Support 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 support 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 included in this document 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
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There are numerous support programmes and resources available for patients with breast cancer, but many focus on early breast cancer (eBC), which can leave patients with ABC/mBC feeling both isolated and neglected. It is crucial that initiatives such as those outlined in this document exist to provide patients with support tailored to the very specific needs of ABC/mBC. By providing patients with ABC/mBC with disease-specific support and resources, these initiatives can help patients to manage and navigate their own disease, improve their quality of life, and maximise their wellbeing while living with ABC/mBC.

While there is a great deal of support available to patients with eBC, there is a lack of tailored, accessible and realistic support options for patients with ABC/mBC. This unmet need is wide-ranging, and includes a lack of:

- Emotional, psychological, and psychosocial support
- Financial support and support for everyday living for low-income patients with ABC/mBC
- Access to free or low-cost health care services and support, including affordable palliative care
- Communication between HCPs and patients with ABC/mBC, leading to poor disease management and navigation
- Disease-management resources specifically for the needs of patients with ABC/mBC
- Motivation to develop initiatives specifically for patients with ABC/mBC, due to a perceived lack of hope for these patients (lack of visible survivorship) and sociocultural/religious taboo
- Support for family members of patients with ABC/mBC
- Support for patients to engage in physical activity
- Support tailored for young patients in their 20s and 30s

Across the world the disease is the same and the prognosis is the same. What we have access to might be different, but there are so many similar journeys.

– Runcie C.W. Chidebe Executive Director Project PINK BLUE

ABC: advanced breast cancer; eBC: early breast cancer; HCPs: healthcare professionals; mBC: metastatic breast cancer
Objectives

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

• Improve QoL for people living with ABC/mBC
• Provide psychosocial support, reduce stress, and improve the emotional and psychological wellbeing of patients with ABC/mBC
• Provide patients with opportunities and support to engage in physical activity in a safe way
• Provide targeted support for patients facing barriers to care and improve access to care
• Offer free or affordable palliative care services to low-income cancer patients
• Provide access to services to overcome adverse events such as for malignant fungating breast wounds
• Offer community support for family members of patients with ABC/mBC

The outcomes of these initiatives are significant and far-reaching, with people living with ABC/mBC across the globe being better supported through initiatives providing a wide range of different forms of support, including emotional and psychological support, financial support, support to access health and palliative care services, as well as support with the management and navigation of their disease – resulting in improved quality of life and disease outcomes for these patients. Furthermore, awareness has been created amongst the general public, and some initiatives have gone on to receive awards.

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

<table>
<thead>
<tr>
<th>Mobile App: My Alma</th>
<th>Country/region: Greece</th>
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<tr>
<td><strong>Hard-to-reach communities targeted</strong></td>
<td></td>
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<tr>
<td>✓ Ethnic, religious, indigenous/native populations and/or other historically marginalised groups</td>
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<td>✓ Patients who lack an adequate caregiver or support system</td>
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<td><strong>Brief description</strong></td>
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<tr>
<td>In Greece there is a lack of support specifically tailored to the needs of patients with ABC/mBC, meaning patients often feel isolated and ashamed. The My Alma app was developed to support patients with ABC/mBC in an easily accessible, friendly, hopeful and realistic manner, bridging the gap between support services and these patients, ultimately improving QoL.</td>
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<td><strong>For more information</strong></td>
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<tr>
<th>Let the Hopes Blossom</th>
<th>Country/region: Turkey</th>
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<tr>
<td><strong>Hard-to-reach communities targeted</strong></td>
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<tr>
<td>✓ Younger patients</td>
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<tr>
<td>✓ Patients who lack an adequate caregiver or support system</td>
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<tr>
<td>✓ Low income patients</td>
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<tr>
<td>✓ Mental health patients</td>
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<tr>
<td><strong>Brief description</strong></td>
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<tr>
<td>Despite evidence suggesting QoL is a crucial factor impacting prognosis, in Turkey there is a lack of psychosocial support for patients with ABC/mBC. This multi-organisation collaborative initiative was developed to provide psychological support for patients with ABC/mBC, as well as raising awareness about the importance of psychological support for these patients.</td>
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<td><strong>For more information</strong></td>
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<td><a href="http://umutlaricekacsin.org/">http://umutlaricekacsin.org/</a></td>
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One-page summaries for each initiative can be accessed [here](#).
**Contributing initiatives**

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<tr>
<th>My Choice Navi</th>
<th>Country/region: Japan</th>
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| **Hard-to-reach communities targeted** | ✓ Older patients  
✓ Patients who lack an adequate caregiver or support system  
✓ Low income patients  
✓ Low health knowledge patients |
| **Brief description** | Patients with ABC/mBC in Japan are often poorly educated about their disease and lack support throughout their treatment. The MY CHOICE Navi account was developed on the Japanese social networking app, LINE, to provide patients with easy access to relevant information on ABC/mBC, as well as supporting treatment continuation via a hospital visit tracker. |
| For more information | https://mychoiceprogram.jp/#line  
Fujita-san Minami (minami.fujita@pfizer.com) |

