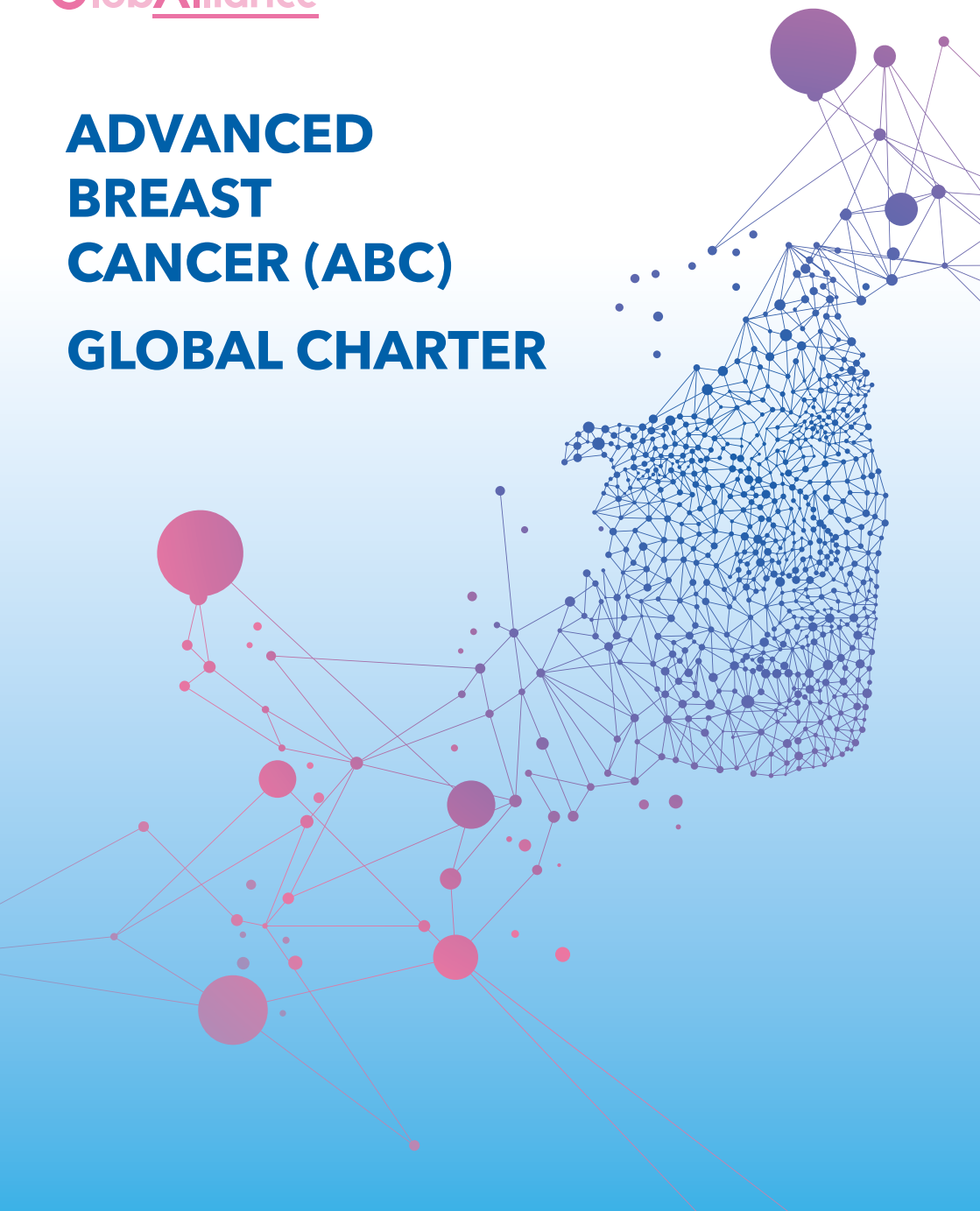




# **ADVANCED BREAST CANCER (ABC) GLOBAL CHARTER**



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## INTRODUCTION

### WHO WE ARE?

The ABC Global Alliance is a multi-stakeholder platform for all those interested in collaborating on common projects relating to advanced breast cancer (ABC) around the world. Our goal is to improve and extend the lives of women and men living with ABC in all countries worldwide and fighting for a cure.

