Breast cancer begins when abnormal cancerous cells in the breast grow and multiply without stopping, creating a tumour; metastatic breast cancer (MBC), a.k.a. advanced breast cancer (ABC) in general means that the cancer has spread from where it started in the breast to other parts of the body. Women with MBC often face different treatments and challenges than women with earlier stages of breast cancer, and EUROPA DONNA – The European Breast Cancer Coalition (ED) has made MBC a priority focus in our strategic plan for 2014-2018. To this end, EUROPA DONNA’s Breast Cancer Advocacy Leader Conference, held in Milan, Italy on 20 September 2014, highlighted MBC. ED was also an advocacy partner in the Advanced Breast Cancer Second International Consensus Conference 2 (ABC2) which was held in Lisbon, Portugal in November 2013. 

The following is an overview of the ESO-ESMO 2nd international consensus guidelines for advanced breast cancer/ABC2 conference summary delivered at the ED Advocacy Leader Conference by ABC2 participants Dr. Olivia Pagani (oncologist and ED Board member), Dr. Lesley Fallowfield (psychologist), and breast cancer advocates Elizabeth Bergsten Nordström (ED Board) and Susan Knox (ED Executive Director). It is essential to follow up after ABC2 to ensure that all our countries are aware of the guidelines developed at the conference and the importance of their implementation across Europe.

A summary is also provided of ED’s involvement in the Breast International Group’s (BIG) AURORA programme. Finally, the results of a workshop held at the Advocacy Leader Conference for 15 women with MBC and the results of a survey completed by these participants are outlined.

ABC (Advanced Breast Cancer) Conferences were initiated by ESO (European School of Oncology), supported by ESMO (European Society for Medical Oncology), under the auspices of The Breast Cancer Research Foundation, OECI (Organisation of European Cancer Institutes), and UICC (Union for International Cancer Control), and are endorsed by many societies, including EUSOMA (European Society of Breast Cancer Specialists), FLAM (Federación Latinoamericana de Mastología) and SIS (Senologic International Society). The EUROPA DONNA coalition is deeply involved; a number of ED leaders attended ABC1 and the Coalition served on the newly developed Advocacy Committee for ABC2. Below are the key points Dr. Pagani synthesized from the conference, from an oncologist’s point of view.

ABC 2, the Oncologist’s Perspective
Olivia Pagani, MD, Breast Unit Southern Switzerland; Institute of Oncology of Southern Switzerland (IOSI)

The Multi/Interdisciplinary Team and the SBU
For the professional who works in metastatic breast cancer, dedication is crucial since management of the disease is complex. A multi/interdisciplinary team composed of medical-, radiation-, and surgical-oncologists, imaging experts, pathologists, gynaecologists, palliative/support care specialists, psycho-oncologists, social aid specialists, breast/specialized nurses is critical. Specialised oncology nurses (if possible specialist breast nurses) navigate patients through the journey.

A specialist breast unit (SBU) must address MBC in a coordinated way. All patients should be offered comprehensive, culturally sensitive, up-to-date and easy-to-understand information about their disease and its management. Following a thorough assessment and confirmation of MBC, the potential treatment goals of care should be discussed. Patients should be told that MBC is incurable but treatable, and women can live with the disease for extended periods of time (many years in some circumstances). This conversation should be conducted in accessible language, respecting patient privacy and cultural differences, and, whenever possible, written information should be provided.

Patient Support
From the time of diagnosis of MBC, patients should be offered appropriate psychosocial and supporting care and symptom-related interventions as a routine part of their care. The approach must be personalised to meet the needs of the individual patient. Patients (and their families, caregivers or support network, if the patient agrees) should be invited to participate in the decision-making process at all times.

Research
There are few proven standards of care in MBC. Inclusion of patients in well-designed, independent, prospective trials must be a priority whenever they are available. It is crucial for medical professionals to encourage patients to participate in independent and academic research projects.