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<tr>
<th>Palliative care and home visit for rural Cameroonian patients with ABC</th>
<th>Country/region: Cameroon</th>
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| **Hard-to-reach communities targeted** | ✓ Patients who mistrust conventional treatments  
✓ Patients who lack an adequate caregiver or support system  
✓ Low income patients  
✓ Low health knowledge patients |
| **Brief description** | In rural areas of Cameroon, 90% of patients with ABC/mBC live without treatment, and breast cancer is often discovered at a very advanced stage due to lack of awareness. This initiative organises home visits and psychosocial support for patients with ABC/mBC, as well as training for traditional healers, HCPs and members of the community in breast health. |
| For more information | www.uicc.org/case-studies/strengthening-palliative-care-services-patients-metastatic-breast-cancer-cameroon |

ABC: advanced breast cancer; HCP: healthcare professional;  
mBC: metastatic breast cancer

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

### Support for those living with incurable BC

**Country/region:** New Zealand

#### Hard-to-reach communities targeted
- Ethnic, religious, indigenous/ native populations and/or other historically marginalised groups
- Older patients
- Low health knowledge patients
- Patients who lack an adequate caregiver or support system
- Low income patients
- Patients a long distance from a specialist centre
- Men
- Mental health patients

#### Brief description
There is a lack of support for patients with ABC/mBC in New Zealand and life expectancy is low for these patients. This initiative offers a holistic programme of social, psychological, emotional, practical and financial support to enable patients with ABC/mBC to live as well, and as long, as possible.

For more information
www.sweetlouise.co.nz
Catrin Devonald (catrin.devonald@sweetlouise.co.nz)

### Winter Mission

**Country/region:** Greece

#### Hard-to-reach communities targeted
- Older patients
- Low health knowledge patients
- Patients a long distance from a specialist centre
- Low income

#### Brief description
Women living in isolated and remote Greek islands encounter social and economic barriers that prevent them accessing breast cancer prevention services. This initiative brings these services to remote locations, as well as offering medical services and informative lectures specifically for patients living with ABC/mBC.

For more information
https://omadaaigaiou.gr/

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ABC: advanced breast cancer; BC: breast cancer; HCP: healthcare professional; mBC: metastatic breast cancer

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

Reusable Wound Kits
for malignant fungating breast wounds (MFBW)

Country/region: Timor Leste

- Ethnic, religious, indigenous/native populations and/or other historically marginalised groups
- Low income patients
- Patients a long distance from a specialist centre
- Patients with uncontrolled comorbidities

Brief description

Women with malignant fungating breast wounds (MFBW) experience limited healthcare support in Timor Leste. This initiative saw a team of Australian volunteer nurses travel to Timor Leste to provide patients with reusable wound care kits, as well as educational support to allow women to self-manage MFBW, maintaining their dignity and subsequently improving QoL.

For more information

https://www.alolafoundation.org/
Jo Lovelock (jo.lovelock@bigpond.com);
Rosie Gillies (rosegillies64@outlook.com)

Meeting patients’ needs
to improve physical self-image and psychological wellbeing

Country/region: Albania

- Older patients
- Low health knowledge patients
- Patients a long distance from a specialist centre
- Low income

Brief description

Patients receiving treatment for BC in Albania lack access to resources such as silicone prostheses and wigs, which negatively impacts the QoL of these patients. This initiative aims to improve the self-image and psychological wellbeing of patients with BC through the provision of both wigs and silicone prosthesis.

For more information

https://www.onkovia.com

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

### HOPE Retreat

**Country/region:** USA

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

**Brief description**
In the US, many single mothers with mBC are below the federal poverty level. This initiative provides financial and emotional support to these women and their children through a series of one-day retreats, including speaking with licensed social workers and therapists, art therapy, breakfast & lunch, and a grocery card to take away.

**For more information**
www.infinitestrength.org/the-hope-retreat
Roberta Lombardi (Roberta@infinitestrength.org)

### Breast Cancer Navigation & Palliative Program (BCNPP)

**Country/region:** Nigeria

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

**Brief description**
In Nigeria, there is stigma and misunderstanding associated with breast cancer, and many patients do not receive adequate support. The BCNPP is a cancer care programme designed to educate cancer survivors and caregivers across Nigeria to become professional patient navigators who can guide women with ABC/mBC.

**For more information**
www.projectpinkblue.org/bcnpp/
Khadijat Banwo (khadijat.banwo@projectpinkblue.org)

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ABC: advanced breast cancer; HCP: healthcare professional; mBC: metastatic breast cancer

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

**SATORI (II) - Self Care and Wellness for Patients**

**Country/region:** India

- **Hard-to-reach communities targeted**
  - Ethnic, religious, indigenous/native populations and/or other historically marginalised groups
  - Low income patients
  - Patients who lack an adequate caregiver or support system

- **Brief description**
  The SATORI (II) initiative is a holistic wellness programme for women who have undergone breast cancer recurrence. The programme provides the training and tools necessary to allow patients to care for themselves in their own home, which otherwise could not be done due to a lack of affordable and accessible services.

