Educating patients about 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 educate patients about 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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5. Challenges
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Unmet needs addressed

Worldwide, accessible information on ABC/mBC for patients and their caregivers is lacking, and patients are often poorly educated about the specifics of the disease and available treatment options, especially in underserved communities. This can lead to poor communication between patients and HCPs, and poor disease management, that can negatively impact outcomes and quality of life. Initiatives such as those outlined in this document are crucial to educate and empower patients on ABC/mBC and help patients and their relatives and caregivers to better understand and manage the disease.

Patients are often poorly educated on ABC/mBC and there is a lack of easy to understand and accessible information. This contributes to a number of different issues, including:

• Low awareness and understanding of ABC/mBC, the available treatment options, commonly used terminology and the importance of genetic testing
• Lack of accessible information on ABC/mBC, including in patients’ native language
• Lack of patient participation in decision-making
• Low digital health literacy and poor access to credible online resources
• Poor patient understanding of and access to clinical trials, especially for older patients, poorly educated patients and LGBTQIA+ patients
• Poor communication between patients and HCPs and patient mistrust of the healthcare system
• Poor patient navigation, including delayed referral to specialist care and sub-optimal treatment
• Lack of diverse and inclusive imagery and voices in available resources and lack of culturally sensitive care
• Lack of tailored support for young mothers to speak to loved ones about their mBC diagnosis

As we moved more digitally to build community, the glaring unmet need of mBC became more visible… so we shifted and prioritised mBC experiences, through documentaries, videos, tools - amplifying the need for more time, better treatments, bringing the patient voice forward and creating change.

– MJ DeCoteau
Founder and Executive Director, Rethink Breast Cancer

ABC: advanced breast cancer; HCPs: healthcare professionals; LGBTQIA+: lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual; mBC: metastatic breast cancer

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

Initiative objectives were all designed to fill gaps in knowledge and educate patients on ABC/mBC:

- Improve patient access to accurate, reliable and specific information on ABC/mBC, including culturally sensitive information and resources
- Improve patient, relatives, and caregiver understanding of ABC/mBC, treatment options and the importance of genetic/biomarker testing
- Improve access to culturally sensitive care and combat medical mistrust
- Promote the use of accurate and specific information on ABC/mBC
- Encourage shared decision-making and empower patients to take an active role in treatment decision-making and disease management
- Understand existing barriers to patient navigation through the healthcare system and improve patient and HCP communication
- Improve outcomes and quality of life for people living with ABC/mBC, including diagnosis rate and initiation of treatment
- Improve understanding of clinical trials and the informed consent process and simplify access to clinical trials, especially for older patients, poorly educated patients and LGBTQIA+ communities
- To provide support for young mothers to talk to their children and loved ones about their mBC diagnosis

The outcomes of these initiatives are significant and far-reaching, with many patients across the globe better educated about their disease, with improved access to ABC/mBC-specific educational materials and in-person or online events. This has resulted in empowered patients who are better able to participate in decisions about their treatment, enhanced disease management and patient navigation, and better adherence to treatment, ultimately leading to improved outcomes and improved quality of life for patients with ABC/mBC.

ABC: advanced breast cancer; HCPs: healthcare professionals; LGBTQIA+: lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual; mBC: metastatic breast cancer

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

<table>
<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><strong>Help For Me – Patient Navigator</strong></td>
<td>Germany</td>
<td>✓ Low income patients</td>
<td>In Germany, patients often lack the ability to navigate the complex healthcare system. This initiative supports patients with ABC/mBC and caregivers in navigating through the healthcare system thanks to a co-created, digital support solution which aims to ensure equity and access to health services. The website has since been expanded to include 9 other indications.</td>
<td><a href="http://www.hilfefuermich.de/">www.hilfefuermich.de/</a> Anja Schmidt (<a href="mailto:Anja.Schmidt@pfizer.com">Anja.Schmidt@pfizer.com</a>)</td>
</tr>
<tr>
<td><strong>Breast Cancer School For Patients</strong></td>
<td>Kazakhstan</td>
<td>✓ Low health knowledge patients</td>
<td>Kazakhstan has a high incidence of breast cancer and significantly lower 5-year survival rates compared to OECD countries. The leading oncology center in the Abay region sees a high number of patients, who often have low health literacy. This initiative provides a series of patient training and education sessions on all aspects of BC to improve treatment outcomes.</td>
<td><a href="https://semeyonco.kz/">https://semeyonco.kz/</a> Kuantkan Zhabagin (<a href="mailto:kuantkan_85@mail.ru">kuantkan_85@mail.ru</a>)</td>
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ABC: advanced breast cancer; BC: breast cancer; mBC: metastatic breast cancer; OECD: Organisation for Economic Co-operation and Development

