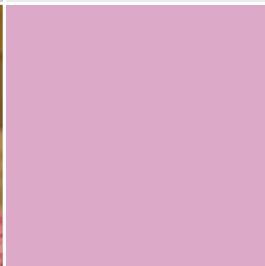
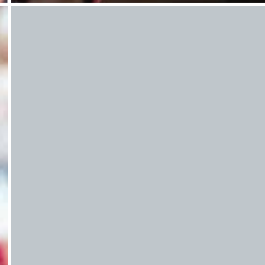
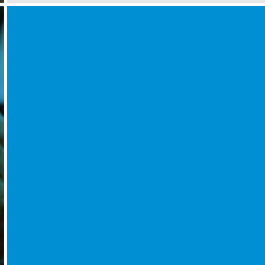
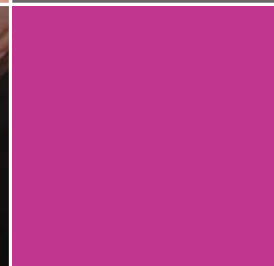
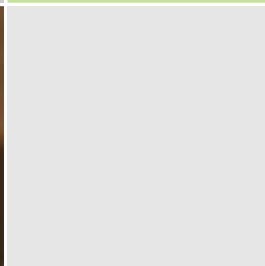
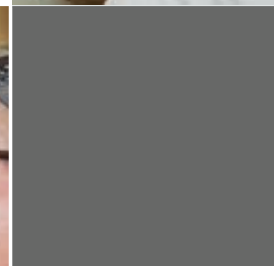
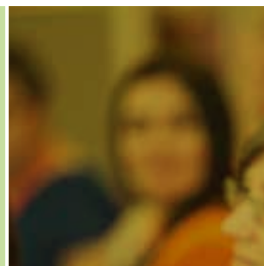
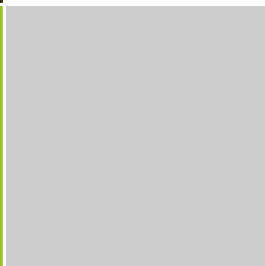


**MBC+ Summit 2018**



**WORKING TOGETHER ACROSS BORDERS  
AND PROFESSIONS TO IMPROVE THE LIVES  
OF CANCER PATIENTS**



**MBC+ Summit 2018**

## SUMMARY

The MBC+ Summit builds on two events in 2016 and 2017. At the 1<sup>st</sup> and 2<sup>nd</sup> MBC Summits a multidisciplinary group worked together across borders and across professions to improve the lives of women with metastatic breast cancer (mBC) worldwide. The group identified communication between healthcare professionals (HCPs) and patients as one of the most important areas for action and developed recommendations for medical guidelines: the PALiMo Recommendations.

At this year's Summit, participants demonstrated that words have been followed by actions. They shared practical examples of promoting the recommendations and tangible outcomes of the collaboration in their local countries or organisations. To make their achievements available beyond mBC, the Summit has been opened up to embrace other oncology indications. This is reflected by the new logo "MBC+".

**"We are opening the door to a new era of collaboration which allows us to move a lot faster and a lot more efficiently. Looking back at when we started a few years ago, it is unbelievable what we have achieved. And I am happy and hopeful that we can achieve much more."**

*Christina Claussen, Director Alliance Management & Patient Relations, Pfizer Oncology, International Developed Markets*



# FOREWORD

*“Once again patients, patient advocates and healthcare professionals came together from all over the world for this Summit. Using the platform we provided, they worked as partners to overcome challenges that metastatic breast cancer (mBC) presents.*

*Only by placing patients first can we share their passion and address their needs. The patients have told us that it is not just new treatments they welcome but also an enhanced interaction with healthcare professionals. Simply put, patients want to be better informed and have their voice heard. Patient centricity and patient engagement are key drivers in this process. These elements give us all a solid foundation to improve quality of life and give hope to patients. Pfizer remain committed to supporting and facilitating this invaluable initiative.*

*At the 2<sup>nd</sup> MBC Summit in 2017, the participants developed the PALiMo (Prepare – Ask – Listen – Motivate) Recommendations which are suggestions for medical guidelines to close gaps in the communication between women with mBC and their cancer care teams. We agreed that it was our shared responsibility to ensure these recommendations are translated into daily clinical practice.*

*At the MBC+ Summit, we witnessed that words have been converted into actions. A stunning 29 posters described diverse projects involving all stakeholders in many different countries and languages. Together, we can drive change and boost patient participation.*

*Let us harness the inspiration and urgency that we have felt at this Summit. Now is the time to expand this meaningful collaboration with equal partners where everybody is contributing and working towards shared goals: to have better communication between the patient community, the healthcare community and the policy community.*

*Allow me to close by thanking all of you for sharing your stories, best practices, and hopefulness.*

*I am looking forward to seeing what lies on the horizon for us together.”*

Roslyn Schneider,  
Global Patient Affairs Lead, Pfizer

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# THE MBC+ SUMMIT

## Driving change and boosting patient participation

After the tremendous efforts of the 2<sup>nd</sup> MBC Summit in Vienna during 2017 to finalise the PALiMo Recommendations, Luzia Travado, psycho-oncologist from Portugal, reminded everybody, “We need each of us to endorse what we’ve done here. To empower ourselves. Bring it into our associations, our networks, to create coalitions, ties within our countries to become stronger. It’s up to us.” And at the MBC+ Summit 2018 in Berlin, that’s just what happened. An impressive number of over 70 participants from 26 countries shared what had been accomplished since the last Summit at local, regional and global levels.

Through discussions, poster presentations and plenary sessions, attendees provided evidence that they had carried the PALiMo Recommendations forward in many different ways in their countries and organisations. However, they had not only worked on PALiMo. They had also taken other tools from previous Summits and adapted them to the specific needs in their countries.

“We can be very proud of what we have achieved so far, like Me&MBC, the Green Book, and the PALiMo Recommendations, last but not least this Summit,” said Martina Weiss, Director Launch Preparation Palbociclib, Pfizer Oncology, International Developed Markets. “This Summit is a true inspiration for our day-to-day work. You are the reason why we go to work every day and try to improve the situation for women with mBC.”



Sharing key achievements, tangible outcomes, and lessons learned showed that driving change in clinical practice is possible. In addition, the publication of the PALiMo Recommendations can help ensure that the cancer community and medical associations recognise the Recommendations as a standard in clinical practice.

A central theme at MBC+ 2018 was hope. In an inspiring lecture, Ben Corn, a professor of Oncology, explored the importance of hope for HCPs and patients.

The MBC+ Summit 2018 also marked the beginning of a new era of collaboration with partners from other oncology indications. “Promoting the PALiMo Recommendations, improving HCP-patient communication, empowering patients or networking are topics that are important to all cancer indications or patient advocacy groups,” explained Christina Claussen, Director Alliance Management & Patient Relations, Pfizer Oncology, International Developed Markets. “This is why we have decided to grow and share our achievements beyond mBC.” At this meeting, a patient advocate representing renal cell carcinoma participated for the first time. Other partners will be invited to join in future meetings for the benefit of even more patients in even more indications.



**“HOPE should be the fuel that propels us forward.”**

*Ben Corn, Professor of Oncology from Israel*

# BUILDING ON THE 1<sup>ST</sup> AND 2<sup>ND</sup> MBC SUMMITS

The MBC+ Summit 2018 in Berlin attracted delegates from 26 countries including 5 oncologists/psycho-oncologists, 4 oncology nurses and 34 mBC patients and patient advocates, including a patient living with mBC for 14 years.

This year’s meeting built on two previous MBC Summits: the 1<sup>st</sup> MBC Summit 2016 in Madrid and the 2<sup>nd</sup> MBC Summit 2017 in Vienna. All of the meetings served as exchange platforms for patients, advocates, doctors and nurses to share their expert perspectives on the unmet needs in mBC and to work together to improve the lives of women living with this incurable disease.

At the 1<sup>st</sup> MBC Summit, an international, multidisciplinary group discussed how to provide better support for women with mBC. The participants determined that concrete guidelines were lacking on communication between patients and HCPs in mBC. Although current medical guidelines in the field of oncology recognise the importance of HCP-patient communication, they do not provide any specific advice on how to achieve meaningful conversations.<sup>1,2,3,4</sup> The group decided to address this gap by developing recommendations on HCP-patient communication, and described this aim in the MBC Summit Position Paper.<sup>5</sup>

One year later, 50 mBC patients and patient advocates, 1 oncologist, 2 psycho-oncologists and 4 oncology nurses from 26 countries across the world came together at the 2<sup>nd</sup> MBC Summit and proposed a series of comprehensive and concrete recommendations for medical guidelines. These guidelines built on three essential aspects of good HCP-patient communication: information and understanding, effective and open communication, and patient preferences around values and needs.



The consensus recommendations are called the **PALiMo Recommendations: Prepare – Ask – Listen – Motivate**. PALiMo stands for four principles that should guide every HCP-patient communication:

**P**

**Prepare** the consultation in advance

**A**

**Ask** the patient if they have understood explanations and whether they agree regarding next steps

**Li**

**Listen** to find out if the patient has any concerns or questions

**Mo**

**Motivate** and encourage patients for the long patient journey together

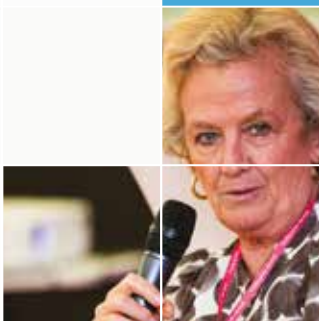
The proposed recommendations are aimed at improving communication between patients and HCPs. In particular, delivering bad news with empathy can help patients maintain hope.

The PALiMo Recommendations were to be introduced to medical associations and other stakeholders in the mBC community with the ultimate goal of having PALiMo established in clinical practice to make a difference for women with mBC worldwide.