- **For more information**
  - www.facebook.com/356250741090060/posts/4184644044917358/
  - Ruby Ahluwalia (ruby@sanjeevani-lifebeyondcancer.in)

**Serene Woman**

**Country/region:** Mexico, Peru and Ecuador

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

- **Brief description**
  Many women with a breast cancer diagnosis suffer from a fear of cancer recurrence and progression. This initiative provides a free training program in strategies for dealing with fear and anxiety for women of low socio-economic status who are within five years of a breast cancer diagnosis in Mexico, Peru and Ecuador.

- **For more information**
  - www.isabelcenteno.com.mx
  - www.unidascontigo.org
  - Isabel Centeno (psychooncology@isabelcenteno.com.mx)

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ABC: advanced breast cancer; HCP: healthcare professional; mBC: metastatic breast cancer

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

<table>
<thead>
<tr>
<th>Palliative Care Services</th>
<th>Country/region: India, Pakistan, Iraq, Philippines, Kenya, Ethiopia, Kosovo, and Australia</th>
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| **Hard-to-reach communities targeted**                               | - Ethnic, religious, indigenous/native populations and/or other historically marginalised groups
|                                                                        | - Older patients
|                                                                        | - Low health knowledge patients
|                                                                        | - Patients who lack an adequate caregiver or support system
| **Brief description**                                                 | Low-income cancer patients often lack access to adequate palliative care services. The PAY-W (‘Pay As You Wish’) Clinic offers free or affordable palliative care services directly and through their not-for-profit partners to cancer patients with low income, primarily from indigenous communities in LMIC and countries affected by civil war.
| For more information                                                  | https://suryaonco.wixsite.com/pay-w-clinic
|                                                                        | Suryakanta Acharya (suryaoncology@gmail.com) |

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<thead>
<tr>
<th>Grant assistance program for single mothers with ABC/mBC</th>
<th>Country/region: USA</th>
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| **Hard-to-reach communities targeted**                   | - Ethnic, religious, indigenous/native populations and/or other historically marginalised groups
|                                                           | - Low income patients
|                                                           | - Patients a long distance from a specialist centre
|                                                           | - Low health knowledge patients
|                                                           | - Patients who lack an adequate caregiver or support system
| **Brief description**                                     | This initiative provides underserved single mothers in the US with financial support of $6,000 for rent, mortgage, utilities and food, as well as free admission to the organisation’s HOPE retreats and quarterly Life Support Series panel discussions.
| For more information                                     | www.infinitestrength.org/
|                                                           | Roberta Lombardi (Roberta@infinitestrength.org) |

ABC: advanced breast cancer; LMIC: low and middle income countries; mBC: metastatic breast cancer; US: United States
## Contributing initiatives

<table>
<thead>
<tr>
<th>Initiative</th>
<th>Country/region: UK</th>
<th>Patient navigation and companionship</th>
<th>Country/region: USA, Peru</th>
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<tr>
<td>Life coaching: Navigating life with uncertainty</td>
<td>Hard-to-reach communities targeted: ✓ Younger patients ✓ Low income patients</td>
<td>Hard-to-reach communities targeted: ✓ Low income patients ✓ Patients a long distance from a specialist centre ✓ LGBTQ+ patients ✓ Men</td>
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<td>Brief description</td>
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<td>There is a lack of emotional and psychological support for young adults living with cancer, including mBC, to handle the impact of their cancer treatment on their quality of life. This initiative offers a 6-week online coaching programme to equip young adults in their 20s and 30s with knowledge and tools to improve their mental well-being and to create a supportive peer community.</td>
<td>Many women with advanced cancer face financial or other barriers to accessing high-quality cancer care. This initiative provides various forms of support including patient navigation, education, transport to appointments, and social support to patients with all advanced cancers, including mBC.</td>
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<td>For more information</td>
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<td><a href="https://www.life-aftercancer.co.uk/">https://www.life-aftercancer.co.uk/</a></td>
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<td><a href="https://www.angelmira.org">https://www.angelmira.org</a></td>
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<td>Ian Boyd (<a href="mailto:Health@trekstock.com">Health@trekstock.com</a>)</td>
<td></td>
<td>Maricarmen Planas-Silva (<a href="mailto:maricarmen@angelmira.org">maricarmen@angelmira.org</a>)</td>
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mBC: metastatic breast cancer