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

<table>
<thead>
<tr>
<th>You Have a Choice Campaign</th>
<th>Metastatic Care: Educational Component</th>
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<tr>
<td><strong>Country/region:</strong> Poland</td>
<td><strong>Country/region:</strong> Mexico</td>
</tr>
<tr>
<td><strong>Hard-to-reach communities targeted</strong>&lt;br&gt;✓ Low income patients ✓ Low health knowledge patients</td>
<td><strong>Hard-to-reach communities targeted</strong>&lt;br&gt;✓ Low income patients ✓ Low health knowledge patients</td>
</tr>
<tr>
<td><strong>Brief description</strong>&lt;br&gt;In Poland, there is low awareness of ABC/mBC and the treatment options available. The “You Have a Choice” nationwide educational/social campaign aims to raise awareness of the benefits of CDK4/6 inhibitors and the importance of patient involvement in treatment decisions, through expert meetings, roundtables, a call to action/manifesto, and online patient training.</td>
<td><strong>Brief description</strong>&lt;br&gt;Following the roll out of previous Médicos e Investigadores en la Lucha contra el Cáncer de Mama (MILC) initiatives, it was identified that many specific needs of patients with ABC/mBC were not being met. This standardised psychoeducational intervention was developed to assess and improve patient understanding of their disease, allowing them to actively participate in decision-making processes and ultimately improve QoL.</td>
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<td><strong>For more information</strong>&lt;br&gt;www.wybierzwybor.pl/Agata Zyla (<a href="mailto:agata.zyla@pfizer.com">agata.zyla@pfizer.com</a>)</td>
<td><strong>For more information</strong>&lt;br&gt;www.milc.org.mx/Alejandra Platas (<a href="mailto:ana1282@hotmail.com">ana1282@hotmail.com</a>)</td>
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ABC: advanced breast cancer; mBC: metastatic breast cancer; MILC: Médicos e Investigadores en la Lucha contra el Cáncer de Mama; QoL: quality of life

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

### I Know! I Can!
**Country/region:** Kazakhstan

**Hard-to-reach communities targeted**
- Low health knowledge patients
- Patients who mistrust conventional treatments
- Low income patients
- Patients a long distance from a specialist centre

**Brief description**
The incidence of breast cancer is increasing in Kazakhstan, but many breast cancer patients have a poor understanding of the disease, treatment and risk factors for relapse. This initiative aims to support and educate patients in Astana in Kazakhstan about the disease, diagnostic tests and treatment, and healthy living for better disease control.

For more information
- Karimbayeva Yerkesh Mukhtarovna (y.karimbayeva@gmail.com)

### LGBTQ+ Diversity in Clinical Trials
**Country/region:** US, Canada and Israel

**Hard-to-reach communities targeted**
- LGBTQ+ patients

**Brief description**
LGBTQIA+ communities and gender minorities are underrepresented in cancer clinical trials and often face barriers such as mistrust and lack of information about access to trials. This initiative provides accessible resources for these populations on access to clinical trials and on how to request information about clinical trials from health care providers.

For more information
- Thomas Wilson (EducationAndOutreach@CancerSupportCommunity.org)
# Contributing initiatives

<table>
<thead>
<tr>
<th>Metastatic Breast Cancer: Everything You Need to Know</th>
<th>Country/region: Mexico</th>
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</thead>
<tbody>
<tr>
<td><strong>Hard-to-reach communities targeted</strong></td>
<td>✓ Low income patients</td>
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<tr>
<td><strong>Brief description</strong></td>
<td>Many mBC patients and their caregivers lack knowledge about mBC and the available treatments, and support that can improve their quality of life. This project aims to educate patients and the general public in Mexico through a website providing information in Spanish about mBC and its treatments.</td>
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<tr>
<td><strong>For more information</strong></td>
<td><a href="https://salvati.org.mx/">https://salvati.org.mx/</a> Adela Ayensa (<a href="mailto:adela@salvati.org.mx">adela@salvati.org.mx</a>)</td>
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<tr>
<th>Spanish-language BC Patient Education Novelas</th>
<th>Country/region: USA</th>
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<tr>
<td><strong>Hard-to-reach communities targeted</strong></td>
<td>✓ Ethnic, religious, indigenous/native population and/or other historically marginalised groups ✓ Low health knowledge patients</td>
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<tr>
<td><strong>Brief description</strong></td>
<td>The lack of available material in Spanish-language on ABC/mBC is a barrier to access for LatinX patients, making discussions with HCPs complex. An original graphic novel was developed on the diagnostic journey of an mBC patient. Following this novela’s success, the organisation is creating a sequel focused on the importance of genetic testing and hereditary cancer.</td>
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<tr>
<td><strong>For more information</strong></td>
<td><a href="https://www.storyhalftold.com/sites/default/files/2020-10/share_mets_novela_spanish_translation.pdf">www.storyhalftold.com/sites/default/files/2020-10/share_mets_novela_spanish_translation.pdf</a> Lillian Arruda (<a href="mailto:lillian.arruda@pfizer.com">lillian.arruda@pfizer.com</a>)</td>
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mBC: metastatic breast cancer; HCP: healthcare professionals

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

## ABC Project

**Country/region:** Japan

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

**Brief description**
While there are many BC support groups in Japan, most are not for people with ABC/mBC and many people with advanced disease have difficulties finding information online. The ABC Project aims to educate and empower people with ABC/mBC, their families, and HCPs, through online seminars, e-learnings, and episodes.

