Application Title:
ABC Patient Academy

General Audience Summary:
The major goal of this project, called ABC Patient Academy is to methodically build sustainable understanding within the patient when it comes to the course of the treatment process and his/her role in it (e.g. the importance of treatment adherence) in a collaborative effort involving nurses and oncologists, with the help of mediators from the patient organization. Taking place in the 10 oncology hospitals in Sofia to facilitate ABC patients’ access to relevant information, it would involve: - Negotiations with cancer treatment centers, engaging nurses as trainers and oncologists as supervisors - Workshops to identify the scope and approach in ABC patient education - Development of training materials/collateral for nurses, which will be finally published as Guidelines for ABC Patients Education for Nurses – both printed in hard-copy and uploaded on relevant websites - Announcing the project among patients: The project will be promoted through posters and mock-ups in the cancer treatment centers. A dedicated facebook page is launched and promoted actively to enter the social network agenda and start discussions on the topic. reader-friendly information is placed in offline and online media where patients tend to look up the subject. - On-going information and guidance service provided by nurses to the patients at the cancer treatment centers to help them understand their condition and their role in managing it - Reporting project results – via detailed questionnaires. Anticipated Impact: - Endorsed and functioning Guidelines for ABC Patients Education for Nurses – part of the standard of care - Developed and standardized program to engage cancer patients in active participation in the treatment process, supported by medical specialists and patient organizations - Conditions for effective treatment where the patient works with the medical team to achieve the best results possible.

Keywords:
National Planning
Patient Navigation
Application Title:
Mama Help Advanced

General Audience Summary:
Mama Help - Advanced (Mama Help - Cancro Avançado) Similarly to other countries in Europe, breast cancer is the most frequent women cancer in Portugal. Five thousand new breast cancers are expected each year. Overall survival has raised in the last ten years and global knowledge regarding diagnosis and treatment of early breast cancer, through public campaigning and support associations, has reached Portuguese women that are now much more aware of all aspects related to the disease. Portugal has several associations dedicated to breast cancer support, which have undertaken a meritorious job. However there is none dedicated specifically to advanced breast cancer. Additionally all the information regarding breast cancer, written in Portuguese conveyed by websites, leaflets and books is specifically for early breast cancer. Women with advanced breast cancer in Portugal, like in many other countries suffer the difference. They don’t have a place to go that they know will understand their fears and needs and will give them the information and support they want regarding their specific situation. We aim at starting to fill this gap for women with metastatic breast cancer in the entire country that seek information in Portuguese through the internet.

Keywords:
Patient Navigation
Application Title:
Breast Cancer Navigation and Palliative Programme (BCNPP)

General Audience Summary:
Project PINK BLUE’s Breast Cancer Navigation & Palliative Programme (BCNPP) is a bottom-top one-on-one support service where unemployed community health workers and retired midwives will be trained on professional palliative care for advanced breast cancer patients to ease their end of life time and diminish the effect of the disease on the family at home. While, a specially trained breast cancer survivor/oncology nurse navigates each patient through their breast cancer diagnosis, treatment and referral pathway to the trained palliative community health workers.

Keywords:
National Planning
Application Title: Fill the gaps in services for MBC patients

General Audience Summary: Statement of Need Since 2005, Breast cancer has become the most common cancer in Thailand and two thirds of patients were diagnosed at advanced stages. Moreover, most of the women were under the universal coverage by the government which does not provide certain medical treatments such as trastuzumab or potent pain killers. There are no medical oncologists or breast surgeons in a district hospital or even in provincial hospitals in Thailand so the majority of this group of patients were taken care by general surgeons. A good palliative care (that should have a radiotherapy (RT) unit and potent pain medications) is limited to university hospitals and some provincial hospitals. All the clinical trials in MBC either global or local trials are also done in the university hospital. Patients with metastatic breast cancer (MBC) should receive multi-disciplinary care and support, as outlined in many breast quality standards. Project Description Project Goals: Addressing gaps in services for MBC patients in the upper Northern part of Thailand including; accessibility, and timeliness for the treatments (medical, radiotherapy, psychological supports, and pain treatments) Project Implementation Our activities will be:

1. Help general surgeons in the district and provincial hospitals that belong to Suandok Cancer Network to give their MBC patients the best possible care with lectures or workshops focusing MBC treatment, and pain treatment, by our expert team.
2. Help general surgeons in the district and provincial hospitals that belong to Suandok Cancer Network to request the express queue online for the emergency palliative radiotherapy to their MBC patients as soon as possible by creating the express channel in our website www.suandokbreastcancer.com.
3. Building and training the health volunteers team (1 health volunteer/ 1 district). This includes teaching the volunteers all MBC information, the psychological support program, and the strategies necessary to find MBC patients in their districts and connect these patients to our network.

