Peer-to-peer support groups or platforms for patients with ABC/mBC

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 examples.

This document has been developed to showcase the important initiatives that have been created to provide peer-to-peer support groups or platforms for patients with 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 addresses at least one of the 12 hard-to-reach populations outlined below:

- Ethnic, religious, indigenous/native population and/or other historically marginalised groups
- Low income patients
- Patients a long distance from a specialist centre
- Low health knowledge patients
- Older patients
- Patients who lack an adequate caregiver or support system
- Mental health patients
- Men
- Patients with uncontrolled comorbidities
- Patients who mistrust conventional treatments
- LGBTQ+ patients
- Younger patients
Peer-to-peer support initiatives are essential to create communities of patients living with ABC/mBC, empowering them to share stories and improve their quality of life. While peer support is common for patients with early breast cancer (eBC), these patients can be reluctant to connect with patients with ABC/mBC, due to fear of their own disease progression. People living with ABC/mBC are often left with limited peer support options and subsequently feel both isolated and neglected. Peer-to-peer support initiatives are essential to bring together patients with ABC/mBC and build communities where patients can share stories and information that meet their needs, resulting in them learning more about their disease, debunking taboo, and empowering them to improve their quality of life (QoL) while living with ABC/mBC.

Without tailored in person or online peer support options, patients with ABC/mBC lack a community where they can discuss their disease, which can lead to a wide array of unmet needs, including:

- Low patient understanding of ABC/mBC and lack of specific disease information
- Myths and taboo around the disease and perceived lack of hope for patients with ABC/mBC
- Lack of psychological support and counselling throughout treatment
- No visibility of women living with ABC/mBC (lack of visible survivorship)
- Neglect of patients with ABC/mBC by their communities, leaving them isolated
- Low quality of life for people living with ABC/mBC
- Lack of awareness and targeted support for patients who undergo menopause as a result of their cancer treatment

For the past few years we have focused on ABC as we have seen a distance between eBC and ABC patients. eBC patients do not want to connect with ABC patients as this is their main anxiety [the disease progressing].

— Mirjam Velting
Borstkankerveniging Nederland

ABC: advanced breast cancer; eBC: early breast cancer; mBC: metastatic breast cancer; QoL: quality of life
Objectives

Initiative objectives were all designed to help overcome barriers to providing disease-specific peer support for patients with ABC/mBC:

- Create a community where patients can source reliable information and share their stories
- Reduce isolation and empower patients through access to a supportive community of peers
- Create a reliable social media platform to promote patient interaction and communication
- Empower and inform patients with ABC/mBC to be able to manage and navigate their disease, including navigating menopause
- Demystify ABC/mBC and debunk current myths and taboos to reduce the stigma associated with the disease
- Give hope to patients living with ABC/mBC
- Improve the QoL and psychological wellbeing of people living with ABC/mBC
- Equip patients with ABC/mBC and their families with the skills and financial means to meet their daily needs

The outcomes of these initiatives are significant and far-reaching, with multiple new communities of patients with ABC/mBC built globally. This has improved QoL for patients living with ABC/mBC worldwide; helped patients navigate through their cancer journey; established long-term connections between patients who have attended workshops and discussion groups; enabled patients to online communities and engage with trained peer counsellors. Some initiatives have even resulted in family members seeking examination, resulting in earlier diagnosis.

ABC: advanced breast cancer; mBC: metastatic breast cancer; QoL: quality of life
 Contributing initiatives

**Through My Eyes Facebook Page**

**Country/region:** Asia

**Hard-to-reach communities targeted**
- Low health knowledge patients

**Brief description**
While there is a lot of information on breast cancer in Asia, there is a lack of specific information and support for patients with ABC/mBC. This Facebook page provides a community specifically for patients with ABC/mBC, including reliable, specific information on their disease, sharing of patient stories, and links to patient organisations with relevant content.

**For more information**
www.facebook.com/throughmyeyesapac

**The HOPE (Helping Others through Personal Experience) Project**

**Country/region:** Ghana

**Hard-to-reach communities targeted**
- Ethnic, religious, indigenous/native population and/or other historically marginalised groups
- Older patients
- Patients who lack an adequate caregiver or support system
- Patients a long distance from a specialist centre

**Brief description**
In Ghana there is a lack of counselling available for patients with ABC/mBC and patients are often led to believe that it is not possible to maintain QoL while living with ABC/mBC. This initiative trains patients to become peer-to-peer counsellors, to help demystify BC and provide advice to patients with newly diagnosed BC or ABC/mBC.