**For more information**
- www.abcproject.cansol.jp/
- www.facebook.com/CancerSolutionskk/
- info@cansol.jp

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ABC: advanced breast cancer; BC: breast cancer; HCP: healthcare professionals; mBC: metastatic breast cancer.

## mBC Dictionary

**Country/region:** USA

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

**Brief description**
The dictionary aims to improve communication between HCPs and newly diagnosed patients and their loved ones. The objective of the dictionary is to explain and provide greater context to the unfamiliar key terms and phrases that are commonly used when talking about ABC/mBC diagnosis, treatments and the experience of living with mBC.

**For more information**
- www.breastcancervision.com/mbc-dictionary
- Katrina Johnson (katrina.m.johnson@pfizer.com)
Contributing initiatives

<table>
<thead>
<tr>
<th>Initiative</th>
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<tbody>
<tr>
<td>One in Eight Women</td>
<td>USA</td>
<td>✓ Ethnic, religious, indigenous/native populations and/or other historically marginalised groups</td>
<td>Black and African American persons have a higher risk of developing breast cancer at an early age, a higher risk of cancer recurrence, and a higher risk of death from breast cancer than White persons. This initiative provides information on breast cancer and health inequalities to empower and educate Black and African American populations in the US, Canada and Israel.</td>
<td><a href="http://www.CancerSupportCommunity.org/Breast-Cancer">http://www.CancerSupportCommunity.org/Breast-Cancer</a> Thomas Wilson (<a href="mailto:EducationAndOutreach@CancerSupportCommunity.org">EducationAndOutreach@CancerSupportCommunity.org</a>)</td>
</tr>
<tr>
<td>Frankly Speaking About Cancer: Triple-Negative Breast Cancer in Black and African American Communities</td>
<td>USA, Canada, Israel</td>
<td>✓ Ethnic, religious, indigenous/native population and/or other historically marginalised groups</td>
<td></td>
<td><a href="http://www.CancerSupportCommunity.org/Breast-Cancer">www.CancerSupportCommunity.org/Breast-Cancer</a> Cinthia Gonzalez (<a href="mailto:cgonzalez@nbcf.org">cgonzalez@nbcf.org</a>)</td>
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ABC: advanced breast cancer; HCP: healthcare professionals; mBC: metastatic breast cancer
### Contributing initiatives

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<tr>
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<td>✓ Ethnic, religious, indigenous/ native populations and/or other historically marginalised groups</td>
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<td>✓ Older patients</td>
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<tr>
<td>✓ Low health knowledge patients</td>
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<td><strong>Brief description</strong></td>
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<td>Informed consent (IC) forms for clinical trials are often long, complex and technical in nature, which can be a barrier to patient enrolment, particularly for poorly educated and older patients. This initiative seeks to improve understanding of the IC process through 3D film or cartoon material, in order to improve access to trials for all patients.</td>
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<td><strong>For more information</strong></td>
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<td><a href="http://www.bordet.be/en/iren">www.bordet.be/en/iren</a></td>
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<td>Patrick Miqueu (<a href="mailto:patrick.miqueu@bordet.be">patrick.miqueu@bordet.be</a>)</td>
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<tr>
<td>✓ Low health knowledge patients</td>
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<tr>
<td>✓ Low income patients</td>
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<tr>
<td>✓ Patients a long distance from a specialist centre</td>
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<tr>
<td><strong>Brief description</strong></td>
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<tr>
<td>It can be difficult for newly diagnosed cancer patients to navigate the wealth of information online. Digitally Empowered™ is an online course aiming to provide patients with knowledge and tools to find credible information about their disease, empowering them to make informed decisions about their treatment, through a series of easy-to-follow video modules.</td>
<td></td>
</tr>
<tr>
<td><strong>For more information</strong></td>
<td></td>
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<tr>
<td><a href="http://www.iamdigitallyempowered.org">www.iamdigitallyempowered.org</a>; <a href="http://www.thisislivingwithcancer.com/">www.thisislivingwithcancer.com/</a></td>
<td></td>
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<tr>
<td>Katrina Johnson (<a href="mailto:katrina.m.johnson@pfizer.com">katrina.m.johnson@pfizer.com</a>)</td>
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IC: informed consent
# Contributing initiatives

## Uncovered: A Breast Recognition Project

**Country/region:** Canada

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

**Brief description**

Black, Indigenous and People of Colour (BIPOC) are underrepresented and lack adequate support in the Canadian healthcare system. Uncovered uses imagery and authentic storytelling to draw attention to the impact of breast cancer, cultural barriers and health inequity on these underserved communities in Canada.

