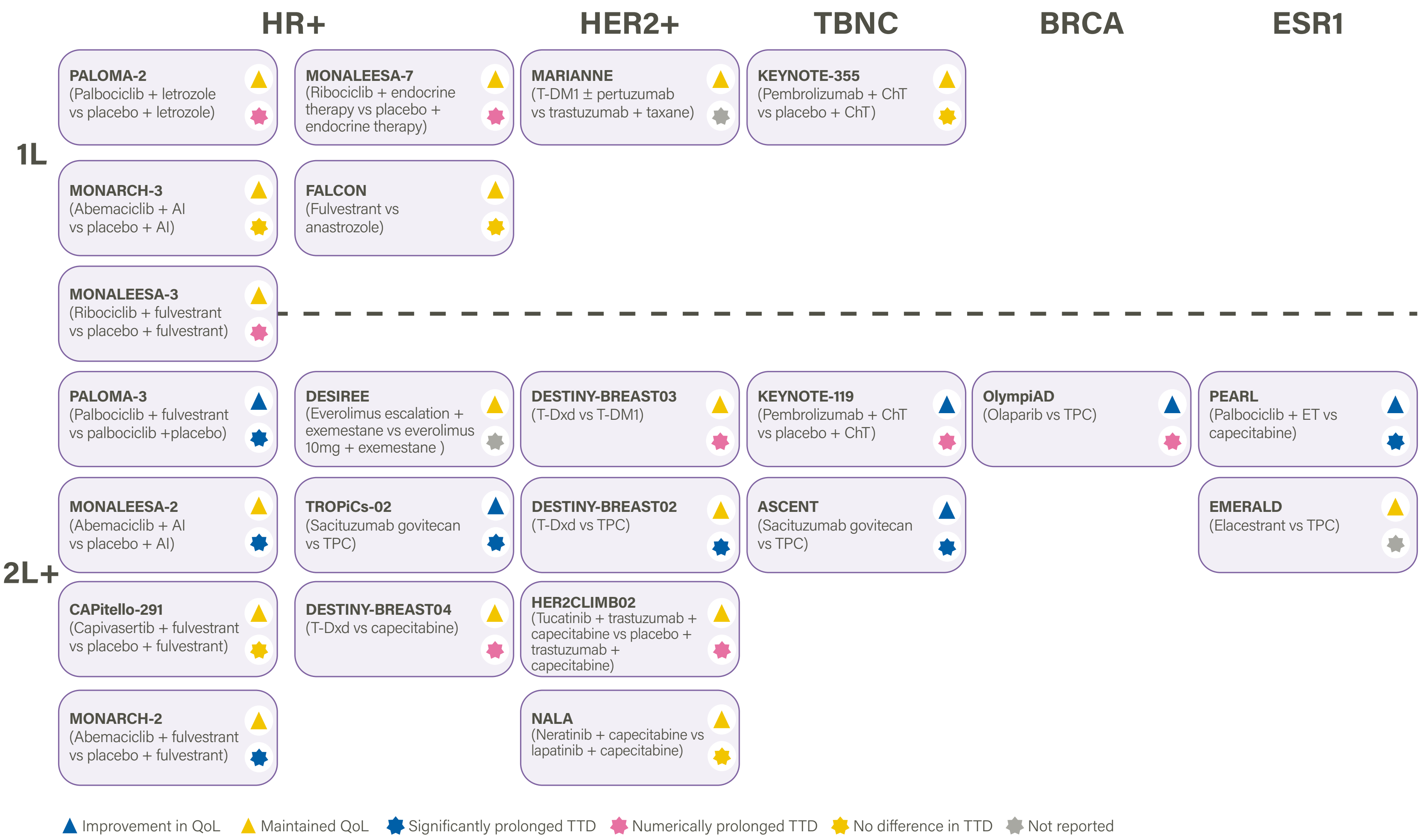
Average clinical trial scores were taken for each year. Where data for conversion to EQ-5D scores were not available, a missing data calculation (based on Berkelmans et al. 2022) was undertaken to give the median score.

These QoL gains have been largely driven by the advent of targeted therapies, which have reduced the need for chemotherapy, leading to improved tolerability and better patient-reported outcomes (PROs).[192] Despite overall improvements, disparities in QoL outcomes persist across subtypes, with some populations still facing significant unmet QoL needs. This mirrors trends seen in ABC survival outcomes (see Goal 1).[11]

Targeted treatments for HER2-positive ABC have demonstrated the most notable QoL improvements this decade, with many studies reporting either a significant QoL benefit, or at least a maintenance of QoL, compared to standard of care approaches (**Figure 14**). The American Society of Clinical Oncology (ASCO) guidelines note the importance of HER2-targeted therapies in improving both clinical outcomes and maintaining QoL in people with HER2-positive ABC.[193] Despite representing 65% of the ABC population and being the subject of numerous clinical trials, QoL for people with HR-positive ABC has only modestly improved this decade (**Figure 14**).[11] Cyclin-dependent kinase 4/6 (CDK4/6) inhibitors in combination with endocrine therapy (ET) have shown to maintain QoL compared to ET alone, and improve QoL compared with chemotherapy.[11] For those with triple-negative ABC, QoL remains a challenge. This subtype, representing 15% of the ABC population, saw the fewest breakthrough therapies and only marginal QoL improvements relative to others (**Figure 14**).[11]

While these findings are striking, factors such as line of therapy should be taken into consideration when reviewing QoL improvements. Furthermore, those enrolled in first-line trials may typically report a higher baseline QoL,[194] and traditional QoL assessments may fail to capture meaningful improvements unless they consider the time until clinically relevant decline. Incorporating time to deterioration (TTD) measurements into QoL assessments could support better understanding of the true impact of treatment on QoL.

Figure 14: QoL outcomes and time to deterioration in ABC clinical trials between 2015–2024



Based on data from: Rugo et al. 2018;[195] Goetz et al. 2020;[196] Fasching et al. 2020;[197] Harbeck et al. 2016;[198] Verma et al. 2018;[199] Oliveira et al. 2024;[200] Kaufman et al. 2020;[201] Harbeck et al. 2020;[202] Robertson et al 2018;[203] Schmidt et al. 2022;[204] Rugo et al. 202;[205] Ueno et al. 2024;[206] Perez et al. 2019;[85] Curigliano et al. 2022;[207] Mueller et al. 2021;[208] Moy et al. 2021;[209] Schmid et al. 2023;[210] Lobil et al. 2023;[211] Mark et al. 2019;[212] Kahan et al. 2021;[213] Cortes et al. 2023;[214] Cescon et al. 2024;[215] Tanja et al. 2024.[216]

1L= first-line; **2L+=** second-line and later; **AI=** aromatase inhibitor; ***BRCA*****=** breast cancer gene; **ChT=** chemotherapy; **ESR1=** estrogen receptor 1; **ET=** endocrine therapy; **T-DM1=** trastuzumab emtansine; **T-DXd=** trastuzumab deruxtecan; **TPC=** treatment of physician's choice.

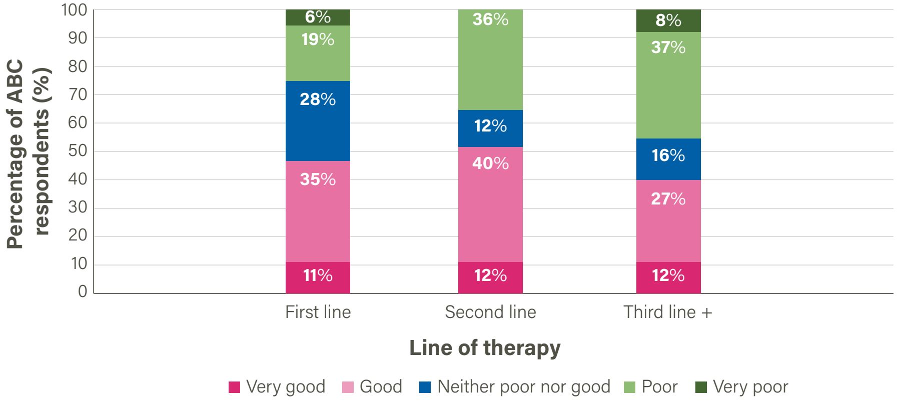
The positive QoL outcomes seen in ABC clinical trials this decade may not reflect real-world experience. Often, clinical trials report "tolerable" side effects or "maintained" QoL with new ABC treatments. However, this can overlook the cumulative impact of persistent, lower-grade side effects that can significantly affect daily life. While severe toxicities (grade 3 or 4) understandably receive the most attention in trials, chronic, lower-grade side effects like fatigue, nausea, diarrhea, or neuropathy can be debilitating, especially in advanced disease where treatment is often life-long.[217-218] These lower-grade side effects often occur early in the disease course, and can progress over time, resulting in high levels of cumulative toxicity.[217] Unlike treatment for early-stage disease, where side effects are often temporary, managing these ongoing toxicities requires a continuous focus on QoL, patient-reported outcome measures (PROMs), and implementation of effective coping strategies to balance treatment effectiveness with its related side effects.[218-219] To truly understand the impact of ABC treatments on QoL and to optimize patient outcomes, we need to move beyond simplistic interpretations of "maintained" QoL and address these often-overlooked challenges.

Treatment toxicity is a major driver of declining QoL in ABC

Treatment toxicity extends beyond side effects, to include the time and financial burden associated with managing them (see Goal 9). As a result, managing ABC requires an approach that focuses on sustained QoL rather than short-term outcomes.

A 2024 European survey by IQVIA and Menarini Stemline on unmet treatment needs and preferences in ABC, highlighted a direct link between treatment toxicity and decline in QoL (**Figure 15**).[220] As patients progressed through lines of treatment, the number of respondents reporting 'poor' or 'very poor' QoL increased substantially (**Figure 15**).[220] The same survey demonstrated the cumulative impact of multiple side effects on QoL, with more than half (61%) of individuals with 'poor' or 'very poor' QoL reporting 11 or more side effects.[220] The impact of side effects on QoL can also affect treatment adherence. A 2024 survey of ABC patients in the United States (US) found that 43% of respondents had missed at least one treatment due to side effects.[221] In line with recent literature, these findings indicate that the burden of treatment-related side effects is a key driver of QoL decline for people with ABC.[217,222]

Figure 15: QoL of people with ABC in first-, second-, and later-lines of treatment



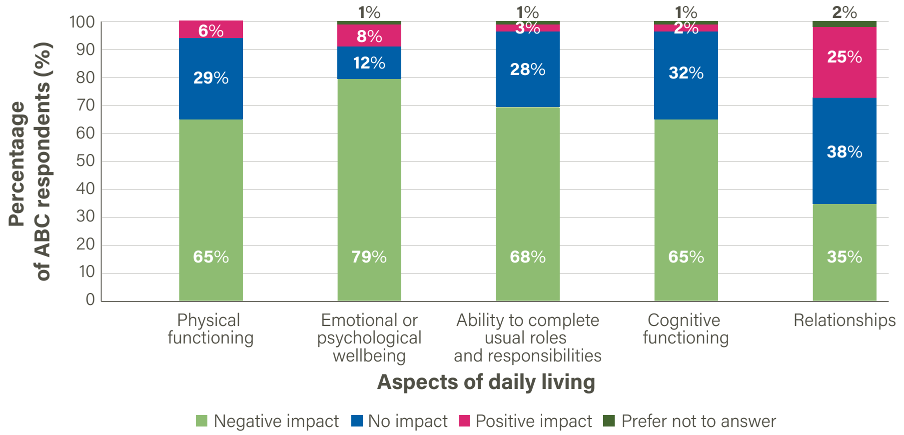
Based on data from a cross-country survey conducted in 2024 by IQVIA and Menarini Stemline. 2024.[220] 'Overall, in the past 4 weeks, how would you rate your QoL compared with other people of your age?'

Historically, treatment strategies have prioritized the 'maximum tolerated dose' (i.e., the highest dose that avoids intolerable side effects), determined in Phase 1 clinical trials.[221] However, even at these doses, many people with ABC struggle with daily activities.[219,221] Emerging evidence suggests that lower doses can maintain effectiveness of ABC treatment while significantly reducing long-term side effects, highlighting the potential to improve QoL without compromising outcomes.[19,223] In response, some trials are optimizing dosing schedules to shift towards 'minimum effective dose'.[19] With even incremental adjustments potentially yielding substantial QoL benefits for patients, this approach warrants further investigation in the coming decade. Project Optimus is an initiative set up by the US Food and Drug Administration (FDA) to reform the drug optimization and dose selection paradigm in oncology drug development.[223] However, with ethics committees often hesitating to approve dose-reduction studies due to concerns about deviating from standard care recommendations and the risks of causing inferior outcomes, conducting such trials remains challenging. Low-resource settings, where access to costly standard treatments is limited, may offer ideal conditions to ethically and pragmatically explore these strategies while generating meaningful, context-specific evidence.

Despite advances, ABC continues to have a profound psychosocial and physical impact on people with the disease

The negative impact of ABC on the psychosocial and physical wellbeing of patients has been widely reported in literature across the last decade.[190,224-225] Findings from the ABC Global Alliance 2024 patient survey (n=1,254) reiterate this, with around two-thirds (62%) of respondents reporting ABC to have a negative impact on their overall wellbeing (**Figure 16**). For emotional or psychological wellbeing specifically, this increased to 79%. Despite this, only 46% of people with ABC reported that their healthcare teams always address their emotional and psychological needs, highlighting the need for improved HCP communication (discussed in Goal 5), information (Goal 6), and support services (Goal 7).

Figure 16: Impact of ABC on aspects of daily living



Based on findings from the ABC Global Alliance 2024 patient survey (n=1,254). 'What impact has advanced breast cancer had on the following areas of your life?'

While the negative impact of ABC on QoL is clear, a small proportion of survey respondents reported a positive impact on some aspects of daily living, including relationships. This category had the widest variation in impact—ranging from positive (25%) to negative (35%). These findings are supported by IQVIA and Menarini Stemline's 2024 European survey, in which 44% of respondents reported ABC to have a positive impact on relationships, 12% reported no impact, and 41% a negative impact.[220] Together these data demonstrate the highly individualized and diverse ways ABC can affect relationships.

QoL in ABC is shaped by financial, cultural, and social factors

The impact of ABC on QoL is influenced by a variety of financial, vocational, psychosocial, and physical factors,[226] and the ABC Global Alliance 2024 patient survey revealed notable differences in reported impact across socioeconomic and cultural contexts.

The long-term QoL impact of ABC on those with lower financial resources is widely reported in literature, with studies demonstrating the negative effect of out-of-pocket expenses and financial hardship on patient QoL (see Goal 9).[227-228] One example is the 2019 Survey of Health, Impact, Needs, and Experiences (SHINE) study, which highlighted the disproportionate impact of ABC on those with limited financial resources.[226] However, the ABC Global Alliance 2024 patient survey revealed a greater negative impact on QoL for people in high-income countries (HICs) compared to those in low- and middle-income countries (LMICs). In HICs, 65% of respondents reported a negative impact across all QoL domains, compared to 50% in LMICs. This perhaps unexpected finding may reflect broader socioeconomic and cultural factors that influence how QoL is perceived and reported. In HICs, where access to healthcare is generally better and daily life may involve fewer competing hardships, ABC can become a central focus—amplifying its perceived impact on QoL. In contrast, those in LMICs often face multiple, concurrent challenges, with ABC representing just one of many daily burdens, potentially lowering its relative perceived impact. The survey also identified significant variation in the emotional and psychological impact of ABC by ethnicity. In these areas, most White respondents (84%) reported a negative impact, compared with 67% of those from Non-White backgrounds ($p<0.05$). These findings point to the complex interplay between socioeconomic, cultural and ethnic factors in shaping patient experiences, and highlight the need for more context-sensitive, equitable psychosocial care.

The impact of ABC on QoL is also influenced by age. The 2019 SHINE study reported that people under 50 with ABC face particularly profound challenges, including heightened financial and personal concerns and greater anxiety about mortality compared to older individuals.[226] Similarly, the Young Survival Coalition's (YSC) Project 528 survey found that more than two in five (41%) young women with ABC experienced difficulty caring for their children after diagnosis.[20] The same survey revealed the substantial psychosocial burden faced by younger patients, with 75% reporting disease-related anxiety, 88% experiencing fatigue, and 51% identifying the management of side effects as a major challenge.[20]

The level of available support—both from formal support services (see Goal 7) and from family and friends—also plays a critical role in shaping QoL outcomes in ABC. Findings from IQVIA and Menarini Stemline's 2024 European survey showed that over half (61%) of people with ABC who were living with children but without a partner reported poor QoL, compared with just over a third (36%) of those living with both a partner and children.[220] These insights highlight the vital role of family and social support in mitigating the impact of ABC.

Taken together, these findings reinforce the urgent need for comprehensive, tailored support strategies that address the diverse factors influencing QoL for people with ABC, ensuring that care is equitable, culturally sensitive, and responsive to the needs of those most disproportionately affected.

The QoL impact on ABC caregivers is now more widely recognized

Caregiving for someone with cancer is physically and emotionally demanding, often involving the coordination of medical appointments, provision of psychosocial support, and navigation of the complex treatment landscape.[229] For caregivers of people with advanced disease, these demands are often intensified, contributing to high levels of stress, anxiety, and depression.[229]

Research indicates that around half of advanced cancer caregivers report low QoL.[230] In some cases, the psychosocial impact on caregivers may even exceed that experienced by the patients themselves.[231] A 2022 study found a direct correlation between the QoL of caregivers and that of the person living with breast cancer,[232] underscoring the interconnected nature of patient-caregiver wellbeing. While the impact on caregivers in advanced cancer is increasingly documented, there remains limited research specific to ABC. Notably, a 2025 global study found that caregivers who continued to work while supporting someone with ABC experienced a greater QoL burden than those who stopped working.[229]

Recognition of caregiver needs is growing. The 6–7th International Consensus Guidelines for ABC, published in 2024, include dedicated information outlining supportive services for caregivers, an enhanced focus compared to earlier editions.[19] Patient advocacy organizations have also expanded their efforts, with the ABC Global Alliance, the Metastatic Breast Cancer Alliance, and Breast Cancer Now all now hosting dedicated online resources for caregiver support and education.[233-235]

Despite this progress, significant gaps remain. Healthcare systems and policymakers must prioritize the development and implementation of comprehensive, accessible and sustainable support structures (see Goal 10) for caregivers of people with ABC, recognizing their critical role in patient care and their own right to wellbeing.

Many QoL assessment tools remain inadequate for capturing the unique needs of people with ABC

The 2005–2015 Global Decade Report identified a critical gap in QoL assessment for people with ABC, highlighting the lack of QoL measurement tools tailored to their unique experiences.[3] While some new instruments have been developed since 2015, most general and breast cancer-specific tools still lack the specificity needed to fully capture the ABC experience, reflecting a stagnation in the field (**Table 4**).

The Functional Assessment of Chronic Illness Therapy (FACIT) system is well established and includes many subscales relevant to ABC, such as those addressing fatigue, bone pain, endocrine symptoms, and treatment-specific effects (e.g., anti-angiogenesis, monoclonal antibodies).[236] However, these tools are often underutilized in ABC clinical trials. Potential barriers include the perceived time and resource burden, limited training and awareness among trials teams, and regulatory reluctance to mandate their use.

Table 4: QoL assessment tools used in ABC clinical trials (2015–2024)

Tool specificity	QoL assessment tool	Date established
Breast cancer QoL	EORTC QLQ-BR45*[237]	2020*
	EORTC QLQ-BR23[241]	1996
	Functional Assessment of Cancer Therapy (FACT)-Breast[242]	1997
General QoL	EORTC QLQ-C30 (3rd edition)[243]	2001
	FACT-General[244]	1997
	FACT-Taxane (version 4)[245]	2003
	EuroQol 5 dimensions level 3 (EQ-5D-3L)[246]	1990
	EuroQol 5 dimensions level 5 (EQ-5D-5L)[247]	2009
	Alopecia Patient Assessment scale[248]	2021
	PGI-TT[249]	1976†
	PRO-CTCAE[250]	2014
	BPI-SF[251]	1983

* The final phase IV study is underway to confirm psychometric properties of the module.
† First established in 1976, newer subscales have been developed since.

While progress has been slow, the past decade has seen some encouraging developments:

- **The European Organisation for the Research and Treatment of Cancer (EORTC) Core QoL Questionnaire-Breast-45 (EORTC QLQ-BR45):** An updated breast cancer-specific QoL assessment tool designed to better capture the impact of treatment on QoL.[237]
- **Core Outcome Set for Metastatic Breast Cancer:** Released in 2022 by the Health Outcomes Observatory (H2O) and accredited by the International Consortium of Health Outcomes Measurements (ICHOM), this set was developed collaboratively by international experts, patients and patient advocates.[238] Its adoption in clinical trials will help to standardize QoL measurement, reduce outcome-reporting bias, improve result interpretation, and support more informed treatment decision-making.[239]
- **EORTC Quality of Life Questionnaire for MBC (MBR44):** A promising collaborative initiative between the EORTC QoL unit and leading breast cancer organizations to create the first QoL tool dedicated specifically to ABC. Covering a broad spectrum of physical, treatment-related, and psychosocial issues,[59] the provisional questionnaire is undergoing international testing and represents a significant step towards a more nuanced understanding of QoL in ABC.[240]

Collectively, these initiatives signal a gradual but important shift towards more precise, patient-centered QoL assessment in ABC. Widespread adoption and integration of these tools into both research and clinical practice will be essential to ensure that the experiences of people with ABC are accurately measured, understood, and addressed.

PROMs support QoL understanding, but implementation in practice remains limited

PROMs play an important role in providing a holistic understanding of QoL impact in ABC.[252-254] When integrated into clinical practice, PROMs enable a more comprehensive evaluation of a patients' wellbeing, strengthen engagement with supportive care services, and facilitate interventions that are better aligned to individual needs.[254] However, the absence of standardized guidelines for analyzing, interpreting, and reporting PROM data limits their utility.[252-253] The lack of ABC-specific measures and wide heterogeneity of instruments used in practice, further complicate meaningful comparison across studies and settings.[254]

For PROMs to deliver real value to people with ABC, they must be collected and acted upon in real time. Innovative approaches to gathering PRO data in real-world settings have demonstrated meaningful improvements in QoL (**Box 7**).[187,255] Over the past decade, research has shown that integrating PROM tracking into routine care can support earlier symptom identification and management, address psychosocial needs more effectively, and may even improve clinical outcomes.[187,255] However, such regular PROM collection can present challenges for people with ABC, especially during periods of QoL decline, highlighting the need for approaches that are both patient-centered and minimally burdensome.

Box 7: Innovative PRO data collection is improving QoL in ABC

Patient-led symptom monitoring with CANKADO PRO-React[187]
CANKADO PRO-React is an EU-registered, interactive, autonomous patient empowerment application that supports patient-led symptom monitoring and does not require HCP input for use. Patients are prompted daily about their general health using a visual interpretation of the EQ-VAS scale and the system recommends contact with a treatment center if required. Results of the Phase 4 PreCycle trial, published in 2023, showed significantly longer time to deterioration of QoL in people with HR+ HER2- ABC using CANKADO PRO-React.

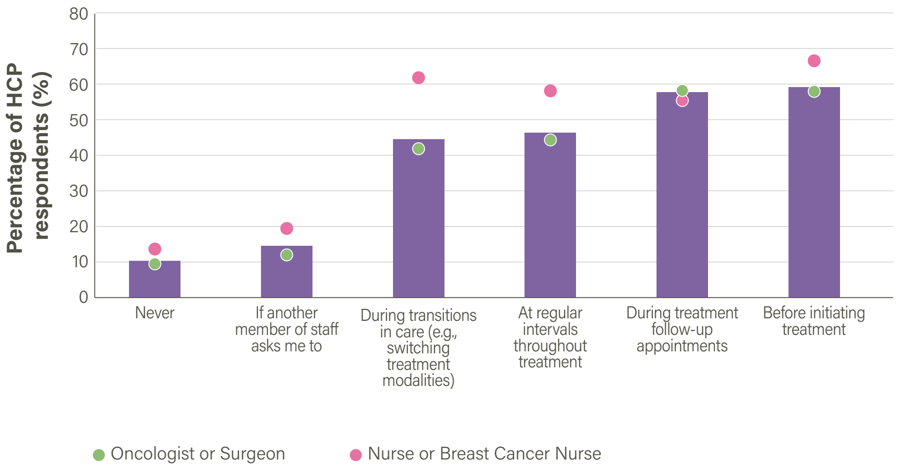
Alert-based smartphone PRO monitoring[255]
The PRO B trial aimed to understand the impact of weekly PRO monitoring combined with an automated alert system within routine ABC care in Germany. People with ABC received weekly questionnaires to their smartphones including elements of the EORTC computerized adaptive test (CAT) Core item banks. If PRO values deteriorated, an automated alert was sent to the treating breast center, which then contacted the person within 48 hours. Results published in 2024 showed decreased fatigue, and improved physical functioning and overall QoL of people with ABC, as well as demonstrating overall survival benefit.

EUonQoL-Kit for self-assessment of QoL[256]
Although not specific to ABC, the EUonQoL-Kit is a PROM designed for self-assessment of QoL at different phases of the cancer journey. Tailored to the individual's health status, it aims to capture the full range of QoL dimensions relevant to cancer patients and survivors in Europe. By identifying unmet needs and mapping all aspects of QoL that matter to patients, the tool has the potential to inform more personalized care. While still in development, the EUonQoL-Kit shows considerable promise for deepening understanding of the impact of cancer on QoL.

Barriers in clinical practice are hindering comprehensive QoL assessment

The QoL of people with ABC evolves over time, making regular assessment essential for monitoring changes and guiding care.[189] However, the ABC Global Alliance 2024 HCP survey (n=461) revealed that this is often not the reality in practice. Fewer than half (46%) of respondents reported conducting QoL assessment at regular intervals throughout treatment, with rates higher among nurses and breast cancer nurses than oncologists or surgeons (**Figure 17**). Alarmingly, 15% of HCPs reported only assessing QoL when prompted by another team member, and 10% reported never assessing it at all. Differences were also seen by facility type: almost half of respondents from cancer centers (47%) and tertiary hospitals with oncology departments (48%) reported measuring QoL throughout treatment, compared to only around a third (35%) of those working in hospitals without oncology departments.

Figure 17: HCP-reported frequency of QoL assessment in ABC care

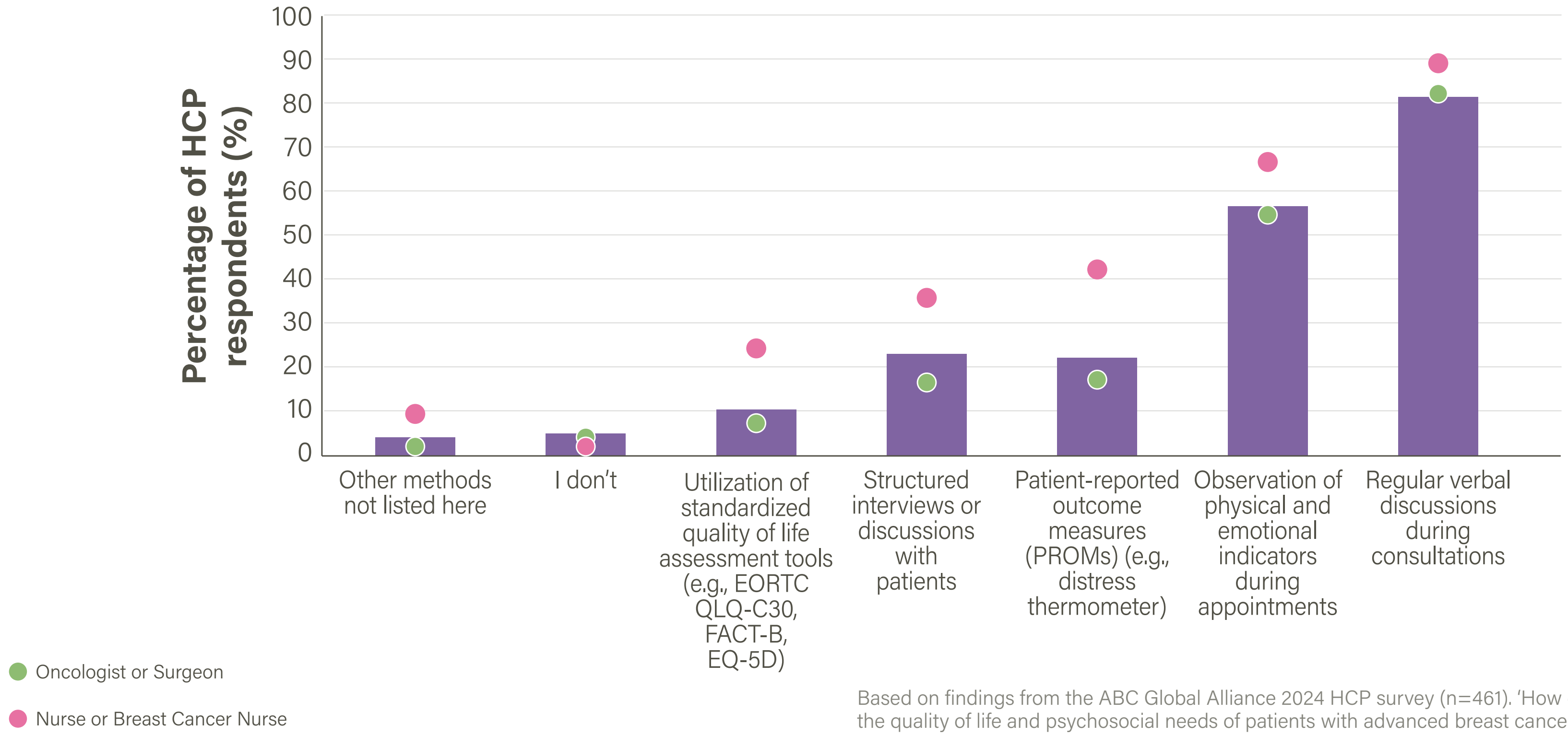


Based on findings from the ABC Global Alliance 2024 HCP survey (n=461). 'When do you incorporate quality of life assessments into treatment planning and ongoing care for patients with advanced breast cancer?'

Furthermore, the use of standardized QoL tools and PROMs in clinical practice was generally low (**Figure 18**). Only 11% of HCPs reported using standardized QoL assessment tools and 23% reported using PROMs. This varied between HCP type, with nurses or breast cancer nurses utilizing QoL tools (25%) and PROMs (42%) more than oncologists or surgeons (8% and 18%, respectively). While formalized tools remain underutilized, many HCPs reported assessing QoL and psychosocial needs through verbal discussion (82%) and observation (57%). This aligns with existing literature showing high rates of verbal QoL assessment in ABC,[257] which, while valuable, may fail to capture the multidimensional and evolving impact of the disease. The underuse of validated QoL assessment tools and PROMs risks limiting the depth and accuracy of understanding of how ABC affects patients' lives and may hinder the delivery of truly patient-centered care.

Barriers to the routine use of QoL assessment tools and PROMs in ABC care are multi-faceted.[254] The ABC Global Alliance 2024 HCP survey revealed that only 29% of respondents considered QoL assessment tools to be essential for understanding patient wellbeing and treatment impact. Around half (48%) viewed them as only useful alongside clinical judgement, and 10% were uncertain of their value; findings that were consistent across doctors and nurses (**Figure 19**). Practical barriers were also common: nearly one in five (19%) respondents felt the tools were too time-consuming or complex for regular use, a quarter (25%) cited a lack of resources, and a third (30%) reported inadequate training. Training gaps varied by facility type, with the highest rates reported in general hospitals without an oncology department (42%), compared with cancer centers (28%) and hospitals with oncology departments (29%). These findings align with existing literature, which

Figure 18: HCP-reported methods of QoL and psychosocial need assessment in clinical practice



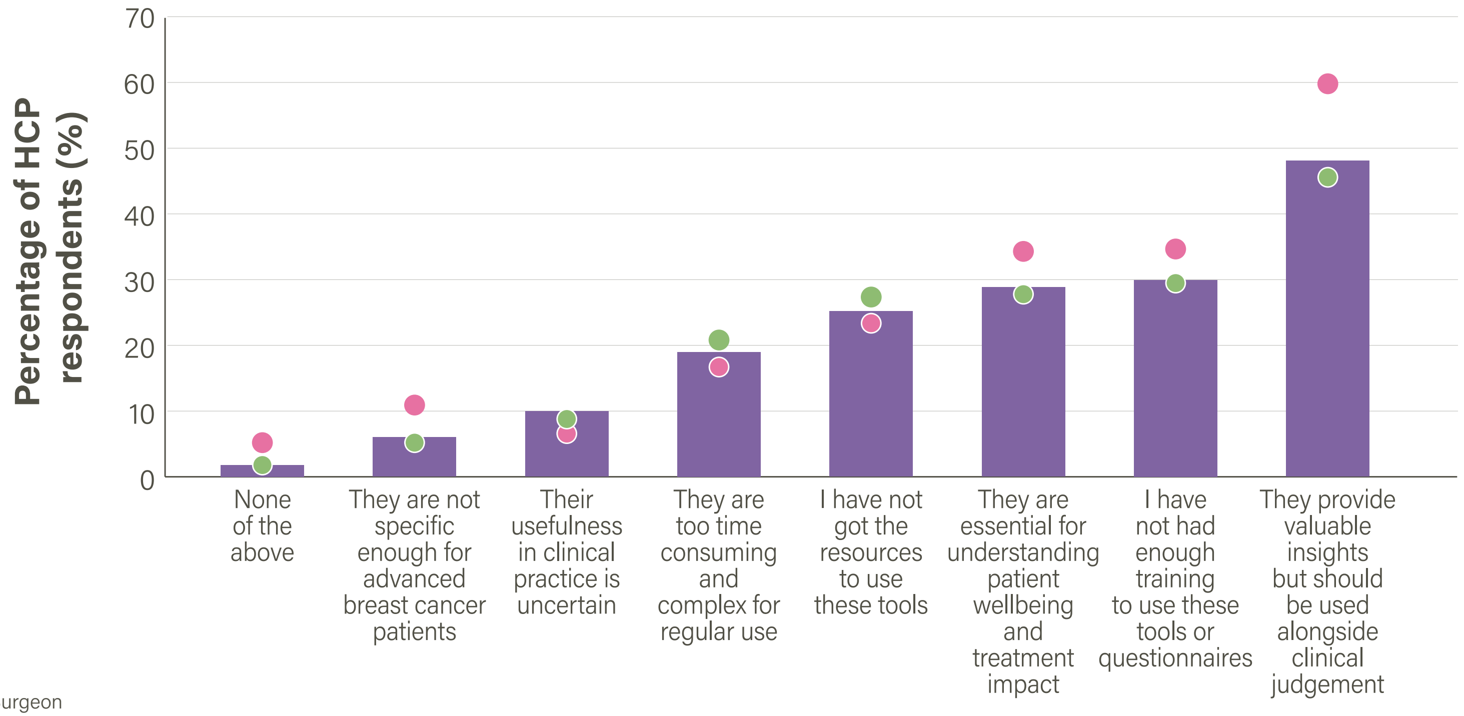
Based on findings from the ABC Global Alliance 2024 HCP survey (n=461). 'How do you currently assess the quality of life and psychosocial needs of patients with advanced breast cancer in your practice?'

highlights a substantial gap in HCP awareness and familiarity with QoL assessment tools.[257] In a 2021 study of QoL in HR-positive ABC patients, nearly a third (32%) of HCPs were not familiar with any QoL tools. Among those who were familiar, fewer than one in five (15%) recognized the EORTC QLQ-breast tools (BR-23 and BR-45) and only one-third (33%) were aware of FACT-B, a widely used instrument for assessing QoL in people with breast cancer.[257] Limited consultation time was also cited as a major barrier, with just 19% of HCPs reporting sufficient time to discuss QoL in-depth.[257]

The ABC Global Alliance HCP survey also revealed disparities in PROM use between regions: only 14% of HCPs in LMICs reported using PROMs in practice compared with 26% in HICs. This gap may be driven in part by training deficits, with more HCPs in LMICs (38%) reporting inadequate training compared with those in HICs (27%). These findings echo broader challenges in healthcare delivery in LMICs, including reliance on manual data collection, which can hinder real-time QoL assessment and analysis.[257-260] Resource constraints, limited data infrastructure, and insufficient research capacity contribute to persistent data gaps on the QoL needs of people with ABC in LMICs, underscoring the urgent need for targeted investment and research to address these disparities.

Another under-recognized barrier is the global comparability of QoL tools. Most widely-used tools were developed in HICs such as the US or the United Kingdom (UK), requiring cross-cultural adaptation for use in other regions.[260] While many domains translate well, others fail to capture specific cultural factors that influence QoL, reducing their validity and usefulness in diverse populations.[260] Addressing this requires both the evolution of existing tools and the development of culturally

Figure 19: HCP opinions on the use of PROMs and/or standardized QoL assessment tools in clinical practice for people with ABC



Based on findings from the ABC Global Alliance 2024 HCP survey (n=461). 'How do you currently assess the quality of life and psychosocial needs of patients with advanced breast cancer in your practice?'

sensitive measures to ensure accurate global assessment of QoL.

Time burden remains a key challenge for HCPs, with many concerned that implementing standardized QoL tools into practice could compromise other aspects of ABC care. Emerging validated tools such as the Distress Thermometer offer a potential solution by enabling rapid screening for psychological distress and prompting timely referral to psycho-oncology services for only those who may need them, thereby optimizing resource use.[261-262]

Collectively, these findings highlight the critical need for enhanced HCP education and training on QoL assessment tools and PROMs; streamlined, practical approaches to QoL assessment and PRO monitoring in ABC care; greater investment in resources and infrastructure, particularly in LMICs; and development and adaptation of culturally relevant, globally applicable QoL measures.

CONCLUSIONS AND FUTURE DIRECTIONS

While the value of QoL assessment and PROMs in ABC is widely recognized, their implementation and impact remain inconsistent both across and within regions. This chapter has identified critical gaps in meeting psychosocial and physical needs of people with ABC, highlighting the urgent requirement for improvements in clinical practice, policy engagement, funding, data collection methods, and the integration of PROMs into routine care.

A clearer, globally aligned strategy is required to enhance QoL for people with ABC, supported by investment in training, infrastructure, and culturally relevant tools. In resource-limited settings, pragmatic approaches, such as the Distress Thermometer, offer a feasible means to expand access and promote equity in care. Ultimately, while enhancing QoL data collection and analysis is an important benchmark, the true measure of success lies not in the tools themselves, but in how effectively the insights they generate are translated into meaningful, individualized improvements in the lives of those with ABC.

Based on this, the ABC Global Alliance community has agreed that this goal should remain in the 2025–2035 ABC Global Charter, with the following revised wording:

Improve the QUALITY OF LIFE 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

4 Availability and access to care from a **multidisciplinary** ABC team

Availability and access to care from a **multidisciplinary** ABC team

INTRODUCTION

A multidisciplinary approach to cancer care is widely recognized by the international oncology community as the 'gold standard,' incorporating specialist collaboration on treatment plans, continuity of care, and timely referrals.[263-264] Depending on the healthcare system, a breast cancer multidisciplinary team (MDT) may consist of an oncologist, radiologist, pathologist, surgeon, specialist nurse, allied healthcare professionals, and health administrators.[174]

The value of multidisciplinary care in advanced breast cancer (ABC) is well established,[265] contributing to more accurate diagnoses, individualized treatment plans, and improved patient experiences.[174,266] However, assessing the true impact of this approach on clinical outcomes is challenging due to variation in meeting practices between institutions and inconsistent reporting of clinical outcomes data.[267] Despite the associated benefits, financial constraints continue to limit the implementation of multidisciplinary care in ABC, and research on the cost-benefit of MDTs is limited.[268]

This chapter will explore the current landscape of multidisciplinary ABC care, highlighting its impact on patient outcomes, challenges, and considerations for improving availability and access. It draws on findings from an ABC Global Alliance analysis of multidisciplinary care recommendations across cancer guidelines, policies, and plans from 12 countries compared to European Society of Breast Cancer Specialists (EUSOMA) standards (**Appendix V**); alongside global patient and healthcare professional (HCP) surveys conducted in 2024.