### WHAT WE DO?



RAISE AWARENESS ON ABC WORLDWIDE



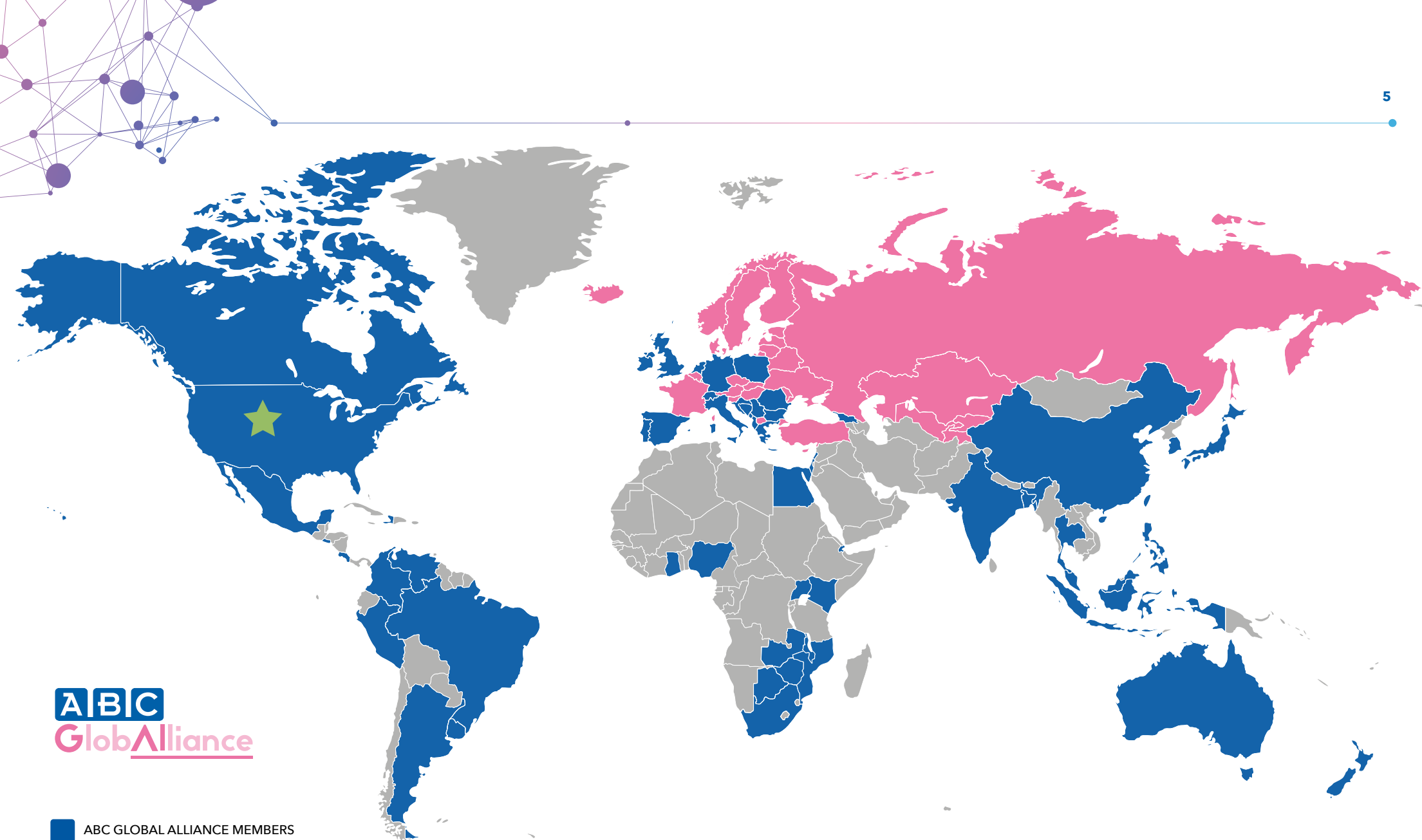
CREATE, COLLECT AND SHARE UP-TO-DATE DATA AND INFORMATION ON ABC, ABC TREATMENT AND CARE OPTIONS



