

Best
practice in
ABC/mBC

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 tank 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 **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**





Contents

- 1 Unmet needs addressed
- 2 Objectives
- 3 Contributing initiatives
- 4 Development process
- 5 Challenges
- 6 Initiative Spotlight





Unmet needs addressed

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:

- Lack of psychosocial support for patients with ABC/mBC
- Low awareness and understanding on the specific needs of patients with ABC/mBC and how these differ from patients with eBC
- Lack of communication between HCPs and patients with ABC/mBC, leading to poor disease management and navigation
- Lack of disease-management resources specifically for the needs of patients with ABC/mBC (i.e. wound care kits)
- Low motivation to develop initiatives specifically for patients with ABC/mBC, due to a perceived lack of hope for these patients and the associated sociocultural/religious taboo



The basic issue mBC patients face is the stigma [...] they also feel neglected, as there are no specific programmes for mBC patients resulting in them feeling left out.

– Christiana Mitsi,
Scientific Director of Alma Zois



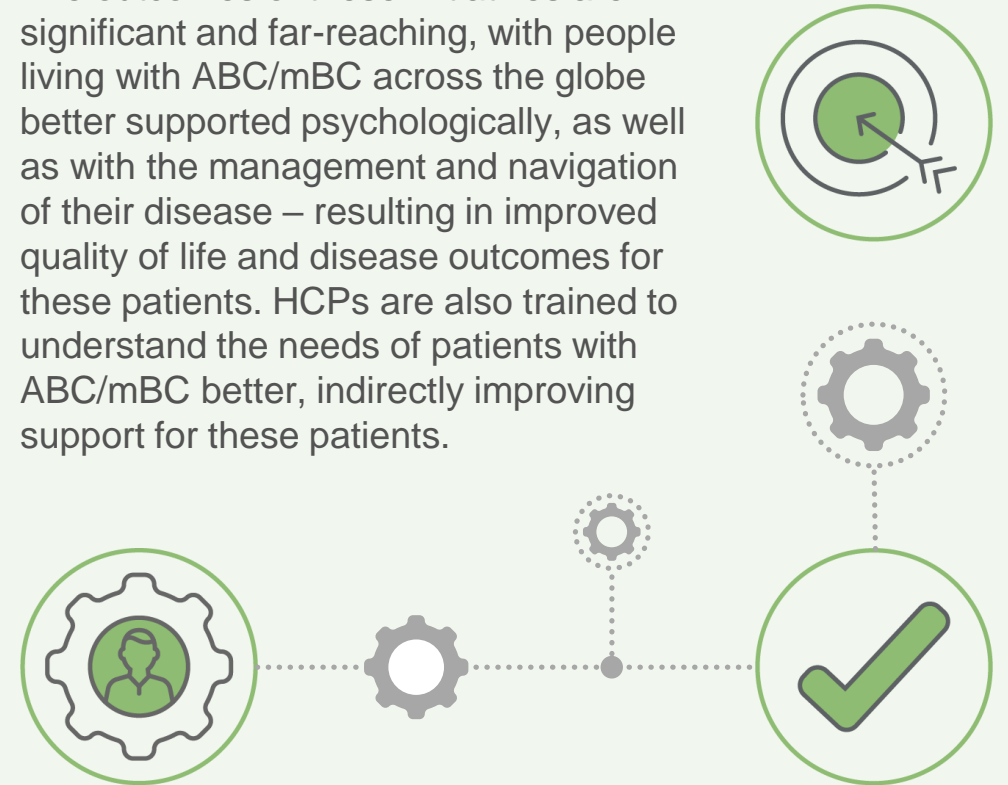


Objectives

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

- Improve quality of life for people living with ABC/mBC
- Promote the use of accurate and specific information on ABC/mBC
- Increase the psychological wellbeing of patients with ABC/mBC
- Train HCPs and local community leaders to better support patients with ABC/mBC
- Promote healthy behaviours in patients with ABC/mBC, including compliance to treatment
- Improve the management of malignant fungating breast wounds

The outcomes of these initiatives are significant and far-reaching, with people living with ABC/mBC across the globe better supported psychologically, as well as with the management and navigation of their disease – resulting in improved quality of life and disease outcomes for these patients. HCPs are also trained to understand the needs of patients with ABC/mBC better, indirectly improving support for these patients.





Contributing initiatives

Mobile App: My Alma

Country/region: Greece

Hard-to-reach communities targeted

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



Brief description

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 and ultimately improving QoL.