STATUS IN 2005-2015

Since the first edition published in 2011, the ABC International Consensus Guidelines have advocated for multidisciplinary care as a standard for the management of people with ABC.[269] In 2013, EUSOMA's updated position paper on the Requirements of a Specialist Breast Centre included multidisciplinary care for the first time, and emphasized the need for an integrated ABC MDT that included high-quality palliative care.[3] Europa Donna – The European Breast Cancer Coalition's 2015 declaration "On the Fight Against Breast Cancer in the European Union (EU)" reiterated the need for multidisciplinary care in specialist breast units, which was further reinforced by the European Breast Cancer Council manifesto, which called for action from policymakers, advocates, and HCPs.[3]

Despite this recognition, the 2005–2015 Global Decade Report highlighted huge disparities in the implementation of multidisciplinary ABC care, with high-income countries (HICs) advancing faster than low- and middle-income countries (LMICs). Inequities were also seen within countries, with rural areas often lagging behind urban centers.[3] Globally, access to supportive and palliative care remained inconsistent, with interdisciplinary team building and HCP education only reported in high-resource settings.[3]

The 2015–2025 ABC Global Charter therefore emphasized the need to increase availability of, and access to, an MDT as one of its ten 'Actions For Change.'[4]

A DECADE IN REVIEW (2015-2025)

EUSOMA standards represent a new benchmark for multidisciplinary ABC care

In 2020, EUSOMA updated their 2013 position paper on the Requirements of a Specialist Breast Centre.[174] The update included defined standards for multidisciplinary care and specific expectations in ABC, including:

- The specialist breast center must treat at least 50 cases of ABC a year, independently from the line of treatment.
- A minimum of 50% of ABC cases should be discussed in weekly MDT meetings attended by the core MDT (outlined in **Table 5**), with the goal of achieving 100% case discussion.

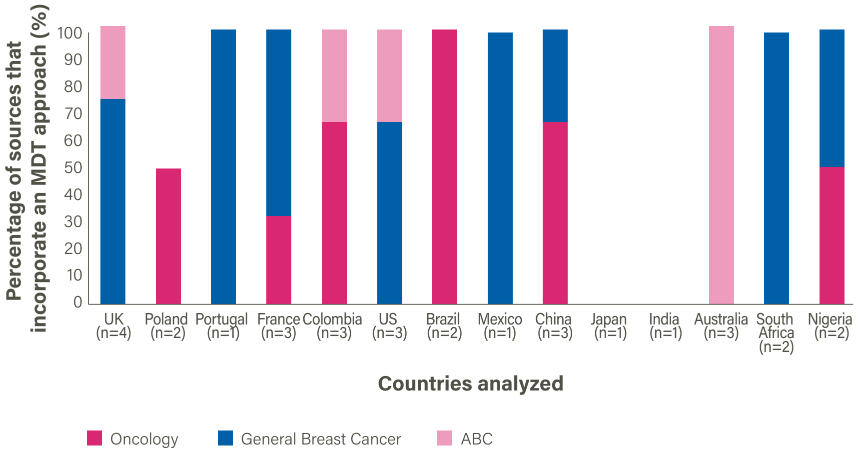
In 2023, EUSOMA and the ABC Global Alliance published Quality Indicators for Metastatic Breast Cancer Care, the first set of standards developed specifically to define, evaluate, and improve the quality of care for people with ABC.[175] The quality indicators set a minimum standard that at least 50% of ABC patients should be discussed at an MDT meeting at least once.[175] Despite their European remit, EUSOMA quality indicators are widely regarded as the global benchmark for ABC multidisciplinary care. However, there is still room to set a higher standard, one where all patients are reviewed, not just once, but whenever a management decision is needed, ensuring ongoing discussions and comprehensive care for people with ABC.

Since their introduction, the phased implementation of the EUSOMA requirements and quality indicators has led to 44 accredited centers across Europe and China as of July 2024.[270] Over half of these are in Italy (59%) due to EUSOMA's collaboration with the ITALCERT certification body, but other countries have independent accreditation of specialist breast centers aligned to EUSOMA standards.[271-273] In Germany, voluntary breast center certification follows guidelines from the German Cancer Society, the German Society of Senology, and other medical societies,[272] while Austria's certification agency uses EUSOMA specifications as a reference. The increase in accredited centers is undoubtedly positive, but 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.[274]

Multidisciplinary ABC care is now recommended in international, regional, and local guidelines

A multidisciplinary approach to ABC care is now widely recommended, with 83% of countries analyzed by the ABC Global Alliance in 2024 recommending multidisciplinary care in at least one source (**Figure 20**). However, the analysis—which looked at multidisciplinary care recommendations in cancer guidelines, policies, and plans from 12 selected countries compared to EUSOMA standards (see **Appendix V**)—revealed global disparities. For example, none of the sources analyzed across Japan and India included any recommendations for multidisciplinary care. While this finding mirrors literature from India that highlights multidisciplinary care to be an urgent gap,[275] it contradicts studies and initiatives in Asia, and Japan specifically, that indicate multidisciplinary breast cancer care is well established.[276] One example of this is the Japan TeamOncology Program (J-TOP), a culturally sensitive approach to advancing multidisciplinary cancer care in Asian countries.[277,278] This evolution of multidisciplinary care for breast cancer patients in Asia, particularly in Japan and Korea, reflects significant advancements in treatment protocols and patient management in the region. Recent guidelines—such as the Pan-Asian adapted European Society for Medical Oncology (ESMO) Clinical Practice Guidelines—emphasize the need for harmonized and tailored MDT treatment approaches that consider the genetic and demographic characteristics of Asian populations.[133]

Figure 20: Oncology, general breast cancer, and ABC sources recommending a multidisciplinary approach



Based on findings from the ABC Global Alliance 2024 analysis of multidisciplinary care recommendations in cancer guidelines, policies, and plans from 12 selected countries compared to EUSOMA standards.

In comparison to breast cancer and general cancer sources, all ABC-specific sources recommended a multidisciplinary approach to care (**Figure 20**), marking a significant improvement since the previous decade, when almost no ABC guidelines including MDT recommendations existed.[3] In addition, all five major international oncology guidelines included in this analysis—ABC Global Alliance (International Consensus Guidelines), National Comprehensive Cancer Network (NCCN), ESMO, American Society of Clinical Oncology (ASCO), and the Pan-Asian adapted ESMO guidelines—now fully integrate an MDT approach, further demonstrating improvement over the past decade.

Adherence to EUSOMA multidisciplinary care standards varies

Multidisciplinary practices vary significantly within and between countries.[267] According to the ABC Global Alliance 2024 HCP survey (n=461), HCPs in specialist centers report significantly higher adherence to EUSOMA multidisciplinary care standards, with 58% of HCPs meeting weekly with their MDT, compared with only about a third (36%) of HCPs in general hospitals without oncology departments ($p<0.05$, **Figure 21**). While this difference is unsurprising, as these standards are designed for specialist breast centers, it highlights potential disparities in care for people with ABC based on their treatment facility.

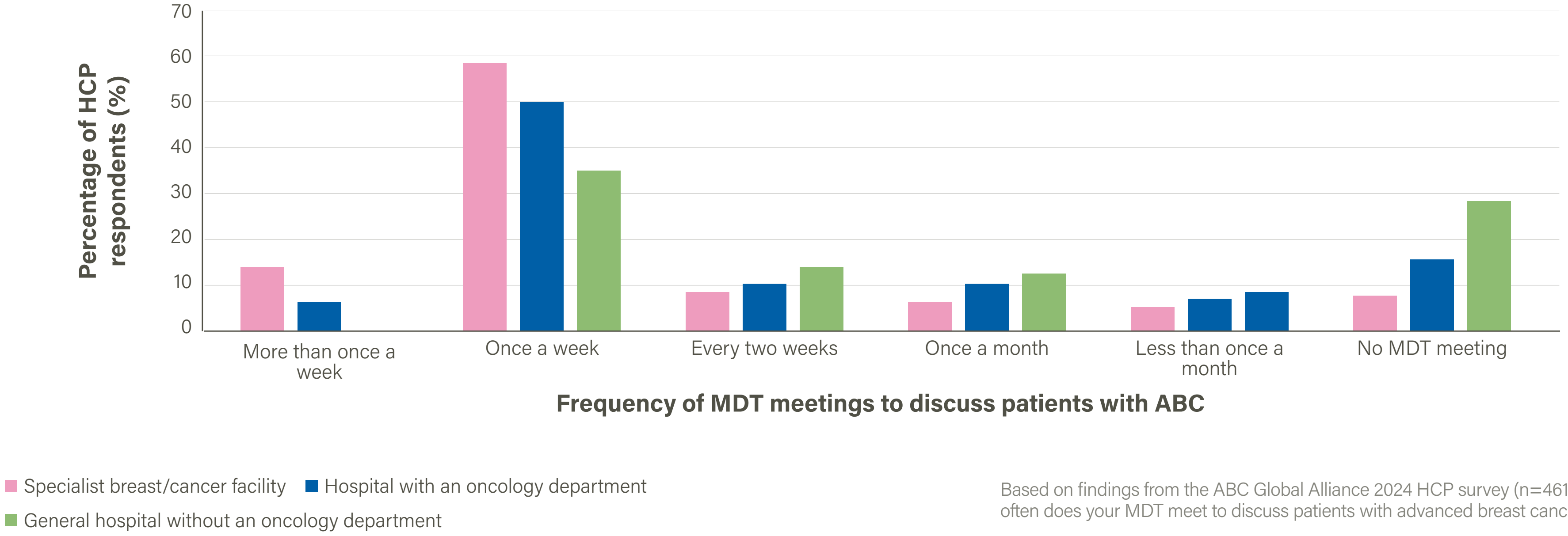
In HICs, 13% more HCPs reported partaking in weekly MDT meetings compared with in LMICs. While resource constraints may be hindering the establishment of specialist breast centers in LMICs currently, the introduction of "one-stop shops" that include both diagnostic and MDT input could serve as a foundational step toward developing dedicated breast centers in these regions over time.

ABC MDTs now include a wider range of disciplines

Although the 2005–2015 Global Decade Report did not report quantitative data on multidisciplinary ABC care, it described a general lack of MDT integration in ABC.[3] In 2020, EUSOMA's Requirements of a Specialist Breast Centre position paper defined standards for core and extended breast cancer MDT members.[174] Since then, international guidelines are increasingly recommending the inclusion of a wider range of disciplines in MDTs, indicating progress over the past decade (**Table 5**).

Unsurprisingly, European guidelines are most closely aligned to EUSOMA MDT standards, incorporating many of the recommended core and extended members. In contrast, the Pan-Asian adapted ESMO guidelines have the fewest MDT members listed, with many extended members excluded, reflecting a lack of progress since the previous decade.[279] Importantly, none of the guidelines analyzed include all EUSOMA-recommended MDT members, highlighting the need for continued global improvement in this area.

Figure 21: HCP-reported frequency of ABC MDT discussions overall and by facility type



Based on findings from the ABC Global Alliance 2024 HCP survey (n=461). 'How often does your MDT meet to discuss patients with advanced breast cancer?'

Table 5: Inclusion of EUSOMA-recommended MDT members in international guidelines

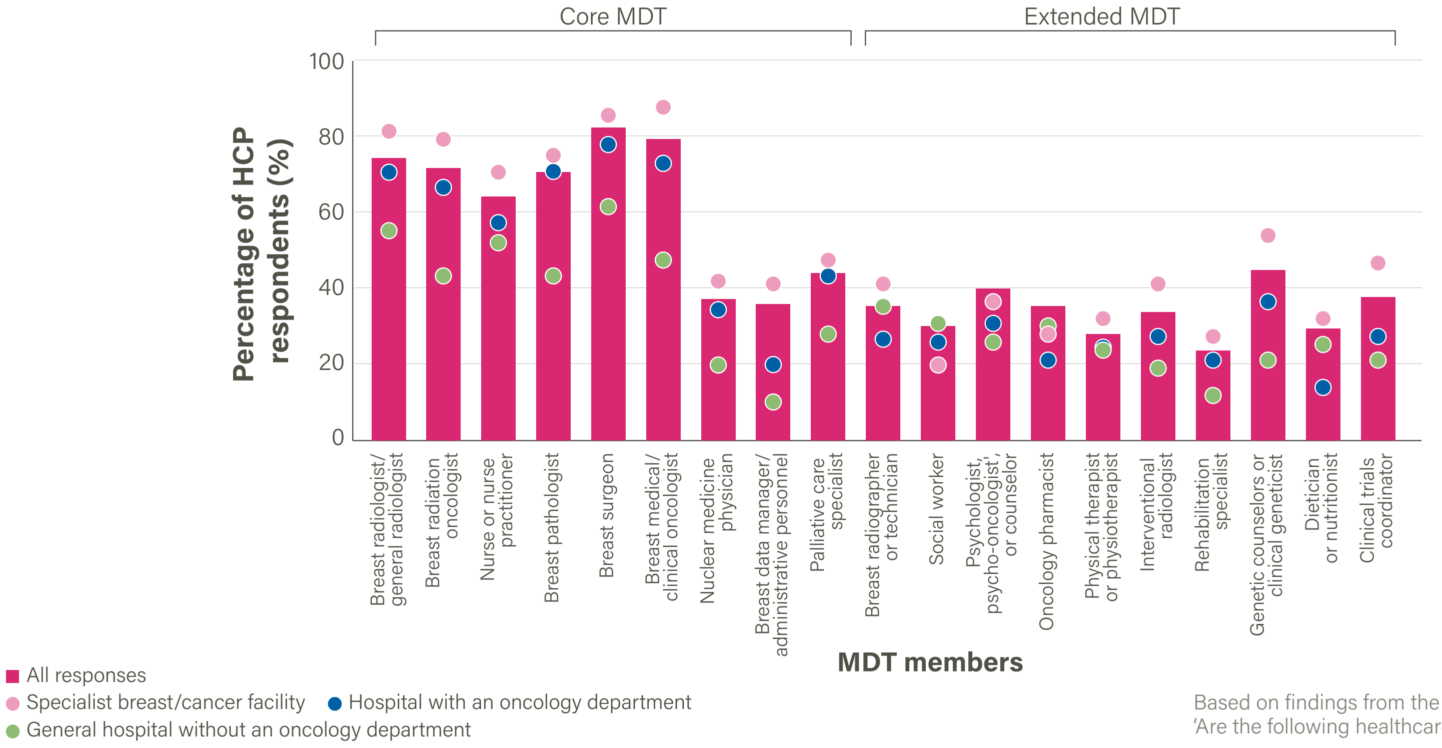
MDT members outlined in EUSOMA recommendations	NCCN (Global) guidelines[280]	ESMO (Europe) guidelines[135]	ASCO (Americas) guidelines[281]	Pan-Asian adapted ESMO guidelines (Asia)[133]	NCCN (Middle East & North Africa) guidelines[134]	NCCN (Sub-Saharan Africa) guidelines[137]	ABC 6 & 7 international consensus guidelines[19]
Cancer focus	ABC	ABC	ABC	ABC	Breast cancer	Breast cancer	ABC
Core MDT members							
Medical oncologists	✓	✓	✓	✓	✓	✓	✓
Radiation oncologists	✓	✓	✓	✓	✓	✓	✓
Breast cancer nurses	✓	✓		✓			
Radiologists	✓	✓	✓	✓	✓	✓	✓
Pathologists	✓	✓	✓	✓	✓	✓	✓
Nuclear physicians							✓
Palliative care specialists	✓	✓	✓		✓	✓	✓
Data Management							
Extended MDT members							
Psycho-oncologists	✓	✓					✓
Surgeons	✓	✓	✓	✓	✓	✓	✓
Pharmacists	✓						
Physiotherapists	✓						✓
Plastic surgeons					✓	✓	✓
Interventional radiologists							✓
Clinical geneticists					✓	✓	✓
Prevention specialists							

The ABC Global Alliance 2024 HCP survey results mirrored these patterns in clinical practice, with wide variation in the inclusion of core MDT members—from only 36% of HCPs reporting inclusion of administrative personnel, to 83% reporting inclusion of breast surgeons. Inclusion of extended MDT members was considerably lower across disciplines (**Figure 22**). HCPs from specialist breast units reported a more diverse ABC MDT than those from hospitals with or without oncology departments. Interestingly, HCPs from hospitals *without* oncology departments reported having more services (financial, nutritional, and spiritual) than those with oncology departments, suggesting that these services may be more common for non-malignant diseases. While extended MDT members and additional financial, nutritional, and spiritual services are not mandated by the EUSOMA Requirements for Specialist Breast Centre,[174] their growing inclusion in guidelines and practice reflects an increasing global commitment to comprehensive ABC care, aligned with evolving standards.

Telemedicine and virtual MDT meetings are emerging as effective solutions to bridge care gaps

In many LMICs, a lack of oncology specialists, resource constraints, and fragmented health systems severely limit access to high-quality multidisciplinary ABC care.[282] These challenges are particularly problematic in settings where presentation with advanced disease is more common due to delayed diagnosis and limited screening infrastructure.[283] That said, establishment of specialized breast MDTs remains a critical priority in LMICs, regardless of disease stage.[284] Innovative solutions to overcome the lack of specialist MDTs in LMICs have emerged in the past decade, including the establishment of virtual MDTs (**Box 8**).

Figure 22: HCP-reported inclusion of different specialties in ABC MDT meetings



Based on findings from the ABC Global Alliance 2024 HCP survey (n=461).
'Are the following healthcare professionals part of your MDT meeting?'

Box 8: Bridging gaps in ABC care through virtual MDTs in Mongolia[284]

A virtual, multi-institution, multidisciplinary breast cancer tumor board was developed to support the National Cancer Centre of Mongolia. The initiative sought to increase access to specialist expertise, enhance clinical decision-making, and promote standardized care, in a country where access to specialists and MDT input is limited.

In a study published in 2023, the cases selected for multidisciplinary input by local-level teams were highly complex, and the virtual MDT made recommendations across systemic therapy (40%), surgical management (33%), pathology re-evaluation (13%), and the need for additional patient imaging (13%), highlighting areas of ABC management where specialist expertise is most valued.

Beyond its relevance in LMICs like Mongolia, this model offers a scalable solution to reduce disparities in access to specialist cancer care for rural and underserved communities, who often face delays to diagnosis, and fragmented ABC care.

Several global initiatives are also driving advances in multidisciplinary care in LMICs through system-level innovation. City Cancer Challenge, in partnership with ASCO, has piloted programs in cities across Colombia, Paraguay, Myanmar, and Ghana, to strengthen multidisciplinary care through city-wide, consensus-based treatment guidelines, and inter-institutional support for implementing MDT practices.[285] In Ghana, virtual MDT meetings introduced during the COVID-19 pandemic as part of this program highlighted the importance of digital tools in expanding access to specialist care.[285] In 2018, the Breast Health Global Initiative developed a strategy to support multidisciplinary care in limited-resource environments. Recognizing that many patients present with late-stage disease, the approach places early emphasis on palliative care. It advocates for a balance between centralizing complex services—to ensure high-quality specialist care—and decentralizing other services to improve accessibility.[282] However, many LMICs face pressure to decentralize cancer care in settings where specialist expertise cannot be developed at pace. MDTs play a crucial role here, facilitating structured referral pathways, and ensuring expert input is available when and where it is most needed. Real-world examples underscore the value of locally adapted solutions: Romania's palliative care scale-up and Brazil's 'one-stop' diagnostic clinics both demonstrate how context-specific innovations can strengthen multidisciplinary care and improve patient outcomes.[282]

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

Palliative care can improve patient experience and quality of life at all stages of the ABC disease trajectory.[286] EUSOMA's Requirements of a Specialist Breast Centre emphasize the necessity of early and continuous supportive, palliative, and psychosocial care for people with ABC.[174] Over the past decade, the inclusion of palliative care in clinical guidelines has increased (**Table 5**). Notably, the NCCN guidelines for North Africa and Sub-Saharan Africa now align with NCCN's broader palliative care recommendations.[137,287-288] However, others such as the Pan-Asian adapted ESMO guidelines, still lack explicit integration of palliative care.[133]

Despite some advances in guideline recommendations, implementation of palliative care remains inconsistent and largely inadequate globally.[263] Less than half (45%) of respondents to the ABC Global Alliance 2024 HCP survey reported the integration of palliative care specialists in their MDTs (**Figure 22**). While specialist centers (48%) outperformed general hospitals (29%), gaps in care remain across all settings. Systemic barriers in many LMICs mean specialist palliative care input is often provided via referral rather than direct participation in MDTs.[282] While this approach ensures some level of specialist input, it highlights the continued need for access to timely and integrated palliative care advice, especially in rural areas, to address complex patient needs and improve quality of life.

Patient awareness and understanding of multidisciplinary care may be limited, particularly in LMICs

Despite increasing recognition of multidisciplinary ABC care at the health system level, patients demonstrate varying awareness and understanding. This disparity was highlighted by the ABC Global Alliance 2024 patient (n=1,254) and HCP surveys: while the majority (87%) of respondents to the HCP survey reported working as part of an MDT—increasing to 92% for those in specialist breast centers—only 67% of patients reported that their case had been discussed by one. In 2023, the Organization for Economic Cooperation and Development's (OECD) 'Cancer Care Performance' survey reported no statistical difference in provision of multidisciplinary oncology care between high- and low-income EU countries, with over three quarters (21/26) reporting to do so

.[268] However, from the patient perspective, geographical disparities are stark: the ABC Global Alliance 2024 patient survey found that those in HICs were 30% more likely to report that their case was discussed by an MDT than those in LMICs, indicating differences in patient understanding between regions.

Discrepancies between HCP and patient-reported data may stem from HCP self-reporting bias, patient misunderstanding around the term 'multidisciplinary,' or lack of physician communication. Ensuring that people with ABC are aware that their cases are reviewed by an expert MDT and understand the implications of this, may improve their care experience.

Barriers to multidisciplinary care implementation persist globally

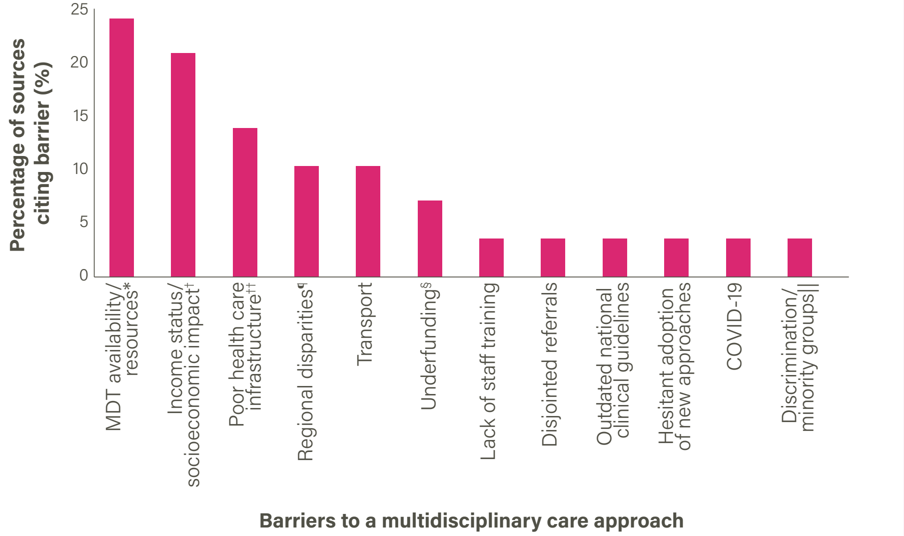
Despite growing recognition of the importance of multidisciplinary care, persistent barriers continue to hinder its effective implementation (**Table 6**). Literature from the past decade highlights challenges that hinder effective MDT working,[289-291] with barriers being particularly pronounced in LMICs.

Table 6: Key barriers to effective multidisciplinary ABC care from literature

Barrier	Description
Resource limitations	Staff shortages, inadequate infrastructure, and underfunding are common, especially in LMICs[292-294]
Time and workload pressures	Increasing case volume puts strain on MDT capacity, risking superficial discussions[292,295]
Incomplete team composition	Non-physician professionals (nurses, psychologists, physiotherapists) remain underrepresented and undervalued in many MDTs[295]
Socioeconomic and regional disparities	Compared to HICs, fewer patients in LMICs report that their case has been discussed by an MDT[292]
Lack of standardized protocols and referral pathways	Non-specialist or rural hospitals lack ABC care pathways, leading to fragmented care[292]

Findings from the 2024 ABC Global Alliance analysis of cancer guidelines, policies, and plans (see **Appendix V**) reinforce the persistence of these barriers to multidisciplinary care implementation. The most frequently cited barrier was the availability of MDT resources, reported in nearly a quarter (24%) of sources analyzed (**Figure 23**). Workforce shortages, another common barrier, further exacerbate this issue. For example, the United Kingdom (UK) faces staff deficits in pathology and radiology, while the United States (US) lacks genetic counsellors.[296] Socioeconomic disparities, identified as a substantial barrier to multidisciplinary care in the 2005–2015 Global Decade Report, remain a critical challenge today.[3] Around a fifth (21%) of analyzed sources cited socioeconomic impact and income status as a barrier to MDT working, with particular concern noted in Africa and other LMICs (**Figure 23**).

Figure 23: Barriers to multidisciplinary care reported in cancer guidelines, policies, and plans



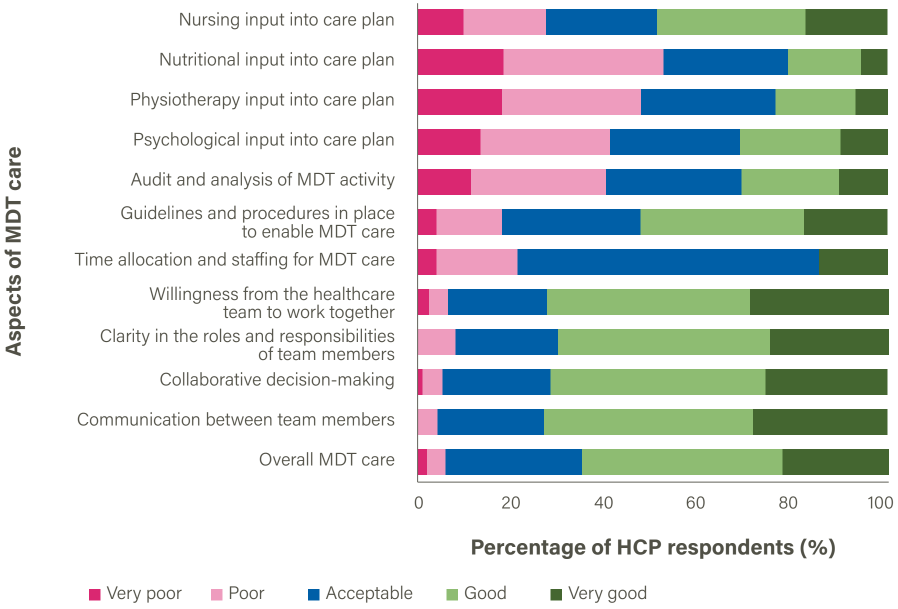
Based on findings from the ABC Global Alliance analysis of MDT integration into ABC care (see Appendix V).
* MDT availability/resources refers to the capacity of a team of HCPs from different disciplines to collaborate effectively in diagnosing, treating, and managing patients.
† Income status/socioeconomic impact refers to disparities that are associated with socioeconomic status in terms of healthcare quality and accessibility.
†† Poor healthcare infrastructure refers to the quality of services and facilities that contribute to the population's wellbeing.
¶ Regional disparities refers to the differences in performance and standards of healthcare that exist across different areas.
§ Underfunding refers to financial limitations on the healthcare ecosystem, including resources, infrastructure, technology, training and development, staff time and workload.
|| Discrimination/minority groups refers to biases, stereotypes, and unequal treatment that hinder effective communication, trust, and collaboration between a patient and the MDT, impacting outcomes.

Despite progress, gaps in multidisciplinary ABC collaboration persist

More than half (65%) of respondents to the ABC Global Alliance 2024 HCP survey rated multidisciplinary care within their network as 'good' or 'very good,' and less than 10% as 'poor' or 'very poor' (**Figure 24**). Although limited literature exists on multidisciplinary care in advanced cancers, qualitative studies have shown that strong organizational support, effective technology use (e.g., videoconferencing), and collegiality can support effective MDT discussions.[292]

Despite these positive perceptions, a pressing need for better multidisciplinary collaboration remains in clinical practice. The survey highlighted suboptimal input into care plans from nutritionists and physiotherapists, with around half (51% and 47%, respectively) of HCPs rating this to be 'poor' or 'very poor' within their center (**Figure 24**). Regional variation in MDT collaboration persists: nutritional input was rated poorest in Oceania, while audit and analysis was the most poorly ranked element of multidisciplinary care by those in North America.

Figure 24: HCP-reported quality of multidisciplinary care in clinical practice



Based on findings from the ABC Global Alliance 2024 HCP survey (n=461). '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.]

Despite geographical differences, commonalities emerge across settings. Literature continues to highlight the persistent underrepresentation of non-physician professionals, such as nurses, psychologists, and social workers in oncology MDT meetings.[295] These professionals play a crucial role in addressing the psychosocial and quality of life impact of ABC on patients and caregivers, but their contributions are often undervalued. The ABC Global Alliance 2024 HCP survey reflects this: less than half of respondents rated nursing input into care plans as 'good' or 'very good.' A culture shift is needed to ensure that the expertise of these professionals is fully integrated into MDT decision-making, enabling a move towards a truly patient-centered approach to ABC care.

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

Implementation of multidisciplinary approaches does not guarantee effectiveness. While multidisciplinary care implementation is increasingly reported, less is known about the quality and outcomes of MDT decision-making. A prospective study from an Australian metropolitan breast cancer center showed that MDT meetings for ABC led to high-impact treatment plan changes in almost a third of patients (28%).[297] Notably, 93% of these recommendations were implemented within four months, demonstrating the effectiveness of MDTs in driving actionable, consensus-based care.[297] While the approach was associated with modest costs, these were likely offset by gains in clinic efficiency and care streamlining.[297]

Findings such as these highlight the clinical value and feasibility of MDTs in influencing meaningful ABC treatment decisions. However, there is a need for better routine review and audit of MDT decision quality, including how often MDT decisions are reassessed over time and the extent of adherence to agreed plans, particularly across healthcare settings. In LMICs, a layered system for evaluating and auditing MDT input may support quality cancer care while accounting for resource constraints and varying health system maturity. Such systems could support the integration of MDTs by starting with universally applicable core indicators, such as the frequency of tumor board discussions and adherence to clinical guidelines.[149] Regardless of setting, embedding quality reviews could support continual improvement of multidisciplinary processes and optimization of patient outcomes.

CONCLUSIONS AND FUTURE DIRECTIONS

While the importance of multidisciplinary care in ABC is widely recognized and progress has been made in all settings, comprehensive implementation of this approach remains inconsistent across and within regions. This chapter reveals critical gaps in access to essential MDT roles that define key services such as nutrition, physiotherapy, and palliative care. It also highlights the importance of measuring the quality of MDT care decisions. While discussing all ABC cases in weekly MDTs is a proposed benchmark, the true measure lies in how well teams function, not just who is in the room. In settings with limited resources, virtual or tele-MDTs present a practical solution to expanding access and improving care equity.

Based on this, the ABC Global Alliance community has agreed that this goal should remain in the ABC Global Charter 2025–2035 with the following revised 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 MDTs specifically for patients with ABC

5 **Communication** between HCPs and people with ABC

Communication between HCPs and people with ABC

INTRODUCTION

The way in which healthcare professionals (HCPs) communicate can have a substantial impact on both patient experience and health outcomes.[298] Poor communication is associated with an increased risk of unnecessary treatment, treatment discontinuation, inadequate pain relief, and lower quality of life (QoL).[298-299] An individualized and empathic approach to communication can positively influence treatment adherence and shared decision-making (SDM), support identification of patients' needs, and improve outcomes.[300-303] In advanced breast cancer (ABC), communication is particularly challenging due to the disease's complexity and mostly incurable nature, making it harder to understand and treat.[304] Communication skills training (CST) across a diverse range of topics is an essential component of medical education for all HCPs. This should begin at medical or nursing school, continue through graduate education where it is one of six core competencies defined by the Accreditation Council for Graduate Medical Education,[305] and into professional development.[306-308]

Oncology bodies such as the American Society of Clinical Oncology (ASCO) and the European Society for Medical Oncology (ESMO) recommend comprehensive HCP communication on prognosis and treatment options, tailored to the individual patient's needs and preferences, to foster trust and support SDM.[309-310] SDM is crucial in oncology, particularly for advanced cancers, due to the wide range of treatment options and the importance of balancing their significant impact on both QoL and outcomes.[311]

This chapter will review progress in the provision of CST for HCPs over the past decade and explore its impact on HCP–patient communication and SDM. It is based on research conducted by the ABC Global Alliance in 2024, primarily two global HCP and patient surveys and an analysis of CST from top-ranking academic institutions and professional organizations globally (**Appendix VI**).

STATUS IN 2005–2015

Inadequate HCP communication was widely reported in the 2005–2015 Global Decade Report, with prognosis and end-of-life (EoL) discussions highlighted as particularly challenging.[3] As a result, people with ABC felt they lacked an understanding of their disease, potential outcomes, and treatment options. At the time, people with ABC expressed a need for greater empathy from their HCPs and over half believed their care could have been enhanced if their HCP listened more.[3]

In the 2005–2015 decade, while the importance of CST for ABC HCPs was recognized, implementation remained limited in both medical school curricula and professional oncology education globally. A large proportion of HCPs (83%) identified 'learning how to share bad news with patients and families' as a key training need, but less than half (43%) reported having received this level of training.[3]

The report emphasized the need for upfront discussions that address multiple treatment goals while considering patient priorities and preferences, and indicated that such discussions could lead to enhanced patient participation and satisfaction.[3] This was noted as particularly important for older people with ABC, to ensure that they are not subject to discrimination.[3]

As a result, the 2015–2025 ABC Global Charter called for improved HCP–patient communication and the provision of communication skills training for HCPs as one of its ten 'Actions for Change.'

A DECADE IN REVIEW (2015–2025)

CST is now a key element of most nursing school and some medical school curricula

CST is an essential part of medical education and should start as early as medical and nursing school.[304] In 2024, the ABC Global Alliance conducted an analysis of publicly available information on 48 top-ranking academic institutions across six continents (see **Appendix VI**). Encouragingly, CST was integrated into the curricula of all nursing schools analyzed, featuring in academic courses across the United Kingdom (UK), United States (US), Australia, South Africa, Japan and Brazil. However, it was less well integrated into medical school curricula, with only 38% of academic courses analyzed featuring this topic. Large geographical disparities were identified, with most of the medical schools offering CST being in North America and Europe, and no training offered by academic courses in Nigeria, China, and Colombia, indicating a potential education gap in these countries. While inclusion of CST in medical and nursing school curricula is important, metrics assessing its effectiveness are lacking and there is little evidence demonstrating its impact in clinical practice.[312]

Oncologist training guidelines now include an expanded range of communication skills

The ESMO/ASCO Recommendations for a Global Curriculum in Medical Oncology are a set of common guidelines for the clinical training required for physicians worldwide to qualify as medical oncologists.[313] First published in 2004, and endorsed by 51 oncology societies, the recommendations aim to ensure that all patients receive care from well-trained oncologists regardless of geography.[314] Encouragingly, research conducted by the ESMO/ASCO Global Curriculum Working Group in 2019 showed that the global curriculum had been adopted in many countries with established training in medical oncology (68%) and adapted in some countries with mixed training such as hemato-oncology or clinical oncology.[315]

The ESMO/ASCO recommendations were updated in 2010, 2016, and 2023, and have included an increasing number of communication skills topics with each edition (**Table 7**), demonstrating clear progress in this area.[313,316-318] The 2023 edition includes an enhanced section on communication skills, with ESMO/ASCO noting the need to expand the set of basic skills in line with newly acquired dimensions in doctor–patient relations.[313] Notable enhancements include reference to using a stepwise protocol to effectively deliver bad news, predicting and responding effectively to patients' emotions, and using agenda setting skills to identify patients' concerns and psychosocial needs.[313]

Table 7: Communication skills topics included in each edition of the ESMO/ASCO Recommendations for a Global Curriculum in Medical Oncology[313,316-318]

Year of publication	2004	2010	2016	2023
Communication skills topic				
Breaking bad news	✓	✓	✓	✓
Shared decision-making		✓	✓	✓
Supporting patients holistically		✓	✓	✓
Usage of correct terminology			✓	✓
Navigating cultural & socioeconomic differences	✓	✓	✓	✓
Communication through patient pathway				✓
Relationship building				
Communicating with upset/ angry patients and families				
Governance and best practice	✓	✓	✓	✓

CST for oncology professionals is increasing, but quality and uptake remain an issue

Professional organizations play a vital role in the continuing medical education of HCPs. A 2024 ABC Global Alliance analysis of 35 national and regional professional oncology organizations across 6 continents showed that only two-fifths (40%) offered CST (Appendix VI). Aligned to the findings of the academic institution analysis, organizations offering training were predominantly based in Europe, North America, and Oceania, with no CST offered by professional organizations in

Africa, Asia, or South America. However, the availability of CST does not guarantee its implementation or uptake. For example, despite the high number of CST programs identified in Oceania, most clinicians in Australia report having received no formal training on communication and collaboration skills,[319] with local research highlighting the need for improved long-term, embedded learning approaches to improve uptake.[320]

Box 9: Collaboration between MDTs to enhance HCP-patient communication in the UK

MDT collaboration is essential for the delivery of quality cancer care, including communication of key information to patients.[321] However, a UK study showed that most teams were unaware of the roles and responsibilities of their colleagues in communicating information to their patients.[321] This resulted in HCPs assuming (without adequate checking) that someone else on the MDT had shared specific pieces of information with patients, and led to gaps in information and understanding.[321]

Even with defined roles and responsibilities among the MDT, patients may turn to the HCP they most trust or have a good relationship with for information on specific topics, highlighting the importance of all MDT members being equipped to confidently answer patient questions.[321-322] The 'Teams Talking Trials' workshops in the UK (which included six breast teams) aimed to improve knowledge of, and confidence in, answering patients' concerns about clinical trials among multidisciplinary cancer teams.[322] Following the workshop, HCPs had significantly higher awareness of trial processes and the roles of MDT members in discussing them with patients.[322] Participants also reported an increase in confidence when communicating with patients about these topics.[322]

Communication challenges for advanced disease, including ABC, have been widely noted, highlighting the need for disease-specific CST for HCPs.[3] Despite this, of the 14 CST programs identified from professional organizations (see **Appendix VI**), only three (21%) were for ABC specifically. There have, however, been several notable efforts to overcome the lack of ABC-specific CST in the past decade:

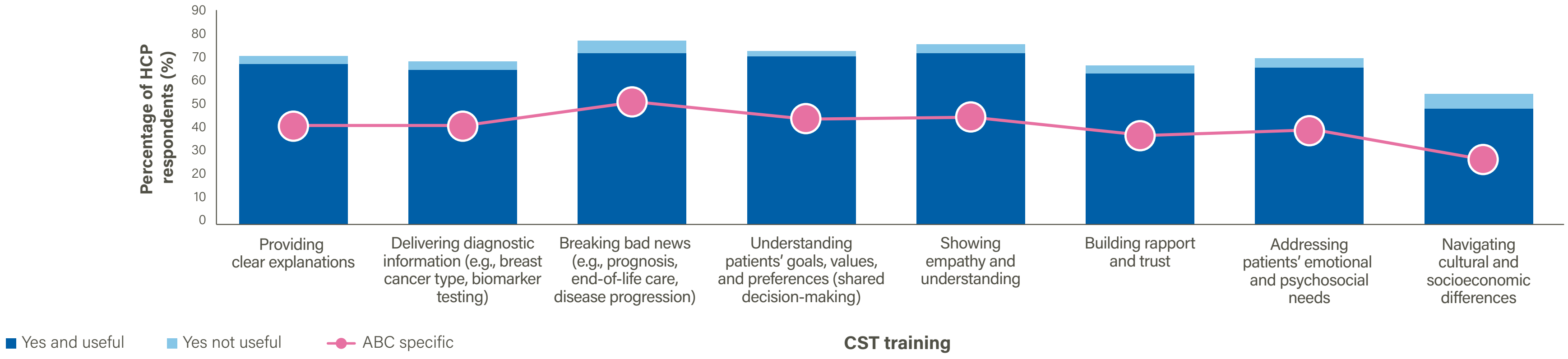
- The European Oncology Nursing Society (EONS) ABC4Nurses Project is a bespoke online ABC curriculum for nurses, established in 2020 and translated into four languages.[323] The training includes a module on supportive care skills in ABC, featuring topics such as communication challenges throughout the ABC trajectory, barriers to therapeutic communication in ABC, using a six-step protocol to give bad news, and communication challenges with family and caregivers.[323]
- In Australia, the McGrath Foundation developed a series of e-learning modules on ABC in 2019, in collaboration with ABC specialists and funded by a SPARC MBC Challenge Grant. [324] The training, which includes topics on communication skills, was completed by all McGrath Breast Care Nurses and has resulted in improved knowledge and confidence across the workforce.[324]

While these data demonstrate progress, challenges with quality and uptake of CST for oncology professionals persist. Educational programs such as 'Talking About Risk in the Context of Genomic Tests (TARGET)' and 'Talking about Risk, UncertaintieS of Testing IN Genetics (TRUSTING)' include clear evaluation metrics that enable demonstration of improved HCP knowledge, communication, and self-confidence on specific topics.[325-326] But the same cannot be said for all HCP CST programs, many of which lack a sound pedagogical methodology, integrate content that is not evidence based, and do not include robust objective evaluation approaches, which limits their validity and impact.[327-328]

Furthermore, CST has historically not been a mandatory part of continuous medical education for oncologists, with workshops often poorly attended due to lack of recognition or associated credits.[329] In an effort to improve this, the European Commission Initiative on Breast Cancer's Quality Assurance Scheme for Breast Cancer Services in Europe now includes a requirement for evidence of continuous CST for HCPs,[330] something that the European Society of Breast Cancer Specialists (EUSOMA) has also recently adopted for accreditation.[174]

Overall, despite some progress, HCP CST remains limited, inconsistently implemented, and often lacking robust evaluation. There is a critical need for mandatory, evidence-based, and ABC-specific programs to ensure effective multidisciplinary teamwork and patient-centered care.