Collaborations
1. Nakornping Provincial Hospital - main network in Chiang Mai province
2. Lamphun Provincial Hospital - main network in Lamphun province
3. Chiang Rai Provincial Hospital - main network in Chiang Rai province
4. Mae Hong Son Provincial Hospital - main network in Mae Hong Son province
5. Payao Provincial Hospital - main network in Payao province

Anticipated Impact
1. Filling the gap...
2. ...

Keywords:
Earlier Diagnoses
Patient Navigation
Application Title:
Building a Community-Based Awareness and Engagement Network around Breast Cancer

General Audience Summary:
The principle goal is to research and implement a public awareness and engagement campaign focused on the issue of metastatic breast cancer by effectively addressing misunderstandings and barriers to treatment in the local population. The project aims to document perceptions and opinions as well as challenges faced by women and communities as a whole to understand the complex collective narrative about advanced-stage breast cancer. We will identify and build a collaborative network of organizational, community and healthcare actors to co-design awareness and engagement activities. We’ll launch an awareness campaign and accompanying community engagement initiatives around the issue of early diagnosis and successful treatment of breast cancer in Haiti. The program would focus on empowering patients and their families to take ownership of the narratives about advanced breast cancer. Through a collaborative and co-creative approach, patients and their families would play an active role in the designing and implementing awareness raising and engagement strategies in their communities. With the patients and medical staff, we’ll design a feedback mechanism for patients and their families to better build and inform systems of care for women with metastatic breast cancer.

Keywords:
Earlier Diagnoses
National Planning
Patient Navigation
Voices for Change
Application Title:
Cancer patients and caregivers web-based information tool

General Audience Summary:
In order to reduce existing barriers of access to online health information for women diagnosed with advanced stages breast cancer, their families and caregivers, a new interactive space will be specifically designed, developed and implemented on several platforms, aimed to offer concrete and simple answers about the most frequently asked questions of this population, tailored to their characteristics and specific needs. To achieve this goal, both qualitative and quantitative research techniques such as focus groups, surveys, bibliographic reviews and expert consultation will be performed, obtaining the information needs, limitations and access barriers to online information. This information will feed a special algorithm that will find the most suitable, effective and accepted response (with or without multimedia) for a particular query any given patient may have. Once the main concerns of patients and caregivers are selected, they will be responded in a simple way. Later, content will be developed and implemented in a new website and shared through institutional online platforms selected for their leadership and support to women diagnosed with breast cancer around the country. The developed content will be evaluated using the NASA-TLX tool to a sample of users, who will measure the overall degree of effort required and satisfaction. It is expected that the final product of this strategy will become the most used source of relevant and trustable information regarding advanced breast cancer for the Spanish-speaking population. Eventually yielding potentially long-term benefits like better use of healthcare systems or even improved clinical outcomes such as quality of life.

Keywords:
Patient Navigation
TOÑY GIMÓN
FORMER PRESIDENT
FECMA
MAHÓN, SPAIN

Application Title:
Cancer in a continuous state

General Audience Summary:
Cancer in a continuous state: the experience of patients with metastatic breast cancer and new challenges for oncological care. This project (study and campaign) aims to contribute to knowledge of the reality represented by patients with metastatic breast cancer. For some time now, thanks to the innovation in the treatment of advanced breast cancer, a great number of patients have survived for years with active periods of illness. This new situation makes it essential to find out both the specific needs of this group of patients and the key elements of oncological care that enable the provision of an effective response that is better tailored to such needs. The approach to this reality may be structured in the following dimensions:

- Time dimension: Cancer in a continuous state, i.e. metastatic, is not the summation of acute episodes.
- Clinical dimension:
  - Diversity of paths: metastatic breast cancer in the first or subsequent diagnosis.
  - Symptom burden: physical and emotional level
  - Innovation in treatments and clinical trials
- Social dimension: cure expectations and the media

GENERAL AIMS

- To find out the critical elements that enable breast cancer patients to reconcile their lives with the impact and challenges presented by metastatic disease.
- To identify the key factors of oncological care that respond to the specific needs of metastatic breast cancer patients.
- To publicise the results on the needs of metastatic disease through a national awareness campaign in every of the 17 regions of Spain

METHODOLOGY

Descriptive and explanatory study based on a qualitative methodology from the perspective of the patients and professionals involved in the treatment of metastatic breast cancer. Focus groups will be created for patients with metastasis in the first diagnosis of breast cancer and patients who have subsequently developed metastasis. Furthermore, the focus group technique will serve to explore the vision of the professionals who belong to hospitals with varying levels of complexity. The study will be conducted in the 17 Autonomous Regions and will therefore cover the whole of Spain.

