

Best  
practice in  
ABC/mBC

# Raising awareness and promoting earlier diagnosis

The Hard-to-Reach ABC/mBC Communities Toolkit has been developed by the ABC Global Alliance and Pfizer to drive collaboration across the global advanced/metastatic breast cancer (ABC/mBC) community and improve access to care for hard-to-reach populations, by forming a resource bank of key initiatives and best practice case examples.

This document has been developed to showcase the important initiatives that have been created to raise awareness and promote earlier diagnosis of ABC/mBC globally. The best practices outlined here have been collated through a combination of written submissions and interviews with the creators of these initiatives. The Steering Committee would like to thank the initiatives that contributed to the best practice examples outlined throughout this document.

Each initiative included in this document addresses at least one of the **5 hard-to-reach populations** outlined below:



**Ethnic, religious,  
indigenous/native  
population and/or  
other minorities**



**Low income  
patients**



**Older patients**



**Rural patients**

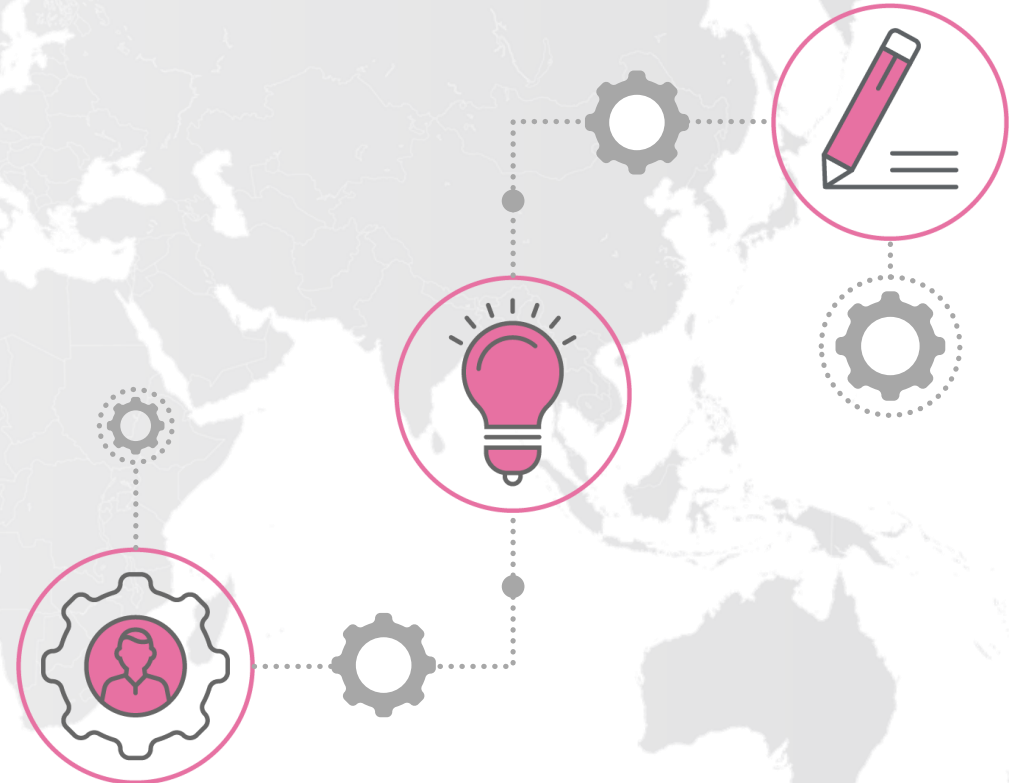


**Low health  
knowledge  
patients**





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# Unmet needs addressed

Initiatives that raise awareness and promote the earlier diagnosis of breast cancer are essential to improve survival and quality of life of people living with the disease. It is well known that early diagnosis with breast cancer is associated with better survival rates and improved quality of life for those living with the disease – but this is not just limited to early breast cancer (eBC). Initiatives that raise awareness of ABC/mBC and promote earlier diagnosis of the relapse/metastases are crucially important in increasing understanding of the disease, allowing for the start of treatment earlier, and ultimately improving outcomes for patients with ABC/mBC. Furthermore, promoting earlier diagnosis of breast cancer will eventually decrease the percentage of patients diagnosed already with ABC/mBC (also called “de novo advanced/metastatic disease”).