**For more information**
www.breastcareinternational.org
drwiafe@gmail.com

One-page summaries for each initiative can be accessed [here].
**Contributing initiatives**

### Discussion groups for people with ABC/mBC

**Country/region:** Netherlands

**Hard-to-reach communities targeted**
- Ethnic, religious, indigenous/native population and/or other historically marginalised groups
- Low health knowledge patients
- Low income patients
- Mental health patients

**Brief description**
Patients with ABC/mBC in the Netherlands have limited access to psychological support and there is a lack of willingness to mix with patients with BC. This initiative organises accessible, monthly discussion groups specifically for patients with ABC/mBC, led by trained cancer coaches, allowing patients to connect, learn from each other and ultimately improve their QoL.

**For more information**
- [www.borstkanker.nl](http://www.borstkanker.nl)
- velting@borstkanker.nl

### Patient Empowerment Workshop

**Country/region:** Lebanon

**Hard-to-reach communities targeted**
- Patients who lack an adequate caregiver or support system
- Low income patients
- Mental health patients

**Brief description**
In Lebanon, support for women with ABC/mBC is unequal to that for with patients with eBC. This annual workshop was created to integrate ABC/mBC into awareness efforts for BC, and to connect, empower and inspire patients with ABC/mBC through educational sessions from specialists in nutrition, sexology, psychology, oncology, meditation and beauty.

**For more information**
- hoballahmirna@gmail.com

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ABC: advanced breast cancer; BC: breast cancer; eBC: early breast cancer; mBC: metastatic breast cancer; QoL: quality of life

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

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<tr>
<th>Malaika (Angel Program)</th>
<th>Country/region: Uganda</th>
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<tr>
<td><strong>Hard-to-reach communities targeted</strong></td>
<td>✓ Low income patients</td>
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<td>✓ Patients who lack an adequate caregiver or support system</td>
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<td>✓ Low health knowledge patients</td>
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<td><strong>Brief description</strong></td>
<td>In Uganda there is limited psychosocial support for patients with ABC/mBC and patients often struggle financially and with obtaining adequate nutrition. This initiative trains patients with ABC/mBC and their families on ways of improving their nutrition and income, as well as providing access to psychosocial support services and community palliative care.</td>
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<tr>
<td>For more information</td>
<td><a href="http://www.uwocaso.org.ug">www.uwocaso.org.ug</a></td>
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<td></td>
<td><a href="mailto:ngertrude@uwocaso.org.ug">ngertrude@uwocaso.org.ug</a></td>
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<td>✓ Patients a long distance from a specialist centre</td>
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<td><strong>Brief description</strong></td>
<td>In Nigeria, there is stigma and misunderstanding associated with breast cancer, and many patients do not receive adequate support. This initiative connects people impacted by breast cancer in Nigeria to support, educate and empower them, through patient navigators, telephone support, monthly support groups, financial support, and educational materials.</td>
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<tr>
<td>For more information</td>
<td><a href="http://www.projectpinkblue.org/abc-sg/">www.projectpinkblue.org/abc-sg/</a></td>
</tr>
<tr>
<td></td>
<td>Khadijat Banwo (<a href="mailto:khadijat.banwo@projectpinkblue.org">khadijat.banwo@projectpinkblue.org</a>)</td>
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ABC: advanced breast cancer; mBC: metastatic breast cancer

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

**Europa Donna Breast Health**  
**Country/region:** Turkey

**Hard-to-reach communities targeted**  
- Low income patients  
- Low health knowledge patients

**Brief description**  
Patients with ABC/mBC in Turkey lack access to validated medical content and social interaction with other patients. Following the success of the Let Hopes Blossom Initiative since 2018, Europa Donna and Pfizer Turkey collaborated again to create this Instagram page for patients with ABC/mBC, offering both medical content and opportunity to engage with other patients.