Figure 25: CST received by ABC HCPs



Based on findings from the ABC Global Alliance 2024 HCP survey (n=461). '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?'

From "breaking bad news" to communicating with clarity – HCP training is expanding

In 2015, only 43% of HCPs reported receiving training on "breaking bad news".[3] A decade later, the ABC Global Alliance 2024 HCP survey (n=461) shows this figure has surged to 77%, reflecting a growing recognition of its importance (**Figure 25**). Notably, doctors were the primary recipients of training on this topic, while other HCPs reported lower rates of participation.

Crucially, CST is no longer limited to a single focus, with only 2% of HCPs reporting receiving training exclusively on "breaking bad news". Instead, nearly half (47%) of those trained in this skill also received training in other essential communication areas, such as providing clear explanations, delivering diagnostic information, understanding patients' goals, values, and preferences, showing empathy and building trust, addressing emotional and psychosocial needs, and navigating cultural and socioeconomic differences. Training on these topics appears to be widespread (received by >50% of HCPs), with many trainings specific to ABC (**Figure 25**). The increased focus on topics such as diagnostic information and treatment options may in part be driven by the increasing complexity of the disease landscape. Nurses were on average nearly twice as likely to receive CST across communication topics compared to doctors (20% vs. 11%, $p<0.05$), highlighting their crucial role in supporting people with ABC.

While this diversification of training signals a shift toward a more patient-centered approach in oncology communication, these positive findings may be influenced by the high number of survey respondents based in specialist breast or cancer centers. It should also be noted that more than a third of respondents (37%) reported no access to any ABC-specific training, indicating an ongoing need for CST tailored to the nuances of ABC.

Usefulness of CST varies by region and role

Oncology CST is widely regarded as useful by HCPs. Among the different training topics, "breaking bad news" remains the highest ranked in perceived usefulness, with 74% of respondents to the ABC Global Alliance 2024 HCP survey finding it valuable (**Figure 25**). Many training topics show notable regional variations:

- "Navigating cultural and socioeconomic differences" was considered useful by 73% of HCPs in North America but ranked lowest globally (51%). This may be due to the region's diverse patient populations, as such training has been shown to enhance providers' ability to deliver culturally sensitive care, which is associated with increased patient satisfaction.[331]
- "Understanding patient goals and SDM" was ranked as the most useful training in Western Europe. This may be a result of patient-centered manifestos like the European Code of Cancer Practice, which states that cancer patients should have the opportunity to participate in how decisions about their care are made, explicitly advocating for SDM.[332]

Nurses consistently rated communication training as more useful than doctors, particularly in areas related to psychosocial support and patient-centered care. This is positive considering nurses generally spend more time in direct patient care, addressing not only medical needs but also providing emotional and psychosocial support. In many low-and middle-income countries (LMICs), limited access to doctors further underscores the importance of equipping nurses and allied health professionals with targeted education.[333] Tailoring communication training to these roles is essential, as effective communication is critical to delivering holistic, patient-centered support in resource-constrained settings.

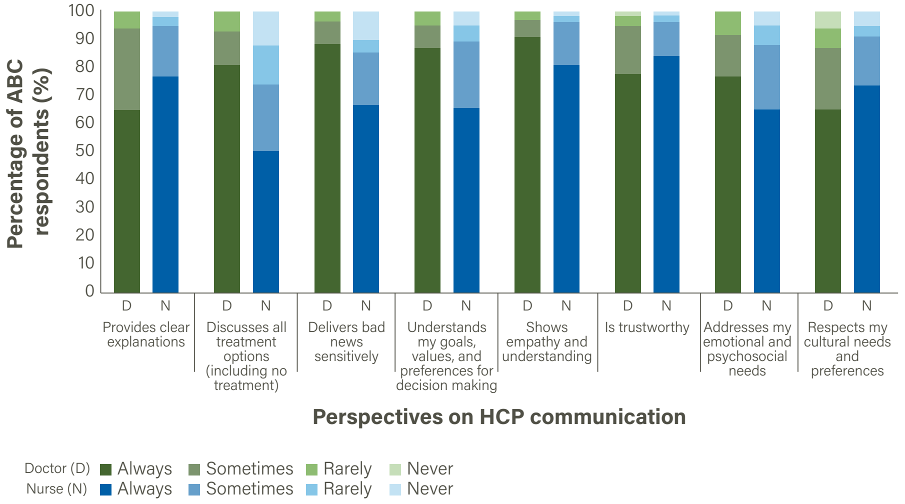
The way in which we communicate is evolving

This decade has witnessed a rise in telemedicine, and with it the opportunity to enhance many aspects of patient care, including the convenience and efficiency of HCP–patient interactions. However, this shift toward remote consultations is not favored by everyone and may even have a negative impact on HCP communication in some cases. A 2020 UK study of telemedicine use during the COVID-19 pandemic, showed that despite general satisfaction with virtual consultations, nearly half of patients said they would not like to receive bad news remotely.[334] Despite these preferences, remote consultations are common in ABC, even in scenarios where bad news is being shared. A global survey by the Young Survival Coalition's (YSC) Project 528 demonstrated shocking findings: almost half (44%) of young women with ABC reported that information regarding their breast cancer diagnosis was first communicated to them on the telephone.[20] Of these, 92% were explicitly told that they had breast cancer over the phone (vs. being asked to come in for a consultation).[20] While the benefits of telemedicine are undeniable, data such as these demonstrate the need for careful consideration of its suitability in certain ABC communication scenarios.

The communication needs of many people with ABC remain unmet

Despite advances in oncology CST, people with ABC continue to express the need for better support from their healthcare team. The 2023 Living with Metastatic Breast Cancer (LIMBER) study continued to highlight significant gaps in patient support, quality of HCP communication, and consistency of information for people with ABC in the UK.[225] One of the most striking and enduring shortfalls in ABC care is the unmet emotional and psychosocial needs of patients, and the ability of HCPs to address these. The ABC Global Alliance 2024 patient survey (n=1,254) showed that fewer than half (46%) of people with ABC felt their doctor 'always' addressed these aspects of ABC care—making this the lowest-rated area of patients' communication experience (**Figure 26**).

Figure 26: Patient perspectives on aspects of doctor 'D' and nurse 'N' communication



Based on findings from the ABC Global Alliance 2024 patient survey (n=1,254). 'Select the options that describe your experience with the doctor most involved in your advanced breast cancer care.'; 'Select the options that describe your experience with the nurse most involved in your advanced breast cancer care.'

The survey revealed substantial differences in communication between doctors and nurses—likely reflecting their unique roles in ABC care. According to patients, nurses were more likely than doctors to address emotional and psychological concerns (66% vs. 46% respectively) and generally performed better in most communication areas, including trustworthiness. Doctors, on the other hand, were only rated higher when discussing treatment options. Importantly, this also included discussion around no treatment.

Trust between patients and HCPs is a cornerstone of effective ABC care, directly impacting treatment adherence, communication, emotional wellbeing, and decision-making.[335] Patients who trust their oncologists are more likely to follow prescribed therapies, leading to reduced recurrence and mortality.[335] Trust also fosters open, empathic communication, empowering people to express concerns and make informed choices about their care.[327] Positively, the majority (81%) of young women with ABC responding to YSC's Project 528 survey reported a good relationship with their oncologist, and 91% felt they could ask questions to their HCP.[20] In the ABC Global Alliance 2024 patient survey, trust in HCPs was found to vary significantly by region. For example, physicians in Africa received lower trust ratings compared to those in the Americas, highlighting potential disparities in care beyond communication alone.

Interestingly, the survey showed that patients reported similar experiences with their HCP in terms of clarity of explanations, empathy, and cultural respect, regardless of their educational background. This suggests that communication challenges in ABC care are not solely driven by differences in education, indicating a need for more tailored and universally accessible communication strategies to improve patient experience. However, many HCPs continue to adopt a stereotyped approach to communication, assuming that people from higher socio-educational groups have a greater understanding of medical concepts and tailoring their communication accordingly.[336-337] Such assumptions risk overlooking the diverse needs of patients and may perpetuate gaps in understanding and engagement.

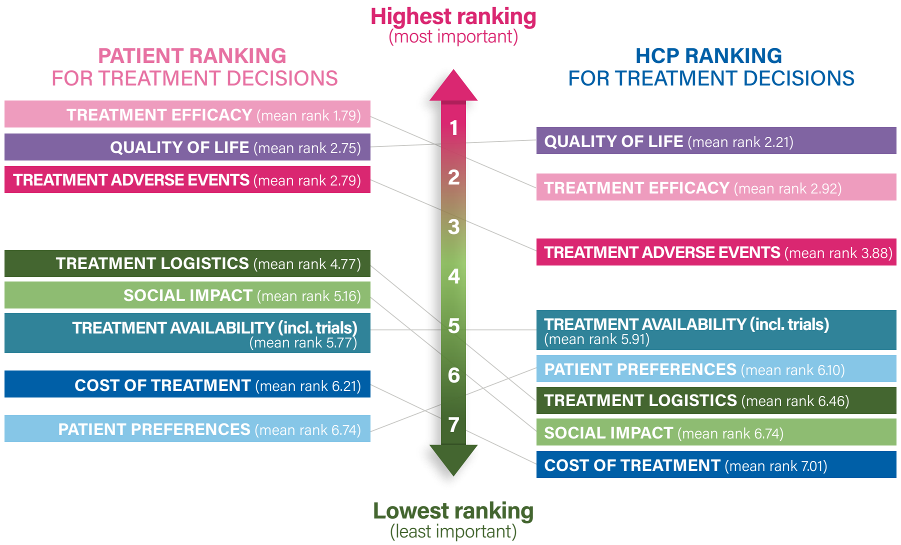
Patient preferences remain inadequately considered in treatment decision-making

Research suggests differences between HCPs' perspectives on patient preference and patients' actual preferences.[338-339] The ABC Global Alliance 2024 HCP and patient surveys revealed interesting differences: although both HCPs and patients clearly placed higher priority on efficacy and QoL over other features of treatment, patients showed a slight preference for treatment efficacy (preferring therapies that offer the best chance of disease control and survival), while HCPs prioritized QoL (focusing on minimizing side effects and maintaining daily functioning) (**Figure 27**).

These findings contradict much of the literature from this decade that suggests HCPs are more efficacy driven in their decision-making,[340] and that patients prioritize QoL.[341] These somewhat surprising survey findings may be driven by their methodology, which required respondents to rank aspects of treatment and did not offer the option for two or more aspects to be ranked as equally important. Furthermore, it is important to consider the potential influence of line of therapy, prognosis, and other confounding factors, which were not accounted for in the surveys.[340] Nonetheless, the findings highlight the complexity and individuality of treatment decision-making in ABC.

Although ranked considerably lower by both patients and HCPs, treatment logistics (such as treatment administration and transport to the hospital), social impact (e.g., personal responsibilities or home support), and cost of treatment were consistently ranked higher by patients than HCPs. This pattern aligns with recent literature indicating that decision-making for people with ABC increasingly incorporates broader contextual considerations beyond clinical outcomes.[340] Regardless of cause, differences between patient and HCP perspectives may lead to misaligned treatment goals and, ultimately, dissatisfaction with care.

Figure 27: Patient- and HCP-reported priorities for treatment decision-making in ABC



Based on findings from the ABC Global Alliance 2024 patient survey (n=1,254) 'Which of the following options are most important to you when making decisions about your treatment?'; and the ABC Global Alliance 2024 HCP survey (n=461) 'How important are the following factors when making care or treatment decisions for patients with advanced breast cancer?' Respondents were required to rank all aspects and could not rank multiple options as equally important.

The influence of individual patient circumstances on treatment decision-making cannot be overlooked. For example, cost of treatment was ranked relatively low on average by respondents to the ABC Global Alliance 2024 patient survey, but this is likely to rank much higher for those living in LMICs or in countries with healthcare systems that require out-of-pocket expenses (discussed in Goal 9). Similarly, treatment logistics may rank higher for patients living in remote or rural locations, or far from a treatment center. A 2025 Australian discrete choice experiment of women with hormone receptor-positive ABC highlighted varied individual preferences for different treatment features but overall showed efficacy to be a stronger driver than side effects for patient decision-making.[342]

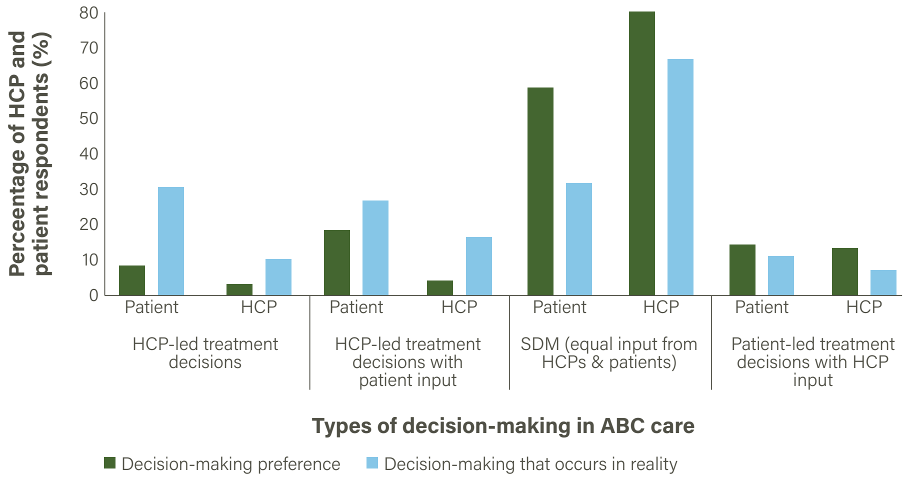
These findings underscore the importance of avoiding assumptions about patient preferences and reinforce the critical role of SDM in ABC care. By incorporating structured conversations—supported by decision aids, patient-reported outcome measures (discussed in Goal 3), and open-ended dialogue— HCPs can ensure that both effectiveness of treatment and QoL are addressed in ways that reflect each patient's individual values, rather than relying on generalized assumptions.

Both HCPs and patients prefer SDM, but the reality falls short

A majority of people with ABC (59%), and an even higher proportion of HCPs (80%), express a preference for SDM—a process in which both parties contribute equally to treatment decisions. Yet, this ideal is often not realized in clinical practice. Findings from the ABC Global Alliance 2024 patient and HCP surveys reveal that SDM occurs far less frequently than preferred, reported by only 31% of patients and 67% of HCPs. In contrast, HCP-led decision-making is more common in reality than desired: while just 9% of patients and 3% of HCPs prefer fully HCP-led decisions, nearly one-third of patients (31%) report experiencing this approach, suggesting a gap in truly collaborative decision-making (**Figure 28**).

Patient-led decision-making remains rare in both preference and practice, but the most striking finding is the disconnect between patient and HCP perceptions of SDM. Two-thirds (67%) of HCPs believe SDM is occurring in practice compared with only around one-third (31%) of patients—a disparity that highlights the need for improved communication, clearer role-sharing in decision-making, and practical strategies to embed SDM into routine ABC care.

Figure 28: Preference vs. reality for treatment decision-making in ABC care, according to people with ABC and HCPs



Based on findings from the ABC Global Alliance 2024 patient survey (n=1,254) '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?'; and the ABC Global Alliance 2024 HCP survey (n=461) '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?'

Regional differences add another layer of complexity to the SDM landscape and should be considered when interpreting survey findings, particularly given the uneven distribution of responses across regions. Subgroup analysis revealed marked differences: while 75% of people with ABC in North America prefer SDM, only 36% in Eastern Europe share this preference.

Educational background also influences SDM preferences. Among people with ABC, those with a college-level and above education were more likely to favor SDM (63%) compared with those with lower education levels (48%). Higher education is often associated with a greater preference for active involvement in decision-making.[343] People with higher education levels tend to have better health literacy, which facilitates understanding of complex medical information and treatment options and enables them to participate more effectively in SDM.[344]

However, this is not universally true, and HCPs should avoid making assumptions about a patient's desire for involvement based solely on educational attainment. Tailoring communication and decision-making approaches to individual needs—rather than perceived demographic indicators—remains essential for equitable, patient-centered ABC care.

Barriers to SDM continue to prevent meaningful patient involvement in healthcare decisions

Despite increasing recognition of the importance of SDM, barriers to universal implementation persist. A 2019 systematic literature review examining obstacles to SDM in oncology (where 63% of the studies were specific to breast cancer) identified barriers including treatment uncertainty, adverse event concerns, and poor physician communication.[345] Ineffective communication between HCPs and patients is a commonly cited barrier to SDM, particularly that HCPs do not always explicitly state when a decision is required, leaving patients unaware of their role in the process.[345-346] Additionally, comprehension barriers, stemming from medical jargon, language differences, or emotional distress, can impair a person's ability to engage meaningfully in discussions.[346]

On the HCP side, a lack of awareness of available choices, difficulty in conveying complex information, and challenges in establishing trust can hinder SDM implementation.[345] Organizational factors, such as insufficient consultation time, a lack of private space for discussions, and suboptimal use of electronic health records, exacerbate these communication hurdles.[346] One in ten young women with ABC responding to YSC's Project 528 survey reported not having enough time to talk to their healthcare provider.[20]

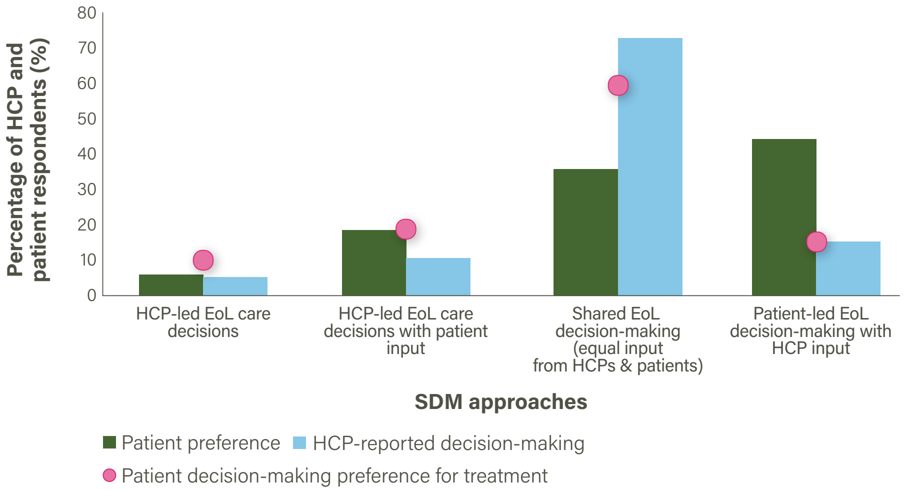
Despite these challenges, effective HCP communication skills have been shown to enhance SDM, with those who actively consider patient preferences, demonstrate empathic and clear communication, and encourage the use of support systems, fostering a more inclusive decision-making process.[345]

The unexpected disconnect in EoL decisions

Surprisingly, while many people with ABC advocate for SDM in treatment planning, they are less likely to prefer this approach at EoL. The ABC Global Alliance 2024 patient survey found that only 35% of patients favor SDM at EoL, compared with 59% for treatment decisions. In contrast, 72% of HCPs report that SDM occurs at EoL, suggesting a notable mismatch between patient preferences and HCP perceptions. The most common patient preference for EoL decision-making was for patient-led decisions with HCP input (43%), yet HCPs report that this approach only occurs in 14% of cases (**Figure 29**). This suggests that patients may seek greater autonomy over EoL decisions than HCPs anticipate, emphasizing the need for greater alignment between the two groups.

These findings highlight the critical importance of open, honest conversations about EoL care to ensure that patients fully understand their options and that decisions reflect their values, priorities and expectations. In the sensitive context of EoL, proactive communication and personalized decision-making are essential to delivering care that is both compassionate and consistent with patient wishes.

Figure 29: HCP- and patient-reported preferences for EoL decision-making in ABC

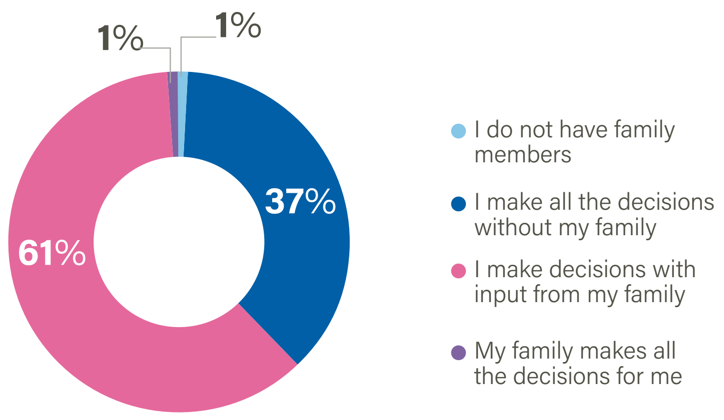


Based on findings from the ABC Global Alliance 2024 patient survey (n=1,058)* 'How would you prefer decisions about end-of-life or palliative care to be made?' and 'How would you prefer decisions about your advanced breast cancer treatment to be made?'; and the ABC Global Alliance 2024 HCP survey (n=461) 'How are decisions made for patients with advanced breast cancer about end-of-life treatment at your center?'
* Patients answering 'Prefer not to say/This does not apply to me' were excluded from this analysis.

Family plays an important role in ABC decision-making

Family involvement in decision-making can range from providing emotional support to actively participating in treatment decisions. In many cases, families help patients to understand their illness and treatment options, and they may also assist in aligning treatment decisions with the patient's values and preferences.[347] The ABC Global Alliance 2024 patient survey highlighted that more than half (61%) of people with ABC preferred to make decisions about their care with input from their family, although only 1% wanted family members to make decisions on their behalf (**Figure 30**).

Figure 30: Patient-reported preferences for involving family members in ABC care decisions



Based on findings from the ABC Global Alliance 2024 patient survey (n=1,254). 'How do you involve family members in decisions about your advanced breast cancer care?'

However, family involvement in ABC treatment decisions is influenced by cultural norms, social dynamics, and the structure of local healthcare systems.[347] Survey respondents from Eastern Europe reported the highest rate of family involvement in decision-making (71%), compared with the lowest rates in Africa (48%). In regions where treatment is not subsidized by the government, family involvement in decision-making may be particularly critical, as decisions can carry significant financial consequences, sometimes leading to financial toxicity (see Goal 9). These differences highlight the need for regionally tailored CST for HCPs, enabling them to navigate the complex interplay between patient autonomy and family expectations. Such training can help ensure that SDM remains culturally sensitive, ethically sound, and aligned to the realities of different contexts.[348]

CONCLUSIONS AND FUTURE DIRECTIONS

The growing inclusion of CST in medical school curricula and professional oncology training marks meaningful progress over the past decade. However, its impact in practice remains limited by a lack of specificity to advanced disease, as well as inadequate methodology and evaluation metrics. As a result, the communication needs of many people with ABC continue to go unmet. Despite strong interest in SDM from both HCPs and patients, adoption in clinical practice is constrained by patient-level barriers—such as differences in education, health literacy, and cultural norms—and systemic barriers, including limited consultation time. Addressing these challenges will require strengthening education for both HCPs and patients, equipping individuals with the skills and confidence to participate actively in care decisions. Importantly, as most patients prefer to make decisions with the input of their families, caregivers must also be supported with accurate information about ABC and opportunities to express their views.

In recognition of this, the ABC Global Alliance community has agreed that this goal should remain in the ABC Global Charter 2025–2035 with the following revised wording to explicitly include caregivers:

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

To achieve this goal, efforts in the next decade 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

Our 10 GOALS

6

Informational needs of people with ABC

Informational needs of people with ABC

INTRODUCTION

People with advanced breast cancer (ABC) and their caregivers must navigate an often-overwhelming and complex disease landscape. This includes understanding treatment options, managing medication regimens and side effects, making difficult financial decisions about cancer care, balancing family responsibilities and career demands, and coping with the profound emotional and social impact of the disease. In this context, reliable, relevant, and accessible information is not simply helpful—it is essential.[349]

High-quality information empowers individuals to understand their disease, make informed decisions about their care, and access vital support services that can significantly enhance their quality of life (QoL; see Goal 3).[349-350] Yet, despite its critical importance, information gaps remain a persistent unmet need within the ABC community. Inaccurate, incomplete, or misleading information can have serious consequences. For example, insufficient treatment information may lead to non-compliance and poorer outcomes, while limited information on support programs can exacerbate financial toxicity.[351] The challenge is compounded by the growing volume of online information, and unverified sources and unqualified "health influencers" sharing misguided advice. In this environment, ensuring that people with ABC have access to high quality, reliable information is more important than ever.[352]

This chapter explores the current informational needs of people with ABC and identifies areas of focus for the global ABC community to address. It draws on results from an informational resource questionnaire distributed to 95 ABC Global Alliance members (Appendix VII), alongside global patient and healthcare professional (HCP) surveys conducted in 2024.

STATUS IN 2005-2015

The 2005–2015 Global Decade Report exposed a critical gap in the quality and availability of information for people with ABC. At ABC diagnosis, information was reported to be of lower quality than for those diagnosed with early disease, often leaving them feeling unprepared and unsupported. At this time, ABC-specific resources were severely lacking, making it difficult for people with ABC and their caregivers to find relevant and reliable disease information.[3,353]

In 2013, the Count Us, Know Us, Join Us survey (n=1,273) revealed that approximately half of people with ABC felt available information did not address their needs.[354] As a result, more than three-quarters of respondents actively sought ABC-specific information on topics such as side effect management, treatment options, sexual or fertility problems, and clinical trials.[354] The lack of information on clinical trials was a particular issue, and the 2005–2015 Global Decade Report found that almost four fifths (78%) of people with ABC surveyed had never been informed about clinical trial opportunities by their HCP.[3] With many people considering HCPs as a trusted source of information, this communication gap represented a significant barrier to trial participation for people with ABC.[3] Recognizing the urgency of this unmet need, the 2015–2025 ABC Global Charter outlined improved availability of and access to information for people with ABC as one of its ten 'Actions For Change'.[4]

A DECADE IN REVIEW (2015-2025)

A wealth of information now exists to support people with ABC

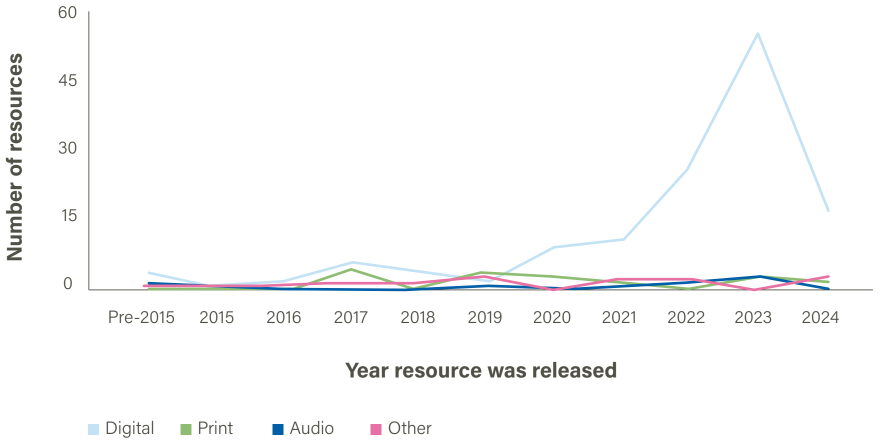
The number of ABC-specific resources continues to grow rapidly

People with ABC require tailored, disease-specific information and support. In 2024, the ABC Global Alliance sent a questionnaire to member organizations to map the current informational resource landscape. A total of 209 resources from 19 countries were submitted for analysis (see **Appendix VII** for methodology).

More than half of resources (58%) focused specifically on ABC, while 36% addressed early or general breast cancer, and the remainder were not breast cancer specific. Release date analysis showed a steady year-on-year increase in the development of ABC information materials (**Figure 31**)—a positive trend that may enhance access to information for people with ABC. Over a third (38%) of informational resources were developed by pharmaceutical companies.

However, the audit also identified significant gaps. Key topics remain under-represented, many resources are not available in multiple languages, and some formats are inaccessible to certain audiences. These limitations contribute to ongoing global disparities in information access and health literacy, underscoring the need for coordinated, inclusive strategies to ensure that all people with ABC can access high-quality, relevant, and culturally appropriate information.

Figure 31: Patient information resources released by ABC Global Alliance member organizations between 2015 and 2024



Based on responses to 'Patient Information Resource' section of an ABC Global Alliance 2024 questionnaire distributed to 95 ABC Global Alliance members.

* Data for 2024 are not fully representative, as collection occurred before the year's end.

The number of digital resources has exploded this decade

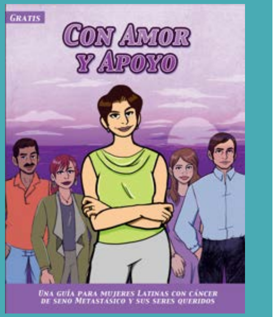
Since 2020, there has been a notable increase in digital ABC resources, likely accelerated by the COVID-19 pandemic. While this expansion offers new opportunities for timely, wide-reaching information delivery, an over-reliance on digital formats risks widening existing inequities. A 2022 study of 15,244 people with cancer in France, including 3,798 with breast cancer, found that low digital health literacy was associated with poorer survival outcomes in people with *de novo* metastatic disease across all cancer types.[355] These findings highlight the critical connection between access to high-quality information and clinical outcomes, and the need to tailor resources to the circumstances and needs of different individuals.

The long-term impact of this digital shift remains uncertain. It may lead to broader online access and greater information equity, but it could also perpetuate—or even deepen—the digital divide. In either scenario, barriers such as limited internet access and low digital literacy must be overcome to ensure that all people with ABC can access reliable, evidence-based information.[356]

Recognizing this challenge, the past decade has seen growing efforts to develop resources in multiple formats designed to meet the varied informational needs of people with ABC (**Box 10**).

Box 10: Unique information formats for people with ABC

Breast Cancer Novelas, SHARE Cancer Support (2017)[357]



Novelas, a traditional print medium, are an important part of Spanish-speaking culture. To help address the shortage of Spanish-language materials for people with ABC, SHARE Cancer Support created a breast cancer novela in 2017. Distributed as hard copies through community-based healthcare centers, the novela explains the ABC diagnostic pathway and emphasizes the importance of genetic and biomarker testing for LatinX individuals. It has received consistently positive feedback, highlighting the value of culturally relevant and accessible information formats for people with ABC

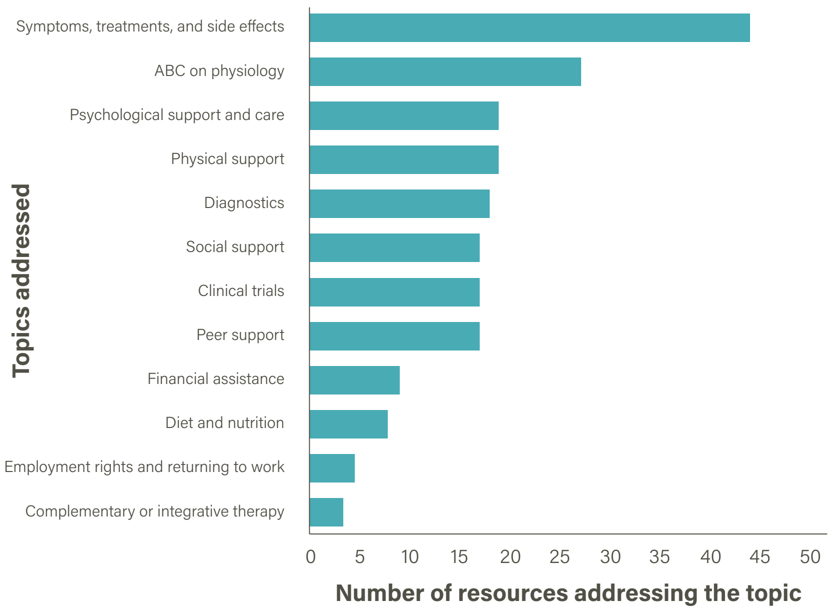
Digitally Empowered®, Patient Empowerment Network (2019–present)[358]

Digitally Empowered® was developed by the Patient Empowerment Network to provide newly diagnosed people with cancer with effective tools to find credible information online. The program utilizes virtual seminars and video tutorials to empower people with cancer to navigate the challenging digital landscape. To date, the program has supported more than 2,000 people in both English and Spanish.

ABC resources cover a broad range of topics, yet certain gaps remain

The ABC Global Alliance questionnaire highlighted the wide range of topics covered by ABC-specific resources, but also a significant imbalance in their focus (**Figure 32**). Most resources (81%) addressed symptoms, treatments, and side effects, and half covered ABC physiology, a topic crucial for understanding prognosis and disease progression. In contrast, coverage of other important topics was minimal: 7% addressed complementary or integrative therapies, only 15% provided dietary or nutritional information, and just 9% covered employment rights. Financial information was included in only 17% of resources.

Figure 32: Topics addressed by member organization-submitted ABC patient information resources released from 2015–2025

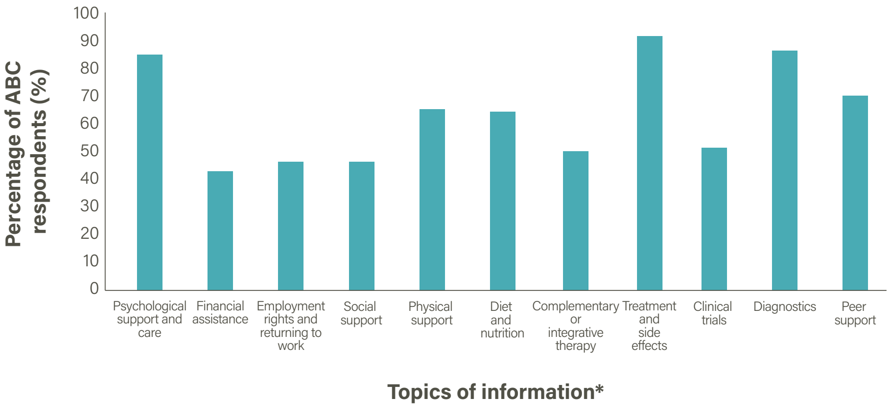


Based on findings from the ABC Global Alliance questionnaire distributed to 95 member organizations, in which 54 resources were ABC-specific and included in this analysis. Each resource was reviewed, and the topics it addressed were recorded; resources covering multiple topics were counted in each relevant category.

These audit findings mirror results from the ABC Global Alliance 2024 patient survey (n=1,254), painting a consistent picture of information access in ABC. The vast majority of respondents (93%) reported receiving information about ABC treatments and side effects (**Figure 33**), reflecting the abundance of resources on these topics. However, access to information on other crucial topics was far more limited—over half reported receiving no information about employment rights (53%) or financial support (56%). These gaps may be partly due to the complexity of such topics and the need for country-specific expertise (see Goal 9).

While the growing number of ABC resources is encouraging, the survey highlights a critical challenge: information is not reaching everyone who needs it. Limited access to practical, non-clinical information—such as employment, financial, and lifestyle guidance—can leave people without the knowledge required to navigate their care effectively, ultimately affecting both quality of life and outcomes.

Figure 33: Information received by people living with ABC



Based on findings from the ABC Global Alliance 2024 patient survey (n=1,254). '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).

Information on clinical trials remains limited for nearly half of all people with ABC

Low enrolment in clinical trials can limit the applicability of results and reduce their potential to improve outcomes.[359-361] The 2005–2015 Global Decade Report highlighted a lack of awareness and understanding of clinical trials and the negative impact of this on participation rates. A decade later, progress appears limited. Findings from the ABC Global Alliance 2024 patient survey show that only around half (52%) of respondents reported receiving information on clinical trials (**Figure 33**).

Access to this information varied significantly by treatment setting: patients attending specialist centers were far more likely to receive clinical trial information than those treated in non-specialist centers ($p<0.05$). This disparity may contribute to the improved outcomes often reported in specialist settings,[174] and highlights a persistent barrier for the many people who cannot access such centers.

Language barriers further restrict ABC clinical trial enrolment. Beyond the complexity of medical and legal jargon in consent forms, some countries, such as Australia, require prior ethics approval before these forms can be translated or used in another language,[362] limiting trial participation among non-English speakers. While advances in digital translation tools may help to address this challenge in the future, the current lack of accessible ABC clinical trial information represents an urgent gap that must be addressed to ensure equitable trial participation.

Differences between the provision of early and advanced disease information persist

The 2005–2015 Global Decade Report found that people diagnosed with ABC were less satisfied with the information they received compared with those diagnosed with early breast cancer.[3] Meeting the informational needs of all people with breast cancer, regardless of disease stage, is essential. For people with ABC, these needs are distinct and often more complex, requiring clear, accessible guidance on advanced disease management, palliative care, and end-of-life options.[3] The challenge is even greater for those with *de novo* ABC, who must immediately navigate the complexities of advanced disease while absorbing an influx of unfamiliar medical terminology.[3]

Despite longstanding awareness of these needs, progress in providing adequate information at the point of ABC diagnosis has been limited.[363] The 2020 Invisible Women Report revealed a decline in the provision of information to people with ABC between 2013 and 2019, with fewer people in 2019 receiving the same or more information at advanced diagnosis compared with their initial diagnosis.[363] This trend suggests that access to ABC-specific information at diagnosis remains inadequate—and may even be deteriorating—highlighting a critical unmet need that demands urgent attention.