Publicity campaign: The results of the study together with its analysis and conclusions will be published and distributed to the Health Administration, medical professionals, patients’ associations and society at large through regional meetings. The study results will be sent to local administrations by the Spanish Federation of Breast Cancer.

Keywords:
National Planning
Application Title: Regional Debates for Parliamentarians on Breast Cancer.

General Audience Summary: The overall objective of the Project is expand access to metastatic breast cancer treatment for patients in the public health system. To do this we will hold five Regional Debates for Parliamentarians on Breast Cancer. The project will provide technical information about advanced breast cancer to urge deputies and senators to find alternatives within their areas of operation that will facilitate the implementation of public policies for access to appropriate treatment of the disease in the public health system.

Keywords: Earlier Diagnoses
National Planning
Voices for Change
Application Title:
Living with Metastatic Breast Cancer

General Audience Summary:
In Brazil, breast cancer is the one with the highest incidence in women and since it is estimated that 50% of new cases of cancer are diagnosed in an advanced stage, there are many patients dealing with the challenges of living with metastatic breast cancer all over the country. This project aims to empower women living with metastatic breast cancer by offering them peer support through a national network coordinated by Oncoguia. Specific education and support materials will be developed so this network can disseminate quality information, guide patients and identify the main barriers that would require advocacy initiatives for better access to patients' rights.

Keywords:
Patient Navigation
Voices for Change
PHILIPPA KIRKPATRICK

BSc
National Policy Manager
Palliative Care Australia
Deakin West, Australia

Application Title:
Living with secondary breast cancer: What is palliative care & how can it help?

General Audience Summary:
The objectives of this project are to provide information to demystify and destigmatise palliative care and to empower women living with secondary breast cancer to make their own, informed care choices. Through consumer consultations and research, we aim to develop resources that provide these women with accessible information in easy language, enabling them with an understanding of what palliative care is, how it can help them and what sort of questions they can ask health professionals. Positive stories from other women living with secondary breast cancer about how palliative care has benefited them will reinforce these resources.

Keywords:
Patient Navigation
HELENA LINARDOU
MD PHD
LEGAL REPRESENTATIVE OF W4O-HELLAS
WOMEN FOR ONCOLOGY-HELLAS
ATHENS, GREECE

Application Title:
Hellenic Alliance for Metastatic Breast Cancer

General Audience Summary:
The majority of women with metastatic breast cancer, upon their metastatic diagnosis are withdrawn from the ‘public eye’, even from the existing support groups. It is as if they feel the “game” is lost for them. We hereby propose the development of a dynamic Forum for Women with Metastatic Breast Cancer in Greece, a ‘physical’ structure in the form of a coordinating pillar and, at the same time, the development of an innovative web-based tool for patient information, education, advocacy and support. Through this pioneering initiative, for the first time in Greece, patient associations and support groups unite with a non-profit organization of women oncology professionals, in a common effort, to empower the patient with MBC in Greece through information and knowledge. This ‘Hellenic Alliance for Metastatic Breast Cancer’ will have 3 main scopes: 1. to create, promote and maintain a web-based platform of education, information, communication, advocacy and support for metastatic breast cancer patients in Greece. 2. to educate patients with MBC, their families and their caregivers on the differences and uniqueness of an MBC diagnosis. 3. to record and ‘map’ the situation across Greece regarding issues of quality of life of women living with MBC. This ‘Alliance’ is of utmost importance at the current time when Greece is facing the fierce effects of the most significant financial crisis in its modern history and patients with cancer need continued support at all levels.

Keywords:
National Planning
Patient Navigation
Voices for Change
Application Title:
Hope for people living with metastatic breast cancer

General Audience Summary:
Introduction: As in any developing countries state of West Bengal in India has a huge burden of metastatic breast cancer patients in advanced stage coming from rural area where awareness regarding the usefulness of palliative care in rather poor. Objective: Our goal is to give a pain free good quality of life in these advanced stage breast cancer patients. Objective of this study is to identify the main difficulties in achieving the above goal in a rural village setting in India. Method: Advanced breast cancer patients in need of palliative care in various villages in of rural India were selected for this study. Their symptoms and managements in that rural surroundings were evaluated by an NGO (under the guidance of a senior palliative care specialist) working in that area. An attempt was made to identify the main obstacles in getting proper palliative care in a rural setting. Results: Pain, fatigue are the main symptoms effecting these patients. In most patients pain and other symptoms control were grossly inadequate due to lack of properly trained manpower in the rural India. However regular home care visits by a group of social workers were of immense help in the last few months of life. NGO team was well guided by a palliative care specialist. Conclusion: There is a wide gap of trained manpower in this filled in rural areas of India. Dedicated groups from rural area itself need encouragement, repeated home visit, awareness built up, proper training to home care giver, so that difficult symptoms can be managed locally along with necessary social and psychological support to these patients.