**For more information**  
[https://www.instagram.com/europadonna_memesagligi/](https://www.instagram.com/europadonna_memesagligi/)

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**Navigating Menopause**  
**Country/region:** UK

**Hard-to-reach communities targeted**  
- Younger patients  
- Low income patients  
- LGBTQ+ patients  
- Patients a long distance from a specialist centre

**Brief description**  
There is a lack of awareness of and support for young patients living with cancer, including mBC, who undergo menopause as a result of their cancer treatment. This initiative provides a 6-week online support programme that aims to create a supportive community of peers and give patients the knowledge and tools to tackle menopause and improve their quality of life.

**For more information**  
[www.trekstock.com/Pages/Category/navigating-menopause](www.trekstock.com/Pages/Category/navigating-menopause)  
Ian Boyd (Health@trekstock.com)

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ABC: advanced breast cancer;  
mBC: metastatic breast cancer
While peer-to-peer support can be provided to patients with ABC/mBC through different channels, such as in-person or online, initiatives all focus on bringing patients together for in-depth discussion of specific topics, sharing experiences and learning from one another. Some initiatives have leveraged advances that have been made in social media to facilitate the creation of online communities, which can be a good way to reach a wide audience with peer support. The Through My Eyes Facebook Page initiative is an online platform for patients with ABC/mBC across Asia, that includes reliable and disease-specific information, links to patient organisations and relevant content, and creates a community of patients by facilitating the sharing of patient stories and experiences. Similarly, Navigating Menopause, a 6-week online support programme for young adults living with cancer including mBC, offers peer-to-peer support, expert advice and information on menopause, and support for navigating the healthcare system.

Alternatively, peer support groups may involve in-person meetings. The Discussion Groups for People with ABC/mBC initiative runs monthly groups for people with ABC/mBC in the Netherlands, where discussions focus around a set theme, such as ‘taking control’ or ‘loved ones’.

The ABC-SG initiative also provides monthly support group meetings in Nigeria to allow patients a safe, open, and non-judgmental environment to discuss ABC/mBC and the impact on their lives.

Similarly, the Patient Empowerment Workshop – We Are Connected initiative brings patients with ABC/mBC together in Lebanon annually to attend educational sessions with experts in fields from nutrition, sexology, psychology, oncology, meditation and beauty, specifically tailored to their needs.

“Social media is getting bigger and bigger, but it is difficult to get the depth that you get with group meetings. The different perspectives that you get from the group meetings are a differentiator.”

– Mirjam Velting
Borstkankervereniging Nederland

ABC: advanced breast cancer; mBC: metastatic breast cancer

Based on written submissions and interviews with initiative owners listed on pages 5-8, 2020-2023.
Key components

Some initiatives also focus on training patients with ABC/mBC to provide peer support to others. The HOPE (Helping Others through Personal Experience) Project, trains BC survivors and people living with ABC/mBC to become peer counsellors, helping to demystify BC and provide advice to patients with newly diagnosed BC or ABC/mBC in Ghana.

As well as providing training to people living with ABC/mBC in Uganda on skills such as nutrition (vegetable growing, permaculture gardening and diet) and finance (income generation, succession planning, and setting up a start-up), the Malaika (Angel Program) initiative also trains survivor navigators to provide support to patients with ABC/mBC and supports them to form peer support groups in their communities. The Discussion Groups for People with ABC/mBC sessions were initially facilitated by volunteer patients with ABC/mBC; however, these individuals found it hard to distance themselves from their own experience and the organisation switched to professional cancer coaches, who were better able to facilitate the sessions. This also allowed the coaches to encourage patients to take an active role in discussions, as many initially found it difficult to engage with the initiative.

When establishing communities of patients and facilitating discussion on important topics specific to ABC/mBC, it is important that information is delivered or ratified by a trained individual or specialist. This is demonstrated by the Patient Empowerment Workshop – We Are Connected initiative, which was developed with the help of many different stakeholders, including: doctors, nurses, specialists, volunteers and coordinators, alongside branding, social media, and PR agencies. The Through My Eyes Facebook Page initiative received expert input and guidance from patient advocacy groups during the development process and The HOPE (Helping Others through Personal Experience) Project worked with a US-based NGO, Carrie’s Touch, to train community survivors to provide peer support. Experts may also be engaged to help to run the initiative, as with the Discussion Groups for People with ABC/mBC initiative, that worked with trained cancer coaches to lead the group sessions and facilitate effective discussions.