Disparities in access to information exist globally

Equitable access to information remains a global challenge in ABC, influenced by factors like education, geography, and socio-economic status. These disparities contribute to poorer outcomes for those marginalized by low literacy, limited income, or stigma.[364] Findings from the ABC Global Alliance 2024 patient survey illustrate this clearly: respondents with college-level education or higher were far more likely to report that ABC information was easy to find compared with those of lower education levels (74% vs. 21%). They were also more likely to receive information on support services (75% vs. 58%). This gap is particularly concerning, as people with low education levels may be less aware of available support programs and therefore more vulnerable to financial toxicity.[365] Given that lower education levels are also associated with higher risks of disease progression and adverse health outcomes, addressing these disparities is essential to achieving equitable care for people with ABC.[366]

Access to ABC information also varies substantially by country. In the survey, the highest proportion of people reporting that information was easy to find were in the US (77%) and Taiwan (70%), compared with only around a third of respondents in Japan (38%). These differences may in part be due to varying healthcare systems, resource availability and the presence of active patient advocacy groups.[367]

Certain populations face additional barriers that further limit access to information, including fear of stigma or isolation that discourages healthcare engagement (see Goal 8), a lack of support networks, and restricted internet access.[289] Overcoming these obstacles requires the development of resources tailored to diverse socio-economic and geographic contexts, ensuring that all people with ABC—regardless of background—can access the information they need to understand their disease and manage their care effectively.[289]

HCPs are a fundamental information source, yet their focus is often narrow

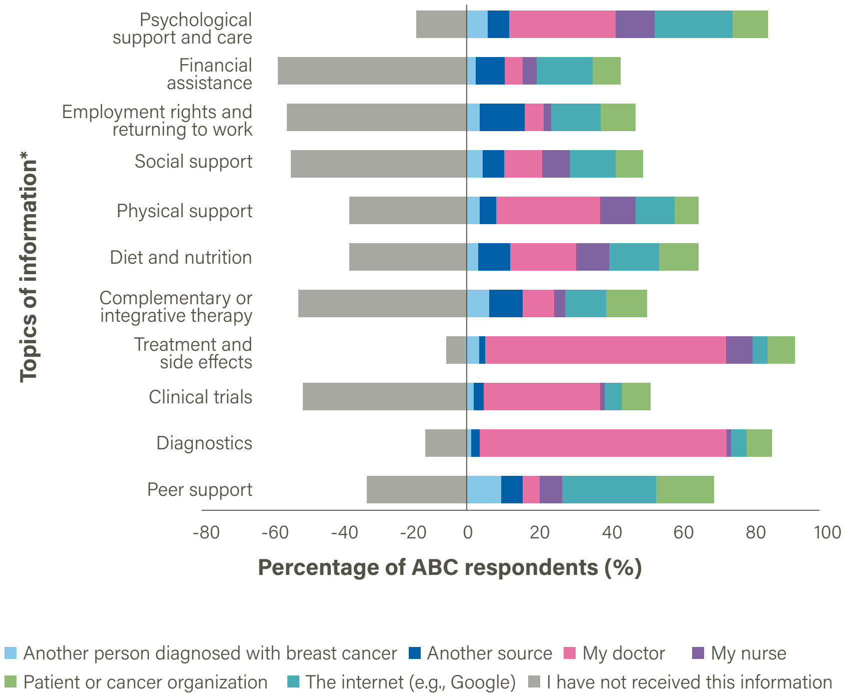
HCPs remain the preferred source of information for people with ABC. The ABC Global Alliance 2024 patient survey confirmed that doctors, specifically, are the most frequently used information source.[368] Similarly, the Young Survival Coalition's Project 528 global survey reported that almost three-quarters (72%) of young adults with ABC feel confident in understanding and asking questions during interactions with their HCPs.[20]

However, the ABC Global Alliance 2024 patient survey also revealed that the information provided by HCPs is heavily weighted towards clinical topics (**Figure 34**). The most common areas covered by HCPs were treatment and side effects (70%) and diagnostics (71%). In contrast, information on non-clinical topics—such as employment rights, financial assistance, and social support—were far less frequently addressed by HCPs, with patient organizations more likely to provide this type of information. Several factors may contribute to this gap, including limited consultation time, a lack of awareness of relevant resources, or insufficient communication training (see Goal 5).[369]

Cultural differences in patient–HCP relationships may also influence the breadth of information provided. In more paternalistic healthcare cultures, such as in Mexico, people may rely solely on HCPs for information rather than seeking out online sources or patient organizations.[370] While this trust can strengthen the therapeutic relationship, it may also mean that people receive information limited to clinical topics, missing opportunities to connect with peer support networks or access non-clinical resources.

As a result of these information gaps, many people with ABC and their caregivers are compelled to seek additional information independently. In the ABC Global Alliance 2024 patient survey, 92% of respondents reported doing so—a process that often requires consulting multiple sources to build a complete picture, combining what they receive from HCPs with information from support groups, charity websites, and online searches.[225] This highlights the need for HCPs to take a more holistic approach to information provision, ensuring people are directed to credible, comprehensive resources that address both clinical and non-clinical needs.

Figure 34: Patient-reported information sources, per topic



Based on findings from the ABC Global Alliance 2024 patient survey (n=1,254). '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).

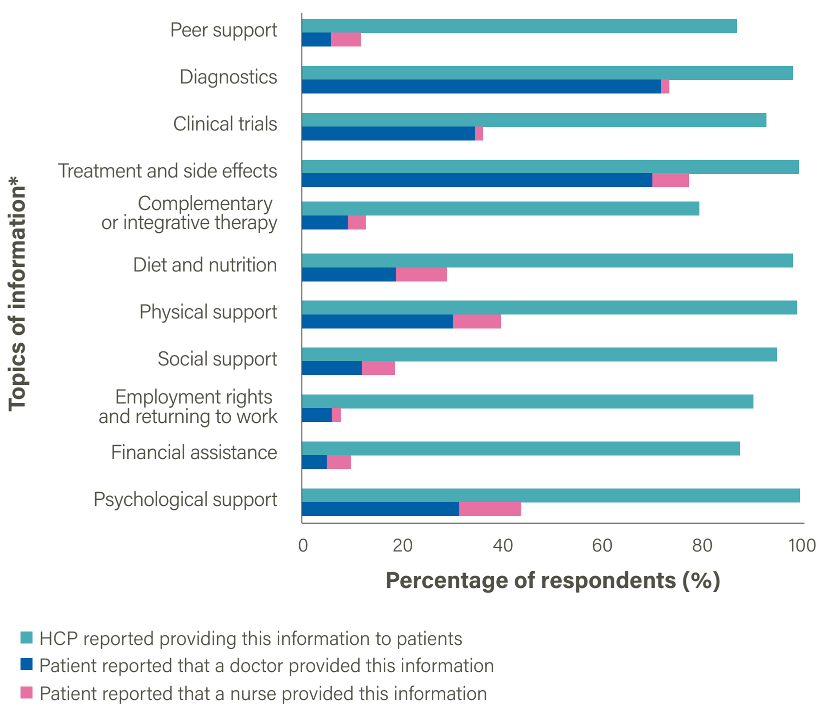
† Respondents who did not receive information have been represented as negative numbers for the purpose of data visualization.

HCPs and people with ABC have misaligned perceptions on information sharing

Compared with the results of the patient survey, the ABC Global Alliance 2024 HCP survey (n=461) revealed a striking contrast: while most HCPs (90%) stated that they provide information across all topics, only 41% of people with ABC reported receiving such information from their doctor or nurse. This discrepancy may partly reflect the well-documented challenge of retaining information during consultations, where 40–80% of content is reported to be immediately forgotten.[371] However, the gap is particularly pronounced in certain non-clinical areas. For example, although 90% of HCPs reported providing information on employment rights, only 7% of people with ABC recalled receiving it. Similarly, for financial assistance, 87% of HCPs said they provided the information, yet just 9% of people with ABC reported receiving it. The same pattern emerged for peer support (86% of HCPs vs. 11% of people with ABC).

This persistent disparity between HCP perception and the experience of people with ABC emphasizes the need for improved information provision from HCPs, ensuring that essential information is both delivered and retained, and closing the gap between what HCPs believe they are providing and what people with ABC actually receive.

Figure 35: Comparison of HCP- and patient-perceived provision of ABC information



Based on findings from the ABC Global Alliance 2024 patient survey (n=1,254). '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.]; and the 2024 HCP survey (n=461). 'How often do you provide the following types of information to patients with advanced breast cancer? [Never; Rarely; Sometimes; Often; Always.]

* 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).

Patient advocacy groups are an increasingly trusted information source for people with ABC

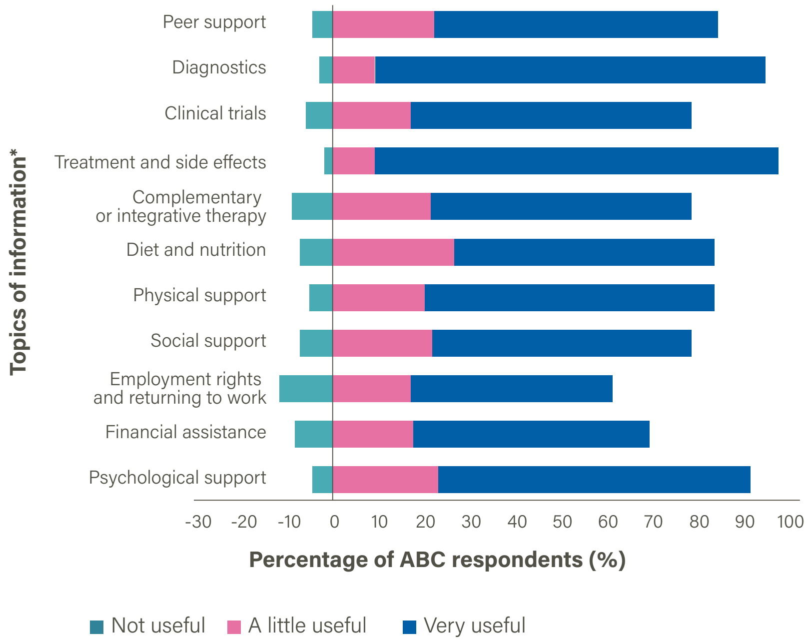
Patient advocacy groups (PAGs) play a key role in meeting the informational needs of people with ABC. In the ABC Global Alliance 2024 patient survey, PAGs were identified as the second-most cited source of information, after HCPs, across all topics (**Figure 34**). While survey respondents were likely to be affiliated with or aware of patient organizations, this finding indicates a notable level of trust in PAGs among people with ABC. This trust is reinforced by results of a 2021 MetUp-UK survey of 178 people with ABC, in which approximately two-thirds reported moderate-to-high trust in information disseminated by individuals, informal groups, and metastatic breast cancer (MBC) groups, including PAGs.[372] This marks significant progress since 2015, when only 13% of people with ABC regarded PAGs as a useful source of information, and many called for improvements in PAG-developed resources.[3]

The growing commitment to address the informational needs of people with ABC is exemplified by the work of major breast cancer and ABC PAGs worldwide. Examples include: Breast Cancer Network Australia's development of dedicated ABC resources,[373] Europa Donna – European Breast Cancer Coalition's creation of a dedicated MBC section on its website and its yearly MBC Advocacy congress,[374] and Make 2nds Count—a Scotland-based PAG established in 2018 specifically to support people with ABC, with a focus on education, support and research.[375] These initiatives demonstrate the expanding role of PAGs in providing trusted, accessible, and patient-centered information, complementing the clinical guidance offered by HCPs.

When received, ABC information is increasingly perceived as useful

The 2005–2015 Global Decade Report found that many available resources failed to meet the informational needs of people with ABC, with a notable lack of ABC-specific content. Encouragingly, this appears to have improved over the past decade. The ABC Global Alliance 2024 patient survey revealed that more than half (60%) of respondents now find information on all topics to be useful. Information on diagnostics and on treatment and side effects were rated as most useful, cited by 84% and 87% of respondents, respectively (**Figure 36**). This aligns with the fact that these topics are the most comprehensively covered and widely available, suggesting that the quality of resources in these areas is high. Interestingly, although information on employment rights and financial matters remains scarce, it was still considered useful by a substantial proportion of respondents, 60% and 68%, respectively (**Figure 36**). This highlights the importance of ensuring that high-quality, accessible resources are developed for these vital but under-represented topics, which can have a significant impact on the quality of life and wellbeing of people with ABC.

Figure 36: Patient-reported usefulness of ABC information



Based on findings from the ABC Global Alliance 2024 patient survey (n=1,254). 'How useful are the following types of information available to you on advanced breast cancer? Select the most appropriate option for each row.' [Not useful;† A little useful; Very useful; Not applicable.]

* 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).

† The 'not useful' respondents have been represented as negative numbers for the purpose of data visualization.

Information barriers are driving people with ABC to alternative sources, risking exposure to misinformation

People with ABC rely heavily on both PAGs and HCPs as trusted sources of information. However, time and resource constraints can mean that their resources are not always updated in line with scientific advancements or the evolving treatment landscape.[376] Combined with previously identified information gaps—such as HCPs' narrow focus on clinical topics and the limited availability of holistic support information—this drives many people with ABC to seek information online. This trend is well documented: in one survey of 193 people with ABC, more than half (58%) reported researching treatment options independently before starting therapy.[20] In the ABC Global Alliance 2024 patient survey, almost all respondents (92%) said they had looked for information online, a finding echoed by a 2023 survey of 246 people with ABC in Ireland and Northern Ireland, where 95% resorted doing the same.[377]

When online platforms can offer rapid access to information, they also present new challenges not seen in the previous decade. Content from patient experts or digital opinion leaders can be valuable, but the accuracy of online information is highly variable.[378] Literature reports that between 30–80% of cancer-related social media content contains misinformation, particularly regarding treatments. One US-based study found that people with cancer were significantly more likely to be exposed to, and share, misleading cancer treatment information on social media.[378] Optimism bias, which is more prevalent among those with advanced cancers, can further increase receptivity to misinformation if it offers hope.[379]

The rise of open-source artificial intelligence (AI) tools, such as ChatGPT, has given people unprecedented access to information. These tools can help people with ABC to enter consultations more informed than ever before and make information-seeking faster and more convenient. However, with such rapid and transformative progress comes caution. AI-generated content is not automatically verified for accuracy and may draw from outdated, biased, or incorrect sources. While AI can empower people with ABC, it also carries the risk of amplifying misinformation if the content is taken at face value, reinforcing the continued need for trusted HCPs and PAGs to guide people toward reliable, evidence-based information and resources.

Although printed materials can also contain inaccuracies, the scale and speed of online dissemination make misinformation more harmful. A single erroneous social post can reach thousands, far exceeding the reach of a printed pamphlet. Incorrect information poses a serious risk, potentially influencing people to abandon proven treatments in favor of alternative therapies, leading to poorer outcomes and reduced survival.[380] To mitigate this, people with ABC must have easy access to high-quality, accurate information that supports informed decision-making and safeguards against the harms of misinformation.

CONCLUSIONS AND FUTURE DIRECTIONS

Despite some progress over the past decade and an increase in the number of ABC-specific resources, disparities in availability of, and access to, information for people with ABC persist worldwide. While HCPs remain the preferred source of clinical information, PAGs are increasingly recognized as trusted sources of non-clinical information, effectively bridging critical gaps in support. As the ABC landscape continues to evolve, the rapid digitalization of information delivery and the emergence of AI tools present both opportunities and risks. These innovations can expand reach and empower people with ABC, but they also heighten the potential for misinformation and may exacerbate health inequities. Ensuring that information is available in diverse, accessible formats, tailored to different languages, health literacy levels, and cultural contexts, will be essential to overcoming disparities.

Accessible, reliable, and evidence-based information is not simply beneficial, it is a critical and urgent need for people with ABC. Meeting this need equitably will require a collaborative multi-stakeholder effort involving HCPs, PAGs, policymakers, researchers, and technology partners.

In recognition of this, the ABC Global Alliance community has agreed that this goal should remain in the ABC Global Charter 2025–2035 with the following revised wording:

Meet the INFORMATIONAL needs of all people with ABC

Concerted, coordinated efforts are required to meet this goal and 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

7 Support services for people with ABC

Support services for people with ABC

INTRODUCTION

People with advanced breast cancer (ABC) face a wide range of medical, physical, and psychosocial unmet needs, driven by burdensome symptoms, anxiety, and a reduced quality of life (QoL).[381-384] Supportive care–defined as the prevention and management of cancer and its treatment across the care continuum, from diagnosis, through treatment, to post-treatment care[385]–can play a critical role in easing this burden. However, given the complexity of ABC and the diversity of patient needs, these services must be tailored to the individual to deliver maximal benefit.

In the context of this chapter, key ABC support services include psychological support, social and peer support, complementary and integrative therapies, wellness and lifestyle support, genetic counseling, survivorship programs, palliative care, and end-of-life (EoL) care **(1)**. These services have historically been categorized as "non-clinical support", but this terminology fails to acknowledge their clinical significance, particularly in the case of psychological support, which is integral to overall patient wellbeing and outcomes.

This chapter explores the global availability and accessibility of support services required for comprehensive ABC care, and the policies and guidelines that guide their development, funding, and delivery. It draws on findings from an ABC Global Alliance analysis of National Cancer Control Plans (NCCPs), which compares the availability and funding of various support services across 5 countries (**Appendix VIII**), and results from an ABC Global Alliance member questionnaire (**Appendix VII**). It also includes insights from global patient and healthcare professional (HCP) surveys conducted by the ABC Global Alliance in 2024.

STATUS IN 2005-2015

In 2002, the World Health Organization (WHO) published recommendations for the development of NCCPs, which included support services–such as psychosocial care, survivorship support, and palliative care–as a key component.[386] This recommendation was echoed by the European Guide for Quality NCCPs in 2015.[386-387] Clinical ABC guidelines also recognized the importance of supportive and palliative care throughout the disease continuum, including the ABC International Consensus Guidelines, the National Comprehensive Cancer Network (NCCN) guidelines, and the National Institute of Health and Care Excellence (NICE) guidelines.[388-390]

Despite increasing recognition of the importance of supportive services, the 2005–2015 Global Decade Report highlighted inconsistent implementation across ABC care.[3] At the time, psychological support was underutilized, with limited access for the majority of people with ABC.[3] The Breast Cancer Center Survey, conducted in 2015, identified supportive care as a priority need for 79% of people with ABC.[3] The survey also highlighted palliative and EoL care as critical components of ABC support, yet both were frequently reported as inadequate. Discussions between HCPs and patients on these topics often occurred too late in the disease trajectory[3] reducing opportunities for timely intervention and personalized care planning.

As a result, awareness of, and referral to, ABC support services was outlined as one of the 10 'Actions For Change' in the 2015–2025 ABC Global Charter.[4]

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(1) Support services include psychological support (e.g., psycho-oncology, counseling), social support (e.g., transport, home care), peer support (e.g., advocacy groups, charities), complementary therapies (e.g., herbal medicine, kampo), wellness and lifestyle services (focused on emotional, physical, and mental wellbeing), genetic counseling, survivorship programs (post-treatment care), palliative care, and end-of-life care.

A DECADE IN REVIEW (2015-2025)

Despite enhanced adoption of national cancer policies, recommendations for support services vary widely

In 2024, the ABC Global Alliance analyzed NCCPs from six countries–Brazil, France, Japan, South Africa, the United Kingdom (UK), and the United States (US) (see **Appendix VIII** for methodology)–to determine how frequently supportive care services are recommended as part of the cancer care pathway (**Table 8**). Encouragingly, five of the six countries have introduced new or updated cancer plans in the past decade. However, only Japan and the UK include all of the support services reviewed, while Brazil's NCCP references just one–palliative care.

These findings align with broader global trends. A 2018 global analysis reported wide variation in policy recommendations for supportive care for people with ABC across countries.[391] More recently, a 2021 review of 237 NCCPs worldwide revealed that fewer than half (41%) referenced psycho-oncology or survivorship support, emphasizing the limited availability of these services globally.[392] Support service recommendations are often particularly lacking in resource limited settings. Here, insufficient funding or limited understanding of the benefits of supportive care can lead to its de-prioritization in favor of ensuring access to fundamental treatments. In these contexts, supportive care may be stratified into 'essential' services (e.g., palliative care) and 'non-essential' services (e.g., nutritional support).

Positively, palliative and EoL care services are now recommended in all cancer plans evaluated, reflecting the WHO's recognition of palliative care as a human right to health[408] and marking significant progress in the inclusion of these essential services. In contrast, despite growing interest and recognition of the value of complementary therapies, they continue to face skepticism,[409-410] and are recommended by only half of the NCCPs analyzed by the ABC Global Alliance.

Table 8: Inclusion of supportive care services in NCCPs in selected countries

Support service	Japan[393-395]	Brazil[396]	South Africa[397-398]	US[399-402]	UK[388,403-406]	France[407]
Psychological support	🔵	🔴	🔵	🔴	🟢	🔵
Palliative care	🔵	🔵	🟢	🔵	🟢	🔵
Social support	🔵	🔴	🔵	🔵	🔵	🔴
Survivorship programs	🔵	🔴	🔵	🔵	🔵	🔵
Support groups	🔵	🔴	🔵	🔵	🔵	🔴
Genetic counseling	🔵	🔴	🔵	🔴	🔵	🔴
Complementary therapies	🔵	🔴	🔴	🔴	🔵	🔵
Wellness support*	🔵	🔴	🔵	🔴	🔵	🔵

🔴 Not included in policy recommendations 🔵 Included but no ABC-specific recommendations 🟢 ABC-specific recommendations included

Based on the ABC Global Alliance NCCP Analysis conducted in 2024.

* Wellness support includes services designed to improve a person's overall wellbeing including their emotional, physical and mental health.

Policy recommendations do not guarantee availability or uptake of support services

Policy frameworks play a crucial role in shaping supportive care services in ABC. When effectively implemented they facilitate patient access to psychological, social, nutritional, and complementary services, enhancing QoL.[411-413] Yet, translation of policy recommendations in practice remains inconsistent worldwide, with implementation ranging from systematic approaches to more *ad-hoc*, fragmented provision:

- **Japan:** In line with policy recommendations for the provision of complementary medicines, *Kampo medicine* (a traditional Japanese herbal medicine that emphasizes holistic diagnosis) is widespread in treatment pathways and is recognized as an approach to alleviating side effects and managing disease symptoms[414-415]
- **UK:** Comprehensive cancer policies recommend provision of social and peer support groups. Yet, in practice it is often left to individual initiatives to provide patients with a supportive environment, community, and emotional wellbeing. One example is the MediCinema breast cancer support group run by Guys and St Thomas' National Health Service (NHS) Trust[416]
- **Australia:** ABC support groups are run in an *ad-hoc* manner by medical centers and community-based organizations. The lack of state or federal standards, guidelines, and funding may lead to disparities in care, limited stability, and overt reliance on independent funders[417]
- **South Africa:** The national breast cancer policy acknowledges that support services are not available across all regions,[398] demonstrating that access can vary within countries despite policy recommendations

Even where policies exist, many ABC support services remain underutilized

The ABC Global Alliance 2024 patient survey (n=1,254) found that psychological (64%) and physical (54%) support were the most frequently used services among people with ABC (**Figure 37**)–an encouraging shift from 2015, when psychological support was notably underutilized.[3] However, uptake of other essential services remains low. Only around a quarter (27%) of patients reported using social support, and roughly a third (30%) using nutritional support, possibly due to out-of-pocket (OOP) costs often associated with these services. Even fewer reported participation in clinical trials (21%) or use of palliative care and EoL services (15%), although this could be partly explained by many survey respondents being at an early stage in their disease trajectory.

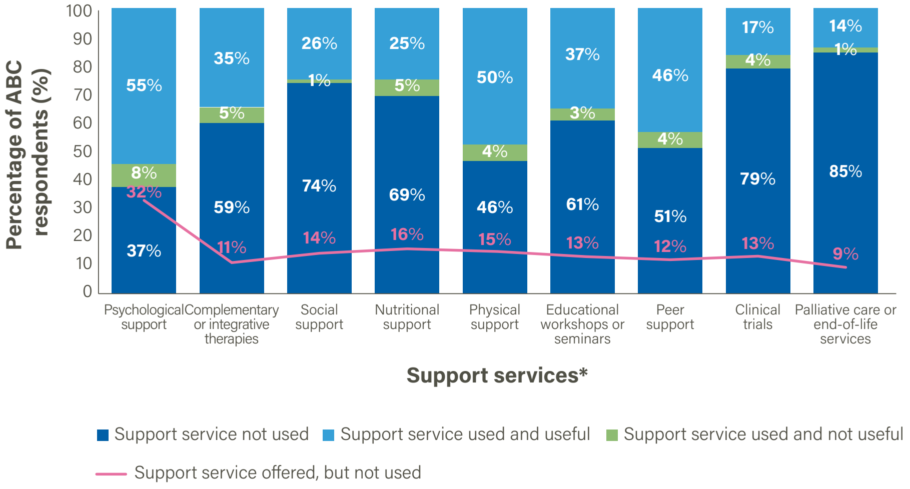
One important area not captured by the ABC Global Alliance survey is fertility support–a growing consideration in ABC care. A global survey conducted by the Young Survival Coalition's (YSC) Project 528 found that fewer than half of young women with ABC (44%) had discussed fertility preservation with their HCP.[20] Furthermore, only 29% reported receiving support for unique challenges such as dating, relationships, intimacy, fertility, parenting, finances, employment, and social isolation.[20] While fertility has traditionally been a concern for women with early breast cancer, it is increasingly relevant in ABC,[418] likely due to improved survival rates[12] and a growing number of patients experiencing long-term complete remission, particularly those with HER-2-positive ABC.[419]

The ABC Global Alliance 2024 patient survey showed uptake of support services to vary significantly by country, and in many cases not to align with policy recommendations. This could be due to suboptimal policy implementation, financial or reimbursement hurdles, or societal factors:

- **Brazil:** Highest reported psychological support utilization (79%), potentially resulting from the country's psychological care mandate,[396] however palliative care utilization remains limited (38%) despite inclusion in cancer plan recommendations
- **France:** Substantially higher utilization of social support services compared to other countries (56%) despite not being included in policy recommendations, which may be explained by many services associated with long-term conditions, including cancer, being covered by Affection de Longue Durée[420]
- **Japan:** Relatively low utilization rates across support services–psychological support (35%), social support (10%), physical support (40%), peer support (30%)–in contrast to the comprehensive national cancer plan recommendations
- **US:** High utilization of peer support services (78%), which could reflect the country's socio-economic status and the high number of active breast cancer advocacy groups
- **UK:** High usage rates for complementary and alternative medicines (CAMs; 63%), physical support (68%), peer support (72%), and palliative care (32%), in line with comprehensive policy recommendations

Overall, use of support services was more common in high-income countries (HICs) than low-middle income countries (LMICs), including psychological support (65% vs. 56%), social support (28% vs. 19%), and physical support (58% vs. 33%).

Figure 37: Use of support services by people with ABC and reported usefulness



Based on results from the ABC Global Alliance 2024 patient survey (n=1,254). '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%.

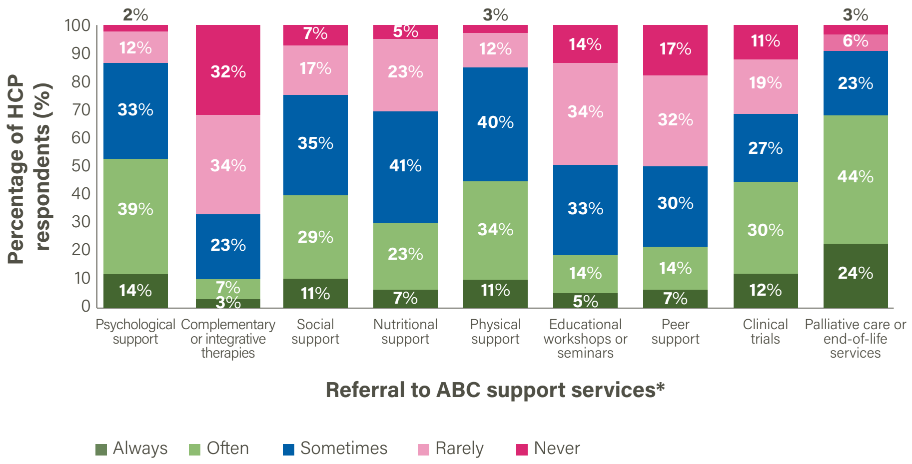
Awareness and referral barriers may be preventing support service uptake

Underutilization of ABC support services globally may be driven by low patient awareness and inconsistent HCP referral practices. Where support services exist, they are not always offered to patients in clinical practice: more than half (55%) of respondents to the ABC Global Alliance 2024 patient survey reported not being offered any support services at all. This varies by geography, with those in LMICs significantly more likely than those in HICs to report not being offered any support services ($p<0.05$), perhaps reflecting the impact of restricted funding and limited policy recommendations in these regions.

When support services are offered to people with ABC, the survey found that very few decline them, and the majority (90%) find them useful. In Japan, despite low overall use of support services, most respondents (83%) report accepting them when offered, suggesting that barriers to uptake are not driven by a lack of interest. Taken together, these findings suggest strong patient willingness to engage with support services, but limited awareness of their availability, which highlights the crucial role of HCP referral in driving uptake. However, results from the ABC Global Alliance 2024 HCP survey (n=461) suggest that referrals may not be occurring consistently across all service types. While a majority of HCPs reported 'always' or 'often' referring their patients to palliative care (68%) and psychological support services (53%), only 10% said they regularly referred patients to complementary or integrative therapies (**Figure 38**). This highlights a persistent gap between patient interest and HCP referral patterns, and suggests that expanding referral practices–particularly for underutilized services–could significantly improve uptake and patient outcomes.

These data, combined with the finding that many people with ABC accept services when offered, may help to explain the underutilization of support services in ABC. That said, the survey did not capture the availability and accessibility of these services: HCPs cannot refer patients to services that are not locally available, and affordability remains a key consideration. Therefore, while encouraging HCP referrals may drive increased utilization, gaps are likely to persist until barriers to equitable access are overcome.

Figure 38: Frequency of HCP-reported referral to ABC support services



Based on results from the ABC Global Alliance 2024 HCP survey (n=461). '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%.

Early integration of palliative care remains limited despite increased global awareness of its importance

The global outlook on palliative care is shifting from a historic focus on EoL support, to more recent recognition of its value early in the patient journey. The past decade has seen increased awareness of the importance of palliative care, with increased availability of services reported by 82% of countries (n=51) in a global study conducted between 2005–2019.[421] In 2020, the International Cancer Control Partnership's Global Atlas of Palliative Care found persistent inequalities in palliative care services worldwide, particularly between Western and Eastern Europe and between HICs and LMICs, where investment remains uneven.[422] The scale of unmet need in many LMICs is illustrated by the situation in Nigeria. Although home to over 230 million people, there are only 17 reported palliative care facilities (mostly tertiary hospital-based teams) and the country is classified as Category 3a ("only isolated palliative care provision") in the Global Atlas, despite a 2021 government mandate to integrate hospice and palliative care across primary, secondary, and tertiary care.[423-424] In 2021, the WHO's introduction of palliative care indicators for use across disease areas, including advanced cancers, created a framework for measuring progress and upholding standards of care, and as a result of this initiative several European countries now register palliative care outcomes.[425]

Early integration of palliative care allows patients to establish trust with their palliative support team and is associated with better outcomes for people with advanced cancers, including improved QoL and reduced symptom burden.[426-427] Yet, historically, access has been restricted to late stages of disease. The 2005–2015 Global Decade Report found that 65% of palliative care conversations occurred only at the end of active treatment.[3] Since then, the ABC International Consensus Guidelines, as well as those from the American Society of Clinical Oncology (ASCO), and the European Society for Medical Oncology (ESMO), have recommended integration of specialized palliative care throughout the entire disease trajectory for people with ABC.[19,390,427-428] Despite this, implementation in clinical practice remains limited.[3] Recent data underscore this gap: a 2024 multi-center analysis of 12 comprehensive cancer centers in France found that only 31% of palliative care interventions occurred more than 3 months before death.[429] In the US, a 2018 study reported that 40% of people with ABC were referred for palliative care too late.[430] These findings highlight a persistent unmet need for timely access to palliative care services, reinforcing the importance of embedding early referral in ABC care pathways as a standard of practice.[19,390,427-428]

While both the oncology and palliative care communities agree that palliative care should not be reserved solely for EoL, 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,[431] while others define "early" as more than three months prior to death.[432] Despite these benchmarks, there is no universally accepted definition, and effective integration ultimately requires a personalized, patient-centered approach.

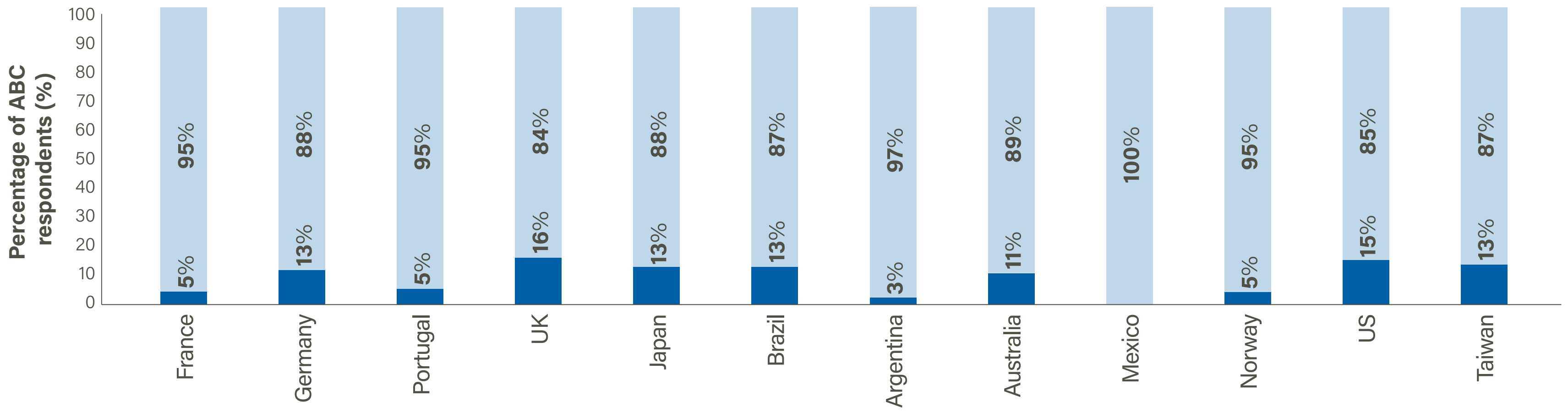
Patient hesitancy represents a further barrier to early integration of palliative care, with some people with ABC more likely to decline these services when offered early in the disease pathway. Analysis of ABC Global Alliance 2024 patient survey findings in countries with low palliative care uptake revealed that almost one-tenth (9%) of respondents reported declining palliative care when it was offered (**Figure 39**). This varied considerably by country–from 0% in Mexico, where all respondents reported not being offered the palliative care and therefore not using it, to 16% in the UK, where patients were offered the service, but chose not to engage. Hesitancy to accept palliative care may be influenced by psychological, cultural, and social factors, most notably the widespread association of palliative care with EoL rather than supportive care throughout the disease trajectory.[433] Addressing these misconceptions through improved patient education and clear communication about the value of palliative care could help more people with ABC to access and benefit from these services earlier, enhancing QoL and symptom management from the outset.

A lack of funding and resources limit ABC support services

ABC support services are highly dependent on funding, which varies between countries and healthcare systems. A 2024 ABC Global Alliance analysis of support service funding coverage across six countries (methodology in **Appendix VIII**), revealed a lack of public funding worldwide, with many services relying on donations from charitable organizations, or patients paying out of pocket for access to them (**Table 9**).

Of the countries analyzed, the UK demonstrated the broadest funding for support services–likely due to the publicly-funded NHS, although some essential services remain excluded from coverage. In contrast, Japan has some of the most comprehensive policy guidelines for supportive care yet provides funding for the fewest number of services. In Brazil and the US, mixed healthcare models contribute to inconsistent funding, with public coverage often means-tested and private insurance coverage varying widely depending on provider plans.[434-439] These findings suggest that despite growing awareness of supportive care in ABC, financial constraints remain a persistent barrier to access for many.

Figure 39: People with ABC not using palliative care services by country



Based on results from the ABC Global Alliance 2024 patient survey (n=1,254). 'Have you been offered any of the following services during care for advanced breast cancer, but not used them?' [subgroup analysis for palliative care]

Table 9: Overview of funding coverage for key support services across six countries

Support service	Japan [440-441]	Brazil [437-439]		South Africa [442-443]	US[434-436]		UK [444-447]	France [420,448]
		Public	Private*		Public	Private*		
Psychological support	🔵	🔵	🔵	🔵	🔵	🔵	🟢	🟢
Palliative care and end-of-life services	🟢	🟢	🟢	🔵	🟢	🟢	🟢	🟢
Social support	⚪	🟢	🟢	⚪	🔵	🔵	🟢	🔵
Survivorship programs	🔴	🔴	🔵	🔵	🔵	🔵	🟢	🔴
Support groups	🔴	🔵	🔴	🔴	🔴	🔴	🔴	🔴
Genetic counseling	🔴	🔵	🟢	🔵	🔵	🟢	🟢	⚪
Complementary and integrative therapies	🔴	🔵	🟢	⚪	🔵	🔵	🔴	🔴
Wellness support†	🔴	⚪	🔵	🔴	🔵	🔵	🟢	🔵

🔴 Service not funded 🔵 Service funded with limitations 🟢 Service fully funded ⚪ No information available

Based on findings from the ABC Global Alliance support service funding analysis.

* Coverage of services by health insurance differs substantially between providers.

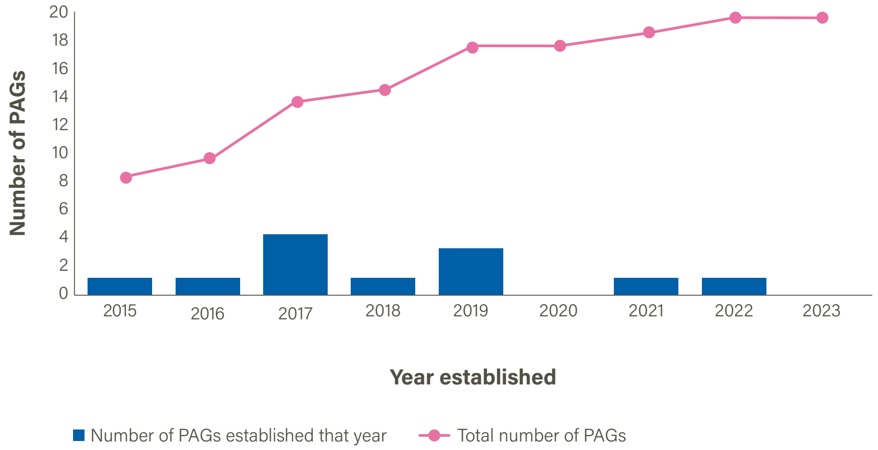
† Wellness support includes services designed to improve a person's overall wellbeing, including their emotional, physical and mental health.

Inadequate infrastructure and workforce shortages may also impact the availability of support services for people with ABC. This is a particular challenge in LMICs but is also evident in many HICs. For example, in a 2017 German study, the majority (84%) of general practitioners (GPs) and community specialists identified limited access to psychotherapists as a key barrier to psychosocial support for people with cancer, particularly in rural areas.[449] Barriers to peer support services vary by context. In the US, the time required to train peer support coaches and incorporate the role into clinical settings has been cited as a key obstacle in other disease areas.[450] In contrast, a UK peer support study reported difficulties recruiting patients, with the authors suggesting that some people may be reluctant to acknowledge a need for support.[451-452] Web-based interventions may help to address these challenges by offering flexible, scalable alternatives to traditional peer-to-peer support models. One example is 'Finding My Way-Advanced,' a digital tool currently being evaluated in women with ABC, which aims to provide accessible psychosocial support regardless of geographic location or local service availability.[453]

Patient advocacy groups are increasingly recognized as an essential pillar of support for people with ABC

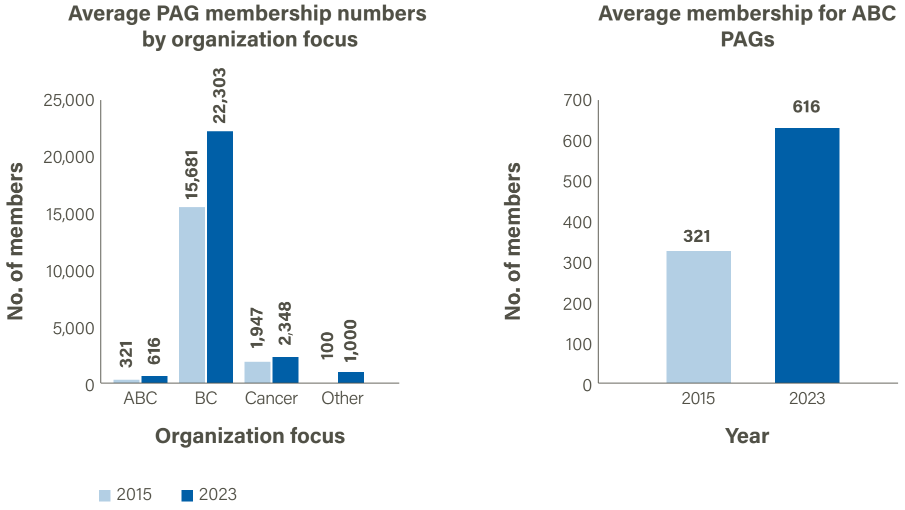
Patient advocacy groups (PAGs) have emerged as vital stakeholders in the ABC care ecosystem, playing an important role in providing patients with support, directing them to resources and services, and amplifying their voices to the broader healthcare community.

Figure 40: ABC and breast cancer PAGs established each year since 2015



Based on findings from the ABC Global Alliance member questionnaire, 2024 (n=26).