Keywords:
Patient Navigation
Application Title:
ABC in Malaysia

General Audience Summary:
National Cancer Society of Malaysia proposes to implement an Advanced Breast Cancer (ABC) project in order to raise the level of advanced breast cancer awareness and support in Malaysia. This programme aims to develop support resources for ABC women and to create support networks as well as to pool together other NGOs, healthcare providers etc. through the creation of a microsite with a LIVE chat window where ABC women get the chance to know each other and at the same time express themselves, not forgetting the ultimate goal of being there for each other. Ultimately, National Cancer Society of Malaysia aims to raise advanced breast cancer awareness in Malaysia and eventually regionally as well as a long-term plan benefiting the Advanced Breast Cancer community.

Keywords:
Voices for Change
GERTRUDE NAKIGUDDE
BACHELOR OF COMMERCE
EXECUTIVE DIRECTOR
UGANDA WOMEN'S CANCER SUPPORT ORGANISATION
KAMPALA, DOES NOT APPLY, UGANDA

Application Title:
Advancing mBC understanding and supportive care in Uganda

General Audience Summary:
Despite growing efforts to improve awareness and early detection of breast cancer (BC) in East Africa, over 75% of breast cancer patients in the region present with late stage disease (stage III or IV). Physical pain and psychological issues have been identified as the most common symptoms among patients with advanced cancer in East Africa. Clinical trials have demonstrated that early palliative care in the management of advanced cancer results in improved symptom control and quality of life and psychosocial support has been identified as a strong motivating factor for women coping with BC, however, provision of these services remains limited. This project will identify the existing challenges and gaps in meeting the needs of advanced BC patients in Uganda, improve awareness of their clinical and psychological needs among providers, advocates, family members, and policy makers and take active steps to address those needs through new tools and improved understanding and services. It will also produce a policy plan for advancing supportive and palliative care along a resource-stratified pathway to allow for coordinated incremental program improvement. This will result in increased access to supportive care for BC patients with advanced disease and improved quality of life. Uganda Women's Cancer Support Organization (UWOCASO) will implement this project in partnership with Uganda Cancer Institute (UCI). UCI being the only treatment centre it will provide expertise on managing MBC patients and link patients to advocates for psycho-social support resources. In addition UCI will play an advisory role on best practices of information flow between advocates, clinicians and policy makers.

Keywords:
Earlier Diagnoses
National Planning
Patient Navigation
Voices for Change
Application Title:
University of Nigeria Teaching Hospital – Breast Cancer Support Group Project

General Audience Summary:
Breast cancer management is currently one of the major health challenges in Nigeria. Most breast cancers patients are diagnosed at advanced stages resulting in limited treatment options and poorer treatment outcomes. The few that present early lack good follow up habits. Furthermore, lack of advanced technology and the high cost of treatment coupled with lack of an effective health insurance system in the country negatively impact treatment outcomes for patients. It is a common observation that after diagnosis of the disease and the first line treatment is given, most patients do not return for follow up or further treatment because of financial reasons, religious inclinations and the wrong belief that they are already cured after a single treatment. The enormous challenge of subsequent treatment with its attendant cost also serves as a major barrier to management. This project intends to address multiple gaps in care through the provision of easier access to palliative care services, improving the follow-up system and multidisciplinary management to ensure better quality of life and increased treatment compliance for patients.