**While people are generally well-informed regarding eBC, many people – including patients with a primary breast cancer diagnosis – are not aware of ABC/mBC and its associated risks, which can lead to late diagnosis.** This may be due to:

- Low education and a lack of available information / resources specifically for advanced/metastatic disease
- HCP resistance to share information on ABC/mBC through fear of scaring their patients
- Patient resistance to understanding the disease and seeking diagnosis, due to:
  - Fear of cancer return
  - Socio-cultural and religious taboo
- Disparities in access to treatment for ABC/mBC
- Low treatment compliance

“

*It is the message about early diagnosis that needs to get out there, as well as early BC diagnosis, it has to be ABC diagnosis as early as possible [...] it is all about finding things early.*

”

– Jo Taylor,  
founder of After Breast Cancer  
Diagnosis (ABCD)



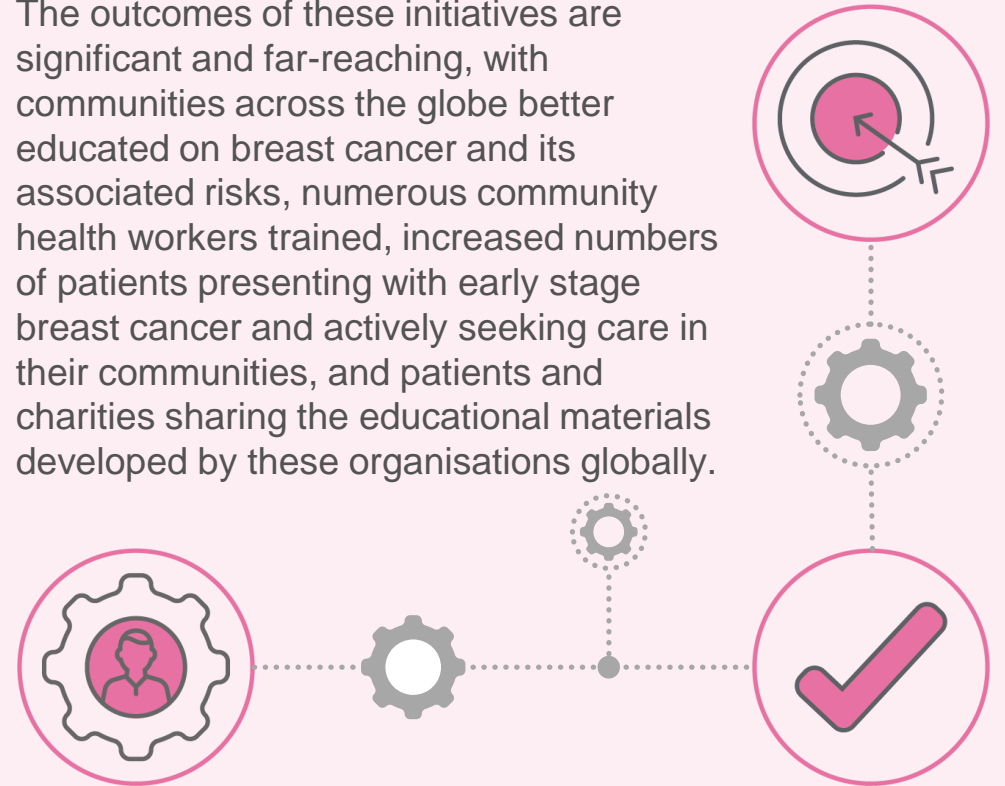


# Objectives

**Common initiative objectives, designed to overcome barriers to ABC/mBC awareness and early detection, include:**

- Understand the existing barriers to early diagnosis and treatment of breast cancer
- Improve patient understanding of advanced/metastatic disease, its signs & symptoms and associated risks
- Promote the use of accurate and specific information on ABC/mBC
- Empower communities to check for signs of breast cancer (including ABC/mBC), seek diagnosis and subsequent care
- Reduce the number of late stage breast cancer diagnoses and improve patient survival rates
- Improve outcomes and quality of life for people living with ABC/mBC
- Improve access, uptake and compliance to optimal treatments for patients with ABC/mBC

The outcomes of these initiatives are significant and far-reaching, with communities across the globe better educated on breast cancer and its associated risks, numerous community health workers trained, increased numbers of patients presenting with early stage breast cancer and actively seeking care in their communities, and patients and charities sharing the educational materials developed by these organisations globally.





# Contributing initiatives

## ABC Infographics

Country/region: England

### Hard-to-reach communities targeted

- ✓ Ethnic, religious, indigenous/ native populations and/or other minorities
- ✓ Low income patients
- ✓ Rural patients
- ✓ Older patients
- ✓ Low health knowledge patients



### Brief description

Following breast cancer diagnosis, many patients are unaware of advanced/metastatic disease and the symptoms to look out for. This initiative comprises two infographics showing simple to understand red-flag symptoms for both ductal and lobular ABC/mBC, for use with patients and as an educational tool for HCP training.