Figure 41: Change in average PAG membership in 2015 vs. 2023 by focus area



Based on findings from the ABC Global Alliance member questionnaire, 2024 (n=26).

An ABC Global Alliance analysis of the oncology PAG landscape (methodology in Appendix VII) showed that the number of breast cancer and ABC PAGs has grown steadily year-on-year, from 8 in 2015 to 19 in 2023, reflecting the expanding role of these groups in ABC care (**Figure 40**). One notable exception was 2020, where no new PAGs were formed, likely due to the impact of the COVID-19 pandemic. Surveys conducted by the Global Cancer Coalitions Network (GCCN) reported that two-thirds of cancer PAGs experienced a drop in income during the pandemic (average decrease of 48%), and more than 10% closed temporarily or permanently.[454]

PAGs have grown in size as well as number over the past decade, with ABC-specific groups increasing their membership by a total of 92% between 2019 and 2023, indicating an enhanced focus on ABC in the oncology patient advocacy space (**Figure 41**).

PAG-led services are increasingly recognized as an essential element of support for people with ABC. Around half (49%) of respondents to the ABC Global Alliance 2024 patient survey reported participating in peer support programs, with nearly all describing them as beneficial. These services may be particularly valuable for younger patients. In YSC's Project 528, 81% of young women with ABC reported being part of an online breast cancer or cancer community. Many expressed a desire for emotional and informational support, with 77% seeking connection with another survivor, 44% wanting more information about their diagnosis, and 69% looking for guidance on daily life and practical issues. Notably, 79% requested content specifically related to ABC.[20] These findings outline the critical role of peer-to-peer support and community-based services, particularly for younger individuals navigating the complex emotional and practical realities of ABC.

Engagement with peer support services, including PAGs, can vary significantly by geographic region, likely influenced by cultural differences, funding availability, and the presence or activity level of PAGs. People with ABC in the UK (72%) and Australia (61%)

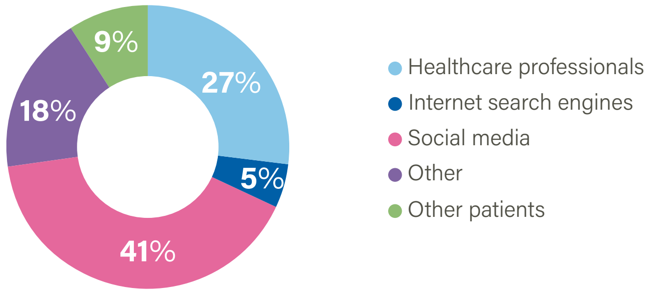
reported the highest engagement with peer support services in the ABC Global Alliance 2024 patient survey, aligning with large increases in PAG membership in those countries between 2015 and 2023 (150% and 63%, respectively). In contrast, membership remains low across the Asia-Pacific, Latin America, and continental Africa, indicating a need to strengthen peer support infrastructure and outreach in these regions.

HCP referral to ABC PAGs remains low

HCPs play a crucial role in connecting people with ABC to support services, yet referral rates to PAGs remain low (**Figure 42**). Among PAGs analyzed by the ABC Global Alliance, only 27% cited HCP referrals as the most common way members discovered their organization, compared with 41% who reported discovery through social media. The reality may be even lower: in the ABC Global Alliance 2024 patient survey, fewer than one in ten respondents (9%) said they learned about PAGs from their doctor or nurse. This gap may stem from a lack of HCP awareness or understanding of available PAGs, uncertainty about their value or quality, or perception that such services are non-essential. These factors can lead HCPs to deprioritize, or even dismiss, referrals to PAGs. Strengthening collaboration between HCPs and PAGs could help to bridge this gap, improving awareness and utilization of these critical resources. In addition, establishing clear quality standards for ABC support groups could increase confidence in these services among HCPs and the wider professional community, encouraging more consistent referrals and ensuring patients are connected to credible, high-quality support.

Figure 42: PAG-reported channels for organization discovery

Primary channels for PAG discovery



Based on findings from the ABC Global Alliance member questionnaire, 2024 (n=26).

CONCLUSIONS AND FUTURE DIRECTIONS

ABC support services have the potential to significantly improve patient QoL, enhance treatment adherence, and reduce healthcare costs by preventing complications and avoiding unnecessary hospitalizations. Yet, globally, referral rates, access, and utilization of these services remain suboptimal. The next decade presents a critical opportunity to redefine the standard of care for people with ABC. By prioritizing equitable access to comprehensive, tailored, and fully funded support services, we can address longstanding inequities and empower patients to navigate their ABC journey with dignity and resilience.

In recognition of this, the ABC Global Alliance community proposes the 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 deliver against this goal, the global 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

8 **Stigma, isolation**, and **understanding** of ABC

Stigma, isolation, and understanding of ABC

INTRODUCTION

The unique physical, financial, and emotional challenges associated with advanced breast cancer (ABC) can be difficult for others to fully understand or relate to.[190,455] These challenges often leave people with ABC feeling misunderstood, excluded, and at times socially isolated.[146,415] Stigma can come from friends, family, colleagues, and even within healthcare settings.[456-457] The emotional and social burden of advanced disease can exacerbate mental health challenges, placing those with ABC at a heightened risk of depression and anxiety.[458]

Much of the stigma and isolation experienced by people with ABC is rooted in a limited understanding of the disease. For instance, the continued association of ABC with low survival rates by some HCPs can lead to them overlooking treatment advances that now enable many patients to live longer, more fulfilling lives.[149] These misconceptions can fuel stigma, discouraging patients from seeking help, building social connections, and adhering to therapy, ultimately contributing to poorer health outcomes.[459]

This chapter outlines how stigma, social isolation, and misconceptions surrounding ABC have evolved globally since 2015. It includes findings from global patient and HCP surveys conducted by the ABC Global Alliance in 2024, a social listening analysis conducted in 2024 for the period 2016–2024 (**Appendix IX**), and results from a structured awareness campaign questionnaire distributed to 95 ABC Global Alliance members (**Appendix VII**).

STATUS IN 2005-2015

In 2009, following efforts by the Metastatic Breast Cancer Network, October 13th was officially designated as National Metastatic Breast Cancer (MBC) Awareness Day. Since 2010, the day has served to raise awareness of the unique challenges faced by people with ABC, particularly in Europe and North America.[460] However, the 2005–2015 Global Decade Report highlighted that, in its early years, the initiative had only a modest impact. Public understanding of the differences between early-stage breast cancer and ABC, and the distinct implications of these diagnoses, remained limited.[3]

The report also revealed that nearly half of people with ABC surveyed at the time had experienced social rejection, often manifesting as isolation, shame, or a sense of being outcast.[3] Alarmingly, a substantial proportion of the general public believed that breast cancer progression or recurrence was a result of patient-related factors, such as poor adherence to preventive measures, missed medical appointments, or failure to follow treatment recommendations.[3] These misconceptions not only placed unjust blame on people with ABC, but also fueled stigma surrounding the disease.

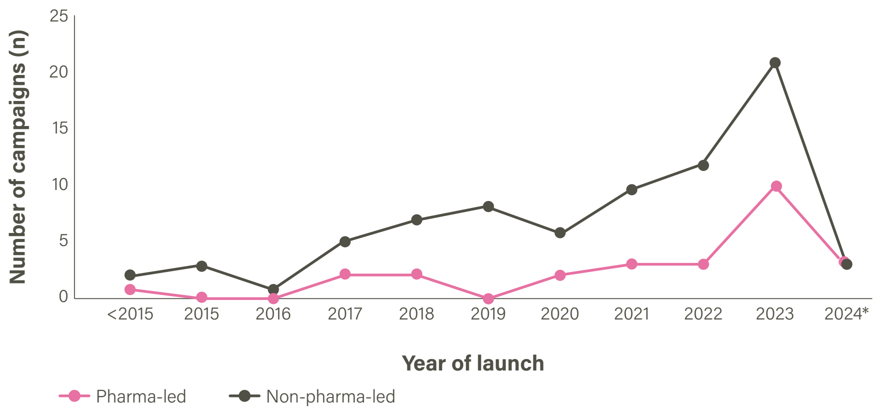
As a result, the 2015–2025 ABC Global Charter outlined the need to improve public understanding of ABC to reduce stigma and isolation, as one of its ten 'Actions For Change'.[4]

A DECADE IN REVIEW (2015-2025)

The number of ABC awareness campaigns has increased since 2015

Growing global attention on ABC is reflected in the increasing number of awareness campaigns launched over the past decade. A 2024 analysis by the ABC Global Alliance of 101 public awareness campaigns submitted by member organizations revealed a steady rise in ABC-focused campaigns since 2015 (see **Appendix VII** for methodology). Campaigns across all categories (general cancer, breast cancer, and ABC) grew consistently year-on-year, peaking in 2023 with the launch of 31 new campaigns. Of these, around a third (32%) were led by pharmaceutical organizations (pharma-led), while the majority (68%) were led by other organizations (non-pharma-led). The only exception to this upward trend was in 2020, when a slight decline was observed, likely due to the impact of the COVID-19 pandemic (**Figure 43**).

Figure 43: General cancer, breast cancer, and ABC public awareness campaigns launched per year



Based on pharmaceutical organization (pharma-led; n=5) and other organization (non-pharma-led; n=29) responses to 'Public awareness campaigns: Launch date' section of an ABC Global Alliance 2024 questionnaire distributed to 95 ABC Global Alliance members, and additional desk research.

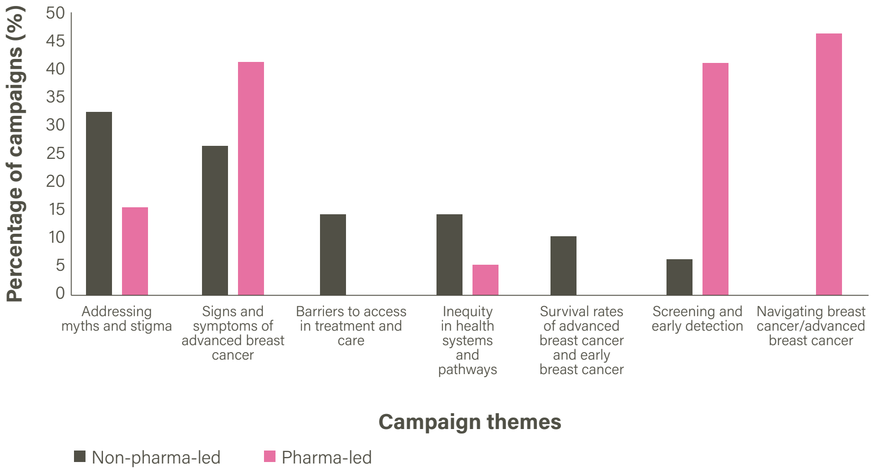
* Data for 2024 are not fully representative, as collection occurred before the year's end.

While the rise in campaign numbers is encouraging, their effectiveness in reducing stigma and improving understanding of ABC remains unclear. Of the 101 public awareness campaigns analyzed, just over half (51%) focused specifically on ABC, marking a positive shift from the 2005–2015 Global Decade Report, which highlighted a lack of ABC-specific campaigns.[3] However, data on reach and impact remain limited. Only a small proportion of campaigns reported key metrics such as audience engagement, making it difficult to determine whether these efforts translate into meaningful improvements in ABC awareness, understanding, or patient experience. Further systematic evaluation is needed to truly assess whether awareness campaigns are helping to reduce stigma, combat misconceptions, and address social isolation, and to identify best practice approaches that can be scaled globally.

ABC awareness campaigns increasingly highlight the patient experience

The ABC Global Alliance's awareness campaign analysis reveals a clear evolution in thematic focus since 2015. Earlier campaigns tended to focus on treatment-related topics such as safety, efficacy, and clinical studies. In contrast, more recent campaigns, particularly those led by non-pharmaceutical organizations, have shifted toward dispelling myths and reducing stigma around ABC. Pharmaceutical organization-led campaigns, however, have remained more focused on topics like ABC navigation (45%), signs and symptoms of ABC (40%), and the importance of screening and early detection (40%), reflecting differing strategic priorities between organization types (**Figure 44**).

Figure 44: Thematic analysis of ABC public awareness campaigns



Based on pharmaceutical organization (pharma-led; n=5) and other organization (non-pharma-led; n=29) responses to 'Public awareness campaigns: Objective of campaign' section of an ABC Global Alliance 2024 questionnaire distributed to 95 ABC Global Alliance members, and additional desk research.

The growing emphasis on addressing ABC misconceptions and stigma aligns with broader recognition–previously noted in the 2005–2015 Global Decade Report–of the significant social and psychological challenges faced by people with ABC. One notable example is 'The Cancer Currency' (**Box 11**) launched in 2023 by Europa Donna – European Breast Cancer Coalition, which highlighted the unique needs of people with ABC.[461] The campaign successfully influenced European policy, with ABC being recognized in Europe's Beating Cancer Plan for the first time.[374]

Box 11: The Cancer Currency

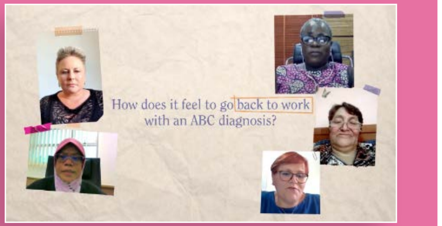
This Europa Donna – European Breast Cancer Coalition initiative employs a symbolic "currency" to represent the invaluable contributions, resilience, and worth of those affected by ABC. By drawing attention to the ongoing challenges faced by people with ABC and advocating for their recognition, the campaign aims to break down barriers such as societal invisibility and foster greater awareness, support, and appreciation for this underserved community.

Over the past decade, the ABC Global Alliance has also launched several campaigns that move beyond treatment to focus on the lived experience and psychological impact of ABC (**Box 12**).[462] 'I Am Advanced Breast Cancer' uses personal storytelling to challenge stigma and highlight the emotional impact of the disease; 'The Truth About Working with ABC' addresses the realities of returning to work after an ABC diagnosis, advocating for more flexible and compassionate workplace policies; and 'The Other Victims of ABC' draws attention to the far-reaching impact of ABC, calling for more inclusive and collective support models.

Box 12: Expanding the ABC conversation: ABC Global Alliance awareness campaigns

- **I Am Advanced Breast Cancer**
  Through short films and personal narratives, this campaign gives voice to the everyday realities of people living with ABC. Using first-person stories, it challenges common misconceptions and highlights the sense of invisibility faced by many people with ABC, advocating for more responsive, person-centered care.

- **The Truth About Working with ABC**
  This initiative breaks the silence around the professional lives of people with ABC. It explores the challenges of balancing employment with ongoing treatment, calling for greater awareness of workplace discrimination and more compassionate, flexible employment policies.



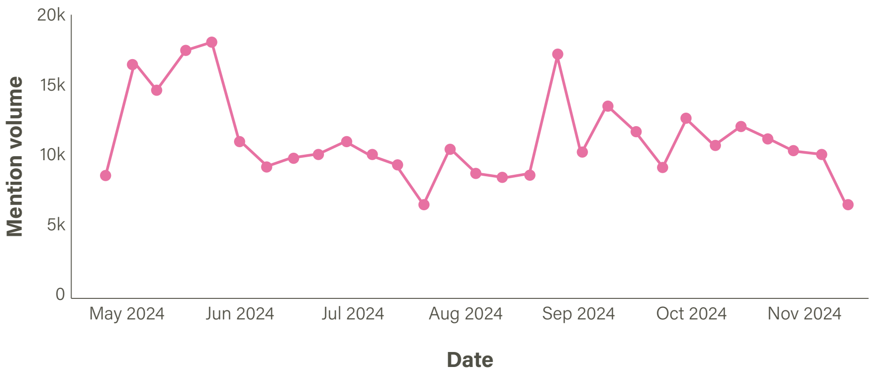
- **The Other Victims of ABC**
  This campaign draws attention to the broader social impact of ABC. It highlights the emotional and practical toll of the disease on families, caregivers, and communities, and calls for a collective, inclusive approach to ABC care that extends beyond the patient.

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

Breast Cancer Awareness Month, in October each year, remains a critical platform for increasing global understanding of breast cancer, including ABC.[463] Annual awareness efforts are beginning to show impact, with a 2023 social listening analysis conducted by Roche indicating that online discussions about breast cancer in the Asia-Pacific region peak each October.[464] A global social listening analysis conducted by the ABC Global Alliance between May and November 2024 (see **Appendix IX** for methodology) revealed similar trends. Interestingly, online conversation specifically about ABC remained steady throughout the year, with no discernible peak during October. This suggests that the public may not strongly associate Breast Cancer Awareness Month with ABC, possibly reflecting a broader decline in ABC visibility during October, as traditional "pinkwashing" campaigns continue to dominate messaging.[465]

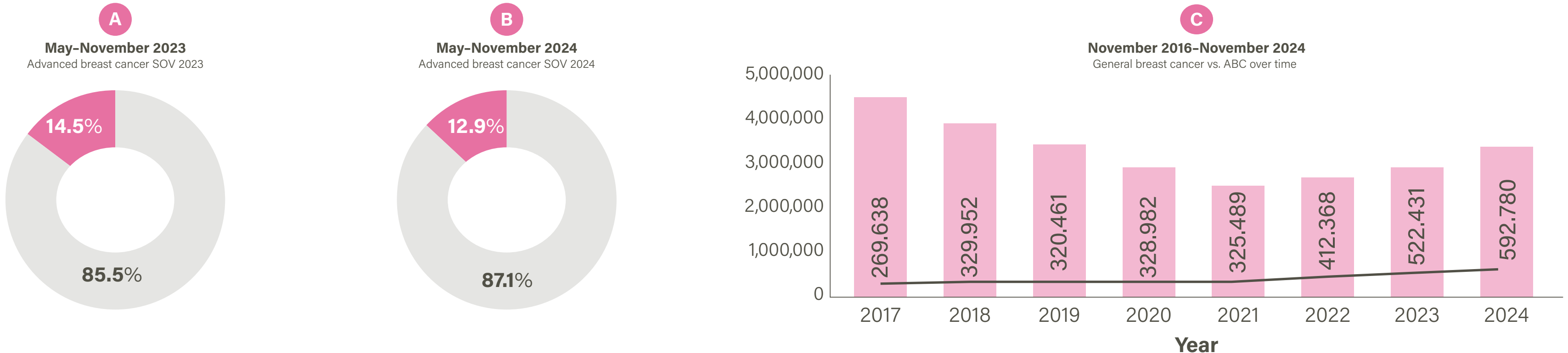
Encouragingly, overall mentions of ABC have grown steadily over time, from approximately 270,000 mentions per year in 2016 to around 600,000 in 2024 (**Figure 45**). However, despite this increase in volume, the share of voice (SOV; the proportion of ABC mentions relative to overall breast cancer) for ABC has declined since 2023. Between May and November 2023, ABC accounted for 15% of total SOV, dropping slightly to 13% between the same period in 2024 (**Figure 46A-B**). These findings highlight the ongoing need for dedicated, year-round ABC awareness efforts that ensure the disease is not overshadowed by broader breast cancer narratives, particularly during high-visibility periods such as Breast Cancer Awareness Month.

Figure 45: Mentions of ABC within the general breast cancer conversation between 01/05/2024–13/11/2024



Based on findings from the ABC Global Alliance social listening analysis conducted in 2024.

Figure 46: Share of voice analysis



Based on findings from the ABC Global Alliance social listening analysis conducted in 2024.
The proportion of ABC mentions relative to overall breast cancer conversations between A) 1/5/2023–1/11/2023, B) 1/5/2024–1/11/2024 and C) 1/11/2016–1/11/2024.

Many people with ABC still face stigma and isolation, fueled by public misconceptions about the disease

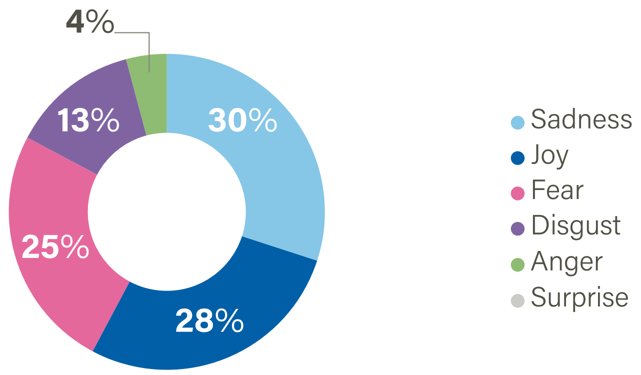
Despite increased recognition of the isolating and stigmatizing nature of ABC through awareness campaigns, understanding of the social and emotional challenges faced by people with ABC has remained limited over the past decade.[190] Findings from the ABC Global Alliance 2024 patient survey (n=1,254) reinforce this: nearly half of people with ABC (47%) reported feeling that others do not understand their situation, while a similar proportion (46%) said they feel different from those around them.

These results are consistent with other studies highlighting widespread misconceptions about ABC. A European survey conducted across France, Germany, Italy, Spain, and the United Kingdom (UK), revealed significant gaps in public understanding, including the belief that age does not affect ABC risk.[466] European social listening analyses have also shown that people with ABC often feel invisible to those around them.[457] This is a particular issue for men with ABC, for whom the perception of breast cancer as a "women's disease" can lead to stigma, potentially contributing to delays in diagnosis and treatment.[464] In the Asia-Pacific region, a 2023 social listening analysis found that gender bias in breast cancer was the second most discussed topic, representing 34% of posts analyzed.[464]

The ABC Global Alliance's 2024 social listening analysis indicates a potential shift in the online narrative around ABC. Mentions of terms such as 'isolated' and 'stigma' declined from 2023 to 2024, while use of words like 'alone' and 'pointless' increased. This may indicate a change in how the ABC experience is being discussed, but also demonstrates that stigma and loneliness remain pressing issues.

To further explore the link between online sentiment and stigma and isolation, the ABC Global Alliance analysis examined the range of emotions expressed by people with ABC online. Sadness (30%) and fear (25%) emerged as the most common negative emotions, while expressions of joy (28%)–often linked to survivor stories and treatment progress–were also observed. Anger (4%) appeared less frequently, typically in response to concerns about survival rate and gaps in awareness (**Figure 47**). It is important to note that while social listening offers valuable insights, it reflects only the experiences and emotions that people with ABC choose to share publicly online, and may not fully reflect the reality of living with the disease.

Figure 47: Emotions expressed in social media discussions by people with ABC between 2016–2024

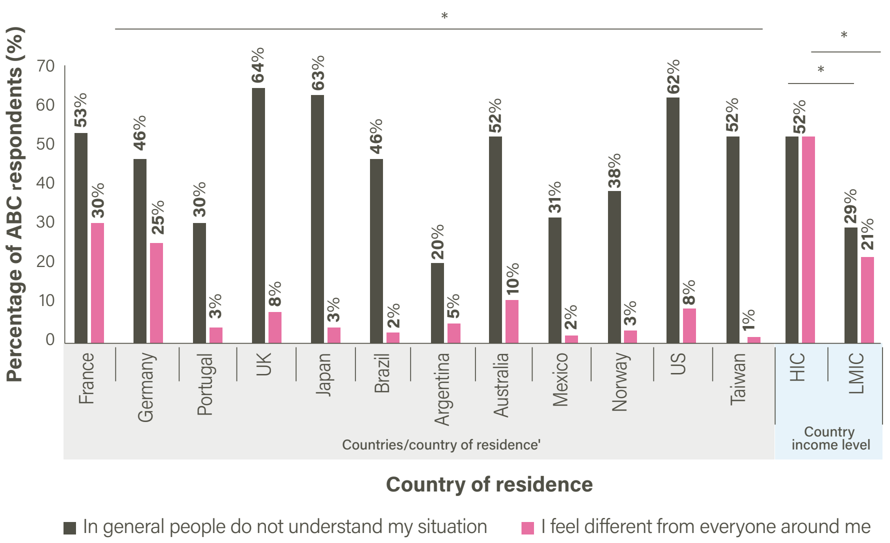


Data collected from the ABC Global Alliance social listening analysis conducted in 2024 for the period 2016–2024.

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

The ABC Global Alliance 2024 patient survey revealed notable geographical variation in stigma and isolation among people with ABC. Respondents from France and Germany reported significantly higher rates of 'feeling different' (30% and 25%, respectively), compared with countries such as Taiwan (1%) and Brazil (2%). Feelings of isolation were most frequently reported in the UK (64%) and the United States (US; 62%) (**Figure 48**). When these findings are considered alongside the ABC Global Alliance 2024 public awareness campaign analysis, an important insight emerges: despite the high number of public awareness campaigns in the UK and US, feelings of isolation among people with ABC in these regions remain prevalent. This suggests that while awareness campaigns play an important role in education and advocacy, they alone may be insufficient to address the deeper social and emotional dimensions of isolation, highlighting the need for more comprehensive, multi-faceted approaches.

Figure 48: ABC patient-reported feelings of isolation and difference



Based on responses to the ABC Global Alliance 2024 patient survey (n=1,254). 'Which of the following have you experienced as a result of your advanced breast cancer diagnosis?' [Respondents can select more than one option.]
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; * $p<0.05$.

Income level also appears to influence experiences of stigma and isolation. People with ABC in high-income countries (HICs) were more likely to report feelings of isolation (52%) and feeling different (52%) compared with those in low- and middle-income countries (LMICs) (29% and 21%, respectively; $p<0.05$) (**Figure 48**). These findings highlight persistent geographical and socio-economic disparities in the social experience of ABC (**Box 13**). It is also important to acknowledge that the COVID-19 pandemic occurred during this decade and imposed widespread social restrictions. Although this survey 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. Further research is needed to evaluate the true impact of awareness campaigns on stigma reduction and to develop targeted strategies that address these disparities, ensuring that efforts to improve global patient experiences go beyond visibility and actively foster inclusion, understanding, and social support.

Box 13: Understanding isolation: cultural and contextual perspectives from co-authors

> **"[Women from LMIC countries] have to take care of family. They have to keep on working. They cannot stop and concentrate on themselves… In some places, women don't feel that they have the right to have these [isolating and stigmatizing] feelings"**
> *Patient Advocate, Kuwait*

Higher reported isolation among people with ABC in HICs compared with LMICs may reflect greater awareness and openness to express emotional challenges in these countries. In addition, in HICs, individuals may live longer with their illness due to access to treatment but often spend extended periods at home, unable to work, which can heighten feelings of isolation despite prolonged survival. In contrast, individuals in LMICs may prioritize immediate survival needs and caregiving responsibilities, often lacking the time, social permission, or autonomy to acknowledge such feelings. Cultural norms can restrict decision-making power, especially among women, and generic campaign messages that do not connect with lived experience may also contribute to underreporting of emotional challenges in LMICs.

Access to treatment is another critical contextual factor. In many LMICs, financial barriers limit access to life-extending therapies, leading to both financial toxicity and premature death. This not only affects patients and their families directly, but also reinforces the perception that ABC is incurable, fueling stigma and deepening isolation.

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

HCPs play a fundamental role in shaping treatment decisions and overall care for people with ABC. However, evidence suggests that life-prolonging treatments are not always prioritized. The 2019 'I Am Still Here' report found that people with ABC in New Zealand received an average of only one line of treatment, with HCPs often reluctant to explore additional therapeutic options.[126] Findings from the 2024 Lancet Breast Cancer Commission offer a possible explanation, indicating that some oncologists may withhold later lines of therapy due to the perception that patients diagnosed with ABC will die soon, despite the availability of treatments that could extend survival.[149] Discrimination based on prognosis has also been observed in crisis situations. During the COVID-19 pandemic, some ABC patients were deprioritized for ventilator access,[467] potentially due to misconceptions about their life expectancy.

HCP perceptions of ABC prognosis differ across care settings, but there is evidence of a gradual shift towards viewing ABC as a chronic disease (**Box 14**). The ABC Global Alliance 2024 HCP survey (n=461) revealed diverse views: 64% of HCPs 'agree' or 'strongly agree' that ABC is virtually incurable, 28% believe it will become curable within the next decade, and 33% consider it potentially curable. Encouragingly, 59% of HCPs agreed that ABC could become more of a chronic disease in the next decade, reflecting an evolving mindset towards long-term disease management (**Figure 49**). However, notable differences were seen between HCP types. While 36% of physicians agreed that ABC is potentially curable, only 21% of nurses shared this view. These findings suggest that although curability remains debated, there is a progressive shift in perception–one that could influence treatment strategies, patient communication, and long-term care planning.

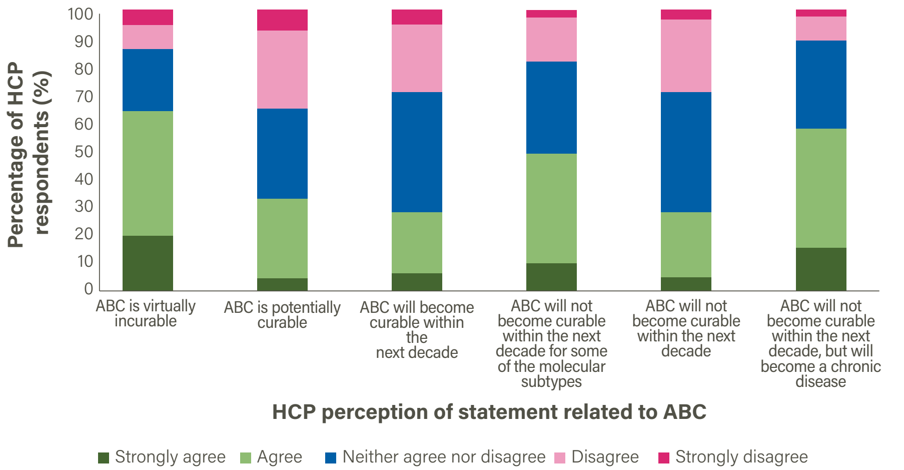
Box 14: Evolving Views on ABC Prognosis

> **"The shift is there. There are some of us who are starting to look with some optimism to the future, saying that maybe some of the [ABC] subtypes can one day be a more chronic disease..."**
> *HCP, Tanzania*

Among specialists who treat ABC regularly, there is growing optimism that the disease could become manageable as a chronic condition or even potentially curable in the future. However, this optimism is mostly limited to experts, while general oncologists and providers such as general practitioners (GPs) often hold more traditional, pessimistic views.

In lower-resource regions, progress is slower due limited access to diagnostics and targeted therapies, though many clinicians are adopting personalized approaches to improve quality of life and extend survival. This evolving mindset appears to vary by region, with early signs of change in parts of Africa, while short-term, guideline-focused decision-making is still prevalent in the Middle East.[468-469] As professional attitudes evolve, there is potential to reshape public perceptions of ABC, but reducing stigma and fostering hope will require coordinated clinical, advocacy, and societal effort.

Figure 49: HCP-reported perceptions of different statements related to ABC

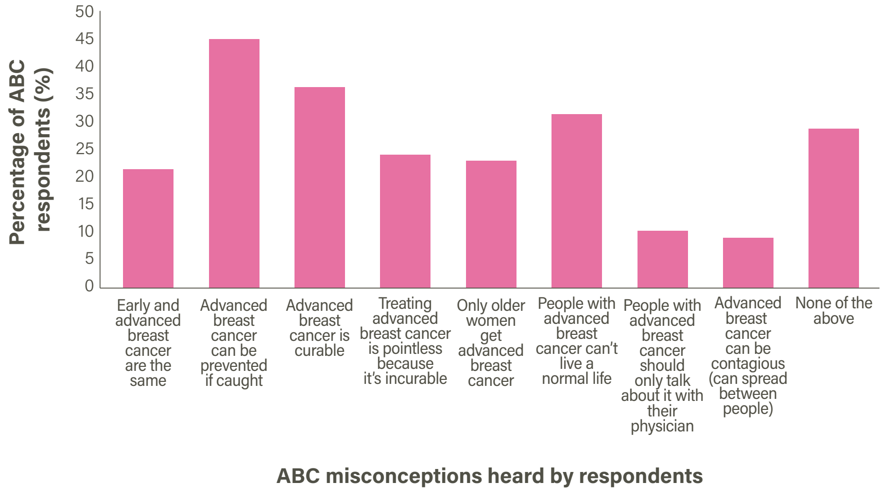


Based on responses to the ABC Global Alliance 2024 HCP survey (n=461). 'How strongly do you agree with the following statements?'

ABC misconceptions remain common but have declined since 2015

The 2005–2015 Global Decade Report found that a substantial proportion of the public believed that early detection and/or treatment of ABC could prevent disease progression (47%–80%), or that it was curable (48%–76%), indicating a widespread lack of understanding about ABC prognosis.[3] Findings from the ABC Global Alliance 2024 patient survey suggest a notable decline in these misconceptions. Only 45% of respondents reported having heard that ABC could be prevented through early detection, and 37% that the disease is curable (**Figure 50**). Although these figures are not directly comparable with earlier data, they indicate that while misconceptions about ABC persist, understanding may be improving. Other common misconceptions heard by people living with ABC include the belief that people with ABC cannot live a normal life (31%), that treating ABC is pointless because it is incurable (24%), and that only older women can develop ABC (23%).

Figure 50: Misconceptions about ABC heard by people with the disease



Based on responses to the ABC Global Alliance 2024 patient survey (n=1,254). 'There are many misconceptions about advanced breast cancer. The following statements are NOT true. Have you heard any of the following statements about advanced breast cancer?' [Respondents can select more than one option.]

Misconceptions also vary geographically. The belief that all subtypes of ABC can be prevented if caught early was most frequently heard by patients from Taiwan (65%) and the UK (57%), while respondents from Taiwan (48%) and Brazil (49%) were most likely to have heard that ABC is curable. In some regions, limited public discussion about cancer fuels misinformation and isolation. For example, in many Asian communities, breast cancer remains a taboo subject, contributing to persistent misconceptions and deepening feelings of isolation and depression among those affected.[464] These cultural barriers, combined with general public misunderstandings, perpetuate knowledge gaps around ABC.

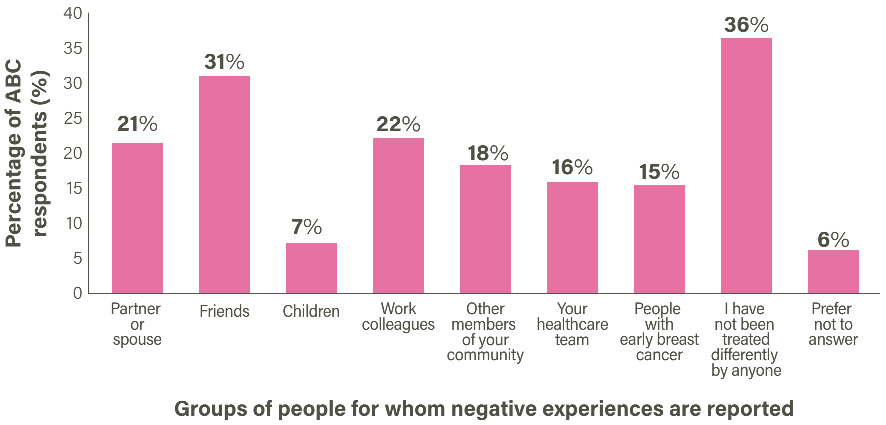
Addressing these misconceptions requires targeted public education. A 2024 European survey revealed strong public interest in learning more about breast cancer, with 88% of respondents expressing a desire for information–particularly on new treatments, life expectancy, and quality of life.[466] Together with the ABC Global Alliance survey findings, this suggests significant potential to improve ABC understanding over the coming decade, and subsequently reduce stigma and isolation.

Despite some improvement, people with ABC continue to experience negative social and workplace interactions

While literature has long documented the social and workplace stigma experienced by people with ABC,[457] the ABC Global Alliance 2024 patient survey suggests that this is not universal. In fact, the most common response to questions about post-ABC diagnosis experiences was "I have not been treated differently by anyone". When negative experiences were reported, they were most often linked to friends (31%), followed by work colleagues (22%) and partners or spouses (21%) (**Figure 51**). Sub-group analysis revealed notable geographic variation: over half (52%) of UK respondents reported negative experiences with friends, compared with only 11% in Portugal. In the workplace, 38% of respondents in Japan reported negative experiences with colleagues, versus just 9% in Mexico.

Beyond interpersonal and workplace dynamics, broader perceptions within the breast cancer community also influence how people with ABC experience stigma. The 2005–2015 Global Decade Report highlighted that people with ABC often felt invisible within the healthcare community, largely due to perceived survival differences between early-stage and advanced disease. This sense of exclusion may persist: in the ABC Global Alliance 2024 patient survey, 15% of respondents reported negative interactions with people who have early-stage breast cancer (**Figure 51**). Alarmingly, 16% of respondents identified their healthcare team as a source of negative interactions (**Figure 51**), a particularly concerning finding given the critical role of HCPs in shaping patient experiences. Anticipation of such interactions can contribute to stigma-related behaviors; for example, one study found that some breast cancer patients concealed their diagnosis from non-oncology HCPs due to fear of stigma.[470] Anticipated stigma can also delay patients from seeking support and treatment, negatively impacting outcomes.[471] Educating HCPs about ABC has the potential to reduce stigma and improve patient experiences. In fact, evidence shows that regular educational interventions can lessen perceptions of stigma and improve early detection and treatment outcomes.[472] Together, these data indicate that both workplace and social environments continue to contribute to negative experiences for people with ABC, highlighting key areas for targeted awareness and education efforts.

Figure 51: Patient-reported negative experiences with different people following an ABC diagnosis



Data collected from the ABC Global Alliance 2024 patient survey (n=1,254). 'Have you had any negative experiences with any of the following people following your advanced breast cancer diagnosis?' [Respondents can select more than one option.]

These interactions often reflect deeper systemic inequities rooted in healthcare structures, policy decisions, and societal norms (**Box 15**). Such dynamics disproportionately affect people with ABC who face intersecting barriers related to race, gender, class, or geography, emphasizing the need for equity-focused stigma reduction strategies.

Box 15: Structural discrimination and the amplification of stigma in ABC

Stigma and isolation among people living with ABC are shaped not only by interpersonal dynamics but also by broader systems of racial, ethnic, and socioeconomic discrimination that operate across healthcare, policy, and society. Globally, minoritized racial and ethnic groups face disproportionate barriers to early detection, diagnosis, and high-quality treatment. For example, in the US, Black women are significantly more likely to receive late-stage breast cancer diagnoses and experience treatment delays compared to non-Black patients.[473] Similarly, individuals living in historically redlined neighborhoods (areas subject to discrimination based on racial segregation) are more likely to develop aggressive subtypes of breast cancer, such as hormone receptor–negative disease.[474]

Discriminatory practices are often reinforced in healthcare settings through unconscious bias, stereotyping, and unequal access to services. In Canada and Latin America, Indigenous women report frequent experiences of disrespectful or dismissive treatment from healthcare workers, leading to distrust and reduced engagement with health services.[475-477]

These findings emphasize that experiences of stigma are not isolated but are shaped by structural forces that intersect across race, gender, class, and geography. Addressing stigma in ABC requires more than awareness; it demands targeted, anti-discriminatory policies and institutional accountability embedded at every level of ABC care delivery.

CONCLUSION AND FUTURE DIRECTIONS

Over the past decade, progress has been made in raising public awareness and understanding of ABC. However, stigma and isolation remain persistent, significant challenges for people living with the disease. Misconceptions, though reduced compared to the previous decade, are still commonly reported by patients and remain prevalent among HCPs. In many regions, stigma is perpetuated by a gaps in education, inadequate public messaging, and limited workplace protections (see Goal 9)–all of which compound the social and emotional burden of ABC.

Looking to the future, the ABC Global Alliance community has reaffirmed their commitment to tackling these challenges in the 2025–2035 period. This goal has been updated with revised wording:

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

To do this, the following key actions need to be prioritized:

- 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

9 **Access** to comprehensive ABC care

Access to comprehensive ABC care

INTRODUCTION

Advanced breast cancer (ABC) requires lifelong care, which is associated with considerable direct and indirect costs that can significantly affect access to comprehensive treatment.[3,478-480] While direct medical costs, such as those associated with pathology and diagnostic testing, inpatient and outpatient care, and various types of cancer treatment, may be covered to varying degrees by national health services or insurance providers, other costs are rarely covered. These include additional medical expenses (e.g., genetic testing, next-generation sequencing (NGS), and other laboratory tests) and non-medical costs (e.g., parking, food and lodging, childcare, and survivorship care).[3,478,481] When coverage falls short, patients and caregivers can bear substantial costs, known as out-of-pocket (OOP) expenses.