CREATE AN ACTIVE ABC COMMUNITY



PROVIDE SUPPORT TO PATIENT ADVOCATES

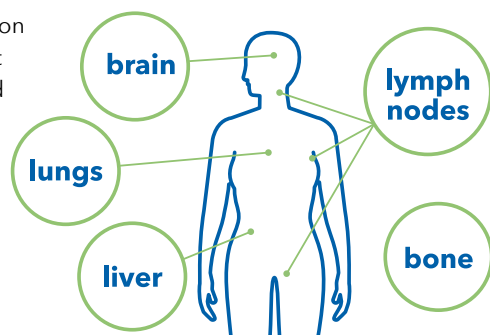


209 MEMBERS IN 93 COUNTRIES AS OF JULY 2022

## WHAT IS ABC?

Advanced breast cancer (ABC) comprises inoperable locally advanced breast cancer (LABC) and metastatic breast cancer (mBC). The latter is also known as stage IV or secondary breast cancer. For the purposes of this document, we use the term advanced breast cancer or the abbreviation ABC.

The most common places for breast cancer to spread to are:<sup>1</sup>



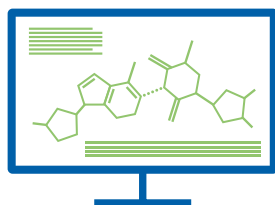
Symptoms vary depending on where the cancer has spread<sup>1</sup>




Management is complex and involves systemic therapy (that goes through all the body) including **chemotherapy**, **endocrine therapy** and **targeted therapy**, as well as **radiotherapy** and **surgery**. Crucial to have a multi-disciplinary approach<sup>2</sup>

Although **treatable**, it remains an **incurable disease**

**New technologies and research** should help to accelerate advances in management<sup>2</sup>



While significant progress have been made in the early breast cancer (EBC) field, major gaps still exist in the treatment and management of ABC. Breast cancer is the top cancer in women worldwide and is increasing particularly in developing countries where the majority of cases are diagnosed in late stages, underscoring the urgent need to address gaps in current care.

 **2.3m**

Breast cancer is the most commonly diagnosed cancer in women worldwide, with **2.3 million** women diagnosed with breast cancer in 2020.<sup>3</sup>



Breast cancer accounts for a **quarter** of all cancers in women<sup>3</sup>



While it is rare, Breast Cancer can also occur in **men**<sup>4</sup>

**1%** of all breast cancer occurs in male patients<sup>5</sup>. In men, the disease is much rarer, but tends to be more advanced when detected compared to women.



Almost **50%** of breast cancer cases and **58%** of deaths occur in less developed countries<sup>5</sup>

Metastatic disease may occur at diagnosis (called "**de novo**") or as a relapse sometime after a diagnosis of early breast cancer (called **recurrent**).

In the developed countries **de novo** ABC represents only **about 10-15%**, while in developing countries it reaches **60 or 80%** of new breast cancer cases.

<sup>1</sup>. Cancer Research UK. Symptoms of Advanced Breast Cancer. Available at: <http://www.cancerresearchuk.org/about-cancer/breast-cancer/advanced/symptoms> [Accessed 1 March 2017] <sup>2</sup>. Global Status of Advanced/Metastatic Breast Cancer 2005e2015 Decade Report. Available at: [www.breastcancervision.com](http://www.breastcancervision.com) and [www.abc-lisbon.org](http://www.abc-lisbon.org) [Accessed 24 February 2017]