Health Technology Assessment
The medical community is aware of the problems surrounding the cost of MBC. Balanced decisions should be made in all instances but patients’ well-being, length of life and preferences should always guide decisions. Furthermore, the age of the patient should not determine the intensity and/or choice of treatment, i.e. the sole reason to withhold effective therapy (elderly patients) or to over-treat (young patients). Treatment choice should take the following into account: HR and HER-2 status, previous therapies/toxicities, disease-free interval (DFI), tumour burden (number and site of metastases), biological age, performance status (PS), co-morbidities and organ dysfunctions, menopausal status (for endocrine therapy (ET)), need for a rapid disease/symptom control, psychosocio-economic factors, available therapies in the patient's country and patient preference. Advocates must lobby for appropriate MBC services for all women.
Various Treatments for MBC

A small but very important subset of patients with MBC, for example those with oligo-metastatic disease (up to 5 detectable metastatic lesions) can achieve complete remission and a long survival. A multimodal approach should be considered for these selected patients.

The value of breast surgery in MBC is currently unknown. It can be considered, in selected patients, if it is technically possible and only if performed optimally. ET is the preferred option for HR+ disease, even in the presence of visceral disease, unless there is concern or proof of endocrine resistance or rapidly progressive disease needing a rapid response. The preferred first line ET for postmenopausal patients is an aromatase inhibitor or tamoxifen, depending on the type and duration of adjuvant ET. Fulvestrant HD is also an alternative option. AI + everolimus is an option after progression on a non-steroidal AI. Having metastatic breast cancer does not mean a patient will automatically need chemotherapy; in HR+ disease, MBC can be properly treated only with endocrine therapy.

Specific populations with MBC need to be addressed, such as male MBC and BRCA-associated MBC. Different sites of metastases also need to be addressed in different ways: liver metastases, malignant pleural effusions, chest wall and regional (nodal) recurrences, and brain metastases.

Anti-HER2 therapy should be offered early to all HER2+ patients, except in the presence of contra-indications. The choice of the anti-HER-2 agent will depend on country-specific availability, the specific anti-HER-2 therapy that was administered previously, and the relapse free interval. After progressive disease (PD) on an anti-HER2 therapy combined with CT, additional anti-HER2 therapy should be offered since it is important to keep blocking the HER-2 pathway. The optimal sequence of all available anti-HER-2 therapies is currently unknown.

Regarding chemotherapy, both combination and sequential single agent CT are reasonable options. Based on the available data, the sequential single agent is recommended. Combination CT should be reserved for patients with rapid clinical progression, life-threatening visceral metastases, or need for rapid symptom- and/or disease-control. The decision of which drug to administer should be individualized and take into account different toxicity profiles, previous exposure, patient preferences, and country availability. Duration of each regimen and number of regimens should likewise be tailored to each individual.

Specific disease sites:
- A bone-modifying agent should be routinely used in combination with other systemic therapy in patients with bone metastases.
- Patients with a single potentially resectable brain metastasis should be treated with surgery or radiosurgery. This may also be an option for patients with a small number of potentially resectable brain metastases.
- Prospective randomized clinical trials of local therapy for patients with liver metastases are urgently needed, since evidence available comes only from series in highly selected patients. No data exists on local therapy's effect on survival. All cases of liver metastases should be discussed in a multidisciplinary meeting. Local therapy is to be proposed to very select patients with good performance status, limited liver involvement, no extrahepatic lesions, and after adequate systemic therapy is shown to control the disease. No current data exists to select the best technique for the individual patient (e.g., surgery, stereotactic radiotherapy (RT), intra-hepatic CT).

Survivorship issues in MBC: what can we do?
- Provide state-of-the-art care/cure
- Address reasonable goals and treatment objectives with patients/families
- Personalize treatment plans and approaches, adapt strategies to disease status and patients’ priorities
- Address home care i.e. children care, housekeeping
- Provide rehabilitation i.e. sexuality, complementary therapies (CAM)
- Address social needs, i.e. job, insurance

Care for MBC Patients

Multidisciplinary care is necessary for MBC patients, with a coordinated treatment plan developed and carried out by experienced professionals. MBC patients should not be separated from other breast cancer patients in their treatments; we need to avoid women entering the MBC “ghetto”.

Supportive care, allowing safer and more tolerable delivery of appropriate treatments should always be part of the treatment plan. Access to effective pain treatment (including morphine, which is inexpensive) should be granted to all patients in need. When active treatment is no longer able to control disease and the toxicities outweigh benefits, the healthcare team should discuss end-of-life care with the patient (and family members/friends, if the patient agrees).