The objectives of this year’s MBC+ Summit were to review how the PALiMo Recommendations and other earlier achievements of the Summit group had been used to drive change and boost patient participation in mBC.

**“Doctors and HCPs must understand that patients are really the actors of this film. If we accept this, things will change more rapidly.”**

*Ana Casas, oncologist from Spain*





# THE IMPORTANCE OF HOPE FOR DOCTORS, PATIENTS AND NURSES – FROM A SCIENTIFIC PERSPECTIVE

“Hope in medicine is not equal to cure,” began Ben Corn, Professor of Oncology at Tel Aviv Medical Center, Israel, in his engaging lecture on hope. “That there is no cure does not mean that there is no hope.” These words were very well received by the Summit attendees who were aware that hope plays a crucial role in the lives of people facing serious illness or end-of-life.

The oncologist believes that hope has an impact on survival and on cure rates although there are no data yet to assert this. It is known, however, that hope can help maintain quality of life. Workshops developed by Ben Corn and other scientists teach skills that are mainly aimed at helping patients and physicians to find goals, new goals or alternative pathways towards set goals. “Sometimes we learn that we cannot reach the goal that we set out to attain. Does that mean that we cannot have hope? No,” said Ben Corn encouragingly. “Hope is a very dynamic process. If your first goal is no longer attainable, you can ‘re-goal’. Sometimes a goal that was plausible yesterday is not plausible today. That should not deter us.” To support his lecture on “re-goaling” and hopefulness, Ben Corn shared examples of patients with incurable cancers who – following open and effective communication with their HCPs – successfully altered their pathways to reach their goals. They gained happiness in end-of-life situations.

Hope is a topic of growing interest for the scientific community. Several research groups in the United States and Israel have started to investigate the impact of hope on cancer patients and oncologists within clinical trials.<sup>6</sup> The aim is to gather evidence and enhance hope among patients with poor prognosis and healthcare providers.

Ben Corn concluded:

*“Together we have a lot to learn and a lot to benefit from this phenomenal concept of hopefulness. Hope is a teachable skill and we can learn it.”*

**“So much of what you said about hope is true. As a patient with mBC, I have been in the process with my family of setting new goals over and over again. Life is not tragedy.”**

*Anita Mäkelä, patient advocate from Finland*

**“Thank you for this incredible talk. Providing treatment and care for a cancer patient is not only about science but also about human relationships and understanding the person in front of you. It is not only about facts but also about feelings.”**

*Nicole Zernik, patient advocate from France*

**“What a truly inspiring talk. This is a talk that needs to be held everywhere. Hope is a really big topic for us as patients and patient advocates.”**

*Berit Eberhardt, patient advocate from Germany*



# DRIVING CHANGE WITH THE PALiMo RECOMMENDATIONS

## Poster and publication

Enthusiastic about the consensus reached on the proposed PALiMo Recommendations at the 2<sup>nd</sup> MBC Summit in 2017, the participants expressed their commitment to promote the proposals through their networks or organisations. They agreed to present the PALiMo Recommendations to medical associations and other decision-makers within the mBC community to drive change. The MBC+ Summit in Berlin provided an opportunity to look back at last year’s resolutions. It revealed that tangible progress had been made.

Doris C. Schmitt, a patient advocate, and Friederike Siedentopf, a gynaecologist, were so inspired by the Summit in Vienna that Doris presented a poster on the PALiMo Recommendations at the Asia Pacific Breast Cancer Summit in Singapore in March 2018. Friederike repeated this initiative at the annual meeting of the German Society of Senology in June 2018 and hopes to present their poster at various other scientific meetings to increase the visibility of the PALiMo Recommendations across borders.

A key step towards implementing the PALiMo Recommendations in clinical practice is to have them endorsed by different professional organisations. To achieve this, the group decided to publish the recommendations on HCP-patient communication in a peer-reviewed journal. An abstract will be submitted by Luzia Travado, psycho-oncologist from Portugal, to the journal “The Breast” which addresses a broad readership in medicine, nursing, psycho-oncology and patient advocacy. Luzia was also able to introduce PALiMo at an international Pfizer HCP meeting.

Pfizer aims to support the co-creation of tools that will help doctors implement PALiMo in their daily work.

The PALiMo Recommendations have been translated into seven languages. The translations can be used to discuss improvements in HCP-patient communication with stakeholders worldwide.

**“To get the recommendations endorsed by different professional organisations, we decided to have them published in a peer-reviewed journal. This will give them credit and bring them to another level.”**

*Luzia Travado, psycho-oncologist from Portugal*

**“There are no recommendations out there for doctor-patient communication in mBC, only for early BC. Now is the time to publish these recommendations and have them endorsed. Our work and all women with mBC deserve this. This is patient-reported outcome generated by 80-100 people working together. What more can you ask for?”**

*Doris C. Schmitt, patient advocate from Germany*

**“With the MBC Summits we’ve hosted, we have provided a platform for you to develop the PALiMo Recommendations. You are the authors. You are the intellectual property owners. It is up to you now to drive the project forward.”**

*Martina Weiss, Director Launch Preparation Palbociclib, Pfizer Oncology, International Developed Markets*



# DRIVING CHANGE WITH THE PALiMo RECOMMENDATIONS

## The HCP perspective

HCPs shared their perspectives on how to promote the recommendations for medical guidelines and improve communication between HCPs and their patients. This is what they said:

### The nurse perspective

“We need to go through organisations and professional societies and spread the word by giving presentations, holding workshops or writing articles. Nurses have a high interest in communication, but they will need evidence. The crucial first step is therefore to get the publication out there, gain evidence and then move forward. It is important to inform doctors, nurses, patients and their families and to educate them on what they need to do. In practice, if patients and family members are proactive, then doctors and nurses are more likely to listen and have an open and honest dialogue with the patient and her family.”

*Carole Farrell, oncology nurse from the United Kingdom*

“Communication is the basis to reach out to the patient and co-workers. When we go into a patient’s room, we need to leave our ego outside and understand what is important for the patient in front of us. Not every cancer patient is the same. We have to listen to, understand and motivate each individual according to their needs. We should not assume that this is going to be easy. And we need to stimulate HCPs to deal with communication issues, and teach communication skills to medical students.”

*Keren Arfi, oncology nurse from Israel*

### The oncologist perspective

“Oncologists are used to deal with science and objective results. They often find it difficult to bring empathy into the conversation with the patient. Cancer news, however, should not be delivered simply as facts. It should be communicated from heart to heart. Bringing in empathy can motivate the doctor and the patient. There is always something positive to say to the patient in front of you. Stay with the truth but always leave space for hope.”

*Ana Casas, oncologist from Spain*

### The psycho-oncologist perspective

“Doctors are mostly not trained to communicate in difficult emotional situations and they are afraid of them. The PALiMo Recommendations can help them develop strategies for effective and satisfying communication. Therefore it is important to have the recommendations published, validated and get feedback from physicians on how they use this tool in clinical practice. This will need to reflect both patients’ and doctors’ needs.”

*Elisabeth Andritsch, psycho-oncologist from Austria*

The HCPs agreed that the PALiMo Recommendations need to be converted from paper into real life. What is needed in the future are data that show that implementing this promising tool in clinical practice makes a difference to both patients and doctors.





# BOOST PATIENT PARTICIPATION: SHARING BEST PRACTICES

## Poster and plenary sessions – summary and trends

Prior to the MBC+ Summit, Pfizer had invited the participants to share best practices of patient participation at a local level. An impressive number of 29 posters had been received from 17 countries (see appendix). The posters were showcased at the Summit and included a brief project description, key steps in the programme development, key achievements as well as recommendations and lessons learned.

The attendees broke up into two teams. Each team looked at one half of the posters. One team was led by patient advocates Doris C. Schmitt, Germany, and Nicole Zernik, France, whereas the other team was guided by oncology nurse Keren Arfi, Israel, and psycho-oncologist Luzia Travado, Portugal. After the authors had explained their projects in detail, the teams came together again and the leaders presented the results to the audience.

“I am totally overwhelmed by what has been achieved,” said Doris C. Schmitt. “The posters reflect that everything we have initiated or worked on in the last four years, like Me&MBC, the Green Book, and PALiMo, has been addressed or implemented in the countries. It has become evident on almost every poster that mBC needs a different kind of awareness than early breast cancer.”

The posters demonstrated tremendous engagement and a strong will to drive change forward for the benefit of patients. But they also showed clearly that one size does not fit all. “We cannot do the same everywhere but have to adapt,” commented Nicole Zernik. “Each country takes what is important for them today. Tomorrow they might do something different. It takes little steps by little steps to reach awareness. Many drops make a river.”

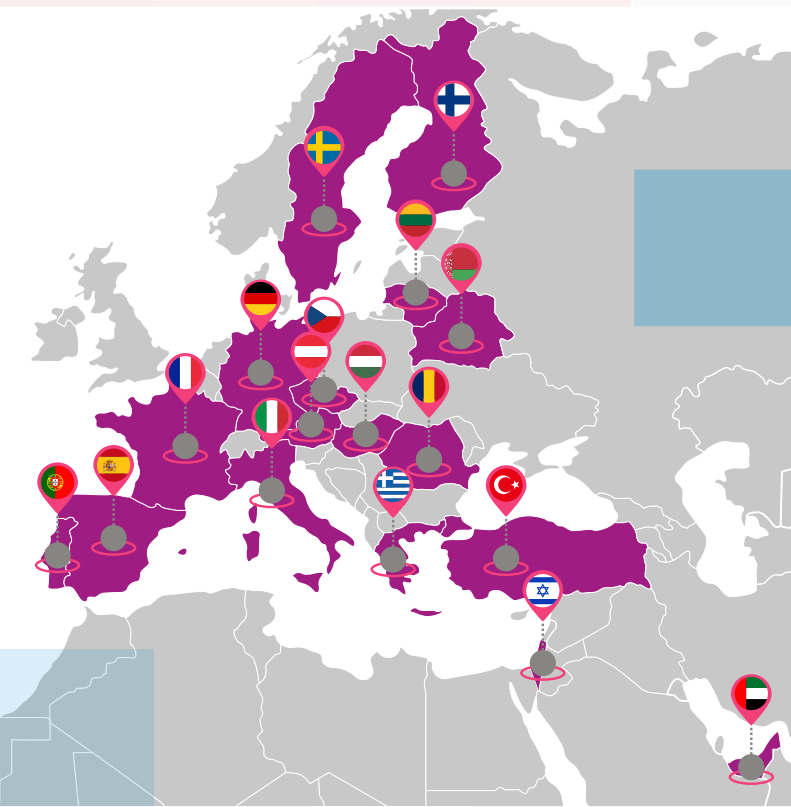
## IDM countries are finding new ways to support women with mBC

**17** countries presented **29** posters at the MBC+ Summit illustrating programmes they have introduced to support women with mBC.