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

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<thead>
<tr>
<th>Initiative</th>
<th>Country/region:</th>
<th>Hard-to-reach communities targeted</th>
<th>Brief description</th>
<th>For more information</th>
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<tbody>
<tr>
<td>Renew</td>
<td>UK</td>
<td>✓ Younger patients</td>
<td>There is a lack of awareness of the benefits of physical activity for cancer patients and a lack of targeted support for young people diagnosed with cancer. The RENEW programme is an 8-week physical activity online programme that aims to create a supportive community of young adults in their 20s and 30s living with cancer, including mBC, who can get active together.</td>
<td><a href="www.trekstock.com/Listing/Category/renew">Link</a> Ian Boyd (<a href="mailto:Health@trekstock.com">Health@trekstock.com</a>)</td>
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<tr>
<th>Initiative</th>
<th>Country/region:</th>
<th>Hard-to-reach communities targeted</th>
<th>Brief description</th>
<th>For more information</th>
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</thead>
<tbody>
<tr>
<td>305 Pink Pack Cancer Support Services</td>
<td>USA</td>
<td>✓ Low income patients ✓ Ethnic, religious, indigenous/native populations and/or other historically marginalised groups ✓ Younger patients ✓ Low health knowledge patients ✓ Patients who lack an adequate caregiver or support system</td>
<td>Low-income and vulnerable communities face many barriers to accessing cancer and recovery care. This program, serving a largely Hispanic population in South Florida, provides a range of services aimed at reducing these barriers and improving equity in care and recovery, including childcare, transportation, self-care services and emotional support.</td>
<td><a href="https://www.305pinkpack.org/">Link</a> Rosemary Carrera (<a href="mailto:rosemary@305pinkpack.org">rosemary@305pinkpack.org</a>)</td>
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mBC: metastatic breast cancer
Development process

Seeking input from experts is important to ensure that initiatives provide support that is medically accurate and appropriate to patients with ABC/mBC and can be run successfully. The medical content included in the mobile app My Alma, which aims to provide support specifically for patients with ABC/mBC in Greece, was validated by experts at the University of Thessaly. Similarly, Sweet Louise relies on a medical advisory team to guide the Support For Those Living With Incurable BC initiative, which offers a holistic support program for patients with ABC/mBC in New Zealand.

The Meeting Patients’ Needs to Improve Physical Self-Image and Psychological Wellbeing initiative, which offers wigs and prostheses for women with BC in Albania following an assessment of their psychological needs, was developed with expert collaborative support from psychologists from local oncology hospitals. The HOPE Retreat was also developed with support from a number of individuals including: social workers, oncology family therapists, art therapists, and grief support therapists.

Serene Woman, which provides an 8-week training programme for women in techniques for dealing with fear and anxiety, was developed on the basis of an existing “Compassion Cultivation Training” developed at the Stanford School of Medicine. The organiser of this initiative completed this training, and with funding support from the school was able to adapt the training into a programme for patients with BC and mBC in Mexico.

Several initiatives – such as Winter Mission, which offers medical support services to patients with ABC/mBC living on remote Greek islands, Reusable Wound Kits for Malignant Fungating Breast Wounds (MFBW), which addresses the very specific need for MFBW wound care resources and support in Timor Leste, and Grant Assistance Program for Single Mothers with ABC/mBC, which provides patients with financial support and access to informative panel discussions – relied on the support of volunteer HCPs, nurses and social workers to develop, run and raise awareness of the initiative.

Try to find experts in different fields to provide guidance, insight and content – medical support from physicians, psychologists, IT, communications experts.

– Christiana Mitsi, Scientific Director of Alma Zois

ABC: advanced breast cancer; BC: breast cancer; HCP: healthcare professional; mBC: metastatic breast cancer; MFBW: malignant fungating breast wounds

Based on written submissions and interviews with initiative owners listed on pages 5-13, 2020-23.
Data collection either before or during the initiative development process may help to validate the need for support of patients with ABC/mBC, as well as supporting funding opportunities. A survey outlining the psychological support needs of young adults living with cancer was the driving force behind Life Coaching: Navigating Life with Uncertainty, a 6-week online coaching programme that supports young adults living with cancer to manage the impact of their cancer treatment and live well. Both this initiative and Renew, a programme supporting young adults living with cancer to keep physically active during and after cancer treatment, were developed through the use of focus groups with young cancer patients. During the development of the Support For Those Living With Incurable BC initiative, Sweet Louise determined the social impact of their initiative compared to other organisations globally. This has allowed them to clearly illustrate the impact of the initiative on patients’ wellbeing and the link to further social and employment benefits, which ultimately leads to the initiative receiving funding from >230 organizations, annually. Similarly, Let the Hopes Blossom ran patient advisory boards during the initiative development process to collect data on the importance of QoL to patients with ABC/mBC, which helped with gaining support from key stakeholders in Turkey.

Some initiatives offer indirect support to patients with ABC/mBC, through training of HCPs to better support patient needs. The Palliative Care and Home Visit for Rural Cameroonian Patients with ABC initiative organises home visits and palliative care for patients with ABC/mBC in rural Cameroon, as well as training for traditional healers, HCPs and members of the community in breast health. The Reusable Wound Kits for MFBW initiative also trained local health workers to supervise distribution and use of the wound kits. Similarly the BCNPP initiative trains oncology nurses in palliative care and home care.

Promotion of initiatives that provide support for patients living with ABC/mBC is important to ensure that the target audience is reached. The initiatives in this document employed a variety of successful promotion methods:

1. Press conferences and press releases
2. Printed leaflets and newsletters for distribution
3. Leveraging an existing fundraising event (promotion via event materials – e.g. t-shirts)
4. TV / social media campaign
5. Collaboration with a local celebrity
6. In-person visits to the target community
7. A dedicated communications manager
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.