ABC 2, the Psychologist’s Perspective

Lesley Fallowfield, Professor BSc, D.Phil, F.Med.Sci, Director: Sussex Health Outcomes Research & Education in Cancer (SHORE-C) Brighton & Sussex Medical School, University of Sussex

For the ABC2 conference a number of specialists were selected by Fatima Cardoso, Breast Cancer Program Coordinator of the European School of Oncology and co-chair of the ABC Conferences, to represent different areas of the disease. All were given provisional consensus statements on the topic of MBC and were tasked to work together to arrive at a consensus. Consensus statements demand a high level of scientific evidence to support what is being said. The group evaluated each statement presented, discussed and defended their positions, and then voted. Below summarises the main points Dr. Fallowfield took from ABC2, representing the psychologist’s perspective.

Psychosocial Aspects of MBC

Compared with early breast cancer (EBC), research evidence on MBC is sparse about what to do when and how. Furthermore, the provision of services is patchy and research is often unrepresentative, concerning small, unrepresentative samples of mainly white, higher socio-educational groups. The ability of more disadvantaged women to request and access support services may be limited.

Psychological Problems and Numbers Affected

Diagnosis of breast cancer recurrence and/or MBC fills most women with dread. It is often worse than first diagnosis: with this diagnosis women are simultaneously confronted with increased threat to life/fear of dying; decision-making about further treatment options; anticipation of side-effects of further treatment; impact of the diagnosis on family and friends; and the occupational implications and financial burdens the diagnosis will bring about. This is in spite of the fact that women diagnosed with MBC often live for a long time, unlike many other tumour sites.
In a study involving 66 women with recurrent breast cancer or MBC diagnosed within the previous six months, a plethora of assessments and semi-structured interviews were completed to delineate key emotional concerns (Turner et al., Psycho-oncology, 2005) in which high levels of psychological morbidity were reported: 57% <55 and 35% >55 years. Younger women also had significantly higher intrusive and avoidant symptoms. Key themes identified were: poor communication with doctors, perceived delays in diagnosis, concerns about family, marital and financial strains, and use of non-prescribed treatments (in their psychologically fragile state, they are prey to dubious claims about alternative unproven therapies).

In a U.S. study of expressive therapeutic writing (known to be a helpful therapy) in 176 women diagnosed with MBC (Mosher et al., Breast, 2013), the participants were encouraged to write down their thoughts. Patients with MBC are women who often do not have a voice: they suffer in silence. 48% reported difficulty talking to others, and they denied the severity of their illness to close friends and relatives. Most experienced shock, isolation and loss of control. Hair loss caused many women to cease activities of daily living (ADL) - primary physical problems, fatigue and pain, led to cancelling activities that then caused guilt. Frequent medical appointments produced emotional strain and an inability to work posed a major challenge and impact on families was distressing.

The numbers of women found to experience psychological morbidity vary widely according to measures used; depression ranges from 1.5 - 46%. The relative risk of anxiety or depression or both in advanced and palliative settings is unreliable/unknown. Poor quality of life might be a proxy indicator of psychological morbidity but there are cause/effect issues to consider; it is most likely that depression and anxiety indicators of quality of life are not determinants. The reliance on psychiatric diagnoses ignores low mood, manifest distress and fear of progression and death. The above reactions of women could be regarded as rational or logical responses rather than maladaptive ones.

Aetiology and risk factors of distress are complicated, with a wide variety of psychological, social, physical, biological and other mediating factors including: younger age; stage of disease; low social and emotional support/poor family dynamics; coping strategies/dispositional ways to manage negative emotions; drugs (e.g. anti-oestrogens may deplete serotonin); proinflammatory cytokines; pain, fatigue and other troubling side-effects; and prior history of psychiatric problems.

What Interventions Help?
We need to think about ways to manage anxiety. Some people do not have good coping strategies. We should find out early on which patients need more support. In treatment of cancer one hears about targeted therapy; we should be doing the same with psychiatric interventions. What helps? The answer is not simple, as one solution does not work for all.