Projects aim to increase public awareness of mBC, acknowledge and address unmet patient needs and improve HCP-patient communication.

Educational patient programmes, independent online platforms, PALiMo introduction schemes and family support meetings are a few of the initiatives being rolled out by the IDM countries.

Many countries have seen their projects achieve great success, building stronger relationships with advocacy groups and creating partnerships with local patients and HCPs.



For Luzia Travado the poster session “was a beautiful opportunity to be inspired by people who are implementing ideas and are getting the word around – not only about PALiMo. What already exists is usually patient-driven or HCP-driven. This is different. PALiMo was coined by all of us together. It is a really innovative approach.”

Other trends that became apparent included employing new technologies such as mobile applications and artificial intelligence to create powerful and effective tools and using social media to help gain public awareness and reach out to influential groups.

The projects underscored the importance of addressing stakeholders at all levels: patients, caregivers, advocates, HCPs, and policy makers – locally, in the countries, and across the world.

Israeli Keren Arfi concluded, “We learned a lot from going through all the posters. This is at the core of being here together. This is our goal and our hope to take home.”





# BOOST PATIENT PARTICIPATION: SHARING BEST PRACTICES

## Poster and plenary sessions – key achievements and tangible outcomes

Three key activities emerged that were used to support women with mBC worldwide: projects focusing on the patient, projects to raise awareness of mBC, and educational projects.

Highlights and achievements of the projects presented included:

### PROJECTS FOCUSING ON THE PATIENT

- Helping mBC patients get out of isolation
  - Providing patients with an opportunity to meet, share precious moments and forget about their disease for a few hours
  - Creating a safe environment for patients to express their emotions
  - Giving answers to patients and their families or caregivers and guiding them through the disease journey
- 
- Spreading the word about the PALiMo Recommendations on the internet and at local, national and international meetings
  - Involving the media to change perceptions of mBC and increase the visibility of mBC in the public
  - Establishing partnerships between patient organisations and medical societies
  - Shifting awareness of the needs of women with mBC amongst policy makers
  - Entering into dialogue with authorities on better access to treatment in mBC

### PROJECT TO RAISE AWARENESS OF MBC



### EDUCATIONAL PROJECTS

- Training patients, caregivers and advocates on mBC and treatment options
- Showing patients ways to improve their physical and mental well-being, and live better with mBC
- Transferring the PALiMo Recommendations into practice thereby sensitising HCPs for patients’ real needs in communication and maximising the quality of interaction
- Enabling HCPs to become multipliers of communication skills within their peer group

## Tangible outcomes – real-life metrics

- **“claudiascancerchallenge”** blog posts on Facebook on the MBC Summits and PALiMo (Austria): 9,650 people reached
- **“EmotionSpace”** mobile application: available in 12 countries and 10 languages, >3,300 downloads in Belarus alone
- **“La Vie Autor”** website (France): 74,000 views; “La Vie Autor” on Facebook: >6,300 followers, around 6,300 likes
- **“Patient Navigator – Hilfe für mich”** website (Germany): 265,820 views for all indications, 86,000 views on mBC
- **“Close to you in MBC”** website and media campaign (Spain): 112,000 website views, 37 media mentions, 20,800 YouTube views, and nearly 26 million people reached
- **“Breast Cancer Matters”** website (Spain): about 200,000 views
- **“Pink Caravan”** (United Arab Emirates): 57 awareness events conducted; 1,516 clinical examinations performed; 3 positive cancer cases confirmed

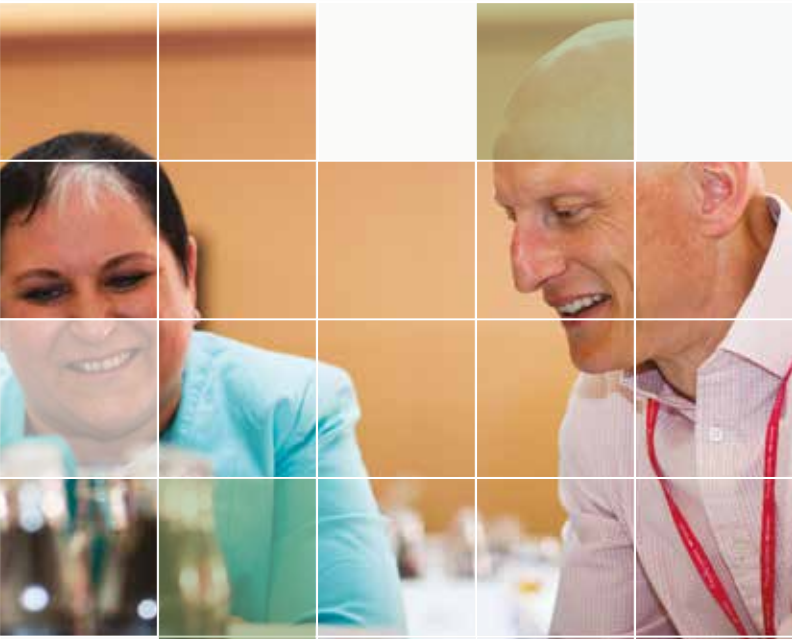
# BOOST PATIENT PARTICIPATION: SHARING BEST PRACTICES

## Poster and plenary sessions – lessons learned

Participants also contributed their experiences on what had worked and what had not worked when developing and undertaking their projects. They shared their lessons learned on what factors lead to success and what potential hurdles should be considered to avoid failure.

### LESSONS LEARNED FROM PROJECTS FOCUSING ON THE PATIENT

- Work with patients and their families/caregivers to identify their needs and how these can be met – needs of men and children differ from those of women
- Engage interdisciplinary groups of experts to develop the right tool for the right person
- Adapt successful tools from other organisations/ countries and localise them to your own needs
- Embrace new technologies but always keep a human touch



### LESSONS LEARNED FROM PROJECTS TO RAISE AWARENESS OF MBC

- Collaborate, co-create and raise awareness through conventional and digital/social media channels
- Use every opportunity to spread the word about PALiMo in your hospital, within your advocacy or professional group, at meetings or congresses
- Be aware of timelines when you plan to submit an abstract
- Involve politicians and the media and invite them early – give politicians some “role”
- Traditional media need to be given early notice and some “sensational” content
- Take awareness campaigns to the global level for wider awareness
- Support efforts to collaborate with other stakeholders/non-government organisations working in the same or related areas – share ideas and best practices
- Patient data are key to raise awareness – create evidence and publish it – no data, no progress

### LESSONS LEARNED FROM EDUCATIONAL PROJECTS

- When developing educational programmes, point out benefits to trainees
- Co-operate with medical associations when training physicians – include burnout prevention modules
- Full-day workshops can make patients tired – consider spreading topics over two days
- Always mention examples of women who value life and know how to find positive aspects even in difficult situations – always leave space for hope

Several delegates expressed a common feeling that sharing ideas and best practices is inspiring and gives hope to take home. It reflects the core of the MBC+ Summit: Together we are stronger!





“I feel very humble as a nurse to learn, especially from the poster presentations, what patients and advocacy groups have actually achieved. We need to take that forward. We need to spread the word of PALiMo.”

*Carole Farrell, oncology nurse from the United Kingdom*

“Never give up no matter what politicians say – our mission is to support patients, not politicians.”

*Doris C. Schmitt, patient advocate from Germany*

“Let us carry PALiMo forward wherever we go: at congresses, within our professions or in advocacy meetings. The more people know about them, the more likely will we succeed in having these recommendations implemented.”

*Luzia Travado, psycho-oncologist from Portugal*

“Patient engagement does not focus on problems but on solutions.”