While it is important to target patients when promoting support initiatives, it is often HCPs who are the gatekeepers to referring patients to these initiatives – getting support from key stakeholders and in particular motivating HCPs to refer their patients can be challenging. Let the Hopes Blossom successfully overcame this challenge by developing brochures and handbooks specifically for HCPs that explained the value of the project and the need for psychological support for patients with ABC/mBC. The initiative also published the results of a patient advisory board, which demonstrated the importance of quality of life for people living with ABC/mBC. The initiative also published the results of a patient advisory board, which demonstrated the importance of quality of life for people living with ABC/mBC. The initiative also published the results of a patient advisory board, which demonstrated the importance of quality of life for people living with ABC/mBC.

The Support For Those Living With Incurable BC initiative tackled this challenge by creating a team of on-the-ground coordinators who build relationships with key stakeholders and HCPs in New Zealand, improving referral of patients to the initiative. The SATORI (II) initiative found that holistic wellness programmes are often mistrusted, which can not only prevent uptake with HCPs but also make funding harder to obtain. By building on the success of a previous project they were able to demonstrate that this could be effective and improve uptake and referrals.

Australian volunteer nurses running the Reusable Wound Kits for MFBW initiative noted language barriers and cultural differences with local healthcare workers in Timor Leste, as well as time constraints that limited the opportunity for relationship building between the two groups – nurses learnt the basics of the Tetun language in order to help with this issue and better communicate with local healthcare workers.

ABC: advanced breast cancer; HCP: healthcare professional; mBC: metastatic breast cancer; MFBW: malignant fungating breast wounds

Getting support from stakeholders and reminding doctors to refer patients to the project can be challenging. To combat this, we planned ad boards and insight focus groups to discuss how psychological support would impact QoL.

– Irem Hanagasi, Pfizer Oncology Turkey

Based on written submissions and interviews with initiative owners listed on pages 5-13, 2020-23.
Challenges

When creating a support initiative for patients with ABC/mBC, a number of different factors can make planning in advance difficult. This means that plans must be adaptable to accommodate for changing circumstances.

The belief that the services provided by 305 Pink Pack Cancer Support Services were already nationally available, proved a barrier to fund raising initially. Upon learning this, the organisers adapted their fundraising outreach to include information about the existing gap in services. The BCNPP initiative has also faced a challenge in recruiting and training BC patient champions and navigators and staff for their dedicated telephone support number. This is due to Nigeria being divided into six geographical zones. In the future, once more funding becomes available, the initiative aims to create support in each of the six zones.

The HOPE Retreat are required to be flexible when planning their meetings as women attending the retreats can often feel too unwell or are unable to get childcare. To combat this, Infinite Strength carefully plan for both full and low attendance at the sessions and provide grocery cards to those who are unable to attend.

The COVID-19 pandemic has exacerbated a number of the challenges already faced by organisations. Some examples include:

• The HOPE Retreat was unable to open a retreat house so instead community centres have been used for meetings.

• The BCNPP initiative saw a decrease in their reach to patients and reduction in the quality of support for patients. To combat this Project PINK BLUE are hoping to create a mobile app for the wider community.

• Difficulties for newly diagnosed patients in finding additional support have been amplified.

Social workers are so depleted, they have too much on their plate. The social workers should be bringing resources like our organisation to the patients, but with hospital staff being overwhelmed, that is not happening as often as it should.

– Roberta Lombardi, Founder and President at InfiniteStrength

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

Based on written submissions and interviews with initiative owners listed on pages 5-13, 2020-23.
Challenges

The delivery of patient support initiatives often remains consistent year-on-year and it is important that the learnings from the previous year are documented and applied to ease the process in the future. This was applied by the organisers of the Let the Hopes Blossom initiative, who documented their learnings while developing and initially running the project – in particular regarding the contracting and paperwork – which streamlined the process for the following year.

Similarly, initiatives can build on the learnings of previous work to ensure that they are not replicating what has been done before and that the new initiative is effectively meeting the needs of the population. An example where this has been done is the SATORI (II) initiative which is a holistic wellness programme for women who have undergone a recurrence. This initiative built on the SATORI (I) initiative which launched in 2015 and has reached >38,000 cancer patients and survivors.

It is also possible for current work to spark new ideas as was the case with the BCNPP initiative, that led to the development of patient support partnership programmes and access to medicine partnerships with pharma organisations.

Developing a digital support solution, such as a mobile app, may come with a specific set of challenges:

• Ensuring compliance with the local data protection laws (e.g. GDPR, which was introduced in Europe in 2018)

• Considerable delays in obtaining a licence for use on the App Store and Google Play store. For the My Alma initiative, it took 7 months to gain approval

• Technical limitations in bringing ideas to life. The My Alma initiative overcame this by working with a digital agency to support the development process and advise on limitations

• Strict regulations around patient-patient communication and sharing of patient experiences through live forums. The MY CHOICE Navi initiative overcame this with the development of default answers and the My Alma initiative created a message wall that is pre-approved by the initiative organisers

It is important to have a thorough understanding of local regulations and compliance issues from the offset, as well as an expert development team to provide technical guidance, in order to avoid challenges during the development process.

GDPR: general data protection regulation
Challenges

The severity of mBC can raise particular challenges for engaging with and supporting patients with mBC, as illustrated by some of the initiatives.