ABC: advanced breast cancer; BC: breast cancer; mBC: metastatic breast cancer; NGO: non-governmental organisation
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.

People living with ABC/mBC often face stigma around their disease, impacting their self esteem and subsequently their willingness to provide peer support, or participate in peer-to-peer support initiatives. The HOPE (Helping Others through Personal Experience) Project found it challenging to identify people living with ABC/mBC who were willing to discuss their diagnosis. To help encourage more patients to participate in the initiative, the organisers were flexible in the level of involvement required from each patient – for example, some only spoke on radio – to ensure they were comfortable with their role. The same challenge was also reported by the organisers of the annual Patient Empowerment Workshop – We Are Connected initiative, who said that patients attending the workshop demonstrated low self esteem due to stigma around ABC/mBC. The Malaika (Angel Program) faced a lack of patient motivation to participate in the initiative. Through the support of survivor navigators and community volunteers the initiative was able to re-engage patients with ABC/mBC who had been left isolated and had previously lost hope.

ABC: advanced breast cancer; mBC: metastatic breast cancer
Challenges

It is important that organisations seek feedback from participants in their peer-to-peer support groups or programs, to ensure that the sessions are fit for purpose and are addressing the patients' unmet needs. However, this can be challenging as patients can be reluctant to provide their thoughts. The Discussion Groups for People with ABC/mBC initiative overcame this by designing evaluation forms for participants to complete at the end of each session, allowing them to shape future sessions to ensure they meet patient needs.

Feedback from participants may also contribute to proving the effectiveness of the initiative to key stakeholders, which could support further funding. Lack of funding is a universal challenge for organisations developing peer support initiatives, but one that was a particular problem for Dr Beatrice Wiafe when running the HOPE (Helping Others through Personal Experience) Project, as many patients in Ghana travelled there, but did not have the financial means to return home after. The ABC-SG initiative also cited a lack of financial support as a key challenge, particularly as grants and donations are prioritising health projects such as masks and vaccinations as a result of the COVID-19 pandemic.

Many initiatives involve the collaboration of several different parties. Ensuring that all parties are aligned can sometimes be difficult. The Europa Donna Breast Health initiative, an Instagram account providing validated medical content for patients with ABC/mBC in Turkey, found getting agreement on content from the three parties involved in the development to be challenging. To overcome these issues, Europa Donna arranged monthly meetings between all partners to discuss strategy, tone of posts, tactics and content.

“Some patients come to the hospital and then don’t have the finance means to get back home. Funding is a big issue. Having more funding would allow us to train more nurses and survivors in different areas, therefore helping more people.”

– Dr Beatrice Wiafe
Breast Care International (BCI)

ABC: advanced breast cancer; mBC: metastatic breast cancer

Based on written submissions and interviews with initiative owners listed on pages 5-8, 2020-2023.
Initiative Spotlight: The HOPE (Helping Others through Personal Experience) Project

While all initiatives that provide peer-to-peer support for patients are important, the steering committee chose to highlight the work of Breast Care International (BCI) in developing the HOPE (Helping Others through Personal Experience) Project initiative, due to its specificity to advanced/metastatic disease, as well as its impressive impact and its ability to be replicated in other hard-to-reach populations and geographies. This initiative was developed in response to the lack of counselling available for patients with ABC/mBC in Ghana, which results in patient belief that living with ABC/mBC and maintaining a good QoL is not possible. This initiative trains patients to become peer-to-peer counsellors, to help demystify BC and provide advice and guidance to other patients with newly diagnosed BC or ABC/mBC.