**For more information**

www.rethinkbreastcancer.com  
Jasmine Sikand (jasmine@rethinkbreastcancer.com)

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## Talking to Kids About Breast Cancer

**Country/region:** Canada

**Hard-to-reach communities targeted:**
- Younger patients
- Patients a long distance from a specialist centre

**Brief description**

Communicating with family and young children about an mBC diagnosis, treatment and end of life can be very challenging, and adds to the burden of navigating the disease. This project developed an educational resource to support young mothers in having these conversations with their children in an open and honest way.

**For more information**

https://rethinkbreastcancer.com/resources-for-young-families/  
Jasmine Sikand (support@rethinkbreastcancer.com)

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BIPOC: Black, Indigenous and People of Colour; mBC: metastatic breast cancer
To ensure that initiatives provide information and education that is meaningful to patients and their caregivers and addresses their unmet needs, it is essential to fully understand the baseline level of education and information needs of the population that you are trying to reach. This was carried out by different initiatives in various ways:

- **Metastatic Care: Educational Component** – in Mexico limited time during HCP appointments resulted in poor patient understanding of their disease. Consultation with patients and HCPs, made it clear that effective HCP-patient communication during these meetings was the issue.

- **ABC Project** - conducted group discussions and surveys to identify the unmet needs and interests of patients with ABC/mBC.

- **Metastatic Breast Cancer: Everything You Need to Know** - identified patient information needs through a four-year social media information campaign.

- **MBC Dictionary** – using the top 20 search terms on the Breastcancer.org website, a dictionary explaining commonly used key terms used in relation to ABC/mBC was developed.

It is important to continue engagement with patients throughout the development process to ratify educational initiative content. The **Help For Me – Patient Navigator** was developed in collaboration with 13 external experts, including patients, advocates, HCPs and lawyers, and content was reviewed by editors, patients and a scientific advisory board. This initiative is considered a ‘living’ resource that is routinely updated to avoid materials becoming outdated. Similarly, for the **Breast Cancer School for Patients** initiative – a series of 12, 2-hour training sessions for patients, available in person or online – feedback from patients was an important step in the development of the training sessions. Feedback was collected through a printed or online questionnaire or through video recording.

**Don’t assume anything – be sure you understand what your patients know. Ask patients/HCPs what they think of the materials, it’s better to develop materials that actually help them – testing is very important.**

– Alejandra Platas, Co-founder of MILC

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

Based on written submissions and interviews with initiative owners listed on pages 5-13, 2020-23.
It is important to take into account that information and education needs may vary across different patient groups and cultural contexts. It is especially important to consult and work with the target audience in the case of historically marginalised communities whose voices are often not heard.

The organisers of LGBTQ+ Diversity in Clinical Trials worked closely with stakeholder focus groups to identify the ultimate target audience and their needs as well, as help shape the reader level, wording and content of the materials they were developing. Black and African-American persons have a higher risk of BC and triple-negative breast cancer, and are at a higher risk of death from breast cancer compared to White persons. To help address this unmet need, the initiative Frankly Speaking About Cancer: Triple-Negative Breast Cancer in Black and African American Communities has developed a factsheet to empower and educate Black and African American populations in the US, Canada and Israel. The factsheet includes information on health inequalities and on the diagnosis, treatment and survivorship of triple-negative breast cancer in these populations. Uncovered: A Breast Recognition Project addresses health inequity and the unmet needs and lack of representation of Black, Indigenous and People of Colour in the Canadian healthcare system. This initiative uses imagery and authentic storytelling to provide culturally relevant education, information, support and a point of connection for these patient populations.

In some cases the sensitivity of a topic can present some challenges for providing needed support. The initiative Talking to Kids about Metastatic Breast Cancer provides a booklet with tools and tips for young mothers on how to discuss their mBC diagnosis with their children. The organisers found that developing a resource on a sensitive a topic as death, dying and after death was incredibly challenging. Engaging with mBC patients and mental health professionals was an important step in creating a supportive resource where the mBC patient voice was accurately represented.

The topic of death and dying is so different in different cultures. This [Talking to Kids About Metastatic Breast Cancer booklet] is something that could help people in other countries start to have these conversations. It could be quite beautiful for other countries to have something like this that is authentic to their culture […] The way we talk about death in Canada is so different from countries in Africa for example.

Jasmine Sikand
Lead of Content, Community and Collaborations,
Rethink Breast Cancer

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

During the development of an initiative it can be hugely beneficial to partner with other individuals and organisations to assist with an initiative for a number of reasons including expanding the reach of an initiative or obtaining a skillset that you otherwise may not have, particularly for smaller organisations. For the Spanish-language BC Patient Education Novelas initiative Latina Share’s partnership with Pfizer allowed all content to be verified by Pfizer’s medical team. Latina Share also recruited expert writers and illustrators to assist with the creation of the Novelas. Similarly, the development of the How to Improve the Informed Consent (IC) Process and Understanding Using 3D film or cartoon material initiative required a range of external input, including project coordinators, multimedia experts, video assembly, qualitative data experts, and translators, and the Digitally Empowered initiative was developed with support from a web developer and animator. The development of Talking to Kids About Metastatic Breast Cancer involved collaboration and input from a Child Life Specialist, an mBC patient advisory board, a psychotherapist and an illustrator living with mBC.