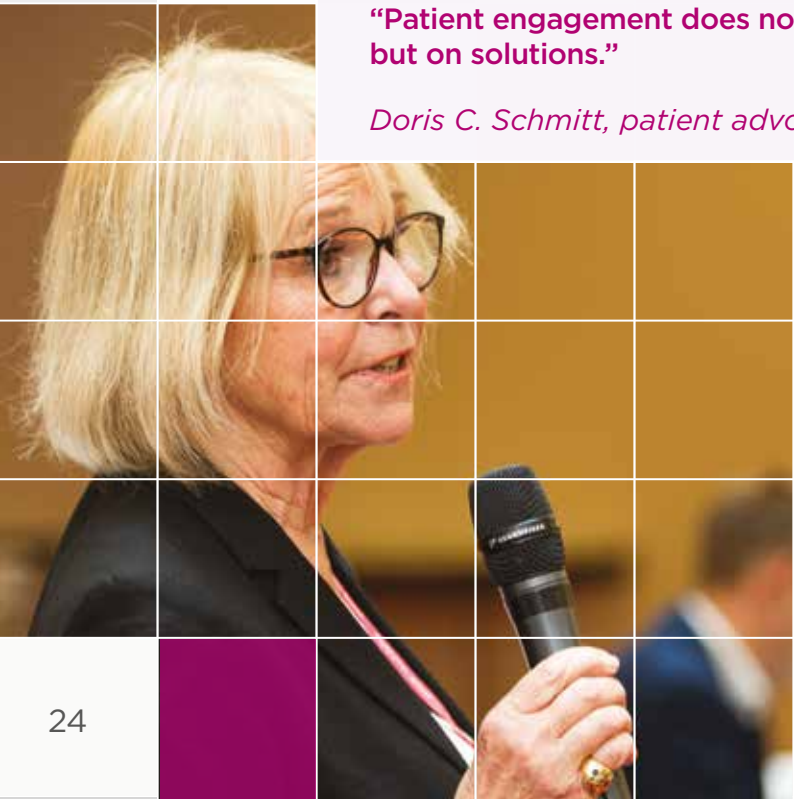
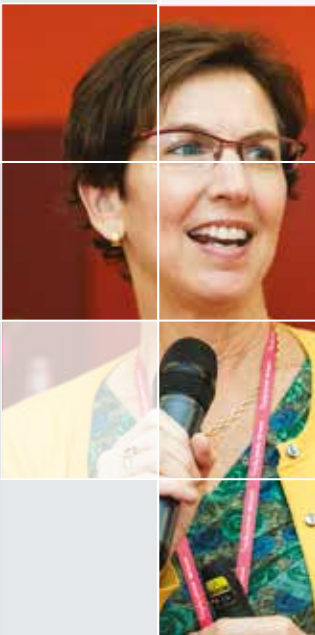
*Doris C. Schmitt, patient advocate from Germany*

“Supporting physicians means supporting patients.”

*Stacy Wiedenmann, Senior Manager Communications, Pfizer Oncology, International Developed Markets*

“It would be useful to have workshops with small mixed groups of doctors, HCPs, patients and family members to discuss how to deal with real-life challenges. We need to learn to interact in a better way.”

*Ana Casas, oncologist from Spain*



# BOOST PATIENT PARTICIPATION: SHARING BEST PRACTICES

## Oncologist communication training

It has been recognised that many medical doctors have not been trained to deliver bad news to patients. However, this scenario is changing with new approaches to the problem.

“Communication is more than a skill, it is a science, like clinical trials, with proven outcomes,” said Stacy Wiedenmann, Senior Manager Communications, Pfizer Oncology, International Developed Markets. “However, learnings are not widely shared in the medical community.” Psycho-oncologist Luzia Travado from Portugal added: “Scientific literature shows that the way how HCPs communicate with patients dramatically impacts on patients’ adaptation and clinical outcomes.” Nevertheless, medical doctors in many countries do not have communication skills included in their training. “Communication skills are learnable,” continues Luzia Travado. “They just need to be made accessible to oncologists.”

A multidisciplinary team of physicians, patients, psycho-oncologists and representatives from Pfizer are now tackling the lack of training by taking a holistic approach. They are combining the science of communication, digital technology and behaviour training to develop a series of evidence-based videos on communication skills training for oncologists. “This project will bring cutting-edge research and best practices in the field of psycho-oncology to medical oncologists,” said Daniel Kalanovic, Senior Director Regional Medical Affairs, Pfizer Oncology, International Developed Markets. The videos will explain why communication training is important to doctors and why it is important to patients.

Doctors will be able to use these self-learning videos at their own pace and time. “This innovative approach fills a gap that has not yet been addressed by the medical societies,” explained Luzia Travado. “We hope that this tool will be widely used.”

“Neuroscience has shown that delivering bad news activates areas in the brain linked with suffering whereas communicating with compassion is a new skill activating brain areas linked with our humanity. This is what doctors want to feel at end of the day. That they make a difference to patients. Doctors place themselves in the solution plan of the patients and feel they have accomplished it.”

*Luzia Travado, psycho-oncologist from Portugal*

“Communication training is my passion because I know what a difference it makes to both physicians and patients.”

*Luzia Travado, psycho-oncologist from Portugal*

“Communication training needs to be accredited, accessible for doctors and easy for their learning.”

*Luzia Travado, psycho-oncologist from Portugal*

“It has become apparent that it is important to address stakeholders at all levels: patients, HCPs, caregivers and policy makers. Everyone needs to know that they have a word and a way to improve what we are doing. It is about all of us. I am not a patient now, but I will be a patient of something in the future.”

*Luzia Travado, psycho-oncologist from Portugal*

“During every meeting we always learn from each other’s experiences and there is always something to take back home to help more patients in their disease.”

*Nicole Zernik, patient advocate from France*

“I am absolutely convinced that the future of cancer treatment will see more focus on communication and on doctor-patient relationships. As therapies are becoming more and more complex, artificial intelligence may help doctors to find the right treatment for the right patient. In a few years time, doctors and patients will have a lot more personalised information available and will be able to make better informed treatment decisions together. I am optimistic that the exponential growth in medical information technology will then free up time and help to build better doctor-patient relationships.”

*Daniel Kalanovic, Senior Director Regional Medical Affairs, Pfizer Oncology, International Developed Markets*

“I strongly believe that collaborative projects and co-creation are the future.”

*Daniel Kalanovic, Senior Director Regional Medical Affairs, Pfizer Oncology, International Developed Markets*



# BOOST PATIENT PARTICIPATION: SHARING BEST PRACTICES

## Broadening our perspective – evolving partnerships

The 1<sup>st</sup> and 2<sup>nd</sup> MBC Summits provided a framework for patient advocates, oncologists, nurses, psycho-oncologists and Pfizer representatives to exchange, collaborate and co-create towards a common goal: to make a difference in the lives of women with mBC. It was determined that now is the time to grow and share the achievements with other patient communities for the benefit of patients with mBC, renal cell cancer, lung cancer or leukaemia.

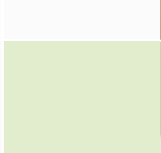
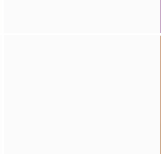
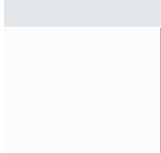
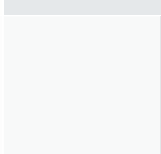
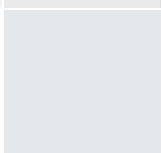
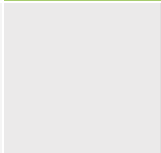
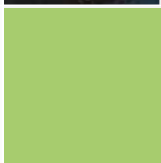
Taking collaboration to another level is the next logical step. Cancer indications have many issues in common that need to be addressed such as compliance, coping, or the rapid evolution of novel therapies. As treatment options become more and more complex, doctors need to find new ways of communicating the relevant information appropriately to the patient within the available time. At the same time, patients should be aware of how to ask the right questions. This will enable them to make better treatment decisions together and hopefully improve treatment outcomes.

Participating partners will be able to benefit from the newly established MBC+ Summit format by sharing innovative ideas, best practices and successful tools across organisations and indications. This should increase efficiency and avoid duplication of work and effort. Ultimately, we are all working towards better communication between patients and all parties involved in cancer care. Pfizer is doing their best to help facilitate and support this.



**“It is wonderful to work together with people who have the same drive. This is very special. This is rewarding.”**  
*Doris C. Schmitt, patient advocate from Germany*

**“Partnerships with patient advocates and organisations are really important. They allow sharing of knowledge and the experience our patients have on treatments. We therefore have a better understanding of how patients cope through their journey and how we can support them to manage their treatment to get better outcomes.”**  
*Ben Watkins, Director Brand/Product Management, Pfizer Oncology, International Developed Markets*



**“Working together with the pharmaceutical industry and across different organisations is so important because we can all learn from one another. We all work on the same topics and we all face similar challenges.”**  
*Berit Eberhardt, patient advocate from Germany*



**“As treatment options become more complex, doctors need to find new ways to appropriately communicate these options, including benefits and risks, to the patient. Ideally the doctor and the informed patient then make a joint treatment decision.”**  
*Arne Engelsberg, Medical Team Lead Immuno Oncology/Lung Cancer, Pfizer Oncology - International Developed Markets*

# CONCLUSION AND FUTURE PERSPECTIVES

The MBC+ Summit 2018 offered all parties who are dedicated to improving the lives of women with mBC an opportunity to share best practices, learn from success and failure, and open new perspectives for the future. This format is highly motivating, wins commitment, and is an invaluable forum for mapping our future goals.

Fulfilling the objectives of the meeting, multidisciplinary groups presented 29 posters providing real examples of how they have put their ideas into practice. A key learning was that no one size fits all. An important step has been the presentation of the PALiMo Recommendations at an international congress. A decision was taken to publish the recommendations to help gain recognition and acceptance by the medical community.

MBC+ delegates confirmed that the PALiMo Recommendations and other valuable tools like EmotionSpace have been translated into numerous languages allowing multiple use across borders. New technology will play an increasingly important role in improving communication between HCPs and patients. We look forward to seeing the initial results of the self-learning videos providing doctors flexible access to communication skills training. We see the need to further enrich the PALiMo Recommendations with more science and more data and continue to approach decision makers at the policy level.

This year’s Summit was especially inspired by the theme of hope. A resolution was taken to continue this theme.

It is a common wish of all MBC+ participants to share these achievements with patient organisations that face similar challenges along the patient journey and broaden the scope of the Summit to include more cancer indications, such as lung cancer, renal cell cancer or leukaemia.

In this manner, we will drive change – for the benefit of patients.



“My wish is to see everyone again next time.”

*Doris C. Schmitt, patient advocate from Germany*

“This whole meeting was an eye-opener about hope to me. I hope that it will be even larger next year and that we will all learn from more and different groups.”

*Berit Eberhard, patient advocate from Germany*

“It has once again been a very good meeting where we have shared our thoughts. We have a good tool in our hands that provides doctors and HCPs with guidance on how to proceed to better understand the needs of patients. We need to communicate better and consider every agent involved.”

*Ana Casas, oncologist from Spain*



“This Summit is a true inspiration for me. We see patients and families as equal partners. This is the only type of venue that does that.”