The Patient Navigation and Companionship initiative provides a wide range of support for low-income women with ABC, including education, transport to appointments, social support and support accessing and navigating the healthcare system. One of the challenges the organisers of this initiative experienced was that it was difficult to find volunteers who were comfortable with accompanying people who are dying or diagnosed with a terminal illness.

Keeping active can be really beneficial for cancer patients, and can help reduce the negative impact of treatment, but physical activity must be done in a safe way. The physical activity programme Renew, which supports young adults living with cancer in keeping physically active, consists of circuit sessions incorporating cardio, flexibility and strength training. However, it can be challenging to ensure the safety of the participants, as the programme is being delivered online. To address this challenge a triage process has been incorporated to screen patients before being accepted onto the programme, and the sessions can be offered in a 1:1 format for patients with complex needs.

Support at the end of life including palliative care services is often a particular area of unmet need, especially in low income countries, but it can be difficult to identify reliable means for delivering such services. The initiative Palliative Care Services provides low income cancer patients from LMI countries and countries affected by civil war with access to free or affordable palliative care services, through partnering with not-for-profit palliative care organisations. But finding suitable partners for providing services have proven difficult in many of their target countries, including Kenya, Ethiopia and the Philippines.

Most BC patients live with fear of cancer recurrence or progression, and we don’t have enough programs in Mexico to address this issue. Cancer patients are expected to be brave, and fear/vulnerability is not completely accepted.

– Isabel Centeno, Founder of Serene Woman

ABC: advanced breast cancer; mBC: metastatic breast cancer; LMI: low-to-middle income
Initiative Spotlight: Mobile App – My Alma

While all initiatives that support patients with ABC/mBC are important, the steering committee chose to highlight the work of the Hellenic Association of Women with Breast Cancer “ALMA ZOIS” in developing the My Alma Mobile App, due to its specificity to advanced/metastatic disease, as well as its impressive impact and ability to be replicated in other hard-to-reach populations and geographies. This initiative was developed in response to the lack of available support options that meet the very specific needs of patients with ABC/mBC in Greece. It aims to provide patients with support that is accessible, friendly, hopeful, and realistic, and bridge the gap between patients and support services, ultimately improving their QoL.

My Alma was launched in 2019 to meet the needs of patients with ABC/mBC in Greece who often feel isolated and ashamed due to stigma associated with the disease. Many support options require physical presence and are only in the big cites – many patients with ABC/mBC, especially those in remote areas, are unable to access these services. The app aims to:

- Provide easily accessible, specific information and emotional support for isolated or ill-informed patients with ABC/mBC
- Improve QoL by increasing healthy behaviours and treatment compliance
- Bring the ABC/mBC community in Greece into the spotlight

While the costs and timelines associated with the initial development of the app were relatively high, its applicability to multiple countries and hard-to-reach populations means that it can be easily adapted for different languages at a relatively low cost, and an English version of the app is due to launch in 2020.

For more information: https://www.almazois.gr/en/my-alma-app

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

Based on written submission and interview with Alma Zois, 2020.
The app includes multiple components that support patients with ABC/mBC:

- Useful information on the latest medical data and services
- A treatment calendar with medication reminders
- Videos of mild exercise and goal setting for healthy behaviours
- Advice on managing feelings & treatment side effects

The app was launched after 2 years of development and hard work from the Alma Zois team to overcome technical and regulatory challenges. More than 400 people with ABC/mBC across Greece currently benefit from the accessible support that the app offers. It has also been recognised with two innovation awards (Greek Healthcare Aware and Greek Mobile Excellence Awards).

Support is clustered in the big cities and the app helps to reach those further afield. We also wanted to bring the mBC community in Greece into the spotlight and highlight that this app is made specifically for them.

– Christiana Mitsi, Scientific Director at Alma Zois

For more information:
https://www.almazois.gr/en/my-alma-app

ABC: advanced breast cancer; mBC: metastatic breast cancer

Based on written submission and interview with Alma Zois, 2020.
Initiative Spotlight: Let the Hopes Blossom

While all initiatives that support patients with ABC/mBC are important, the steering committee chose to highlight the collaborative work of Europa Donna Turkey, The Turkish Medical Oncology Association (TTOD) and Pfizer Turkey in developing the Let The Hopes Blossom initiative, due to its specificity to advanced/metastatic disease, as well as its impressive impact and ability to be replicated in other hard-to-reach populations and geographies. The initiative was developed in response to a lack of psychosocial support for patients with ABC/mBC in Turkey and, as well as providing free psychological support sessions for patients with ABC/mBC, the initiative aims to raise awareness of the importance of this support for patients living with ABC/mBC.

The Let The Hopes Blossom initiative was based on research from TTOD showing that, although it is rarely offered in Turkey, psychological support is particularly important following an ABC/mBC diagnosis and can significantly improve QoL and treatment outcomes. This initiative has two key objectives:

- Offer five free, specialized psychological support sessions to patients with ABC/mBC from a validated psychological centre
- Raise awareness of the importance of and need for psychological support for patients with ABC/mBC

The initiative was a truly collaborative effort from the three contributing organisations, each playing an important role in development. It has been running since 2018 and has overcome initial challenges in obtaining support from stakeholders and motivating HCPs to refer their patients for the support sessions offered by the initiative.