<sup>3</sup>. Globocan 2020, Available at <https://gco.iarc.fr/today/home> [Accessed 18 August 2022] <sup>4</sup>. American Cancer Society. What are the Key Statistics About Breast Cancer in Men Available at <https://www.cancer.org/cancer/breast-cancer-in-men/about/key-statistics.html> [Accessed 24 February 2017] <sup>5</sup>. Philips Foundation. 2020, Improving survival rates of breast cancer in underserved communities. Available at <https://www.philips-foundation.com/a-w/articles/pink-ribbon-2020.html#:~:text=It%20is%20estimated%20that%20worldwide,less%20developed%20countries%20%5B2%5D> [Accessed 18 August 2022]



**700.000**

Almost **700 000** people **worldwide died** from breast cancer in 2020, the majority of whom with advanced disease.<sup>3</sup>

**142.000**

women in Europe die from breast cancer every year.<sup>3</sup>



**2-3 years**

**Median survival of all ABC subtype is about 3 years.**

For HER2+ and for ER+/HER-2 negative subtypes median survival is now reaching 5 years.<sup>3,6</sup>

## 10 GOALS TO DRIVE GLOBAL IMPROVEMENTS IN ABC CARE



<sup>3</sup>. Globocan 2020, Available at <https://gco.iarc.fr/today/home> [Accessed 18 August 2022] <sup>6</sup>. F. Cardoso, et al. ESO-ESMO 5th International Consensus Guidelines for Advanced Breast Cancer (ABC 5). Published in Annals of Oncology (Annals of Oncology, volume 31, issue 12, September 2020, DOI:<https://doi.org/10.1016/j.annonc.2020.09.010>)

## WHY THE ABC GLOBAL CHARTER?

The ABC Global Charter has been developed to address the most urgent and actionable gaps in treatment and care of patients with advanced breast cancer (ABC) and define achievable and realistic goals to ultimately improve and extend their lives.

These gaps and correspondent goals have been identified through intense discussion with all stakeholders involved in the field but mostly by patients and advocates.

The ABC Global Charter aims to drive change in the care of patients with ABC, tailoring actions to make them relevant and feasible for different geographies and capacities. The Actions for Change aim to achieve near and longer-term goals, to give patients a voice, bring patient needs to the fore for driving decision-making and ultimately improve and extend their lives.

## HOW WAS THE ABC GLOBAL CHARTER DEVELOPED?

The ABC Global Charter addresses gaps in care, access to resources and support, and treatment outcomes for patients with ABC, as identified in the Global Status of Advanced/ Metastatic Breast Cancer 2005-2015 Decade Report.<sup>1</sup>

A steering committee of global multidisciplinary advanced breast cancer advisors, comprising physicians, leaders of patient-support organizations, and patients, contributed to the development of the report.

An earlier collaboration between ESO and Pfizer led to the development of the preliminary mBCVision2025 'Call-to-Action'. This important work has been taken forward by the multi-stakeholder ABC Global Alliance to become the ABC Global Charter.

The content for the Call-to-Action was determined by consensus from mBC Vision 2025 Taskforce members.

Following an open consultation process to gain feedback and input on the Global Charter from the ABC community, the ABC Global Alliance Interim Steering Committee revised and finalised the ABC Global Charter in 2017.

The Charter has been revised in 2018 for better wording and clarification and approved by the ABC Global Alliance Executive Committee.

The latest revision dated in 2022 includes further clarification of the content, text restructuring, and graphic upgrade.

### REFERENCES

1. Global Status of Advanced/Metastatic Breast Cancer: 2005-2015 Decade Report. <http://breastcancervision.com>. Published March 2016. Accessed August 2017.

## KEY GAPS AND AREAS FOR IMPROVEMENT

### ➔ PATIENT OUTCOMES AND DISEASE BURDEN

Patient outcomes in ABC have improved minimally over the past decades, with substantial variation according to subtype of breast cancer, and there is currently no cure. Despite some advances, there is limited understanding of how to achieve disease remissions and also to improve tolerability of therapy and quality of life (QoL) for patients living with ABC. Currently, disease burden and unmet needs are difficult to measure due to widespread lack of accurate, population-based data for patients with ABC.