• Pharmacologic remedy is relatively safe with depression but selective serotonin reuptake inhibitors (SSRIs) may be contraindicated with some hormone therapies
• Exercise is supported by many studies as being comparable to psychotherapy or medication, lowering depression and pain levels, and it is vital with fatigue and bone metastasis. Meta-analysis in cancer showed modest reductions in depression, pain and fatigue and improved quality of life (Craft et al, 2011)
• Supportive-expressive group and individual therapy (SEGT) was found to improve mood, stress and adaptive behaviors (but not necessarily survival) (Classen et al, 2001)

Who Should Offer Interventions and When?
Given the potential complexity of issues, a key nurse with specialist MBC knowledge could help reduce anxieties and promote coping (Mackie & Warren, 2011). Many patients are now managed on an ambulatory basis so there is limited face-to-face contact (Findlay, 2008). Thirty percent of clinical nurse specialists’ time is spent on the telephone, according to a recent study which examined calls from 229 MBC patients (Warren et al, 2012). These calls led to a mean of six interventions per call clustered into 4 areas: meeting information needs (29%), symptom management (26%), psychosocial issues (33%), other (12%). Forty percent of calls were from patients with stable disease, a group thought to prefer self-management.

Clinical nurse specialists could assess and properly prescribe anti-depressants and anxiolytics. A Norwegian study of 17,753 patients who died from cancer (17% MBC) showed 22% had anti-depressant prescriptions in the last year of life, four times that of the general population (Brelin et al, Psycho-Onology, 2013). Approximately 10% of anti-depressants are prescribed for the first time 30 days before death; this is too late. Intervention depends on the individual. There is a need to regularly assess patients, pick out those at greatest need and intervene. Doctors should not forget that if vigilant from the beginning they will have healthier and happier patients. Therapies—yoga, MBSR, group therapy, family counseling—must be tailored and targeted, based on individual need.

A New Quality Standard for Psychosocial Care in MBC
There is a growing consensus that all psychosocial care should be integrated into routine care (Jacobsen & Wagner, JCO, 2012). In addition, the emphasis is changing from how long to how well patients live. Although currently the provision and receipt of psychosocial care is patchy, three major developments in the past decade enhance the likelihood that it will become a component of comprehensive cancer care: 1. defining standards; 2. the development of clinical practice guidelines; and, 3. the development and implementation of measurable quality indicators.

Patients should be regularly assessed at all stages of disease using validated instruments. Those most in need should be referred to an appropriate specialist (a CNS, counselor, psycho-therapist etc.). Prevention of anxiety and distress which might include: 1. vigilance about symptoms and side-effects of disease and treatment enabling rapid ameliorative intervention; and 2. better, honest and supportive communication and good quality information.

The ESO-ESMO 2nd international consensus guidelines for advanced breast cancer can now be found online. The level of evidence supporting the statement and the methodology are very solid and can be used in ED advocacy efforts.
ABC 2 the Advocacy Perspective

Elizabeth Bergsten Nordström, Board of Directors, EUROPA DONNA and Susan Knox, Executive Director, EUROPA DONNA

Elizabeth Bergsten Nordström described her experience taking part in ABC2 from the patient/advocate perspective. She was one of 38 experts, and one of two patient advocates (along with Doris Fenech (ED Malta)) involved in the ABC2 consensus guidelines panel. According to Elizabeth, patient participation in the conference was significant with regard to both speeches and workshops, and with significant patient influence. Documentation had been prepared beforehand with a number of statements for best known treatments. The panel members were tasked with going over the statements, one by one, and changing them to reflect best scientific evidence. Panel members were extremely involved in the process and documentation developed was comprehensive. Discussions were not always smooth and consultation of high quality research was of great importance to the process. The revised statements the panel developed were sent out for additional comments, and the follow-up process was rigorous. During the voting process, time was allocated for questions and remarks. Work is on-going and Elizabeth remains involved. For her, taking part in the process of commenting on the consensus guidelines has been a difficult but rewarding journey of learning. She had the fourth edition of the “European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis” (EU Guidelines) and the guidelines from the ABC1 conference to build on. She recommends that all breast cancer advocates carefully read the ESO-ESMO 2nd International Consensus Guidelines for Advanced Breast Cancer (ABC2). Advocates need to develop good relationships with health professionals so that they can be used as a resource for questions and ideas. Having engaged in the process of ABC2 as a panel member, Elizabeth learned the extreme importance as an advocate to back up all arguments with facts; changes will come in breast cancer advocacy only with facts, not just passion for the cause.

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Susan Knox began her presentation asserting that for breast cancer advocates, having the most updated facts is of vital importance. Information on the disease should not just remain with the experts. We as advocates need to be at conferences such as ABC2 and convey the information learned to our countries. We need to know what is being recommended so we can go out and advocate for it. Professionals don’t always tell patients all practices are available. Advocates need to fight for best practice even if it isn’t available in all countries.