For more information:
https://umutlarcicekacsin.org/

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

Based on written submission and interview with Pfizer Turkey, 2020.
Initiative Spotlight: Let the Hopes Blossom

Since its launch, this initiative has had an impressive reach, with more than 30 million people reached across channels such as YouTube, Twitter and Facebook. This was aided by an impactful promotional campaign consisting of:

- Brochures and a handbook for medical oncologists
- Information booklets distributed to hospitals for patients
- A social media campaign including a song written by a famous Turkish singer, for patients with ABC/mBC

Crucially, this increased awareness has resulted in increased patient participation in the initiative, with 325 patients with ABC/mBC from across Turkey having attended at least one free psychological support session in the two years since the initiative launched.

“For an important unmet need is discovered, it’s important to conduct the project […] if you believe your idea can have an impact on peoples lives, even if just starting with a small focus group, it’s important to pursue the project as we can touch the patients’ lives.”

– Irem Hanagasi
Pfizer Oncology Turkey

For more information: https://umutlarcicekacsin.org/

ABC: advanced breast cancer; HCP: healthcare professional; mBC: metastatic breast cancer

Based on written submission and interview with Pfizer Turkey, 2020.
While all initiatives that support patients with ABC/mBC are important, the steering committee chose to highlight the work of Infinite Strength in developing the HOPE Retreat, due to its specificity to advanced/metastatic disease, as well as its impressive impact and ability to be replicated in other hard-to-reach populations and geographies. The retreat was developed in response to the lack of available emotional and financial support available for single mothers with ABC/mBC. The initiative provides financial and emotional support to these women and their children through a series of one-day retreats, including speaking with licensed social workers and therapists, art therapy, breakfast & lunch, and a grocery card.

The HOPE Retreat was launched in 2021 to meet the needs of underserved single mothers with ABC/mBC in the US that are below the federal poverty level. These women often have a poor understanding of the disease and lack the opportunity for their children to engage with other children who are in a similar situation. The retreat aims to:

• Offer community support to underserved single mothers with mBC and their children
• Educate patients on the disease and teach them how to advocate themselves
• Provide healing time through art therapy and creative activities they would not necessarily have access to without the programme

The initiative was developed with social workers at healthcare organisations in the state of Connecticut, along with oncology family therapists, art therapists, and grief support therapists.

For more information:
https://www.infinitestrength.org/the-hope-retreat
Email: Roberta Lombardi (Roberta@infinitestrength.org)
The monthly retreat consists of multiple components that support patients with ABC/mBC:

- The mothers are first given time with a licenced social worker/therapist who specialises in oncology support
- Whilst this occurs, the children undergo creative art therapy with a professional art therapist and socialise with other children in the same situation
- Breakfast and lunch is provided to all and a $100 grocery card is given to mothers to take away to help them get through the month until the next retreat

The COVID-19 pandemic prevented the opening of a retreat house as was initially planned but community centres have instead been used for the retreats. Retreats have been held once a month with an aim to increase this to twice a month in the future. Whilst the initiative has not been running for long, many of the families who were involved in the first retreat have returned for the second event. This indicates the success and value of the initiative as they valued the access to a therapist that they otherwise would not have alongside the value of the support group.

For the support piece, it is really important that it takes place with a licenced therapist who specialises in BC. The retreat does not always catch on immediately, it is slow starting with some families. Success isn't how many people, but more that you are helping people.

– Roberta Lombardi, Founder and President at Infinite Strength

For more information:
https: www.infinitestrength.org/the-hope-retreat
Email: Roberta Lombardi (Roberta@infinitestrength.org)

Based on written submission and interview with Roberta Lombardi, 2021.

ABC: advanced breast cancer; BC: breast cancer; mBC: metastatic breast cancer
While all initiatives that support patients with ABC/mBC are important, the steering committee chose to highlight the collaborative work of Project PINK BLUE- Health & Psychological Trust Centre (PPB-HPTC) in developing the Breast Cancer Navigation and Palliative Program (BCNPP) initiative, due to its specificity to advanced/metastatic disease, as well as its impressive impact and ability to be replicated in other hard-to-reach populations and geographies. The initiative was developed in response to the stigma and misunderstanding that is associated with BC in Nigeria resulting in many people not receiving adequate support. The BCNPP is a cancer care programme designed to educate cancer survivors and caregivers across Nigeria to become professional patient navigators who can guide women with ABC/mBC.

The BCNPP initiative was developed by an oncologist and psychologist and launched in 2015 to help address the lack of financial, psychological and educational support available for women with BC, alongside a lack of visible survivorship and palliative care. This initiative has two key objectives:

- Build nurse and patient navigator capacity and capability to support people living with ABC/mBC
- Improve the QoL of people with mBC/ABC

The initiative is now run by 10 Project PINK BLUE patient navigators but has been placed under additional stress by the COVID-19 pandemic resulting in a reduction in the number of staff. In order to ensure the initiative can reach more people at a lower cost they are aiming to develop a mobile app to help provide information to patients.