### For more information

[www.abcdiagnosis.co.uk/resources/infographics](http://www.abcdiagnosis.co.uk/resources/infographics)

Jo Taylor (jo@abcdiagnosis.co.uk)

## Care-A-Van Breast Cancer Project

Country/region: Malaysia

### Hard-to-reach communities targeted

- ✓ Ethnic, religious, indigenous/ native populations and/or other minorities
- ✓ Low income patients
- ✓ Rural patients
- ✓ Low health knowledge patients



### Brief description

In Malaysia, there are multiple barriers to early diagnosis and treatment of BC, and outreach projects often work in silos and only in big cities. This collaborative, multi-organization initiative aims to increase early BC diagnosis in urban poor communities, as well as provide information, support and care specifically for patients with ABC/mBC.

### For more information

[www.thrive-malaysia.com/](http://www.thrive-malaysia.com/)

One-page summaries for each initiative can be accessed [here](#).





# Contributing initiatives

## The “CIMA Model”

Country/region: Mexico

### Hard-to-reach communities targeted

- ✓ Low income patients
- ✓ Rural patients
- ✓ Low health knowledge patients



### Brief description

People living in marginalized areas of Mexico are often diagnosed with late stage breast cancer due to limited information on the risks of BC and early detection methods. This initiative aims to train a network of health promoters to raise awareness of BC and lower the number of diagnoses at advanced/metastatic stage, as well as improving QoL for those diagnosed.

### For more information

[www.facebook.com/tvguanajuato/videos/863856633821506/](https://www.facebook.com/tvguanajuato/videos/863856633821506/);  
[https://youtu.be/dJu\\_kq4uCHk](https://youtu.be/dJu_kq4uCHk)

Alejandra de Cima (alejandra@cimafundacion.org)

## Community Outreach Programme

Country/region: Ghana

### Hard-to-reach communities targeted

- ✓ Ethnic, religious, indigenous/ native populations and/or other minorities
- ✓ Low income patients
- ✓ Rural patients
- ✓ Older patients
- ✓ Low health knowledge patients



### Brief description

Women in Ghana, especially those in villages and deprived communities, have low awareness of BC and often do not have easy access to early detection methods. This initiative aims to reduce the rate of late stage BC diagnosis by travelling to these communities to offer education, breast examination, advice and support (including for patients with ABC/mBC).