Differences in healthcare system policies and reimbursement practices contribute to significant disparities in access to care across populations. Some groups are burdened with high OOP costs for diagnostics and treatment, and for some these services are not accessible at all.[481-482] Access can be further restricted by limited healthcare system infrastructure, personnel, and financial investment. Uneven distribution of services is a particular issue in low- and middle-income countries (LMICs), or for those with lower socioeconomic status, and other underserved populations.[483]

ABC can have a profound impact on patients' ability to work, which may in turn restrict access to insurance coverage, and therefore treatment.[484] The indirect costs of ABC are substantial, with lost productivity from both paid employment and unpaid labor driving significant financial strain for individuals, families, and the wider economy.[363,479,485-486] This burden is particularly pronounced in ABC, where approximately 99% of those affected are women, many of whom carry a disproportionate share of unpaid responsibilities such as caregiving and household management.[487-488]

ABC care extends beyond cancer medicines, requiring a multidisciplinary approach (see Goal 4) and treatment decisions that respect patient preferences (Goal 5) while balancing treatment efficacy, life extension (Goal 1), and quality of life (QoL; Goal 3). While comprehensive care includes support services such as financial assistance (Goal 7), this chapter focuses specifically on access to diagnostics, biomarker testing, optimal anti-cancer treatment, and supportive and palliative care medication. It is based on a targeted literature review focused on economic burden (see **Appendix X** for methodology), assessment of key studies from experts across the ABC community, and global patient and healthcare professional (HCP) surveys conducted by the ABC Global Alliance in 2024.

STATUS IN 2005-2015

The 2005–2015 Global Decade Report described the significant economic burden of ABC treatment and care on healthcare systems, patients, caregivers, communities, and society.[3] At the time, data demonstrating the specific costs of ABC were lacking, particularly for LMICs. Most available data either addressed breast cancer as a whole or focused on high-income countries (HICs).[3] OOP payment was required for a wide range of ABC services, including medical expenses–such as pathology testing, scans, therapies, and surgery–and non-medical costs related to travel, complementary therapy, and practical support.[3] Consequently, access to these services was restricted to those who could afford to pay.[4] The economic impact of ABC extended beyond healthcare costs, with productivity losses significantly impacting both society and patients.[3] Financial hardship and toxicity were widely reported, and one European study found that 1 in 10 women experienced a 50% reduction in household earnings following an ABC diagnosis.[489]

The 2015–2025 ABC Global Charter outlined the need for people with ABC to have access to treatment regardless of their ability to pay as one of its ten 'Actions For Change'.[4]

A DECADE IN REVIEW (2015-2025)

The total cost of ABC continues to climb, impacting access to care

The total direct costs for cancer care are comparable to other high prevalence chronic diseases, such as diabetes, dementia, and coronary heart disease–placing significant strain on healthcare systems worldwide.[490-492] While breast cancer ranks third by cancer type in terms of global economic impact, ABC imposes a greater societal cost than early-stage breast cancer. This is largely due to the need for continuous treatment and end-of-life (EoL) care, and substantial productivity losses.[486,493-495] Notably, these costs are increasing year-on-year, with direct costs rising more rapidly than indirect costs. One study projects a 70% increase in total ABC costs in the United States (US), from $63.4 billion in 2015 to an estimated $107.8 billion by 2025 (**Figure 52**).[479] Improved survival rates and growing ABC incidence are in part driving this increase, emphasizing the urgent need for investment in early detection strategies to reduce the recurrence of ABC from early breast cancer.[479,485,495-496]

Figure 52: Projected US costs for ABC over time

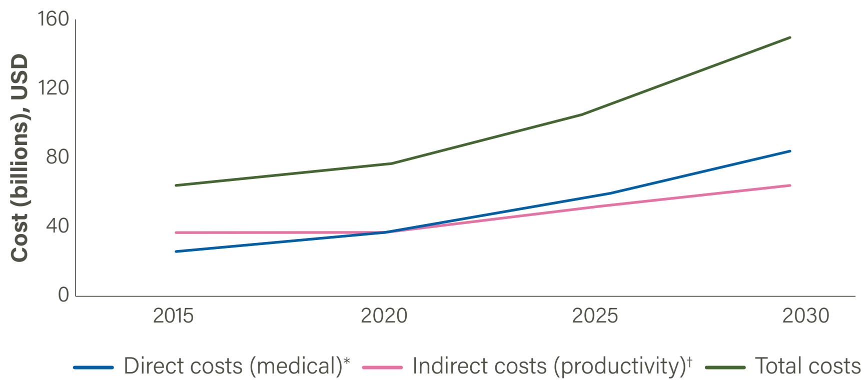


Figure adapted from Gogate et al., 2021479

* Medical costs were calculated from the 2003–2014 North Carolina cancer registry data linked with administrative claims from public and private payers (in USD = United States dollars), and included inpatient, outpatient, physician visits, and prescriptions.

† Productivity costs represented the value of lost work days from analysis of the National Health Interview Survey and lost productive years due to premature mortality.

Cancer therapies are a major driver of rising direct costs in oncology, with spending on treatments increasing at a rate far outpacing cancer incidence, and exceeding expenditure in many other disease areas.[497-498] Over the past decade, ABC drug costs have risen sharply in line with the introduction of new therapies.[496] In HICs, the combination of high drug prices and a rapidly expanding treatment landscape is driving decision-makers to place greater weight on budget impact when evaluating coverage for cancer treatment.[498] However, drug costs are only part of the equation, with human resources also representing a significant share of healthcare expenditure.[499-501]

Active treatment costs for ABC vary by subtype, largely influenced by the standard of care. HER2-positive ABC is associated with higher costs, reflecting the use of more expensive targeted treatments across multiple lines of therapy.[494,496,502] Historically, treatment costs for triple-negative breast cancer and hormone receptor-positive (HR-positive) ABC have been lower; however, the recent introduction of innovative, higher-value targeted therapies for these subtypes is beginning to close this cost gap.[494,496,502] At the same time, market dynamics, such as loss of exclusivity for established drugs and increased competition from new entrants, are helping to reduce treatment costs.[503-504]

Active treatment represents only part of the direct cost burden of ABC.[502] A significant share of these costs are concentrated in the final year of life, largely driven by hospital admissions, inpatient symptom management and, in many cases, overly aggressive EoL care, despite recommendations against such practices.[493,502,505-507] Evidence suggests that home-based or community care, along with early referral to palliative care services, can help to reduce these often avoidable costs, highlighting the need for more effective palliative and EoL care management (discussed in Goal 7).[508-510]

While our understanding of the economic burden of ABC has improved this decade, substantial data gaps persist. Reported costs vary widely between regions, and are likely underestimated due to persistent challenges in accurately capturing recurrence and staging data (discussed in Goal 2).[511-512] Indirect ABC costs, in particular, represent a major data gap, and current estimates often overlook the profound economic impact of ABC on unpaid work.[479,486] For example, a 2024 United Kingdom (UK) study estimated that lost productivity from unpaid work accounts for almost one-third of the total indirect societal costs of breast cancer.[485] The rapidly changing ABC treatment landscape adds further complexity, as much of the available data does not yet reflect the cost implications of the latest therapeutic innovations.[479,494,496,502] Furthermore, inconsistent methodologies for measuring and categorizing direct costs make it challenging to compare trends and develop a comprehensive understanding of the evolving economic landscape.

Diagnostic barriers delay access to timely and optimal treatment

Access to optimal ABC treatment relies on timely diagnosis and testing to identify the subtype and key biomarkers.[19] However, in LMICs, diagnostic imaging and pathology services are often restricted by a lack of high-quality facilities and trained pathologists and radiologists.[22,513-516] Where such facilities exist, they often require OOP payment, limiting access for many patients.[517] As a result, delayed ABC diagnoses are common in LMICs, and it is not uncommon for patients to begin treatment without knowledge of their specific subtype.[518]

Access to newer or more complex testing techniques, used to identify actionable mutations–such as the breast cancer susceptibility genes *BRCA1* and *BRCA2*, the phosphatidylinositol-4,5-bisphosphate 3-kinase catalytic subunit alpha (*PIK3CA*), the estrogen receptor 1 (*ESR1*), and the *AKT* serine/threonine kinase 1 (*AKT1*) genes) or other biomarkers like programmed death-ligand 1 (PD-L1)–remains limited across geographies.[22,513] Public funding constraints, reimbursement challenges, and limited investment in infrastructure further restrict access. In many cases, reimbursement of biomarker testing is uncoupled from its associated therapy, resulting in situations where a treatment is reimbursed but the corresponding test is not.[22,498] One example of this is in France, where ABC therapies are fully reimbursed by national health insurance, but associated tests receive only partial reimbursement.[519] In some regions, such as Southern and Eastern Europe, pharmaceutical company donation programs help to bridge the gap in public reimbursement for testing.[520] Even when genetic testing is reimbursed, it is often restricted to certain populations, although this is gradually changing as evidence demonstrates benefit in broader populations, and guidelines evolve.[521-522]

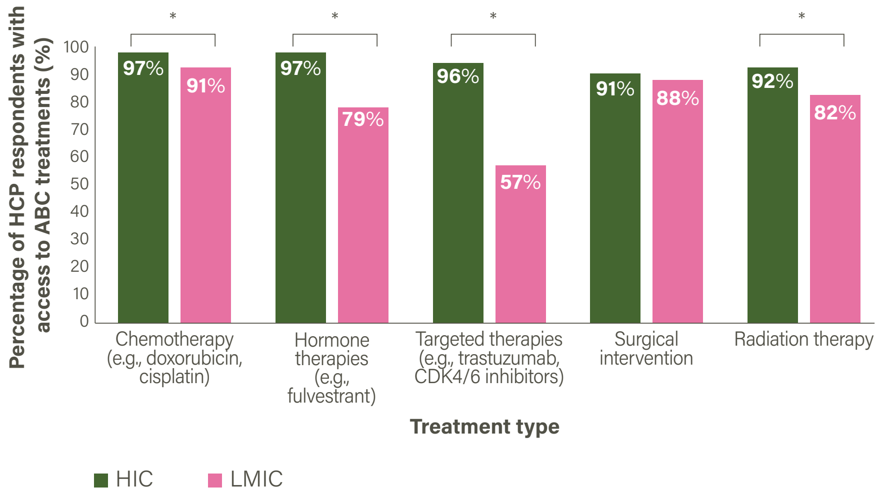
Despite the growing emphasis on precision medicine and targeted therapies in ABC, the limited availability and affordability of appropriate diagnostics remain a critical barrier to optimal treatment. This is particularly acute in LMICs, where access to even basic techniques remains limited.

Access to ABC treatment remains unequal between and within countries

Globally, disparities in access to ABC treatment are widening between LMICs and HICs, prompting global calls to prioritize equitable access to existing cancer therapies alongside continued innovation.[481,523] Findings from the ABC Global Alliance 2024 HCP survey (n=461) highlight these disparities, with HCPs in HICs significantly more likely to report easy access to chemotherapy, hormonal therapy, targeted therapy, and radiation therapy compared to those in LMICs ($p<0.05$) (**Figure 53**).

The reported gap was most pronounced for targeted therapies (39% difference between HICs and LMICs), compared with other therapy types (3–18%). This is likely influenced by their high cost and the associated requirement for biomarker testing. Regional divides within Europe further highlight inequities: while almost all (98%; n=116/119) of HCPs in Western Europe reported easy access to targeted ABC treatments, this was the case for only 81% (n=25/31) of Eastern European HCPs. These findings align with published literature and may also reflect the high proportion of survey responses from lower income countries outside of the European Union (EU) **(1)**.[481,498,524]

Figure 53: HCP-reported access to ABC treatment by country income status

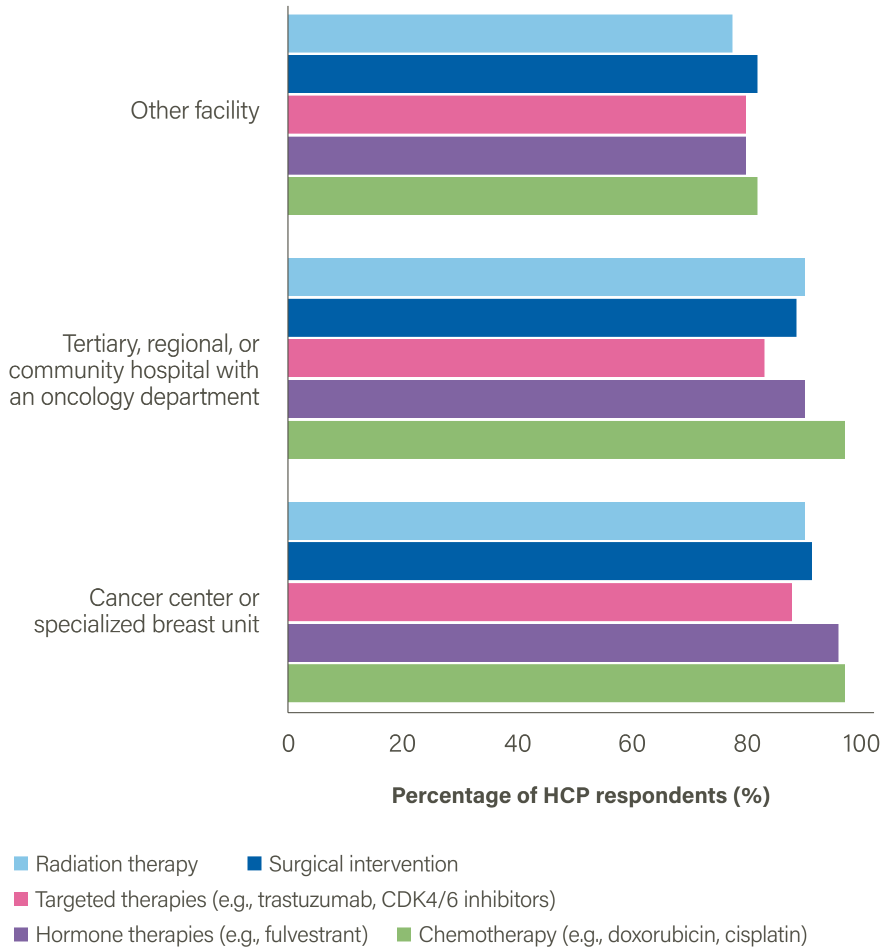


Based on findings from the ABC Global Alliance 2024 HCP survey (n=461). 'How accessible are the following treatments or interventions for patients with advanced breast cancer at your center?' [Respondents that selected sometimes accessible or easily accessible]
CDK4/6 = cyclin-dependent kinase 4/6.

Countries classed by income group according to Word Bank classifications; * $p<0.05$.

Timely access to ABC treatment may also vary within countries, influenced by patient demographics or treatment settings.[525] Findings from the ABC Global Alliance 2024 HCP survey revealed significantly better access to nearly all types of ABC treatment (with the exception of surgical intervention) in more specialized hospitals or clinics ($p<0.05$), most notably for hormonal and targeted therapies (**Figure 54**). Geographical barriers to treatment may be compounded for people from lower socioeconomic backgrounds or ethnic minority groups, as specialized cancer facilities are typically concentrated in more affluent and urban locations.[525-526] In countries without universal health coverage, affordability and insurance status further compound these disparities. This is well reported in the US, where Medicaid expansion has been directly associated with timely treatment initiation, improved survival rates, and reduced racial disparities in ABC outcomes.[527-528]

Figure 54: HCP-reported access to ABC treatment by facility type



Based on findings from the ABC Global Alliance 2024 HCP survey (n=461). 'How accessible are the following treatments or interventions for patients with advanced breast cancer at your center?' [Respondents that selected sometimes accessible or easily accessible]

'Other facility' refers to those selecting 'general hospital without an oncology department' or 'other' to the question: 'What type of treatment facility do you work in mostly?'

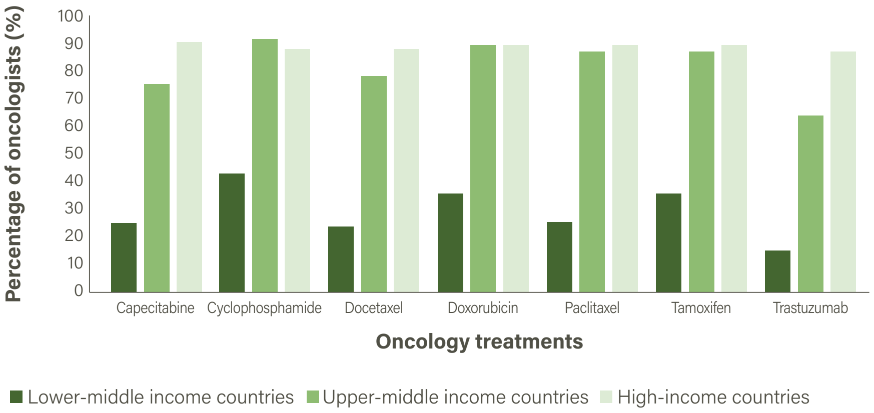
Comprehensive healthcare coverage varies, even for essential treatments, and remains limited in LMICs

OOP healthcare expenses have remained consistently high worldwide over the past decade, acting as a key barrier to ABC treatment access. In Europe, 15% of healthcare spending in 2020 came directly from patients,[529] and a 2019 US study found OOP costs for breast cancer to be higher than any other form of cancer.[478] For ABC specifically, a recent global survey conducted by Young Survival Coalition's (YSC) Project 528 revealed that over a third (40%) of patients reported their care was at least partially funded by themselves or their family.[20]

The World Health Organization (WHO) Essential Medicines List (EML) is intended to ensure affordable access to high priority medicines across the globe. In 2015, vinorelbine, capecitabine, gemcitabine, trastuzumab, and anastrozole, were added to existing WHO EML treatments for ABC.[530] However, universal access to these medicines remains limited in LMICs, where many are still only available at substantial cost to patients (**Figure 55**).[481-482] Multiple studies demonstrate that access to trastuzumab–a high-cost targeted ABC therapy–and its biosimilars remains low in LMICs, and is only available at risk of catastrophic cost to most patients.[481-482,524,531]

A series of surveys conducted by the European Society for Medical Oncology (ESMO) International Consortium between 2016 and 2023 explored global access to key oncology medicines deemed high-value to patients.[481,524,531] While these surveys provide a snapshot of an ever-evolving landscape and do not account for the complexities of individual healthcare systems, they reveal significant disparities in ABC treatment coverage based on country income status. Findings from these surveys suggest that even for essential medicines, access to early breast cancer treatment continues to be prioritized over ABC in LMICs. For example, despite being on the WHO EML for both indications, only 51% of LMICs report free access to trastuzumab and its biosimilars for ABC, compared with 59% for early breast cancer.[481] In contrast, HICs report more equitable access, with 93% providing trastuzumab at no cost for ABC, and 95% for early breast cancer.

Figure 55: Oncologist-reported universal* availability of WHO EML medicines for ABC



Source data adapted from Fundytus et al. 2021.[482]

* Universally covered at no cost to patients. While data shows therapies relevant, but not specific, to ABC, availability generally correlates between indications.[524]

Even in HICs, affordable access to ABC treatment remains inconsistent. According to the ESMO studies, only 59% of surveyed HICs reported that all queried ABC therapies were available at little or no cost to patients in 2023 **(1)**.[481] In some cases, patients have resorted to inefficient and prohibitive processes to secure treatment access, such as in Romania where patients have reported litigation against the government.[532-533] Meanwhile, New Zealand lags behind other HICs in offering affordable ABC treatments, largely due to persistent budget constraints.[534] Within countries, regional budget allocations further exacerbate disparities, as seen in the UK, Switzerland, and Spain, where access to care varies by region.[535-537] These variations highlight the fragmented and inconsistent nature of healthcare decision-making processes across HICs (**Box 16**).

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(1) Countries reporting to offer all treatments from Cherny et al., 2025 at no cost or <25% cost to patients.

Box 16: Trastuzumab deruxtecan for HER2-low ABC in the UK

While trastuzumab deruxtecan is available for people with HER2-low ABC in Scotland, coverage was rejected by the National Institute for Health and Care Excellence (NICE) in England and Wales. The use of the severity modifier was widely cited as the reason for the treatment not meeting the cost effectiveness threshold.[538] This example illustrates the differences in processes employed by independent bodies despite availability of well-regarded value frameworks.[539-540]

"This means that thousands of mums, daughters, sisters, wives, colleagues, and friends who want to be there and create special memories, now face the unbearable reality of knowing a treatment that could have been a lifeline for them exists, but remains out of reach, while women in Scotland have been granted access."[541]

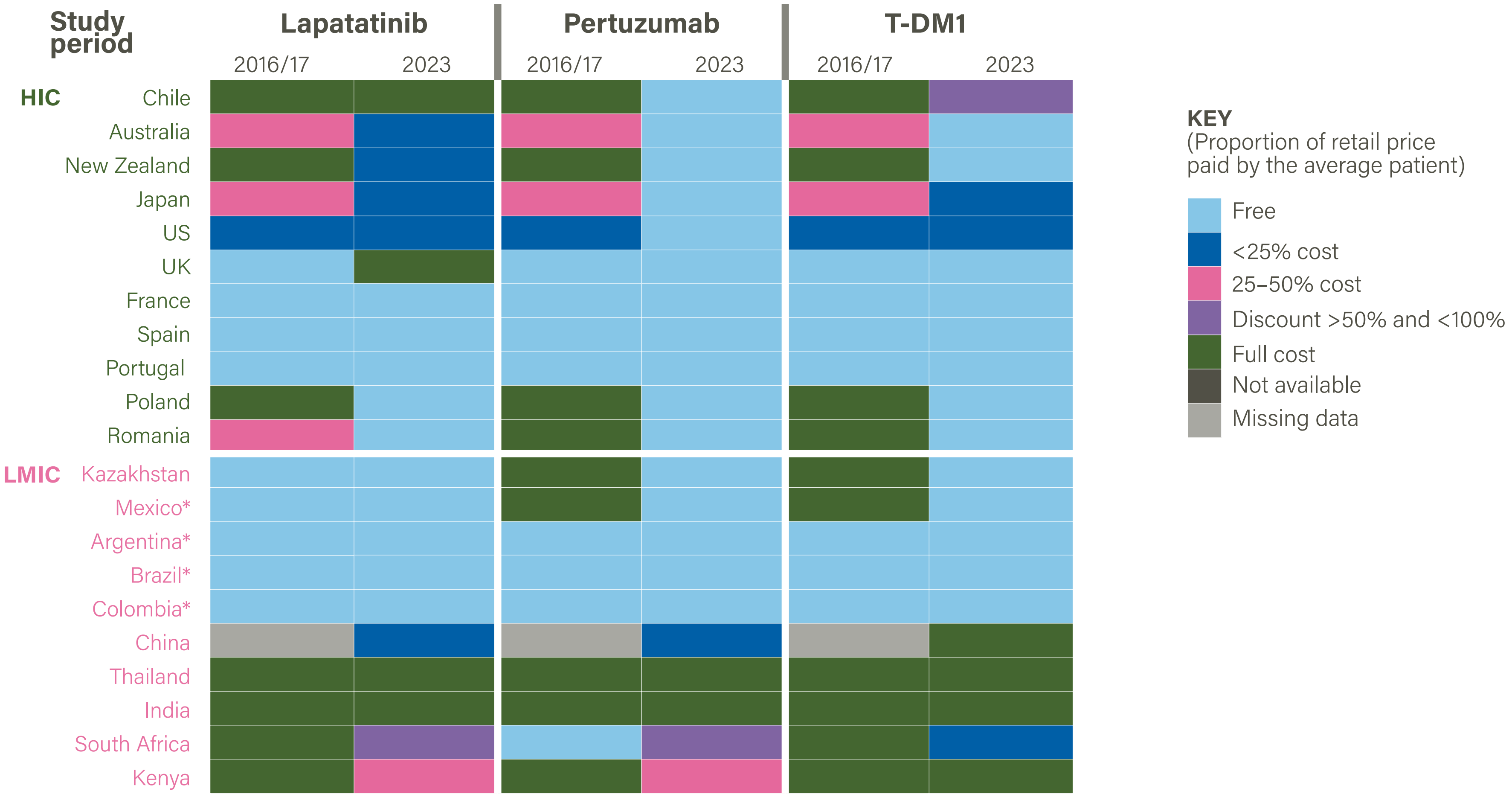
Baroness Delyth Morgan, Former Executive Officer, Breast Cancer Now

The 2023 ESMO survey suggests that cyclin-dependent kinase 4/6 (CDK4/6) inhibitors are available at a low percentage cost to patients across most HICs; however, access varies significantly based on insurance coverage.[542] Without mechanisms to cap OOP expenses, even partial coverage can leave more expensive targeted treatments financially inaccessible. This creates notable disparities, particularly in the US, where those from lower socioeconomic backgrounds often face high-deductible plans or lack insurance entirely.[228] For these patients, treatment affordability frequently hinges on navigating complex financial assistance programs.[542]

Despite these persistent challenges, some progress has been made. In 2015, Australia added trastuzumab–previously listed only for early breast cancer–to the Pharmaceutical Benefits Scheme for ABC.[543] Meanwhile, Poland, Romania, Australia, and New Zealand all incorporated pertuzumab and ado-trastuzumab emtansine (T-DM1) into their formularies for ABC at no cost to patients between the 2016/2017 and 2023 ESMO survey study periods (**Figure 56**). These therapies–considered newer, expensive medications in the initial study period–illustrate the typical delay in reimbursement for innovative treatments in many HICs.[498] Among upper-middle-income countries, progress in Kazakhstan stands out, demonstrating how expert-guided, evidence-based approaches to formulary development, grounded in value frameworks, can substantially improve access to valuable cancer treatments despite budget constraints.[481,524,544]

Established tools, like the American Society of Clinical Oncology (ASCO) Value Framework and the ESMO Magnitude of Clinical Benefit Scale, aim to standardize prioritization of cancer treatments.[539-540] However, use of these tools, and reimbursement of ABC treatments, continues to vary significantly across countries with similar income levels and healthcare expenditures.[481,545] In LMICs, resource-stratified guidelines developed by organizations like the Breast Health Global Initiative, ASCO, and National Comprehensive Cancer Network (NCCN), play a critical role in optimizing care within constrained resources.[281-282,546] In Europe, newer legislation offers hope for more equitable access to ABC treatment in the future. A centralized and harmonized health technology assessment process is being implemented to streamline decision-making and ensure more timely and consistent access to therapies across the region.[547]

Figure 56: Change in ABC treatment accessibility and cost over time*



Source data from Cherny at al. 2016, Cherny et al. 2017, and Cherny et al. 2025.[481,524,531] Countries classed by income group according to World Bank classifications.

* While this figure uses published data from the ESMO Consortium studies, data from Latin America may not reflect the situation for the average patient.

Access to treatment is further disrupted by supply and procurement challenges, particularly in LMICs

Supply challenges continue to hinder the availability of ABC treatments, particularly for lower-cost generic medicines.[524,548] In Europe, tamoxifen shortages have been attributed to low production and distribution, driven by a lack of financial incentives for manufacturers.[524,549] Similarly, in response to ongoing platinum therapy shortages in the US, ASCO have issued guidelines explicitly stating that use of platinum agents should be limited in the non-curative breast cancer setting during national shortages.[550-551]

In LMICs, unreliable supply of essential medicines is a more widespread and persistent issue.[481,531,552] Although the availability of generic WHO EML drugs in public healthcare systems has improved modestly–from 29–54% in 2009, to 38–68% in 2024[553]–many patients still face significant barriers to accessing necessary treatments. Supply constraints in LMICs are often intensified by preferential treatment distribution to higher-profit markets.[554] In countries such as Nigeria, challenging economic conditions discourage local pharmaceutical manufacturing, increasing reliance on inefficient third-party distributor models and directly impacting treatment availability.[553,555] This trend drives higher prices, strains already limited healthcare budgets, and restricts procurement capacity.[556] Unpredictable supply chains further complicate forecasting and procurement planning, creating inefficiencies that hinder consistent access to essential treatments.[556-557]

Compounding the problem, poor medication quality remains a significant concern in many LMICs, with WHO estimates indicating that at least 1 in 10 medicines are substandard or falsified.[558-559] Factors such as complex, fragmented, supply chains, restricted treatment availability, and less stringent regulatory oversight create opportunities for low-quality therapies to enter the market.[553,558] Beyond the direct health risks, these quality issues increase the economic burden on patients and healthcare systems, and undermine confidence in both providers and manufacturers. This erosion of trust can further limit uptake of legitimate ABC treatments, creating additional barriers to access.[558]

Addressing the multifaceted barriers to ABC treatment availability and affordability in LMICs requires a sustainable, multipronged approach involving collaboration with local stakeholders and policymakers. In these contexts, non-profit organizations play a critical role in bridging gaps and facilitating access to treatment (**Box 17**).

Box 17: Non-profit organization partnerships are improving access to ABC treatments in LMICs

The Access to Oncology Medicines (ATOM) Coalition: Launched in 2022, and led by the Union for International Cancer Control (UICC), this initiative aims to improve access to essential cancer treatments through a multifaceted approach. The ATOM Coalition facilitates donation programs for otherwise unavailable treatments, enables licensing for generics of patented medicines, and provides a digital procurement platform for affordable medicines. Additionally, it supports packaging, branding, drug registration, quality assurance, and distribution solutions to create a more efficient and streamlined supply chain.[553,560]

The Humanitarian Partnership for Access to Cancer Treatment (PACT): In 2023, the Humanitarian PACT was expanded to include ABC through a collaboration between The Max Foundation, ABC Global Alliance, American Society of Clinical Pathology, and pharmaceutical partners.[561] The program aims to provide free treatment to people with HR+/HER2- ABC, while simultaneously strengthening healthcare infrastructure, offering HCP training, and supporting patient services.[562] Initially launched in 5 countries, the initiative plans to reach 28 countries by 2025.[561]

Radiotherapy resources and infrastructure fall short of growing demands

Radiotherapy is a critical and cost-effective component of ABC treatment, particularly for the management of bone and brain metastases, which are common in advanced disease.[19] However, global access to radiotherapy remains limited and is often deprioritized in national cancer control plans.[563-565] Across most regions, there is a shortage of high-quality facilities, up-to-date equipment, and adequately trained personnel to meet rising demand.[564,566-569] Access disparities are stark: HICs average 9.44 machines per million inhabitants, compared with just 0.07 in low-income countries, with the most significant shortfalls in Africa and the Asia-Pacific region.[570]

In LMICs, even where radiotherapy facilities exist, service delivery is frequently undermined by outdated machinery and the emigration of trained personnel to higher-income areas.[565,571] Limited maintenance capacity often results in prolonged out-of-order periods, further complicating treatment delivery.[565] Adoption of hypofractionation schemes–which could reduce treatment duration and increase the number of patients treated in a given time frame–remains rare due to insufficient financial incentives, technical complexity, and the need for specialized training.[565,572] Outdated fee-for-service reimbursement models, which pay per fraction or session rather than for a complete course of treatment, continue to disincentivize patient-centric care, even in some HICs such as France, the UK, and Italy.[573-574] While this challenge has a greater impact on early breast cancer, it also limits access to stereotactic radiotherapy techniques for metastatic disease.[565]

Despite these systemic challenges, targeted investment and coordinated initiatives have delivered some progress over the past decade.[565,569] In Europe, the average number of radiotherapy machines increased from 6.7 to 7.8 per million inhabitants between 2010 and 2020, with Bulgaria improving from 5.9 to 10.0 per million.[575] In Africa, International Atomic Energy Agency (IAEA) partnerships with governments and patient advocates drove a 45% increase in radiotherapy capacity between 2012 and 2020.[569,576] However, these gains remain uneven, with facilities concentrated in a limited number of countries and centers, leaving significant disparities across the region and unmet demand.[565,569,577] While encouraging, these pockets of progress underscore the need for sustained investment to close the global radiotherapy gap and address the growing cancer burden.[565,567]

Clinical trials can offer early access to innovative treatment, but uptake remains low globally

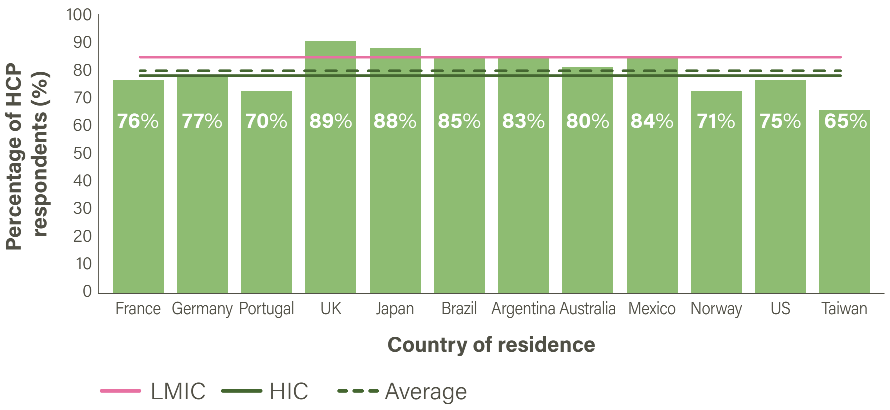
The clinical trial landscape has grown increasingly complex over the past decade, creating global challenges in trial set-up and recruitment across diseases, including ABC.[578] While some countries, such as China and Spain, have seen increased investment and growth in trial sites, many Western countries have experienced a relative decline.[578] Findings from the ABC Global Alliance 2024 patient survey (n=1,254) highlight persistent barriers to ABC trial access, with 79% of respondents reporting no participation in a trial for ABC (**Figure 57**), a figure virtually unchanged from the 78% reported in the original Global Decade Report.[3]

Participation rates were significantly lower in LMICs, where 84% of patients reported no trial involvement compared with 78% in HICs ($p<0.05$). Clinical trial sites remain heavily concentrated in HICs, with financial and logistical challenges limiting their establishment in LMICs.[579] Although some HIC-based investigators have increased investment in LMIC trial sites, attracted by lower operational costs and larger participant pools, concerns persist regarding the applicability of resulting data due to differences in survival outcomes and standards of care.[580] Furthermore, LMIC trials are often not led by local investigators, and their contributions frequently go unrecognized, further discouraging research investment in these regions.[580]

The ABC Global Alliance patient survey also revealed substantial variation in trial participation regardless of country income status. For example, nearly 90% of UK-based respondents reported no trial participation, higher than all other HICs and LMICs analyzed (**Figure 57**). Interestingly, these low patient-reported participation rates contrast with findings from the ABC Global Alliance 2024 HCP survey, in which 51% of HCPs stated that clinical trials were easily accessible. This disconnect suggests that barriers to participation are complex and multifaceted, extending beyond simple trial availability.[581] Notably, 13% of patients reported declining an offer to participate in a clinical trial, further highlighting the complexity of these barriers and the role of patient perception, communication, and trust in trial recruitment.[582]

Key obstacles to participation include inadequate discussions between patients and HCPs, and uneven distribution of trial sites within countries.[583-586] Sites are often located in specialized cancer centers, creating accessibility challenges that mirror broader inequities in specialist care.[585-586] These barriers are compounded for patients from ethnic minority groups or lower socioeconomic backgrounds, who may face financial constraints, increased distance to trial sites, reduced willingness to participate, or even HCP referral bias.[583-584,587] Recent US data suggests some progress, showing no significant difference (after adjusting for other variables) between ethnic groups in the likelihood of HCP–patient trial discussions or acceptance when offered.[588] However, representation of diverse ethnic groups in clinical trials remains inadequate.[589] For instance, Black women accounted for just 1–3% of participants in trials supporting ABC treatment approvals in 2019, reflecting persistent inequities and missed opportunities for inclusive evidence generation.[583]

Figure 57: Patients reporting no participation in ABC clinical trials



Based on findings from the ABC Global Alliance 2024 patient survey (n=1,254). 'Have you used the following services during your care for advanced breast cancer? If so, how useful were they?' [Respondents who selected 'no, I didn't use'] Responses to the option 'clinical trials' are indicated in the figure.

Countries classed by income group according to World Bank classifications.

Figure 58: HCP-reported 'easy access' to ABC palliative and supportive care medication

Based on findings from the ABC Global Alliance 2024 HCP survey (n=461). 'How accessible are the following treatments or interventions for patients with advanced breast cancer at your center?' [Not accessible; Sometimes accessible; Easily accessible.] Responses to the option 'palliative or supportive care medications' are indicated in the figure.

* 'Hospitals with an oncology department' includes cancer centers or specialist breast units, and tertiary, regional, or community hospitals with an oncology department. 'Hospitals without an oncology department' includes general hospitals without an oncology department or other facilities. Countries classed by income group according to World Bank classifications.

Beyond anti-cancer therapies, access to supportive care medication remains highly unequal

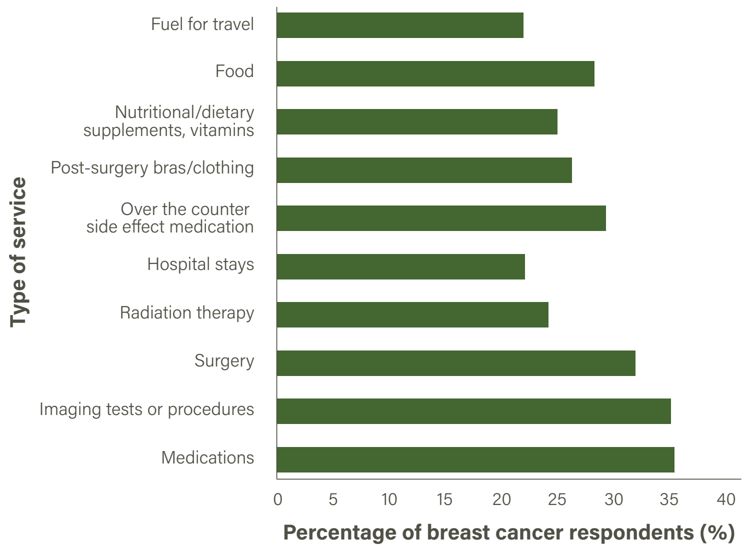
Pain medication is globally recognized as a critical component of comprehensive care for ABC. Yet, despite efforts by organizations such as the WHO, ASCO, ESMO, and the UICC this decade, global access remains highly uneven.[590-593] In 2021, over 80% of reported morphine consumption occurred in HICs, particularly in North America and Europe.[590] Findings from the ABC Global Alliance 2024 HCP survey reflect this imbalance: while three-quarters (76%) of respondents reported easy access to palliative and supportive care medicines in their practice, this varied substantially by country income status (**Figure 58**). Variation was also seen across Europe, consistent with findings from recent literature,[594] and between hospitals with an oncology department and non-specialized facilities. In the latter, administrative hurdles, limited HCP training, and inconsistent supply chains may restrict access.[590,594]

Despite the relatively low cost of pain medication, access barriers remain common in LMICs.[590,595-596] Restrictive legislation, taxation, and inefficient distribution systems frequently inflate prices compared with HICs, while logistical challenges and low consumption further disrupt supply chains.[590,597] Globally, stigma and fear of addiction continue to shape public perception, healthcare practices, and policy, often resulting in overly restrictive regulations and inadequate pain management.[590] These issues are particularly acute outside of Western Europe and North America, where stigma around opioid use significantly limits patient access.[590,597] In the US, concerns over opioid misuse and addiction have led to reduced prescribing, even for patients with terminal cancer pain.[598] For women with ABC, these systemic barriers may be compounded by gender disparities in pain management, with evidence suggesting that female patients often receive less adequate pain relief than their male counterparts.[599] Addressing these inequities requires coordinated strategies that tackle stigma, modernize restrictive policies, and streamline administrative processes–ensuring equitable access to pain management worldwide.

High OOP expenses for ABC are driving growing financial burden

High OOP expenses and reduced ability to work remain major drivers of the financial burden experienced by people with ABC.[478,480] OOP costs extend well beyond treatment-related expenses, to include diagnostics, supportive services, travel, lifestyle adjustments, and even basic living costs–each of which can be substantial (**Figure 59**).[363,478,480] A 2022 US study found that more than 1 in 5 people with breast cancer reported unexpectedly high costs for essentials such as food, fuel for travel, nutritional supplements, and over-the-counter medications.[478] In France, until recently, supportive care costs were only reimbursed during active treatment, leaving many ABC patients to cover these expenses themselves (**Box 18**).[600] These findings highlight the need for comprehensive coverage models that address the full continuum of ABC care, including supportive services.