Participating breast cancer advocates at ABC2 were: CJ Corneliusen-James of METAvivor Research and Support (USA), Susan Knox of EUROPA DONNA Coalition (Italy), Amelia Pinto Leite of ED Portugal, Musa Mayer of AdvancedBC.org (USA), Shirley Mertz of Metastatic Breast Cancer Network (USA), Maxine Morand of Australia Breast Cancer Network (Australia), and Kimberley Sabelko of Komen Foundation (USA).

At ABC2, the scientific experts were very open to the advocacy component of the conference. Advocates were involved in setting up parallel sessions to the scientific ones. Patient Advocate Sessions were attended by 68 patient advocates representing 49 organisations and 25 countries. The task they undertook was to identify the greatest MBC patient challenges and determine how they are reflected in and addressed by the EU Guidelines.

All countries reached agreement on the following points:

- MBC patients in particular have a need for care provided by a multi-disciplinary team (MDT)
- Breast unit or similar is necessary to ensure:
  1. Patient navigators to guide patients through their journey
  2. Continuity
  3. Shared decision making
  4. Support must include: psycho-social, family, nutrition, complementary medicine, sexual dysfunction, and rehabilitation
- Healthcare systems must provide MBC patients with:
  1. Access to clinical trials
  2. Up-to-date treatment
  3. Accredited treatment centers
  4. Development of tumour banks
  5. Cancer registries (especially important since many countries have no statistics)

Societal concerns include the fact that MBC is highly misunderstood and stigmatized, and MBC patients often feel alienated and as a result underestimate the problems they are facing. Economically, MBC often brings difficulties in that careers may change or end; there is a need for accommodation for employees with MBC and disability coverage is essential.

Further advocacy input at ABC2 included:

- Reviewing and suggesting edits to ABC1 consensus guidelines
- Producing a report at the plenary on Saturday from ABC Advocate Committee
- Holding a panel on survivorship
- Meeting with and asking experts about future research and advocacy initiatives for MBC during an open session
- Advocate Doris Fenech delivering an outstanding keynote presentation on one patient’s personal journey with MBC
- Advocate members on Voting Consensus Panel

ED’s input at ABC2 was important. With the information we learned from our advocates who have MBC during the 2014 Advocacy Leader Conference MBC Workshop, we will be able to present actual data from women with MBC at ABC3.

ED has posted a link to Second International Consensus Guidelines for Advanced Breast Cancer (ABC2) on our website at:

http://www.europadonna.org/links-media/links-and-resources/
EUROPA DONNA's Involvement in Research on MBC
Susan Knox, Executive Director, EUROPA DONNA; Karen Benn, Head of Policy/Public Affairs, EUROPA DONNA

During the presentation on EUROPA DONNA’s collaboration with the Breast International Group (BIG), Karen Benn described ED’s current involvement in BIG’s innovative MBC programme, AURORA. BIG is an international non-profit organisation and the largest global network (over 50 countries across 5 continents) of academic groups dedicated to breast cancer research. Launched in 2013, AURORA is the first international programme for women with MBC; it aims to use molecular screening to improve the understanding of breast cancer and its response/lack of response to available drug therapies. For the first time, MBC tissue specimens are being collected and characterised on a large scale, with the added value of identifying targets for future treatments that can significantly improve survival. A total of 1,300 women and men from about 60 hospitals in 15 European countries are expected to take part initially.

Objectives of the study:
• Improve the understanding of MBC and its underlying causes
• Determine why some tumours respond poorly to standard treatment while others respond well
• Identify potential predictive biomarkers for response and resistance to commonly applied anticancer agents

Susan Knox and Karen Benn both serve on the Steering Committee for the AURORA programme.

Workshop for Women with MBC
Leaders: Lesley Fallowfield and ED Vice President Evi Papadopoulous

A special workshop for advocates with MBC was held during ED’s 2014 Advocacy Leader Conference and was attended by 15 women with MBC from 15 countries: Czech Republic, Cyprus, Finland, France, Georgia, Ireland, Israel, Malta, Netherlands, Norway, Russia, Slovenia, Spain, Turkey, and the U.K. The workshop leaders gave a brief overview of what ED hoped to achieve in the workshop: to develop the ED position on MBC and reach a summary position on improving care and services for women with MBC that we can present at ABC3. They explained that those present should try to agree on priorities, including what was needed and what was wanted. They told the attendees about the ED survey on MBC that they should complete at the end of the workshop; they also mentioned ABC3 and EBCC10, ED’s involvement in these conferences and their importance for MBC advocates.