### For more information

[www.breastcareinternational.org/bci-community-outreach-program](http://www.breastcareinternational.org/bci-community-outreach-program)  
Beatrice Wiafe Addai (drwiafe@gmail.com)

One-page summaries for each initiative can be accessed [here](#).





# Contributing initiatives

## Community-Based Women's Cancer Awareness

Country/region: Haiti

### Hard-to-reach communities targeted

- ✓ Low income patients
- ✓ Rural patients
- ✓ Low health knowledge patients



### Brief description

Communities in Haiti have low awareness of BC and often do not engage with cancer care services until the disease is at a very advanced stage. This research-led initiative aims to raise BC awareness through a multimedia campaign, designed in Creole, including pamphlets, videos, t-shirts, and wallets for the public and a training manual for HCPs.

### For more information

[www.kanseayiti.com](http://www.kanseayiti.com)

Dr. Vincent DeGennaro ([innovatinghealthinternational@gmail.com](mailto:innovatinghealthinternational@gmail.com))

## Male Breast Cancer Global Alliance

Country/region: Global\*

### Hard-to-reach communities targeted

- ✓ Ethnic, religious, indigenous/ native populations and/or other minorities



Male Breast Cancer  
Global Alliance

### Brief description

Globally, there is low awareness and stigma around male BC and male mortality rates are rising steadily. This organisation advocates to change the BC conversation and provide men with the same access to research, clinical trials and drugs as their female counterparts. As part of their work they have developed breast self exam cards specifically for males.

### For more information

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

Cheri Ambrose ([cambrose0214@gmail.com](mailto:cambrose0214@gmail.com))

\* With focus on US, Australia, South Africa, UK, Japan, and Kenya  
ABC: advanced breast cancer; mBC: metastatic breast cancer, HCPs: healthcare professionals



# Contributing initiatives

## Treat Me Well

Country/region: Brazil

### Hard-to-reach communities targeted

- ✓ Low income patients



### Brief description

Patients with BC in Brazil often face delays in diagnosis and starting treatment, and are unaware of their rights to care. The annual awareness campaign during 'Pink October' has been created by FEMAMA with the aim to change public policy – by empowering patients, informing them on their rights and the possibilities of better access to care in Brazil.

### For more information

[www.metratedireito.femama.org.br](http://www.metratedireito.femama.org.br)

FEMAMA ([comunicacao@femama.org.br](mailto:comunicacao@femama.org.br))

## Givemetime.now

Country/region: Sweden

### Hard-to-reach communities targeted

- ✓ Ethnic, religious, indigenous/ native populations and/or other minorities
- ✓ Older patients



### Brief description

This multi-channel awareness campaign has been created to highlight the unequal uptake of CDK4/6 inhibitors across Sweden despite there being a national recommendation to use them within their label. The campaign consists of a film and web-page which will be promoted via digital and traditional channels to raise awareness and help increase the uptake of CDK4/6 inhibitors.

### For more information

<https://brostcancerforbundet.se/gemigtid/>





# Development process

**While the development process for different initiatives may vary, building a strong team and a clear plan is important.**

- Assembling the right team and ensuring that there is a collaborative development process is an important factor in the success of many initiatives. Whether this is a multi-disciplinary project team, including patients and HCPs, or a partnership between organisations to provide their expertise, the importance of teamwork cannot be overlooked
- The **ABC Infographics** initiative relied on devoted volunteers – including a web specialist, patients with ABC/mBC, and clinicians – throughout the development process
- Involving patients and HCPs in development is a good way to ensure that the initiative is evidence-based and relevant to patient and/or clinician needs. This interaction should not stop once the initiative is developed, with many initiatives highlighting the importance of continuing to engage and collect feedback from these stakeholders
- The **givemetime.now** initiative built on a previous 3-year collaboration with the Swedish national patient organisation for BC to increase knowledge and engagement around BC

Collaboration may occur from project initiation – such as with the **Care-A-Van** initiative in Malaysia. The University Malaya's REBUNG partnered with multiple organizations including Care-A-Van from Pfizer Malaysia to develop a multimedia breast cancer awareness and education campaign. The aim of this was to increase early BC diagnosis in poor communities, as well as to provide information, support and care specifically for patients with ABC/mBC. This initiative also sought further support from drivers, nurses and volunteers.