*Carole Farrell, oncology nurse from the United Kingdom*

“I want to thank Pfizer for revolutionising communication between HCPs and patients. I am really happy to be part of this and hope to come back next time. This is like family. Thank you to all of you for all the work you do.”

*Tamara Milagre, patient advocate from Portugal*



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# APPENDIX – POSTER SESSION



Project Title

Pink Cooking

Organization

Flag

Country



Austria



What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☒ Other \_\_\_\_\_

Project description including target audience

Pink Cooking event with breast cancer patients at the cooking school "www.ichkoche.at" together with the magazine WIENERIN (leading woman magazine in Austria) to give metastatic breast cancer affected women a place where they can feel courage, strength and a piece of joy. A follow-up report of the Pink Cooking event was published in the magazine.

Pictures



Key steps in the program development

- Discovered the blog "Claudia's Cancer Challenge" of an Austrian MBC patient - Initiated the Pink Cooking Event in cooperation with Claudia Altmann-Pospiszek and WIENERIN - Having numerous followers suffering from MBC, Claudia invited some of her followers to cook a healthy menu together, to enjoy the moment.

Key achievements

Cooking, eating, drinking, chatting, laughing - all with a pink touch. The culinary event with 30 breast cancer ladies in the Viennese cooking school turned out to be funny, lively and very relaxed! In a familiar and warm atmosphere, the women helped each other, were able to be cheerful for some hours and also talked about cancer, the topic that unites them.

Recommendations and lessons learned

The event enabled development of contacts between the pharmaceutical industry and patients.



Project Title

Blog postings on [www.facebook.com/clauidiascancerchallenge](https://www.facebook.com/clauidiascancerchallenge)

Organization

Flag

Country



Austria



What was the inspiration behind the initiative?

- ☒ Program from a previous MBC Summit
- ☒ Discussion with other MBC Summit participants
- ☐ Other \_\_\_\_\_

Project description including target audience

I run a German Facebook Blog named CLAUDIA'S CANCER CHALLENGE ([www.facebook.com/clauidiascancerchallenge](https://www.facebook.com/clauidiascancerchallenge)) with more than 4.500 followers. While and after attending the amazing MBC Summit in Vienna, I made 4 postings - giving my views on the event and also explaining what PALiMo means.

Pictures



Key steps in the program development

- Attending the MBC Summit

- Interacting with other MBC patients

- Finding a multidisciplinary approach

- Working on the recommendations

- Making 4 postings concerning the Summit, the PALiMo recommendations and my own experience

- Getting in touch with people

Key achievements

4 BLOG POSTINGS

- People reached: 9.650

- Likes: 341

- Comments: 23

- Many interested questions about the Summit and the PALiMo recommendations

Recommendations and lessons learned

- Try to do regional follow-up events, - Spread the word on social media, - Stay in contact



Project Title

mBC patient support in Belarus. Mobile application EmotionSpace.

Organization

Flag

Country



**BELARUS**



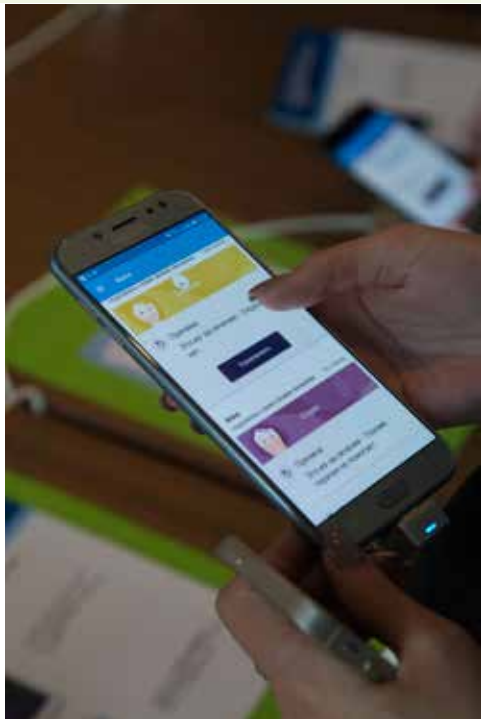
What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☒ Other Pfizer Regional Project as an opportunity to support mBC patients in Belarus

Project description including target audience

Oncology is the top priority of the Ministry of Health in Belarus. Screening, diagnostic and treatment. But not oncopatient as a person. We started with localization of Pfizer International project in Belarus – Application EmotionSpace for smartphones – for psycho-emotional support of mBC patients. Our target is to improve quality of life for our oncopatients.

Pictures



Key steps in the program development

•It's important to adapt content to local women habits and behaviors. •Pre-launch:mBC awareness campaign in mass media; collaboration with PAG; partnership with OncoPsychologists; talks with Oncologists about patients unmet needs. •Launch: Oncologists; PAG;press-conference for journalists; •After launch:keep up the promotion

Key achievements

• Since ES launch (Sep'17) total results in Apr'18: 3,323 downloads; 2,863 users;1,766 returning users. (Belarus population 9.5M. Per year 1,250 new mBC patients). • In May'18 the OncoPsychology Training Course was in the National Oncology Center. This is the first time in Belarus. •"How to tell bad news" training for Oncologists will be organized in 2018.

Recommendations and lessons learned

Think about needs of women with mBC. Remember about supporters. They are willing to help.



Project Title

Voice of patients

Organization

Flag

Country



**Czech Republic**



What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☒ Discussion with other MBC Summit participants
- ☐ Other \_\_\_\_\_

Project description including target audience

Voice of patients is a independent platform in the Czech Republic in the field of mBC. As partners cooperate Onko Unie (PR campaign, cooperation with media), Aliance žen s rakovinou prsu (patients, their experiences), Dialog Jessenius (education of patients and nurses), Amelie (psychological and social help for patients) + coordination of Ustav lékového průvodce to improve

Pictures



Key steps in the program development

June 2017 - formations of the platform  
July 2017 - 1st round table at the Ministry of Health  
October 2017 - public awareness campaign/meeting with mBC patients = International mBC Day (13. 10.)  
March 2018 - Press conference: How to pass obstructions in the (mBC) treatment

Key achievements

- acknowledgement of the platform among all stakeholders and politicians  
- building of credibility of the Voice of patients  
- communications with the state regulatory authority  
- partnership and cooperation with Czech oncologist's society (doctors)  
- acceptance of the platform as a key partner

Recommendations and lessons learned

Cooperation with other NGO's in the same field (mBC/BC) as partners is very useful





Project Title

MBC Networking

Organization



Flag



Country

Finland

What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☒ Other discussions in the MBC Support group

Project description including target audience

The idea came from the needs of the support group members. At the moment there are two active peer support groups for MBC women: in Helsinki and Tampere. Since these two groups are located in southern Finland, weekend retreats are especially important to those living elsewhere. The other important group to reach are family members.

Pictures



Key steps in the program development

- 1) Families with young children are a minority and often feel isolated. Support for breast cancer patients themselves is easily found but often the situation for the family members is more difficult.
- 2) Men and women should be provided the opportunity to meet in their own groups.

Key achievements

- 1) Wellness and peer support weekend for MBC patients with 20 participants from all over Finland, March 2018.
- 2) Peer support weekend for families in June 2018 including discussion groups for patients, partners and activities for children.
- 3) Peer support by phone once a week, started May 2018.

Recommendations and lessons learned

Family meetings on weekends, every member of the family need to have own activities.



Project Title

VIK MBC Chatbot - Launch October 13th 2018, MBC day

Organization



Flag



Country

FRANCE

What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☒ Other Declinaison of our original Early Breast Cancer chatbot

Project description including target audience

Vik MBC is an Artificial Intelligence Program we are cocreating on Messenger. It is a virtual companion, as we like to call him. Patients and relatives can ask questions, discuss with the AI, learn about the disease, the side effects, the life with a MBC, support care ... They can key in their medication and appointments reminders (and soon get a medication log) ...

Pictures



Key steps in the program development

- Securing the financing with our partners
- Organising Focus Groups with MBC patients to make sure we will answer their specific needs
- Reviewing the content and betatesting the AI
- Launch for MBC Day October 13th 2018,
- Organising PR and Communication

Key achievements

We have already launched the early breast cancer Chatbot  
Our partners are enthusiastic about the project  
The MBC Vik project is still ongoing but we are half way there.  
The Focus Groups were extremely powerful

Recommendations and lessons learned

Embrace new tech but always keep a human touch and focus on MBC Patients needs



Project Title

"Cancer et Citoyenneté": a pluridisciplinary event on mBC

Organization

Flag

Country



France

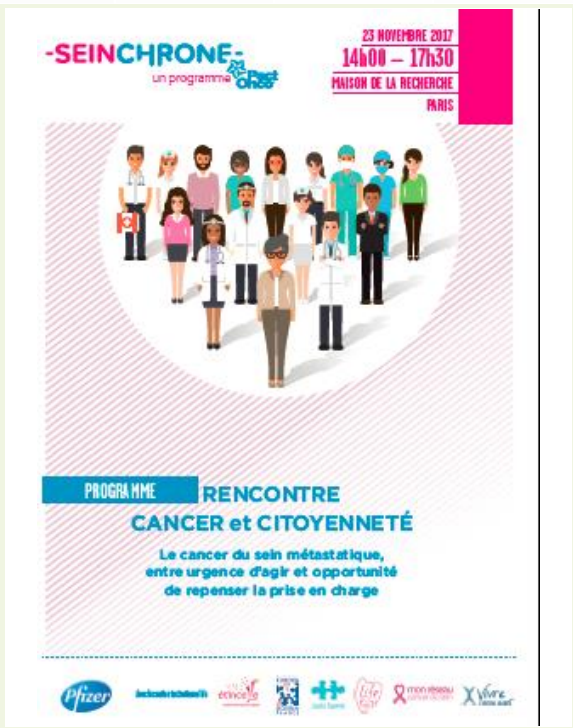
What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☒ Discussion with other MBC Summit participants
- ☒ Other Discussion with representatives from french Patients Advocacy Groups

Project description including target audience

Pfizer France organized, in 2017, a meeting about 'mBC and Citizenship' in partnership with 6 PAGs. This collaborative event gathered a strong number of multidisciplinary attendees (HCPs, health authorities and patient advocates) around experts of high level for an exchange on the place of metastatic breast cancer patients in the french Society.