The women then introduced themselves. All mentioned at what date they became metastatic and what organs were affected. They were also asked to comment on what they saw the issues (top 2) as being in their countries or on what services were in place and what their personal involvement is. Their responses can be summarized as follows:
• 7 advocates described treatment, care, and access to drugs as being good
• 5 mentioned that access to drugs was a definite problem, several noting that patients must pay privately for these
• 3 highlighted the need for better psychosocial support and support from the community and social networks

The major issues continue to be around lack of support and feelings of “invisibility” in terms of the breast cancer world, though clearly improvements have been made over the last few years, and some of the ED groups are particularly supportive. Some ED organisations now offer special “sub-groups” for MBC women, along the lines of the young women’s groups, and some women have access to specialized MBC groups through other breast cancer organisations in their countries. Online social networks are extremely important for some women with MBC and can help with their feelings of isolation.

In terms of service provision, some countries now have quite well-developed pathways for MBC; oncopsychological support, which all present identified as being of paramount importance both for women with MBC and their families, is sometimes provided but by no means always. Decision aids were also identified as being very important, especially in the MBC context where so many treatment options may be offered. Some of the women present had been involved in the development of these decision aids.

Financial issues are still very important; some women bear very high out-of-pocket costs; one described how she now has no money, as is her family, because she needed so much treatment for multiple metastases. Others described how their only access to the latest treatments was through clinical trials. Access to the latest drugs etc. is of crucial importance still and differences in reimbursement in the different countries was very important. The women present all seemed to be aware that there were differences in reimbursements between countries and also that each country negotiated individually with the pharmaceutical companies for drug prices.

The workshop was then divided into 2 groups for the participants to brainstorm amongst themselves to determine the main priorities for women with MBC.

Group 1
1. Involvement in decisions is crucial – active participation in decision-making in your treatment is of paramount importance and education is key, as is seeking guidance and second opinions; doctors should encourage this too, they speak a different language but should show more compassion for the woman’s situation
2. Family care and support – pathways should be developed for this and guidance should be provided, including “how to tell the children”; material should be developed on how to communicate an MBC diagnosis to children
3. Social, professional, legal and financial issues – for example insurance and lack of access to same; family support - who will help the woman under treatment with her usual tasks both inside and outside the home? What about transport, etc.? And who will pay for this support? The out-of-pocket costs for some women are very high and are part of the individual cancer burden – these costs should be borne by society; data should also be collected on these costs: work and the right to return to work are also very important; for those who are working, both annual leave and sick leave get taken up with medical appointments
4. **Quality of life** – support to improve self-esteem is important; it is not part of the cure but it helps tremendously because better self-esteem makes us stronger.

5. **Communication with doctors** – sometimes appointments are too short (20 minutes) and there appears to be a lack of compassion; it’s important that communication is bottom-up, not just top-down. Bring a buddy, to take notes.

For this last point, it was discussed that communications skills for doctors should be a mandatory part of continuing medical education (CME) in all countries (as it is in UK); there is evidence from well-controlled trials showing that it is effective.

**Group 2**

1. **Raise awareness of MBC** – with both the general public and other breast cancer patients; people with MBC can be isolated and stigmatized; sometimes there are cultural problems so we need more MBC support groups and resources for these and we also need to promote a more positive image.

2. **Access to treatments** – access to existing drugs and to new drugs; in EU Guidelines a baseline of care should be emphasized.

3. **MDT** – there must be guidelines and protocols for the operation of multidisciplinary teams, this ensures quality across countries; the MDT is crucial in terms of care for people with MBC.

4. **Data collection** – data on MBC is lacking; numbers are unknown, if you don’t know the size of the problem you can’t provide adequate services. We should advocate for improved data collection and the resources and cooperation necessary for this; we should ensure this is included in future health policy demands.

It was suggested that an ED MBC network, similar to the young women’s network, could help the group to continue to collaborate and support each other and share their views on best practice and policy.

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**MBC Survey 2014**

EUROPA DONNA designed a survey for women with MBC attending the Advocacy Leader Conference in September; there were 26 questions and it is important to note that the data reported reflects the knowledge and personal experience of the individual ED member with MBC only.