“

*This project has been created by passion, wanting to make change, other people getting on board with it.*”

– Jo Taylor,  
founder of ABCD





# Development process

**While the population targeted in this toolkit are considered hard-to-reach, initiatives used a variety of channels to reach their target audience:**

- The **Male Breast Cancer Global Alliance** and **ABC Infographics** developed simple, visual materials to be shared online, via social media, and printed
- The **Community Outreach Programme** raised awareness in rural Ghana by taking HCPs and patient representatives to these locations on a bus, and **The CIMA Model** trained local health promoters to deliver awareness campaigns in marginalised communities in Mexico
- Face-to-face HCP-patient interaction is important in countries with stigma around ABC/mBC
- It is possible to reach a wider population using email, social media, press and website development. The **Treat Me Well** awareness campaign aimed to change public policy in Brazil and **Givemetime.now** created a film, webpage and marketing to highlight the unequal access to care.

**Many initiatives secure funding through grants, or individual donors, but it is possible to have a large impact with relatively low development costs.** Once set up, initiatives can run for many years – either over a specific time period, such as **Treat Me Well** which runs annually during ‘Pink October’, or ongoing, such as the **Community Outreach Programme** which has been running in Ghana since 2002.

**Although the exact development process varies between initiatives, several key steps were followed no matter where or how the initiative was conducted:**

1. Choose your team carefully
2. Identify the specific population you are targeting
3. Choose the best channel(s) to reach your target audience
4. Gain feedback from experts and a subset of your target population before rollout
5. Routinely assess if the initiative is achieving what it was initially set out to

*Based on written submissions and interviews with initiative owners listed on pages 5-8, 2020-2021.*



# Challenges

**All initiatives face challenges during their development and many organisations are employing inventive ways to overcome them.** There is opportunity to learn from the challenges faced by others and apply these learnings when developing similar initiatives in other countries or hard-to-reach ABC/mBC populations. **Potential challenges for organisations leading initiatives may be overcome through collaboration, persistence and flexibility.**

**HCPs can be resistant to telling their patients about the reality of ABC/mBC due to the fear of upsetting or stressing them.** This is particularly relevant in countries such as Malaysia, Ghana, and Haiti where there is stigma associated with advanced disease, but is no less of a challenge in countries such as the UK. This may be overcome by sharing real patient insights and preferences for the information that they receive about their disease with HCPs.

When developing **ABC Infographics**, ABCD founder Jo Taylor overcame this challenge by persuading HCPs that fear of cancer return is more concerning to patients than knowing the truth about their disease. The infographics help to address this fear and subsequently improve the mental wellbeing of patients with breast cancer, as they better understand the signs of ABC/mBC and are more aware of the associated risks.

“

*It is a clinician duty of care to advise about this [risk of recurrence]. Is there any other disease where people are not being told about it? Why is cancer so scary that people are dying because they do not know about their disease?*

– Jo Taylor,  
founder of ABCD

”





# Challenges

**Resistance to discuss ABC/mBC is not limited to HCPs – in communities with cultural or religious taboo, patients can be reluctant to seek support for the disease.** Involving patients in the care of others is a potential way to overcome this challenge – the **Community-Based Women's Cancer Awareness** initiative trained cancer survivors as community-health workers in Haiti, and the **Community Outreach Programme** encouraged patients living with breast cancer to share their stories in Ghana, both helped to alleviate stigma around ABC/mBC in these communities.

**Promoting initiatives to successfully reach populations with poor access to social media can be particularly challenging.**

Partnering with local hospitals, radio stations, work places and places of worship may be helpful for reaching rural or isolated communities, as was the case for the **Community Outreach Programme** initiative in Ghana.