Pictures



Key steps in the program development

- Before the event: REALITES survey and patients round tables to understand needs
- During the event: presentation of French data, debate with PAGs, HCPs and health authorities on new organisational, health-economic and social models for mBC patients' care pathways
- Communication (public authorities, press)

Key achievements

- 50 attendees
- A voice for PAGs: call-to-action
- Meeting minutes were sent to MPs from "groupe cancer" and to a target of 100 people
- Communication in key French media
- Strong commitment of the attendees and PAGs --> next steps: ask for a mBC day in France & implementation of dedicated actions

Recommendations and lessons learned

Together, we are stronger/ Communication is crucial/ this reflexion can be extended to other mC



Project Title

Pact Onco & La Vie Autour: a beyond-the-pill approach

Organization

Flag

Country



France

What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☒ Discussion with other MBC Summit participants
- ☒ Other Discussion with representatives from french Patients Advocacy Groups

Project description including target audience

LVA is an interactive tool mapping the supportive care offer in France and allowing patients and their caregivers to find associations providing the help they need near their home. PACT is online resources (documents, trainings, itw) providing information to cancer patients and their caregivers (HCPs, carers) to optimize therapy management and personalize care pathway.

Pictures



Key steps in the program development

- PO and LVA were designed following discussions with PAGs
- Those tools were designed with them
- Communication by Pfizer (on social media) and through PAGs networks
- Update with PAGs : creation of a new website for Pact Onco to give more visibility to our contents (with a multichannel communication)

Key achievements

- From June 2017 to June 2018:  
Pact Onco Website : 4279 views/ Average time on site : 1'42"/ Bounce rate : 67%  
La Vie Autour Website : 74 000 views/Average time on site : 1'19" /Bounce rate : 66%  
La vie Autour Facebook Fan Page (since sept) 6332 followers / 6272 people like the page
- Enhance Pfizer's reputation

Recommendations and lessons learned

Work with patients following a demand-driven approach (the right tool for the right person)



Project Title

Seinchrone or why patients data are crucial to raise awareness on mBC

Organization

Flag

Country



France

What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☒ Discussion with other MBC Summit participants
- ☒ Other Discussion with representatives from french Patients Advocacy Groups

Project description including target audience

SEINCHROME program is an initiative led by Pfizer France which aimed at bringing together all stakeholders involved in the care of mBC patients to develop concrete and innovative solutions to improve patients' and carers day-to-day life: patients, HCPs, public authorities...This program was co-built with 6 PAGs.

Pictures



Key steps in the program development

- Understand patients needs: quantitative research (REALITES survey) and qualitative research (patients round tables)
- Develop tools (Me&myMbc handbook)
- Open the debate on new organisational, health-economic and social models with PAGs, HCPs, public authorities
- Give visibility to mBC and our commitment

Key achievements

- French data on mBC : presentation at the SFSPM 2016, publication in Oncology, KOL involved in steering committees
- Development of tools: me and my mbc handbook (+ Pact Onco + la vie autour)
- Authorities are sensitized to these issues (next step: ask for a mBC day in France)
- Communication in Le Monde, Odyssea.fr...

Recommendations and lessons learned

Patients data are key to raise awareness on mBC/Cooperation between all stakeholders is crucial



Project Title

Patient Navigator - [www.hilfefuermich.de](http://www.hilfefuermich.de)

Organization

Flag

Country



Germany



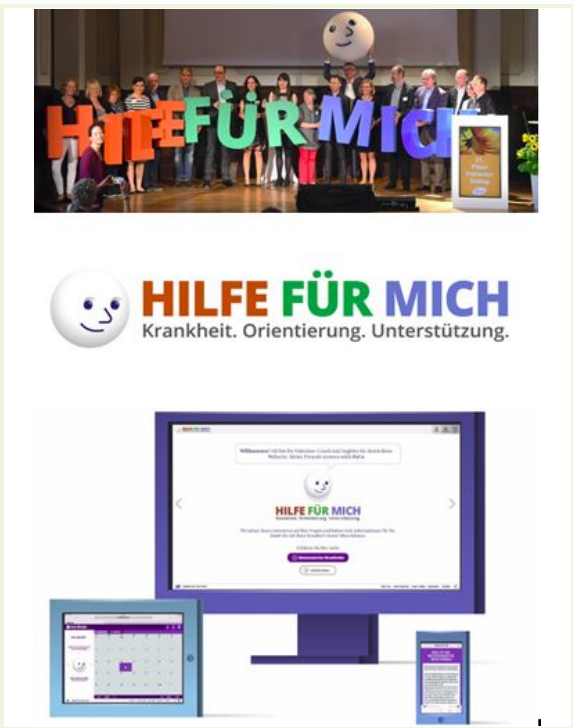
What was the inspiration behind the initiative?

- ☒ Program from a previous MBC Summit
- ☒ Discussion with other MBC Summit participants
- ☒ Other Discussion Pfizer Patient Dialogue

Project description including target audience

The patient navigator is a website created by patients and HCP together with Pfizer. All content and design is led by patients.This digital tool guides patients and caregivers through a local healthcare system to ensure patients find local external resources from medical to daily life support. The guide is called PaCo = Patient Coach

Pictures



Key steps in the program development

- set up an interdisciplinary group of experts (patients, physicians, lawyer) who will give valuable input throughout the whole project development
- take the views of this group into account and implement them

Key achievements

- Positive Feedback from all stakeholders (patients, relatives, physicians, politics, lawyers)
- Increasing number of website users (265.820 all indications, 86.000 mBC, June 5th)
- Best practice: this project will also be rolled out in other countries, e.g. Sweden

Recommendations and lessons learned

Set up this project from the beginning in co-creation with an interdisciplinary group of experts





Project Title

**Prepare-Ask-Listen-Motivate (PALiMo):communication strategies mBC**

Organization

Flag

Country



**Germany**



What was the inspiration behind the initiative?

- ☒ Program from a previous MBC Summit
- ☒ Discussion with other MBC Summit participants
- ☐ Other \_\_\_\_\_

Project description including target audience

Many cancer conferences offer abstract submissions. Friederike Siedentopf, Eva Schumacher-Wulf and Doris C. Schmitt developed an abstract and designed a poster according to the recommendations of the Pfizer mBC Summit 2017 in Vienna/Austria. Doris was able to present this poster at the Asian-Pacific Breast Cancer Symposium in Singapore.

Pictures



Key steps in the program development

Develop an abstract describing the need for better doctor-patient-communication in metastatic breast cancer. Present the PALiMo recommendations and outline the advantage for patients and health care professionals. Apply for oral or poster presentation. Design a poster according to the conference guidelines after invitation to present.

Key achievements

The recommendations could be presented for the first time at an international conference and raise awareness for the importance in communication with mBC patients.

Recommendations and lessons learned

Start early with sending in the abstract. Be aware of the deadlines and regulations.



Project Title

**Communication skills of health care professionals working with cancer patient**

Organization

Flag

Country



**Greece**



What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☒ Discussion with other MBC Summit participants
- ☐ Other \_\_\_\_\_

Project description including target audience

The project included 26 hours training (theory and practice) of 30 Health Care Professionals (physicians, nurses, social workers) working in Oncology Units in Athens. The training included modules such as communication skills (including PALiMo-Recommendations), treating metastatic patients, metastatic patient's needs e.t.c. Participants were funded 5€/per hour.

Pictures



Key steps in the program development

- Prepare a training guide with topics of interest
- Find trainers with expertise in Psycho-Oncol.
- Secure funding
- Inform Medical Associations, Public Oncology Units and University Medical Departments about the training and invite them to participate

Key achievements

- Participants evaluated the training as helpful and necessary and reported that they gained new knowledge and that they would definitely recommend it to colleagues.
- Trainees worked as role models for their colleagues in their practice and they "spread the word" about the necessity of the training.

Recommendations and lessons learned

Co-operate with Med.Associations. Give motive to trainees. Include burnout prevention modules.



Project Title

Metastatic Breast Cancer in the Focus

Organization

Flag

Country



Hungary



What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☒ Discussion with other MBC Summit participants
- ☒ Other queries from patients and discussions with partners locally

Project description including target audience

An educational program for patients with MBC on critical issues e.g.: handling side-effects of drugs; possible correlations between type of BC and its metastasis; pain management; a belly-dancers' peer support group. The primary goal of the program was to help patients better understand their illness. We also wanted to raise attention to MBC, so organized the event on a boat - reaching the Parliament the participants let 600 green-purple-pink balloons up in the air.

Pictures



Key steps in the program development

1. sending query out on MBC issues that are interesting to patients - needs assessment
2. choosing a very visible location
3. inviting professionals to make the presentations
4. advertising the program through Facebook and partner organizations
5. invitations to politicians and media
6. booking, decorations, balloons, finger food, evaluation forms; photos and live-streaming

Key achievements

1. Immediate educational impact on participants
2. Secondary educational impact via Face-book live-streaming
3. Media appearances

Recommendations and lessons learned

1. Politicians need to be invited much sooner than we did and need to be given some "role"
2. Media need to be given earlier notice and more "sensational" content



Project Title

MBC Seminar , Lin medical Center, Haifa

Organization

Flag

Country



ISRAEL

What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☒ Other A request from Lin MC

Project description including target audience

Lin MC oncologist arranged an afternoon seminar for MBC patients & caregivers. Audience heard 2 main lectures - one about treatments, second about the connection between body and soul, and then a talk from Michal Melamed Cohen (Member of Me&MBC handbook stirring committee) and Keren Arfi (palliative nurse).