Engaging in partnerships like those described above can allow organisations to seek specialist support and resources that otherwise they would not have access to. This can be crucial in ensuring that initiatives can begin to support patients in a timely, cost effective and accurate manner.

Seeking support from a partner can also help to secure the required funding to turn an idea into a reality. Funding for an initiative can come from a number of different sources, including through grants, individual donors, or specific fundraising events. I Know! I Can! was sponsored by a Pfizer Quality Improvement Grant that allowed a team of specialists from the Multidisciplinary Medical Centre to develop the initiative.

“Securing the funding is obviously a challenge – think about this ahead of time and make sure that you have the resources that you need.”

Lillian Arruda
Medical Director, Breast Cancer, Pfizer Oncology

Based on written submissions and interviews with initiative owners listed on pages 5-11, 2020-23.
Challenges

The dissemination and promotion of educational content and resources is key as it can sometimes be difficult to reach the intended target audiences, and it is important to consider what channels are likely to be most effective and impactful.

To overcome this challenge, many organisations choose to disseminate their materials and resources through multiple channels. The organisers of the LGBTQ+ Diversity in Clinical Trials initiative promote their materials on all of their Cancer Support Community channels. They also use social media posts on LinkedIn, Twitter and Instagram, as well as link to current events and news to further raise awareness of their publication. The You Have a Choice initiative, a nationwide educational/social campaign raising awareness of the benefits of CDK4/6 inhibitors and the importance of patient involvement in treatment decisions, also used multiple formats and channels to disseminate their message. This included expert meetings, round tables, a call to action, and online patient training.

Partner organisations can also help with dissemination efforts. The organisers of Frankly Speaking About Cancer: Triple-Negative Breast Cancer in Black and African American Communities worked with local network partners that helped distribute and promote the educational factsheet in print and on social media.

More direct outreach approaches can also be effective in overcoming this hurdle. One in Eight Women is a multi-faceted initiative that provides information, education and support to underserved Hispanic communities through multiple channels, including outreach events in communities and support on accessing healthcare resources provided directly through patient advocates.

"One of the barriers we found that we need to address is that while of course young adults are also affected by cancer, a majority of LGBTQ+ individuals who have cancer will probably be in the older age range. And we’re talking about people who experienced don’t ask, don’t tell. … Most of our promotion is using social media and online spaces, but we also need to think about how to reach that older and often forgotten generation."

– Thomas Wilson
Manager, Education & Outreach, Cancer Support Community

ABC: advanced breast cancer; LGBTQ+: lesbian, gay, bisexual, transgender, queer, questioning; mBC: metastatic breast cancer
Challenges

Potential challenges faced by organisations leading initiatives may be overcome through consideration of multiple viewpoints and planning ahead to limit disruptions. 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.

A collaborative approach to initiative development is a commonly used approach, but ensuring that all parties are aligned can sometimes be challenging.

Organisers of the Help For Me – Patient Navigator initially found it difficult to obtain internal support for the first co-created project conducted by this group, and the thirteen external experts collaborating on its development all had varying opinions. However, as stated by the organisers: if you are convinced of an idea, you should pursue it and not let barriers prevent you from doing so. Gaining alignment and taking multiple viewpoints into consideration can be hard, and this can be the case with external stakeholders as well as internal. The Metastatic Care: Educational Component initiative found it challenging to develop educational materials that were both useful for patients, as well as convenient and helpful for HCPs. Ratifying content with both patients and HCPs along the development process is one way to overcome such an issue. It is however important that the review process is accounted for in advance as if not done this can cause delays, as was the case with the Spanish-language BC Patient Education Novelas.

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

It can be challenging to ensure that the initiative reaches its intended target audience, especially for historically marginalised, underserved and underrepresented communities. This can be overcome by building trust with patients during the initiatives development. This was the case with Uncovered: A Breast Recognition Project, an initiative developed to improve representation and amplify the voices and experiences of Black, Indigenous and People of Colour in breast cancer care and to provide relevant and culturally sensitive resources. A key component of the initiative was a series of celebratory spotlighting stories and images of black women with breast cancer, but it proved difficult to recruit participants. To overcome this challenge it was necessary to build trust by taking the time to listen to and develop authentic relationships with the BIPOC communities.

I Know! I Can! is an initiative that aims to educate patients on mBC in Kazakhstan and reduce patients’ fear of seeking medical help through educational materials including a native language navigator brochure, a dedicated WhatsApp group, and a lecture series. Patients were invited to participate in the project, but several patients were hesitant to take part. The project organisers met with the patients one-on-one to explain the objectives of the project and benefits for patients.