For initiatives targeting a global audience, the challenge of translation is one that must be overcome.

The **Male Breast Cancer Global Alliance** enlisted the help of doctors, nurses and friends of the organisation to translate their breast self exam cards – underscoring the importance of teamwork.

**While initiatives do not necessarily require a large amount of funds to be impactful, obtaining sufficient funding to develop and run these important initiatives can be challenging.** Dr Beatrice Wiafe, a general surgeon and founder of Breast Cancer International, initially provided services at her own expense when starting the **Community Outreach Programme** in Ghana.

Hard-to-reach populations can often be invisible and it is important to clearly outline the need and rationale for the project in order to secure funding or support from stakeholders. Winning people over can take time, with the **ABC Infographics** initiative taking 4 years from concept to adoption by NHS England – proving that persistence is key.





# Initiative Spotlight: ABC infographics

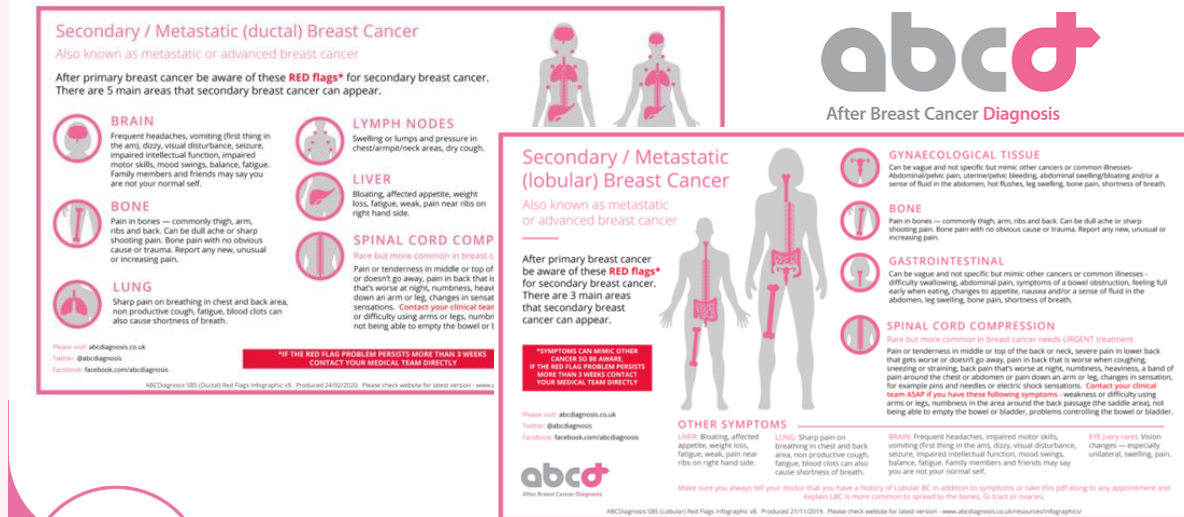
ABC/mBC  
awareness &  
promotion of  
earlier  
diagnosis

While all initiatives that raise awareness and promote earlier diagnosis of breast cancer are important, the steering committee chose to highlight the work of **After Breast Cancer Diagnosis (ABCD)** in developing the **ABC Infographics** initiative, due to its specificity to advanced/metastatic disease, as well as its significant impact and its ability to be replicated in other hard-to-reach populations and geographies. This initiative was developed in response to low patient awareness of ABC/mBC, even following a primary breast cancer diagnosis. It consists of two infographics showing simple to understand red-flag symptoms for both ductal and lobular ABC/mBC, for use with patients and as an educational tool for HCP training.