Pictures



Key steps in the program development

EG given to Lin MC  
Connecting Michal Melamed Cohen & Keren Arfi to Lin MC's oncologist

Key achievements

- Enabling MBC patients share Michal Melamed Cohen's journey and attitudes
- Enabling MBC patients hear Keren Arfi's agenda regarding palliative care for MBC patients
- Distributing Me&MBC handbook to the participants.

Recommendations and lessons learned

Copy & Paste





Project Title

OH, What a Beautiful Morning

Organization

Flag

Country



ISRAEL

What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☒ Other a request from Israel Cancer Association & Gamani

Project description including target audience

A different morning for MBC patients in which they can meet, share and empower. Last December was the 4th meeting in this tradition, sponsored by Pfizer Israel Oncology unit. Patients enjoyed a Photo-therapy workshop and heard a lecture about the importance of having a list of dreams & goals.

Pictures



Key steps in the program development

EG given to ICA & Gamani

Key achievements

Empowering MBC patients

Recommendations and lessons learned

It's the 4th time we hear MBC patients' compliments regarding these mornings. Must continue!



Project Title

1. TRAINING on MBC for Patient Advocates  
2. ADVOCACY initiatives and involvement of the Institutions

Organization

EUROPA DONNA ITALIA

Flag



Country

ITALY



What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☐ Other 1. Professionalization of care-givers associations  
2. Establishment of the Italian Metastatic Breast Cancer Awareness Day

Project description including target audience

**1. TRAINING on MBC of Patient Advocates**  
The training program was divided into two editions. In the first, lasting one day, in-depth analysis of clinical content has been presented, together with issues related to patients' daily lives and needs. The second edition, lasting one day and a half, included the themes of therapeutic innovation and clinical trials, a focus on advocacy and a role-playing session on patient-doctor communication. A specific session was dedicated to the presentation of materials: "Me & mBC": the green handbook, and the leaflet and brochure for doctor-patient communication. The teachers were oncologists, psychologists, case-managers and advocates, supported by direct patient testimonies.

**2. ADVOCACY initiatives and involvement of the Institutions**  
With the collaboration of some senators, a public event was organized in the Senate to get politicians' consensus and support for the establishment of the National MBC Awareness Day, with the personal contribution of some patients and the participation of the 130 EDI members Associations

Pictures



Key steps in the program development

- 1. Training courses**
- Invite 1-2 oncologists with communication skill
  - select 2-3 patients willing to tell their experience
  - identify and invite: a psychologist  
a case-manager
  - individue a suitable venue, spread the invitation, collect registrations, prepare and distribute the material and evaluation questionnaires
- 2. Meeting with Institutions**
- Relying 2-3 Parliament members who are sensitive to the cause and ask them to sponsor the event
  - Define speakers (patients, doctors, politicians) and topics
  - Spread the invitation to the public and the press, prepare a press release with the statements of the protagonists.
  - Give emphasis to the initiative trough Social media

Key achievements

- 1. Training courses**  
Advocates received the basic clinical information about the disease and treatments and were able to interface directly with the patients, to acknowledge their problems they and understand how to help them in their relationship with the doctors and the care structure.
- 2. Meeting with Institutions**  
As a consequence of the event, a week later a draft law on MBC was presented in the Senate, subscribed bay a group of Parliament members.

Recommendations and lessons learned

- 1. Training courses**  
The MBC patient's message can cause anxiety in the most emotionally fragile BC survivors. It is important to always bring examples of women who value life and know how to find positive aspects even in a difficult condition.
- 2. Meeting with Institutions**  
Whatever the result, we must continue to talk about the problem, insist on all the stakeholders and constantly monitor the development of the law.





Project Title

**Integrative Oncology Service and "Voltati, Guarda, Ascolta" Campaign**

Organization

Flag

Country



Italy



What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☒ Other LISTENING THE UNMET NEEDS OF PATIENTS

Project description including target audience

At "Integrative Oncology Service" of the Multidisciplinary Breast Cancer Center mbc patients have the opportunity to benefit from several well-being activities. Moreover, in 2018 Komen Italia strenghtens its collaboration with Pfizer Italia, supporting "VOLTATI, GUARDA, ASCOLTA", an innovative project with the aim to change the perception of mbc and to break the silence.

Pictures



Key steps in the program development

- Identifying a specialized staff
- Organizing new academic opportunities for HCP's
- Creating a "virtual community" on Facebook
- Arranging events outside the hospital for sharing MBC patients'experiences, especially during Race for the Cure series.
- Creating new opportunities to talk with media

Key achievements

- Managing pain, side effects of the therapies.
- Helping women with MBC patients to meet other women who are living the same experiences.- Increasing awareness about the importance to guarantee to MBC patients the right to the best possible quality of life.- Representing to the Insitutions and the media the unique needs of MBCcommunity.

Recommendations and lessons learned

These experiences are an effective tool and helps MBC patients to get out of isolation.



Project Title

**Kiekviena diena brangi (Every day is precious)**

Organization

Flag

Country



Lithuania



What was the inspiration behind the initiative?

- ☒ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☐ Other \_\_\_\_\_

Project description including target audience

A successful patient organisation umbrella project „Every day is precious” was running between 2016 and 2018. Onkologija.lt expands its activities and works with cancer sufferers, especially women, and prepares press publications to reflect that.

Pictures



Key steps in the program development

The Association addresses the healthcare policy makers calling for a mutual dialogue for access to adequate treatment. In Lithuania, the advanced cancer therapies are not accessible for all types of the disease.

Key achievements

With the help of doctors and Lithuania's oncological groups and societies we target politians with hopes of a dialogue.

Recommendations and lessons learned

Summits give us a chance to hear about the experiences of other European patient organizations



Project Title

THE BURDEN OF HEREDITARY BREAST CANCER

Organization

Flag

Country



PORTUGAL



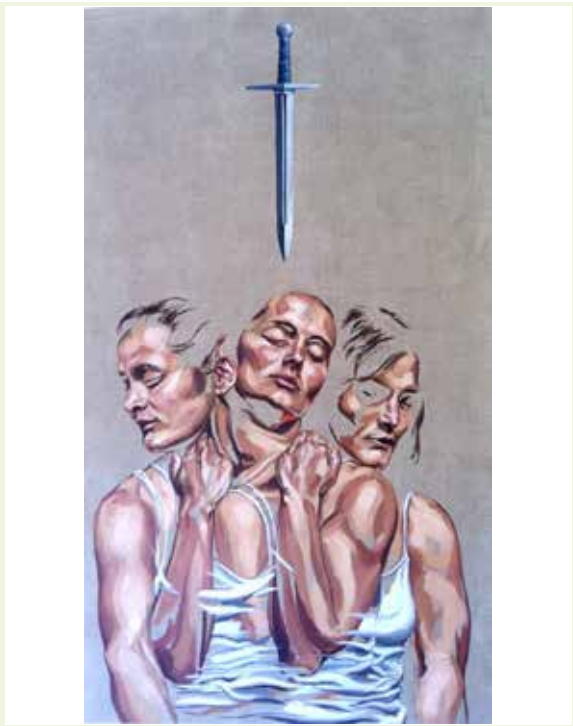
What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☒ Other Total absence of data for hereditary breast cancer

Project description including target audience

To all stakeholders: Discussing all over patient centered sustainability of the NHS, we need data, prevention and early stage diagnoses. Breast cancer is the most frequent female cancer in the world; 5% - 10% (~46.400/ y in EU) take place in hereditary cancer syndromes with the biggest potential for prevention/ early detection and future R & D potential but no data

Pictures



Key steps in the program development

- Creating big data on European level for Hereditary Cancer Syndromes
- Joining forces
- Bringing stakeholders together
- Creating evidence elaborating the game changing report: THE BURDEN OF HEREDITARY CANCER IN EUROPE

Key achievements

DATA – INVESTIGATION – DEVELOPMENT  
– SAVING LIVES – IMPROVING QUALITY  
OF LIFE AND CARE – EQUITY - SAVING  
PUBLIC MONEY

Recommendations and lessons learned

No data - no progress; the numbers will provide a basis for prioritizing cancer control actions



Project Title

KNOWING BETTER PATIENTS REAL NEEDS IN COMMUNICATION

Organization

Flag

Country



Portugal



What was the inspiration behind the initiative?

- ☒ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☐ Other \_\_\_\_\_

Project description including target audience

Dissemination towards healthcare professionals of the PALiMo recommendations

Pictures



Key steps in the program development

As an attendee or speaker at conferences/ congresses or any meeting in oncology, talking about the PALiMo recommendation as an important tool to improve communication between healthcare professionals and (metastatic) patients. Share them.

Key achievements

Sensitizing healthcare professionals for patients real needs in communication. Maximizing the quality of interaction while having a small time frame.

Recommendations and lessons learned

Whenever you have the opportunity, share PALiMo recommendations with professionals



Project Title

IMPROVED QUALITY OF LIFE FOR MBC PATIENTS IN ROMANIA

Organization



Flag



Country

ROMANIA

What was the inspiration behind the initiative?

- ☒ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☒ Other The UICC grant

Project description including target audience

The project aims to advocate for the introduction of the PALIMo Recommendations as a basic standard in oncology in Romania.

Target audience: medical providers, MBC cancer patients and caregivers, medical authorities

Pictures



Key steps in the program development

- 1) Translate the PALIMo Recommendations
- 2) Design the "Recomandarile PIAMo" brochure
- 3) Present "Recomandarile PIAMo" to medical providers and cancer patients organizations, get consensus and support to present the recommendations to the medical authorities.

Key achievements

- 1) The PALIMo Recommendations translated in Romanian
- 2) The "Recomandarile PIAMo" Brochure developed

Recommendations and lessons learned

It is important to have the MBC patients present the MBC patients' needs and requirements!