BC: breast cancer; mBC: metastatic breast cancer; BIPOC: Black, Indigenous and People of Colour
While all initiatives that educate patients & HCPs about ABC/mBC are important, the steering committee chose to highlight the work of Pfizer Germany in developing the Help For Me – Patient Navigator, 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. Patients with ABC/mBC often find it difficult to navigate the highly complex healthcare system in Germany. The Patient Navigator is a co-created, digital support solution, that aims to improve equity and access to health services in Germany through educating patients with ABC/mBC, and their caregivers, about the disease and helping them to navigate the healthcare system.

The Help For Me – Patient Navigator was developed following feedback from patients that brochures were not sufficient to help them to navigate the complex German healthcare system. The initiative aims to:

- Help patients with ABC/mBC, their relatives and caregivers, to understand and manage the disease and to navigate the complex healthcare system
- Improve patient access to high-quality information and support services, therefore improving outcomes

The ABC/mBC section of the website was developed by a team of twenty, including 13 external experts (HCPs, patients, patient advocates, and lawyers). While the initial concept and design was resource-intense, the navigator has since been expanded to include 10 different indications. The initiative is considered a ‘living tool’, with new sections continuing to be developed and existing sections regularly updated, with a medical writer involved in the development of content.

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

For more information: https://www.hilfefuermich.de/
Email: Anja.Schmidt@pfizer.com

Based on written submission and interview with Anja Schmidt, Pfizer, 2020.
Initiative Spotlight: Help for me – Patient Navigator

The navigator comprises different components, all designed to educate patients on their disease and help them to navigate the system, including:

• Q&A section with 160 questions across 8 categories (disease information, living with the disease, investigations, treatment, job & social, support, rehabilitation and help for relatives)
• ABC/mBC patient pathway, including links to parts of the Q&A
• Information touchpoints, with links to relevant websites (i.e. conferences)

Since its launch, the initiative has been successful, with over 3 million site visits, 1,150 Q&As, 12 patient pathways across 10 indications, and 67 expert collaborators. The ABC/mBC section remains the largest due to the significant unmet need that still exists for these patients.

The mBC section one of the most important because the patient need is still so big unfortunately. The patient need is so tremendous! Patients, physicians, carers and all stakeholders work together very hard to improve this situation.

– Christina Claussen, Director Patient Relations, Pfizer Germany

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Email: Anja.Schmidt@pfizer.com

Based on written submission and interview with Anja Schmidt, Pfizer, 2020.

ABC: advanced breast cancer; HCP: healthcare professional; mBC: metastatic breast cancer; Q&A: questions and answers
Initiative Spotlight: Metastatic Care – Educational Component

While all initiatives that educate patients & HCPs about ABC/mBC are important, the steering committee chose to highlight the work of Médicos e Investigadores en la Lucha contra el Cáncer de Mama (MILC) in developing the Metastatic Care: Educational Component 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 communication challenges between HCPs and patients with ABC/mBC in Mexico, as well as low patient understanding of their disease. This standardised psychoeducational intervention was developed to assess and improve patient understanding of their disease, allowing them to actively participate in decision-making processes and ultimately improve QoL and outcomes.

MILC was founded in 2013 by a group of HCPs who recognised that breast cancer was being identified too late for the majority of patients in Mexico, with around 70% diagnosed at stage 3 or 4. During an initial program to provide psychological support to patients with ABC/mBC, it became clear that many patients did not understand that they had advanced/metastatic disease or what this meant. To combat this, an educational component was formed with the aim to:

- Improve patient-HCP communication, resulting in better patient understanding of their disease
- Promote the use of supportive and integrative care services to enhance QoL of patients with ABC/mBC
- Incorporate the intervention systematically into routine ABC/mBC care in Mexico

This initiative was developed through a collaborative process led by a team of medical oncologists and psycho-oncologists, with support from research assistants and regular feedback from patients and other clinicians during the development process.

For more information:
https://www.milc.org.mx
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ABC: advanced breast cancer; HCP: healthcare professional; mBC: metastatic breast cancer; MILC: Médicos e Investigadores en la Lucha contra el Cáncer de Mama

Based on written submission and interview with Alejandra Platas, MILC, 2020.
Initiative Spotlight: Metastatic Care – Educational Component

The initiative includes a simple, standardised framework for improving patient understanding of their disease, that could be easy to replicate in other hard-to-reach populations:

1. Initial assessment of understanding and desire for information on prognosis
2. Education with an oncologist and psycho-oncologist (via a specially-designed video) – dependent on the desired level of information
3. Repeat of the initial questionnaire to assess learnings

It has reached ~50 patients since it's launch, with the learning assessment showing increased patient awareness of disease stage, treatment options and objectives, and patients reporting high levels of satisfaction and improved confidence in their decision-making.

"With materials, what we always do is to always ask patients [and clinicians] what they think and if they understand – that helps to develop something that really helps them."