The questionnaire was divided into:

- **Context and diagnosis** - what data is available and from what sources? What information is given to people diagnosed with MBC? How is MBC diagnosed?
- **Content** - MBC treatment, care and guidelines - what is the standard of care, and of support, and what guidelines are available?
- **Advocacy** - what are ED member organisations doing for people with MBC? Is this group well-served? And what should ED advocate for?

### RESULTS

#### Context and diagnosis

17 women from 16 countries attended the survey workshop. Countries attending were Cyprus (2), Czech Republic, Finland, France, Georgia, Ireland, Israel, Italy, Malta, Netherlands, Norway, Russia, Slovenia, Spain, Turkey, and UK.

The introductory questions were about terminology: “Advanced Breast Cancer (ABC) is also known as Metastatic Breast Cancer (MBC) or Secondary Breast Cancer. Please could you tell us which is the term most commonly used in your country? And please also tell us what is your preferred term?” To this, the overwhelming majority, 14, said MBC is the term used in their country, and 3 said ABC or SBC. 10 said that MBC is also their preferred term, with 4 saying they preferred ABC and only 1 SBC. One person commented that metastatic was the term used in her country but she preferred advanced because metastatic “sounded like death”. However another person commented that metastatic was preferred because it “does not hide truth” and another said “I am used to it now”. A further person said she preferred metastatic because it is more definitive than advanced on the basis that stage III breast cancer can also be called “advanced”.

The first three questions related to data collection on incidence of MBC. “1) Is there information in your country about the incidence of MBC?” 9 said yes, 6 said no and 2 said don’t know. When asked in question two if this information came from a National Cancer Registry (NCR), 3 said yes, one said no, 5 said don’t know and 8 as N/A. A few commented that this was information from their local breast cancer association or from local charities and organisations. One said it was collected by the department of health statistical office but not a national cancer registry.

The sub-questions of question 2, were therefore answered by the 3 people who had responded positively to question 2 itself and plus one other; 2 people said that the data collected by the NCR included a) the number of newly diagnosed MBC patients; one said it b) included treatments received; one said c) cause of death was included in the NCR and 2 said d) all of these.

When asked in question 3) Does your country have a National Cancer Registry? 12 said yes, 3 said no, 1 said don’t know and one was N/A.

Question 4 changed the topic to treatment and asked 4) Were you treated in a) a cancer centre b) a specialist breast unit (SBU) or c) other (please specify); 14 people said they were treated in a cancer centre and 4 said an SBU.

Question 5 asked 5) Was this service provided by a) National Health System (NHS) b) private hospital/clinic or c) other - 13 respondents said they had been treated by the NHS. 3 said in a private hospital and one was “other”.

Question 6 asked 6) Were you given information about the signs and symptoms of MBC during primary breast cancer treatment or follow-up? 6 said yes, 9 said no and 2 said N/A (because they were diagnosed with MBC). In question 7, we wanted more detail on question 6 and asked 7) If Yes, when were you given this information? 3 said at the beginning of treatment for primary breast cancer; one said during treatment for primary breast cancer; and 2 said at follow-up. Further, question 8 asked 8) if yes to 7) above, were you given contact details of where to obtain further information? 3 said yes, 2 said no and one was N/A.

Question 9 asked 9) How is MBC usually detected in your country? a) by screening b) due to symptoms c) during follow-up and d) other (It should be noted that this could be very subjective; many women may only know how the detection applied to them, not what is “usually” the case). 10 said by screening, 15 said due to symptoms and 11 said during follow-up.

The next question was 10) How was your diagnosis of MBC delivered? In person or by phone were the possible answers and the vast majority, all but three, said they received their diagnosis of MBC in person.
CONTENT

The “content” or treatment questions followed, starting with whether there were national guidelines in the country on the treatment of MBC (again, it should be noted that not all women would be aware if there were, or not). 9 said yes, 4 said no and 4 said don’t know.  

The next question was 12) If SBUs or centres exist in your country can a patient with MBC return there for follow up or treatment plans/ support after diagnosis? 14 people said yes, they could. 2 said no and 1 said don’t know.  

The next question in this section was 13) Did you have access to a “key worker” that is a health professional (specialist breast care nurse or core team member with professional psychological training) to whom you could turn if you had questions, and who coordinated your care? 6 said yes, 10 said no and 1 said don’t know.  