Project Title

Close to you in the mBC; web site lauch



Organization



Flag



Country

Spain

What was the inspiration behind the initiative?

- ☒ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☐ Other \_\_\_\_\_

Project description including target audience

More than 30% of women with breast cancer feel that they are invisible to the society and they don't have enough support. They are women with MBC. We have adapted the website Me and MBC to help and support these women. This website is created also to make this disease more visible.

Pictures



Key steps in the program development

Revision and advising of all the contents of the website according to the Spanish situation  
A survey among the general population to know the knowledge regarding the MBC  
Video  
A social media campaign: SEO, SEM, Youtube

Key achievements

We have reached 26.990.000 of people.  
37 impacts on media  
20.800 of viewers on youtube.  
112.000 visit to the web  
Positive reviews from MBC women.

Recommendations and lessons learned

It is important to make a global campaign in order to get better results and create awareness





Project Title

Roswitha Britz tells her story on Breast Cancer Matters

Organization

Flag

Country



Spain

What was the inspiration behind the initiative?

- ☒ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☐ Other \_\_\_\_\_

Project description including target audience

Breast Cancer Matters is a website that brings together the voices and stories of those people and organizations working every day to improve the lives of women living with breast cancer and metastatic breast cancer.

Pictures



Key steps in the program development

Breast Cancer Matters highlights the voices the work of physicians, patients, advocates, families, researchers, organizations, institutions, and decision makers. Our hope is to provide better understanding of the current situation and where improvements are needed.

Key achievements

Since it launch in November 2015:

- Thirty stakeholders have participated and told their stories
- Approximately 200T visits to the website

Recommendations and lessons learned

There are so many people doing great work in the area of BC and MBC: BCM tells these stories!



Project Title

PatientNavigator

Organization

Flag

Country



Sweden

**PATIENTNAVIGATOR**  
Kompassen för dig med spridd bröstcancer

What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☒ Other "Hilfefurmich" - the original site in Germany

Project description including target audience

When you are diagnosed with cancer you are left with many questions. The challenge is to find answers that are valid and reliable. PatientNavigator is a digital platform with different functions for patients living with MBC (metastatic breast cancer). 1. Q&A linking to external sites already available 2. calendar to register your pathway. 3. overview of organizations and seminars.

Pictures



Key steps in the program development

1. Ask patients living with MBC if their is a need for a product like PatientNavigator.
2. Create a panel of experts (oncologists, nurses, patients and counselor) with purpose to review the current site and adapt to local situation.
3. Ask patients living with MBC to review the test site for possible changes before launch.

Key achievements

1. Gather experts to develop the content along the project \*quality stamp\*
2. Press release with KOL to comment about the platform and what it means for patients.
3. Planned roll-out through local patient organizations and their internal newsletter, Twitter, Face book channel as well as oncology clinics.

Recommendations and lessons learned

Always ask the customer, in this case the patient, what is the need and how it can be met.



Project Title

Take Care Of Yourself - Metastatic Breast Cancer Special Workshop

Organization

Flag

Country



Turkey

What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☒ Other \_\_\_\_\_

Project description including target audience

Our project aims to improve the quality of life of woman who had diagnosed metastatic breast cancer by showing them how to look better, feel better, eat better and living better with cancer. We organize workshops monthly including seven topics which are supervised by professionals. Our workshops teach beauty techniques to woman with breast cancer.

Pictures



Key steps in the program development

There was no physical change related projects in Turkey, until our another project called Let My Hair Be Yours. This and Take Care of Yourself are the first projects launched in this area for women who had diagnosed with cancer. Due to the circumstances in the country, there is no possibility to ask more questions to the doctors for the patients.

Key achievements

Take Care Of Yourself workshops offer a great deal of information while presenting an opportunity for women to enjoy the moment. Women are able to forget about their disease for a couple of hours. Many women say the moment they begin to see the effects of their treatment is when they look at the mirror and do not recognize themselves.

Recommendations and lessons learned

A full-day workshop can make our patients tired. So we plan to divide the courses into two days.



Project Title

Pink Caravan shines a light on an often overlooked segment of society, MBC

Organization

Flag

Country



United Arab Emirates



What was the inspiration behind the initiative?

- ☒ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☐ Other \_\_\_\_\_

Project description including target audience

Handbook "Me & MBC": Pink Caravan looks at providing a Middle Eastern context & translation into Arabic, providing a valuabel tool for both oncologists & newly diagnosed patients  
Digital media: produce healthy eating videos focused on prevention, to address a wider audience  
Public events: to help inform public perception around MBC & patients leading productive lives

Pictures



Key steps in the program development

- MBC handbook translation to Arabic + press release to coincide with October 2018
- Public awareness event, to be sponsored by Pfizer for 3rd year, JBR The Walk, Dubai with clinical screening from medical booth
- Videos on social media by nutritionist & fitness expert, Zena Habi

Key achievements

Pink Caravan activation at JBR, The Walk, 27 & 28 October 2017:  
Clinical examinations performed - 158  
  
Total Pink Caravan wellness days in 2017:  
Awareness events conducted - 57  
Clinical examinations performed - 1,516  
Confirmed positive cancer cases - 3

Recommendations and lessons learned

During the public event there was a keen interest from both public and media to learn more about MBC. Pink Caravan is strongly driving the distribution of the handbook as a meaningful resource



Project Title

International Breast Cancer Academy Workshop Challenging Communication

Organization

Flag

Country



International educational program



What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☒ Other International educational program for oncologist

Project description including target audience

The International Pfizer Breast Cancer Academy in Frankfurt, with participating physicians from 12 countries, included an interactive workshop on effective communication between doctors and patients. After key note lectures, faculty and participants joined in breakout groups for scenario discussions and then presented the results in plenum.

Pictures



Key steps in the program development

1. Present key messages in doctor-patient communications in a busy clinical reality (key note lecture).
2. Prepare and present challenging scenarios collected beforehand.
3. Organize round-table breakout groups to discuss challenging situations and prepare role play with presentation, discussion and evaluation in plenum.

Key achievements

Attending physicians had the opportunity to share their experience and opinions in dealing with difficult scenarios and find ways how to break bad news to patients and family. Role plays provided active practice and triggered many discussions, including highlighting cultural differences, as well as ideas and inspiration on how to improve in the clinic.

Recommendations and lessons learned

Attending physicians had the opportunity to share their experience and opinions in dealing with difficult scenarios and find ways how to break bad news to patients and family. Role plays



Project Title

Workshop Optimising Communications with Patients/ELEVATE 2 2018 Vienna

Organization

Flag

Country



regional Pfizer meeting



What was the inspiration behind the initiative?

- ☐ Program from a previous MBC Summit
- ☐ Discussion with other MBC Summit participants
- ☒ Other transfer PALiMo into practice and improve communication

Project description including target audience

In one of the interactive workshops participants can share experiences from the clinic and optimize communication with their patients. In group works they discuss a difficult patient case and present how to share difficult news with patients with HR+/HER2- mBC. A role play demonstrated the challenges doctors and patients are facing when breaking difficult news.

Pictures



Key steps in the program development

Present key messages in doctor-patient-communication (Power Point). Prepare a typical patient case in mBC in collaboration with a breast cancer physician. Prepare time and handling of role play. Get information about the amount of participants for group work preparation. Provide interactive communication.

Key achievements

Workshop should have enough time for discussion and evaluation.

Recommendations and lessons learned

Workshop participants can evaluate their own attitude and behavior in regards of doctor-patient c





Project Title

EmotionSpace

Organization

Flag

Country



regional

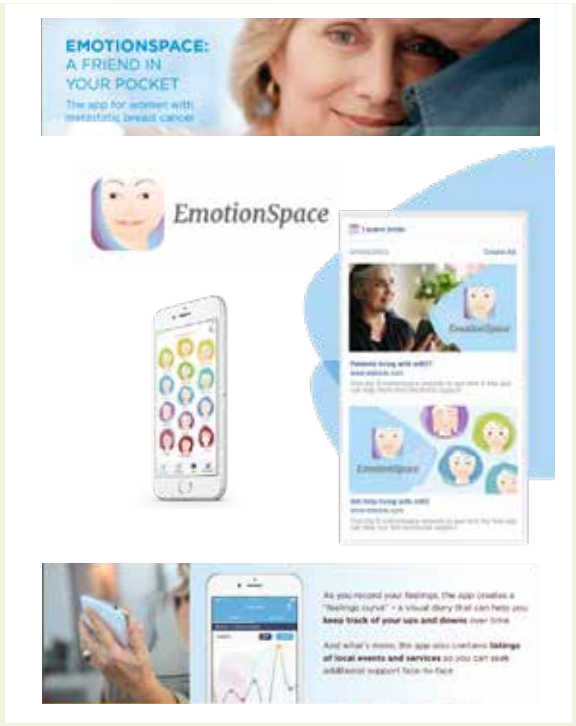


- What was the inspiration behind the initiative?
- ☐ Program from a previous MBC Summit
  - ☒ Discussion with other MBC Summit participants
  - ☐ Other \_\_\_\_\_

Project description including target audience

Research shows that patients with mBC experience social isolation and feelings of reduced self-worth. Hence many are reluctant to speak about their diagnosis and they can often bottle-up their emotions. EmotionSpace is an app that helps women with mBC express their feelings, find suggestions of things that might help them feel better, and seek support from others.

Pictures



Key steps in the program development

EmotionSpace is part of our ongoing commitment to put Patients First. EmotionSpace was developed based on a spirit of co-creation. Options are inspired by insights from women around the region and patients provided feedback on a number of key points during the development process that helped create the app's features.

Key achievements

The EmotionSpace App is available in 12 countries and 10 languages and has reached over 5000 downloads.

More than 60% of users return to the App and continue to rely on the solution to alleviate the emotional rollercoaster that comes along with the mBC diagnosis.

Recommendations and lessons learned

Collaborate, co-create and raise awareness through traditional and digital/social media channels