Figure 59: Patient-reported OOP expenses for breast cancer in the US



Source data from Breastcancer.org, Special Report: The Cost of Breast Cancer Care.[478]

Box 18: Legislation to improve access to breast cancer treatment in France[600]

In February 2025, French legislation expanded national insurance coverage for breast cancer care, significantly reducing OOP expenses for patients. Previously, while active treatments such as chemotherapy, radiotherapy, hormonal therapy, and surgery were fully covered, patients incurred substantial OOP costs for a range of essential services. The updated law now broadens coverage to include:

- Care and devices related to breast removal and reconstruction, such as medical tattooing, implant replacement, or specialist underwear
- Supportive care services, including nutritional and physical support, provided not only post-treatment but now also during active treatment
- Supportive medicines commonly prescribed but previously not fully reimbursed, including gels, creams, and nail varnishes used to manage treatment side effects such as skin dryness or nail loss

This legislative update goes some way towards addressing critical gaps in access to supportive services in France and represents a significant step toward comprehensive breast cancer care.

> **"All of those extra costs–whether for childcare during treatment, the drugs you need to control symptoms, a wig you might need if appearance is important at your job–can add up enough to put people over the edge financially."**
>
> *Medical oncologist, US*[478]

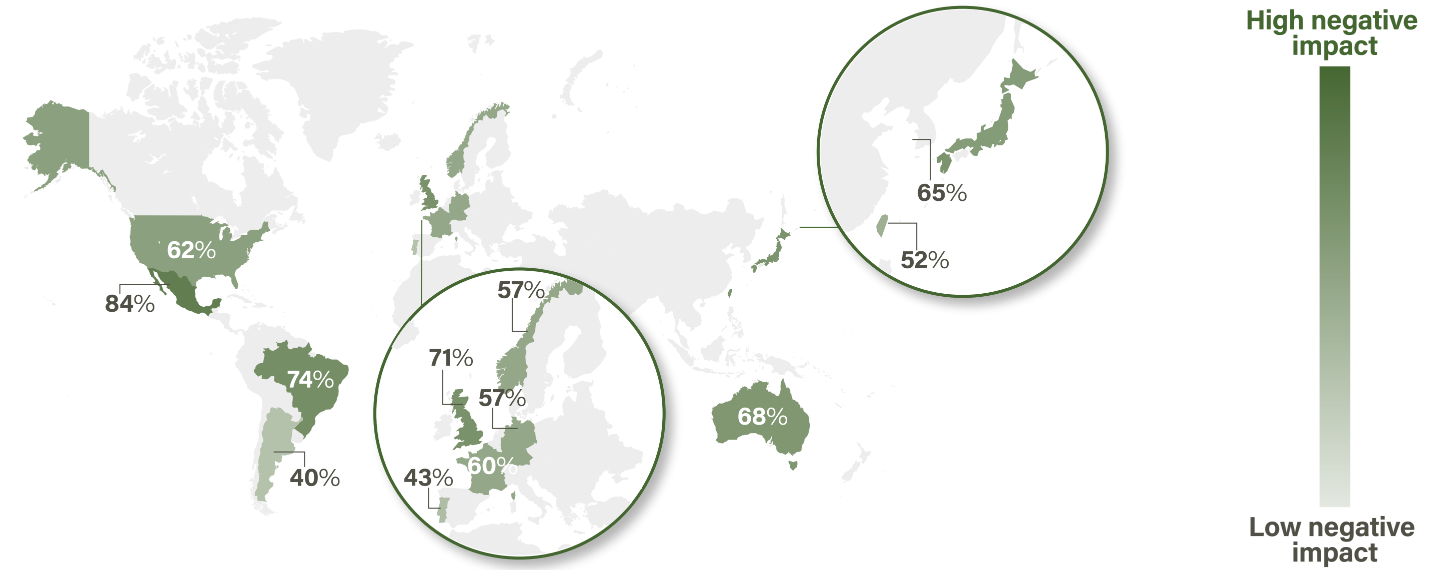
High OOP spending contributes directly to widespread financial toxicity for people with ABC. A recent meta-analysis reported pooled financial toxicity rates of 78.8% for breast cancer patients in LMICs and 35.3% in HICs.[601] While catastrophic spending on cancer medicines is more common in LMICs, one in five households in Europe also report such costs.[482,602] In the US, insured individuals with ABC report being contacted by debt collectors (30%), struggling to meet monthly expenses (30%), or even filing for bankruptcy (41%), with the situation even more severe for those without insurance.[228] Globally, YSC's Project 528 found 40% of young women with ABC incurred medical debt as a result of their diagnosis and treatment.[20]

Even in countries with publicly funded healthcare, such as France, 51% of people with advanced cancer report financial distress.[603] This burden often forces patients to reduce spending on essentials such as food, clothing or leisure activities, or even miss medical care by forgoing prescriptions or appointments.[227,604]

Nearly two-thirds (60%) of respondents to the ABC Global Alliance 2024 patient survey reported a negative impact of ABC on their financial security. This burden was particularly severe for individuals with dependents or lower household incomes, who often resort to coping strategies such as selling assets or discontinuing treatment.[605-606] While no significant differences were found between LMICs and HICs overall, notable variations emerged within healthcare systems (**Figure 60**). For example, some HICs with universal health coverage, such as the UK and Australia, reported higher negative impact on financial security than the US. Across Latin America, disparities were stark: 40% of patients reported negative financial impact in Argentina compared with to 85% in Mexico. These findings highlight the complexity of the financial impact associated with ABC, extending far beyond healthcare expenses, and requiring targeted, system-level interventions to mitigate this burden.

Evidence suggests that this burden may be worsening over time. A European study found that between 2013 and 2019, the proportion of patients reporting behavioral changes such as 'reduced spending' or 'difficulties paying for things' nearly doubled, while the proportion reporting a negative impact of financial burden on wellbeing rose from 39% to 69%.[363] The persistently high financial burden of ABC likely limits access to optimal treatment and care for many patients, not only in LMICs but also in HICs, representing both a critical equity challenge and a barrier to achieving optimal health outcomes.

Figure 60: Patient-reported ABC impact on financial security



Based on findings from the ABC Global Alliance 2024 patient survey (n=1,254). 'What impact has advanced breast cancer had on the following areas of your life (specifically: financial security)?' [Respondents that selected negative impact]

CONCLUSIONS AND FUTURE DIRECTIONS

Despite substantial treatment and care advances for ABC in the past decade, significant disparities in access persist both within and between countries. Policymakers face increasingly complex decisions as they balance constrained healthcare budgets, growing economic burden, and the pressure to fund newer, high-cost treatments. These disparities are widening–while people with ABC in HICs often experience delays in accessing the latest innovations, many in LMICs struggle to access even the most fundamental diagnostics, treatment, and care. Access to clinical trials, which could offer access to innovative treatment options, remains limited for most individuals worldwide.

Healthcare systems in LMICs require substantial investment at every level to improve access to ABC care. However, even in HICs, access is far from universal, with many patients facing high OOP expenses that disproportionately impact underserved populations. These costs extend beyond medical treatment, including essential expenses such as food, travel, and lifestyle adjustments, compounded by lost income and caregiving responsibilities. The resulting financial toxicity places a heavy burden on individuals, families, and society as a whole.

Ensuring timely, affordable, and equitable access to comprehensive ABC care is a global responsibility. Achieving this goal requires international collaboration across the ABC ecosystem to address systemic barriers, implement sustainable solutions, and develop strategies to mitigate the growing financial toxicity associated with the disease.

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 2025–2035 goal will require 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

10 **Legal** and **workplace rights** for people with ABC

Legal and **workplace rights** for people with ABC

INTRODUCTION

One of the many difficult challenges faced by people with advanced breast cancer (ABC) is the ability to continue working. The decision and capacity to remain in or return to employment are often shaped by financial pressures, access to insurance and benefits, the availability of social support, and the psychological need to maintain a sense of normalcy. However, multiple barriers can impede this, including the ongoing medical burden of ABC, delayed or long-term treatment-related adverse events, and the lasting effects of the disease on physical, cognitive, and emotional functioning. As a result, the ability to continue or return to work frequently hinges upon the existence of legal protections and a supportive workplace willing to provide reasonable accommodations.[363,607-608]

A persistent and damaging misconception is that people with incurable diseases, like ABC, have limited value in the workplace. This is often driven by a lack of awareness of the realities faced by those living with advanced cancer, resulting in inadequate systemic support, stigma, and discrimination. These challenges are further compounded for individuals who already face discrimination, including older adults and those from ethnic minority backgrounds.[609]

This chapter explores the current landscape and future opportunities to strengthen the legal rights of people with ABC, as well as the associated impact on informal caregivers. It includes a legal analysis conducted by the McCabe Centre for Law and Cancer (**Appendix XI**) and findings from a global patient survey conducted by the ABC Global Alliance in 2024.

STATUS IN 2005–2015

The 2005–2015 Global Decade Report identified a lack of awareness and education among employers, colleagues, and medical professionals on how to best support people with ABC to remain in or return to work. It also highlighted the limited availability of information for people with ABC about their workplace rights and the support available to them.[3]

At the time, workplace cancer policies were scarce. In a 2006 United Kingdom (UK) survey of 219 member organizations of the Chartered Institute of Personnel and Development (CIPD), nearly three quarters (73%) reported having no formal policy for managing employees with cancer. Similarly, a Canadian study published in 2011 found that one in four employees expressed concern that they would be expected to ‘pick up the slack’ for a colleague returning to work while undergoing cancer treatment.[3] Such attitudes contributed to stigma and discrimination, and likely played a role in the high proportion of people with ABC who returned to work only to leave their employment within a year.[3]

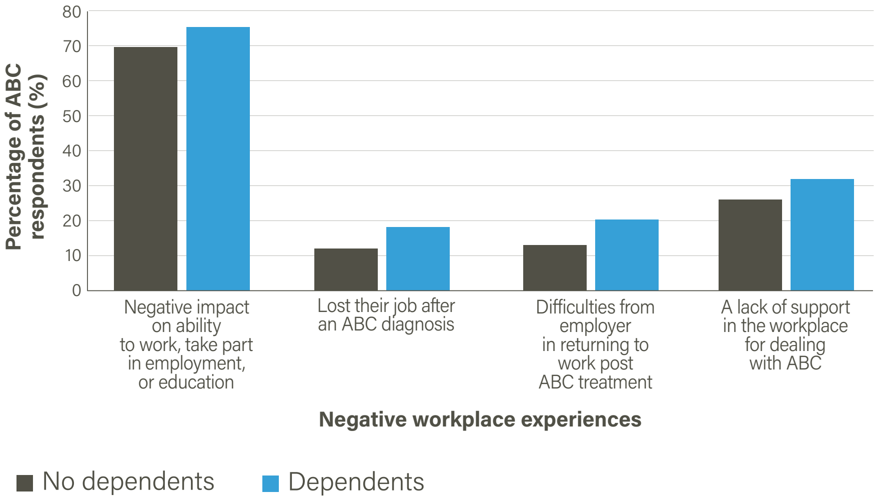
Legal protections for people living with chronic illnesses were also limited, with cancer not always recognized within this category. Once sick-leave-related benefits were exhausted, people with ABC were often left reliant on social security or related programs, where available, resulting in significant financial strain. These challenges extended beyond formal employment: homemakers and unpaid informal caregivers were ineligible for such benefits, despite any reduction in their ability to fulfil their roles potentially leading to economic hardship and increased social isolation.[3]

A DECADE IN REVIEW (2015–2025)

ABC substantially impacts individuals’ ability to participate in and retain employment

Despite increased awareness efforts and legal reforms aimed at supporting people with ABC, the ability to continue or return to work following an ABC diagnosis may have worsened over the past decade. In the ABC Global Alliance 2024 patient survey (n=1,254), nearly three quarters (73%) of respondents reported a negative impact of their diagnosis on their ability to take part in employment or education (**Figure 61**). Similar trends have been reported elsewhere: one study found that the proportion of individuals experiencing a change in employment status after an ABC diagnosis rose from 50% in 2013 to 74% in 2019,[363] while another observed a drop in employment from 87% at diagnosis to just 38% at the time of the study.[146]

Figure 61: Negative workplace experiences for people with ABC with and without dependents



Based on findings from the ABC Global Alliance 2024 patient survey (n=1,254). '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?' [option to select: Difficulties from employer in returning to work after undergoing treatment for ABC; A lack of support in the workplace for dealing with ABC]. 'What impact has advanced breast cancer had on the following areas of your life?' [option to select: Ability to work, take part in employment, or education].

The challenges are multifaceted. Treatment-related side effects, such as fatigue, chronic pain, and cognitive impairment, can make it difficult to meet job demands.[609] The emotional toll of living with advanced disease, including anxiety, depression, and the psychological shock of diagnosis, further complicates workforce participation.[609] In addition, frequent and complex hospital visits–often involving multiple departments, tests, and therapies spread across different days and locations–consume substantial time, energy, and mental capacity for people with ABC.[7]

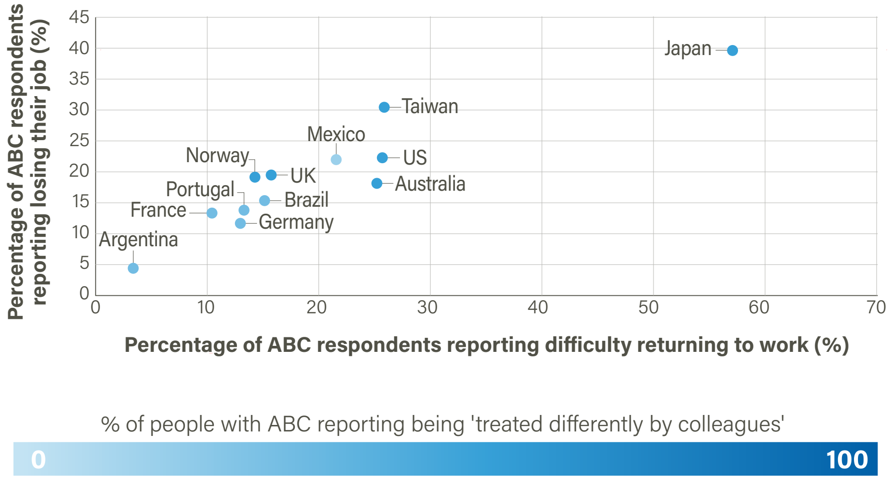
Responsibilities outside of the workplace can exacerbate these difficulties. The ABC Global Alliance 2024 patient survey found that people with dependents (children or other family members who require care) were more likely to report difficulty returning to work (21% vs. 14%) and a lack of workplace support (33% vs. 26%) compared with those without dependents (**Figure 61**). An ABC diagnosis also significantly reduces a person's capacity to manage responsibilities at home, including housework, childcare, and caregiving.[363,610] In fact, 68% of survey respondents reported a negative impact on their ability to carry out everyday roles. A UK-based study estimated the economic cost of this unpaid work loss to be £776–951 million in 2024–a burden largely absorbed by society (see Goal 9).[610]

Evidence suggests that the negative impact on employment is greatest for people diagnosed with advanced disease at time of presentation (e.g., *de novo* ABC)[609] and for those in lower-income households, possibly reflecting more physically demanding and less accommodating work environments.[484] Interestingly, the ABC Global Alliance 2024 patient survey found that respondents from high-income countries (HIC) were more likely to report a negative impact of ABC on work or education than those from low- and middle-income countries (LMIC) (77% vs. 56%), suggesting a complex interplay of economic, cultural, and workplace factors.

The impact on younger people is particularly notable. The Young Survival Coalition's (YSC) Project 528 survey conducted in 2024 found that 64% of young women with ABC experienced changes in employment–25% at diagnosis, 31% during treatment, and 8% after–highlighting the profound and ongoing effect of the disease on the working lives of young people.[20]

Country-level analysis of the ABC Global Alliance 2024 patient survey revealed significant variation in employment retention (**Figure 62**). Perhaps unsurprisingly, countries reporting higher return-to-work difficulty also had higher reported rates of job loss following an ABC diagnosis. The highest reported difficulty returning to work was in Japan, where over half (58%) of respondents reported challenges, and two fifths (40%) lost their job due to their diagnosis. High rates of job loss and return-to-work difficulty were also reported in Taiwan and the United States (US), where respondents were more likely to describe being treated differently by colleagues, indicating less supportive workplace cultures. While job loss and employment retention rates in the ABC Global Alliance 2024 patient survey are lower than in some other studies,[146] the findings nonetheless highlight the persistent and severe workplace challenges faced by people with ABC worldwide.

Figure 62: The impact of ABC on employment retention, returning to work, and workplace experience



Based on findings from the ABC Global Alliance 2024 patient survey (n=1,254). '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.]

Insufficient workplace support is rooted in limited awareness and inadequate policies

Systemic workplace support for people with ABC remains inadequate. Addressing this gap requires understanding of the key factors that contribute to these shortcomings. Evidence shows that while people with advanced cancers often report relatively high levels of support during sick leave, their experiences upon returning to work vary widely.[607] In the ABC Global Alliance 2024 patient survey, approximately one-third (29%) of respondents reported insufficient workplace support, with unmet needs particularly high in Portugal (46%) and the US (38%). These findings align with a 2022 Portuguese survey in which only 38% of women with ABC were able to maintain their work status, with the remainder unemployed (51%), on medical leave (25%), or retired (24%).[611] In contrast, a 2021 UK survey of 1,241 people with breast cancer found that 93% had been given time off for medical appointments, 78% had access to flexible working arrangements, and 70% could work from home.[607] However, people with ABC were consistently less likely to report positive workplace experiences than those with early-stage disease.[607]

The ABC Global Alliance 2024 patient survey also revealed geographic and socioeconomic disparities. In HICs, patients with household incomes above $100,000 were more likely to report insufficient support–possibly reflecting limited flexibility in senior or managerial roles. In LMICs, those with lower household incomes reported reduced support, likely due to the physically demanding nature of manual labor and fewer formal workplace protections.[609,612]

One major barrier is employers' reluctance to formalize cancer-specific workplace policies. In a 2016 global survey, 60% of employers said they would offer accommodations as needed, but only 40% would reduce workload and 43% would allow remote work,[611] though work-from-home culture has evolved since then. Even so, a 2024 UK study found that only 4% of workplaces had a cancer-specific policy in place, despite almost half of human resources (HR) managers believing one was necessary.[613] Where policies do exist, they are often poorly communicated. In the same 2016 global survey, almost half (46%) of employers cited managers' ability to support employees with cancer as a major concern, with 38% calling for better training for managers and 34% for improved communication of company policies.[611] A 2021 UK report by Breast Cancer Now reinforced these findings, highlighting infrequent and inconsistent communication between employees, line managers, HR representatives, and occupational health professionals.[607]

Stigma and discrimination further compound these structural gaps. Misconceptions about the capabilities of people with ABC can lead to social exclusion,[608-609,613] and stigma is often more pronounced for advanced cancer than early-stage disease.[609] This can result in individuals feeling misunderstood, their desire and willingness to work underestimated, and their social interactions in the workplace diminished.[608] Colleagues may feel uncertain about how to offer support, particularly when sensitive topics such as mortality arise.[608] Such stigma can contribute to wrongful dismissal or termination based on health status.[609,614] Consequently, many people with ABC chose not to disclose their diagnosis, limiting opportunities for constructive dialogue and tailored support.[609]

Flexible work accommodations are a critical part of overcoming these challenges. A 2019–2021 Portuguese study used national prevalence estimates of 2,151 working-aged women with ABC and average wage data to estimate that disease-related non-employment resulted in €28.7 million in lost productivity over three years.[146] Modelling suggested 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.[146] This demonstrates how well-designed, flexible workplace policies not only help people with ABC remain employed but also deliver tangible benefits for public finances and the wider economy.

Workplace challenges for ABC informal caregivers are under-recognized

An ABC diagnosis has implications that extend far beyond the individual, yet research into the work-related impact on informal caregivers remains limited. Evidence suggests that caregiving responsibilities can significantly disrupt employment. A 2021 study found that one-third (33%) of ABC informal caregivers changed their employment status after assuming a caregiving role, with 13% leaving the workforce entirely.[229] Those who continue to work often adapt by moving to less demanding roles, reducing hours, or altering schedules or shift patterns, and many take formal time off–both paid and unpaid–to provide care.[615] In some cases, caregiving can also lead to increased work hours, particularly when caregivers feel financial pressure to compensate for lost household income. One study found that spouses of cancer survivors worked an average of 1.5 hours more per week than spouses of those without cancer.[615] Another reported that, on average, 8% of ABC caregivers increased their work hours, ranging from 14% in the US, to 6% in the UK, and 3% in Germany–likely reflecting differences in healthcare systems and national informal caregivers support policies.[229]

A lack of systemic support for informal caregivers contributes to higher absenteeism, driven by the physical and emotional demands of caregiving, which in turn reduces productivity. The economic impact is substantial: a UK breast cancer study estimated informal caregivers productivity losses at £20–215 million in 2024–nearly 10% of the total economic cost of breast cancer to the national health service (NHS) and society (£2.6–2.8 billion).[610] In Brazil, the productivity loss among caregivers of people with ABC was estimated at more than 115 million hours per year in 2018.[616]

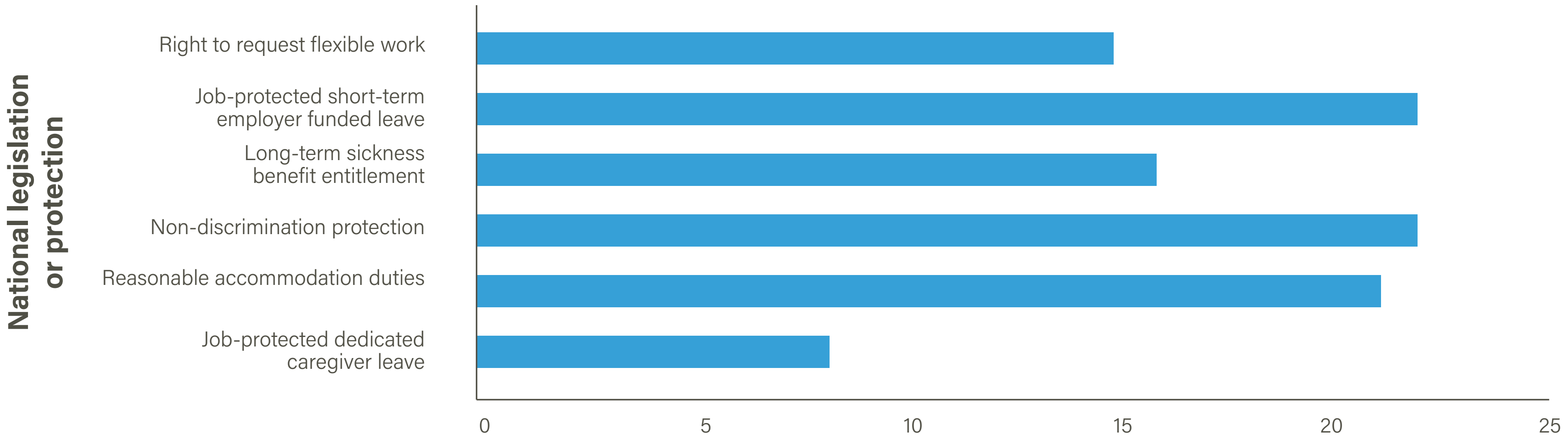
National legislation and protections are inconsistent across countries for people working with cancer and their informal caregivers

A 2024–2025 review of national legislation by the McCabe Centre for Law and Cancer highlights significant gaps in the extent of workplace protections across 24 countries from diverse regions and resource levels. This is despite all countries in the review having obligations under international human rights law to advance work rights and ensure non-discrimination. While some progress has been made–and several countries have laws covering all key areas–the review found that no country has a national legal framework in place sufficiently comprehensive to fully uphold the rights of individuals with ABC and their informal caregivers (for full details and references, see **Appendix XI**). In part, this may be due to the often complex and overlapping nature of applicable laws, the ongoing tension between protecting employee rights and meeting employer needs, and differing national policy approaches to sickness and disability. In many countries, workplace protection laws apply only to those in the formal employment sector, leaving informal workers–such as those who are self-employed or 'gig' workers paid per task or job–without coverage. Furthermore, although the review did not focus on implementation issues, it found that in many countries existing laws are not operating as effectively as intended, limiting their real-world impact.

Reasonable accommodations and the right to request flexible work

The McCabe Centre's review found that most countries have enacted laws outlining employers' duty to provide reasonable accommodations in the workplace (**Figure 63**). These are defined as adjustments to ensure that those who would otherwise be excluded from work can be accommodated, unless such accommodations constitute a disporportionate burden on the employer. In some cases, additional guidance is provided through regulations, codes of practice, or directives.

Figure 63: Countries with workplace protections in national legislation that may apply to people with cancer, including ABC



Based on findings from the McCabe Centre for Law and Cancer's analysis (see Appendix XI).

Of the 24 countries surveyed, 15 have laws that address flexible work, including 10 that contain a specific right for employees to request flexible working arrangements. In certain juristictions, this right is limited to specific groups–for example, public sector/government employees in Samoa. In five countries, flexible work is permitted under broader employer requirements to promote equal opportunity and/or to make reasonable adjustments to accommodate employees with disability (Table 10), demonstrating the overlap between anti-discrimination and labor laws.

Where flexible work laws exist, they generally do not include substantive rights to flexible work; rather, they outline an individual's right to request such arrangements, while mandating that an employer consider these requests. Some laws limit employer discretion by requiring employers to agree to requests unless there is a genuine business reason to refuse. Crucially, whether reasonable accommodation laws apply to people with ABC often depends on how 'disability' is defined in those laws. In 12 countries, the legal right to request flexible working arrangements extends to informal caregivers, with some placing strict boundaries on employer discretion in response to such requests.

Table 10: Countries surveyed with legal rights to request flexible work that may apply to people with cancer, including ABC

Region	Right to request flexible work and/or reasonable adjustments	Limited legal protection/no legal protection*	Countries covered
Africa	Kenya*/South Africa*/Uganda*	Nigeria (working hours set by mutual agreement or collective bargaining)	4
Americas	Canada/Colombia/US*	Brazil (by collective bargaining) Mexico (telework decree)	5
Eastern Mediterranean		Iran (reduction in work hours for people with severe disabilities and caregivers)	1
Europe	France/Norway/Poland/Portugal Spain/Sweden*/UK		7
South-East Asia		Indonesia	1
Western Pacific	Australia (employees with disability including cancer) New Zealand	China (subnational laws) Japan (government guidelines) The Philippines (government guidelines) Samoa (public service employees)	6
Total countries	15	9	24

Note: Eligibility criteria may apply. For example, in Australia eligibility criteria includes 12 consecutive months of employment with the same employer. In Canada, all employees have the right to request flexible work after 6 consecutive months with the same employer.

* Laws in some countries do not specifically refer to flexible work, yet similar entitlements may exist under employer responsibilities to promote equal opportunities and/or make reasonable adjustments to accommodate employees with disabilities.

Employer-funded sick leave

Leave entitlements can provide vital support to people with ABC, helping to stabilize employment while they navigate treatment, symptom management, and their broader care journey. These laws largely seek to establish a baseline for minimal mandated entitlements, while enabling individual employers to offer additional discretionary benefits. The McCabe Centre's review identified laws in multiple countries that guarantee both financial and non-financial entitlements for individuals unable to work due to illness. Nearly all countries surveyed (22 of 24) had national laws specifying minimal entitlements to short-term employer-funded sick leave (**Table 11**). However, there was notable variation in eligibility criteria, evidence requirements, duration of leave, and rate of pay–factors that can significantly impact the accessibility and adequacy of support for people with ABC. In some countries, employees who are unable to return to work after exhausting their sick leave benefits may qualify for alternative entitlements linked to long-term incapacity. Yet, the minimum legal thresholds for qualifying for such benefits varies widely between countries, potentially leaving some individuals without sufficient financial protection during extended periods away from work.

Table 11: Countries surveyed with short-term employer-funded paid sick leave entitlement that may apply to people with cancer, including ABC

Region	Legally mandated employer-funded short-term sick leave			Countries covered
	Yes		No/limited protection	
Africa	Kenya	14 days		4
	Nigeria	12 days		
	South Africa	30 days (within 3 years)		
	Uganda	2 months		
Americas	Brazil	15 days	US*	5
	Canada	10 days		
	Colombia	2 days		
	Mexico	3 days		
Eastern Mediterranean	Iran	3 days		1
Europe	France	May supplement allowance from day 8 onwards		7
	Norway	16 days		
	Poland	33 days		
	Portugal	3 days (max. twice per year)		
	Spain	From day 4 to day 15		
	Sweden	14 days		
	UK	From day 2 to 14		
South-East Asia	Indonesia	12 months		1
Western Pacific	Australia	10 days	Japan[†]	6
	China	Depends on employee's length of service		
	New Zealand	10 days		
	The Philippines	60 days (special leave for women)		
	Samoa	5 to 20 days depending on employee seniority		
Total countries	22		2	24

Note: These entitlements may be subject to eligibility requirements and qualifying periods. Rates of payment vary between and within countries; for example, in Kenya the first week is at full pay and the subsequent week is at half pay. In Indonesia, the first four months are at full pay, then 75% for the following four months and 50% for the remaining four months.
* There is no US federal law, but entitlements may exist under state and municipal laws.
† Eligible employees in Japan may be entitled to a social insurance allowance (Shōbyō Teate-kin) if unable to work due to non-work-related illness.

Dismissal and non-discrimination protections

Legal dismissal protections are essential to ensuring job security for people with ABC who need to take time off work. These laws generally serve to protect employees against dismissal under circumstances deemed 'unfair' or 'without just cause,' or on discriminatory grounds–including while an employee is away from work, such as on sick leave or caregiver leave. However, they typically do not protect against dismissal if an employee is later deemed 'unfit' for work. These requirements are set by law, but the burden of proof in wrongful dismissal cases varies by country: in some, the employer must prove that the dismissal was lawful, while in others, the responsibility lies with the employee. If wrongful dismissal is found to have taken place, remedies may include reinstatement, placement in similar and reasonably suitable employment, and/or financial compensation.

The majority of countries reviewed (22 of 24) have federal laws protecting individuals against workplace discrimination based on disability or other protected characteristics (**Table 12**), with several including relevant guarantees in their constitutions. However, these laws vary widely in scope, the types of discrimination considered unlawful, the extent of employer responsibilities, available complaint and enforcement mechanisms, and the remedies provided. In 12 countries, non-discrimination laws clearly apply to individuals with ABC, as protections are based on having 'cancer,' 'illness,' 'chronic illness,' or 'health conditions.' In other countries, people with ABC may be protected under disability discrimination laws–if cancer falls within the law's definition of 'disability.' This means that the terminology used in legislation plays a decisive role in determining whether anti-discrimination laws apply to people with ABC, and determining whether a person is considered to have a disability for the purpose of discrimination protection is not always clear-cut (**Table 12**).

Table 12: Countries surveyed with workplace discrimination protections based on grounds of cancer, health, and/or disabilities

Region	Protected grounds specifically include cancer	Protected grounds include health or illness	Protected grounds include disabilities*	Limited/no legal protection	Countries covered
Africa	Kenya		Nigeria South Africa Uganda		4
Americas	Brazil Colombia	Mexico (health condition)	Canada US*		5
Eastern Mediterranean				Iran	1
Europe	UK	France (state of health) Poland (chronic illness) Portugal (chronic illness) Spain (health)	Norway Sweden*		7
South-East Asia			Indonesia		1
Western Pacific	The Philippines	Australia[†] New Zealand[†]	Japan Samoa*	China (unclear definition)*	6
Total countries	5	7	10	2	24

* Note: Whether each of these laws applies to people with ABC depends on the definition of 'disability' in the applicable law.

† Some countries define disability to include illnesses or the presence of organisms in the body causing illness.

Leave entitlements for informal caregivers of people with ABC

Job-protected leave entitlements can also support informal caregivers of people with ABC, enabling them to take time off work to fulfil caregiving responsibilities. In 11 of the countries analyzed by the McCabe Centre, federal laws protect against workplace discrimination based on caregiving or family responsibilities. Of these, eight countries offer dedicated caregiver leave entitlements, while an additional three provide paid leave that can be used for purposes including (but not limited to) caregiving. In France and Japan, employers are prohibited from refusing a caregiver leave application, provided all legal requirements are met.

However, there is again considerable variability in the coverage of these laws. Differences in eligibility criteria, qualifying periods, notice requirements, duration, pay rate, definition of care recipient, and funding source all influence the accessibility of paid leave for informal caregivers. In many countries, due to the absence or inadequacy of dedicated caregiver entitlements, it appears to be common practice to use other forms of leave–such as sick leave or unpaid leave of absence–for caregiving purposes.

Persistent shortcomings include restrictions on the circumstances under which paid caregiver leave can be taken and the degree of employer discretion in approving or rejecting leave applications. Relatively few countries offer unpaid job-protected leave specifically for informal caregivers, although laws providing alternative avenues of financial assistance were in place in several countries, such as caregiver benefits and tax credits in Canada.

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

Although the focus of the McCabe Centre's analysis was to map the landscape of relevant workplace entitlements, their research also identified significant shortcomings in the implementation of existing laws, highlighting an unmet need for greater clarity, consistency, and effective enforcement (**Table 13**).

Table 13: Challenges in implementing existing laws in cancer care today

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 mean 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

The McCabe Centre's analysis highlights several opportunities to enact reform, including:

- 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 employer needs)
- 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 the same 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

Crucially, there is limited global evidence to underpin the case for investing resources in improving leave entitlements for people living with chronic illnesses, including ABC, highlighting a significant and urgent unmet need.

CONCLUSION AND FUTURE DIRECTIONS

The McCabe Centre's survey of the global legal landscape for people with ABC found that, 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. This legislative gap reflects a deeper, systemic issue: a widespread misconception about the value and capabilities of people living with ABC in the workplace.

Too often, limited awareness of the lived experiences of those with cancer fuels stigma, inadequate support structures, and discriminatory practices, particularly in employment. These challenges are further compounded for individuals already facing structural inequalities, such as older adults and ethnic minority groups. Addressing this requires countries to not only strengthen their legal frameworks, but also draw on international human rights law and the guidance of institutions such as the International Labor Organization (ILO) to better define, interpret, and meet their obligations. Crucially, achieving meaningful change will demand both legislative action and a shift in societal attitudes–recognizing the contributions, capabilities, and rights of people with ABC across all spheres of life, including work.

In recognition of this, the ABC Global Alliance community has included the following goal as part of the 2025–2035 Global Charter:

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 lens of individuals with ABC and their informal caregivers

Appendices

Appendices

APPENDIX I: CLINICAL TARGETED LITERATURE REVIEW

Objective:

- Evaluate the clinical efficacy of ABC treatments in randomized controlled trials (RCTs) over the past decade and assess their impact on survival outcomes

Methodology:

A search was conducted for studies that have reported on the clinical efficacy of treatments associated with ABC. The search for clinical data was conducted on Embase (via Embase.com), using the search terms listed in **Table 14**.

The key inclusion and exclusion criteria for the studies identified by the searches are summarized in **Table 15**.

Information from the full-text articles of the studies accepted for inclusion were extracted independently into a data extraction table. The specific data elements captured for each study are summarized in **Table 16**.

	Search terms	Hits
1	'mBC'/exp OR 'metastatic breast cancer' OR 'advanced breast cancer' OR 'stage IV breast cancer' OR 'secondary breast cancer' OR 'locally advanced breast cancer' AND [Publication date from 01/01/2015 to 19/06/2024]	548
2	'treatment outcome'/exp OR 'therapy' OR 'treatment' OR 'chemotherapy' OR 'hormonal therapy' OR 'endocrine therapy' OR 'targeted therapy' OR 'immunotherapy' OR 'CDK4/6 inhibitors' OR 'PI3K inhibitors' OR 'PARP inhibitors' OR 'HER2-targeted therapies' OR 'immune checkpoint inhibitors' OR 'antibody drug conjugates' OR 'mTOR inhibitors' OR 'selective estrogen receptor degraders'	15,357,433
3	'randomized controlled trial' OR 'RCT' OR 'random allocation' OR 'placebo-controlled' OR 'placebo controlled' OR 'clinical trial' OR 'head-to-head' OR 'head to head' OR 'comparative effectiveness' OR 'systematic review' OR 'systematic literature review' OR 'meta-analysis' OR 'meta analysis'	2,725,658
4	'overall survival'/exp OR 'progression free survival'/exp OR 'survival rate' OR 'survival analysis' OR 'treatment outcome'	1,878,999
5	#1 AND #2 AND #3 AND #4	335
6	'Animal' OR '*In vitro*'	8,736,202
7	'letter' OR 'editorial' OR 'case report' OR 'observational study'	5,730,768
8	#5 NOT #6 NOT #7	**318**

Table 14: Search terms used in the clinical targeted literature review and the associated number of hits

The limits for this search included only items with abstracts. EMBASE accounts for both US and UK spelling.

	Inclusion criteria	Exclusion criteria
Population	mBC patients (also referred to as advanced breast cancer or progressive breast cancer)	Patients without a primary diagnosis of mBC
Intervention	Inclusion of licensed pharmacological treatments, standard of care or pharmacological treatment under investigation will be included.	Studies that report on efficacy data for non-pharmacological treatment or treatments not considered standard of care. Studies evaluating the preferred sequence of treatments. Treatments aimed at managing complications of mBC.
Outcomes	· Survival (OS) · Morbidity (PFS, TTP)	Publications that do not report efficacy outcomes
Study Design	· RCTs (Phase III only) · SLRs or meta-analysis	Case reports, comments and editorials, animal/*in vitro* studies, observational studies
Date Limit	Publications indexed in the databases since 2015	Publications indexed in 2014 or previous years

Table 15: Inclusion and exclusion criteria for clinical targeted literature review

mBC= metastatic breast cancer; **OS=** overall survival; **PFS=** progression free survival; **RCT=** randomized controlled trial; **SLR=** systematic literature review; **TTP=** time to progression.

Category	Data elements
Study Characteristics	· Name of the trial · Study design (Phase 3 leading to FDA/EMA approval only) · Publication date · Geographic location · Intervention & control arm (if applicable) · Duration of treatment (cycle length, number of days per cycle)
Patient Characteristics	· Age median (range) for each arm · Female (%) · *De novo* status (if recorded) · Subtype (e.g., HR, HER2, TNBC) · Other relevant cytogenetics (e.g., *PIK3CA* status)
Efficacy Data	· Timing of assessment · OS (median months, rates) · PFS (median months, rates)

Table 16: Data elements captured for the studies included in the clinical targeted literature review

EMA= European Medicines Agency; **FDA=** Food & Drug Administration; **HR=** hormone receptor; **HER2=** human epidermal growth factor receptor 2; **OS=** overall survival; **PFS=** progression free survival; ***PIK3CA*=** phosphatidylinositol-4,5-bisphosphate 3-kinase catalytic subunit alpha; **TNBC=** triple negative breast cancer.