For more information:
https://www.projectpinkblue.org/abc-sg/
Email: Khadijat Banwo (khadijat.banwo@projectpinkblue.org)

ABC: advanced breast cancer; HCP: healthcare professional; mBC: metastatic breast cancer; QoL: quality of life
The BCNPP initiative consists of a number of different components that support patients living with ABC/mBC:

- BC patients (champions) are trained to become navigators and advocates to support BC patients and caregivers
- Oncology nurse training in palliative care (also provide home care)
- Dedicated telephone support number: Nigeria’s first telephone support centre for information on BC diagnosis, treatment, palliative care
- Navigators guide and information materials
- Mobile app: for the wider community (conceptual)

The initiative has also led to the development of patient support partnership programmes and access to medicine partnerships with pharma organisations. More details on the further work done by Project PINK BLUE are outlined in the Peer-to-Peer Support Groups or Platforms for Patients with ABC/mBC Best Practice Summary Document. There are also ambitions to extend the initiative to fund staff to provide support to patients at oncology centres once the required funds have been obtained.

The main reason the initiative has been successful is because it was patient-focused, it wasn’t business focused at all – we wanted to ensure patients get the right information, resources and support they need which is normally European and US focused.

– Runcie C.W. Chidebe, Executive Director Project PINK BLUE

For more information:
https: www.projectpinkblue.org/abc-sg/
Email: Khadijat Banwo (khadijat.banwo@projectpinkblue.org)
Initiative Spotlight: Serene Woman

While all initiatives that support patients with ABC/mBC are important, the steering committee chose to highlight the collaborative work of Travesías de Tinta y Unidas Contigo AC and Compassion Corps Alliance in developing the Serene Woman initiative, due to its unique focus on compassion training and providing emotional and psychological support, which is a very significant area of unmet need for patients with ABC/mBC. As a fairly low-cost initiative this program also has a great potential for being replicated with other hard-to-reach populations and geographies. The initiative was developed to help women with ABC/mBC of low socio-economic status who are within 5 years of breast cancer diagnosis in Mexico, Peru, and Ecuador. It aims to educate women living with ABC/mBC on how to deal with the fear of cancer recurrence and progression.

The Serene Woman initiative was developed by Professor Isabel Centeno, a psycho-oncologist, with the support of one of her students. Many patients diagnosed with cancer experience fear of recurrence and progression, and lack support or knowledge of psychological techniques to handle these emotions. This initiative aims to address these challenges by providing a free online cognitive behavioural therapy training program.

This initiative has one key objective:

- To teach women with breast cancer techniques in compassion for self and others, communication and reducing feelings of fear

The initiative built on the existing Compassion Cultivation Training developed at the Stanford School of Medicine and Fear of Recurrence Therapy developed in Canada. The initiative received their first funding and is now running their second training program.

ABC: advanced breast cancer; mBC: metastatic breast cancer

For more information:
Email: psychooncology@isabelcenteno.com.mx

Based on written submission and interview with Isabel Centeno, 2023
Initiative Spotlight: Serene Woman

The Serene Woman initiative consists of a core online training course that support women living with ABC/mBC and comprises of the following:

• 8 week online training programme with weekly sessions in small intimate groups of 12-16 participants
• A journal for each participant to be used throughout
• Flexible attendance to accommodate hospital appointments
• Available to patients from both the public health and the private health system

Fear of progression and compassion were assessed before the programme, immediately after and 3 months after the program ended. The initiative resulted in decreased fear of progression whilst perceptions of compassion increased. After this period, fear increased again slightly, which could be because women may respond better when they were united as a group. There are ambitions to extend and develop the program, with the support of additional sponsorship. The next step is to develop a compassion training program with a focus on sexuality.

"This programme address social narratives around BC and mBC. [...] It is based on CBT. We work on the fear cycle and narrative to understand what happens and how to live with the disease. Talking about fear, fear of dying or what we fear in the body. It is a wonderful programme. I hope it could be replicated."

– Isabel Centeno, Founder of Serene Woman

ABC: advanced breast cancer; CBT: cognitive behavioural therapy; mBC: metastatic breast cancer

For more information:
Email: psychooncology@isabelcenteno.com.mx

Based on written submission and interview with Isabel Centeno, 2023.
Based on written submission and interviews conducted in 2020-2023 with: Alma Zois; Pfizer Turkey; Fusako Ishigami, Pfizer; Prof Nkegoum Blaise, Clinique Medicale Camassistance; Catrin Devonald, Sweet Louise; Pfizer Hellas; Jo Lovelock, Aloha; Spitali i integruar PAI Onkologjik; Roberta Lombardi, Infinite Strength; Khadijat Banwo and Runcie C.W, Chidebe PPB-HPTC; Isabel Centro, Compassion Institute; Suryakanta Acharya, PAY-W Clinic; Ian Boyd, Trekstock; Maricarmen Planas-Silva, Angel Mira; Rosemary Carrera, 305 Pink Pack.

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.