The Hope Project was developed to help address the lack of clinical counselling that is currently available for patients with breast cancer in treatment centres, in order to help patients navigate their disease, as well as improving their quality of life and providing them with hope. The initiative consists of:

• An initial three day workshop to train BC survivors and patients living with ABC/mBC as peer counsellors, including: basic disease information, sharing experiences, listening to others, and helping patients to navigate their disease
• Careful matching of BC survivor peer counsellors to people newly diagnosed with BC, and peer counsellors living with ABC/mBC to those with advanced disease
• Connecting patients, peer counsellors and trained community nurses from the same local area, as well as providing telemedicine support, in order to ensure patients feel comfortable receiving care in their local community
• Two peer counsellors permanently employed at Peace and Love Hospitals, and between two and 10 counsellors joining BCI on outreach activities

ABC: advanced breast cancer; BC: breast cancer; BCI: breast care international; HOPE: helping others through personal experience; mBC: metastatic breast cancer; QoL: quality of life
Initiative Spotlight: The HOPE (Helping Others through Personal Experience) Project

Since its launch, this initiative has had an impressive reach, with outreach programs conducted in 8 out of the 10 regions of Ghana. This has resulted in:

- A reduced number of patients who refuse treatment
- An increase in the number of BC survivors joining the Peace & Love Survivors Association (PALSA), to more than 800 people
- Identification of the need to upskill nurses in Ghana in breast cancer care, which has subsequently been addressed through another BCI initiative

For more information:
https://www.breastcareinternational.org
Email: drwiafe@gmail.com

The bond of friendship is normally instant! Counselling by a fellow survivor offers so much hope, understanding and support, that patients complain about not receiving it at other facilities.

– Dr Beatrice Wiafe
Breast Care International (BCI)
While all initiatives that provide peer-to-peer support for patients are important, the steering committee chose to highlight the work of the Borstkankervereniging Nederland (BVN) in developing the Discussion Groups for People with ABC/mBC initiative, due to its specificity to advanced/metastatic disease, as well as its impressive impact and its ability to be replicated in other hard-to-reach populations and geographies. This initiative was developed in response to the need for psychological support specifically for patients with ABC/mBC in the Netherlands, separate to what is available to patients with eBC. It organises accessible, monthly discussion groups specifically for patients with ABC/mBC, led by trained cancer coaches, allowing patients to connect, learn from each other and ultimately improve their QoL.

The first discussion group was started in 2010 in an effort to help patients living with ABC/mBC to maximise their QoL by connecting them with other patients to discuss topics aligned to the very specific needs of patients with ABC/mBC. The initiative has two key objectives:

• Connect patients, allowing them to learn from each other, build resilience and maintain control while living with ABC/mBC
• Provide support and improve QoL for patients living with ABC/mBC

Following the initial rollout of the initiative, the group was so highly sought after that patients travelled across the country to join. To cater for this large unmet need, the initiative has since been expanded to four groups, which are now led by professional cancer coaches rather than patient volunteers, to allow for more effective facilitation of the sessions. Patients are referred to the initiative through their hospital, with the sessions hosted at cancer walk-in centres. There are plans to further extend the initiative to 10 groups in 2021.

ABC: advanced breast cancer; eBC: early breast cancer; mBC: metastatic breast cancer; QoL: quality of life
To ensure consistency across the groups and allow for group leaders to learn from each other, the sessions focus on a set of key topics, such as: work, talking to your doctor, clinical trials, communicating with your family and friends, palliative care, how you want to be remembered, and anxiety. Each group is limited to 8-10 patients with ABC/mBC to ensure that all members are able to actively contribute to the sessions, and new participants are only accepted twice a year to ensure consistency.

The initiative reaches 40 patients with ABC/mBC every year, and is continuing to grow – it has empowered these patients to take control of their lives, manage their disease and consequently, has improved their QoL.

Within these groups they experience mutual recognition, they make use of each other’s strengths and differences – learning from and with each other.

– Mirjam Velting
Borstkankervereniging Nederland

For more information:
https: www.borstkanker.nl
Email: velting@borstkanker.nl

ABC: advanced breast cancer; mBC: metastatic breast cancer; QoL: quality of life

Based on written submission and interview with Mirjam Velting, BVN, 2020.
Based on written submission and interviews conducted in 2020-2023 with: Pfizer Emerging Markets; Dr Beatrice Wiafe Addai, BCI; Mirjam Velting, BW; Mirna Hoballah, The Lebanon Breast Cancer Foundation; Gertrude Nakigudde, UWOCASO; Khadijat Banwo, Project PINK BLUE, Pfizer Turkey; Ian Boyd, Trekstock.

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.