It was then asked 14) After your diagnosis with MBC was the support, including psychological support, given satisfactory, not very satisfactory or not at all satisfactory. 5 said it was satisfactory, 5 said “not very” and 5 said not at all; 2 did not respond. So more than 2/3 indicate not very or not at all satisfactory.  

Regarding information: 15) Do you feel that the amount of information given when you received your MBC diagnosis was a) about right b) insufficient and/or not well-explained or c) too much, impossible to take in. This was a better result overall since 12 people said it was about right, 4 said insufficient and 1 said too much.  

The following question was about patients’ involvement in treatment: 16) Were you personally involved in decisions about monitoring your situation? That is, could you ask for more frequent, or fewer, blood tests, scans etc.? A high number, 15, said they were involved in these decisions with just 2 saying they were not involved.  

It was then asked 17) Upon your diagnosis with MBC, did you feel that you were given enough information about the signs and symptoms which could indicate further progression of the disease? 8 said yes 8 said no and 1 said don’t know.  

Did you receive a written treatment plan? was the next question. Just 6 said yes to this with the rest saying no.  

The following question asked 19) Did you see the same health professional (specialist breast care nurse or core team member with professional psychological training) to whom you could turn if you had questions, and who coordinated your care? 6 said yes, 10 said no and 1 said don’t know.  

The next key question was: 20) Did your treatment for MBC start in a timely manner? Fortunately, the vast majority, 15, said yes but 2 said no.  

Then family support was considered: 21) Do you feel that partners, carers, children and family members of women with MBC are supported in your country? Most did not think so with just 6 saying yes. Following-up on this question, is the support service counselling provided through health services? 8 said yes and/or through support groups, 13 said yes.  

Advocacy, advocacy groups and patient organisations  

The final set of questions was about patient support groups and advocacy organisations involved with MBC. We firstly asked if patient organisations provide MBC patients with information: 12 said yes, 2 said no and 3 said don’t know.  

The next question asked 23) Do women with MBC find support and information regarding absence from work, home help, etc.? 6 said yes, 7 said no and 4 said don’t know.  

Followed by 24) Do women with MBC participate actively in your local breast cancer support or advocacy group activities/meetings, etc.? 9 said yes, 5 said no and 2 said don’t know.  

It was then asked 25) Do you feel that the local breast cancer support or advocacy group adequately meets your needs for information and support? 11 said yes, 5 said no and 1 said don’t know. This is a definite improvement on past surveys where the majority of people with MBC have felt that their needs were not necessarily well-met by local support groups.  

Then a number of questions was asked about whether and what advocates should advocate for, where MBC is concerned. 26) Do you think there is a need to advocate for special rights for people with MBC regarding information, treatment and counselling? All 17 answered yes to this and also to the next 3 questions which were:  

27) Should the need/rights for information and treatment for people with MBC be included in national guidelines regarding the treatment of breast cancer?  

28) Should the needs/rights for information and treatment of people with MBC be included in the next edition of the “European Guidelines for quality assurance in breast cancer screening and diagnosis?”  

29) Should the needs/rights for information and treatment of people with MBC be included in an EU Declaration and voted on by the European Parliament?  

The final question was, 30) In general do you feel treatment and services for people with MBC in your country are adequate today? This had a very mixed response; 8 said yes, 7 said no and 2 said don’t know. People were then asked to comment and several people felt there was no clear strategy or plan for women with MBC. Comments included:  

“No clear strategy for MBC patients, needs are unknown, no special services for their particular needs.”  

“Things have improved but no defined plan. Medical treatment is in general good but there is a lack in the provision of services such as psychosocial support, support with financial issues, support for families especially those with children or adolescents.”  

“I believe they are never enough. I am always wanting better services and treatment especially the administration and availability of the latest and best medication.”  

“We are in good hands but doctors’ communication could improve!”  

“Women with MBC need more info for their treatment and psych support, end of life care, health rights etc.”  

For updates on Metastatic Breast Cancer and International Consensus Guidelines for Advanced Breast Cancer (ABC3) see www.europadonna.org
EUROPA DONNA - The European Breast Cancer Coalition, is an independent, non-profit organisation whose members are affiliated groups from countries throughout Europe.

The Coalition works to raise awareness of breast cancer and to mobilise the support of European women in pressing for improved breast cancer education, appropriate screening, optimal treatment and care and increased funding for research. EUROPA DONNA represents the interests of European women regarding breast cancer to local and national authorities as well as to institutions of the European Union.