— Alejandra Platas
Co-founder of MILC

ABC: advanced breast cancer; HCP: healthcare professional; mBC: metastatic breast cancer; MILC: Médicos e Investigadores en la Lucha contra el Cáncer de Mama

For more information:
https: www.milc.org.mx
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Based on written submission and interview with Alejandra Platas, MILC, 2020.
Initiative Spotlight: Spanish-language BC Patient Education Novelas

While all initiatives that educate patients & HCPs about ABC/mBC are important, the steering committee chose to highlight the work of Share/Latina Share and Pfizer in developing the Spanish-language BC Patient Education Novelas, 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. There is a lack of available material in Spanish-language on ABC/mBC and this acts as a barrier to access for LatinX patients, making discussions with HCPs complex. To combat this, an original graphic novel was developed outlining the diagnostic journey of an mBC patient. Following this novela’s success, this initiative is creating a sequel focused on the importance of genetic testing and hereditary cancer.

Latina Share identified that there are a number of myths in the LatinX community regarding BC. To combat these myths they developed the Spanish-language BC Patient Education Novelas. The first novela discussing the mBC journey was released in 2016 and following its success a second novela is now in development. These novelas aim to:

• Dispel myths that exist in the LatinX community regarding BC in a culturally tailored and unintimidating manner
• Raise awareness of the importance of genetic/biomarker testing
• Educate the LatinX population with ABC/mBC on hereditary cancer and the patient journey for the disease

The novelas were developed by Latina share in partnership with Pfizer Medical Affairs and the Pfizer Advocacy Liaisons, with all content verified by Pfizer’s medical team to ensure accuracy. 5 focus groups with professional facilitators were held during the first novelas development to identify what myths exist amongst the LatinX community.

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Based on written submission and interview with from Lillian Shahied Arruda, Pfizer, 2021.
Initiative Spotlight: Spanish-language BC Patient Education Novelas

This initiative consists of two separate novelas tailored specifically for the LatinX community both designed to dispel potential myths that exist regarding BC and aid patient navigation of the disease. The two novelas are:

• Original Spanish-language novela describing the journey of a woman diagnosed with ABC/mBC as a guide for women with ABC/mBC, their loved ones and the general community – an English version of this novela has since been created (to allow it to be used by a wider community and to allow HCPs to understand what was being distributed)

• Sequel novela focused on genetic testing and hereditary cancer, entitled “Genetic and Biomarker Testing: Gifts of Knowledge for You and Your Family”

Since 2016, more than 10,000 copies of the initial mBC novela have been distributed across various community locations. The novela is also available online for free to reach a much greater number of individuals. Whilst the second novela has not yet been launched, outcomes similar to the first novela are expected. The novelas serve as a needed resource to provide important patient education to this underserved community.

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

All metastatic patients often feel overlooked. There is not much out there to connect with them and their journey. This could reach a population which is really overlooked as they do not always connect to those programs which are predominantly focused on eBC.

– Ivis Sampayo, Share Cancer Support

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Based on written submission and interview with from Lillian Shahied Arruda, Pfizer, 2021.
While all initiatives that educate patients about ABC/mBC are important, the steering committee chose to highlight the work of Rethink Breast Cancer in developing two of their initiatives. **Uncovered: A Breast Recognition Project** was selected for its aim to improve care for a distinct patient group, as well as for its focus on giving voice and representation to an underrepresented population. **Talking to Kids About Metastatic Breast Cancer** was selected due to its specificity to metastatic disease, as well as its focus on providing resources for emotional and psychosocial education and support, which is a critical unmet need.

Rethink Breast Cancer was founded by MJ DeCoteau in 2001. It is a small, patient-centric organisation with a collaborative model and strong links to the community. Storytelling is a central tool in their work. Both of Uncovered: A Breast Recognition Project and Talking to Kids About Metastatic Breast Cancer are part of the equity, diversity and inclusion focused work of the organisation.

**Uncovered: A Breast Recognition Project** consists of a digital and print resource with imagery and authentic storytelling that aims to provide education, information and support for Black, Indigenous and People of Colour with breast cancer, as well as to draw attention to the impact of breast cancer, cultural barriers and health inequity on these underserved communities in Canada.

The **Talking to Kids About Metastatic Breast Cancer** initiative provides an educational booklet, available online and in print, with support and tips for young mothers living with mBC on how to navigate difficult conversations with their children and loved ones about their mBC diagnosis, treatment and end of life. The booklet was developed for a Canadian audience, but has also been distributed to Australia, UK, Europe, and the US.

Rethink’s mission is focused on the unmet needs of young women with mBC and underserved communities. The way we organise our work, model and flow is part of the reason we can create resources like these. We start by addressing isolation and fostering community and bringing people together. It’s about listening and providing psychosocial support.

— MJ DeCoteau, Founder and Executive Director, Rethink Breast Cancer

For more information:
https: www.rethinkbreastcancer.com
Email: support@rethinkbreastcancer.com

Educating patients about ABC/mBC

ABC: advanced breast cancer; mBC: metastatic breast cancer; HCP: health care professional; UK: United Kingdom; US: United States

Based on written submission and interview with Jasmine Sikand and MJ DeCoteau, Rethink Breast Cancer 2023.
Initiative Spotlight: Rethink Breast Cancer

Both initiatives were developed collaboratively with input from the BC community.