KEYWORDS:
Patient Navigation
Application Title:
Quality of life among Zambian women with advanced stage breast cancer

General Audience Summary:
Though breast cancer incidence rates among sub-Saharan African (SSA) women are among the lowest in the world, mortality rates are as high as for women in high breast cancer incidence countries. Among SSA women the breast cancer burden is heavier among younger women, with the percentages of new cases and of deaths that occur at <age 50 more than double that in the United States. Driven by the forces of population growth, changing reproductive patterns, and dietary habits, the number of new cases of breast cancer in SSA is expected to double by 2030. Between 45 to 90% of breast cancers in SSA are diagnosed at stages III/IV and SSA have a 5-year relative survival well below 50%. In Zambia, breast cancer is the second most common cancer diagnosed in adults and the vast majority of women present with advanced stage disease. The primary goal for this project is to identify key quality of life concerns among Zambian women diagnosed with stage III/IV or recurrent breast cancer. The limited literature available suggests that lack of social support, most importantly spousal support, has the greatest adverse impact on quality of life in survivorship for women in SSA with breast cancer. This project seeks to validate these findings using the FACT-G and FACT-B questionnaires and will go further to elicit unmet needs through focus groups, with the goal of designing interventions to improve quality of life. This project would significantly contribute to this scarce body of knowledge by using an internationally validated tool to assess quality of life. We will also use open-ended discussion questions in a focus group context to elucidate concerns not addressed in the questionnaires and to provide breast cancer survivors a voice for change, and an opportunity to help shape health systems and policy.

Keywords:
Voices for Change
Application Title:
Breast Cancer Associations in Rwanda

General Audience Summary:
This patient-centred project will establish Breast Cancer Associations (BCAs) by training designated staff to foster patient self-empowerment as well as ownership of the disease. Led by the trained “patient navigators”, the BCAs will provide a forum for peer support among women with both early stage as well as advanced breast cancer through discussion, group problem solving of psycho-social challenges, breast cancer education, and health system navigation mentorship. The patient navigators will provide clear expectations and advice regarding the treatment and palliative care options available across the health sector from the community to national levels. Ultimately, BCA participants will be empowered to take ownership of their disease through self-management and confident navigation of a complex healthcare system. In addition, trained staff will gain skills that allow them to meaningfully educate and empower patients in rural Rwanda even beyond the grant period and in other forums.

Keywords:
Patient Navigation
Application Title:
Quality of Life Support for Turkish Advanced Breast Cancer Patients

General Audience Summary:
Our Metastatic breast cancer online and phone support program is one of a kind for women living with metastatic breast disease in Turkey. Our project aims to address the isolation of women diagnosed with metastatic breast cancer and the lack of understanding of the disease in Turkey. To date, there has been no services provided specifically geared towards metastatic patients in Turkey. Our nonprofit is the only organization to publish a booklet and video for metastatic breast cancer patients. The needs of the metastatic patient group differ from the rest of the breast cancer patients of other stages. The side effects of continuous therapy, pre test/scan anxieties, life being in limbo and feeling insecure about the future, potential resistance to drugs, lack of social and psychological understanding prevents these patients from living life to the fullest and with the best quality of life. We have surveyed 102 metastatic breast cancer patients recorded in our patient database and asked them to identify the 3 key areas where support is needed. The results of the survey indicate these patients need a separate platform where they can talk to other metastatic breast cancer patients, share support and tips for side effects and reciprocate psychological support. Our project is designed to address these needs by leveraging technology regardless of the patient's location.

Keywords:
Patient Navigation
Voices for Change
ELDA VECCHI
BS POLITICAL SCIENCE
CONSULTANT
ASOCIACION MEXICANA CONTRA EL CANCER DE MAMA A.C.
MEXICO CITY, MEXICO

Application Title:
Creating Spaces for Patient Voices

General Audience Summary:
We want to create a virtual space for all MBC patients in Mexico and other spanish speakers countries in order to access information about their condition available treatments options, emotional and psicological support through a web page and other social media tools. The purpose of this Project is to empower this patient through the information this platform could provide. We will invite our two coalitions: "Coalición Mexicana por la Salud Mamaria" that is a Mexican coalition formed by 23 NGO’s with the same purpose working with breast Cancer women and with Breast cáncer Metastasic women, and Ulaccam "Unión Latinoamericana Contra el Cáncer de la Mujer " this is a latinamerican coalition formed by 8 countries, 19 NGO’s. the porpused of this coalition is to improved changes in public policies that contribute to a better life quality for all breast cáncer patients.

Keywords:
Voices for Change
Application Title:
Support Groups in the field of advanced breast cancer

General Audience Summary:
The Israel Cancer Association (the ICA) support groups for metastatic breast cancer patients constitute a source of emotional support, while creating the conditions for reciprocal empathy, to reinforce solidarity and a sense of belonging, alleviate loneliness during the disease trajectory, bolster self-confidence, impart tools to cope with crisis and provide information for patients. Based on the experience we have accumulated in Hebrew speaking groups, we would kindly request assistance in expanding and initiating this important activity for metastatic breast cancer patients in Arabic and Russian (for Russian speaking patients who immigrated from the Common Wealth of Independent States-former Soviet Union).

Keywords:
Patient Navigation