APPENDIX II: INTERVIEWS WITH GLOBAL REGISTRIES

Objective:

- Gather insights on national data registries globally to understand best practices, successful methodologies, and the challenges faced in data capture

Methodology:

Virtual, structured interviews (~30 minutes) were conducted with national data registries from five countries (**Table 17**), to discuss key themes:

- Perspectives on the effectiveness of current data collection methods for ABC
- Types and quality of ABC data currently being collected
- Key challenges in registering relapse data within cancer registries
- Barriers encountered in the collection of ABC data
- Suggested improvements to enhance data collection processes, support research, and improve patient outcomes in ABC
- Reflections on progress made over the past decade and future goals for ABC data systems

Date of interview	Country	Registry
9th July 2024	New Zealand	Te Rēhita Mate Ūtaetae - Breast Cancer Foundation National Register
8th July 2024	France	Épidémio-Stratégie Médico-Economique (ESME)
11th July 2024	The Netherlands	The Netherlands Cancer Registry
19th August 2024	The United Kingdom	National Audit of Metastatic Breast Cancer (NAoMe)
22nd August 2024	Germany	The OPAL registry

Table 17: Information on the national registries interviews

APPENDIX III: QUALITY OF LIFE INSTRUMENT CONVERSION METHODOLOGY

Objective:

- Assess the impact of novel treatments on QoL over the past decade

Methodology:

A search was conducted for all the FDA-approved ABC treatments with reported QoL outcomes from 2015–2024. A total of 18 trials reported QoL outcomes that could be converted to EQ-5D, which was selected as the uniform measure, due to the widespread acceptability.[617]

The following studies were included in the final QoL conversion analysis:

Study	Year	Type	Converted EQ-5D value	Original QoL instrument	Method of QoL measurement
PALOMA-3	2016	HR-positive	0.8134	EORTC	At baseline of intervention
PALOMA-2	2018	HR-positive	0.6300	EQ-5D	At baseline of intervention
MARIANNE*	2019	HER2-positive	0.8201	EORTC	At baseline of intervention
MONALEESA-3*	2020	HR-positive	0.8359	EORTC	At baseline of intervention
MONALEESA-7*	2020	HR-positive	0.7797	EORTC	At baseline of intervention
MONARCH-2	2020	HR-positive	0.7828	EORTC	At baseline of intervention
MONARCH-3	2020	HR-positive	0.7909	EORTC	At baseline of intervention
NALA*	2020	HER2-positive	0.8492	EORTC	At baseline of intervention
PEARL	2021	*BRCA* mutated	0.6400	EORTC	At baseline of intervention
DESTINY-BREAST03*	2023	HER2-positive	0.9264	EORTC	At baseline of intervention
KEYNOTE-119*	2023	TNBC	0.7871	EORTC	At baseline of intervention
ASCENT-03	2023	TNBC	0.7834	EORTC	At baseline of intervention
OlympiAD*	2023	ESR1	0.8160	EORTC	At baseline of intervention
CAPitello-291	2024	HR-positive	0.8137	EORTC	At baseline of intervention
TROPiCs-02	2024	HR-positive	0.7431	EQ-5D	At baseline of intervention
DESTINY-BREAST02*	2024	HER2-positive	0.7916	EORTC	At baseline of intervention
DESTINY-BREAST04	2024	HER2-positive	0.8403	EORTC	At baseline of intervention
KEYNOTE-355	2024	TNBC	0.8019	EORTC	At baseline of intervention

Table 18: Converted quality of life survey comparisons from 2015-2024

* Missing data calculation was performed to allow conversion. ***BRCA*=** Breast Cancer gene; **ESR1=** Estrogen Receptor 1; **HR=** hormone receptor; **HER2=** human epidermal growth factor receptor 2; **TNBC=** triple negative breast cancer.

Scheme of conversion:

The conversion from EORTC QLQ-C30 to EQ-5D was based on the study (Kontodimopoulos et al, 2009).[618]

Missing data calculation:

In cases where data was not complete, a missing data calculation was performed based on Berkelmans et al 2022, to give a median value for sub domains in the EORTC QLQ-C30.[619]

APPENDIX IV: HUMANISTIC TARGETED LITERATURE REVIEW

Objective:

- Evaluate the studies that report humanistic burden (e.g., HRQoL and caregiver burden) associated with ABC

Methodology:

A search was conducted for studies that have reported on the humanistic burden (e.g. HRQoL, caregiver burden) associated with ABC. The search for humanistic data was conducted on Embase (via Embase.com) has been listed in **Table 19**.

The key inclusion and exclusion criteria for the studies identified by the searches are summarized in **Table 20.**

Information from the full-text articles of the studies accepted for inclusion were extracted independently into a data extraction table. The specific data elements captured for each study are summarized in **Table 21.**

	Search terms	Hits
1	'mBC'/exp OR 'metastatic breast cancer' OR 'advanced breast cancer' OR 'stage IV breast cancer' OR 'secondary breast cancer' OR 'locally advanced breast cancer' AND [Publication date from 01/01/2015 to 19/06/2024]	747
2	'treatment outcome'/exp OR 'therapy' OR 'treatment' OR 'chemotherapy' OR 'hormonal therapy' OR 'endocrine therapy' OR 'targeted therapy' OR 'immunotherapy' OR 'CDK4/6 inhibitors' OR 'PI3K inhibitors' OR 'PARP inhibitors' OR 'HER2-targeted therapies' OR 'immune checkpoint inhibitors' OR 'antibody drug conjugates' OR 'mTOR inhibitors' OR 'selective estrogen receptor degraders'	15,369,275
3	'randomized controlled trial' OR 'RCT' OR 'random allocation' OR 'placebo-controlled' OR 'placebo controlled' OR 'clinical trial' OR 'head-to-head' OR 'head to head' OR 'comparative effectiveness' OR 'prospective study' OR 'prospective' OR 'retrospective study' OR 'retrospective' OR 'systematic review' OR 'systematic literature review' OR 'survey'	6,999,469
4	'quality of life' OR 'QoL' OR 'patient-reported outcome' OR 'patient-reported outcomes' OR 'PRO' OR 'satisfaction' OR 'functional status' OR 'physical function' OR 'health-related quality of life' OR 'HRQoL' OR 'well-being' OR 'wellbeing' OR 'patient-reported outcome tool' OR 'quality of life tool'	1,934,609
5	#1 AND #2 AND #3 AND #4	148
6	'Animal' OR '*In vitro*'	8,740,426
7	'letter' OR 'editorial' OR 'case report' OR 'meta-analysis' OR 'observational study'	6,144,134
8	#5 NOT #6 NOT #7	122

Table 19: Search terms used in the humanistic targeted literature review and the associated number of hits

The limits for this search included only items with abstracts. EMBASE accounts for both US and UK spelling.

	Inclusion criteria	Exclusion criteria
Population	mBC patients (also referred to as advanced breast cancer or progressive breast cancer)	Patients without a primary diagnosis of mBC
Intervention	Inclusion of licensed pharmacological treatments, standard of care or pharmacological treatment under investigation will be included	Studies that report on humanistic data for non-pharmacological treatment or treatments not considered standard of care
Outcomes	· HRQoL (including but not limited to, impact of treatments, factors associated with impaired HRQoL, or use of FACT-B, EORTC-QLQ-30, EQ-5D-5L or SF-36 for measurement of HRQoL) · PROs (to include all PRO instruments)	· Publications that do not report humanistic outcomes · Caregiver burden
Study Design	· Prospective and retrospective humanistic studies · RCTs and SLRs · Surveys or economic analysis	Case reports, comments and editorials, animal/*in vitro* studies, observational studies
Date Limit	Publications indexed in the databases since 2015	Publications indexed in 2014 or previous years

Table 20: Studies that report on humanistic data for non-pharmacological treatment or treatments not considered standard of care

HRQoL= health related quality of life; **PRO=** patient-reported outcome; **mBC=** metastatic breast cancer; **RCT=** randomized controlled trial; **SLR=** systematic literature review; **TTP=** time to progression

Category	Data elements
Study Characteristics	· Name of the trial · Study design (Phase 3 leading to FDA/ EMA approval only) · Publication date · Geographic location · Intervention & control arm (if applicable) · Duration of treatment (cycle length, number of days per cycle)
Patient Characteristics	· Age median (range) for each arm · Female (%) · *De novo* status (if recorded) · Subtype (e.g., HR, HER2, TNBC) · Other relevant cytogenetics (e.g., *PIK3CA* status)
Humanistic Data	· Response rate for HRQoL/PRO measures, % (n/N) · Description of health states/AEs · HRQoL/PRO results for symptom and functional scales · HRQoL/PRO by health states/AEs · HRQoL/PRO over time · Impact of pharmacological treatments on HRQoL/PRO

Table 21: Data elements captured for the studies included in the humanistic targeted literature review

EMA= European Medicines Agency; **FDA=** Food & Drug Administration; **HER2=** human epidermal growth factor receptor 2; **HR=** hormone receptor; **HRQoL=** health related quality of life; **OS=** overall survival; **PFS=** progression free survival; ***PIK3CA=*** phosphatidylinositol-4,5-bisphosphate 3-kinase catalytic subunit alpha; **PRO=** patient-reported outcome; **TNBC=** triple negative breast cancer.

APPENDIX V: ANALYSIS OF MDT INTEGRATION IN ABC CARE

Objectives:

Evaluate how MDT approaches are recommended and implemented in the treatment and care of patients with ABC across national, regional, and local levels. Specifically to:

- Determine the extent to which MDT approaches are recommended in national, regional, and local-level sources
- Identify the typical composition of MDTs, including key roles and specialties
- Compare and contrast regional differences in the recommendation and implementation of MDT approaches

Methodology:

To address these objectives, a structured search was conducted across 12 countries (Australia, Brazil, China, Colombia, France, India, Japan, Mexico, Nigeria, Poland, Portugal, South Africa, UK, US), selected to represent diverse geographies, income levels, and healthcare systems. A total of 200 webpages were reviewed, leading to a focused analysis of 40 sources.

Searches were performed systematically at three levels:

- Local (e.g., oncology hospitals and clinics)
- National (country-specific policies and guidelines)
- Regional (continental or global frameworks)

Cancer-specific search terms included:

- 'metastatic/advanced/secondary/stage IV breast cancer'
- 'breast cancer/oncology'
- 'cancer/oncology' (used in ascending order of generality)

Search terms related to document types included: 'guidelines', 'recommendations', 'policy', 'care', and 'plan'. If no results were found, document-specific terms were excluded. To assess implementation, additional terms such as 'implement', 'evidence', 'adherence', 'progress', 'achieve', 'applied', 'target', and 'improved' were included, especially in the context of MDT-related content.

Where implementation evidence was not provided in the main document, supplementary searches were conducted within the source's website and more broadly at the regional or local level. Preference was given to follow-up publications released at least one year after the original guideline to allow for real-world application, although exceptions were made for continuously updated guidelines.

Documents reviewed included but were not limited to: national and regional care guidelines, cancer control plans, policy papers, consensus statements, and peer-reviewed publications. Only sources published between 2015 and 2024 were included; documents prior to 2015 were included if they outlined plans relevant to the 2015–2024 period. A full list of sources analyzed can be found in **Table 22:**

All identified sources were assessed against EUSOMA MDT requirements and global best practice guidelines to evaluate progress since the 2005–2015 Global Decade Report.

Region, Country	Name of source analyzed	Type of source	Full reference of source
Global	6th and 7th International Consensus Guidelines for the management of ABC	Guideline	Cardoso F, Paluch-Shimon S, Schumacher-Wulf E, et al. 6th and 7th International consensus guidelines for the management of advanced breast cancer (ABC guidelines 6 and 7). *Breast*. 2024 Aug;76:103756.
Europe	The requirements of a specialist breast centre	Guideline	Biganzoli L, Marotti L, Cardoso F, et al. The requirements of a specialist breast centre. *Breast*. 2020;51:65-84.

Table 22 continued on next page

Region, Country	Name of source analyzed	Type of source	Full reference of source
Europe	ESMO Clinical Practice Guideline for the diagnosis, staging and treatment of patients with metastatic breast cancer	Guideline	A. Gennari, F. André, C. H. Barrios, et al, on behalf of the ESMO Guidelines Committee. ESMO Clinical Practice Guideline for the diagnosis, staging and treatment of patients with metastatic breast cancer. *Ann Oncol.* 2021(32)
Europe, England	Clinical Guidelines for the Management of Breast Cancer	Guideline	NHS. Clinical Guidelines for the Management of Breast Cancer. 2016. https://www.england.nhs.uk/mids-east/wp-content/uploads/sites/7/2018/02/guidelines-for-the-management-of-breast-cancer-v1.pdf
Europe, England	Breast Cancer Clinical Guidelines	Guideline	NHS Northern Cancer Alliance. Breast Cancer Clinical Guidelines. 2018. https://www.northerncanceralliance.nhs.uk/wp-content/uploads/2019/02/NCA-Breast-Cancer-Guidelines-v2-.10.pdf
Europe, England	LCA West and South Breast Cancer Clinical Guidelines	Guideline	London Cancer Alliance West and South. LCA West and South Breast Cancer Clinical Guidelines. 2016. https://rmpartners.nhs.uk/wp-content/uploads/2017/03/lca-breast-cancer-clinical-guidelines-october-2013-updated-march-2016-.pdf
Europe, England	Advanced breast cancer: diagnosis and treatment	Guideline	National Institute for Health and Care Excellence. Advanced breast cancer: diagnosis and treatment. 2017. https://www.nice.org.uk/guidance/cg81/resources/advanced-breast-cancer-diagnosis-and-treatment-pdf-975683850181
Europe, Poland	Cancer Control Strategy for Poland 2015-2024	Care plan	PwC. Cancer Control Strategy for Poland 2015-2024. 2014. https://www.iccp-portal.org/system/files/plans/Cancer%20Plan%20Poland.pdf
Europe, Poland	NCCN Guidelines® Insights: Breast Cancer, Version 4.2023	Guideline	Gradishar WJ, Anderson BO, Abraham J, et al. NCCN Guidelines® Insights: Breast Cancer, Version 4.2023. *J Natl Compr Canc Netw*. 2023;21(6):594-607.
Europe, Portugal	360 Health Analysis (H360) - A Proposal for an Integrated Vision of Breast Cancer in Portugal	Publication	Coelho S, Sousa B, Lunet N. 360 Health Analysis (H360) - A Proposal for an Integrated Vision of Breast Cancer in Portugal. *Eur J Breast Health*. 2020;16(2):91-98.
Europe, France	Compliance with clinical guidelines for breast cancer management: A population-based study of quality-of-care indicators in France	Publication	Cowppli-Bony A, Bossard N, Dantony E, et al. Compliance with clinical guidelines for breast cancer management: A population-based study of quality-of-care indicators in France. *PLoS One*. 2019;14(10):e0224275.
Europe, France	Political declaration and list of actions against cancer recommended by a panel of European stakeholders	Policy	The French National Cancer Institute. Political declaration and list of actions against cancer recommended by a panel of European stakeholders. 2022.
Europe, France	French-language recommendations for clinical practice concerning the management of breast cancer in Saint-Paulde-Vence 2022-2023	Guideline	Gligorov J, Benderra MA, Barthere X, et al. French-language recommendations for clinical practice concerning the management of breast cancer in Saint-Paulde-Vence 2022-2023. 2023.
North America, US	Systemic Treatment of Patients With Metastatic Breast Cancer: ASCO Resource–Stratified Guideline	Guideline	Waks AG, Korde LA, Anderson BO, et al. Systemic Treatment of Patients With Metastatic Breast Cancer: ASCO Resource–Stratified Guideline. *J Glob Oncol*. 2024;10:e2300285.

Table 22 continued on next page

Region, Country	Name of source analyzed	Type of source	Full reference of source
South America, Colombia	Addressing the rising burden of cancer in Colombia: Challenges & opportunities An analysis of Colombia's Health System and Cancer Control Policies	Report	Integrated Cancer Control Initiative in Latin America. Addressing the rising burden of cancer in Colombia: Challenges & opportunities An analysis of Colombia's Health System and Cancer Control Policies. 2021. https://www.hsph.harvard.edu/health-systems-innovation-lab/wp-content/uploads/sites/2633/2023/03/UICC-ICCILA-Colombia-Report-English-June-2021-FA.pdf
South America, Colombia	Clinical Practice Guideline (CPG) for early detection, comprehensive treatment, Follow-up and rehabilitation breast cancer	Guideline	Instituto Nacional de Cancerología ESE. Clinical Practice Guideline (CPG) for early detection, comprehensive treatment, Follow-up and rehabilitation breast cancer. 2013. https://www.minsalud.gov.co/sites/rid/Lists/BibliotecaDigital/RIDE/INEC/IETS/GPC_Prof_Sal_Mama.pdf?ID=1160
South America, Colombia	Improving outcomes for women with triple-negative breast cancer in Latin America	Report	Manzano A, Hofmarcher T. Improving outcomes for women with triple-negative breast cancer in Latin America. The Swedish Institute for Health Economics. 2023. https://ihe.se/app/uploads/2023/08/IHE-Report-2023_6_.pdf
North America, US	Metastatic Breast Cancer Guidelines for Patients	Guideline	National Comprehensive Cancer Network. Metastatic Breast Cancer Guidelines for Patients. 2023. https://www.nccn.org/patients/guidelines/content/PDF/stage_iv_breast-patient.pdf
North America, US	How We Treat Breast Cancer	Website	Dana-Farber Cancer Institute. How We Treat Breast Cancer. Accessed April 2024. https://www.dana-farber.org/cancer-care/types/breast-cancer/treatment
North America, US	Breast cancer care at Mayo	Website	Mayo Clinic. Breast cancer care at Mayo. Accessed April 2024. https://www.mayoclinic.org/diseases-conditions/breast-cancer/care-at-mayo-clinic/mac-20352479
South America (LATAM)	Advanced Breast Cancer Guidelines in Latin America: Assessment, Adaptation, and Implementation of Fifth Advanced Breast Cancer Consensus Guidelines	Publication	Valencia F, Gomez H, Arrieta O, et al. Advanced Breast Cancer Guidelines in Latin America: Assessment, Adaptation, and Implementation of Fifth Advanced Breast Cancer Consensus Guidelines. *J Glob Oncol*. 2024;10:e2200067.
South America (LATAM)	Improving outcomes for women with triple-negative breast cancer in Latin America	Report	Manzano A, Hofmarcher T. Improving outcomes for women with triple-negative breast cancer in Latin America. The Swedish Institute for Health Economics. 2023. https://ihe.se/app/uploads/2023/08/IHE-Report-2023_6_.pdf
South America, Brazil	Cancer care in Brazil: structure and geographical distribution	Publication	da Silva MJS, O'Dwyer G, Osorio-de-Castro CGS. Cancer care in Brazil: structure and geographical distribution. *BMC Cancer*. 2020;20(1):113.
South America, Brazil	Scientific Production Report 2019	Report	A.C. Camargo Cancer Centre. Scientific Production Report 2019. 2019. https://accamargo.org.br/sites/default/files/2022/12/accamargo_producao-cientifica-2019-en.pdf
South America, Mexico	Mexican consensus on breast cancer diagnosis and treatment, 9th revision	Guideline	Mexican consensus on breast cancer diagnosis and treatment, 9th revision. 2019. http://www.consensocancermamario.com/documentos/RevistaGamo2021En.pdf

Table 22 continued on next page

Region, Country	Name of source analyzed	Type of source	Full reference of source
Asia	Pan-Asian adapted ESMO Clinical Practice Guidelines for the diagnosis, staging and treatment of patients with metastatic breast cancer	Guideline	Im, Gennari, Park, et al. Pan-Asian adapted ESMO Clinical Practice Guidelines for the diagnosis, staging and treatment of patients with metastatic breast cancer. *ESMO Open*. 2023 Jun;8(3):101541.
Asia, China	Chinese Society of Clinical Oncology (CSCO) Breast Cancer Guidelines 2022	Guideline	Chinese Society of Clinical Oncology (CSCO). Chinese Society of Clinical Oncology (CSCO) Breast Cancer Guidelines 2022. 2023. https://tbcr.amegroups.org/article/view/63879/pdf
Asia, China	Guidelines for diagnosis and treatment of advanced breast cancer in China (2022 edition)	Guideline	China Advanced Breast Cancer Guideline Panel. Guidelines for diagnosis and treatment of advanced breast cancer in China (2022 edition). *J Natl Cancer Cent*. 2024;4(2):107-127.
Asia, China	Multi-disciplinary Therapies for Cancer	Website	Beijing Puhua International Hospital. Multi-disciplinary Therapies for Cancer. Accessed April 2024. http://www.puhuachina.com/content/?5.html#:~:text=Beijing%20Puhua%20International%20Hospital%20use,maintain%20your%20quality%20of%20life.
Asia, China	Breast Cancer Treatment Multidisciplinary Team	Website	Modern Cancer Hospital Guangzhou. Breast Cancer Treatment Multidisciplinary Team. Accessed May 2024. https://www.asiancancer.com/cancer-treatment/breast-cancer-treatment/
Asia, Japan	The Japanese Breast Cancer Society Clinical Practice Guidelines for systemic treatment of breast cancer, 2022 edition	Guideline	Watanabe T, Aogi K, Iwata H, et al. The Japanese Breast Cancer Society Clinical Practice Guidelines for systemic treatment of breast cancer, 2022 edition. *Breast Cancer*. 2023;30(6):847-903.
Asia, India	National Cancer Grid Breast Cancer Management Guidelines 2019	Guideline	National Cancer Grid. National Cancer Grid Breast Cancer Management Guidelines 2019. 2019. https://www.ncgindia.org/assets/ncg-guidelines-2019/ncg-guidelines-for-breast-cancer-2019.pdf
Oceania, Australia	Clinical practice guidelines for the management of advanced breast cancer	Guideline	Cancer Council Australia. Clinical practice guidelines for the management of advanced breast cancer. 2021. https://www.cancer.org.au/assets/pdf/breast-cancer-optimal-cancer-care-pathway
Oceania, Australia	Advanced breast cancer: An update to systemic therapy	Publication	Carson E, Dear R. Advanced breast cancer: An update to systemic therapy. *Aust J Gen Pract*. 2019;48(5):294-299.
Oceania, Australia	Guide for women with secondary breast cancer	Guideline	National Breast and Ovarian Cancer Centre. Guide for women with secondary breast cancer. 2010. [https://www.melbournebreastcancersurgery.com.au/wp-content/themes/ypo-theme/pdf/guide-for-women-secondary-breast-cancer.pdf]

Table 22: MDT Sources for analysis in ABC care

APPENDIX VI: GLOBAL AUDIT OF COMMUNICATION SKILLS TRAINING

Objectives:

- Identify communication skills training programs offered by top academic institutions for medical and nursing students and by professional oncology organisations for HCPs working with people with ABC
- Compare key characteristics of available training programs, including specificity to ABC, geographic availability, and core topics
- Identify global trends in the availability and focus of communication training for medical, nursing, and oncology professionals

Methodology:

A global scan was conducted across 12 countries, including the Australia, Brazil, China, Colombia, France, India, Japan, Mexico, Nigeria, Poland, Portugal, South Africa, Spain, United Kingdom, and United States, to identify and evaluate relevant communication training initiatives. The analysis focused on two main sources:

- **Academic Institutions:** Top 3 medical schools and the top nursing school in each of the countries aforementioned, based on the QS World University Rankings by Subject 2024: Medicine[620]
- **Professional Oncology Organizations:** National and regional oncology and breast cancer-specific organizations offering training for HCPs. 35 organizations were evaluated in total (**Table 23**).

Communication training materials were sourced from institutional websites and publicly available resources. Key data points were extracted into a structured matrix, including: program title and launch date, target audience and training format, learning objectives and thematic focus, specificity to ABC, and accreditation (e.g., CPD points or academic credit).

Where data were unavailable online, institutions and organizations were contacted directly to gather further details.

Professional oncology organization	Region
African Cancer Association of South Africa (CANSA)	Africa
African Cancer Institute at the Faculty of Medicine and Health Sciences, Stellenbosch University	Africa
African Organisation for Research and Training in Cancer (AORTIC)	Africa
American Cancer Society (ACS)	North America
American Society of Clinical Oncology (ASCO)	North America
Argentine Society of Mastology	Latin America
Australasian Society for Breast Disease (ASBD)	Oceania
Australasian Society of Breast Physicians (ASBP)	Oceania
Brazilian Society of Clinical Oncology	South America
Breast Cancer Initiative East Africa (BCIEA)	Africa
Breast Cancer Now	Europe
Breast Health Foundation (South Africa)	Africa

Table 23 continued on next page

Professional oncology organization	Region
Cancer Council Australia	Oceania
Cancer Research UK	Europe
Colombian League Against Cancer	South America
European Cancer Organisation (ECO)	Europe
European Oncology Nurses Society (EONS)	Europe
European Society for Medical Oncology (EMSO)	Europe
Global Chinese Breast Cancer Organizations Alliance	Asia
Indian Cancer Society	Asia
International Psycho-oncology society (IPOS)	International
Japanese Breast Cancer Society (JBCS)	Asia
Japanese Society of Cancer Nursing (JSCN)	Asia
Japan Cancer Society	Asia
Latin American Cooperative Oncology Group (LACOG)	South America
Mammory Fold (Association of Breast Surgery)	Europe
Mayo Clinic School of Continuous Professional Development (Medical Breast Training Program Online CME Course)	North America
National Breast Cancer Foundation (NBCF)	North America
National Comprehensive Cancer Network (NCCN)	North America
Novartis	International
Peruvian Breast Cancer Society	South America
Susan G Komen Breast Cancer Foundation	North America
The European Breast Cancer Coalition - Europa Donna	Europe
Union for International Cancer Control (UICC)	International
World Cancer Research Fund (WCRF)	International

Table 23: Professional oncology organizations and associated regions

APPENDIX VII: ABC GLOBAL ALLIANCE MEMBER QUESTIONNAIRES

Objectives:

- Examine the current landscape of ABC advocacy activities, including the availability of patient resources and awareness campaigns
- Compare resources developed by pharmaceutical and non-pharmaceutical organizations worldwide
- Identify existing gaps and areas of saturation in ABC-related information to support future resource development and advocacy efforts

Methodology:

A structured questionnaire was distributed to 95 organizations partnered with the ABC Global Alliance. The survey sought information across three domains:

- Organizational information (26 responses received)
- Patient information resources developed from 2015 onwards (57 responses received)
- Public awareness campaigns run since 2015 (33 responses received)

Type of information	Information requested from respondents
Organizational information	Year established
	Focus area (options: breast cancer, ABC, general cancer, other)
	Geographical scope
	Number of patient members in 2015 and 2023
	Percentage of patient members with ABC (if known/available)
	How most patients find organization (e.g., online, HCP, peer)
Patient Information Resources	Link to resource
	Title
	Author/ contributors (e.g., ABC Global Alliance)
	Format
	Focus of resource (either patient or non-patient) · Patient resource · Non-Patient resource
	Geographical scope
	Topics covered by the resource: · Treatment and side effects · Diagnostic · Psychological support and care · Peer support · Physical support · Dietary and nutrition · Clinical trials · Complementary or integrative therapy · Social support · Employment rights and returning to work · Financial assistance · Symptoms · ABC information on physiology

Table 24 continued on next page

Type of information	Information requested from respondents
Public awareness campaigns	Title of campaign
	Launch date and duration
	Objective of awareness campaign
	Target audience(s)
	Geographic scope
OPTIONAL: Patient Information Resource & Public Awareness Campaign Engagement Metrics	Number of clicks/ visits
	Number of downloads
	Average time spent on resource
	Number of shares/retweets
	Number of replies/comments
	Number of likes/views

Table 24. Information requested in the ABC Global Alliance questionnaire

Patient information resources from 2015 onwards

Organizations were asked to describe their 'most successful' ABC-related patient information resources, considering the following criteria:

- Relevance and accuracy of information for people living with ABC
- Accessibility and geographic reach

Respondents were also asked to report quantitative engagement metrics (e.g., clicks, downloads, time on page). However, due to limited responses, analysis focused primarily on qualitative content.

57 resources were received, yet 3 were excluded due to non-specificity to ABC. The remaining **54 resources** were compiled into an Excel matrix for thematic analysis to identify areas of high and low content availability.

Public awareness campaigns

A total of **34 survey responses** (29 from patient advocacy groups and 5 from pharmaceutical companies) were received regarding awareness campaigns. Due to the limited sample, additional desk research was conducted to identify further campaigns, using predefined inclusion criteria:

- A core objective of raising public awareness of ABC
- Audience reach beyond patients, caregivers, and healthcare professionals
- Supported by significant amplification efforts (e.g., earned/paid media, stunts, social media campaigns)

Campaigns were excluded if:

- Limited in duration or scope (e.g., one-day events without amplification)
- Conducted exclusively in non-English languages (with minimal supplementary searches in French, Spanish, Italian, and German)

In total, **101 campaigns** were reported or identified, of which **52 met the inclusion criteria** for ABC-specific public awareness initiatives. Only 18 campaigns provided partial engagement metrics; therefore, the findings are primarily qualitative.

Limitations

- Low response rates on reach and engagement metrics limit the ability to draw firm conclusions about resource or campaign impact
- The analysis was primarily limited to English-language resources and campaigns, potentially underrepresenting activity in non-English-speaking regions

APPENDIX VIII: SUPPORT SERVICE POLICY AND FUNDING ANALYSIS

Objective:

To evaluate the integration of seven critical support services into national cancer plans and their funding origin. These services included: Palliative and end-of-life care, social support, peer support, complementary and integrative medicines, wellness and lifestyle support, genetic counseling, and survivorship programs.

Methodology:

National Cancer Plan Analysis

Government-led policies, guidelines, and cancer strategies were selected for review as they play a central role in the provision and funding of support services, enabling direct cross-country comparisons. However, the influence of non-governmental organizations' guidelines on supportive care services was acknowledged, as in some countries, such as the US, the government's role may be limited due to a primarily privatized healthcare system. A summary of the key policies and cancer plans reviewed is provided in **Table 25**.

Country	Key policies*
Brazil	· National Policy for Cancer Care, 2005[619] · National Policy for Cancer Prevention and Control, 2013[619]
France	· France Ten-Year Cancer Control Strategy: 2021-2025 Roadmap[407]
Japan	· Cancer Control Act, 2006[393] · Basic Plan to Promote Cancer Control Programs, 2018[394] · Japanese Breast Cancer Society Clinical Practice Guidelines for the Systemic Treatment of Breast Cancer, 2022[395]
South Africa	· National Cancer Strategic Framework, 2017[397] · Breast Cancer Prevention and Control Policy, 2017[398]
United Kingdom	· NICE (National Institute for Health and Care Excellence) guidelines, various dates[388,403-405] · NHS (National Health Service) Long Term Plan, 2017[406]
United States	· National Cancer Act, 1971[399] · Affordable Care Act, 2010[400-401] · National Cancer Plan, 2022[402]

Table 25: Key policies and national cancer plans evaluated for each country of focus

* Policies that pre-date 2015 are included in cases where these are the most recent policies and are still active

Funding Analysis

The assessment of funding and healthcare providers for each of the seven key support services was then researched using publicly available claims data and reports, as shown below in **Table 26**.

Country	Provider of healthcare	Data source
Brazil	Private (approximately 25% of people) and public systems occurring in parallel[439]	Published claims data[437-439]
France	Statutory health insurance*	Published claims data[448] Affection de longue durée[420]
Japan	Universal Health Care Insurance System: Payment for personal medical services provides relative equality of access, with fees set by a government committee. All residents of Japan are required by the law to have health insurance coverage	Published claims data[440-441] JMDC (Japan Medical Data Center) Claims Database
South Africa	Private (for higher earners) and public systems (lower incomes only) occurring in parallel[442]	Published claims data[442-443,620]
United Kingdom	Private and public systems occurring in parallel	Published claims data[444-445,447,621]
United States	Public and private provision[436]	Published claims data[434-436,622]

Table 26: Country healthcare system and funding data source

* The French government covers many medical expenses (including support services) related to long term illnesses, including breast cancer

APPENDIX IX: SOCIAL LISTENING ANALYSIS

Objectives:

- To identify and evaluate public online conversations related to ABC, with a focus on understanding the visibility, sentiment, and key themes surrounding ABC discourse in English-speaking countries
- To provide indicative insights into public awareness, advocacy, and comparative framing of ABC within broader breast cancer discussions

Methodology:

A social listening analysis was conducted using Brandwatch, a digital consumer intelligence platform, to monitor publicly available online conversations related to ABC. The analysis covered the period from November 1, 2016, to November 13, 2024, and was geographically limited to English-speaking countries.

A search was conducted to capture a comprehensive range of relevant discourse, using search queries listed in **Table 27**:

Query remit		Search terms
Comparative references to early-stage breast cancer and other disease stages		"breast cancer" OR "advanced breast cancer" OR "early breast cancer" OR "breast cancer awareness" OR bcam OR #bcam OR "advanced breast cancer vs early breast cancer" OR "abc vs ebc" OR "advanced breast cancer v early breast cancer" OR "abc v ebc" OR
General disease terminology related to advanced breast cancer		"stage 4 breast cancer" OR "stage iv breast cancer" OR #stage4breastcancer OR #stageivbreastcancer OR "metastatic breast cancer" OR "secondary breast cancer" OR "busy living with mets" OR "late-stage breast cancer" OR "breast cancer support" OR "breast cancer advocacy" OR "late stage breast cancer" OR
Mentions of specific organizations and advocacy groups	ABC Global Alliance	"abc global alliance" OR url:www.abcglobalalliance.org OR abc-global-alliance OR engagingWith:abc-global-alliance OR #abcglobalalliance OR abcglobalalliance9631 OR engagingWith:abcglobalalliance9631 OR abcglobalall OR engagingWith:abcglobalall OR
	Make 2nds Count	"make 2nds count" OR url:make2ndscount.co.uk OR #make2ndscount OR make2ndscount OR engagingWith:make2ndscount OR make2ndscount46 OR engagingWith:make2ndscount46 OR make-2nds-count OR engagingWith:make-2nds-count OR
	METUPUK	metupuk OR #metupuk OR "met up uk" OR url:metupuk.org.uk OR "dying for a cure" OR #dyingforacure OR #darkerpink OR engagingWith:metupuk OR metupukorg OR engagingWith:metupukorg OR #metupukorg OR metupuk8644 OR engagingWith:metupuk8644 OR
	Europa Donna	"europa donna" OR url:www.europadonna.org OR "european breast cancer coalition" OR #europadonna OR #europeanbreastcancercoalition OR europa_donna OR engagingWith:europa_donna OR europadonna OR engagingWith:europadonna OR europadonnaeur OR engagingWith:europadonnaeur OR #europadonnaeur OR europa-donna-the-european-breast-cancer-coalition OR engagingWith:europa-donna-the-european-breast-cancer-coalition OR europadonnachannel OR engagingWith:europadonnachannel OR
	Metastatic Breast Cancer Alliance	"metastatic breast cancer alliance" OR "mbc alliance" OR url:www.mbcalliance.org OR mbcalliance OR engagingWith:mbcalliance OR #mbcalliance OR metastatic-breast-cancer-alliance OR engagingWith:metastatic-breast-cancer-alliance
Exclusion terms		NOT (bagdad OR author:atheeralhorof OR author:0jama OR author:hassan37692844 OR "starry night" OR "mbc radio" OR "songwriting credits" OR #jabalia_genociade OR genociade OR israel OR palestine OR judaism OR "donald trump" OR maga OR god OR #god OR "the set" OR "ceramic brake pads" OR necesitara OR administrada OR hiv OR predator)

Table 27: Search queries used to identify range of ABC relevant discourse

Collected data was analyzed using descriptive methods, focusing on:

- Volume of mentions over time
- Sentiment analysis (positive, negative, neutral)
  - Keywords mentions in the ABC only conversation: "different", "alone", "isolated", "incurable", "prevented", "curable", "stigma", "preventable", "fault", "wasted", "lonely", "hopeless", "left out", "pointless", "no point", "no hope", "waste of time"
- Identification of key recurring themes and topics within the conversation

Limitations:

The analysis only included data from publicly available sources, excluding closed or private online communities, forums, and platforms with restricted data access (e.g., LinkedIn, TikTok). As such, the findings may not fully capture the breadth of ABC-related conversations. In addition, the conversations on social media may reflect the views of more digitally active or advocacy-engaged individuals and may underrepresent broader patient, caregiver, or HCP populations.

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.

Finally, alterations to the functionality and data access policies of X (formerly Twitter) in late 2022 may have impacted data completeness and reliability from that source during the latter part of the analysis period.

APPENDIX X: ECONOMIC TARGETED LITERATURE REVIEW

Objectives:

- To understand the economic burden (out-of-pockets (OOPs), direct and indirect costs) associated with the treatment of ABC over the last decade
- To explore the available economic evaluations of pharmacological treatments used in ABC over the last decade

Methodology:

A search was conducted for studies reporting economic data relating to ABC treatment using Embase (via Embase.com) and search terms listed in **Table 28**.

The limits for this search included only items with abstracts. EMBASE accounts for both US and UK spelling.

The key inclusion and exclusion criteria for the studies identified by the searches are summarized in **Table 29**.

Information from the full-text articles of studies accepted for inclusion were extracted independently into a data extraction table. Specific data elements captured during data extraction are outlined in **Table 30**

Search Criteria	Search Terms	Hits
1	'mBC'/exp OR 'metastatic breast cancer' OR 'advanced breast cancer' OR 'stage IV breast cancer' OR 'secondary breast cancer' OR 'locally advanced breast cancer' AND [Publication date from 01/01/2015 to 19/06/2024]	5,933
2	'cost effectiveness' OR 'cost effective' OR 'cost-effectiveness' OR 'QALY' OR 'economic value' OR 'cost benefit' OR 'efficiency' OR 'cost efficiency' OR 'cost'/exp OR 'cost' OR 'economic' OR 'meaningful benefit' OR 'financial burden' OR 'health care cost'	2,261,222
3	'economic' AND 'burden'	53,900
4	#2 OR #3	2,261,222
5	#1 AND #4	269
6	'randomized controlled trial'/exp OR 'RCT' OR 'random allocation' OR 'placebo-controlled' OR 'head-to-head' OR 'head to head' OR 'comparative effectiveness' OR 'systematic review' OR 'survey' OR 'economic analysis' OR 'economic evaluation' OR 'clinical study' OR 'letter' OR 'systematic review' OR 'meta-analysis' OR 'observational study' OR 'retrospective study'	10,299,280
7	#5 AND #6	220
8	'case report' OR 'editorial' OR 'comment' OR 'review' OR 'note'	5,250,294
9	#7 NOT #8	219

Table 28: Search terms used in the economic targeted literature review and the associated number of hits

	Inclusion criteria	Exclusion criteria
Population	· ABC patients (also referred to as advanced breast cancer or progressive breast cancer)	· Patients without a primary diagnosis of ABC
Intervention	· Inclusion of licensed pharmacological treatments, standard of care or pharmacological treatment under investigation will be included	· Studies that report on economic data for non-pharmacological treatment or treatments not considered standard of care
Outcomes	· OOPs · Direct and indirect costs	· Publications that do not report economic outcomes
Study Design	· Prospective and retrospective economic studies · Full economic evaluations · RCTs and SLRs · Surveys	· Case reports, comments and editorials, animal/*in vitro* studies
Date Limit	· Publications indexed in the databases since 2015	· Publications indexed in 2014 or previous years

Table 29: Economic targeted literature review inclusion and exclusion criteria

ABC= advanced breast cancer; **OOP=** out-of-pocket; **RCT=** randomized controlled trial; **SLR=** systematic literature review.

Category	Data elements	
Study Characteristics	Name of the trial Study design Publication date	Geographic location Intervention & control arm (if applicable) Duration of treatment (cycle length, number of days per cycle)
Patient Characteristics	Age median (range) for each arm Female (%) *De novo* status (if recorded)	Subtype (e.g., HR, HER2, TNBC) Other relevant cytogenetics (e.g., *PIK3CA* status)
Economic Data	Direct costs (e.g., ABC treatment or AE management costs, outpatient visits, hospitalizations) Indirect costs (e.g., productivity, patient travel, accommodation, caregiver costs) OOPs Cost source data Resource use source data	Cost valuation Currency Cost year Definition of total costs Definition of cost components

Table 30: Economic targeted literature review key elements for data extraction

AE= adverse event; **EMA=** European Medicines Agency; **FDA=** Food & Drug Administration; **HR=** hormone receptor; **HER2=** human epidermal growth factor receptor 2; **OOP=** out-of-pocket; ***PIK3CA*=** phosphatidylinositol-4,5-bisphosphate 3-kinase catalytic subunit alpha; **TNBC=** triple negative breast cancer.

APPENDIX XI: MCCABE CENTRE FOR LAW AND CANCER ANALYSIS

Objectives:

- To understand the key workplace protections that are in place for people living with ABC and their caregivers including flexible work arrangements, paid sickness and caregiver leave, dismissal protection and non-discrimination protection including reasonable adjustments.
- To explore the barriers to the implementation of these existing workplace laws.

Methodology:

A comparative analysis of primary sources of law and relevant case law from 25 countries, as well as responses to the Work Rights Survey, was conducted by the McCabe Centre.

National laws addressing key workplace protections and entitlements were evaluated in 14 priority countries; Australia, China, Colombia, France, India, Japan, Mexico, Poland, Portugal, Spain, South Africa, United States of America, United Kingdom and Nigeria. An additional 11 countries were also included; Aotearoa New Zealand, Brazil, Canada, The Philippines, Indonesia, Iran, Kenya, Norway, Sweden, Samoa and Uganda. Cross-country comparisons were made, excluding India whose laws could not be analyzed in detail due to large-scale employment law reforms in the country.

Limitations:

The analysis only included national laws to allow for cross-country comparisons. Therefore, the sub-national level laws that are in place in many countries are not included, and the findings may not fully capture the employment laws in each country. Additionally, other countries may have laws that stipulate other important approaches to workplace protections that are not included in the analysis. Finally, although touched upon, a comprehensive analysis of the implementation of the identified laws is missing. This is vital in order to fully understand the value of these workplace protections.

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