The idea for Uncovered: A Breast Recognition Project came from BC patient Michelle Audoin in the wake of the murder of George Floyd in 2020. Rethink Breast Cancer worked with Audoin to create a resource with imagery and storytelling to give voice to and support BIPOC communities in navigating the Canadian healthcare system. They recruited participants through their community network and worked with Black creatives for the development of the resources to help create a safe space and empower participants. In its second year the resource was evolved to include a call to action for HCPs.

Talking to Kids About Metastatic Breast Cancer was developed as a supportive tool for people who were unable to benefit from in person support programmes. The booklet was developed on the basis of learnings from a book on talking to kids about breast cancer as well as from support groups that the organisation provides to the community. The resource was co-created with input from an mBC patient advisory board, to capture the patient perspective, as well as a psychotherapist, an illustrator living with mBC and social worker.

For more information:
https://www.rethinkbreastcancer.com
Email: support@rethinkbreastcancer.com

ABC: advanced breast cancer; BC: breast cancer; BIPOC: Black, Indigenous and People of Colour; mBC: metastatic breast cancer; QoL: quality of life

Based on written submission and interview with Jasmine Sikand and MJ DeCoteau, Rethink Breast Cancer 2023.
While all initiatives that educate patients about ABC/mBC are important, the steering committee chose to highlight the work of Cancer Support Community in developing LGBTQ+ Diversity in Clinical Trials, due to its specific focus on supporting LGBTQIA+ communities and gender minorities, populations who are historically marginalised and experience many unmet needs. These populations are underrepresented in cancer clinical trials and often lack information about eligibility for participation in clinical trials. This initiative provides a digital educational booklet with information on access to cancer clinical trials and enrolment and seeks to improve representation and participation of LGBTQIA+ communities and gender minorities in clinical trials.

Cancer Support Community used a collaborative approach to ideation and validation from the outset. The development of LGBTQ+ Diversity in Clinical Trials started with the establishment of an advocacy board and an alliance with the National LGBT Cancer Network to help gather insight into the target population and their needs. The three key issues identified were discrimination, medical mistrust and lack of support/information. The LGBTQ+ Diversity in Clinical Trials initiative aims to:

- To provide accessible information and resources for LGBTQIA+ communities and gender minorities on access to cancer clinical trials
- To combat medical mistrust
- To educate HCPs to help them build good relationships with this patient community

Cancer Support Community worked with focus groups to further develop and adapt the content, wording and reader level of the educational booklet.

ABC: advanced breast cancer; HCP: healthcare professional; LGBTQ+/LGBTQIA+: lesbian, gay, bisexual, transgender, queer, questioning, intersex, asexual; mBC: metastatic breast cancer

Based on written submission and interview with Claire Saxton, Rachel Saks, Anissa Williams and Thomas Wilson, Cancer Support Community 2023.
Initiative Spotlight: LGBTQ+ Diversity in Clinical Trials

The LGBTQ+ Diversity in Clinical Trials initiative comprises a digital educational booklet covering information on the barriers, access, cost, disparities, and needs of LGBTQIA+ communities in relation to participation in cancer clinical trials.

The booklet was published at the end of 2022. Cancer Support Community used social media as a means to disseminate and promote their resource, as well as to connect with the grassroots community to support the dissemination efforts. They also worked with their research and policy teams to help disseminate their booklet to HCPs. Equity perspectives will continue to be a key focus for Cancer Support Community, and the organisation is looking into providing translations of all of their materials into Spanish and French, including cultural adaptations.

A lot of members of LGBTQ+ communities don’t have the familiar support that Cancer Support resources often direct people towards. And [there is] a lack of information just because people from LGBTQ backgrounds may think they are not eligible for clinical trials due to their status. At least in the United States, it wasn’t until recently that gay men were able to donate blood.

– Thomas Wilson
Manager, Education & Outreach, Cancer Support Community

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ABC: advanced breast cancer; HCP: healthcare professional; LGBTQ+/LGBTQIA+: lesbian, gay, bisexual, transgender, queer, questioning, intersex, asexual; mBC: metastatic breast cancer

Based on written submission and interview with Claire Saxton, Rachel Saks, Anissa Williams and Thomas Wilson, Cancer Support Community 2023.
Based on written submission and interviews conducted between 2020-2023 with: Anja Schmidt, Pfizer; Kuantkan Zhabaquin, Center of Nuclear Medicine and Oncology; Agata Zyra, Pfizer; Alejandra Platas, MILC; Karimbayeva Yerkesh Mukhtarovna, Multidisciplinary Medical Center; Thomas Wilson, Nick Power, Rachel Saks, Anissa Williams and Claire Saxton, Cancer Support Community; Adela Ayensu, Salwati; Lillian Arruda, Pfizer; Katrina Johnson, Pfizer; Patrick Miqueu, Institut Jules Bordet; Jasmine Sikand, Rethink Breast Cancer; Cinthia Gonzalez, NBCF.

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.