**ABCD was founded by Jo Taylor in 2013, following her own diagnosis with breast cancer in 2007. She was diagnosed with ABC/mBC a year later in 2014.** By raising awareness of the red-flag symptoms of ABC/mBC in primary breast cancer patients, as well as people not diagnosed with breast cancer, the initiative aims to:

- Increase early diagnosis of advanced/metastatic disease, therefore improving treatment options and outcomes
- Address fear of cancer return, and subsequently improve quality of life and mental health of patients living with BC

**The relative simplicity of the output of the initiative and the large unmet need that it addresses has led to great success.** This simplicity means that the infographics are widely accessible and can easily be adapted for different cultures and languages. While this initiative did not require a lot of funding, it did rely on the hard work and determination of Jo and a dedicated team of volunteers.



**For more information:**

https: [www.abcdiagnosis.co.uk/resources/infographics/](https://www.abcdiagnosis.co.uk/resources/infographics/)

Email: [jo@abcdiagnosis.co.uk](mailto:jo@abcdiagnosis.co.uk)

Based on written submission and interview  
with Jo Taylor, ABCD, 2020.

ABC: advanced breast cancer; mBC: metastatic breast cancer, HCPs: healthcare professionals





# Initiative Spotlight: ABC infographics

ABC/mBC  
awareness &  
promotion of  
earlier  
diagnosis

After 4 years of development, and overcoming initial resistance from HCPs to share this information, the infographics were adopted by NHS England in 2018 and are considered a “gold standard” document.

- They are being incorporated into personalised end of treatment plans for breast cancer patients in some parts of England, facilitating patient-HCP discussion around ABC/mBC
  - They have been approved for inclusion in The Greater Manchester Cancer’s end of treatment summary report, a copy of which is also shared with the patient’s GP
- They are included in GatewayC, a free online cancer education platform for HCPs in England
- They have been used and promoted by charities in the UK, Canada and the US and are frequently shared between patients with ABC/mBC, highlighting the importance of discussion around risk of recurrence
- They overcome resistance from HCPs to talk about ABC/mBC as the fear of cancer returning is more concerning to patients than knowing the truth

**Most importantly, the infographics have been shown to be successful, leading to earlier diagnosis and increased awareness of ABC/mBC.**

“

*Some patients have taken this information to their GP and clinical team, got referred and have been diagnosed with ABC, and if not, they would have been sent away with ‘oh don’t be silly there is nothing to worry about.’*

”

– Jo Taylor,  
founder of ABCD



**For more information:**

https: [www.abcdiagnosis.co.uk/resources/infographics/](https://www.abcdiagnosis.co.uk/resources/infographics/)

Email: [jo@abcdiagnosis.co.uk](mailto:jo@abcdiagnosis.co.uk)



ABC: advanced breast cancer; mBC: metastatic breast cancer, HCPs: healthcare professionals

*Based on written submission and interview  
with Jo Taylor, ABCD, 2020.*





Based on written submissions and interviews conducted in 2020 and 2021 with: Jo Taylor, ABCD; Pfizer; Alejandra De Cima, Cima Foundation; Dr Beatrice Wiafe Addai, BCI; Dr. Vincent DeGennaro, IHI; Cheri Ambrose, Male Breast Cancer Global Alliance; FEMAMA, Swedish Breast Cancer Association; Marina Eriksson, Pfizer.

The Hard-to-Reach ABC/mBC Communities Toolkit was developed as a collaboration between Pfizer Oncology and the ABC Global Alliance, with funding and support provided by Pfizer. ABC Global Alliance members and Pfizer colleagues were invited to submit breast cancer community-based initiatives that address specific needs of underserved patient populations with advanced/metastatic breast cancer. Initiatives were evaluated against criteria determined by a steering committee with members from both Pfizer and the ABC Global Alliance. Initiatives were selected for inclusion in the toolkit to highlight best practices in addressing the unique needs of this patient population. All organizations who submitted their initiatives for consideration have provided permission for the initiative information to be included in the toolkit and shared publicly. Pfizer and the ABC Global Alliance bear no responsibility for the contents of the toolkit.