For more information

<https://www.almazois.gr/en/my-alma-app>

Let the Hopes Blossom

Country/region: Turkey

Hard-to-reach communities targeted

- ✓ Low income patients
- ✓ Low health knowledge patients



Brief description

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.

For more information

<http://umutlarcicekacsin.org/>

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





Contributing initiatives

My Choice Navi

Country/region: Japan

Hard-to-reach communities targeted

- ✓ Low income patients
- ✓ Older patients
- ✓ Rural 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)

Palliative care and home

visit for rural Cameroonian patients with ABC

Country/region: Cameroon

Hard-to-reach communities targeted

- ✓ Rural 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

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 minorities
- ✓ Low income patients
- ✓ Older patients
- ✓ Rural 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.sweetlouse.co.nz

Catrin Devonald (catrin.devonald@sweetlouse.co.nz)

Winter Mission

Country/region: Greece

Hard-to-reach communities targeted

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



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 the remote locations, as well as offering medical services and informative lectures specifically for patients living with ABC/mBC.

For more information

<https://omadaaigaiou.gr/>

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

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

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

Hard-to-reach communities targeted

- ✓ Low income patients
- ✓ Rural patients



Brief description

Patients receiving treatment for BC in Albania lack access to resources such as silicone prostheses and wigs, which negatively impacts the quality of life 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](#).





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.

Several initiatives – such as **Winter Mission**, which offers medical support services to patients with ABC/mBC living on remote Greek islands, and **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 – relied on the support of volunteer HCPs and nurses to develop and run 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





Development process

As well as providing direct support to patients with ABC/mBC, some initiatives also do this indirectly, 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.

Data collection during the initiative development process may help to validate the need for initiatives that support patients with ABC/mBC with key stakeholders, as well as supporting funding opportunities. During the development of the **Support For Those Living With Incurable BC** initiative, Sweet Louise were able to determine the social impact of their initiative and then compare this against data from 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.

Funding for an initiative can come from a number of different sources, including through grants, individual donors, or specific fundraising events.

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 for local distribution
3. Leveraging an existing fundraising event (promotion via event materials – e.g. t-shirts)
4. TV / online commercial
5. Collaboration with a local celebrity
6. In-person visits to the target community





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 **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.

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.



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





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.

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 from Apple to use the app on their App Store
- 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 users can upload motivational messages to, which are 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.





Initiative Spotlight: Mobile App – My Alma

Support for
patients with
ABC/mBC

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 its 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 quality of life.

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 cities – 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 are 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.



Initiative Spotlight: Mobile App – My Alma

Support for
patients with
ABC/mBC

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





Initiative Spotlight: Let the Hopes Blossom

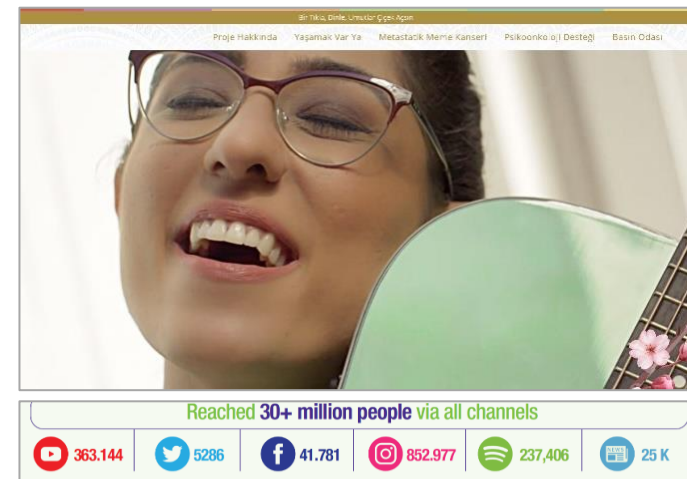
Support for
patients with
ABC/mBC

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 its 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 patients with ABC/mBC with free psychological support sessions, 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 quality of life and treatment outcomes. This initiative has two key objectives:

- Offer 5 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: <http://umutlarcicekacsin.org/>



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



Based on written submission and interview with Pfizer Turkey, 2020.



Initiative Spotlight: Let the Hopes Blossom

Support for
patients with
ABC/mBC

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.

“

If 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: <http://umutlarcicekacsin.org/>





Based on written submission and interviews conducted in 2020 with: Alma Zois; Pfizer Turkey; Fusako Ishigami, Pfizer; Prof Nkegoum Blaise, Clinique Medicale Camassistance; Catrin Devonald, Sweet Louise; Pfizer Hellas; Jo Lovelock, Alola; Spitali i integruar PAI Onkologjik.

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.