### ➔ PUBLIC PERCEPTION AND STIGMA

Stigma and isolation are commonly experienced by those with ABC, highlighting a need for increased support and awareness in the broader community. The general public, though differing by country and region, has misperceptions around ABC, driven by a lack of education about the disease, the notion of survivorship in breast cancer, and scientific progress in EBC to date.

### ➔ SOCIAL AND CAREGIVER RELATIONSHIPS

Societal understanding of ABC is limited, which can apply additional pressure to the immediate family and caregivers of patients, who have deeper understandings of the patient experience. This increased burden, specifically on caregivers, results in emotional, financial, professional and practical unmet needs.

### ➔ ADVOCACY INITIATIVES

Many patient support organizations include patients with ABC in their care and outreach. Despite recognition of the greater needs of patients with ABC compared to those with EBC, too few organizations are able to secure adequate resources to support ABC-specific initiatives and policies.

### ➔ WORKPLACE INITIATIVES

Despite willingness and financial pressures to return to work, patients with ABC often do not receive recognition or the opportunity for adequate adjustments within the workplace. Many employers have limited understanding of the specific needs and impact of ABC, which result in insufficient support for their ABC employees during diagnosis and treatment. Most patients with ABC are forced to leave or adapt their professional activity with significant psychological and financial consequences.

### ➔ POLICY

ABC has been and will continue to be associated with a significant economic burden to society and healthcare systems. Despite this, there remains limited ABC-focused policies to drive improved levels of cost-effective and quality care.

### ➔ PATIENT CARE CONTINUUM

Comprehensive care gaps exist in breast cancer centers along the care continuum, from diagnosis through to end of life. Improvements in supportive care services, such as psychosocial care and access to multidisciplinary teams, are needed.

### ➔ HEALTHCARE PROVIDER COMMUNICATION AND SUPPORT

There is a lack of ABC-specific training and educational materials to support HCPs engaging in a two-way dialog with patients. This limits conversations around diagnosis, treatment decisions, disease progression and end of life, leaving people with ABC unprepared for what lies ahead.



## 10 ACTIONS FOR CHANGE

1

### HELP PATIENTS WITH ABC LIVE LONGER BY DOUBLING ABC MEDIAN OVERALL SURVIVAL BY 2025

- There has been limited improvement in patient outcomes in ABC over the past decades, and the burden of disease is expected to continue to rise.
- All patients with ABC must be treated by a multidisciplinary, specialized team, and according to high quality international/ national guidelines.
- Policy environment should allow access for all patients with ABC to the best available therapies and to supportive/ palliative measures.
- Dedicated and coordinated research is needed specifically focused on ABC.
- The patient voice needs to be included (via experienced patient advocates) in the design of clinical trials and development of clinical registries/criteria.

2

### ENHANCE OUR UNDERSTANDING ABOUT ABC BY INCREASING THE COLLECTION OF HIGH QUALITY DATA

- Generally, cancer registries around the world only collect information about initial cancer diagnoses and mortality; most do not document cancer recurrences that represent the majority of ABC cases and therefore it is currently unknown how many patients with ABC exist.
- Readily accessible, good-quality data at the time of ABC progression, recurrence, and survival (i.e. of robust epidemiology and outcomes data for ABC) are urgently needed and can be useful for shaping policy decisions.
- Provide guidance and input to help establish uniformity of the ABC data collection.
- Increase knowledge about ABC by developing and implementing robust Big Data (Analytic) systems/processes, around the world.
- Include the patient voice (via experienced patient advocates) in the design of clinical trials and development of clinical registries/criteria.

3

### IMPROVE THE QUALITY OF LIFE (QOL) OF PATIENTS WITH ABC

- Improve the wellbeing of patients living with ABC by raising awareness about the need to collect and act upon quality of life data.
- Limited utilization of QoL tools in clinical practice can be partially attributed to a non-standardized definition of QoL and inadequate measurement tools for advanced and metastatic patients. Increased focus on development and implementation of ABC-specific QoL measurement tools in clinical practice and policy making is essential to improve QoL and care of patients with ABC.
- Systematically include QoL, PROMs (patient-reported-outcomes) and PREMs (Reported Experience Measures) in clinical research to understand patient perspective of living with ABC and the burden of treatment.
- QoL should encompass physical, social, and emotional well-being including relationships, supporting the need for a holistic and multidisciplinary approach to care.
- Patients input regarding what type of QoL issues to measure, respecting geographical and cultural differences, should be sought.
- Empower patients to raise QoL expectations and discuss this with their healthcare professionals as well as their treatment

4

### ENSURE THAT ALL PATIENTS WITH ABC RECEIVE THE BEST POSSIBLE TREATMENT AND CARE BY INCREASING AVAILABILITY OF AND ACCESS TO CARE FROM A MULTIDISCIPLINARY TEAM

- Patients with ABC require access to multidisciplinary clinical care and specialists to improve treatment, outcome and overall QoL.
- Support should differ from that for early breast cancer (EBC) patients, particularly regarding types of available information.
- Increase availability and access to multidisciplinary care, including palliative, supportive, and psychosocial assistance for patients, families, and caregivers to ensure patients are receiving the best treatment experience.
- The development of access to remote multidisciplinary tumour boards is essential for patients living in a long distant from all major care centres.
- Ensure that each patient with ABC has access to a "key contact" who is also a member of the multidisciplinary team and who coordinates their care throughout the care continuum, including when elements of that care take place outside the specialist breast unit/centre.
- A range of materials should be available and tailored to meet patients' specific needs and to empower patients when making treatment decisions; support should be offered to patients when reviewing the content.
- Gaps in support for sexual health and relationships should be acknowledged and addressed.
- Address the needs of families and caregivers in a culturally sensitive way, including the needs of children, adults including spouses, siblings, parents and non-related caregivers.



5

#### IMPROVE COMMUNICATION BETWEEN HEALTHCARE PROFESSIONALS (HCP) AND PATIENTS WITH ABC THROUGH THE PROVISION OF COMMUNICATION SKILLS TRAINING FOR HCPS

- Advanced Communication skills should be included as an essential component of healthcare provider education programs for all HCPs caring for patients with ABC including at medical school core curriculum level. The ESMO-ASCO Global Oncology Curriculum should be implemented in all countries.
- Within communication training programs, there should be an emphasis on ensuring that HCPs understand what matters to patients and carers in order to support and guide them through treatment decisions.
- Learnings can be drawn by HCPs from other advanced and some chronic diseases to drive change in patient perception of ABC - from that of a death sentence to a condition with which patients can live for a prolonged period of time. There is a need to validate the effectiveness of education and communication tools in different languages.

6

#### MEET THE INFORMATIONAL NEEDS OF PATIENTS WITH ABC BY USING EASY TO UNDERSTAND, ACCURATE AND UP-TO-DATE INFORMATION MATERIALS AND RESOURCES

- Increase access to existing materials for those seeking them rather than creation of new ones; increase networking and sharing of best practice examples between organisations.
- Materials should be focused on messages most relevant to patients with ABC, such as patients' fears of pain and uncertainties about their disease and its outcome. Materials should assist patients in the decision-making process, including addressing individual patient needs.
- It is critical that resources in low- and middle-income countries are explicit in what treatments are available to patients specifically in their own. However, information should also be provided on treatments available in other countries, to allow patients to access these if they are able.

7

#### ENSURE THAT PATIENTS WITH ABC ARE MADE AWARE OF AND ARE REFERRED TO NON-CLINICAL SUPPORT SERVICES

- Outside of clinical care, patients are often unaware of available services, such as local volunteer/advocacy organizations, to assist with daily activities and living. Awareness of these services should be raised, and patients referred to them as appropriate.
- Policies are needed to help minimize access barriers to supportive services and assist in efficiently connecting patients to the services they need.
- Increased access to and provision of non-medical patient navigators and care coordinators is needed to help patients understand services available and what they are entitled to receive, as well as to facilitate access to and increase uptake of those services required.

8

#### COUNTERACT THE STIGMA AND ISOLATION ASSOCIATED WITH LIVING WITH ABC BY INCREASING PUBLIC UNDERSTANDING OF THE CONDITION

- The stigma and isolation felt by patients with ABC can be attributed to limited understanding of the disease by the general public.
- There is a need to educate the general public on what the terms "advanced breast cancer" and "metastatic" mean. Education is needed to highlight that patients can live with the disease while also transparently conveying the truth, particularly around the median overall survival.

9

#### ENSURE THAT PATIENTS WITH ABC HAVE ACCESS TO TREATMENT REGARDLESS OF THEIR ABILITY TO PAY

- Strive for all patients with ABC to have financial support for treatment, care and assistance if unable to work.
- Provide a mechanism to avoid financial catastrophe in the event that patients lose employment.
- Work to ensure that patients with ABC have or maintain health coverage, even if unemployed.
- Support access to treatment regardless of the ability to pay, through policy and accountability mechanisms.
- Work to ensure patients have access to additional financial support where needed e.g. for childcare, transport to access their treatment.
- Support patients with financial advisory services, empowering them to better manage their finances throughout treatment.

10

#### HELP PATIENTS WITH ABC CONTINUE TO WORK BY IMPLEMENTING LEGISLATION THAT PROTECTS THEIR RIGHT TO WORK AND ENSURES FLEXIBLE AND ACCOMMODATING WORKPLACE ENVIRONMENTS

- Many patients with ABC want or need to continue working through their diagnosis and treatment; however, there are very few policies and guidelines that focus on employment during cancer treatment for metastatic disease.
- Most patients with ABC are not protected in the workplace and are often denied employment flexibility to deal with effects of the disease and its treatment. In addition, patients with ABC may face discrimination based on disease misperceptions.
- Protection against discrimination should come from individual employers and the employment system and patients should be empowered through provision of information and knowledge to request support and protection.

Our goal is to unite the ABC community by **CATALYSING CHANGE TO IMPROVE ABC PATIENT OUTCOMES.**

Healthcare professionals (HCPs), governments, health policy makers, patient advocates, members of the breast cancer community, and anyone whose life is touched by ABC should unite to **TAKE ACTION** at local and international levels to help achieve the objectives described by 2025 and in doing so ensure that advanced breast cancer patients feel included in the Sustainable Development Goals vision of “leaving no one behind”.

## CONTRIBUTORS TO THE ABC GLOBAL CHARTER

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## SPONSORS AS OF 2022

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### SPONSOR



The ABC Global Alliance is grateful to PLMJ for the pro bono services provided.



The ABC Global Alliance would like to extend its gratitude to Novobanco for their contribution to some of our events and initiatives.



**1 IN 4 PEOPLE  
WITH ADVANCED  
BREAST CANCER  
WILL BE ALIVE  
5 YEARS AFTER  
THEIR DIAGNOSIS<sup>1</sup>**



I ...  
Do solemnly promise,  
To combat the gaps in care.  
So nobody feels like a burden,  
Is shunned by their village,  
Shamed by neighbours,  
This is why I make this vow,  
To close the gaps in breast cancer care.  
So no one,  
No one ever in the world,  
Suffers poor care,  
Or dies before they might,  
Of Advanced Breast Cancer.

**The ABC Global Charter  
has outlined 10 achievable  
goals for the next 10 years  
to drive change in advanced  
breast cancer (ABC) care**



*Be the change*

[www.abcgloballiance.org](http://www.abcgloballiance.org)

1. Cardoso F, Spence D, Mertz S, Corneliussen-James D, Sabelko K, Gralow J, et al. Global analysis of advanced/metastatic breast cancer: decade report (2005-2015). The Breast. 2018 Jun;39:131-8.



#### STAY IN TOUCH WITH US

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